TERMINAL PATIENTS AND THE ROLE
OF THE GENERAL PRACTITIONER

By

Christopher James Todd

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Thesis submitted for the degree of Doctor of Philosophy in the Faculty of Social Science at the University of Durham.

Department of Psychology. University of Durham.

I declare that the work contained in this thesis has not been previously submitted for any other degree.

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Research into doctor-patient communication and their roles is reviewed. Two series of semi-structured interviews were conducted with general practitioners (GPs) and patients separately. In the first series, GPs each selected 6 patients for 3 groups: terminally ill with knowledge, terminally ill without knowledge, and chronic controls. Content analysis of patient transcripts revealed differences in frequency of utterances classed as showing knowledge. Differences between groups and qualitative analysis of all interviews verified GPs' categorization. Knowledge was not simply absent or present, since all groups showed awareness, but differed in the degree to which the nature of illness was openly acknowledged. One GP reported routinely informing patients, but others did not, although agreed this is occasionally appropriate. A typology of methods GPs use to control information exchange is proposed. GPs' role formulations appear to underpin their reported communicative behavior.

In the second series, 22 GPs were interviewed. Again, they were asked to select patients, but few did within the time allotted; therefore analysis focused upon GPs' reported communication strategies. Content analysis of interviews splits GPs into two groups: informers and non-informers. Qualitative analysis of GPs' reported communication strategies suggests that underlying this simple dichotomy is a continuum from revelation through simple disclosure to concealment. Strategies are implemented by various tactics such as euphemism, uncertainty, denial, evasion, and prompting. Differences in reported intentions and behaviors are interpreted by recourse to GPs' descriptions of their roles during terminal care. Those who conceal attempt to maintain the Parsonian curative physician role and are reluctant to classify patients as terminal. Those who reveal try to abandon this role for a model of counselor. Nearly all experience role ambiguity and attempt to resolve this in ways predicted by role theory.
General practitioners, terminal illness and terminal care at home.

Let me die a youngman's death
not a clean & inbetween
the sheets holywater death
not a famous-last-words
peaceful out of breath death

When I'm 73
& in constant good tumour
may I be mown down at dawn
by a bright red sports car
on my way home
from an allnight party

Or when I'm 91
with silver hair
& sitting in a barber's chair
may rival gangsters
with hamfisted tommyguns burst in
& give me a short back and insides

Or when I'm 104
& banned from the Cavern
may my mistress
catching me in bed with her daughter
& fearing her son
cut me into little pieces
& throw away every piece but one

Let me die a youngman's death
not a free from sin tiptoe in
candle wax & waning death
not a curtains drawn by angels borne
'what a nice way to go' death

"Let me die a youngman's death."
Roger McGough
Hippocrates in the 4th century B.C. recognised the importance of the relationship between doctor and patient when he wrote,

"The patient though conscious that his condition may be perilous, may recover his health simply through contentment with the goodness of his physician". (Hippocrates, 1923 translation)

Since that time great strides may have been made in terms of the technological interventions available to the doctor for treatment of the patient, but death has not been conquered. In many cases every year all that modern technical medicine can offer is a rearguard action to stave off the inevitable fatal hour, and the doctor still depends on his or her charisma as a good physician to keep the patient content, if no longer well.

Death is still a taboo in western society. In that oft quoted yardstick of contemporary mores, the mass media, death is more often than not the young man's death of McGough's poem, violent and sudden (Gerber, 1980). Death is represented to us as either the stylised death and glory of cops and robbers soap operas, or the alien deaths of Beirut, Belfast, Soweto or the other so called trouble spots of the moment. And yet the death that awaits most of us is very different. Only 3% of deaths which occur in Britain today are the result of such violent sudden causes and most of those are on the country's roads (Office of Population Censuses and Surveys, 1985). The vast majority of people who died in this country today will have done so from respiratory and circulatory
diseases, with cancers coming a close third. In 1979 over 40,000 men and women died at home from cancer, after a period of several months of treatment from doctors, during which period they were regarded as terminally ill. The total number of people who do most of their dying at home under the care of their general practitioner (g.p.) is almost certainly much higher (c.f. Wilkes, 1980). However, the exact numbers involved are obscured by the lack of differentiation in the available statistics between those patients, who are released from hospitals to die, and those who enter hospital for the last minute life saving efforts of medics.

Whilst over the last decade or so there has been a considerable research effort directed at investigating terminal illness and terminal care, the vast majority of that work has been inspired by the pioneering leads set in this country by Cicely Saunders and the "hospice movement" (see e.g. Saunders, 1981; Kastenbaum, 1979; Holden, 1980), and in the United States by the writings of Elizabeth Kübler-Ross (1970, 1975, 1979). Consequently research has focussed on institutional care for the dying; hospitals and hospices. But hospices, as well as providing specialist physical facilities, operate under principles and attitudes to care, in which concepts such as dignity, serenity, confidence, spirituality, intimacy and personal attention are paramount. Thus in hospices, at least, most patients know that they are dying and are able to talk about it with their doctors and nurses with
apparent ease (Saunders, 1978), since it is a central tenet of the "hospice philosophy" that they should be able to do so. But hospices are special places, catering for a small self selecting population of patients who choose to go there to die, and are fortunate enough to live in a locality served by a hospice. At the time the research to be reported in this thesis was initiated, there were only a handful of hospices in the U.K., each with facilities for only a small number of patients (for example, perhaps the most famous, St. Christopher's, had 54 beds). Although the number of hospices has increased dramatically recently they can only cater for a tiny proportion of people who die after a period of terminal illness. Nor are hospices a panacea for all deaths, since for some patients the spiritual approach may be unpalatable. More importantly hospices need to be situated in a densely populated urban area to be really successful. This is because one of their main attractions to many dying patients is their homeliness; they permit the patient to receive good and constant medical attention, in a technical sense, without the alienation which this entails in a hospital. This characteristic feature (homeliness) of hospices is negated if relatives are not able to attend regularly, as would be the case if they lived far away (Clark, 1981).

Since many thousands of people not only die at home, but also do most of their dying there, the personal care and open communication reported to exist in hospices, although
highly publicised, probably does not reflect the typical experience of the terminally ill in this country. The more typical experience revolves around the patient's home and involves g.p. care. But this has barely been investigated to date. The present research then is aimed at this more widespread and mundane experience of terminal illness and specifically investigates the relationship between g.p.s and patients dying from terminal illnesses at home. We thus turn to consider the nature of these two populations: g.p.s and terminal patients dying at home.

General Practitioners In 1982 there were 28,065 g.p. principals practicing in the U.K. (Central Statistical Office, 1984), the majority of whom worked in partnerships of 3 or more doctors. Of these 82% were males and approximately 50% under the age of 45. The typical g.p. is a male Anglo-Saxon in his mid 30s to early 40s, who works with 2 partners and has about 2,000 patients on his books. 75% of g.p.s practice in urban areas, 22% in rural and 3% in mixed urban rural areas. They make up something in the region of a third of the doctors practicing in the U.K. and between them were paid £867 million in 1981 by the N.H.S. for the services they provided (C.S.O., 1983).

On average males consult their g.p.s 3.2 and females 4.4 times per annum, although there are wide variations related to age and socio-economic group membership.
Some 12% of people who consult the g.p. are referred to hospitals for tests, investigation or treatment (C.S.O., 1981).

The job definition of the g.p. made by the Royal College of General Practitioners specifies that the g.p. should supply:

"personal, primary and continuing medical care (intervening) educationally, preventively and therapeutically."

(R.C.G.P., 1972; p.1)

The g.p. in the U.K. is usually self-employed and paid a Capitation Fee for each patient per year, plus certain allowances depending on the geographical location of the practice (e.g. whether it is rural or urban), the services he or she provides patients, (e.g. contraceptive advice), how long she or he has been in practice etc. Fuller descriptions of the N.H.S. organisation and the position of g.p.s therein are provided by numerous sources (e.g. Mechanic, 1978; pp. 315-334).

The g.p. is contractually responsible to provide all "necessary and appropriate medical services... at his practice premises or if the condition of the patient so requires, elsewhere in his practice area" (Coleman, 1982; p.34). To aid them fulfill their contractual obligations g.p.s often employ nurses and nearly all employ clerical staff and/or receptionists. In fact 24% of practices employ one or more nurses (Reedy, Philips and Newell, 1976). Nurses are also provided by Local Health
Authorities (L.H.A.), in the form of district nurses, health visitors and midwives, all of whom make home visits. In 1974 68% of English g.p. practices had L.H.A. nursing staff attachments, although there was great regional variation in this figure (from 17% to 80%). Traditionally L.H.A. nurses have treated patients at home while practice employed nurses have worked in the surgery. This however is slowly changing, as Reedy's (1979) review of the composition of the health team reveals.

Terminal Patients

Plainly speaking a terminal patient is one who is suffering from an illness from which he or she is dying. There are approximately 600,000 deaths each year in the U.K. of which 3% are from external causes (e.g. road accidents). Table 1.01, which has been adapted from O.P.C.S. figures (O.P.C.S., 1984; pp.14-19), shows the number of deaths in 1982 for the major causes of death. Although respiratory and cardiovascular diseases account for more deaths per annum than the cancers, they tend not to be treated as terminal illnesses because their outcome tends to be less certain. There is also a sense in which they tend to be used as default options on the death certificates of the elderly since "old age" is not an acceptable cause of death for this medico-legal document.

Terminal illnesses are special cases, in so far as the death of the patient is expected, if not by the patient him or herself at least by people who are caring for him
or her. The terminal patient has been defined as one, for whom:

"following accurate diagnosis, the advent of death is certain and not too far distant and for whom treatment has changed from the curative to the palliative."


The terminal stage may last only a few days, but in the cases of many cancer patients and a few patients suffering from certain less common diseases, it often lasts a number of months or even years. Since the vast majority of terminal patients suffer from forms of cancer we now consider aspects of the disease and its treatment. This is of particular importance since cancer and its treatment forms much of the backdrop to those aspects of dying patients which we will be considering in this thesis. Moreover the treatment of the patient's disease is the raison d'etre of interactions between doctors and patients and the context within which communication takes place. Such contextualisation of communication within the action of treatment will have important implications for the communication. This is a point often overlooked in the literature of doctor patient communication (e.g. the work of Ley reviewed below). However, the importance of such contextualisation is clearly revealed by more descriptive studies. Sudnow (1967), for example, shows how aspects of physical treatment and the structuring of medical work set parameters on communications about death and dying, can be used to control communication by medics, but also in itself is informative to patients, relatives and staff.
Table 1.01
Deaths by cause and sex in 1982

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
<th>% All causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancers</td>
<td>70,026</td>
<td>52,422</td>
<td>122,448</td>
<td>21%</td>
</tr>
<tr>
<td>Circulatory system diseases</td>
<td>139,717</td>
<td>144,529</td>
<td>284,246</td>
<td>49%</td>
</tr>
<tr>
<td>Respiratory system diseases</td>
<td>43,652</td>
<td>44,459</td>
<td>88,111</td>
<td>15%</td>
</tr>
<tr>
<td>All other diseases disorders and conditions</td>
<td>25,199</td>
<td>42,247</td>
<td>67,446</td>
<td>12%</td>
</tr>
<tr>
<td>Accidental deaths</td>
<td>7,658</td>
<td>5,649</td>
<td>13,307</td>
<td>2%</td>
</tr>
<tr>
<td>Other external causes</td>
<td>3,914</td>
<td>2,389</td>
<td>6,303</td>
<td>1%</td>
</tr>
<tr>
<td>All diseases</td>
<td>278,594</td>
<td>283,657</td>
<td>562,251</td>
<td>97%</td>
</tr>
<tr>
<td>All external</td>
<td>11,572</td>
<td>8,038</td>
<td>19,610</td>
<td>3%</td>
</tr>
<tr>
<td>Total deaths</td>
<td>290,166</td>
<td>291,695</td>
<td>581,861</td>
<td>100%</td>
</tr>
</tbody>
</table>

Cancer  Cancer currently accounts for approximately 20% of annual mortalities. In 1980 there were 201,533 new cases of cancer diagnosed and registered in England and Wales. On any one day some 14,559 N.H.S. hospital beds are in use for the treatment of cancer out of a total number in use in England and Wales of 157,889 (C.S.O., 1983; D.H.S.S., 1983a, 1983b). The average stay in this bed for a cancer patient is 13.3 days compared with 12.1 days for all causes. Thus approximately 10% of hospital beds are occupied by a cancer patient at any one time. Figure 1.01 below shows incidence and mortality for some selected cancers.

-8-
Cancer registrations (approximate incidence) (ICD 140-209)

<table>
<thead>
<tr>
<th>Number</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,639</td>
<td>Eye, brain and other nervous system</td>
<td>1307</td>
</tr>
<tr>
<td>1,990</td>
<td>Mouth and pharynx</td>
<td>1274</td>
</tr>
<tr>
<td>1,948</td>
<td>Oesophagus</td>
<td>1564</td>
</tr>
<tr>
<td>27,293</td>
<td>Lung</td>
<td>21,927</td>
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<td>7,260</td>
<td>Stomach</td>
<td>6,874</td>
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<tr>
<td>2,846</td>
<td>Pancreas</td>
<td>5,157</td>
</tr>
<tr>
<td>10,485</td>
<td>Large intestine and rectum</td>
<td>2,568</td>
</tr>
<tr>
<td>5,752</td>
<td>Leukaemias and lymphomas</td>
<td>4,772</td>
</tr>
<tr>
<td>10,581</td>
<td>All other cancer</td>
<td>9,015</td>
</tr>
<tr>
<td>92,307</td>
<td>Total cancer</td>
<td>89,783</td>
</tr>
</tbody>
</table>

Cancer deaths (ICD 140-209)

<table>
<thead>
<tr>
<th>Number</th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,509</td>
<td>Eye, brain and other nervous system</td>
<td>1,069</td>
</tr>
<tr>
<td>927</td>
<td>Mouth and pharynx</td>
<td>591</td>
</tr>
<tr>
<td>2,085</td>
<td>Oesophagus</td>
<td>1,623</td>
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<tr>
<td>26,978</td>
<td>Lung</td>
<td>11,015</td>
</tr>
<tr>
<td>6,698</td>
<td>Stomach</td>
<td>7,646</td>
</tr>
<tr>
<td>3,008</td>
<td>Pancreas</td>
<td>4,253</td>
</tr>
<tr>
<td>7,526</td>
<td>Large intestine and rectum</td>
<td>8,904</td>
</tr>
<tr>
<td>4,703</td>
<td>Prostate</td>
<td>3,784</td>
</tr>
<tr>
<td>2,939</td>
<td>Bladder</td>
<td>2,153</td>
</tr>
<tr>
<td>605</td>
<td>Skin</td>
<td>1,504</td>
</tr>
<tr>
<td>4,248</td>
<td>Leukaemias and lymphomas</td>
<td>3,673</td>
</tr>
<tr>
<td>6,754</td>
<td>All other cancer</td>
<td>6,313</td>
</tr>
<tr>
<td>68,107</td>
<td>Total cancer</td>
<td>56,681</td>
</tr>
<tr>
<td>295,505</td>
<td>Total deaths of which cancer is</td>
<td>290,396</td>
</tr>
</tbody>
</table>

Figure 1.01

This figure is reproduced from the "Report of the Advisory Committee on Cancer Registration, MBI no. 6" (Acheson, 1980: p.6) with the kind permission of the authors.
Although "cancer" is a term regularly used and accepted in common parlance it does not actually refer to a single disease entity. "Cancer" refers to a family of related diseases characterised by the presence of a tumour or tumours in the host. Tumours (or neoplasms) consist of an abnormal mass of cells, together with a supporting connective tissue framework. Although in some ways the cellular structure of neoplasms may be similar to that of normal cellular growth, it is characteristically uncontrolled and seemingly independant of the factors which control and restrain normal growth. Some tumours are "benign" in that they remain localised and are thus normally curable. others however are "malignant" growing not only by expansion, but also by infiltration, whereby cells become detached and invade other areas of the body. Tumour cells which settle in distant parts of the body give rise to "secondary" or "metastatic" tumours. Tumours are generally classified by oncologists on the basis of two characteristics.

a) **Tissue of origin.** Malignant neoplasms arising from the epithelial surfaces of the body (e.g. lung tissue) are called carcinomas. Those arising from non-epithelial cells (e.g. muscle or bone) are known as sarcomas.

b) **Microscopic structure.** Both carcinomas and sarcomas are subclassified by their microscopic cellular structure. There are also several other categories, which are highly specific in nature. These are described by Portlock and Goffinet (1980), who also give further references for
classification and staging of cancers (p.303).

The growth of a tumour or tumours in the body eventually causes damage to systems of the body thereby giving rise to symptoms. If the growth of the tumour goes unchecked, it will eventually damage a vital system of the body to such a degree that death will ensue. This characteristic of cancer gives rise to one of the major problems for a clinician attempting to make a diagnosis, since it does not result in a recognisable and unique set of signs and symptoms upon which to base a diagnosis of cancer. The symptoms which occur as a result of a cancer developing in an organ or system are no different from those which occur as a result of many other disorders of that organ or system. Even the presence of a mass is not conclusive evidence, although it may raise the clinician's "index of suspicion". It is rare for a differential diagnosis not to be considered first, thus inhibiting prompt intervention. Certain diagnosis is rarely possible without hospital investigation, using specialist (and normally invasive) techniques. The most commonly used diagnostic techniques include: x-ray photography after the introduction of some opaque substance, isotopic or ultra-sound scanning, endoscopy and investigative surgery.

As well as diagnostic difficulty there are other factors which result in delays occurring before treatment is implemented. For example before a patient will go to a doctor, she or he must first notice symptoms considered
sufficiently important and worrying. In many cases by the time the neoplasm is causing noticeable symptoms it has already grown to a dangerous size and/or spread. There are other possible reasons for patients not seeking medical help immediately they become aware of a state of ill health (Zola, 1973).

Treatment of Cancer In Britain a potential patient will normally first present to his or her g.p. Within the N.H.S. system the patient can routinely access hospital and specialist services only through this channel and even in the private sector this is the usual route to specialist services (Silverman, 1984).

In more than 2/3s of cancer cases a referral is made by the g.p. to a specialist (Sellwood, 1977). This may be either because of the seriousness of the illness or because of diagnostic difficulty. The patient with cancer has an average of 5.1 consultations with his or her g.p. whilst the mean for all diseases is 1.7 consultations per episode. Cancer is thus more associated with multiple g.p. consultations than other illnesses. This is in itself not surprising, given that few illnesses result in this sort of multiple consultation. However, these figures belie the possibility that a subset of the cancer patients receive the majority of the consultations. Also these figures are incapable of revealing any qualitative difference
between g.p. consultations with cancer patients and those with other patients. Research into g.p. consultations is reviewed in Chapter 2, but one obvious possibility is that consultations with cancer patients are longer than the 6 minute average g.p. consultation reported by Balint and Norell (1973).

According to Sellwood (1977) the g.p. most often makes the referral to a surgeon, who must then organise investigations leading to certain diagnosis and management. Once the diagnosis is made treatment aimed at cure may be initiated. Treatment relies on 3 major modes which may be used separately, in conjunction or in sequence depending on the nature of the specific cancer. The 3 pillars of treatment are

1) **Surgery** The tumour(s) and surrounding tissue are surgically resected.

2) **Radiotherapy** The tumour and/or affected tissue are bombarded with radiation(s) of the electromagnetic spectrum in the $10^{-3}$ cm to $10^{-1}$ cm range (x-rays, gamma and beta rays/particles).

3) **Chemotherapy** Chemicals are given to the patient in an attempt to destroy the tumour. More than 30 chemicals are at present in use in cancer treatment (Fairley and Tattersall, 1977).

All three modes of treatment are highly invasive for the patient and cause in many cases unpleasant and distressing side effects, as well as requiring hospitalisation. For
example the present generation of anti-cancer drugs have the disadvantage that they do not specifically target the cancer cells, but also attack and destroy healthy cells. Thus these cytotoxines have the effect of making the patient feel more ill while destroying cancer cells. For an indication of how specific cancers are treated using these 3 modes of treatment the reader is referred to Portlock and Goffinet (1980).

There is thus great diversity in the treatment regimens used, resulting in differences in the treatment of very similar cases. This is reflected in Portlock and Goffinet's disclaimer (p.xi) that their manual is in any way "a cookbook of management". Thus it is important to recognise that the terminal patient tends to have received, and/or is (still) receiving a variety of treatments which can be highly distressing and may have major psychological affects. We turn now to briefly consider the psychological concomitants of cancer and its treatment.

Psychological Concomitants of Cancer

Galen (A.D. 131-201) is attributed with an early report of a relationship between psychological variables and cancer when he observed that cancer was more frequent in "melancholic" than in "sanguine" women. Since that early observation the literature on the relationship between psychological variables and cancer has burgeoned. Fox's scholarly review, now nearly 10 years old, focusing on
one issue within this literature (psychological factors in the etiology of cancer) adjudges to the size of the literature since it runs to 88 pages and cites more than 400 contemporary publications (Fox, 1978). Much of this literature is within the tradition of psychosomatic research seeking causal factors for cancer, (e.g. relationships between stress and rate of cancer growth) and seeks to identify any mediating psychobiological pathways. However, a review of this literature is beyond the scope of this thesis. The collection edited by Stoll (1979), and the review papers of Fox (1976, 1978) Greer (1979) and Greer and Silberfarb (1982) provide excellent introductions to this complex area of research. A more comprehensive bibliography of the literature is available from the present author on request.

Since we are interested in terminal care, we will briefly consider the effects of treatment on patients' psychological state. When considering the papers reviewed below, it is necessary to appreciate that it is difficult, if not impossible, to completely isolate treatment effects from the other concomitants of a specific cancer, be those concomitants cause or effect of the cancer per se. A further caveat as regards this literature is that, for both methodological and theoretical reasons a high proportion of studies have elected to investigate women with breast cancer, and this is particularly true of more recent studies. Since women are more likely to die in hospital than men (Cartwright, Hockey and Anderson, 1973),
it is not clear to what degree the studies to be reviewed, even when conducted in this country, reflect the same population as that which is the object of our studies.

Psychological responses to the treatment of cancer The treatment of cancer is invariably highly invasive for the patient and can require periods of hospitalisation for surgery, radiotherapy, chemotherapy or a combination of these. The average person will find any of these procedures threatening, or bluntly frightening. Thus one may expect the very treatment of the cancer to affect a patient's psychological state.

A number of studies have reported the psychological effects of treatment regimens per se on patients. A brief overview of this research literature is given with the aim of equiping us with information pertinent to the patient population of our studies. The review is by no means exhaustive and care has been taken to present only well conducted studies and report only their most soundly based findings. It is beyond the scope of the present review to enter into a number of the debates raging within this literature, except in the most superficial terms, since they revolve around the specifics of different treatment regimens different methods of defining and staging patients' cancers etc.
Surgery In a prospective study of women adjusting to treatment of breast cancer by mastectomy, Morris, Greer and White (1977) found that women who remained stressed by the operation at two year follow up were characterised by high preoperative neuroticism levels as assessed by E.P.I.. Preoperative depression (assessed by Hamilton Rating Scale) also predicted poor adjustment, but psychosocial variables (e.g. marital, sexual and interpersonal relationships) were not related to postoperative adjustment.

One of the most radical operations currently performed, is in treatment of anorectal tumours and consists of abdominoperineal resection of the rectum with construction of a permanent colostomy. The problems of patients who have received this operation are extensive. They commonly include postoperative depression, social isolation and sexual difficulties which in many cases threaten the marital stability of the patient (Devlin, Plant and Griffin, 1971). Similar findings have been reported for various major surgical interventions for various cancers (Sutherland, Orbach, Dyk and Bard, 1952; Sutherland, 1967), for disfiguring surgery for maxillofacial cancers (Rozen, Ordway, Curtis and Cantor, 1972) and for ileo-conduit procedures for bladder cancers (Miller, 1977).

Whilst the above studies of major surgical interventions paint a sad picture for the patients, the development of
surgical techniques by which the damage can be "put right", may hold out some ray of hope for patients. Goin and Goin (1981) conducted open ended interviews with mastectomy patients before and after breast reconstruction. They report that younger women reacted more openly, with staged feelings of denial, anger, despair and depression. Older middle-aged women either never moved beyond the stage of denial, or by-passed the early stages and moved quickly into one of "pseudoacceptance". Breast reconstruction relieved many of the women of the "sense of mutilation", gave them more confidence in their appearance with which to face life, especially as anchored in their sexual relationships. The central argument of this report is a refutation of assertions by previous authors that older women are less upset by mastectomy than young women, because their breasts "have served their purpose" (e.g. Renneker and Cutler, 1952).

Schain, Wellisch, Pasnau and Landsverk (1985) report that patients, who had reconstructive surgery at the time or within one year of mastectomy, verbalised significantly less upset than women who did not have reconstructive surgery for more than a year after mastectomy. The picture drawn by way of psychological inventories, however, is somewhat different. The early reconstruction group both exceeded the normal range and displayed a significantly higher level of depressive symptoms than the other two groups. The early group also exceeded the
normal range on 3 further scales but did not differ significantly from the other 2 groups on these. The authors are unable to offer any clear explanation for this pattern of results. Whilst receiving radio- or chemo-therapy did not appear to cause patients to delay having reconstructive surgery, the chemotherapy patients (24% of sample) had higher scores on all scales than did the non-chemotherapy patients, significantly so for 4 scales, somatization, obsessive-compulsive, depression and psychoticism. Common motivations for seeking reconstructive surgery were the wish to wear a wider range of cloths and be rid of prosthesis (75% mentioning), and desire to improve sexual relations (39%).

Steinberg, Juliano and Wise (1985) compared patients who had one year previously undergone radical mastectomies with those who received lumpectomies plus radio-therapy, using standard psychological inventories and interview. The groups did not rate themselves differently in terms of present physical health. Lumpectomy patients reported less loss of feelings of attractiveness and were less self conscious of their appearance. They also received more social support, were more comfortable talking about their sexuality and saw their sexual partners as more sexual than did the mastectomy patients. The mastectomy patients rated themselves as less comfortable talking to their partners about their surgery. The groups did not differ significantly in anxiety or depression, but the mastectomy
group showed greater adjustment difficulties to life after surgery than did the lumpectomy group. Overall the researchers conclude that there are "some important psychological advantages associated" with lumpectomy over mastectomy where it is practicable.

**Chemotherapy** Holland (1977), in a paper addressed to clinicians, proffers practical advice in the management of cancer patients receiving chemotherapy, and stresses the psychological impact of treatment side effects. Holland alludes to a paradox facing oncologists telling patients about the treatment they are to receive. On the one hand, informing patients about side effects that may occur often makes them easier to bear when they do. But on the other hand, anticipatory anxiety can in some cases stimulate the side effect, thus nausea and vomiting can arise before the patient receives the drug. He also points out that some side effects have different significance and cause different problems for different groups of patients. Alopecia, a common side effect, is a case in point, being reportedly particularly distressing to women, teenagers and young adults of both sexes. Weakness and fatigue, which occur as a result of some antitumour agents, can cause distress via the social isolation they engender. The neurotoxicity of a variety of drugs have a variety of affects, which include confusion, delerium, depression, hyperactivity, insomnia, dizziness, ataxia, paralysis and stuttering. These affects are a consequence of direct neuronal damage, and
this is not always reversible. Effects on the autonomic nervous system can cause gastrointestinal cramps, constipation, and impotence, each of which will have psychological consequences. In one study conducted by Holland, Fasanello and Ohnuma (1974) the chemotherapy agent administered reportedly caused affects comparable to psychiatric symptomology in 26% of patients who received it.

Silberfarb, Philibert and Levine (1980) used a battery of standard tests to assess the cognitive functioning and behaviour of a group of patients admitted to hospital for chemotherapy. In summary, their central finding is that, regardless of the specific agent being administered, the site of the primary tumour, or the presence or absence of metastases, patients receiving chemotherapeutic agents exhibited lower levels of cognitive functioning than did nonchemotherapy patients. Patient scores on tests of affect ruled depression and/or anxiety levels out as factors causing the low cognitive functioning of the patients. The results of this study would suggest a reevaluation of conclusions drawn in studies such as that of Davies, Quinlan, McKeegney and Kimball (1973), who report that physical factors related to the illness appear to be the most important determinants of patients' psychological adjustment to advanced cancer. The patients in the Davies et al. study were all receiving chemotherapy, but no attempt appears to have been made to take the effects
of treatment into account in the analysis of results. It thus seems reasonable to attribute their findings at least in part to effects of the cytotoxins with which patients were being treated. Thus their "paradoxical" finding, that patients exhibiting impairment of "brain functioning" survived longer than those without cognitive impairment, may well reflect differences in treatment regimens and their psycho- as well as cyto- toxic effects. But, interpretation of these results remains problematic because of the compounding of treatment and illness effects; a problem which bedevils research in this field.

Radiotherapy Although designed with the intention of finding a solution to a clinical problem, a study by Parsons, Webster and Dowd (1961) clearly demonstrates that radiotherapy can have dramatic effects on patients. Parsons et al., in a double blind study, evaluated the effect of the administration of placebos in the treatment of radiation sickness caused as a side effect of radiotherapy. They report that "61 to 72% of all patients suffering from so-called radiation sickness would respond favorably to placebo medication" (p.129). Although site of irradiation, cumulative radiation dose and sex of patient are related to the effectiveness of placebo, what is clear is that radiotherapy effects a large proportion of patients in a way that, since it is responsive to placebo treatment, must be psychologically mediated. The present author would suggest that the prime contender for this mediation is the expectation by both medical staff
and patients that radiotherapy will cause vomiting, an expectation alluded to by Parsons et al. in their paper. But in spite of this finding, it is still commonly believed that radiotherapy causes nausea and vomiting (see Crowther, 1982: p.213).

Forester, Kornfeld and Fleiss (1978) compared levels of anxiety and depression of two groups of patients receiving either betatron or halflinear accelerator therapy. Anxiety and depression levels were high in both groups, but decreased for patients receiving treatment on the linear accelerator and increased in betatron patients over the ensuing weeks. These results are explained as resulting from gross physical differences in the nature of the two machines and the rooms in which they were situated: the linear accelerator being small, quiet and rotating during operation, the betatron large noisy and stationary. This explanation was born out by patient reports. Patients treated on the former machine did not express any strong emotions or attitudes about it, but those treated on the betatron machine reported being terrified by the experience. Patients who reported not knowing their diagnosis were initially less depressed than patients who knew they had cancer. But as treatment progressed the former became more depressed, although their depression scores were still lower than those who knew at the end of treatment. One caveat must be made concerning this study. Patients were receiving treatment for a variety of different cancers. The two machines were
differentially used for treatment of different forms of cancer, although there was "no hard and fast rule". It is thus possible that the differences in affective responses may have been a function of the diseases, rather than the machines used for treatment. While the authors reject this interpretation they fail to provide good evidence that this is not the case. Similarly no data is provided upon the basis of which one could reject a disease based hypothesis to explain the different affective responses of patients who knew their diagnoses compared to those who did not.

Combinations of treatments Silberfarb, Maurer and Crouthamel (1980) studied women receiving 3 different levels of treatment for their breast cancers. The categories of treatment represent the 3 major treatment strategies for breast cancer. Primary therapy consists of mastectomy aimed at cure, and occasionally includes adjunctive radio- or chemo-therapy. Recurrent therapy occurs at the first recurrence of cancer, is primarily palliative and typically consists of radiation or ablative hormone therapy. Final therapy is the last potential line of disease control, is purely palliative and consists of chemotherapy. The commonest problem for all 3 groups of women was situated in their relationships with their sexual partners. The most emotionally disturbing period was the first recurrence of the cancer, which was clearly due to the realisation that cancer had not been cured the first time round. Perhaps surprisingly the women
receiving final treatment reported less depression and anxiety than did those in the other two groups. Physical disability was not simply and linearly related to an increase in emotional disturbance. Whilst the receipt of radiation therapy, especially at primary treatment, was associated with higher levels of distress, receipt of adjunctive chemotherapy was not. The authors suggest that radiotherapy may increase patients' feelings of loss of control over the illness mediating their distress.

In summary then it is clear that there are a number of psychological and social concomitants of cancer. Some psychological effects are related to the disease process itself. These may be mediated either physiologically via biochemical changes occurring in response to the pathology, or socially, via for example patient self perception. There are clearly also psychological responses to treatment, again mediated physiologically and socially. To complicate the issue further it is clear that there are psychological and social factors which are precursors of cancer. These may predispose people to develop the disease and/or influence the prognosis. We may thus expect to find in our patient sample a sizeable proportion of patients suffering from psychological effects of cancer and its treatment. It should be noted that since, for example, the psycho-toxic effects of cyto-toxins are not restricted to patients who know their diagnosis, such psychological effects are likely to be spread throughout the sample. What is more, since we are
interested in patients being treated at home it is likely that the more extreme psychological disturbances will not be represented in the sample. This is because such extremes are more likely to be hospitalised.

Under the modern treatment regimen of cancer the patient is not simply referred by a g.p. to a specialist who hospitalises the patient for treatment which is either successful, resulting in cure and return home, or unsuccessful in which case the patient dies in hospital during treatment. Many cancer patients enter hospital for initial tests and treatment and then experience an extended period of return visits both as outpatients and as inpatients to the hospital for further treatment. In the case of chemotherapy for example it is not uncommon for a patient to spend 1 week in 4 in hospital for treatment over a period of 6-9 months or more. During this period the degree of contact with the g.p. can differ greatly, depending on a number of factors. The factors involved may include the specific nature of the treatment, psychological features of the g.p., the patient and their relationship, the family, the patient's health, the g.p.'s practice organisation, workload etc. These factors can interact in a complex fashion and may result at one extreme with no contact between g.p. and patient and at the other with extremely regular contact, perhaps in excess to that required.

The extended period of treatment may be successful,
resulting in cure of the patient (at least in terms of the 5 year survival criterion usually used), or unsuccessful in that the patient's condition deteriorates and she or he eventually dies, either at home or in an hospital or other institution. This aspect of patient death is of some importance to ourselves and it is considered more fully below.

Place of death and place of terminal care

Table 1.02 below shows the number of deaths that occurred in 1982 in different places for all causes of death (O.P.C.S., 1984).

Table 1.02
Deaths in 1982 by sex and place death occurred: All causes.

<table>
<thead>
<tr>
<th></th>
<th>N.H.S Hospitals</th>
<th>Other Institutions</th>
<th>Private Homes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>162,413</td>
<td>20,304</td>
<td>107,449</td>
<td>290,166</td>
</tr>
<tr>
<td>Females</td>
<td>164,475</td>
<td>41,667</td>
<td>85,553</td>
<td>291,695</td>
</tr>
<tr>
<td>Total</td>
<td>326,888</td>
<td>61,971</td>
<td>193,002</td>
<td>581,861</td>
</tr>
</tbody>
</table>

Some 56% of both males and females died in N.H.S. hospitals, while 30% of males and 25% of females died in their own homes. A greater proportion of women than men die in institutions other than N.H.S. hospitals (12% compared to 5% respectively). Cartwright et al., (1973) report a similar finding in a sample of deaths which were followed up and offer the interpretation that as women die at an older age than men, a woman is more likely to nurse
her spouse at home during his last illness and then have no-one to help her at home as she becomes frailer and enters her own final illness. Thus the female is more likely than the male to enter an institution towards the end of life and subsequently die there.

Table 1.03, based on O.P.C.S. (1984) figures, breaks down the causes of death by illness to consider where people die from cancer, as compared to other diseases. The table reflects the oft quoted statistic that two thirds of deaths in the U.K. happen in hospital, whereas the proportion in the U.S.A. is somewhat higher at approximately 80%. It is perhaps surprising to note that the percentage of deaths from cancer occurring in hospital remains similar to the overall figures, with 68% of cancer deaths taking place in hospitals, compared to 66% of deaths from other illnesses occurring there.

Table 1.03
Deaths in 1982 by place death occurred and cause as a percentage of total deaths from diseases

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>N.H.S Hospitals</th>
<th>Other Institutions</th>
<th>Private Homes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>14%</td>
<td>2%</td>
<td>8%</td>
<td>24%</td>
</tr>
<tr>
<td>Other diseases</td>
<td>42%</td>
<td>9%</td>
<td>25%</td>
<td>76%</td>
</tr>
<tr>
<td>Total</td>
<td>56%</td>
<td>11%</td>
<td>33%</td>
<td>100%</td>
</tr>
</tbody>
</table>

It is, however, unclear how much of the terminal care of these cancer patients actually occurred in hospital, since a patient does not necessarily receive the majority of his or her terminal care in the place in which he or she
eventually dies. It is not uncommon for a patient to receive months of care at home and then just before death to be admitted to hospital. This may be because a serious downturn in the patient's condition results in the family not being able to cope at home, or because "last minute" measures to prolong life require hospitalisation. Alternatively it is possible that after months of treatment in hospital aimed at cure, it becomes clear to the medical team that cure is impossible. The patient may then be released from hospital, eventually to die at home. In their study Cartwright et al (1973) report that 37% of patients who died at home, had spent time as inpatients during the year preceding death; 18% of all the patients who died, had been released from hospital in the months immediately prior to death. In these cases 71% of the deaths were expected by relatives. By comparison 39% of deaths at home with no history of hospital treatment were expected.

The other estimate of interest for ourselves in this vein is that 89% of people who died (whether at home or in hospital) spent most of the previous year at home. The available statistics do not distinguish between the two antagonistic processes ("release to die" and "last minute heroism") so it is difficult to accurately identify how many people receive the majority of their terminal care at home per annum. What is clear is that of the 130,000 or so deaths per annum from cancer a sizeable proportion will have received care from their g.p. at home. On the
basis of the available statistics we estimate that in excess of 40,000 cancer patients per annum do most of their dying at home under the care of their g.p..

There are thus considerable numbers of people receiving substantial amounts of terminal care from their g.p.s each year in this country. As we shall see when reviewing the literature, previous studies of terminal care have predominantly been carried out in hospitals and other institutions such as hospices. But at least a third of terminal care seems to occur in the patient's home under the supervision of the patient's g.p.. In these cases many of the problems facing terminal patients will be very different to those encountered in hospital. It also seems reasonable to suspect that the patient groups (i.e., terminal patients dying at home and terminal patients dying in hospital) may themselves differ on a number of dimensions (psychological, social, as well as medical).

The content of terminal care

The report of the working group on terminal care of the D.H.S.S. standing sub-committee on cancer asserts that,

"The main aim of those providing terminal care should be to improve the quality of daily life by removing or alleviating unpleasant symptoms and helping prevent the patient from suffering fear or loneliness. Many distressing symptoms may be relieved by good basic nursing care.... Surveys have confirmed that pain is a major problem among terminal cancer patients, and also that most of the pain is unnecessary and due to poor medical management."

(Wilkes, 1980; p.3)
According to Cartwright et al's (1973) report the main help required by patients at home prior to death are lifting, washing, bathing, (un)dressing, using the lavatory and getting into and out of bed, help with housework (such as shopping and cooking), help to get out of the house (e.g. a driver) and someone to collect the pension. The major medical help needed by patients is in taking medicine or tablets, relatively few require injections or the dressing of wounds. Although these figures refer to deaths from all causes and one may expect terminally ill cancer patients to need more medical help, it is apparent that the burden of terminal care does not require great expertise and can be carried out by a healthy relative. Even the more technical skills of (e.g.) giving injections and dressing wounds can be taught to a willing relative, with the g.p. and to some extent the district nurse, taking a supervisory and monitoring role. But nursing a dying relative can be extremely hard work, especially if the illness continues over a period of months, and not all relatives are capable or willing to supply the help needed. The responsibility for care of the dying patient normally falls to the spouse and/or daughter, with sons, siblings, and other relatives respectively playing lesser parts.

Although this thesis is primarily concerned with the g.p. and the terminally ill patient, g.p.s today rarely practice in isolation, but involve a number of other professional workers in their patient care. A brief
resume of the care proffered by other professionals is necessary. Approximately 33% of patients who die and have been at home during the previous year receive help from the district nurse. Much of this care is relatively short term in nature, half being for less than a month, the latter presumably during a crisis before the patient dies or enters hospital. Cartwright et al (1973) report that there is also a sizeable number of patients who receive regular visits from a district nurse. If we extrapolate their figures to our estimate of 40,000 patients doing most of their dying at home some 5,000 patients would be visited by a district nurse at least daily for 1 to 3 months, and 3,500 for between 3 months and a year. The work done by the district nurse for the terminal patient obviously differs greatly according to individual circumstances. However much of it is similar to that provided by relatives, lifting, washing, bedmaking etc. Beside the g.p. the district nurse is probably the most important professional involved in the home care of the terminally ill. In fact the district nurse is likely to have more contact with the patient and his or her family than the g.p., or any other professional worker (Table 1.04).
<table>
<thead>
<tr>
<th>Professional or service</th>
<th>% aided by this professional or service</th>
</tr>
</thead>
<tbody>
<tr>
<td>District Nurse</td>
<td>33%</td>
</tr>
<tr>
<td>Health Visitor</td>
<td>8%</td>
</tr>
<tr>
<td>Other nurse</td>
<td>5%</td>
</tr>
<tr>
<td>Social Services</td>
<td>10%</td>
</tr>
<tr>
<td>home help</td>
<td>10%</td>
</tr>
<tr>
<td>Special Laundry Service</td>
<td>2%</td>
</tr>
<tr>
<td>Chiropodist</td>
<td>11%</td>
</tr>
<tr>
<td>Minister of Religion</td>
<td>29%</td>
</tr>
<tr>
<td>Other local authority or voluntary service</td>
<td>12%</td>
</tr>
<tr>
<td>None of above</td>
<td>41%</td>
</tr>
</tbody>
</table>

(adapted from Cartwright et al, 1973; Table 19 p. 33)

The category other local authority or voluntary organisation includes an important source of help for a number of terminal cancer patients. A number of voluntary organisations aim their services at areas not adequately covered by the statutory authorities. Of major importance are the night sitting services provided by such organisations as the Marie Curie Memorial Foundation and the National Society for Cancer Relief. Although the help received from these sources is of major importance to those who receive it, the number helped is a small proportion of those who would benefit from such help.

Communication between the district nurse and the terminally ill. The rest of this thesis focuses on the communication between the g.p. and terminal patient. Yet district nurses tend to have far more and regular contact with the patient and spend more time with the
A word of explanation appears pertinent as to why we have investigated g.p.s rather than nurses. The g.p. is the person who is responsible for the care of the patient and he is (at least theoretically) pivotal in the administration and coordination of the patient's care. The g.p. is thus the one who must make decisions about the patient's care even though responsibility for carrying it out may be delegated to others. The nurse carries out the day to day routine care, but in a sense this is done under the authority of the g.p.. Even though the nurse may actually be an employee of the N.H.S. Local Health Authority (and thus under the authority of its Nursing Officer), the nurse is perceived by the majority of patients and their families to be the agent of the general practitioner and acting under this authority. Nurses also consider, in most cases, the doctor to be the correct person to make decisions about treatment and related issues. Thus a decision to communicate information about illness or treatment to a patient or family is customarily seen by all involved to be the doctor's perogative. This point is confirmed by Tiffany's (1977) assumption that it is "the doctor who has had a "chat" with the patient," (p. 75) in his discussion of nursing cancer patients. Further it is a point amply exemplified in the literature, (e.g. McIntosh, 1978; pp. 71-80; Field, 1983).

The nurse not only sees the doctor as the correct authority for decisions about treatment etc., 79% of
nurses also consider the g.p. to be the best person to impart any information to a patient (Cartwright et al., 1973). Only 2% of nurses responded that the nurse would be the best person to do this. The district nurses interviewed by Cartwright's team described a number of ways for dealing with inquisitive terminal patients. 31% of nurses reported that they would tell the patient to ask the doctor and 65% would avoid the question. Overall the responses suggest that this is widely accepted, probably resulting from training. One respondent for example is quoted as saying: "Usually advise doctor. It is not our place to tell them. We've had this drilled into us." (Cartwright et al., 1973; p.183).

Nurses do not regularly or routinely inform patients of their illnesses, either in hospital or outside. Even in those rare cases when a nurse does inform a patient, it is likely to be done on the authority of the doctor following discussion (Field, 1983). On the other hand the g.p. is not only considered by others, but also considers himself to be the best person to tell. The g.p. is the primary source of information for most patients, with approximately 60% of patients who died and who knew about their condition, reportedly being informed by their g.p.s (calculated from Cartwright et al; 1973: table 64 p.164). But there is a difference in who informs the patient depending on the patient's illness. For diseases other than cancer more than 3 times as many patients are told by their g.p.s than are told by hospital doctors.
whilst for cancer there is about an even split between g.p.s and hospital personnel. One reason this may occur is because the diagnostic difficulties associated with cancer result in firm diagnosis only being made in hospital. But this is probably not the only reason since numerous other disease processes require confirmatory tests to be carried out in hospital. Whatever the reasons underlying this difference the result is the same; g.p.s are responsible for nearly 50% of the telling of terminal cancer patients.

But in the Cartwright et al. (1973) study 50% of the cancer patients who definitely knew they were dying had never been told by a doctor, and 85% had never been told by anybody. Although there are methodological problems with the Cartwright study, the most important being their dependence on third party reports of deceased patients' knowledge, the study reveals that many more patients know they are dying than have been formally told by doctors. A statistic that is regularly quoted in this vein is that

"80% of dying patients know that they are dying and would wish to talk about it and that 80% of doctors deny this and believe that patients should not be told"

(Fletcher, 1973; p. 29)

These figures are however of uncertain validity and probably reflect the difficulties experienced by doctors and terminal patients in communicating with each other.

The findings of Cartwright et al (1973) pose something of
a problem since according to them 50% of cancer patients and 23% of the other patients, who knew that they were dying, were not told by their doctor. In fact only 10% of cancer and 5% of other patients who knew were told by anyone. These statistics reveal one of the issues, which constitute the central core of this thesis. If in the region of 85% of patients, who "definitely knew" that they were dying, had never been told by anyone, how did they arrive at such a firm, accurate, though pessimistic conclusion about their futures?

The other central problem to be tackled in this thesis is reflected by the quotation from Fletcher. Whatever the validity of the figures quoted it is generally recognised that British doctors do not for the most part tell patients when they have cancer and are dying. This has been the focus of considerable media attention over recent years with more than one documentary addressed at the issues involved. For example during the period when the fieldwork reported in this thesis was being undertaken, the B.B.C. screened their "Doctors' Dilemmas" series, one report of which specifically considered the problems of telling cancer patients. The problem can be stated in general terms quite simply. If g.p.s do not tell terminal patients, how can we explain this reticence? Is it simply a function of desire not to upset patients or are other factors involved? This problem will be more carefully formulated later once we have had the opportunity to consider some of the relevant
literature. But let us now consider the plan of this thesis.

Chapter 2 consists of a wideranging and at times disparate review of literature. The main thread of this review is a consideration of empirical research into doctor patient communication. Chapter 3 then reviews a large body of work which has grown up on the basis of the application of role theory notions to the medical endeavour. Chapter 4 describes the research design and core methodologies used throughout the reported research. Chapters 5, 6 and 7 report the results of the first study. A resumé and discussion of these results is given in Chapter 8. This leads into the way the research paradigm was modified for the second study. Chapters 9, and 10 then report the results of the second study permitting us to bring the various threads together again in our discussion and conclusions in Chapter 11.
Fear of death. This matter is one that the patient usually discusses more readily with the chaplain.

Weatherall et al. (1983).
Oxford Textbook of Medicine.
(p. 14)
Good communication between doctors and patients is often considered axiomatic of good terminal care. The D.H.S.S. working group on terminal care asserted that:

"Many problems can be prevented if information is effectively communicated. When the dying patient asks for information the truth should usually be given in a kindly and optimistic way, but still in a way which is recognisably the truth. As their illness progresses patients often wish to know more and often past lies form a barrier so that the patient feels anxious and isolated."

(Wilkes, 1980; p.4)

This statement must be recognised for what it is; a normative description of the way things ought to be. This reflects the nature of the document from which it was drawn; a policy document making recommendations for implementation at a national level. However, there are a number of problematic features in the above statement. First, the assertion commencing with the words "as their illness progresses", is based on the clinical experience and impressions of the authors, not empirical evidence. Second, implicit within the document as a whole is an assumption reflected in the above quotation, that it is simply a matter of doctors telling patients something like, "you have such and such an illness and this will happen", for patients to know what is wrong and the likely outcome. However, the research reviewed below reveals this to be an over simplistic view of what occurs in doctor patient interactions. Finally, it seems reasonable to infer from the above quotation that since the authors feel that it is necessary to extol the virtues of telling patients, not telling them is widespread. Before turning to the specific issue of telling the
terminally ill we consider the more general literature of
doctor-patient communication.

**Communication Between Doctors and Patients**

There have been many studies of the communication between
doctors and patients, the majority of which have been
conducted in institutional settings, normally outpatient
clinics. These studies can be broadly (if
somewhat artificially) divided under two headings; process
and outcome studies. Although there is a certain amount
of overlap, this distinction is used to structure this
section of the review. The purpose of this review is to
expose the general features of and principles underlying
what occurs during consultations. The review is by no
means exhaustive. The primary interest is the
information exchange that occurs during consultations. We
thus concentrate on verbal behaviours during the
consultation, although briefly considering non-verbal
aspects of doctor-patient interactions.

**Outcome Studies of Doctor-Patient Communication**

The major psychological outcome variables which have
received the attention of researchers have been patient
understanding of and memory for information, satisfaction
with the consultation and compliance with prescribed
treatment. The premise underlying the choice of these
variables for study is that high levels of all 4 are
consistent with effective medical treatment. This premise
is made explicit in Ley's model (Ley, 1983) (Figure 2.01).
The important link with treatment in this model is compliance, since if the treatment is to be effective the patient must follow doctor's orders. We will review the major findings for each of these 4 variables in order.

![Diagram of understanding, satisfaction, compliance, and memory](image)

**Figure 2.01**
Ley's cognitive model of the relationship between patient understanding of and memory for medical information, satisfaction with the consultation, and compliance with treatment regimen. (After Ley, 1983)

**Understanding:** The investigation of patients' understanding of medical communications has approached the problem from a number of different directions using different methodologies. One indirect method has been the use of general medical knowledge tests. These assess the likelihood that persons as patients would understand what a doctor told them. While this technique can only unearth common misconceptions, it has done so on a number of occasions. For example Boyle (1970) investigated out-patient clinic attenders' understanding of such ubiquitous medical terms as "diarrhoea", "constipation", "piles", "arthritis" and "a medicine". He found that the number of patients responding correctly to definitions of the words ranged from 37% to 88%. When it came to
identifying the location of major organs in a body outline diagram patients fared even worse. Only 20% correctly identified the location of the stomach. Other organs (e.g. kidneys, heart, lungs) were correctly located by about 50% of the sample and the position of the intestines most reliably identified with 77% correct. It is worth noting, however, that not all of the doctors completing the same questionnaire responded correctly to all questions. Although the locations of all but one of the organs were correctly identified by all doctors, there was some disagreement on the meaning of a number of the medical terms. For example, 31% of the doctors disagreed with the 'textbook' definition given for "diarrhoea". These results could be interpreted in two ways. Firstly they call the validity of the test instrument into question. But such results might also suggest that the doctors were better anatomists than communicators.

Of particular relevance amongst the studies using the general medical knowledge questionnaire methodology is a study conducted by Spelman and Ley (1966). Their questionnaire dealt with the cause, symptoms, treatment and prognosis of 10 common illnesses and was administered to a volunteer sample of the general public. Spelman and Ley report the results of this study as related to subjects' knowledge of lung cancer. While 92% of the sample identified cigarette smoking as a known cause of the disease and 75% that it was commonly treated by radiotherapy, only 55% knew that a persistent cough was
one of its early symptoms and 56% that sufferers of the disease "usually die within 2-3 years of cancer being diagnosed", 17% responding that it is frequently cured. Spelman and Ley interpret these results as indicative of poor knowledge of lung cancer prognosis, especially amongst the "heavy smokers" in their sample of whom 30.4% "erroneously said that lung cancer is frequently cured by treatment" (p. 210).

Findings that patients often have very different understandings of medical terms to doctors and poor knowledge of illnesses, suggest that it is likely that numerous failures of communication in medical settings are related to these divergences in language usage. But linguistic sophistication, in terms of middle class norms, may also play a part. To investigate patients' potential understanding of medical information a number of studies have applied readability formulae to a variety of different medical leaflets and pamphlets. Ley (1982, 1983) reviewing 7 studies conducted by various researchers concludes that over 70% of the leaflets would be understood by less than half the population.

Another method of assessing understanding of medical communications in common usage is patient self report. Although prone to the error that patients report understanding when in fact they do not, even this measure suggests that patient understanding is often low. According to Ley (1980) between 7% and 53% of patients
report not understanding what their doctor told them during the consultation. Behavioural measures of understanding probably give more valid and reliable data on the degree of patient understanding. The preferred method for such studies consists of comparison of consultation content with post consultation patient report of what the doctor said. Since this method inevitably compounds understanding with memory we consider the results of these studies under the heading of memory.

Memory for medical information: Patients' memory for the information given to them by doctors has most often been assessed by interview, although in a small number of studies questionnaires have been used. Most studies have tested patient subjects immediately after or within an hour of the consultation. But some studies have assessed patients' memory at later dates, up to a month after the consultation. However, in none of the studies is there a significant correlation between the proportion of information forgotten and length of time elapsing between the consultation and patients' recall being tested (Ley, 1979a).

Comparisons of the amount of information given by the doctor to the patient and how much the patient recalled on testing, have resulted in a wide range of estimates of the proportion forgotten. For example, whilst Robinson and Merav (1976) report that 70% of the information given to patients preoperatively was forgotten, Bergler,
Pennington, Metcalfe and Freis (1980) say that only 28% was forgotten by another, similar, group of surgical patients. In overview of the research however it seems safe to accept the more conservative estimates based on the work of Ley and various associates which puts the range of the proportion forgotten by patients as between 37% and 50% (Ley, 1982).

Since they consider g.p. and cancer patients, 3 studies are particularly salient. Two studies conducted by Ley and associates (Ley, Bradshaw, Eaves, and Walker, 1973; Ley, Whitworth, Skilbeck, Woodward, Pinsent, Pike, Clarkson and Clark, 1976) investigated patients attending g.p.s and found that, respectively, 50% and 44% of information given by the g.p. was forgotten by the patient. The third study of interest considered cancer out-patients' recall for information presented while obtaining consent to treatment and reports 31% of the information was not recalled by the patients (Cassileth, Zupkis, Sutton-Smith and March, 1980a, 1980b). Clearly these findings are compatible with other findings in this field and suggest that patients attending g.p.s and/or with cancer recall similar quantities of information as more general patient populations.

Overall in this field of research a number of differences between studies may have contributed to differences in the amount patients recall and it is difficult to isolate the specific factors operating in each study. Amongst the
Correlates of memory for medical information have received considerable investigation. The findings for age of patient have been inconsistent. Ley and Spelman (1965) reported that older patients recalled more than younger
ones. But a more common finding is that there is no relationship between age and the amount remembered (Joyce, Caple, Mason, Reynolds, and Mathews, 1969; Ley, 1979a; Brody, 1980). But Anderson (1979) qualifies his finding that there is no clear trend for recall to decline with age, by noting a marked drop in recall amongst the more elderly extreme (70+ years) in his sample.

The relationship between patient anxiety levels and recall is also uncertain. Anderson (1979) reports a linear relationship between anxiety and recall, such that the more anxious the patient rated him or herself to be during the consultation, the higher the recall. But Ley and Spelman (1965), measuring anxiety by the relevant factor of the 16PF, found an inverted U-curve relationship between anxiety and recall, such that moderate levels of anxiety were associated with better recall. Theoretically this later finding is more plausible, and Anderson's results may well be a function of the validity of the self report measure used.

Social class (Anderson, 1979) and sex (Anderson, 1979; Ley 1982) have not been found to be associated with recall. Neither has intelligence per se been found to significantly correlate with recall (Ley, Whitworth, Skilbeck, Woodward, Pinsent, Pike, Clarkson and Clark 1976), although Bertakis (1977) and Anderson, Dodman, Kopelman, and Fleming (1979) found better recall to be associated with higher levels of education. A finding
which has been consistently reported by Ley and coworkers is that recall correlates with the general medical knowledge of the patient (see for examples Ley, 1982).

Above we reported that the way information is presented by the doctor to patients affects the amount patients recall. The sort of information given by the doctor is also of apparent importance as to whether or not it will be recalled at a later stage. Ley and Spelman (1965), for example, report that 86% of diagnostic statements, 44% of advice statements and 62% of other statements made by the doctor were correctly recalled by the patient. This pattern of findings was confirmed by other studies (Ley, 1979a). There have been numerous reports indicating that diagnostic information is recalled most accurately, statements concerning instructions and advice recalled worst, and other statements made by the doctor (e.g. reassurance) being well recalled (Ley and Spelman, 1965; Ley et al, 1973; Ley, Whitworth et al, 1976; Ley, 1979a, 1979b). But more recently the pattern of findings in the earlier studies was shown to be largely a function of primacy and "importance" effects (Ley, 1972). Ley (1979a) asserts that these 2 factors probably account for the majority of remembering.

One finding that seems to be universally confirmed by authors reporting relevant data is that there is a negative correlation between the amount of information presented by the doctor and the proportion of that
information which is correctly recalled (Ley and Spelman, 1965, 1967; Ley et al, 1973; Ley, 1972, 1979a, 1982, 1983; Anderson, 1979; Joyce et al, 1969). So although patients may remember more in terms of absolute numbers of items of information if told more by the doctor (Anderson, 1979), they forget a higher proportion of what the doctor says as he or she gives them more information.

In overview then, work in the area of memory for medical information is one in which the dominant cognitive paradigm of 'pure' memory research has been applied to a practical problem. The results obtained have tended to conform to what one would predict on the basis of cognitive theories of recall memory as outlined in introductory texts to this area of psychology (e.g. Lindsay and Norman, 1972). In conclusion, on the basis of the studies reviewed in the region of 30% to 50% of information given to general practice and cancer patients by their doctors is likely to be forgotten by the patient. While age, sex, socio-economic status and intelligence of the patient are not good predictors of the amount of information the patient will remember, medically sophisticated patients and those who experience moderate levels of anxiety related to seeing the doctor tend to remember a greater proportion of what the doctor tells them. Whether diagnostic or treatment related types of information are well remembered is probably a function of a number of variables. These include aspects of how the doctor presents such information, how much information
overall the doctor gives the patient and the patient’s perception of the importance of the specific information presented. This latter item is one which may directly influence the degree to which the patient complies with the treatment prescribed by the doctor. However, compliance is also related with patient satisfaction, and it is this subject to which we turn next.

**Satisfaction** Firstly let us note a penetrating observation made by Eisenberg (1977).

"It is... curious that dissatisfaction with medicine in America is at its most vociferous just at a time when doctors have at their disposal the most powerful medical technology the world has yet seen. The 'old fashioned' general practitioner, with few drugs that really worked and not much surgery to recommend, is for some reason looking good to many people— in retrospect at least."

(Eisenberg, 1977; p.235)

Rachman and Philips (1978) account for such dissatisfaction, at least in part, in terms of changes in expectations about medicine and health held by the general public. Specifically they point to the lower degree to which we today are willing to put up with discomfort in comparison to the denizens of yesteryear. But whether the patients of today are less satisfied and less willing to put up with illness, than patients of those halycon days, is untestable.

Koos (1955) surveyed a random stratified sample regarding medical care. The biggest criticism, expressed by 64% of the sample, concerned the nature of relationships they had experienced with doctors. A majority of Freidson's (1961)
sample felt that good medical care required that the doctor be interested in the patient as a person. More recently Doyle and Ware (1977) found that the strongest influence on patient satisfaction with medical care was the doctors' conduct toward the patient.

Taking a less direct indicator of patient satisfaction than satisfaction expressed during interview, it was found by Blum (1957, 1960) that doctors who experienced repeated malpractice litigations were insecure with patients, bothered by patients' emotions and derogatory of patients as people. Gray and Cartwright (1953) report that considerable numbers of adults change doctors because of "inadequate treatment and attention", and Kasteler, Kane, Olsen, and Thetford (1976) found that patients' dislike of the doctor as a person, their dissatisfaction with time spent waiting to see the doctor, and perception of doctors' lack of interest in seeing them was significantly related to increased "doctor-shopping".

These studies all point to very general aspects of medical care and vague doctor characteristics as resulting in patient dissatisfaction. Other studies have attempted to identify specific aspects of doctor-patient encounters which influence patient satisfaction levels. But although studies of patient comprehension and recall have used definitions of information sufficiently similar to permit comparison between studies, this is not so clearly the case for studies which have investigated satisfaction.
The main problem here is in differences in the object of patients' reported satisfaction. Whilst Ley and coworkers have been primarily concerned with patients' satisfaction with communication during the consultation (e.g. Ley, Bradshaw, Kincey, and Atherton, 1976; Ley, 1982), other researchers have been more generally concerned with satisfaction for the consultation process overall (e.g. Korsch, Gozzi and Francis, 1968; Korsch and Negrete, 1972), or with satisfaction with the medical care received (Royal Commission on the N.H.S., 1979). Hulka (1979) proposed a composite satisfaction index consisting of three components: satisfaction with (1) professional competence (2) personal qualities of the physician and (3) costs and convenience of care. However, whatever the exact object of the patients' satisfaction or dissatisfaction there has been a fair level of consistency in the proportion of patients who report being dissatisfied. A brief summary of this research is presented in Table 2.01. The first part of this table (Table 2.01a) summarises general levels of patient satisfaction and the second (Table 2.01b) factors associated with patient satisfaction.
Table 2.01
Patients' satisfaction/dissatisfaction with medical treatment.

(a) Levels of patient dissatisfaction with medical services.

<table>
<thead>
<tr>
<th>Patient sample</th>
<th>Percentage of patients dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>N.H.S. hospital inpatients</td>
<td>53% median 18-65%</td>
</tr>
<tr>
<td>N.H.S. general practice patients</td>
<td>35% median 21-51%</td>
</tr>
<tr>
<td>Various U.S. patient groups</td>
<td>36% median 8-51%</td>
</tr>
</tbody>
</table>

(b) Factors associated with patient satisfaction or dissatisfaction.

<table>
<thead>
<tr>
<th>Study</th>
<th>Level of satisfaction</th>
<th>Variables shown to be related to satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Korsch et al (1968)</td>
<td>-</td>
<td>Dr gave no reassurance</td>
</tr>
<tr>
<td>Korsch et al (1971)</td>
<td>+</td>
<td>Dr showed friendly interest</td>
</tr>
<tr>
<td>Korsch &amp; Negrete (1972)</td>
<td>+</td>
<td>Dr discovered concerns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dr dealt with expectations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dr gave specific instructions</td>
</tr>
<tr>
<td>Larsen &amp; Rootman (1976)</td>
<td>+</td>
<td>Dr conformed to patient expectations</td>
</tr>
<tr>
<td>Roter (1977)</td>
<td>-</td>
<td>Increase in patient questions after experimental intervention</td>
</tr>
<tr>
<td>Romm &amp; Hulka (1979)</td>
<td>+</td>
<td>Patient memory of specific information given</td>
</tr>
<tr>
<td>DiMatteo et al (1979)</td>
<td>+</td>
<td>Patient age, sex, S-E group, education level, evaluation of doctor's behaviour and seriousness of illness</td>
</tr>
<tr>
<td>Friedman et al (1980)</td>
<td>+</td>
<td>Dr's personality and non-verbal expressiveness</td>
</tr>
<tr>
<td>Levy (1983)</td>
<td>+</td>
<td>Patient understanding of instructions</td>
</tr>
</tbody>
</table>

* + satisfaction; - dissatisfaction;
Thus it appears that there is a strong relationship between satisfaction overall and satisfaction with the communication skills of the doctor (DiMatteo, 1979). Ley (1982) claims in this vein that it is "likely that satisfaction with communication is a strong determinant of more general satisfaction with the medical encounter" (p.251). Whether it is possible to disentangle the quantitative aspects of doctors' information communication from more general aspects of an individuals' interactive style and medical performance remains to be seen. But however that may be, it appears overall that doctors who are good information communicators satisfy their patients.

Compliance The requirement to cooperate with the doctors' orders is, as we shall see later, a central feature of the patient's "sick role" (Parsons, 1951a, 1951b). It is the recognition that a sizeable proportion of patients fail to comply with treatment that has lent the main thrust to a majority of the studies we have reviewed above. Since levels of patient compliance are of only tangential concern to ourselves, no extensive review of this literature will be given, and the reader is referred to DiMatteo (1979), Ley (1979c, 1981, 1982, 1983), and Stone (1979) for specialist coverage of this issue. However, it is worth noting that non-compliance with treatment is rife, with reports of up to 95% of patients failing to follow doctors' advice as revealed in Table 2.02 below.
Table 2.02
Compliance with medical treatment. Percentages of
patients who fail to follow medical instructions and
advice. Figures given are summaries of the numerous
studies reviewed in three sources: (1) Ley (1976),
(2) U.S. Food and Drug Administration (1979, 1980), and
(3) Barofsky (1980).

<table>
<thead>
<tr>
<th>Type of medication</th>
<th>(1)</th>
<th>(2)</th>
<th>(3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics</td>
<td>39%</td>
<td>42%</td>
<td>43%</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>39%</td>
<td>42%</td>
<td>42%</td>
</tr>
<tr>
<td>Anti-hypertensive</td>
<td>-</td>
<td>43%</td>
<td>61%</td>
</tr>
<tr>
<td>Anti-tuberculosis</td>
<td>39%</td>
<td>42%</td>
<td>43%</td>
</tr>
<tr>
<td>Other</td>
<td>48%</td>
<td>54%</td>
<td>46%</td>
</tr>
</tbody>
</table>

Range failing
to comply 8-92% 11-95% 6-83%

Ley (1979c), summerising the findings of studies which
have attempted to identify the characteristics of
non-compliant patients, concludes that neither patient
socio-demographic and personality variables, nor doctor
characteristics, nor illness variables, appear to be
related to patients compliance or non-compliance.
Variables which appear to be related to non-compliance
include duration and complexity of treatment, patient
levels of dissatisfaction, lack of supportive follow-up,
patients' perceptions of their vulnerability to the
consequences of the illness, seriousness of the illness,
the effectiveness of treatment and the problems treatment
cause patients (Ley, 1979c). These claims are however
problematic, since contradictory findings not considered
by Ley do exist. As Lorenc (1986) argues, the nature of
patient, doctor and illness characteristics which may
predict compliance levels is still an issue open to considerable debate.

Communication, memory, satisfaction and compliance: A brief resume of outcome studies.

Whilst there is considerable evidence of correlations between patient understanding, memory, satisfaction and compliance suggestive that improvements in doctors' communications with patients result in improved levels of compliance from patients (Ley, 1983; Morris and Halperin, 1979), improvements in communication and memory are not invariably associated with increased levels of satisfaction and/or compliance (see e.g. Hulka, 1979; Sackett, Haynes, Gibson, Sackett, Taylor, Roberts and Johnson, 1975). What is more, a recent report of new data and a reanalysis of previous data by Anderson (1986) clearly indicates the existence of a ceiling to patient memory capacities, such that the oft quoted figure of patients recalling about 60% of what they are told by their doctor is only true for the standard doctor patient interaction in which the doctor gives on average some 10 pieces of information. Anderson (1986) reports that the patients of doctors who give large quantities of information forget the vast majority of it, with a memory ceiling of something like 15 items. Some patients in fact clearly suffer information overload effects and would clearly benefit, in terms of amounts recalled, if their excessively informative doctors gave them less information. Another point of importance made by
Anderson (1986) is that there is an assumption that patients share the medico-scientific paradigm of the doctor. That the patient has been able to repeat during the post-consultation recall test, what the doctor said during the consultation has been taken by most researchers as evidence that they understood and recalled it correctly. But this does not necessarily follow. Anderson found that patients' interpretations of what the doctor meant diverged widely from doctors' intended meanings. Thus patients' lay beliefs and cultural expectations about health and illness altered the meanings of what was said so greatly, that only in the most superficial sense did they correctly recall what they were told. Although the sampled population of the latter study was largely a traditional Chinese group, and this certainly exacerbates the difference between lay and medico-scientific belief systems, there are still major differences between doctors and patients' understandings in contemporary British society (Williams, 1983).

Thus although the hypothesis that improved communication will lead to improvements in memory, satisfaction and compliance stands, it is clear that the mechanisms relating the factors are complex and our understanding merely tentative. The literature lacks the definitive prospective studies which could answer many of the outstanding issues raised above. But more tellingly perhaps, there is a tendency within the literature to confound quantity of information with quality, assuming
the more said the better the doctor's communication.

Dunbar, Marshall and Hovell (1979) review a number of methods that have been used to improve compliance, for the most part based on learning theory principles of behaviour modification. As with so many applications of such techniques (see e.g. Linton's (1982) review of behaviour modification of pain) on close scrutiny of studies the exact variables which facilitate changes in behaviour are not easily identifiable, although the various researchers have a tendency to attribute changes to behavioural variables.

It is also worth noting that the underlying assumption of much of the literature reviewed above, that the improvements in clinical efficacy associated with good communication are primarily mediated via increases in patient compliance, remains dubious on the basis of findings reported in another tradition within the medical psychology literature. An association between preoperative psychological state and postoperative recovery (e.g. Janis, 1958) has been the basis of considerable study of the effect of preparing patients for surgery. Patients have been found to require less medication, to recover more quickly and to leave hospital sooner if visited preoperatively by members of the surgical team, given instructions and informed of the effects of surgery (Egbert, Battit, Welch and Bartlett; 1964). Whilst compliance is invoked to explain...
relationships between communication and outcome of treatment in the literature reviewed, only rarely is this the case in the literature concerned with surgical recovery. In this latter literature stress is most commonly identified as the mediator between communication and outcome (see Mathews and Ridgeway, 1981; Ridgeway and Mathews, 1982; Wallace, 1986). This difference in emphasis is possibly a result of the settings in which the research has been conducted. Whilst compliance is an obvious candidate for the role of mediator between communication and outcome in outpatient settings, its role is less clear in the highly structured and supervised situation in which an immediately post-operative patient finds him or herself.

One final point needs to be considered in reviewing this literature. If understanding, memory, satisfaction and compliance in medical settings are to be improved then the doctors themselves must be knowledgable of the findings of the body of research and act on its recommendations. Burton (1986) in a study of surgeons attitudes towards patients, reported on their communicative strategies towards patients, whom they felt did not seem to understand what they were being told. In summary the strategies adopted are, for the most part, totally maladaptive and result in little improvement in patient understanding. For example, a number of doctors repeated information, but in so doing became even more technical in their descriptions, adding more and more
detail. To a patient having difficulty in understanding such an approach only makes them more confused. Lorenc (1986) reports that both g.p.s and hospital doctors have very little knowledge of compliance related issues and that the majority of what they do is based on clinical impressions gleaned during practice. This is often at odds with the results of empirical research.

In conclusion, this body of research suggests that we will encounter many patients who are ignorant of the nature of their illnesses, because of deficiencies in communications between doctors and patients which exist even during simple illnesses. In cases where the patient has a terminal illness these problems may well be exacerbated by the nature of the information to be communicated, since it is both complex and affectively threatening. In order to understand the issues involved here, we need a more detailed picture of what occurs during consultations than is offered by outcome studies.

The Consultation Process.

In reviewing research on outcomes we did not differentiate between studies on the basis of settings, since our interest was only in general principles. Outcome measures such as memory and satisfaction did not appear to be greatly affected by setting. But there is good evidence that the processes involved within interactions between doctor and patient are differentially affected by
settings. Hospital environments, the proximal availability of the technology of diagnosis and treatment, and the way that work is organised within hospitals all make for very different consultations in hospitals compared to those which occur in general practice (Freidson, 1963; Perrow, 1965; Croog and Ver Steeg, 1972; Tuckett, 1976a; Suedfeld, 1979). Whether or not the patient is paying privately also appear to influence behaviour during consultations (Silverman, 1984). But not only these structural factors influence the consultation. The expectations brought by both patient and doctor to hospital consultations differ from those brought to consultations held outside hospital environments with differential effects (Reader, Pratt and Mudd, 1957; Skipper, Mauksch and Tagliacozzo, 1963; Tuckett; 1976a). Thus in reviewing literature on consultation processes and behaviour we concentrate on N.H.S. general practice consultations. On the few occasions that reference is made to studies of consultations other than general practice ones, the nature of the setting is indicated.

Processes and behaviours in general practice consultations

The standard medical model of the consultation, traditionally taught to medical students early during training, describes what should in medical terms happen. The prescribed procedure follows a problem solving logic of (1) history taking, (2) examination, (3) diagnosis, and (4) treatment. Byrne and Long (1976) use this sequence
to define the logical form of the g.p. consultation (Table 2.03). They then applied this to the analysis of audio-recordings of interactions that occurred between some 2,500 patients and their g.p.s. The doctors involved in the study were all volunteers (60 were U.K. g.p.s and 43 practicing overseas), who also controlled the recordings of interactions which were forwarded to the researchers for analysis. Although this selection of doctors and interactions may result in some bias to their data, it is clear that the range of behaviours which occurred in their recordings was wide, from "professionally dreadful" to "outstandingly good" practice. Thus although one may question the frequency of occurrence data for specific behaviours reported, it seems sound to accept the qualitative forms reported.
Table 2.03
The logical form or sequence of events in g.p. consultations as defined by Byrne and Long (1976, p.21).

I The doctor establishes a relationship with the patient.
II The doctor either attempts to discover or actually discovers the reason for the patient's attendance.
III The doctor conducts a verbal or physical examination or both.
IV The doctor, or the doctor and the patient, or the patient (in that order of probability) consider the condition.
V The doctor, and occasionally the patient detail treatment or further investigation.
VI The consultation is terminated usually by the doctor.

Byrne and Long report that the logical form is an ideal which is rarely observed in practice. But some 60% of consultations bear resemblance to the general pattern, although phases are omitted, repeated and returned to out of sequence. In 95% of the consultations the g.p. is in control of what occurs and the style in which it happens. 75% of everything that occurs during consultations is doctor initiated, and in one continuous hour of consulting a g.p. uses 85% of his or her normal range of behaviours. These behaviours are classified by Byrne and Long using a power-shift analogy. They identify 7 styles of doctor behaviour, which range from doctor centred to patient centred (Table 2.04). These styles are adopted by most g.p.s and maintained with little variation between consultations. This suggests that doctors' interactional styles and behaviours are relatively limited and rigid, a
finding that is repeated on numerous occasions in the literature (Bloor, 1978; Tate, 1983; Verhaak, 1986).
Table 2.04
G.p.s' interactional and diagnostic styles as described by Byrne and Long (1976, pp. 105-112).

<table>
<thead>
<tr>
<th>Use of patient's knowledge and experience</th>
<th>Use of doctor's knowledge and skill</th>
</tr>
</thead>
<tbody>
<tr>
<td>Silence</td>
<td>Clarifying and Analysing</td>
</tr>
<tr>
<td>Listening</td>
<td>and Gathering and Probing</td>
</tr>
<tr>
<td>Reflecting</td>
<td></td>
</tr>
<tr>
<td>Offering observation</td>
<td>Broad question</td>
</tr>
<tr>
<td>Encouraging</td>
<td>Clarifying</td>
</tr>
<tr>
<td>Clarifying</td>
<td>Challenging</td>
</tr>
<tr>
<td>Reflecting</td>
<td>Repeating for affirmation</td>
</tr>
<tr>
<td>Bringing patient ideas</td>
<td>Seeking patient ideas</td>
</tr>
<tr>
<td>Seeking patient ideas</td>
<td>Offering observation</td>
</tr>
<tr>
<td>Indicating understanding</td>
<td>Concealed question</td>
</tr>
<tr>
<td>Using silence</td>
<td>Placing events</td>
</tr>
<tr>
<td></td>
<td>Summarising to open up</td>
</tr>
<tr>
<td></td>
<td>Direct question</td>
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<tr>
<td></td>
<td>Correlational question</td>
</tr>
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<td></td>
<td>Placing events</td>
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<tr>
<td></td>
<td>Repeating for affirmation</td>
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<tr>
<td></td>
<td>Suggesting</td>
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<td></td>
<td>Offering feeling</td>
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<td>Exploring</td>
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<td></td>
<td>Broad question</td>
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<td>Closed question</td>
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<td>Correlational question</td>
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<td></td>
<td>Placing events</td>
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<td></td>
<td>Summarising to close off</td>
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<tr>
<td></td>
<td>Suggesting</td>
</tr>
<tr>
<td></td>
<td>Self-answering questions</td>
</tr>
<tr>
<td></td>
<td>Reassuring</td>
</tr>
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<td></td>
<td>Repeating for affirmation</td>
</tr>
<tr>
<td></td>
<td>Justifying self-chastising</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Use of patient's knowledge and experience,</th>
<th>Use of doctor's knowledge and skill,</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor permits patients to make decision</td>
<td>Doctor defines the limits and requests the patients to make decision</td>
</tr>
<tr>
<td></td>
<td>Doctor presents problem. Seeks suggestions and makes decisions</td>
</tr>
<tr>
<td></td>
<td>Doctor presents tentative decision subject to change</td>
</tr>
<tr>
<td></td>
<td>Doctor sells his decision to the patient</td>
</tr>
<tr>
<td></td>
<td>Doctor makes decision and announces it</td>
</tr>
<tr>
<td></td>
<td>Doctor makes decision and instructs patient</td>
</tr>
</tbody>
</table>

-65-
Raynes' (1980) investigation differentiated those activities in g.p. consultations which are routine, from those which are responsive to patient presenting characteristics. She reports that whilst modes of questioning and the prescribing of psychotropic drugs are responsive, the use of physical examination, referral to patient records, referrals to specialists, memory for the patient and the writing of medical certificates are more ritualistic.

Boreham and Gibson (1978) investigated the sorts of information offered by family practitioners to patients during consultations in Australia. They report that information about the diagnosis was usually given during the initial consultation. Few patients ever asked the doctor questions about diagnosis, so that what patients were told depended predominantly on what information was offered. In only one of the 80 consultations studied did the doctor fail to answer a patient's question about diagnosis. Similarly for treatment information, patients rarely asked questions and information transmission was doctor initiated. Thus what patients learned depended on what the doctor told them and this did not often extend beyond the name of the drug to be taken. Initial consultations differed from subsequent ones, such that most information was given and the patient twice as likely to ask questions during the first consultation than during follow-ups. Boreham and Gibson conclude that there is little evidence of the doctors manipulating patients.
They interpret their results as an acceptance by the patients of the doctors' dominant position in the relationship and support the notion that to ask implies a lack of confidence in the doctor. This notion, they argue, is also supported by their finding that both the doctors' and patients' concept of a "good" patient was one in which the patient was essentially passive and deferential.

Such a mutual and reciprocal relationship is in contrast to that described by Stimson and Webb (1975) in British general practice consultations. Their analysis of the consultation process emphasises the way in which it is managed as a social activity, and pays special attention to the patient's perspective. Prior to going to the doctor the patient must decide whether this is the appropriate agency for his or her problems; that is whether or not they are ill. As many other authors have pointed out (e.g. Atkinson, 1977; Zola, 1973) other persons often play a major part in this decision, advising and validating the patient's experience. During the consultation this is often apparent in what the patient says to the g.p.. Patients often open the interaction by justifying the reason for their visit. Patients thus arrive at the consultation with a number of expectations, which Stimson and Webb divide into 3 types; background, interactional and action expectations. Background expectations cover general expectations about normative behaviours in consultations, the basic routine
of the consultation, such that even very infrequent attenders know the agenda. Interactional expectations are more individualistic, based on previous experience with specific g.p.s and his or her behaviour patterns [analagous to the doctor's style described by Byrne and Long (1976)]. On the basis of their recognition of differences in style between g.p.s, patients will if possible choose to see one whom they feel complements themselves. Patients also plan what to say during the consultation on the basis of their own interpretation of symptoms. Patients' plans identify, the order of information presentation, what to emphasise and the appropriate language in which to phrase information, so as to maximally influence the doctor to act in the desired way. These plans are rehearsed by patients, usually in imagination in the waiting room, but on occasion with peers prior to going to the surgery. Action expectations relate to what the patient expect the g.p. to do about the illness. Two thirds of patients expect to receive a prescription, but expectations differ greatly and some patients clearly did not know what to expect. Constraints also exist and patients recognise limits on the degree to which they can influence the course of the encounter. These include the fact that the consultation is taking place on the g.p.'s territory, that there is both a competence gap and social distance between doctor and patient, and that the patient has only a few minutes allocated with the doctor which require that the patient be businesslike and get straight to the point.
One area of particular interest to ourselves which Stimson and Webb discuss is the information given to patients about their illness and the treatment regimen. The g.p.s' information giving is according to Stimson and Webb "selective and controlled" comprising for the most part of only general explanations. Diagnostic labels, even when given, are not always very explicit (e.g. "a rash", "a mild infection"). And g.p.s expect such labels to be accepted as explanations. Seldom do g.p.s name the drug which they are prescribing ("I'll give you some tablets") although this information must by law be clearly marked on the bottle by the dispensing pharmacist. Some g.p.s argue that patients would not be able to understand the complexities of the illness condition and treatment regimen and therefore they do not tell them.

Bennett, Knox and Morrison (1978) report a postal questionnaire study of the problems g.p.s encounter during consultations. They compare differences in the problems reported by g.p.s, who act as trainers on vocational training schemes, to those reported by non-trainers and trainees. Three categories of patient were indicated as producing most problems, husband and wife consulting together, adolescents and medically qualified patients. The reasons why these particular patient groups were considered problematic are not revealed to any depth, but one may hypothesize that the sorts of problems presented by both the married couples and adolescent groups may be
more sexual/psycho-social in nature than is the norm and these sorts of problems are known to cause g.p.s disquiet (Verhaak, 1986). The g.p.s also reported on consultations in which they had particular communication related difficulties. All doctors reported difficulties in treating drug addiction, exploring the possibility of child abuse and refusing prescriptions or certificates. Trainees indicated that they found interacting with terminal patients difficult, significantly more frequently than the other two doctor groups. However, the difficulties involved in telling patients about a fatal illness were reported by 15% of the sample, the second most frequently mentioned specifically communication related problem area. Bennett et al. (1978) suggest that the problems encountered by g.p. trainees in dealing with terminal illness reflect deficiencies in medical school training, especially the emphasis placed on physical aspects of disease. But they also underline the difference in age between the terminal patient and the trainee as a potential source of problems.

Pendleton (1979) reports a study of g.p. patient communication within the framework of Argyle's (1969) social skills model, in which g.p.s filled in a questionnaire immediately after completing consultations. Approximately 20% of consultations reportedly contained some communication difficulty. A number of variables were discovered to significantly discriminate between consultations which contained communicative difficulties
and those which did not. In order of predictive power these were: patient regarded as tense, doctor does not feel relaxed, patient of lower social class, doctor has previously seen patient often for this complaint, youth of patient. The g.p.s rarely identified themselves as sources of difficulty in consultations, usually attributing difficulties to factors outside of themselves which were only rarely immutable. Pendleton suggests on the basis of his analysis that the two most useful communicative skills needed by a g.p. to attain his goals in a consultation are the ability to influence his patients attitudes and behaviour and to be skilled in the two-way transmission of information.

Traditionally such "bedside manners" were assumed to be something that doctors developed naturally (or did not as the case may be). But over the last decade or so there has been a growing recognition that "bedside manners" consist of trainable skills. There have been a number of studies of methods of training medics, especially students, in such communication skills. Maguire and Rutter (1976) revealed serious deficiencies in the history taking skills of senior medical students. Maguire, Clark and Jolley (1977) compared the history taking skills of 3 groups of students, who received different courses on communication skills. One group received seminars guided by printed handout materials and discussed video recordings of consultations on the basis of these guidelines. A second group's seminars were not guided by

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handouts. The students discussed the video material freely and the printed handouts were distributed only at the end of the seminar sessions. A third group received a traditional didactic course on communication skills. Both video courses were shown to be more effective modes of teaching communication skills than the traditional approach. The free discussion group of students gained better results than those who received the more structured course.

Pendleton and Wakeford (1979) video recorded medical students first interactions with patients and randomly assigned them to two groups. One group reviewed their video tapes in tutorial sessions, paying particular attention to affective aspects of the interactions. The control group received more traditional tutorials on medical history taking and examination. Subsequent interactions with patients were video recorded for both groups. All video recordings were rated by independent scorers, blind to group membership, using a content analysis type schedule. The experimental group's scores improved significantly on measures of their interpersonal skills such as questioning, listening, coping with patient affect and clarifying information. In conclusion it seems that such straightforward feedback approaches to clinical communication skills training are highly effective, and training at an early stage in a medic's career an eminently sensible approach.
Non-verbal communication  As with other interpersonal communications (Argyle, 1975) non-verbal components clearly operate during doctor-patient interactions. One important way in which doctors gain information about patients' illnesses is inherently non-verbal; but the physical examination is not normally viewed as being in the province of non-verbal communication. And yet non-verbal components may play an important part in, for example, diagnostic decision making, with olfaction being included in lists of non-verbal sources of information available to doctors (Pendleton, 1983). Although a number of authors have attempted to explain the importance of non-verbal components of communication to medical readers (e.g. Pietroni, 1976; Friedman, 1979; Argyle, 1983) there have been few specific studies of non-verbal aspects of communication in medicine. Since about one third of g.p. consultations are made for reasons that include a psycho-social complaint (Fitton and Acheson, 1979; Verhaak 1986), the ability to accurately recognise patient emotional states is clearly one that it would be advantageous for doctors to possess. However, the present author knows of no research into the accuracy of g.p.s' judgements, although it seems that most people possess fairly accurate non-verbal communication perception abilities (Buck, 1984).

In a review aimed at g.p.s, Pietroni (1976) points to the importance of non-verbal communication during g.p. consultations. He differentiates between (1) proxemics-
the use of space, time, position and artifacts, (2) kinesics- facial expression, body posture etc. (3) paralanguage- nonverbal vocal components of language and (4) touch, as important parts of non-verbal communication in consultations. Further he urges g.p.s to pay greater attention to non-verbal aspects of consultations and use these to create more friendly and intimate interactions with patients. While such study of their consultations is clearly of value it is not of direct relevance to ourselves except in so far as they act to alter the meanings of verbal messages for participants. What is more not all non-verbal aspects of interactions are open to change. G.p.s are often constrained in the way they arrange an office purely by the space available, or because the consulting room is used by a number of partners, so that it is not totally amenable to goffmanesque stage management. Although the across-desk interaction is identified by Pietroni as more formal and less interactive than other possible ways of positioning, it is possible that a g.p. who by nature interacts more with patients may use this as a defense and a way to restrain vigorous interactions. Patients may also feel less inhibited and be able to interact more with a doctor who maintains a degree of professional distance, mediated for example by the positioning of the desk. Thus contrary to what one may expect from most other social interactions patients may reveal more intimate details to a doctor who keeps his or her affective distance because they are clothed in a
professional anonymity (c.f. Patterson, 1976).

Little research has directly addressed the issue of non-verbal communication in g.p. consultations and although it is generally assumed that non-verbal communication is likely to influence such interactions it is unclear to what degree it is autonomous of other variables, both individual and structural, and thus open to manipulation. Although training does appear to help doctors to improve their interactional styles with respect to non-verbal components, this is best achieved early during careers (Wakeford, 1983). For a fuller discussion of the teaching of non-verbal skills and effects on doctor patient rapport see DiMatteo (1979). DiMatteo generally concludes that nonverbal components of medical interactions have important effects on the socio-emotional aspects of patient care and there is plenty of room for improvement in many doctors' performances which may be amenable to training.

The picture drawn by this review of doctor patient communication is perhaps somewhat disturbing. Patients understand and remember only about 50-65% of what they are told by their doctors. However, one of the most likely pieces of information with which a patient leaves a consultation is a diagnostic label. But such a label is often very vague, in many cases little more than a description of symptoms, and many patients are dissatisfied with the medical care they receive. It is
thus hardly surprising to discover that many patients fail to comply with their doctors' instructions, given that many did not understand them in the first place, or had forgotten them by the time they left the surgery. G.p.s' interactions with patients consist of a series of behaviours, which are typically oriented towards physical aspects of disease. These are initiated by the g.p. with little variety in patterning or responsiveness to patient characteristics. Patients on the other hand do attempt to exert some influence over the interaction and plan what to say. But rarely do patients question their g.p.s, and most information gleaned is dispensed at the g.p.'s discretion. The g.p. is clearly in charge of the agenda and this is implicitly accepted by patients. When the g.p. allows the patient to steer the interaction more (as in a patient centred style) the limits of the patient's freedom are prescribed by the doctor. The question of the nature of the doctor's power is one that has received considerable attention in the literature. Waitzkin and Stoeckle (1972, 1976) forward the hypothesis that doctors restrict information in order to maintain power in the relationship. This however begs the question of the basis of the doctor's power, since restriction of information is itself an exercise of power. This point is missed by Waitzkin and Stoeckle who base their analysis of power on the work of Dahl (1957). More sophisticated analyses (e.g. Lukes, 1974) indicate that control over the agenda is itself an aspect of power. However, the nature of the power relationship is only a peripheral interest for
ourselves, except in so far as to point out that power is often greater when it is not visible.

Talking about Cancer, Dying and Death.

In a series of publications Feifel argues that death has many meanings, which differ not only between cultures but also within cultures and within single individuals over time (Feifel, 1959; 1963; 1969a; 1969b). Thus the points in both time and space upon which a researcher centres may be of crucial importance to the results, death can be a gentle night or a great destroyer. It may reflect the cessation of pain and suffering, reunion with loved ones, loss of control, punishment, glory, to name but a few possible meanings. Feifel (1969a) points to developmental changes, cultural conditioning, religious orientation, personality characteristics and level of threat as major shaping powers to the individual conception of death. Contradictory attitudes may coexist in a single individual concurrently, for example, realistic acceptance of death and its rejection exist in a subtle equilibrium in many seriously ill patients (Feifel, 1965). These may serve adaptational needs of the patient who must organise resources for oncoming extinction and maintain communal associations. What is more, treatment of the seriously and terminally ill is often conditional on the considerations and wants of the healthy rather than to the needs of the sick (Feifel, 1959). Although there

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is a dominant if unspoken assumption that talking of death is to be avoided, since it is damaging to the patient. Some evidence suggests that patients not only learn to live with the stress of knowing, but "grow and change under its goad... impending death has fostered creativity rather than paralysis" (Feifel, 1969a; p.294). In a study of 92 terminally or seriously ill patients and matched healthy controls, Feifel (1969b) reports that being close to death and contemplating it from a distance call forth different defense strategies. In the dying group there is more denial and avoidance, while in the healthy more intellectualisation. Younger patients and those with children were more rejecting of personal death than older ones. Patients who had known of the import of their illness for more than 6 months revealed less fear than those who had known for shorter periods. The healthy were more concerned with the fear of dying than of death. A group of 81 doctors investigated by Feifel (1969b) revealed greater fear of death than either the patient or healthy groups. Although the doctors wanted to be informed if they were dying, they would be less willing than dying patients to inform others people of this. This finding suggests that doctors may possess different attitudes to death than both patient and general populations. Feifel (1963) hypothesised that doctors take up medicine because of their above average fear of death. He reports that physicians have more materialistic physical extinction concepts of death than either patients or healthy individuals (Feifel, 1969b). We thus turn
our attention to doctors and what is known of their attitudes and beliefs toward death.

Doctors attitudes to death A number of studies have investigated doctors' attitudes to death and dying patients, doctors' anxieties about their own death and the like. Dickinson and Pearson (1979) mailed Likert scale questionnaires to 3 year cohorts of graduates of 5 American medical schools, obtaining a 71% return rate. Doctors were categorised by specialty to investigate the relationship between attitudes toward terminal patients and specialty. Dickenson and Pearson report that oncologists were the group of medics who felt most comfortable with dying patients, were least likely to rate terminal care negatively, and found it easiest to tell patients they were dying. Oncologists believed strongly that physicians referred terminal patients to colleagues in order to avoid them themselves. General practice was a specialty included in this survey and g.p.s were middle ranking on all but two of the scales. G.p.s did not believe that doctors referred dying patients on in order to avoid them, but felt depressed when a patient died. Only paediatricians and psychiatrists reported feeling more depressed than g.p.s at the death of a patient.

Schulz and Aderman (1979) found that physicians' death anxiety scale scores were significantly related to the length of time their terminal patients survived after admission to hospital. Patients under the care of
doctors with high death anxieties were in hospital on average 5 days longer before dying than patients whose doctors scored medium or low on the death anxiety scale. These results were interpreted as evidence that doctors with high death anxiety were less willing to accept patients' terminal states and thus more likely to use heroic measures to keep them alive. However, we suggest an alternative explanation. It is possible that the doctors with higher death anxieties admit their patients into hospital earlier than those with medium or low levels of death anxiety.

Feifel's hypothesis that death anxiety is the causal variable in students' decisions to study medicine must be rejected. Feifel forwarded this hypothesis on the basis of doctors' death anxiety levels and interpreted this finding as a trait. A more parsimoneous explanation is that the results are a consequence of training. Thus the finding that doctors are more "materialist" about death (Feifel, 1969b) is probably a function of the biological, scientific orientation of medicine rather than indicative of a deep rooted trait. Studies of medical school intakes reveal numerous sociodemographic variables and individual differences which distinguish medical school intake from both the general population and university intakes into other disciplines. These include social class, sex, race, educational attainment etc. such that medical school intake in the U.S. is overrepresentative of the upper middle class male "W.A.S.P." at the expense of
other groups (see for detailed breakdown Mechanic, 1978; pp. 379-390). Such a sociodemographic bias is also the case in the U.K., although the sex difference has now nearly disappeared (Allen, 1986).

Howells and Field (1982) in a study of medical students at a British medical school, report that medical students did not differ from a control group of students in their fear of death as assessed by questionnaire. Both groups of students feared death of a significant other most, dying themselves less and being dead least. Females were more fearful than males. There were significant correlations between E.P.Q. (Eysenck and Eysenck: 1975) neuroticism scale scores and all three scales on the fear of death questionnaire.

In overview then Feifel's hypothesis that doctors have higher death anxiety levels than people in general and that this can be used as an explanatory mechanism to account for their behaviour in terms of a psychological trait is untenable. Work, such as that of Dickenson and Pearson, (1979) or Rea, Greenspoon and Spilka (1975) (to be reviewed below) require more complex interpretations which take into account the doctor's specialty and frequency of contact with dying patients amongst other factors. Nevertheless, what is clear is that many physicians do find it difficult to discuss death and dying whether this is for reasons of personality, medical school training, or whatever.
The proportion of doctors who tell patients that they are dying. There have been many studies which have attempted to estimate the proportion of doctors who tell terminal patients when they are dying. These estimates vary widely, which in part reflects the changes that have occurred in doctors' readiness to convey such information over the past 30 years or so. However, contrary to the position taken by Veatch and Tai (1980), the differences between studies in definitions of telling, research methodologies and groups sampled, make it impossible to conclude that differences in findings reflect a simple change over time. As one line of support for this assertion, we cite the finding that although most studies have used questionnaires, the design and wording of questions are so divergent, that it proved impossible to reliably summarise the findings as a table of the percentage of doctors reported by each study who always, usually, occasionally and never tell. Thus we have been forced to report the studies following the wording of the original authors, which reduces the degree to which it is possible to compare the results of the various studies.

Fitts and Ravdin (1953) report that of the doctors in Pennsylvania responding to their questionnaire, 3% always and 28% usually told, whilst 12% never and 57% usually did not tell. Rennick (1960) reports that of the respondents to an U.S. nationwide postal survey, 16% always, 62% sometimes and 22% never tell. Oken (1961)
reports that 88% of his sample of staff members of a Chicago hospital had the usual policy of not telling patients. Of these 3% often, 29% occasionally, 47% very rarely and 9% never made an exception to this policy. Friedman (1970) surveyed physicians on the staff of a Boston hospital and reports that 25% always, 66% sometimes and 9% never tell. Rea, Greenspoon and Spilka (1975) report that 39% of their U.S. sample acknowledged "some degree of negativity toward informing", 22% would refuse to tell, whilst the remainder (feeling the patient "must" be told. Noyes, Jochimsen and Travis (1977) compared the results of a questionnaire they administered in 1971 and again in 1976 to groups of medical students, recent graduates and faculty members of the University of Iowa medical school. In 1971 the proportions of each of the 3 groups respectively who "frequently told" were 60%, 54% and 44%, while in 1976 they were 80%, 78% and 61%. Novack, Plumer, Smith, Ochitill, Morrow and Bennett (1979) in Rochester, N.Y., administered a questionnaire very similar to that Oken had used nearly 20 years previously. They found that 98% reported their usual policy to be one of telling. Of these 7% never, 61% very rarely, 28% occasionally and 2% often made an exception to this policy.

Cartwright, et al. (1973) conducted a study in the U.K based on the follow up of a representative sample of deaths. They report that 65% of the g.p.s who had cared for the deceased would tell the truth to a 55 year old dying
businessman who asked, but 22% would lie, and 13% would either change the subject or give a qualified answer. If the patient were a young mother who did not ask, or an elderly widower who said "this won't kill me doctor will it?" the percentage of G.P.'s who would tell the truth dropped to 2% and 13% respectively.

Another line of research that is closely related to the one we have just considered, has attempted to estimate the proportion of doctors who tell patients they have cancer. In some of the studies reviewed above items were included in the questionnaire which asked if the respondent would inform patients of a cancer diagnosis. Yet in other studies informing a patient of a cancer diagnosis was implicitly equated with informing them they were dying. One study which has explicitly investigated what proportion of doctors are willing to inform patients they have cancer is that of Greenwald and Nevitt (1982). They interviewed doctors who were "cancer-oriented" practicing in the Midwest of the U.S.. They report that 30% agreed strongly, 51% agreed, 16% disagreed and 3% disagreed strongly with the statement that cancer patients should be told their diagnosis. But whilst thus 81% thought patients should be told, fully 40% thought that patients preferred not to know.

Whatever the specific proportions involved, it is clear that there is considerable reticence amongst doctors in telling patients they have cancer and/or that they are
going to die. The majority of the studies considered were carried out in the United States, where the doctor's legal position differs somewhat to that of doctors in the U.K.. American doctors are more likely to face litigation if they do not inform patients about illness than their British counterparts and such considerations are likely to effect their behaviour. For example, Glaser and Strauss (1965a) describe an incident in which a patient is told of his cancer by a doctor who clearly would have preferred to say nothing, but does so for fear of facing a court case if he did not. Thus the U.S. data are likely to report higher levels of telling for purely structural reasons, and are thus of only limited relevance to general practice in the U.K.. Furthermore there are major methodological problems and inadequacies associated with many of these questionnaire studies. One important issue is the relationship between reported and actual behaviour, not only in the sense of doctors faking good to questionnaire items, but also in terms of respondents not having clear insight into their own behaviour. Secondly questionnaires inevitably restrict the response set and do not permit consideration of the diversity of possible situations in which the doctor may face decisions to tell or not. This point is cleverly approached by Cartwright et al's (1973) specification of different sorts of patients whom the g.p. was asked to consider. Such a technique is not used in any of the other studies considered. Finally given the difficulties in communication already reviewed and the
proportions of information not understood or forgotten by patients, there may be considerable differences between the doctors' intentions and their realisation. That is doctors may think they tell patients but patients may think otherwise.

Do people want to know when they are dying? As previously mentioned Fletcher (1973) asserts that 80% of dying patients know they are dying and would prefer to talk about it. Fletcher cites Cramond (1970) as his authority, but Cramond says merely:

"It has been said that 80% of patients know that they are dying and would wish to talk about it... My experience with patients in chronic renal failure showed that all these patients had considered their own death with awareness and relief."

(Cramond, 1970; p.389)

Clearly this is insufficient evidence to resolve the issue of whether or not people would prefer to know that they are dying. However a number of researchers have investigated the issue more systematically and it is to these studies of peoples' information preferences that we now proceed.

Cappon (1962) reports that 91% of non-patients would wish to know if a serious illness was terminal. In a Gallup poll of a representative sample of Americans, it is reported that 82 to 92% would want to be told if they had a fatal illness, depending on age, sex, socio-economic status and geographical region (Blumenfield, Levy and Kaufman, 1978). In another study Cappon (1978)
interviewed members of the general public on their attitudes toward death. 88% reported they would prefer to be told they had a terminal disease by their doctor and only 8.5% would prefer a member of his or her family to inform them. This result probably reflects a general awareness that the doctor is the person most likely to have the relevant knowledge. [20% of respondents wanted only minimal notice of death, 10% a day, the remainder giving conventional answers of 6 and 12 months.] However approximately a quarter of the sample responded "from birth," a finding that is highly suspect suggesting weaknesses in interview techniques. Moreover the sampling procedure used in this study is not clearly described and the sample is probably neither random, nor stratified and thus the generalisability of the results is unclear. Interview questions were not such that a respondent could easily answer that he or she would prefer not to be told of approaching death. It is thus difficult to draw firm conclusions about information preference from this study.

Do people want to be told they have cancer? Kelly and Friesen (1950) report that 82% of a sample of non-cancer patients, asked if they would want to be told if they had cancer answered in the affirmative. They also asked a group of cancer patients if they thought their diagnosis should have been disclosed to them and received an 89% affirmative response. However, only 73% of this group thought that a diagnosis of cancer should be revealed to
people in general. For the first group of patients the possibility of their having cancer was fairly remote and their responses thus not truly representative of a group for whom it was a realistic threat. For the latter group, cancer had already been diagnosed and they knew this. Their affirmation that it was correct to tell them of the cancer may thus result from some form of cognitive reappraisal following, for example, a cognitive dissonance model. This is especially likely given their lower level of belief that telling people in general was the correct thing to do. The critical population to be sampled thus is one for whom having cancer is a realistic possibility, but one that has not yet been confirmed or denied. Kelly and Friesen (1950) also studied a large group of patients attending a cancer detection centre, and report that 98.5% of this group wanted to be told if their cancer tests were positive. This research is now somewhat dated and the population investigated resident in the U.S.A.. It is thus unclear how relevant it is to a population in contemporary Britain. What is more, many of the studies have been conducted without any clear reference to the context within which communication occurs. That is a patient does not just see a doctor one day, who says, "You have X, and...". The patient is likely to have had considerable contact with the medical profession over an extended period by the time he or she becomes terminal. We must thus place such questions as telling or not telling into context, specifically the context of terminal care.
At the turn of the century Osler (1906) reviewed the cases of 500 dying patients, of whom 90 suffered physical pain and distress, 11 "apprehension", two "terror", one "remorse", and one "spiritual elation". But the vast majority of Osler's patients exhibited "no sign one way or the other". According to Hinton (1963) no further reports on dying patients were published for more than half a century, until he published research in this area. Hinton (1963, 1966) conducted a series of interviews with 102 hospitalised dying patients and controls hospitalised for serious but non-fatal illnesses. Patients were rated on a number of scales, which included physical distress, depression, anxiety, and awareness of dying. The dying were rated as more physically distressed, depressed and anxious than those who were not dying. At first admission more than 50% of the dying patients were aware that their illnesses may prove fatal and 6% were certain of this. Depression and anxiety were associated with physical symptoms, the distress caused by these (especially nausea, vomiting and dyspnoea), the length of time over which these had been endured, patient age and whether the patient had young children. Depression was also correlated with awareness of the possibility of death. As patients neared death they became more aware of its possibility, suffered more physical distress and to some degree more depression and anxiety. However these were mitigated by increasing mental impairment, in part due to
the use of Bromptom's mixture. At least 75% of the patients were aware they were dying by the time it occurred. Those patients who became aware of dying while in hospital were particularly prone to depression and anxiety. Retrospectively 30% of patients were assessed as "denying" that they were dying, while 70% "accepted" it to varying degrees. This acceptance ranged from wanting to get it over, through accepting without great distress, accepting but expressing regret, to accepting but finding it distressing and wanting to live longer. On the subject of telling or not telling patients, Hinton recommends answering "sincere" questions honestly, but essentially leaving it up to the patient to ask such questions. Although Hinton's study is historically important, the methodology is somewhat crude by contemporary standards. The measures are of uncertain validity and reliability and not administered blind to patient group. Further patients were allocated to the study on the basis of unclearly specified criteria and from the wards on a highly prestigious teaching unit. They were thus probably not representative of the population of patients dying in hospitals, nor, as Hinton himself points out, representative of the general population of dying patients since at the time the majority of deaths occurred at home.

Wilkes (1964, 1965) conducted what is probably the first study of cancer patients, who were not in hospital but receiving care from G.P.s while dying at home. The first of the two papers reports the epidemiological background
to the study, revealing that only a third of all cancer patients died in acute hospitals and fully 55% died in their own homes in his area of study. Only 9% of patients who died from cancer had never attended hospital for this disease and this non-referral was related to age. Younger patients were almost always seen in hospitals. On the basis of g.p. questionnaire responses, Wilkes (1965) reports that 51% of patients receiving terminal care at home under the g.p. needed some difficult nursing care and 13% required hospitalisation which was not forthcoming. In contrast to Hinton's (1963) report, 75% of patients in this sample "had no knowledge" that they had cancer, let alone that they were dying, 25% "had a good idea of the truth, although it has never been put to them" and 11% "definitely knew" they had cancer. Patients' knowledge made no difference from the g.p.s' viewpoint to the ease or difficulty of treatment. The relatives of patients were usually told earlier rather than later about the diagnosis and this was reported as "helpful" for treatment at home. 22% of cases merited special praise from g.p.s, because of how patients, relatives or both coped with the situation. But 4% of cases were criticised by the g.p.s for how they coped, or more properly failed to cope, in the g.p.'s opinion. The g.p.s had often known and treated the patients for years, built up intimate relationships with patients and thus became personally involved with their terminal care. Overall Wilkes draws attention to the scale of domiciliary terminal care and calls for more facilities to be made available for its successful
performance. On the subject of g.p.s telling patients about their illness Wilkes has nothing to say. However the study depends on g.p. reports and no g.p. reported on more than 2 cases. Thus the statement within the paper that even the 25% who "had a good idea of the truth" had never had it "put to them" suggests that the amount of telling by g.p.s is very low if not non-existent.

A study which directly addressed the problem of telling cancer patients of their diagnosis is that of Aitken-Swan and Easson (1959). Their study however was specifically aimed at patients whose cancers were amenable to treatment with a good likelihood of success. The rationale was that if a nucleus of patients who knew they had been cured from cancer was created the public misconception that it was incurable could be dispelled. [An earlier study (Peterson and Aitkin-Swan: 1954) had reported that 64% of the general public did not know that "cancer could be cured".] Consultants reported telling 231 selected patients, who were later interviewed, ostensibly on the medical history, and indirect attempts to elicit the patients "reaction to the consultant's explanation" were made. Those patients who approved of being told (66%) stressed the practical value of knowing and the reduction of the anxiety caused by uncertainty about the illness. However they also felt that only patients who could be cured should be told. Patients who disapproved of being told (7%) "claimed to have been upset by the knowledge" and were especially shocked by the frank
use of the word cancer. 19% of patients "denied" having ever been told and the remaining 7% of patients were classified as "inconclusive" since Aitken-Swan and Easson were unable to assess their reactions to being told. Aitken-Swan and Easson conclude that 7% disapproval is "a small price to pay" and assert that more patients should be told about their cancers. However there is no empirical reason to stress the 7% disapproval, a less value laden way of looking at the results is to say that 2/3s approved of being told, while 1/3 did not positively do so. Moreover no account of the quality of life of patients is made. It is possible that for the 66% who approved being told it made little impact on quality of life, either as improvement or reduction, whilst seriously damaging the quality of life for those who disapproved. The categorisation of patients as denying having been told is problematic, since although some of these patients may in fact have been overtly told by their doctors that they had cancer and deny it, it is clear from the quotations from interviews that others were not told in terms they understood. But Aitkin-Swan and Easson assume that doctors' reports that they have told patients is an objective record of whether or not patients were in fact told. Thus a discrepancy between the doctor's and patient's account represents denial by the patient. The assumption that doctors' reports are true, whilst those of patients false is highly spurious; a point that will turn up again on more than one occasion during this thesis.
Glaser and Strauss conducted an observational and interview investigation of patients' awareness of dying and the ways in which hospital staff interact with patients (Glaser and Strauss, 1964a+b, 1965a+b, 1968; Glaser, 1966). Their publications provide numerous insightful observations into behaviours in a large public hospital and we can give only the most general overview of their findings here, concentrating on the communication and awareness of dying. They report that rather than making a general standard for telling or not telling most doctors prefer the rule that each patient should be judged on individual merit. However in practice it appears that most doctors have "a general standard from which the same decision flows for most patients" (Glaser, 1966; p.227) and hence the majority either tell all or tell none of their patients (Glaser and Strauss, 1965a; pp.119-120).

And yet doctors give reasons for informing and not informing patients who are dying, as if these formed the basis of individual decisions. For not informing, these include the doctor feeling he could not adequately explain the complex nature of the illness adequately to the patient; if wrong he would be liable for malpractice; and doctors not wishing to cause a "scene" on the ward. Conversely doctors' reasons for informing include a desire to maintain patient confidence in their ability, given that the patient might well find out anyway. Telling is also used to justify radical treatment and clinical research procedures. The effect of these considerations is reportedly that when in doubt the doctors do not tell
and although this withholding may be done in collusion with the patient, patients may find out in other ways (Glaser and Strauss, 1965a).

Glaser (1966) proposes a 4 stage model of the process of response to being informed about illness. Following disclosure patients invariably become depressed but later either accept or deny the information revealed. Thereafter patient behaviour is oriented to either preparing for death (actively or passively) or fighting the illness. Two characteristic features of the disclosure process are revealed. First, whilst patients are told they are certain to die, they are never told how long they have to live. Second, doctors typically do not give details of the illness and patients do not ask. Together these characteristics result in "short, blunt announcements" which doctors justified in terms of "sharpening the blow" and forcing direct confrontation with reality. However on occasion the informing was done less overtly, by implication, but nonetheless this was still sharp in its delivery. Patients' responses are identified as depending on personal features and aspects of how he or she was told and subsequently treated by hospital staff. Those who actively prepared for death did so in a number of ways; "living life to the full", "settling affairs" and suicide all being represented. Characteristic responses amongst those who passively prepared include taking the disclosure "nonchalantly", "calmly resigning", and the "nonverbal" patient who never
talked about the information but simply accepted his fate. Patients who fought the illness did so by "intensive living", going to "marginal doctors or quacks", and participating in experimental procedures. Patients who denied their approaching death established this stand with staff by "juggling time", testing for denial by, for example, forcing staff to give normalising answers to questions, comparing themselves with other patients, blocking communication, becoming intensively active, emphasising a future orientation, and creating "reciprocal isolation" so that professionals and even family avoid the topic of dying and often all other unnecessary contact.

This model of disclosure and coping is however problematic for a number of reasons, and often includes implicit value judgement. For example, living intensively appears in all types of behavioural response described, yet the descriptive terms assigned to such behaviour are value loaded depending on whether or not it is judged to be acceptance or denial based. Further while some patients are described as accepting even though never talking about the illness, others, who similarly never talk, are described as denying. The basis upon which such distinctions are made is never clear, and although the authors may be basing their judgements on subtle indicators of psychological states they leave themselves open to the charge of attributing such states to their subjects. The analysis proffered can be described as medico-centric. Patients are described as forcing doctors
and nurses to avoid the taboo subject of personal impending death on the basis of staff accounts. And yet there is no clear reason as to why one should accept the medics' version of being coerced into not talking in preference to patients being subtly coerced by medical staff and institutional structure into taking such a position. There are other possible explanations of the interactions which are more mutual and reciprocal in nature. Finally there are the generic problems associated with the stage models of psychological processes during terminal illness, namely that stages are not necessarily distinct, successive and exclusive. In particular this model commences with a formal disclosure event at which the doctor "tells" the patient and the process unfolds from there. Account is taken neither of the possibility that the patient may know or suspect prior to the formal disclosure, nor of the converse possibility that the formal disclosure may fail to convey the crucial information about dying to the patient. Considering the latter, "denial" may be a simple consequence of the patient not hearing the doctor's terse announcement, rendering the denial label inappropriate.

No review of this area would be complete without mention of the work of Kübler-Ross (1973, 1975) since her analysis brought dying into the public eye. Based on clinical observations and interviews with over 200 terminal patients, Kübler-Ross presents a framework of 5 sequential psychological stages of dying through which patients pass.
The first stage is "denial and isolation". Denial usually occurs at the time of diagnosis and characterises the patient's disbelief in the seriousness of the illness. It consists of an "it isn't true" response and a turning inwards to define the situation as a "private problem".

The second stage is anger ("Why me, and not him?"), and patients' lack of control over the situation turn into angry outbursts. The third stage is bargaining. The patient attempts to postpone death by making a deal, either with his or her god ("I'll be good if...") or with their doctors. The penultimate stage is depression and it often coincides with the appearance of visible and disabling effects of the illness. This fourth stage is conceptualised as one of preparatory grief by the person about to be separated from the world. The fifth and final stage is acceptance. The patient has few feelings, is devoid of the anger, depression, etc. of the earlier stages and ceases to struggle.

Such an analysis is open to numerous criticisms. These can only be sketched here, but Charmaz (1980) elucidates the conceptual and theoretical ones most fully. First, there is the problem of the social context, since Kubler-Ross's analysis is based purely on observations made in a specific hospital. It seems likely that the stages identified are a result of the hospital context in which they were made rather than reflecting an universal process through which all patients pass. Second, the analysis is based on selected cases from the total patient
population which was available to Kübler-Ross, without any clear selection criteria being specified. Third, Kübler-Ross's analysis appears to be subjective and there is a danger that she imposed her stage analysis onto the data rather than drawing her stage theory from the data, since even in her book (1973) there are many cases quoted which conflict with a simple sequential stage analysis. The term "denial" is an elastic category in that it consists as much in what the viewer perceives as the patient's actual behaviour. Denial is thus apt to be identified when practitioners sense or ascertain that the patient has a viewpoint that conflicts with their professional objectives. Thus in Kübler-Ross's scheme denial seems to consist of any lack of overt talk about the illness on the patient's part. Finally, what may have been descriptions have actually become prescriptions in some cases (see e.g. Garfield, 1978; Simpson, 1982). But possibly the most serious defect in Kübler-Ross's stage theory is that other researchers have failed to confirm her stages. Weisman (1970) found no clinical justification for the concept of stages amongst the patients he studied, but suggests that there is a continuous intermingling of emotional responses throughout the dying process. In their review Schulz and Aderman (1974) conclude that patients do not go through stages, but rather, adopt a pattern of behaviour which is persistent until death. Pattison (1978) prefers to replace the concept of stage with that of phase, in a "living-dying process". The way in which these phases
develop is related to different types of "trajectories", or sets of death expectations set up by the "crisis of knowledge" about death. Thus patients' awareness of their mortality and psychological state change over time, but as a function of the way he or she is treated by caregivers rather than following an universal and characteristic pattern of responses to approaching death. This phase analysis shifts the emphasis to ask what is the appropriate task of the caregivers at any one time. Thus the important variables are again what is communicated and how to the patient, but placing these onto a timescale ultimately ending at death.

The study by McIntosh (1977) bears many similarities to that of Glaser and Strauss considered above, and was carried out closer to home in a cancer ward in the U.K.. Again by a combination of interviewing and observation, communication processes and patient awareness of illness were investigated, so as to permit description and explanation. In contrast to the report by Glaser and Strauss of formal announcements by doctors about illness, McIntosh reports that:

"all the doctors on the ward... firmly believed that the great majority of patients should not be told that they had cancer or be given their prognosis... Patients were to be given as much information as possible about their condition and treatment short of divulging the precise nature of the illness and consistent with their retention of hope."

(McIntosh, 1977; p.28)

Thus the basic thrust of McIntosh's work is to unveil the ways in which patients gain precise information about
their illnesses and the information management strategies adopted by the doctors. Communication was routinised, ensuring consistency in the information received by similar cases and from different sources. This was achieved by regular ward meetings at which uniform stories were constructed, and by clear delineation of responsibility for decisions about telling to senior staff. Uncertainty was also an important factor in communication and as in the case of polio reported by Davis (1960) was used to advantage by doctors. The routine procedures for telling identified by McIntosh were split into those volunteered by doctors and those which were responses to patient questions. Information was volunteered in cases in which the tumour was benign or easily cured. In these cases the doctor emphasised the non-serious nature of the illness whilst if the tumour was probably benign this probability was stressed in addition to assertions about its "harmlessness". In cases in which the prognosis was uncertain or unfavourable information had to be given at two stages: to persuade the patient to enter hospital and to gain consent to treatment. In these cases again the uncertainty was stressed and the tests or treatment dressed up in "better to be safe than sorry" terms. Conditions were described in euphemistic terms (suspicious cells), further implying uncertainty, and as "potentially" rather than actually serious, implying better prognoses. After the initial series of tests and treatment, further interventions were presented as ways of ensuring good outcomes, and patients invariably were given
encouraging information concerning their progress. In serious cases the communicative routine was characterised by a gradual build up to the announcement that major surgery was required. In such cases results of tests would be presented so as to stress the seriousness of the situation and hence obtain the patient's cooperation to (e.g.) amputation. Again euphemistic reference to cancer was preferred. Phrases such as "going malignant" were used, but it was implied that by performing this operation the problem could be stemmed. Of paramount importance for the doctors was the timing of communication. This was designed to facilitate the imparting of information gradually and in stages. To this end doctors diverted patients' attention from potentially meaningful indicators, forestalling questions by the very information they did give. On occasion doctors used humour in order to play down seriousness, and thus imply that since they were willing to joke they could have no doubts about the success of treatment.

When facing questions from patients the routine responses given closely resembled those used when volunteering information, but adapted to be appropriate to the situation. Most frequently such responses would envoke uncertainty, stress the failsafe function of treatment and avoid precise diagnostic information through euphemism. Overall this routinisation of communication precluded patients from gaining more succinct information, since to do so requires they reject the whole mode of the
communication and press the point when asking. Thus routine is used to imply the normality and hence solubility of the problem.

In his analysis McIntosh identifies 9 categories of patients' awareness. These differ on dimensions of overall awareness (knew, suspected, did not suspect, mislead), degree of desire for information (want/don't want) about diagnosis and prognosis, and benign patients for whom the information was not considered problematic. Of the cancer patients in the sample, 88% knew or suspected they had cancer, but only about a quarter of these patients actually said they knew. Patients gained their awareness in a number of ways, self diagnosis being the most common. However, some patients picked up on clues provided by rapid admission to hospital and radiotherapy or had access to community knowledge that the ward was a "cancer" ward, or the consultant a cancer specialist. Yet such awareness permitted considerable uncertainty about the nature of the illness which formed a sort of defence since it afforded hope. Only a minority of patients who suspected the nature of the illness wanted confirmation of their suspicions and attempted to seek it. Those who preferred uncertainty also sought information. But the information sought was of a different nature, that they did not have cancer and that the outlook was good. This was done by constantly seizing upon and interpreting cues which confirmed this hopeful view and ignoring or reinterpreting contradictory information. Thus the
euphemistic pronouncements of the doctors were well suited to the situation, since they permitted patients to either maintain this uncertainty and ambiguity, or identify what they were actually being told accordingly. Yet if the patients who wanted unambiguous information attempted to gain it by enquiry, "the truth remained elusive". Staff maintained uncertainty and reiterated their euphemistic descriptions in preference to straightforward answers. But such information as was gleaned from doctors, along with discussion with relatives, comparison between patients, and the recognition of treatment, symptoms etc. provided sufficient information for those who sought it to unequivocally know.

As McIntosh points out, this study is limited since the communication routines identified are highly context bound and dependant upon the level of environmental control enjoyed by hospital staff. Thus whether similar routines exist on other oncology or general surgery wards is uncertain. Thus although giving general indicators and sensitizing us to the subtleties of communication, the situational specificity of McIntosh's work precludes direct comparison to communicational possibilities in general practice. Furthermore the physical proximity of patients engenders comparison processes between patients which will not be available at home.

Stedeford (1981a, 1981b) followed 41 couples from admission to a continuing care unit through the death of
Most patients were referred to the researcher/therapist in her capacity as psychiatric registrar, because of problems in response to impending death. But approximately a third were selected to permit comparison between referred and non-referred patients. Stedeford reports a number of psychosocial problems resulting from coping with dying. Half the patients were suffering from depression and/or anxiety as a result of failure to cope with specific difficulties. Patients who coped best were not necessarily those who had least problems, but rather those who were most supported by others. Whilst the commonest occurring problem area involved patients' adjustment reactions to the disease and its treatment (e.g. hair loss), the second most common (31 cases) problem presented by patients for intervention related to communication difficulties, either with relatives or medical staff. Almost all dissatisfied couples wanted more information. Hospital doctors were judged to be the least successful communicators of the medical staffs considered (hospital doctors, g.p.s, and unit staff being rated in that order). The major problems experienced by the couples in their communication with one another related to their not being told the diagnosis simultaneously. Thus marital partners concealed knowledge from each other in a "conspiracy of silence" and this was often a source of tension between them, resulting in depression and anxiety. In considering these results it must be remembered that the patient sample was selected on
the basis of referral for psychiatric intervention and hence the pervasive unsatisfactory communication reported may be overrepresented for the general population of terminal patients. However it is significant that in 3/4s of the cases poor communication was identified as an underlying factor of the disturbance. Since communication with medical staff is immediately open to improvement, in a way that the (side) effects of the disease and treatment are not, a large proportion of the failures to cope with terminal illness could be avoided by making medical communications more "user friendly".

Traditionally it has been argued that deficiencies in communication such as those identified by Stedeford are due to the ignorance of doctors regarding patients problems, and ignorance of how to communicate. Rosser and Maguire (1982) take this view to task and argue that deficiencies in the care of cancer patients by g.p.s also arise from the conceptual and structural framework of general practice. They point out that the ideology of medicine as an applied science emphasises mastery through intervention based on knowledge. But g.p.s are positioned at the juncture of medicine with the social, moral and psychological worlds of their patients. Thus g.p.s must reconcile the biomedical ideology with the personal experience of illness. G.p.s thus adopt an ideology of caring for the whole person or a "Biographical Medicine" approach (Armstrong, 1979). The recognition by g.p.s that medical knowledge, the source of technical
mastery, is limited gives rise to dilemmas in practice. Cancer is a paradigmatic case of a disease which defies the ideology of medicine, it is "the standardised nightmare" (p.316). As such cancer poses a threat both to medicine in general and the status of the g.p. in particular, since it challenges his role. Consideration of g.p.s' views of cancer reveals that the impact of cancer derives from its unpredictability, the uncertainty it engenders and the inadequacy of scientific explanations within their daily practice. Thus g.p.s find that they cannot account for aetiology or predict treatment outcome, both crucial questions for the patient and the g.p. The descriptions of cancer treatment expressed by the g.p.s interviewed reflect the two perspectives of scientific hospital and biographical medicine. In accepting the scientific perspective g.p.s must acquiesce to the greater knowledge of the specialist, accepting though perhaps resenting a subordinate status vis a vis patients, and therefore acknowledge their role as referral agents. On the other hand the biographical perspective stresses the importance of patients' subjective experiences, resulting in questioning the validity of subjecting patients to treatments of uncertain therapeutic value which effect the patients' quality of life. There is thus considerable conflict for the g.p. between his two interrelated practice perspectives, and his role in the structure of medicine. In practice the g.p.s adopt a policy which conforms to the scientific ideal, referring to the hospital and then attempting to ameliorate the
problems caused. G.p.s thus experience a dilemma between maintaining professional distance and becoming personally involved with patients, which may be resolved by avoidance of discussion of the patient's emotional problems. The upshot of this argument is that conflicts within the g.p.'s role may result in avoidance of discussion of cancer patients' problems with them. Thus improving communication between cancer patients and g.p.s is not a simple matter of education as suggested by the "ignorance hypotheses", but a problem inhering within the practice perspectives of general practice.

While agreeing with the general thrust of Rosser and Maguire's argument that communication problems are not purely a function of ignorance, the present author would argue for a change of emphasis from the generalities of ideological perspectives discussed by Rosser and Maguire to the specific problems of acknowledgement of inability to cure. This curative function of the doctor is central to the role notions stemming from the work of Parsons (1951a) which are reviewed in Chapter 3. One reason underlying the change in emphasis is the problem Rosser and Maguire's argument has in accounting for communication difficulties in situations other than general practice. As our review reveals g.p.s are not alone in finding discussion of cancer with patients difficult. The work of McIntosh (1977), to name but one example, reveals the lengths to which hospital specialists will go to avoid explicit disclosure to patients. Such
doctors are presumably paragons of the scientific medicine ideal and minimally tainted by the biographical perspective. Thus recourse to conflict between perspectives as an explanatory mechanism vis à vis their communicative behaviour is hardly applicable. Furthermore Stedeford's finding that g.p.s are more satisfactory communicators than hospital doctors suggests that the biographical perspective may be a boon to communication rather than causing deficiency. However these points are not meant to deny that the conflict experienced by g.p.s is central to the problems they experience, but merely to indicate that the conflict may be even more deep rooted in the practice and ideology of medicine than acknowledged by Rosser and Maguire.
CHAPTER 3

Literature review: 2 Role theory and medicine. The social roles of doctors and patients.

"A man, in order to establish himself in the world, does everything he can to appear established there."
La Rochefoucauld Maxims.
(1665)
The concept of role has been used for many years in the analysis of complex aspects of human behaviour. The use of the role concept in the history of the human sciences can be traced back to the early roots of contemporary British psychology and sociology (Thomas and Biddle, 1966). Role theory utilises the dramaturgical analogy of persons as actors to analyse behaviour, presenting a model in which behaviours are regulated, modified and internalised in accordance with commonly held expectations related to the part being played. Such roles can thus be used to predict and explain behaviour. But the familiarity of the concepts upon which role theory is based and the everyday usage of such terms is problematic, for they are also used as technical terms with precise meanings. The word "role" is derived from the Latin rotula (little wheel) - thus relating it to "roll" - and its present meaning developed through the use of parchment rolls upon which actors lines were written (Moreno, 1960). This implies something fixed as in the roles of Créon and Antigone, which, although open to different styles of acting, are immutable and inexorable (Anouilh, 1954). This connotation of "role" with rigidity, suggests that social scientists should be cautious when using such words in their analysis of the theatre of the real. As has been repeatedly pointed out in role theory literature, this familiar and everyday usage has resulted in different authors using the same terms very differently (e.g. Biddle and Thomas, 1966; Sarbin and Allen, 1968; Biddle, 1979; Heiss, 1981). This
problem is one among a number which have led some writers to reject the notion of role in favour of other concepts, such as "social representations" (Farr and Moscovici, 1984) or "typifications" (Schutz, 1967, 1970). But while this work is of obvious importance and has influenced the present author's thinking, we prefer to retain the role concept for a number of reasons. Firstly, the very familiarity of role concepts in everyday language, as in "playing a role" and a "professional role" can be advantageous. Thus role theory concepts mirror the language of the objects of enquiry (i.e. doctors and patients) and clearly reflect the way they think (about) and account for their behaviours. Secondly, a large research literature concerning doctor-patient relations and phrased in terms of roles, has developed from the work of Parsons (1951a, 1951b). Mapping this literature onto the conceptual frameworks and language of social representations or typifications, would be a considerable (albeit perhaps worthwhile) undertaking in itself, prior to using the fruits of the literature for the further analysis of doctor-patient relationships. On the other hand it is a more manageable task to retain role concepts while recognising that not all authors use these identically.

There are a number of theoretical issues and unresolved debates within the field of role theory as a whole, and within the way in which it has been applied to analyses of doctor and patient behaviours, health and illness as
specifics. These theoretical debates are in part reflected by differences in the ways individual authors use role terms. To simplify this matter we have used the work of Biddle (1979) to compare the ways in which different authors use role terms. We thus translate different authors into a common role terminology using Biddle as a dictionary. Further, since Biddle's glossary of terms covers the whole gamut of role theory, we have generally followed these definitions (Biddle, 1979; pp. 381-397) in our own use of terms. But certain of his definitions are rejected on theoretical grounds, following the incorporation of the notion of ideal types into discussion of roles. The other major source on role theory concepts is Heiss (1981), whose ideas are more compatible with our own theoretical perspective. Thus our own use of the word "role" refers to expectations about behaviour rather than to the behaviours per se (Note 3.01). Further discussion of the issues involved is left until later, but throughout this thesis, where the reader is uncertain as to the meaning of a role term used, it may be safely assumed that Biddle's definition is intended.

The Parsonian Analysis of Doctor and Patient Roles

Parsons first described the complementary roles of doctor and patient to exemplify his account of social systems (Parsons, 1951a, 1951b). The former he called the "physician role" and the point of departure for its analysis is the professional nature of the medical
endeavour, focusing on the technical-specificity of professional activity as a basis for achieved status and autonomy. Parsons wrote that:

"The role of the physician centers on his responsibility for the welfare of the patient in the sense of facilitating his recovery from illness..." (Parsons, 1951a; p.447)

In order to fulfil this responsibility the physician must develop a minimum, but high, standard of technical proficiency. Since this high level of required technical competence implies a specificity of function, the task of caring for the sick has to be a functionally specialised full time professional activity. This functional specificity then impels the professional to limit his or her attention and activity to the rigidly circumscribed sphere of those items which are properly "medical". This delineation between what is properly "medical" and what lies outside of that sphere is of course problematic, since at times physicians may be drawn to sets of concerns beyond the biological and technical considerations routinely taught at medical school (Carr, 1983; Field, 1983).

A central tenet of the analysis of illness for Parsons is that it is deviant. Thus the physician is an agent of social control, and maintains the status quo (equilibrium) of the social order. This is done in part by legitimizing the social deviance of the patient, but doing so conditionally and temporally. The physician is charged by society with the job of returning affected persons to
full social functioning, reversing the tide of withdrawal so that the patient may again take up the threads of social obligation. This is to be achieved by permitting the patient "time out" from normal obligations in order to facilitate full return to normal. The professional orientation to be adopted in order to achieve this is termed by Parsons "universalism", which is a tendency to treat all patients as similar. This is meant in the sense, not of treating all patients with identical regimens, but as viewing all patients as equal in a universe of health and illness. Clinical judgement is thus to be guided by technical and objective criteria, which are applied to individual cases, identified (diagnosed) according to a rational classification scheme. Thus the powerful position enjoyed by the physician is itself normatively regulated, and the practitioner is, as a representative of dominant cultural values, expected to approach the patient in objective and scientifically justified terms. Furthermore, the ideology of the medical profession emphasises the welfare of the patient, which the physician is expected to put above his own interests. The professional attitude toward the patient has many facets, but its core, that of doctor as applied scientist acting in the patient's interest, is probably to be found in what Parsons termed "affective neutrality". Thus the physician must not become over involved with patients, but should distance him or herself emotionally. The ideal practitioner exhibits sympathy rather than empathy.
intuitive understanding without full-scale involvement, and should understand the patient's feelings without feeling them him or herself. This norm, although one of the most essential elements of the professional role, is hard to maintain and is probably regularly violated, since there are so many ways it may be disturbed (Bloom and Wilson, 1972).

In summary, then, Parsons's description of the physician role is one of a technically equipped curative agent, who approaches patients in scientifically justified terms, maintains affective neutrality and places a patient's interests above her or his own. This role is one which may be helpful to doctors themselves, since:

"By defining his role in this way it was possible to overcome or minimise resistences which might well otherwise prove fatal to the possibility of doing the job at all"

(Parsons, 1951a: p.459)

The role of physician cannot be considered in isolation from the complementary social role of the patient. In order to become a patient a person must embrace what Parsons termed the "sick role", which, as well as conferring certain rights and benefits to the person, also requires that he or she fulfill certain duties and obligations. The sick role has the following features. Firstly, the person is incapacitated and it is beyond his or her powers to overcome this incapacity. Secondly, the sick person is not (normally) held to be responsible for the incapacity. Thirdly, some kind of therapeutic
process or intervention is conceived to be necessary for recovery to take place. Fourthly, incapacity defined as illness is a legitimate basis for the exemption of the sick individual from his or her normal role and task obligations. Fifthly, being ill is a legitimated state, and an essential condition of its legitimation is the recognition by the sick person that to be ill is inherently undesirable. Thus he or she has an obligation to try to get well and to cooperate with others to that end. Finally, one cannot expect spontaneous forces to operate adequately or quickly to enable a return to health. The sick person and others involved in his or her welfare, especially members of his or her family, have an obligation to seek competent help and cooperate with those agencies in their attempts to enable cure. Illness is thus viewed in this analysis as a form of deviance, and just as in other analyses of deviance (Cohen, 1971) there is the deviant individual, the patient, and the defender of the social order and abitrater of social reality, the doctor.

Critiques of Parsonian sick and physician roles
Over the years since its inception this analysis of doctor and patient roles has been expanded and criticised by a number of authors. Central to the criticisms has been Parsons' functionalist perspective, which as such reflects a major debate in contemporary sociological theory between structuralism and functionalism. However, the central themes of the Parsonian analysis of illness as
deviance and the central concept of role analysis have been largely retained. Thus the question of whether or not patterned expectations exist is not at issue, but the theoretical assumptions about the nature of these expectations are. Whereas Parsons averred that the patient-doctor relationship was harmonious and that both participants had similar goals and expectations, structuralist writers, such as Freidson (1970a), have replaced the mutuality and reciprocity dynamics of this analysis, by hostility, ambivalence and conflict.

A system of expectations does not guarantee that a doctor will fully live up to these standards, nor that doctors will be selected on purely achievement criteria. The role centres on treatment of the sick and this requires technical and highly specific competence. But as Mechanic (1978) points out, although doctors’ competence in human affairs is specific, they certainly are called upon to deal with many problems outside the scope of their technical competence, and some doctors come to regard themselves as experts in areas in which they have little technical competence. What is more, the expectation that doctors treat all patients equally is an ideal seldom, if ever, attained. Doctors, like the rest of us, are subject to personal preferences and these are likely to influence the ways they treat different patients. The work of Sudnow (1967), for example, reveals how implicit value judgements about patients exert influence over the treatment proffered by doctors. However, this issue has
received little study and "doctors do not consider them polite areas of conversation" (Mechanic, 1978; p.116). But such defensiveness about the violation of norms points to the importance of the role delineations, not perhaps as descriptions of behaviour, but as underlying expectations about its acceptability. Such observations led Freidson to assert that such expectations are:

"the normative segment of the formal organisation of professions... formal claims and officially held expectations, perhaps ideals, but not necessarily the operative norms of performance."

(Freidson, 1970a; p.160)

Freidson thus concentrates on the formal bodies of medicine, the professional organisations, to analyse the structures imposed and the way these regulate doctors' behaviours. The major thrust of Friedson's work is aimed at an analysis of routinisation, professional authority and prestige, and the structure of the profession (1970a, 1970b). In essence Freidson argues that these bodies, rules etc. although ostensibly protecting the public, do more to maintain the integrity of the profession and the practitioners of medicine.

But it is Freidson's analysis of the "clinical mentality" that particularly interests us here and this is based upon some basic tensions to be found in the nature of medical work. Freidson writes that since medicine is

"the practical solution of concrete problems, it is obliged to carry on even when it lacks scientific foundation for its activities; it is oriented toward intervention irrespective of the existence of reliable knowledge. The practitioner is more comfortable
Thus, according to Freidson, the physician role may be the ideal, that is taught in prestigious medical schools, but it is other forces and expectations acting on doctors that play a major part in guiding behaviour. This has led him to reject the notion of role as a viable concept central to the analysis of the behaviour of members of the profession. Yet, as Bloor and Horobin (1975) point out, Parsons's (1951a, 1951b) precise delineation of roles is not to be taken as a law or empirical generalisation, but as an ideal type (in the Weberian sense), in relation to which courses of action become understandable. The rigidity of the commonplace concept of role is thereby relaxed. Thus roles, and the ideal types from which these are generated, can continue to provide powerful analytic tools. Bloor and Horobin question Parsons's assumption that the relationship between doctor and patient is fundamentally reciprocal and draw attention to elements of the relationship which generate conflict. They argue that the expectation held by doctors, that patients should use their own judgements as to when to seek medical advice, contradicts the expectation that once the patient has sought help, he or she should defer responsibility to the doctor. These expectations place the patient in a "double-bind", since he or she should evaluate, define and make a decision about the illness prior to consulting the doctor, but once the doctor is engaged the patient no
longer participates in definitions of the illness, nor decisions about its treatment. This is, however, a potential for conflict which is in fact relatively infrequently realised, since overt conflict is not endemic in consultations. This Bloor and Horobin assert is because doctors and patients employ techniques of impression management (Goffman, 1971) to stabilise the interaction and attain their own goals. Impression management may be used either to manipulate the other party to one’s own end, or because they are learned behaviours which are part of the ceremonial order. Bloor and Horobin suggest that overt conflict may be avoided either because of its inherent distastefulness or because of differential power relations in the consultation. Furthermore, patients tend to have relatively little experience of the two roles involved in the dyad, whilst the doctor has great experience of both. Bloor and Horobin write,

"one might go so far as to question whether most patients have any clearcut expectations of the doctor’s role and their own patient role divorced from specific illness contexts. Rather one might argue that expectations occur among patients in relation to specific illness problems".

(Bloor & Horobin, 1975; p.281)

This point is representative of an argument presented by numerous writers, and is derived from Freidson’s (1961) observation that when one examines actual cases of occupancy of the sick role they rarely correspond with the ideal typical description of Parsons. Siegler and Osmond (1979) take the lack of correspondence between
actual cases of occupancy of the sick role and the ideal
typical description of Parsons as evidence which "casts
doctor on the usefulness of the concept". They argue that
the patient role is a "highly unstable social role" and

"far from being adhesive as some people fear, it is
very difficult to keep people in the sick role even
when the illness in question falls undisputedly within
the province of medicine."
(Siegler and Osmond, 1979; p.163)

They further maintain that the patient is likely to leave
the sick role for any one of a number of alternative
roles at a number of different points during occupancy of
the sick role and point out that,

"the critical information for maintaining the sick
role is the progress of the patient's own illness."
(Siegler and Osmond, 1979; pp. 160-161)

Such information must come from the doctor, as the
legitimate agent, in order for the patient to stay in
role.

In their study of acute, hospital inpatients, Tagliacozzo
and Mauksch (1979) focused on the way that the context
within which patients are sick modifies behaviours.
They reveal that patients experience a conflict between
sick role expectations and being "good" hospital patients.
A "good" patient is seen by both patients and nurses as
one who cooperates with and does not make great demands
on nurses (and to a lesser extent on doctors) by putting
up with discomfort, doing as much for themselves as
possible, and not criticising nurses. But the sick role
demands that the patient complies with the doctor orders, and should thus insist that the nurse carries out doctors' instructions. Further, the sick role gives the patient the right to be cared for; moreover for the serious acute illnesses studied, it demands that the patient be passive and not "get up to do small things". Tagliacozzo and Mauksch (1979) suggest that the patients' role expectations "are not adequately described by isolating attitudinal and normative responses to the role theme itself. The full repertory of role behavior must be placed into the context of organizational processes if it is to encompass realistic orientations and behavior" (p.200). They thus consider their findings to be supportive of Merton's concept of the role-set, in which roles are made up of conflicting norms (Merton, 1957; 1976). Yet the results of their study are also compatible with the Parsonian ideal type, which patients have internalised and use to guide behaviour, albeit without total success because of conflict with other roles normally held by the patient. Such "normal" roles emphasise instrumental activity and autonomy and comprise central parts of patients' identities (Heiss, 1981). As such this is good evidence for the sick role ideal type for it demonstrates that the role is not a simple construct of the hospital environment. However, this later point is not made by Tagliacozzo and Mauksch, since they do not clearly distinguish between expectation (role) and behaviour (role performance), but instead split their notion of role into "functional and positional
segments" (p.201). Thus, without rejecting the basic notion of the sick role, with its attendant rights and privileges, they explain why patient behaviour does not always correspond to the ideal type by recourse to a "segmentation" of the role, dependent on the structural constraints imposed by the institutional context within which the patient receives treatment. But such a division is contrary to the concept of role as it is understood by ourselves, for it confuses expectation with behaviour. These findings are better explained by simply accepting that the role is only one factor that specifies behaviour and other are the situations and structures in which behaviour occurs.

Such criticisms of the initial sick role formulation in the contemporary literature have given rise to a plethora of variants to the original sick role described by Parsons. In the following pages we review the most influential of these variants of the sick role. It is generally accepted, at least implicitly, that the roles of doctor and patient form a role-complement, be it one characterized by mutual reciprocity or conflict. That is the roles fit together within a social system, such that they are characteristically interdependent. Changes in one role should bring about changes in the other, in order to maintain complementarity. Yet although the sick role has received considerable attention, little has been given to any affect that sick role variants may have on the role of the doctor. We return to doctors' roles later in this
Post-Parsonian variants of the sick role.

Central to most critiques of Parsons's sick role have been two common and distinct forms of illness: "mental illness" and "chronic illness". The former is, as most psychologists will recognise, highly problematic. Debate still rages at the heart of contemporary psychiatry as to whether such disorders are properly identified as "illness" and amenable to the disease theory perspective underlying medical practice (see e.g. Clare, 1980). We will not be drawn into this debate, but will concentrate on chronic illnesses and the problems these raise for the classical sick role formulation. The central problem for the sick role formulation posed by chronic illness is that whilst the sick role is temporary, and the patient enters the role because it holds out the promise of return to normal functioning, this is by definition not the case for chronic illness. Thus the basic argument presented by researchers who have considered chronic illness can be paraphrased as "Chronic illness violates one of the central features of the sick role. Thus behaviour observed in the chronically sick cannot be guided or explained by recourse to the sick role formulation". Let us now consider a selection of these publications in more detail.

Gordon (1966) attempted to "validate the (sick role) concept empirically" (p.xvii) in an interview study of
1000 people carried out in 1957. His interviews revealed a variant of the sick role which he named the "impaired role". In the impaired role the sufferer's state is fixed once and for all (as in blindness, being crippled, etc.) and will no longer respond to any intervention. The person in this role must accept lower status than a normal person and cannot fully occupy normal social roles. According to Gordon, the expectations associated with this role are very different from the sick role and it is the degree of incapacity, rather than prognostic factors, that determine responses towards the individual vis-a-vis his or her exemption from social responsibility, care for self and dependence on technically competent help. On the basis of this first "sick role variant" a number of researchers have developed further conceptions of the roles involved in illness behaviour.

Fabrega and Manning (1972) consider the sick role as a deviant role, which results in labelling of the patient both by him or herself and by others. Once labelled the imputed identity may become the basis of a lasting identity for the labelled person, and thus the basis of a deviant self-image or self-concept (Turner, 1978), resulting in a deviant career. Put simply if the transient role label of "sick" sticks, it may become central to the image of who the person is and thus have long lasting effects on behaviour and its symbolic meaning. In their analysis, Fabrega and Manning distinguish between 4 main types of illness. These are
short term acute illness (Type I: e.g. pneumococcal pneumonia), long term non-stigmatized illness (Type II: e.g. diabetes mellitus), long term stigmatized illness (Type III: e.g. tuberculosis or leprosy), and mental illness (Type IV: e.g. schizophrenia). Normally when people speak of illness they tend to mean short term acute types of illness, of the sort amenable to the disease theory of illness and compatible with Parsons’s sick role analysis. Onset of this sort of illness is rapid and predictable, symptoms are unambiguous, and since the underlying biological process is well understood by doctors, diagnosis is certain and treatment effective and curative. The patient and doctor roles assumed are those described by Parsons and the sick role is temporary and has few, if any, long term social consequences.

On the other hand, at the onset of long term illnesses the clinical picture for both types II and III is similar. Onset is often slow and insidious, symptoms are unclear, and whilst diagnosis is fairly certain once made, it tends to require sophisticated tests. Treatment of long term illnesses may be moderately effective, but it is not necessarily curative and the long range implications of these diseases are considerable. Patients often have to visit the doctor regularly, for check-ups at least, and even if controlled the disease never really ends. The patient then will always be said to be under medical supervision and is often required to modify his or her life habits and those of the family considerably. In the
case of illnesses of type II the degree to which the person internalises the role and allows it to impinge substantially on other concepts of him or herself is greatly under his or her own control. This is less often the case for type III illnesses. In type III the patient is significantly discredited in the eyes of others and is likely to experience considerable social constraint because of the external rendering of the deviant label, which will also affect the self concept considerably.

Mental illness differs from the other three types greatly and is most predictable in its very unpredictability. Onset may be sudden or slow and insidious, symptoms are ambiguous, diagnosis is unreliable and treatment of equivocal effectiveness. Perhaps the most important difference that Fabrega and Manning point out is that whilst the other illnesses fundamentally represent breaches in the biological basis of behaviour, mental illness represents breaking of the social rules of behaviour. If the person is manifest through his or her expressive behaviour, the rules broken are those pertaining to selfhood, to one's very humanity.

In summary then, Fabrega and Manning (1972) consider that the deviant identity which arises from the perception by others that an individual is sick, also supplies a label and a set of expectations, a role. If the individual continues to see him/herself as others do, as sick, then the individual is launched on a career. Whilst Parsons
assumes that the sick role is a temporary and curable
deviance, one in fact motivated by the promise of cure,
this is often not the case. In the case of long term
illness (type II) the individual must assimilate into
their self-concept, at least in part, the notion that one
of their roles is akin to the sick role. In stigmatized
long term illness (type III) external social pressures
insist that the self-concept accomodate to this notion and
that other roles become subservient. Thus Frabega and
Manning contend that:

"The sick role based on a single deviant identity is
too broad a notion for understanding illness
behavior... To speak of the sick role, as much
previous work has done, is to vastly simplify the
nature of responses to bodily processes or social
phenomena that are associated in illness behavior."
(Fabrega and Manning, 1972; p.99)

For our purposes this work is important for two reasons.
Firstly, it identifies 4 parameters of disease that may
distinguish between whether or not an illness will result
in the patient passing through the sick role in the way
assumed by Parsons: duration, prognosis, degree of
discomfort and disability, and stigmatization.
Secondly, Fabrega and Manning point to the importance of
others' definitions or labelling of a diseased individual
for that person's entrance into a role, role
maintenance and its internalisation into a self-image or
even self-concept (Turner, 1978). As is mooted by Fabrega
and Manning, the most salient other may often be the
doctor.
Gallagher (1979) criticises the capacity of the classical sick role analysis to account for the case of chronic illness. Gallagher maintains that Parsons, in his later writing, came to view "somatic health as the adaptive capacity of the human organism which underlies and sustains behavior directed toward the attainment of goals" (p.163). This according to Gallagher is a different view to that of illness as "deviance", which Parsons put forward in his earlier writing. This assertion is contentious and Parsons for one asserts that he did not propose adaptation as an alternative to deviance, but that they merely reflect a different emphasis (Parsons, 1978). However that may be, it is clear that the sick role model cannot easily accommodate the case of chronic illness. Chronic illness is problematic in so far as it can last an indefinitely long time, and hence:

"exemption from normal social obligations cannot be justified by the prospect of a return to productive function and social participation. Neither can the obligation to seek treatment or to cooperate with treatment orders be so justified."

(Gallagher, 1979; p.166)

Gallagher proposes that the conception of both the patient and the "treater" in the situation of chronic illness require elements which lie outside of the deviance framework, of which "value conceptions concerning human dignity and quality of life play an important part" (p.16). According to this reformulation the problem confronting the patient is not one of how to become well, but of how to adapt within the general social system to the illness at a "unit level" rather than in relation to a
more "uniform, universalistic standard". The question of what constitutes good adaptation comes to depend on patterns at the broadest societal level and the way in which these are articulated within communities and social groups. Thus what may be an acceptable level of adaptation for one person, (e.g. a 65 year old widower) will not necessarily be so for another, (e.g. a 20 year old bachelor). Nonetheless, what the patient must learn is to adapt, that is to accept the limitations of his or her condition, neither overestimating the liabilities and thus exhibiting excessive dependancy, nor underestimating them by denying or rebelling against the condition. The patient should learn to manage his or her own treatment within the limits of what a doctor can properly delegate; for example, behavioral skills for self medication and diet, using prostheses and performing tests of body function. Thus this analysis of chronic illness accords a substantial autonomous component to the patient, who is not merely a paramedic acting upon him or herself under the delegated authority of the doctor. While in the case of acute illness the initiative and decision making are in the doctor's hands, in the case of chronic illness the autonomy necessarily granted the patient has the result that "neither the doctor's technical skill nor his moral authority are sufficient to ensure the optimum feasible result" (p.170). nor, for that matter, the continued cooperation of the patient. The adaptation of the patient must be judged in societal terms on a value scale outside of that necessarily held by the doctor.
Whilst chronic illness may have existed for centuries, and may even have been the norm before the rise of modern scientific medicine, terminal illness is largely a creation of modern medical science. Its occurrence requires sure knowledge both of the fatal course of the illness, and also of the ineffectiveness of available treatment, except in the control of pain. These are necessary conditions for the modern "dying role", (Noyes and Clancy, 1977) so-called to contrast it with the "sick role". Following Parsons, Noyes and Clancy write that the sick role,

"...is a constellations of expectations involving both rights and duties... a patient is, first of all, exempt from the responsibilities of his normal social role. Important business or social obligations may be broken without fear of censure... (The patient's) second right is that of being cared for... The duties of the sick person are twofold as well. (Firstly) because society regards illness as an undesirable state, the patient must wish to get well... Secondly, the sick person is obligated to obtain competent help in an effort to regain... health and is expected to co-operate with the treatment prescribed."

(Noyes and Clancy; 1977, p.13)

According to Noyes and Clancy the person in a dying role has rights similar to the sick person, but his or her duties differ. First, it is important for the dying person to desire to remain alive, unless subjected to excessive suffering or disability.

"He may relinquish unrealistic hope of recovery but must retain the 'will to live' "

(Noyes and Clancy, 1977; p.14)

Second, the dying person transfers his or her healthy
social roles to others on a more permanent basis than is the case with the merely sick person.

"The person who fails to execute a will or participate in decisions regarding the future of his business or family may become an object of disapproval."
(Noyes and Clancy, 1977; p.14)

Third,

"the dying person has an obligation to avail himself of the necessary supports to life and to co-operate in their administration."
(Noyes and Clancy, 1977; p.14)

Fourth, the dying person is expected to accept

"the curtailment of freedom and loss of privileges imposed by caregivers."
(Noyes and Clancy, 1977; p.14)

And finally, and perhaps more contentiously,

"dependency is encouraged in the sick role, whereas independence, within the limits of an individual's declining resources, is encouraged in the dying role."
(Noyes and Clancy, 1977; p.14)

Thus the dying role is proposed as yet another variant of the sick role. It is one in which the patient's rights remain the same as those in the sick role, but involve a different set of obligations. Unlike the chronic or impaired roles, but like the sick role, the dying role is transitory. But the transition is not one of returning to normality, but to extinction.
Implications of sick role variants for the physician role

According to Parsons (1951a) the physician's role is primarily curative. It thus complements the sick role rather than the chronic, impaired or dying role variants. Papers discussing sick role variants have considered only in the most cursory fashion the implications for the physician role of differences in the patient role. But if the two roles form a role complement and hence "mesh" together in the way suggested by Parsons, and generally assumed in the literature, then each role needs an alter reflecting its central concerns. Thus Gallagher (1979) intimates that the physician role must in some way be modified to provide the chronically ill patient with tutelage in adaptation to the chronic role, but he goes no further. The alternative to such modification is to contend that the doctor's role does not carry the same importance as an alter-role for these variants of the sick role. That is the roles no longer constitute a role complement. Noyes and Clancy (1977) accept this route out of the problem and regard treatment aimed at cure of the sick rather than care of the dying as a proper or primary role for a doctor. The two patient roles are "defined by physician authority", and having transferred a patient from the sick to the dying role,

"the doctor no longer holds a position of primary importance in the person's care, although he may oversee supportive and palliative treatments. Society reserves the physician's role for the more important restorative function and, in doing so, jauntily guards against inroads upon the physician's time and energy."

(Noyes and Clancy, 1977; p.14)
This view that the doctor's role is primarily curative and does not complement the situation when the patient is dying is widely held (c.f. Garfield, 1978; Taubman, 1978; Fitton and Acheson, 1979). Thus Kübler-Ross uses it to explain the inadequate care of the dying by traditional medical institutions, and feels it necessary to urge that "the primary physician does not desert the patient" who is dying, referring implicitly to the temptation to do so "when a patient's condition cannot gratify the physician's need to cure, to treat, to prolong life." (Kübler-Ross, 1982; p.25). Yet if this is the case we must abandon the notion of the physician role as a way of understanding a large set of doctor-patient behaviours, except to say that any problem observed is a function of the violation of the curative ethic contained within the role. Such a position is clearly untenable, for it renders the ideal typical role notion incapable of making further predictions about behaviour, and explanation of complex expectations, impossible.

Few writers have considered the possibility that the doctor's role may be more variable than the physician role described by Parsons. As a starting point in discussing this possibility it is worth noting that a number of writers point to Parsons's medico-centricism as being a core problem with his analysis. For example, Bloor and Horobin (1975) conclude that "Parsons has merely draped doctors' assumptions... in a sociological cloak" (p.282).
A further problem is that not only is Parsons’s analysis restricted to industrial Western societies (Herzlich, 1973; Haan, 1979), but it is also historically specific. The observations upon which Parsons bases his analysis of the physician role were made in American teaching hospitals during the 1940s. Thus Parsons described the physician role at a time and place when hospital medicine was approaching its zenith, prior to the reemergence of generalism and the holistic medicines of the present day. Since then it has never been seriously contested that the physician ideal type is a major guide to behaviour. But roles are not static entities cast for all time and playable with only minor stylistic variation. They are dynamic guides to behaviour, and open to constant evaluation by the audience and performer. Roles are also subject to change as societal demands alter. Thus roles change at the individual level, evolving on a wider social plane, and to avoid extinction they must fit a niche.

General practice in the U.K. during the 1980s is a very different animal to teaching hospital medicine in the U.S.A. during the 1940s. To contrast the differences between them is beyond the scope of this thesis, and the reader is referred to Freidson (1970a), Brotherston (1971), Mechanic (1978) and Armstrong (1982, 1983, 1984) for an introduction to this area. However, a few words of introduction to the history of general practice are in order. General practice emerged to meet the needs of the social requirements of the early nineteenth century on the
basis of developing scientific medical knowledge, and the nascent profession. The history of this professionalisation can be characterised as a power struggle between three orders of medical practitioners: the physicians, surgeons, and apothecaries. This struggle culminated in the 1858 Medical Act, the creation of the G.M.C. and the unification of the three castes into one profession of registered practitioners. But whilst the nineteenth century history of medicine had a theme of unification, that of the twentieth has a theme of fragmentation (Stevens, 1966). The power base of the profession consolidated its position in the hospitals, generating an ideal type of the profession in the image of hospital medicine. Thus the medicine of the specialist exerted control over funds, technology, and teaching, whilst the medicine of the generalist was relegated to a subservient position. The creation of the N.H.S. in 1948 saw g.p.s displaced almost completely from the hospitals, and the near extinction of practitioners who offered comprehensive patient care both in hospital and at home, [Berger and Mohr (1976) offer a vivid study of one such practitioner].

More recently general practice has begun to achieve higher status. The creation in 1955 of the Royal College of General Practitioners is one indicator of this progress. This increase in status within the profession has been achieved, in part, by the promotion of the paradoxical notion of generalism as a specialism in its own right.
perhaps culminating in the introduction of the mandatory requirement for g.p.s to pass through Vocational Training Schemes (Hasler, 1983). Such schemes are intended to teach the sorts of skills needed by g.p.s, skills very different to the sort required by and taught in hospitals (Metcalfe, 1983; Hasler, 1983). Thus the physician ideal type may represent the formal claims and officially held expectations, of the type of medical man and medical work to be found in teaching and research institutions of medicine. These are the ideals inculcated into students of medicine (Fox, 1959; Lief and Fox, 1963; Field, 1976) and accepted as ideals by the vast majority who work in the relative obscurity of everyday practice (Freidson, 1970a). The professional values outlined by Parsons may not be manifest strongly or as a whole set by g.p.s, but they are still there (Mechanic, 1970; Gambrill, 1973; Drinkwater and Roberts, 1978). As a net result of the way it has developed, one of the striking features of general practice has been the lack of clear cut definition of its purpose and requirements, counterpointed with a recognition that it is central to the N.H.S. (Brotherston, 1971; c.f. R.C.G.P., 1972).

What is being suggested is that there may be a lack of correspondence between the physician role and the role of the g.p. Such an idea is not totally novel, but has normally been expressed in terms of intra-role conflict within the physician role. For example, Merton's (1976) discussion of the ambivalence of physicians is couched in
these terms. To Merton a role is a set of norms and values which are required to be internalised by a profession or society to prescribe behaviour. But for every norm there is likely to be another that if not incompatible, differs sufficiently to make it difficult to live up to both. Merton (1957, 1976) lists 21 such pairs of norms, although noting this list is not exhaustive. For example:

"Physicians must have the kind of detailed knowledge that often requires specialized education. But: They must not become narrowly specialized: they should be well rounded and broadly educated."

(Merton, 1976; p.67)

Thus doctors experience ambivalence in their roles because unclear choices must be made in behaviour. What is more, according to Merton,

"medical students are also being systematically exposed to professional values and norms that are probably "higher" -that is more exacting and rigorously disinterested- than those found in the run of medical practice."

(Merton, 1976; p.70)

Tuckett (1976b) also considers the conflicts that are "innate" to the social role of being a doctor, basing his analysis on the Parsonian ideal type. In particular, he stresses the conflicts that arise from the tenet that the physician should put the patient first. For example, which patient is to be put first when it comes to allocating scarce resources? Even when only one patient is involved, one still has to balance the conflicts between the patient's present (e.g. avoiding pain) and long term interests (removing the cancer). Thus, argues Tuckett,
the tenet that the patient should be put first is of little help to the doctor in guiding her or his behaviour. The ideal type then is not a simple and clear guide to behaviour, but open to individual interpretation when performing the role. Moreover, it seems that the Parsonian ideal typical role may not be sufficient when attempting to analyse present day practice, and that other roles must act as guides for behaviour given that the doctor can continue to perform when the sick role (as alter) does not conform to the ideal typical role complement.

Summary
In this chapter we have presented an introductory discussion of doctor and patient roles stemming from Parsons's physician and sick role analysis. A number of criticisms of the sick role formulation were noted, which have given rise to variants on the sick role being forwarded in relation to specific disease entities and illness types. Particularly pertinent are the impaired role, chronic role, and dying role, but others do exist, for example, the mentally ill role. Four disease parameters, duration, prognosis, discomfort and disability, and stigmatization, are identified by Fabrega and Manning (1972) which may distinguish between whether or not patients will pass through the normally transitory sick role presented by Parsons. Sick role performance is also affected by where the patient is ill. Tagliocozzo
and Mauksch (1979) reveal, perhaps surprisingly, that hospitalisation places demands on a patient which conflict with the demands of the sick role. In spite of such demands the patient is still visibly sick (in role terms), and this goes some way to demonstrating the power of the sick role to guide behaviour. This point is connected with our rejection of an oft made criticism of the sick role, namely that the low correspondence between observed behaviour and role description renders the role notion redundant as an explanatory mechanism. Such an argument confuses role qua performance with role qua normative expectations. Thus we argue that the role as an ideal type acts to guide behaviour rather than prescribe it.

The assumption that the patient's role forms a role complement with the doctor's role is generally accepted in the literature. Thus in the traditional Parsonian formulation the sick role complements the physician role. But introduction of variants of the sick role implies that the role of the doctor will also vary from the traditional physician role. But the implications for the doctor's role, that variation in the role of the patient implies, has received little consideration in the literature. Thus, although the possibility of a change in the doctor's role is acknowledged by Gallagher (1979), this is as far as he goes. Noyes and Clancy (1977) on the other hand, consider that once the patient is dying, the physician's role is no longer of central importance, or no longer meshes to form a role complement. But doctors
continue to see dying patients, and still have a role to play. This then is to be a central thread in this thesis. What is the doctor's role during terminal care at home, where the patient is dying (rather than just becoming dead) over an extended period of time? Such an analysis of a situation in which aspects of the physician ideal type are clearly violated should then also give us some insight into the relationship between the ideal type and the role played by contemporary g.p.s.
CHAPTER 4

Design, methodology and performance of studies
This chapter consists of 4 sections and describes the core research methodologies used in the studies reported in this thesis. The first section consists of a brief introduction to the central research technique used, the interview, and a discussion of practical and theoretical issues involved in interviewing g.p.s and seriously ill patients. The second section reports a pilot study, the aim of which was to aid in the development of the interview schedules used in this research. We then turn to the research per se, and the third section describes the design of Study 1. In the final section we consider the analytical procedures used in the analysis of the interview data.

**Interviewing: Some Introductory Remarks.**

The research interview has for many years provided one of the main sources of data for social-psychology and sociology (Brenner, 1981; Brenner, Brown and Canter, 1985). A research interview has been defined as a speech event (Hymes, 1962) in which one person extracts information from another (Labov and Fanchel, 1977) and as such can be seen to be a goal orientated conversation (Allen and Guy, 1974). The research interview is delineated by a set of boundaries, which Silverman (1973) explicates in his list of definitive features of the interview as:

"(i) A series of questions and answers, in which (ii) answers are taken to stand for underlying patterns relevant to future decisions rather than the present talk... while questions will be read as seeking to elicit what "lies behind" the talk of the
respondent... (iii) except where it has been specifically arranged as off-the-record, interview-talk is known to be on-the-record.... (but) answers are "confidential" or "for statistical purposes only"... (iv) questions provided by one person, or set of persons and the talk of some other person is to be seen as answers-to-questions, and where (v) one person ("the interviewer") is alone legitimately responsible for doing the beginning and ending of the interaction, for introducing new topics and ending existing ones and for formulating the talk... This allows the interviewer to plan the ordering of his questions with the aim of eliciting more accurately the underlying pattern... (vi) while, as in all talk, judgement about meanings are made partly on the basis of the sequencing of utterances, in an interview this sequencing is attended to as routinely a managed product of one talker (the interviewer)... (vii) members attend to a predicted or known report of the interviewer ("the official outcome") as providing grounds for reading the sense of what occurred."

(Silverman, 1973; pp. 38-45)

As is clear from this quotation an interview is a structured conversation. But the degree of preassigned structure can differ greatly between different forms of interview, and approaches to interviewing spread across a spectrum from "casual informal" interviews to "structured formal" interviews. The latter, traditional, approach views the interview as a measurement technique. Such an approach stresses the desirability of "socially sterile" conditions, to minimise the bias introduced in the recording of the "facts" elicited (Cannell and Kahn, 1968; Moser and Kalton, 1975). In this tradition interviews consist of a prescribed set of questions to be asked verbatim in a specified order. Such questions are normally "closed", and designed to elicit unambiguous answers, such as "yes", "no", or some other categorical answer defined in the response set of the interview. At the other end of the spectrum there is an approach
which has been dubbed the non-directive, depth or non-guided interview. In such interviews, the interviewer does not exercise the same degree of rigid control over the situation as in the formal interview. The task orientation remains, and the informant is encouraged to talk about the subject under investigation. But there are no set questions and often no predetermined framework. The interviewer confines himself or herself to elucidation of doubtful points and general probing. The most radical version of such interviews are the "casual" or "conversational" interviews. Here, the interview is merely a conversation with respondents, in which the interview or task nature of the conversation is not even made explicit to the respondent (Zweig, 1948).

Clearly such diverse forms of interview form the basis for the generation of very different sorts of data and are applicable to different research problems. The structured formal interview is applicable for survey interviewing of large samples, where for example the attitudes of a population are of interest. Such interviews presuppose a previously thoroughly researched area, about which there is considerable information to permit the clear delineation of problems to be answered. Extensive piloting of interviews is required to avoid the bias that may be introduced by imposing artificial constraints on responses and/or asking irrelevant questions (Moser and Kalton, 1975; Brenner, 1985a). The unstructured format permits greater scope in the interview, and allows the
researcher to "dig deeper", without imposing
preconceptions about an object of research onto the data.
But unstructured interviewing can suffer from problems
when it comes to comparing independent interviews, since
the subject matter may be so disparate. On the other
hand, as even advocates of formal interview techniques
point out,

"formal interviewing may limit the investigation to
too superficial a level to be appropriate. A method
that is suitable for ascertaining a person's age is
not necessarily the best for discovering the structure
of his attitudes to homosexuality."
(Moser and Kalton, 1975; p.299)

Between the two extremes of formal and casual interviews
lies the possibility of informal semi-structured
interviews. In this approach although there is a
prearranged set of questions to be asked, the rigidity of
formal interviewing is dispensed with in favour of
flexibility to individual situations. The interview
consists of open-ended questions to be answered in the
respondent's own words. The wording of questions is
designated prior to the interview and adhered to as
closely as is possible and appropriate by the interviewer.
The questions are organised in an order to be followed
during the interview and as such the order is at least in
part specified by the logic of the interview's subject
matter. Such prior ordering and wording of questions can
also be used as a "funnel", to direct the respondent from
general issues to more specific ones. This offers the
possibility of subtly directing an interview towards an
issue without necessarily revealing that this is the
central issues of interest to the researcher. In such a way it is possible to generate interviews which reflect respondents' perspectives but are also permit comparison across respondents, but without necessarily asking very direct questions.

The value of data derived from interviews, however, has been questioned from a number of normally antagonistic perspectives: interactionism, ethnomethodology and positivistic experimentalism. The central critique of the interview as a research methodology leveled from these perspectives is, as Hammersley and Atkinson (1983) point out, that the best kind of data are somehow "untouched by human hands" -neutral, unbiased and representative. Thus in the view of all of these perspectives the interview is an artificial setting which biases data. Therefore it is preferable to either concentrate on naturally occurring settings in which behaviour can be observed or to set up quasi-natural settings in which variables may be manipulated in order to observe "natural" behaviour as an outcome of definable causation. In essence then such approaches emphasis behaviour arguing that reports of behaviour are too indirect to be valid. But as was pointed out in Chapter 3, behaviour is the ultimate variable for role theory analyses. Thus explanation of behaviour, at least in part, requires analysis of the reasons and intentions (or justifications) underlying that behaviour. As such we can treat interview data as "accounts", although in this study the negotiation process
implied by Harre and Secord (1976) for account collection
is not rigorously followed. Unlike many other studies
(c.f. Chapter 2) we do not assume that g.p.s' accounts
more accurately reflect states of affairs, than patients'
versions. Nor do we assume like Denzin (1970) that
agreement between different respondents is necessarily
good evidence that the described state of affairs
represents some objective fact. Although the agreement
between different respondents may indicate that the
description is one that is valid it is safer to accept the
position of workers such as Hammersley and Atkinson (1983)
that accounts display the perspectives of groups.
Thus when different accounts agree, we take this as
agreement in perspective rather than indicating a fact.
In this vein we clearly accept Garfinkel's (1967)
argument that accounts are part of the world they
represent. Thus while we accept that agreement is to
some extent evidence of validity, we recognise that the
validity remains problematic as it does with most social
psychological and sociological analyses (Giddens, 1979).

Issues involved in interviewing g.p.s and terminally ill
patients. Two issues are particularly pertinent for
interviews with g.p.s and terminally ill patients, access
and distress. The sorts of problem encountered with
g.p.s are similar to those met in any attempt to research
a high status group (Dexter, 1970). In addition g.p.s may
be reluctant to take part in a study in which they are
themselves subjects, seeing this as an audit of their
personal performance. However, an ideal implanted at medical school is that, as scientists, doctors should take part in, or cooperate with, the scientific project to advance medical knowledge (General Medical Council, 1980). Thus in order to gain access to g.p.s we emphasised the patient as object of study. This course appears to have been effective in securing cooperation. It may also have had another effect. As we shall see, since they accepted the patient to be the central object of study, many g.p.s spoke confidingly to the interviewer. Thus it is possible that the design reduced the amount of self monitoring of their disclosures practiced by the g.p.s, than if they had seen themselves as subjects. The second problem of import centres more on patient interviews, that is how to interview patients about such an upsetting issue as their own terminal illnesses. This problem is compounded, since we wanted to investigate patients who did not know about the nature of their illnesses as well as those who did. Clearly, the study could not be described to patients as one of terminal illness or cancer. But the design of the study permitted us to describe it as one of chronic illness, without actually being untruthful. Because of the nature of the samples and the illnesses under consideration interview questions had to avoid bluntness. Thus they were designed to open up the possibility of discussion about cancer, without mentioning it, or demanding such discussion. In practice it did turn out that asking general questions did afford the possibility to patients to answer them more
specifically.

Design of Interviews

The interview technique used in these studies can be broadly described as a semi-structured informal interview. Questions were designed to take into account the factors of accessibility, cognition and motivation (Cannell and Kahn, 1968). The interview followed a "funnel" format in which, after an initial phase of introductory remarks and straightforward demographic questions to introduce the respondent to the "interviewee role", the questions moved from the general to the specific. Since respondents were permitted to talk in their own words answering as fully as they saw fit, on occasion interview questions or topics can be covered spontaneously by the interviewee. On such occasions the interviewer permits, and even encourages the respondent, by asking questions relevant to the topic and/or probing as applicable so that the topic area was fully explored in the way required by the schedule. Once this topic was exhausted the topic under previous discussion would be returned to if the questions had not been completed. In many ways it is thus best to conceptualise the present interview as a set of topics each to be explored using the interview schedule as a prompt or guide to ensure that each topic is covered. Since the schedule followed a logic reflecting the natural history of illness events the order of topics was often but not inevitably followed when the patient was spontaneously giving answers to unvoiced questions.
Pilot Study

The pilot study was carried out to fulfill two objectives. The first of these was the standard need to pilot the proposed interview schedules in order to identify and rectify any major problems in the schedules. The second was to give the researcher experience in interviewing medical personnel and some indication of what it is like to interview patients. On the basis of the objectives, proposed design, and ethical constraints imposed on our studies (see research protocols, Appendix 1), 3 provisional interview schedules were drawn up. The schedules and format will not be described here, but resembled those eventually adopted. These interview schedules were then tested on two groups.

Group 1: Doctors Four doctors, acquaintances of the researcher, were approached. The design and objectives of the study were described and their co-operation secured. Three of the 4 doctors were female, 1 male. At the time, none were working full time in general practice. However, one was a g.p. trainee, one deputised for local g.p.s part time as well as working part time in a local hospital, one was a houseofficer (S.H.O.) in a local teaching hospital, and one a community physician. Their mean age was 27.25 years and they had been qualified for between 1 and 5 years. The 4 doctors were interviewed either in their own homes or place of work. The researcher used the provisional interview schedules,
following the proposed interviewing format as closely as possible. At the beginning of the interview, respondents were asked to answer questions as if they were at present working in full time general practice, but to base answers on experience. They were also asked to comment on questions as they saw fit, and to suggest questions they felt should be included or rephrased. At the end of the interview, respondents were encouraged to generally discuss the interview and to voice any criticisms. All interviews and discussions were audio-recorded.

Group 2: Role play "patients" Although role play methodologies have been criticised on a number of grounds (Miller, 1972), it was decided that this presented the only feasible method for the development phase of the present research. Four volunteer subjects (2 male, 2 female; mean age 24.5 years) took part in a role play exercise (Kelman 1967), designed to aid in the development of patient interviews. The design and purpose of the study was explained to each subject. Each participant was then allocated at random to play one of the 4 roles while being interviewed. The roles were explained on instruction sheets, which were given "blind" to the participants. Each participant thus received an instruction sheet consisting of a standard introductory paragraph plus one of the specific "patient" roles (Table 4.01). All interviews were audio-recorded. At the end of the interview a discussion of the interview took
place in which participants were encouraged to voice their impressions of the interview task.

Table 4.01
Role Play Instructions

During the interview you are to play the part of a patient, who received major chest surgery 6 months ago. After a period of hospital treatment, which included the operation, you were released from hospital and returned home. You are now feeling unwell again and your general practitioner is coming to see you regularly. However you also:

Role 1:
know that the operation you had was for lung cancer, that it was not a complete success and that you are not expected to live more than a year.

Role 2:
suspect that the operation was for lung cancer, that it was not a complete success and that you are not expected to survive. However you have never been told.

Role 3:
have no idea what was wrong or why you had the operation, except that you needed to have it, but you have never dared ask about it.

Role 4:
know that you have a bronchitic condition which will take some time to clear up, but that eventually it will be cured and you will be well again.

Discussion of pilot interviews

Interview recordings were not subjected to a formal analysis, but were reviewed a number of times and systematic notes were made. From this review process 2 things were clear. First, the doctors had little difficulty in answering any of the questions, either by referring to their own experience or to their expectations based on training. Certain questions were obviously redundant and others needed rephrasing. Second, the "patients" had great difficulty in completing the task.
They were not sufficiently acquainted with the role of the seriously ill patient to offer more than stereotypical responses of the "soap opera" genre. They all had particular difficulty in reporting symptoms and treatments. But more importantly for the purposes of the study, they all found it hard to describe their relationship with their g.p., since only one female saw the g.p. with any regularity. None of the 4 subjects were sufficiently skilled actors/actresses to succeed at attempts to act in what they felt was an affectively appropriate manner. Thus attempts to act in, for example, an anxious manner resulted in embarrassment, laughter etc. All 4 expressed the opinion that the interview was a "pointless exercise" at some point.

It was thus concluded that the role play exercise was too artificial and required that the player enter a role too divorced from his or her own experience to yield any useful information for our purposes. This conclusion is in line with criticisms of the technique levied by a number of writers (e.g. Freedman, 1969). The possibility of training players more fully into the role was considered. This approach was rejected on the grounds that training would render any results even more artificial than the above exercise. Moreover, since subjects would be trained according to the preoccupations and expectations of the researcher himself, this would inevitably introduce a high degree of bias (Aronson and Carlsmith, 1968).
On the basis of the interviews with the doctors, interview schedules for use with g.p.s were developed. These schedules are reproduced in Appendix 1. The interviews with the doctors also contributed towards the development of schedules for use with patients, as the doctors supplied technical medical information and information based on their own experiences with patients (e.g. patients' preoccupations and psychological states). The sparse information from the patient role play exercise was supplemented by informal discussions with a friend, whose partner had died from cancer after a prolonged illness at home, 9-12 months previously. These discussions of her problems enabled modification of the interview schedule for patients. But more importantly, valuable experience was gained in how to talk about such an affectively threatening topic with someone who had been personally involved.

**Design of Study 1**

The study was designed to identify and investigate a broad spectrum of potentially salient aspects of general practice care of terminal patients. Specifically we were interested in g.p.s' attitudes to death and dying and their normal procedures for care of the terminal patient. Of particular interest was the extent and quality of communication of information about the illness and g.p.s' decision making processes involved in any communication of information. On the other side of the dyad we wished
to consider, the influence of any communication on the patients' psychological state, the relation of this to individual differences, and patients' evaluations of care, illness, discomfort, and needs (c.f. research protocol, Appendix 1). In terms of the performance of the study there are 3 phases which followed a fixed sequence, with each phase temporally as well as logically distinct (Table 4.02). All interview schedules are reproduced in Appendix 1.

Table 4.02
Temporal and logical sequence of Study 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>First interview with g.p. on his approach to</td>
<td>Interviews with patients blind to group</td>
<td>Second interviews with g.p.s. described as</td>
</tr>
<tr>
<td></td>
<td>care of the terminally ill. G.p. selects</td>
<td>membership. S.T.A.I. administered.</td>
<td>case history interview.</td>
</tr>
<tr>
<td></td>
<td>3 groups of patients.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thus the first phase of the study involved the selection and interview of a group of 5 g.p.s. Interview 1 investigated the g.p.s' approach to the treatment of the terminally ill. At the end of the interview each g.p. was requested to put the researcher in contact with 6 patients. G.p.s then allocated patients to the study and patients contacted the researcher directly to arrange an appointment for interview. Patients were to be in 3 groups, with 2 patients in each group, matched across groups for age, sex, socioeconomic group, and site and severity of illness. Patient group membership was not to be disclosed to the researcher until after all patients had been interviewed, thus permitting patients to be
interviewed "blind". The 3 patient groups were

(1) Terminally ill patients who knew the nature of their illness.
(2) Terminally ill patients who did not know the nature of their illness.
(3) Non-terminal chronic control patients.

The design of the study is thus similar to a randomised blocks design (Keppel, 1973) with the g.p.s forming the blocks and the patients, in 3 groups, forming the levels of a fixed organic factor (Table 4.03).

Table 4.03
Random blocks design of Study 1

<table>
<thead>
<tr>
<th>PATIENT GROUPS</th>
<th>Terminal Knowing (K)</th>
<th>Terminal Ignorant (I)</th>
<th>Chronic Controls (C)</th>
</tr>
</thead>
<tbody>
<tr>
<td>V</td>
<td>2</td>
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<td>Z</td>
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<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

During the second phase of the study patients were interviewed in their own homes. Interviews were designed to investigate the patients' perspective on their illness and its treatment without specifying the nature of the illness. State-Trait Anxiety Inventories (S.T.A.I.) (Spielberger, Gorsuch & Lushene, 1970) were administered at the beginning of the interviews and demographic information was obtained from the patients.
Phase 3 of the study was initiated after completion of the series of patient interviews when g.p.s were again contacted and interviewed. This second interview was described to g.p.s as a case history interview, and they were asked to give the case history of each patient interviewed. Specific questions prepared on the basis of the interviews with the patients were asked, as well as a series of standard prepared questions. Patient group membership was identified by the g.p. at this point. Questions about how the g.p. was treating specific patients with reference to the approach described during the first interview were asked as appropriate at the end of the interview session. This second session was described as a case history collecting session, this however was not its only purpose. The interview was also intended to collect information about g.p.s' attitudes and behaviours regarding specific patients for comparison with (1) the abstract descriptions they had supplied during the previous interview and (2) with the accounts proffered by patients. Thus whilst the g.p.s probably considered this interview as their opportunity to supply the researcher with the "objective facts" of each case, the researcher considered it in terms of merely another account of complex social phenomena.

First, this design permits comparison of the 3 patient groups to be carried out. Since patients were matched as closely as possible the independent variable could be specified as patient group membership. The chronic
control group therefore acted as controls for the two terminally ill groups on the dimension of the life threatening nature of the illness, by supplying a baseline of the effects of suffering from an illness, receiving treatment for a comparable time period and receiving regular g.p. contact. The two terminal groups would permit comparison of the effects due specifically to the sort of illness and the patient's knowledge about the illness. Secondly the design permits comparison across g.p.s of the ways in which individual g.p.s approach the problems involved in treatment of the terminally ill, especially how they communicate information about the illness diagnosis and prognosis to patients, and their own subjective reaction to this sort of patient. Furthermore, measurement of patient responses (anxiety and satisfaction) carried out at the time of interviewing patients enables assessment of g.p.s' approaches in terms of effects on patients.

Performance of Study 1

G.p.s practicing in the geographical area of the Durham Area Health Authority and registered with the Durham Family Practitioner Committee (Durham F.P.C., 1980) were chosen at random from the F.P.C. list. The only exclusion criterion implemented was that another member of the practice should not be taking part in the study. Initial contact was made by a personalised standard letter of introduction (Appendix 1). This was followed up by telephone and personal visit to the surgery as required.
In order to secure the co-operation of 5 g.p.s, 12 were approached, a refusal rate of 58%. Requests by g.p.s for specific information about the design of the study were politely refused with reference to bias and expectation effects. The g.p.s were interviewed in their surgeries at their convenience and the study design described at the end of the interview. One g.p. dropped out of the study during phase 2. Due to time restraints on the project it was decided not to replace this g.p..

Performance of interviews
All interviews were audio-tape recorded using a small unobtrusive Sony TC310 cassette recorder.

G.p. interview 1 Questions were grouped under 4 main headings or topic areas of increasing specificity. The 4 topic areas were:-
1) Personal information about the g.p.
2) Information about the practice organisation and demography.
3) General information about patients seen in daily consultations, information about chronic patients and terminal patients who consult.
4) Information about the way in which the g.p. treated terminally ill patients.

Each topic was introduced by an introductory explanation as given in the schedule (Appendix 1). Questions were asked as far as possible verbatim, and in the prescribed
order. But when this was inappropriate questions were asked when or in the manner that was appropriate. Clarification of points raised was requested as required, using the neutral probe questions (Appendix 1).

At the end of the interview the g.p. was requested to select 6 patients in 3 groups as previously described. In order to facilitate the description of patient group allocation to g.p.'s an example was used. The g.p. was told that if he allocated a male, married, miner of 61 years who was dying from a carcinoma of the bronchus and knew about his illness to the terminally ill with knowledge group thus he should try to find another working class married male in his early 60s suffering from a lung cancer and dying, but who did not know about the nature of his illness, to allocate to the terminally ill without knowledge group. And to the chronic control group he should allocate another working class married male of approximately 60 who was suffering from chronic bronchitis emphysema. It was pointed out that this example was something of an ideal towards which the g.p. should strive, and that we recognised that choices may be limited. Further we recognised that not all terminal illnesses had chronic illnesses that resembled them symptomatically as closely as bronchitis emphysema did lung cancer. However as far as was possible the g.p. should attempt to match patients as closely as possible given that in practice he was most likely to first select a terminal patient.
Contacting patients  The procedure adopted for contacting patients was designed to conform with the demands of ethical committees. Essentially the procedure:

(1) protected the confidentiality of the patient by ensuring he or she gave consent to his or her identity being revealed to the research project before it was revealed;

(2) ensured that patient group membership was not revealed prior to the patient interview, thus ensuring that personal medical information was not revealed prior to consent being given;

(3) permitted us to obtain the lowest possible patient refusal rate without coercing patients; and

(4) gave individual patients sufficient information about the study to permit informed consent to be given without revealing the possible nature of the illness to a patient who did not already know this.

Since two thirds of the patients would not know about the nature of their illness or would have non-terminal illnesses the study was described as one of chronic illness in all cases. The g.p.s were supplied with standard letters, reply forms and prepaid return envelopes (Appendix 1) and requested to give these to patients during the first routine visit after selection of the patient for the study.

Patient interviews  Patients who returned these forms
indicating that they were willing to take part in the study were visited at home at the prearranged time. The study was outlined in a way consistent with the description given in the introductory letter. It was stressed that the interviewer was not medically qualified, that he would be unable to answer any questions about the patient's illness, and that furthermore he had not been informed about the patient's illness by the doctor. It was emphasised that the interviews were completely confidential, for research purposes only and that nothing that the patient said about the doctor or treatment would be repeated to anyone concerned unless the patient expressly requested that this be done. Also it was ensured that the patient understood that he or she had the right to refuse to answer any question should he or she wish to do so. An undertaking was also given that the interview could be curtailed by the patient at any point and the recording immediately destroyed. It was also explained that at a later date the interviewer would like to see the g.p. to discuss the history of patient's present illness. Therefore the patient's consent to permit the researcher to have access to his or her medical records for the present illness was required.

Once these points had been made and the patient had given written consent, basic demographic information was collected and it was confirmed that the patient was consulting the relevant g.p. regularly. The patient then completed the State-Trait Anxiety Inventory.
Before the interview commenced the audio-recording equipment was set up, so as to be as unobtrusive as possible. The interview was guided by the schedule shown in Appendix 1.

Field notes on each interview were made immediately after its completion. They consisted of items specific to the interview, which could be used as future "aide memoire". Interviewer impressions of the interviewee and the interaction during the interview were noted in an attempt to record as fully as possible those aspects of the interview which would not be apparent from an audio-recording. It was thus accepted that there is a level of social interaction which is difficult to codify but which is nonetheless an existant social reality. Thus intuited information was noted and as far as possible its source explicated. As far as possible notes were made without preconceptions and as such they were an exercise in "mundane phenomenology" (Thines, 1977). One item was consistently included in notes made after patient interviews, a guess at the patient's group membership. Where possible this guess was supplemented by an indication of certainty about the veracity of the guess and the information upon which this was based.

Case history interviews with g.p.s. The g.p. was interviewed for a second time after all his patients had been interviewed. This interview was again semi-structured and informal in nature. The g.p.s were
permitted to use patient medical records to aid them when answering questions about patients. The g.p. was asked simply to go over each patient's medical history from the time the patient first presented with the illness for which they were at present being treated, or if there was a significant event prior to this from this event. Certain questions of a general nature were asked of all patients (Appendix 1). Clarification of medical terms used, sequence of events, nature of diagnosis etc. were sought as necessary during the interview. Specific questions based on information obtained from patients were asked as appropriate. Questions based on patient accounts which conflicted with that of the g.p., were not asked until the end of the interview when the g.p.'s account had been completed. Questions referring to aspects of the g.p.'s description of his approach to terminal illness as described at the first interview and how he reported approaching these specific cases were also deferred until the end of the interview.

Six month follow up questionnaire Six months after the second interview with the g.p. follow up questionnaires were forwarded to each doctor. The questionnaire was designed to: (a) Discover how cases had progressed in medical terms. (b) Discover if the g.p. had since told patients about their illnesses when they did not already know. (c) Ascertain if there had been any major changes in the psychological state of any patients, as perceived by the g.p.. (d) Check g.p.s' prognostic forecasts for
both outcome of medical condition and patient psychological state. (e) Check for effects (especially adverse effects) on patients of taking part in the study. The questionnaire is reproduced in Appendix 1.

Analytic Procedures

All interviews were transcribed verbatim from the audio recordings. All personal information was removed from tapes prior to transcription and stored separately. To protect confidentiality all place and surnames were replaced by code letters/numbers on transcripts. The transcripts were then subject to two complementary forms of analysis, qualitative analysis and quantitative content analysis. Whereas the statistical analysis permits hypothesis testing, the qualitative analysis aims to reveal the depth and diversity of human experience, but more importantly the sense underlying that experience.

Qualitative analysis

Qualitative analysis was carried out by careful reading of all transcripts, extraction of relevant passages for comparison, compilation of précis of each transcript, and the writing of a commentary on each transcript. These commentaries related aspects of transcripts to other points within the transcript, to the rest of the body of interviews and to the work of other researchers. From these careful readings and compilations certain themes common to transcripts emerged. This analysis is reported
in depth in Chapters 6 and 7.

Quantitative analysis Content analysis has been defined as

"any technique for making inferences by systematically and objectively identifying specified characteristics of messages."

(Holsti, 1968; p.601)

The analysis is performed by the application of explicitly formulated rules, which are used to identify specified characteristics of a message. Thus systematic analysis is obtained by inclusion or exclusion of content in categories according to consistently applied criteria. When agreement between independent coders of the message is obtained one essential requirement of the empirical scientific endeavour, that of objectivity, or more properly inter-subjectivity, is met (Popper, 1959).

Holsti (1968) provides a thorough review of the theoretical and practical issues involved in the design and implementation of content analysis schemes. Viney (1983) provides a recent review of the use of the technique in psychology, surveys content analysis scales available for psychological research and diagnosis, and discusses the use of content analysis of verbal communications in assessment of psychological states.

Development of the content analysis schemes Two content analysis schemes were developed. One for the content analysis of the first interviews with G.P.'s and one for the analysis of interviews with patients. The standard
procedure for content analysis development (Holsti, 1968) was followed. When designing a content analysis scheme the first item that must be considered is the coding units to be used. The decision on what units to use should ideally not only be based on the nature of the material to be analysed and the purpose of the analysis, but also should be theoretically grounded. On the basis of our theoretical perspective to interviewing, it was decided that the most appropriate units to use were the theme, (a single assertion about some subject) as the recording unit and the paragraph, (a complete response to the interviewer's question) as the context unit. Thus interviewer questions act as boundaries of the context units. Holsti (1968) describes in detail the use of recording and context unit in content analysis. Briefly the context unit is used to define the amount of text within which multiple occurrences of the same recording unit will only be counted once. The combination of units used has the advantage of reducing the assumption that there is a simple relationship between the frequency of utterance and the importance of the content attribute to the maker of the utterance. It also facilitates the characterisation of content attributes making it highly applicable to data of these sort.

Prototype schemes were tested by the researcher against one of each of the g.p. and patient interviews selected at random. Gross inadequacies of the schemes were corrected at this point. Provisional instruction sheets
for the modified schedules were drawn up for future use of independent coders. These provisional schedules were tested by the researcher by coding 6 patient and 3 g.p. interview transcripts, henceforth referred to as the "development transcripts". These development transcripts comprised of:

(a) The transcripts of interviews with the 3 patients of the g.p. who dropped out of the study, plus 3 further transcripts, one from each patient group, selected at random from the data set.

(b) The transcript of the interview with the g.p. who dropped out of the study, plus 2 of the other 4 g.p.s' interview transcripts selected at random.

These development transcripts were recoded by the researcher 2 weeks later and test-retest reliabilities calculated using Cohen's Kappa co-efficient (Cohen, 1960) for each category of the content analysis scheme. The values of Kappa derived were reasonably high (>0.68 in all cases). This suggests that the content analysis scheme would prove to be a reliable instrument. However judgement on this point should be held over until reliability statistics from independent coders are obtained. Validity of content analysis categories was assessed by comparing the scores on category items for each transcript with protocols drawn up for each transcript analysed. These protocols were essentially précis of the overall interview meaning drawn up by an independent reader, who was naive to the content.
analysis categories and who played no further part in the analysis of interviews. Thus, for example, the scheme was considered to be valid if a large score in a "knowledge of diagnosis category" was reflected by a judgement in the respective protocol that the patient clearly knew his or her diagnosis. Minor modifications to the categorisation scheme and category definitions were made on the basis of the results of this piloting of the content analysis scheme. Codings used for piloting purposes were discarded. The content analysis schedule developed was put into the form of an instruction manual for independent coders and this is reproduced in Appendix 2.

**Piloting of content analysis with independent coders**

Three independent coders were trained in the use of the content analysis schedules, two coders for patient interviews and one for g.p. interviews. Training consisted of briefly explaining the nature of content analysis as a method of obtaining objective data from interviews, allowing each coder to read the relevant content analysis instruction manual in his or her own time and then answering any queries the coder had after attempting to analyse a short passage of text culled from transcripts of interviews. Independent coders and the researcher then analysed the development interviews in a preassigned order. One transcript selected at random from those analysed by each coder, was reanalysed 7-10 days later for test-retest purposes. Test-retest and
intercoder reliabilities were calculated between each of the independent coders' codings and the codings of the researcher and validity assessed using the procedure previously described. Test-retest and intercoder reliabilities were reasonably high for all content categories. Mean interview Kappa values for each of the comparisons carried out are shown in Table 4.04.

<table>
<thead>
<tr>
<th>CODERS COMPARED</th>
<th>Interscorer</th>
<th>Test-retest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Transcript</td>
<td>1v2</td>
<td>1v3</td>
</tr>
<tr>
<td>1</td>
<td>0.61</td>
<td>0.72</td>
</tr>
<tr>
<td>2</td>
<td>0.45</td>
<td>0.66</td>
</tr>
<tr>
<td>3</td>
<td>0.73</td>
<td>0.84</td>
</tr>
<tr>
<td>4</td>
<td>0.58</td>
<td>0.76</td>
</tr>
<tr>
<td>5</td>
<td>0.77</td>
<td>0.81</td>
</tr>
<tr>
<td>6</td>
<td>0.71</td>
<td>0.77</td>
</tr>
<tr>
<td>G.p Transcript</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>0.81</td>
<td></td>
</tr>
</tbody>
</table>

Thus the content analysis schemes can be accepted as reasonably reliable instruments for the analysis of the transcripts of interviews carried out with g.p.'s and patients. On the basis of the comparisons made between the negotiated meaning protocols of interviews and the scores attained by patients for various content categories, it appears that the content analysis schemes have reasonable face validity. These two content analysis schemes were used to analyse all g.p. and
patient interview transcripts by further independent coders. Results of these analyses are reported in the following chapter.
CHAPTER 5

Quantitative analysis of Study 1 data.
This chapter reports the quantitative analysis of the results of Study 1 and is organised in the following way. We firstly consider the demographic and epidemiological profiles of the samples. We then report the intercoder and test-retest reliability of the content analysis. Following an introductory consideration of statistical methods and the way in which data were normalised, we report the results of the S.T.A.I administered to patients, before turning to an analysis of the interview content per se. In this analysis we concentrate on patient interviews, since the small number of g.p. interviews conducted in this study does not meaningfully lend itself to statistical analysis. Finally we present a summary of the statistical findings. Fuller discussion of these findings is held over until Chapter 8 following presentation of the qualitative analysis of the interview data.

Demographic and epidemiological profiles of the samples.

1. The g.p.s. The data reported here were provided by g.p.s during interviews, but were checked as far as possible against other sources [i.e. G.M.C. (1981) and Durham F.P.C. (1980) registers]. No substantial discrepancies between g.p. supplied information and that from these sources were found. Table 5.01 presents basic demographic information for the 4 g.p.s all of whom were married men with children. Individual g.p.s are identified by code letter.
Table 5.01
Demographic profiles of the 4 g.p.s.

<table>
<thead>
<tr>
<th>Dr</th>
<th>Age</th>
<th>Years qualified</th>
<th>Years at this practice</th>
<th>Description of location</th>
</tr>
</thead>
<tbody>
<tr>
<td>V</td>
<td>39</td>
<td>14</td>
<td>4</td>
<td>Mining village</td>
</tr>
<tr>
<td>W</td>
<td>46</td>
<td>23</td>
<td>10</td>
<td>Semi-industrial suburb</td>
</tr>
<tr>
<td>X</td>
<td>31</td>
<td>7</td>
<td>5</td>
<td>Mining village</td>
</tr>
<tr>
<td>Z</td>
<td>53</td>
<td>30</td>
<td>26</td>
<td>Industrial new town</td>
</tr>
</tbody>
</table>

Dr. V was the only one of the 4 g.p.s who was not born and trained in the United Kingdom. He was of Indian ethnic origin and trained in the sub-continent, whereas the other 3 were all born in the North-East of England and trained here (W and X) or in Scotland (Z). Table 5.02 presents aspects of each g.p.'s practice. All 4 practices had attached L.H.A. district nurses, health visitors and midwives. Thus the 4 practices resemble the national model of general practice (c.f. Chapter 1).
Table 5.02
Practice information for the 4 g.p.'s

<table>
<thead>
<tr>
<th>G.P.</th>
<th>V</th>
<th>W</th>
<th>X</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>No.f/time partners</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>No.p/time partners</td>
<td>-</td>
<td>1+</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Practice</td>
<td>1 P.S.</td>
<td>1 H.C.</td>
<td>2 H.C.</td>
<td>1 H.C.</td>
</tr>
<tr>
<td>accomodation *</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Appointment system</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Total patients</td>
<td>4,000</td>
<td>3,500</td>
<td>17,000</td>
<td>16,000</td>
</tr>
<tr>
<td>Own patients</td>
<td>2,000</td>
<td>2,100</td>
<td>2,000</td>
<td>2,500</td>
</tr>
<tr>
<td>Practice nurse</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Patients/surgery</td>
<td>20</td>
<td>18</td>
<td>20</td>
<td>20-25</td>
</tr>
<tr>
<td>Mins/pt.in surgery</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>House calls/day</td>
<td>4</td>
<td>3-8</td>
<td>8-10</td>
<td>6-8</td>
</tr>
<tr>
<td>Mins/house call</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

+ refers to g.p. trainee attached to practice
* P.S.= Privately owned surgery accommodation
  H.C.= Health centre accommodation

2. The patients
Individual data for the 24 patients, who completed the study are reported in Table 5.03. As can be seen from this table all terminal patients were suffering from some form of cancer, whilst only one of the chronic controls had such a disease. The patient diagnosis indicated in Table 5.03 is the one reported by the g.p. during the case history interview, as the patient's most serious present complaint. There were 16 females and 8 males, with an age range of 45 to 88 years (Table 5.04). Socio-economic composition of the sample was judged using the Office of Population Censuses and Surveys classification (O.P.C.S., 1980). The way in which the sample was distributed across these 3 demographic variables by patient groups, and by g.p. is presented in Tables 5.05 and 5.06 respectively.
Table 5.03
Patient age, sex, socio-economic status and primary diagnosis by group and g.p..

<table>
<thead>
<tr>
<th>PATIENT GROUP</th>
<th>PATIENT NUMBER</th>
<th>AGE</th>
<th>SEX</th>
<th>S-E GROUP</th>
<th>PRIMARY DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>TERMINAL</td>
<td>01</td>
<td>V</td>
<td>60</td>
<td>F</td>
<td>II</td>
</tr>
<tr>
<td></td>
<td>02</td>
<td>V</td>
<td>76</td>
<td>M</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>03</td>
<td>V</td>
<td>71</td>
<td>F</td>
<td>IV</td>
</tr>
<tr>
<td></td>
<td>04</td>
<td>V</td>
<td>70</td>
<td>M</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>05</td>
<td>V</td>
<td>60</td>
<td>M</td>
<td>II</td>
</tr>
<tr>
<td></td>
<td>06</td>
<td>W</td>
<td>56</td>
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<td>IV</td>
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<td>I</td>
</tr>
<tr>
<td></td>
<td>08</td>
<td>W</td>
<td>75</td>
<td>F</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>09</td>
<td>W</td>
<td>50</td>
<td>F</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>W</td>
<td>57</td>
<td>F</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>X</td>
<td>73</td>
<td>M</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>X</td>
<td>70</td>
<td>M</td>
<td>IV</td>
</tr>
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<td></td>
<td>13</td>
<td>X</td>
<td>65</td>
<td>F</td>
<td>IV</td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>X</td>
<td>80</td>
<td>F</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>X</td>
<td>67</td>
<td>M</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>X</td>
<td>70</td>
<td>M</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>X</td>
<td>68</td>
<td>F</td>
<td>IIIm</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>W</td>
<td>45</td>
<td>F</td>
<td>IIIm</td>
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</tr>
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<td>W</td>
<td>56</td>
<td>F</td>
<td>IIIm</td>
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<td>21</td>
<td>Z</td>
<td>86</td>
<td>F</td>
<td>IIIm</td>
</tr>
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<td></td>
<td>22</td>
<td>Z</td>
<td>78</td>
<td>F</td>
<td>II</td>
</tr>
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<td>23</td>
<td>Z</td>
<td>80</td>
<td>F</td>
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<td>Z</td>
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<td>IIIm</td>
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<td>26</td>
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<td>75</td>
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<td>IIIm</td>
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-175-
### Table 5.04
**Patient group mean ages by sex**

<table>
<thead>
<tr>
<th>PATIENT GROUPS</th>
<th>Terminally Ill</th>
<th>Chronically Ill</th>
<th>All Sample Controls</th>
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</thead>
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<tr>
<td>Males</td>
<td>64.2</td>
<td>74.0</td>
<td>67.25</td>
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<tr>
<td>Females</td>
<td>62.5</td>
<td>76.0</td>
<td>67.0</td>
</tr>
<tr>
<td>Both sexes</td>
<td>63.0</td>
<td>75.25</td>
<td>67.1</td>
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</table>

### Table 5.05
**The number of patients in each group distributed within the three demographic variables.**

<table>
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<tr>
<th>PATIENT GROUPS</th>
<th>Terminally Ill with Knowledge K</th>
<th>Terminally Ill without Knowledge I</th>
<th>Chronically Ill Controls C</th>
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<tbody>
<tr>
<td>Age</td>
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<td></td>
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<tr>
<td>below 60</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>60 - 69</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>70 - 79</td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>80 &amp; above</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>mean age</td>
<td>60.7</td>
<td>66.0</td>
<td>75.2</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>no. of females</td>
<td>6</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>(out of 8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socio-economic groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I &amp; II</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>IIIN</td>
<td>1</td>
<td>0</td>
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</tr>
<tr>
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<td>5</td>
<td>3</td>
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<tr>
<td>IV</td>
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Table 5.06
The number of each g.p.s' patients distributed within the three demographic variables.

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<th>DOCTORS</th>
<th>V</th>
<th>W</th>
<th>X</th>
<th>Z</th>
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</thead>
<tbody>
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<td></td>
</tr>
<tr>
<td>below 60</td>
<td>0</td>
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<td>2</td>
</tr>
<tr>
<td>60 - 69</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>70 - 79</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>80 &amp; above</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
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<td>62.0</td>
<td>69.33</td>
<td>70.33</td>
</tr>
<tr>
<td>Sex</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of females (out of 6)</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td>5</td>
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<tr>
<td>Socio-economic groups</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>I &amp; II</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>IIIN</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>IIIM</td>
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<td>2</td>
<td>4</td>
<td>2</td>
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<tr>
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<td>2</td>
<td>1</td>
<td>2</td>
<td>0</td>
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</tbody>
</table>

As can be seen from the tables the majority of the patient sample are skilled or semi-skilled manual workers, or their spouses. The skilled manual (IIIM) group comprise the largest number of patients, probably reflecting the geographical region and the sort of communities these g.p.s service. Historically male employment in 3 of the 4 communities was in primary industries which required skilled labour. Although the overall socio-economic composition of the communities has altered, changes have occurred primarily in younger generations than our patient sample. The absence of socio-economic group V is probably due only in part to the socio-economic composition of these communities.
Socio-economic group V suffer both social and economic disadvantage, living in poor quality housing, with low access to facilities and services, which can concatenate into a whole nexus of problems (Rutter and Madge, 1976; Coffield, 1981). Members of this group are less likely to remain at home during a severe illness, since the minimum requirements for home care are unlikely to be met (Cartwright et al., 1973). Thus the absence of socio-economic group V from our sample probably reflects their relative absence from the target population, viz. patients receiving terminal care at home from a g.p..

The age of the males is on the whole slightly higher than that of the females (Table 5.06). One effect of age is mentioned above, in that the age of the sample specifies when they entered the workforce. Age may thus be associated with occupation and hence the socio-economic composition of the sample. It is also important to note that the majority of the sample were married and living with a spouse, since the spouse is likely to be the main caregiver in most cases. All of the men lived with a spouse who could nurse them if need be, as one would expect on the basis of Cartwright et al’s (1973) study. But the picture for the women is somewhat different with 4 of the 11 dying women and none of the 5 chronically ill women living with a spouse. However these chronically ill patients tended not to need nursing care of the sort required by the terminally ill and were not so severely
restricted as to be bedfast. Of the 4 terminally ill women (3 widows, 1 divorcee) who did not live with a spouse, one had moved to the home of in-laws, and the others had made arrangements to ensure that the help they required was available in their own homes from relatives, neighbours and/or social services. At the time of the study none of these women had any major nursing needs, but in 2 cases the g.p. indicated that when the patient deteriorated she would probably have to be institutionalised. Again such a finding is in line with what one would expect on the basis of previous studies. Thus although the women are at present living at home they are more likely to be admitted into hospital before dying than are the men. The age difference between the terminally ill male and female patients probably reflects a complex function comprising of the different availability of a spouse to supply the nursing required by homecare and different life expectancies of males and females (itself in part due to the different diseases from which the sexes suffer). Thus the observant reader may have noticed that given the morbidity of lung cancer in males this group appears to be under represented in our sample. This is however not surprising if one takes into consideration the rapid course of this disease, which reduces the probability that such patients would be receiving care at home during the "allocation period" of the study. It thus appears safe to conclude that the demographic and epidemiological composition of the sample reflects the target population of study, and the g.p.s'
attempts to fulfill our criteria for patient acceptance in the study.

**Intercoder and Test-Retest Reliabilities**

1. **Patient interviews** All patient interview transcripts were content analysed by the researcher (coder 1) and one independent coder (coder 2), in randomly preassigned sequences, using the schedule reproduced in Appendix 2. Randomly selected subsets of interviews were also coded by two further independent coders (coders 3 & 4). Further random subsets were recoded by coders 1 and 2 at least 4 weeks after their initial coding of the interviews. Intercoder and test-retest reliabilities were calculated using Kappa (Cohen, 1960) for all possible intercoder and test-retest comparisons. Mean interview Kappa values for these comparisons are presented for intercoder reliabilities in Table 5.07 and for test-retest reliabilities in Table 5.08 below.
Table 5.07
Intercoder reliabilities. Mean interview Kappa values for codings of patient interviews for each comparison made.

<table>
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<th>Patient Number</th>
<th>1 vs 2</th>
<th>1 vs 3</th>
<th>1 vs 4</th>
<th>2 vs 3</th>
<th>2 vs 4</th>
<th>3 vs 4</th>
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Table 5.08
Test-retest reliabilities. Mean interview Kappa values for codings of 4 randomly selected patient interviews.

<table>
<thead>
<tr>
<th>Patient number</th>
<th>Coder 1</th>
<th>Coder 2</th>
</tr>
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<tr>
<td>04</td>
<td>0.72</td>
<td>0.64</td>
</tr>
<tr>
<td>10</td>
<td>0.68</td>
<td>0.70</td>
</tr>
<tr>
<td>20</td>
<td>0.84</td>
<td>0.58</td>
</tr>
<tr>
<td>21</td>
<td>0.61</td>
<td>0.66</td>
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11. G.P. interviews
Eight independent coders, naive to the exact nature of the study and who had not been involved in the earlier development of the content analysis, coded the G.P. interview transcripts. Each
coder coded one transcript selected at random, so that each transcript was independently coded twice. Two coder recoded their transcripts 4-6 weeks later to permit test-retest reliabilities to be calculated. Mean interview Kappa values for each interscorer and test-retest comparison are presented in Table 5.09

Table 5.09
Intercoder and test-retest reliabilities. Mean interview Kappa values for codings of g.p. interviews for each comparison made.

<table>
<thead>
<tr>
<th>GP Transcript</th>
<th>Mean Kappa Intercoder</th>
<th>Mean Kappa Test-retest</th>
</tr>
</thead>
<tbody>
<tr>
<td>V</td>
<td>0.72</td>
<td>0.73</td>
</tr>
<tr>
<td>W</td>
<td>0.78</td>
<td>—</td>
</tr>
<tr>
<td>X</td>
<td>0.65</td>
<td>0.71</td>
</tr>
<tr>
<td>Z</td>
<td>0.77</td>
<td>—</td>
</tr>
</tbody>
</table>

These values of Kappa indicate a reasonably high level of intercoder reliability. Inspection of the category values of Kappa from which the means were calculated, reveals the lower values (<0.60) to be the product of lack of total agreement between coders rather than disagreement. That is coders often used closely related, but different, categories to code the same item. To give an example from the patient content analysis scheme, one of the coders may use the category "denies" for an item while another coded the item "disbelieves". These two categories are clearly closely related semantically. "Denial" may have a more active connotation than "disbelieves", but both refer to an absence of consciously expressed knowledge. A weighted Kappa (Light, 1971;
Fleiss, 1971, 1973) takes into account this sort of close but not perfect agreement and would produce higher Kappa values. However, the problems involved in assigning a priori weights to a coding scheme, which is not based on a nominal scale, precluded its use, since weights would be arbitrary.

The obtained values of Kappa are, if anything, conservative in their estimation of agreement and it is safe to conclude that there is good intercoder and test-retest reliability. Thus the content analysis schemes represent objective measures of the interviews. As only 4 g.p.s took part in this study, the sample is too small to be ammenable to statistical analysis of the content per se. Thus the content analysis of the present set of g.p. interview transcripts was used to check the reliability of the content analysis scheme only. The scheme will, however, be used for analysis of further sets of g.p. interviews.

Statistical Methods
The data were analysed using F tests where appropriate. The use of tables of the F-statistic is a reasonable approximation to a randomisation test, which forms the proper model where sampling is not random from a clearly defined population (Edgington, 1980). Since g.p.s form the blocks of a randomised blocks design each main effect or interaction between factors was tested against the corresponding interaction or higher order interaction as
error term (Keppel, 1973). The main effects and interactions involving the g.p.s themselves were tested against the "within cells", error variance, each cell consisting of the two patients in each of that g.p.'s groups. Where the assumption underlying the use of the F-statistic were clearly not met, a non-parametric test was used.

The data were first subjected to an exploratory data analysis (E.D.A.) (Tukey, 1977) and relevant patterns in the data have been extracted for the confirmation statistics reported here. Where appropriate the scale of measurement has been transformed (Tukey, 1977). No attempt is made to report every possible comparison or correlation, nor has any attempt been made to combine the variables into a single multivariate analysis.

Normalisation of raw data Transcript length varied widely and thus the raw number of utterances is not an appropriate measure of differences between patients, as it would primarily reflect differences in the total amount said by a patient during an interview rather than any underlying psychological variables. Moreover interview length may be only distantly related to patient psychological state, since it may be dependant on some interviewer or situational variable. Frequency of utterance is thus used as a measure of patient psychological state. This normalisation was achieved by calculating the mean number of utterances per page of
transcript for each category. A number of categories of the content analysis scheme had very low frequencies in the relevant cells, because they were seldom used by coders. Two categories which were seldom used were "denial" and "disbelief". Since these two are similar in meaning, they are combined to form a single category "denial or disbelief". The other categories seldom used were all in the "source of knowledge" classification section of the content analysis scheme. Those categories relating to sources of information other than the g.p. were thus combined. Analysis of source of knowledge is therefore based on a dichotomous classification; "knowledge from g.p." vs "knowledge from other sources". Such amalgamation of categories is a standard practice in research using content analysis schemes, and is one advantage of using hierarchical schemes such as ours (Holsti, 1968).
Results of State-Trait Anxiety Inventory

Group mean A-state and A-trait scale scores for the 3 patient groups are presented in Figure 5.01. There are no significant differences between groups on either the A-state or A-trait scales by a one way analysis of variance (F<1 in all cases). The anxiety levels measured by the two scales in this sample of patients are well within the normal range, group means approximating published population norms (Spielberger et al, 1970).

Figure 5.01
Patient group mean scores on the State-Trait Anxiety Inventory scales A-state and A-trait.

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Analysis of Interview Content

Degree of knowledge about illness

At the beginning of the study all 4 g.p.s expressed doubt about their ability to fulfill an essential requirement of the study, namely accurate selection of patients for the 3 groups. Although they expressed certainty about being able to find an adequate number of terminally ill patients to make up their sample overall, all 4 indicated that they were often uncertain as to whether or not a patient knew about the nature of his or her illness.

Figure 5.02 shows the group means for the 3 patient groups for the "complete knowledge" category for both diagnosis and prognosis. From this figure it is clear that members of the terminally ill with knowledge and chronic control groups spoke to roughly similar extents about their diagnoses. The terminally ill without knowledge group spoke considerably less about diagnosis than the other two groups. The overall shape for prognosis is similar to that for diagnosis, although the group mean levels are lower, indicating less talk about prognosis for all 3 groups. Furthermore the chronic control group mean and individual levels are relatively lower than those for the terminally ill with knowledge group, probably reflecting the fact that chronic illness does not in a sense have a prognosis. The terminally ill without knowledge group differs from the other groups with an even lower group mean. Only two members of this group made any mention of prognosis during their interviews. The
differences between groups for expression of knowledge of diagnosis and prognosis are statistically significant \([p<.01]\).

![Graph showing differences between groups for expression of knowledge of diagnosis and prognosis]

Figure 5.02

Group mean frequencies of utterance per page of interview transcript of the "complete knowledge" category for both diagnosis and prognosis for the 3 patient groups.

Thus the pessimism expressed by the g.p.s about their ability to discriminate between terminally ill patients who knew and those who did not, when selecting and allocating patients for the study, appears to be unjustified. The 4 g.p.s were able to separate patients who knew from those who did not, at least in terms of the patients' willingness to express knowledge about their illness, especially knowledge about prognosis. However, "complete knowledge" is a category which implies considerable certainty and clarity about information, and since there are many levels at which one might be said to
know something other than explicit certitude, this can only act as one indicator of knowledge. Thus we now consider the knowledge categories more fully.

Figure 5.03 shows group mean frequencies of utterance for the 4 knowledge categories "complete knowledge", "suspicion", "not known" and "denial or disbelief" for both diagnosis (open histograms) and prognosis (shaded histograms). Comparison of the left hand pair of histograms for each group in Figure 5.03 again reveals that utterances coded as "complete knowledge" occur more frequently about diagnosis than about prognosis [$F_{1,3}=27.47$, $p<0.05$]. Further this is true for each patient group judging both from the histograms and the analysis of variance, since there is no interaction between groups and the prognosis/diagnosis factor [$F_{2,6}=1.44$, $p>0.1$]. Yet the groups do differ in overall frequencies of utterance of "complete knowledge" [$F_{2,6}=19.09$, $p<0.01$].
Figure 5.03
Group mean frequencies of utterance per page of interview transcript of the 4 knowledge categories for diagnosis and prognosis separately for the 3 patient groups.

As far as it is possible to judge from the sparse data there is no such difference between diagnosis and prognosis for the "denial or disbelief" category. But there is a difference for the "not known" category and it is in the same direction as "complete knowledge", at least for the terminally ill without knowledge group of patients [p=0.016 by Sign Test] (Siegel, 1956). The difference between diagnosis and prognosis is reversed for the "suspicion" category, which is expressed more often for prognosis than diagnosis [F1.3=17.69, p<0.05]. Again the difference between diagnosis and prognosis is similar for each group [for the interaction, F<1], but in this
case the overall frequencies do not differ between groups \(F<1\). These differences probably occur because the implied certainty of the "complete knowledge" and "not known" categories is less appropriate to prognosis than it is to diagnosis. "Suspicion" therefore may be a relatively more appropriate category of utterance for prognosis than diagnosis, no matter to which group the patient belongs.

Since our main interest at this point is in group differences and these appear to be the same whether the knowledge category concerns diagnosis or prognosis, we combined diagnosis and prognosis for each of the knowledge categories in order to provide more powerful tests of null hypotheses. All further analysis is based on categories of utterance expressing different degrees of knowledge about diagnosis and/or prognosis combined. Figure 5.04 presents the data considered above in this form. The "complete knowledge" block of histograms reveal how the 3 groups differ overall in their expressions of knowledge about their illnesses, a difference which is statistically significant \(F_{2,6}=19.09, \ p<0.01\). There are no statistically significant differences between the groups in expression of "suspicion" about the nature of the illness, \(F_{2,6}=1.09, \ p<0.05\). But there were significant differences in the "not known" \(p=0.0013\) by randomisation tests] and the "denial or disbelief" categories \(p<0.05\) by an approximate randomisation test, Still and White, 1981").
Figure 5.04
Group mean frequencies of utterance per page of interview transcript of the 4 knowledge categories (diagnosis and prognosis combined) for the 3 patient groups.

Figure 5.05 shows the patient group mean frequencies for "complete knowledge" for each of the g.p.s separately. The group differences appear to be about the same for each g.p., and patient groups do not differ significantly [F<1] as a function of g.p. nor is there any g.p. by patient group interaction [F<1].
Figure 5.05
Patient group mean frequencies of utterance per page of interview transcript of the "complete knowledge" category (diagnosis and prognosis combined) for each of the 4 g.p.s separately.

Source of knowledge
Figure 5.06 shows the mean frequencies per page of those utterances coded under the source of knowledge categories for each of the 3 patient groups. There is a significant simple effect of group for utterances about source of knowledge \([F_{2,6}=14.59, p<0.01]\). Thus the group of terminally ill patients, who did not know about their illness, speak less than either of the other two groups about sources of knowledge. There is also a significant interaction between groups and source of knowledge \([F_{2,6}=14.29, p<0.01]\). The terminally ill patients with knowledge about their illness made relatively more utterances indicating that their knowledge
came from a source other than their g.p.. The chronic control patients made more references to the g.p. as the source of their knowledge about their illness.

![Graph showing mean frequencies of utterance per page of interview transcript of source of knowledge categories for the 3 patient groups.

K = Terminally ill with knowledge
I = " without knowledge
C = Chronically ill

**Figure 5.06**
Group mean frequencies of utterance per page of interview transcript of source of knowledge categories for the 3 patient groups.

**Evaluation of relationship with and competence of g.p.**
Although the content analysis categorisation scheme permits a coder to make an evaluative distinction between utterances, no utterances were coded negatively to indicate the relationship with the g.p. was bad or that the g.p. was considered to be incompetent. Thus all evaluative utterances were indicative of patient approval.
Figure 5.07 shows group mean frequencies for the evaluative utterances. There were only slight differences between groups and these were not significant. There was, however, a difference between g.p.s. More evaluative utterances were made by the patients of Dr. V (Figure 5.08). This main effect of g.p.s was significant \( F_{3,12}=3.92, \ p<0.05 \). Dr. V was of Indian ethnic origin and nearly all of his patients referred to this, going on to assure the interviewer that he was an excellent doctor. This racial preoccupation probably accounts for the differences found.
Figure 5.07
Group mean frequencies of utterance per page of interview transcript of the "evaluation of relationship with" and "competence of" the g.p. categories for the 3 patient groups.

K = Terminally ill with knowledge
I = "" "" without knowledge
C = Chronic control
Length of interview  There was a significant difference between groups in the length of interviews, as reflected by number of pages of transcript (Figure 5.09). The terminal patients with knowledge of their illness produced transcripts that were on average approximately twice as long as those of the other two groups. Interview length was ostensibly under control of the patients, however it is possible that the interviewer unintentionally influenced interview length. Although interviews were conducted "blind" to group membership, on occasion it became clear to which group the patient belonged during the interview. To check whether the interviewer had
influenced the interviews in this way, his perception of group membership, as guessed at the end of the interview, were used to classify the patients into 3 "guessed groups". Analysis of the interview length data, when patients are classified on the basis of guessed group membership rather than actual group membership, resulted in no significant differences between groups being found \( F_{2,21}=2.88, \ p>0.05 \). This is evidence that the difference between groups is best accounted for by differences between the patients per se, rather than being an artifact created by the surmises and expectations of the interviewer himself.
Correlations amongst dependent variables.

Product-moment correlations between A-state scores and the various categories of the content analysis and transcript length for the three groups were small and not significant. Similar low correlations were found for A-trait, except within the terminally ill without knowledge group. In this group A-trait correlated with transcript length (0.76) and the "not known" category (-0.71) and differed significantly from zero (p<0.05); while the correlation with "complete knowledge" (0.50) was not significant. In addition there was a significant positive correlation (0.77) between "complete knowledge"
and transcript length in the terminally ill with knowledge group and a negative correlation (-0.83) for the chronic control group (Figure 5.10).

![Scatter plot of mean frequencies of utterance per page of interview transcript of the "complete knowledge" category against log transcript length in pages.](image)

**Figure 5.10**
Scatter plot of mean frequencies of utterance per page of interview transcript of the "complete knowledge" category against log transcript length in pages.

Associations with demographic variables.

(i) Socio-economic status. The patients in the terminally ill without knowledge group were all manual workers, whereas the other groups contained several non-manual workers (Table 5.05). It is possible that manual workers are less likely to make utterances implying knowledge of diagnosis and prognosis, whether or not they actually have knowledge. It follows that the difference in the frequencies of utterance categorised as knowledge...
of diagnosis or prognosis could be a function of socio-economic status, rather than of knowledge itself. If so, a difference due to socio-economic status should appear within the other two groups. But mean frequency per page for the transcripts of interviews with the manual workers in these two groups was 0.58, while for those with the non-manual workers it was 0.45, a non significant difference which is not in the direction predicted by this argument. Overall the mean transcript length was 32.75 pages for manual, 27.5 pages for non-manual; this difference is not significant and again is not in the predicted direction.

(ii) Sex. The mean for "complete knowledge" was 0.64 amongst the men, 0.61 amongst the women in the terminally ill with knowledge group; 0.13 and 0.25 respectively in the terminally ill without knowledge group; and 0.39 and 0.43 in the chronic control group. These differences and also comparable differences for transcript length, were well within chance expectation. Men were significantly more variable in their frequencies of utterances expressing "complete knowledge" than women; when each frequency was expressed as the modulus of its normal deviate, then men had significantly higher deviation scores (F1,22=7.90, p<0.02). Inspection of the individual scores suggests that this was to some extent true of each group, though less so for the terminally ill without knowledge group.
(iii) Age. Differences involving the chronic control group against the rest (Tables 5.04, 5.05 and 5.06), could in principle be accounted for as a function of age, but in none of our dependent variables did this group of patients differ straightforwardly in this way. The differences revealed by Figure 5.06, where groups differ in sources of knowledge, could be explained if patients' sources of knowledge change from "other sources" to g.p.s as they get older. But the correlations within groups between age and these two categories were small and well within chance expectation, which suggests that the differences are not a function of age.

Low correlations were found between age and both "complete knowledge" and transcript length in both the terminally ill with knowledge and the chronic control groups. The correlations within the terminally ill without knowledge group were larger (Table 5.10). Taking A-trait and age as the predictor variables, the multiple correlation with "not known" was 0.88, with "complete knowledge" 0.92, and with transcript length 0.80. Thus 77% and 85% of the variance was predicted in the case of the two knowledge categories. A-trait contributed most of the variance in both cases, though the low correlation between A-trait and age suggests that age made an independent contribution. This was confirmed in the case of "complete knowledge" since the partial correlation with age when A-trait was held constant was -0.90 (F1,5=10.36, p<0.01). In the case of "not known", however, the partial correlations were
0.75 with A-trait when age was held constant, 0.40 with age when A-trait was held constant, which were close to the ordinary correlations.

Table 5.10
Product-moment correlations between five variables amongst the terminally ill patients without knowledge group.

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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>1. Trait Anxiety</td>
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<td>-.81**</td>
<td>.50</td>
<td>.76*</td>
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</tr>
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<td>2. Age</td>
<td></td>
<td>.17</td>
<td>-.64</td>
<td>.43</td>
<td></td>
</tr>
<tr>
<td>3. &quot;Not known&quot;</td>
<td></td>
<td></td>
<td>-.71*</td>
<td>-.50</td>
<td></td>
</tr>
<tr>
<td>4. &quot;Complete knowledge&quot;</td>
<td></td>
<td></td>
<td></td>
<td>.21</td>
<td></td>
</tr>
<tr>
<td>5. Transcript length</td>
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</table>

* significant at p=.05  
** significant at p=.01

Summary
The results of the statistical analysis of this study can be summarised as follows:
1. The three groups, terminally ill with knowledge, terminally ill without knowledge, and chronic controls, differed in frequency of expression of knowledge about the illness, the terminally ill with knowledge group showing the most, terminally ill without knowledge the least.
2. The terminally ill with knowledge group were relatively more likely to get knowledge from "other sources" (usually a hospital), the chronic control group
3. The transcript lengths of the terminally ill with knowledge group were longer than those of the other two groups, possibly reflecting a greater willingness to talk about aspects of their illness and treatment.

4. The frequency of "complete knowledge" utterances was positively correlated with transcript length in the terminally ill with knowledge group, negatively in the chronic control group.

5. The groups did not differ on either Trait or State Anxiety Scale scores.

6. In the terminally ill without knowledge group (but not the other groups) Trait Anxiety and age were correlated positively with transcript length and (most clearly in the case of age) with frequency of "complete knowledge" utterances, negatively with frequency of "not known" utterances.

7. Men were more variable in frequencies of complete knowledge utterances than women.

Discussion of these results is held over until Chapter 8, after consideration of the qualitative analysis of these interviews.
CHAPTER 6

Before St. Peter calls: A qualitative analysis of g.p. and patient interviews.

"It's not that I'm afraid to die. I just don't want to be there when it happens." Woody Allen: Love and Death
In this chapter we present a qualitative analysis of the interviews with g.p.s and their patients. In this analysis, themes common to many of the interviewees will be drawn out to explicate the preoccupations of patients and doctors. As well as similarities, differences between both groups and individuals are exposed also. Before turning to the analysis itself and in line with the points about analytic method made above a few words on the status of the face value of what is said by informants. A number of questions request the g.p. to explain, for example, his policy on telling or not telling terminal patients about the nature of the illness. These stated policies are considered in comparison to one another, as well as in comparison with what is revealed about how it may work out in practice and/or statements contradicting a stated policy. Two lines of questioning adopted during Interview 1 with g.p.s are of particular relevance. First, the stated policies of the g.p.s were predominantly elicited by questions 7 to 12 of the interview schedule. Since each g.p. had prior warning of the fact that he would be interviewed about terminal care it would be reasonable for him to expect questions of this sort. Hence he might think more than he would normally about the issues involved, even if he did not consciously attempt to present an over favourable image of himself (fake good). Thus responses to these questions may represent "authorised versions" consciously considered and rehearsed. But several questions during the interview which were not overtly seeking information about...
policy, elicited responses revealing aspects of that policy. Questions that asked the doctor to describe previous experiences with terminal patients tended to result in responses revealing aspects of policy. Second, while discussing patient case histories, all of the g.p.s made comments which revealed aspects of policy. Most of these were to point out how the case in question exemplified a stated policy, but some indicated how or why the case under review contradicted that policy and/or was problematic. On the other hand some comments did not appear to be recognised by the g.p. as conflicting with what had been said at some other time. Although these examples refer to g.p. interviews, the same principles apply to interviews with patients. Discrepancies within patient and g.p. interviews, and between patient and g.p. interviews may occur for a number of reasons, representing either intentional misrepresentation or genuine ambivalence by either or both parties (c.f. Chapter 4 Section 1).

We now turn to the analysis of interviews and the next section primarily considers g.p. interview 1 (note 1). Thus the analysis in this section consists of a presentation of the doctors' perspectives to terminal care, when questioned in the abstract about their approach to the care of the terminally ill. We then turn to consider the interviews with patients and the g.p. case history interviews. The analysis here then is concerned with concrete examples of terminal care at home, for which
we have accounts from two sources, patients and g.p.s. In particular we will be considering how much the patients know about their illnesses, how they gained such knowledge (where this is appropriate), and how much the g.p.s know about what their patients know. To these ends we consider each patient in the two terminal groups with the intention of painting for the reader a picture of the interactions that occur between these g.p.s and patients. The final section presents a brief summary of the interview analysis presented in this chapter. This acts as a bridge to Chapter 7 in which we forward a typology of strategies used by g.p.s and patients when interacting developed from the analysis reported in this chapter. A more complete summary of the present chapter is presented at the beginning of Chapter 8.

G.P.'s Perspectives

Meaning of terminal illness When describing what was meant by terminal illness the g.p.s all referred to the incurable nature of the illness, that it would result in the death of the patient within a matter of months and that their own task would be to offer some kind of palliative treatment. Thus all the g.p.s' definitions include all 4 of the defining characteristics of terminal illness to be found in the "text book" definition. However, in addition they all said that cancer was the commonest sort of terminal illness, and mentioned "cancer" as if, even though it was not actually part of the textbook definition, it was almost a synonym
Aim of treatment The aims of the g.p.s when treating the terminally ill were highly similar. All stressed the need to offer palliative care to make the patient's life as comfortable as possible until he or she died. Although they had to offer "some medication to make life easier" (Dr. Zi), this was only one part of palliation. They felt that the best terminal care could be offered to a patient in his or her own home, with the proviso that the patient's family had to be willing and able to cope with the nursing load that home care required. Home care was not only preferred, typically this was where such patients were treated. The rationales for preferring home treatment proffered were very similar. Central to all four was the assertion that patients were happier in the familiar surroundings of home, free from the regimentation imposed in hospital. One g.p. went so far as to assert that if he did not treat a patient at home then he was "abdicating (on his) responsibility to the family" (Dr. Wi). Responsibility to the family, rather than the patient per se, was another point on which there appeared to be agreement. For whatever his policy toward informing the patient about his or her illness, each one said that he always informed a close relative.

Informing terminal patients. In contrast to the general agreement revealed above, the g.p.s' policies on informing the terminally ill patient about the illness differ in a
Dr. V espouses a passive policy on whether or not to tell a patient he or she is dying, the initiative being ostensibly left to the patient. Before being asked V spontaneously explained that,

"...what I do with my patients who are terminally ill unless they are very forthcoming and they straight away ask "Doctor am I having cancer, will I die?", then I think I will tell them straight away that, yes, they are probably dying. But most of them, the majority of patients won't ask that sort of question, so I don't tell them that they are dying, because I don't think it is fair to them to tell them".

(Dr. V)

(6.1)

Later when explicitly asked, he replied:

"No I don't tell them, unless the patient is bold enough or courageous enough to ask me straight away something like, "Am I suffering from cancer or from this or from that?" At that time I don't lie to them. I tell them the facts. But normally as routine I don't tell my patients that they are going to die from cancer or from a heart attack or whatever it is unless they ask me. My attitude to this is to keep them comfortable. I don't promise anything you know, I don't promise them they are going to get better, but at the same time I don't say that you are going to die.... Something happened to me once.... It was not here but when I worked in a hospital and at that time I had a patient who.... when he saw things were not right he asked me straight away, "Doctor, will you please give me an honest answer?" I said "sure, what is your problem?" and he said "well tell me am I suffering from cancer or this or that?" and he was and so I had to tell him, because at that point it wasn't fair that I shouldn't. When somebody is asking I should do it. I should keep them in the picture. I shouldn't keep the information away from him, because he is entitled to know if he wants to. After all it is his own life and he is entitled to know... just that once it has been like that... No, I haven't told any patient except that one".

(Dr. V)

(6.2)
The "I think" in the forth line of Quotation 6.1 may express a real uncertainty and not be just a pause filler. Only one patient has ever asked Dr. V the necessary question and that was in hospital where the situation is very different to that in general practice. It follows from V's remark that he has never told a patient about impending death in his present practice, and his avowed policy of telling if asked, has never been put to the test. Further V did not make the distinction between passively waiting for a question and actively eliciting one. Both awaiting a question and prompting it may represent policies of not telling unless asked, and be described in similar terms by G.P.s, but they clearly are quite different.

Like V, Dr. Z does not usually tell his patients. In response to questioning about whether he ever tells patients he says:

"No, never. I think probably they are aware but I don't sort of say you've got cancer, this is it no... Well. I'm thinking now, I can't say, no, I can't recall actually telling somebody they've got cancer or they're going to...no."

(Dr. Z) (6.3)

A possible exception is when the patient has to make a decision based on knowledge of the diagnosis, but the example he gives which initially appears to illustrate this is of a patient whose operation was unsuccessful, and who died 6 weeks before he was due to receive a pension.
As a result his widow did not qualify to receive the pension either. If the illness had been allowed to run its natural course the patient would almost certainly have survived the 6 weeks, and the outcome, in terms of the widow's financial circumstances, would have been better. Dr. Z gives several other examples of individuals who have been informed, and those where patients who have reacted adversely and should not in his opinion have been informed, are more than balanced by patients who took the news in their stride and were clearly better for it. Nevertheless.

"...I think they are better off if they don't know on the whole, this has been my experience... I think that on the whole people don't want to know really, you know... they would prefer to suspect, you know, they like to, they're like ostriches, they like to put their heads in the sand to a certain extent and I would go along with this, you know, if it is a terminal sort of illness".

(Dr. Z) (6.4)

And yet,

"...well, people they get weaker and they get iller, and, you know, you sort of stay with them you know. They don't loose faith in you and, you know, they twig. I think they twig, it dawns on them gradually that they are not going to get better, but, you know, they may talk about it at home, maybe husbands and wives talk about it. I'm sure some do... generally when I'm speaking to them I don't mention it, the outcome..."

(Dr. Z) (6.5)

There is conflict here between the g.p. not telling his patients because it is better if they don't know, and his recognition that in fact they do know, either through their experience of the illness, or through talking about
it with their spouses (whom Z usually tells), or through being told by another doctor (c.f. Chapter 5). Thus Z's stated policy, like V's, is to make no explicit statement about impending death, but not otherwise to prevent information reaching the patient. He explained that:

"I think this is one of the sort of areas that young doctors find difficult to handle and they don't say to folk, you have got cancer because they don't quite know how to say it... I did a year as a trainee in Scotland and I visited an old farmer who was dying you know, and he said to us as I walked in and he said to me, "Oh you can't do anything for me today doctor", meaning that he was dying... I was most embarrassed... I didn't know what to say".

(Dr. Zi)

(6.6)

This candid admission to feeling embarrassed as a young man when faced by a patient, who verbalised his knowledge that he was dying and that Z and his medicine were powerless to save him, may go a long way in explaining Z's ambivalence toward telling terminal patients in later life.

Whereas V and Z express policies that do not routinely result in either informing patients, or acknowledging a patient's knowledge, X has a less clearcut policy. Asked whether or not he tells a patient when a terminal illness is diagnosed, he replied:

"More often than not, no. It depends upon the nature of the person and how well I know him. Not always does the knowledge of the patient help. Certainly initially, probably none of them know the diagnosis, if they are to be told at any stage, then it will be when the time is right, if it gets right. Sometimes the opportunity doesn't arise, sometimes there's an unseen or unsaid request from the patient not to tell them. To keep it in disguised forms, and they indicate
that, you know, they don't really want to know. "Yes, I want to know but please don't tell me if I'm right". That sort of attitude. I have made a mistake and told one person who absolutely broke down... I think she probably said something like, you know, "it's alright, you needn't kid me any more, I know all about it". But I am afraid that once the nature of the illness was confirmed to her then she had a rather hysterical reaction. And contrary to what she was leading me to expect she might be like, she was more or less telling me she had adapted to it prior, or at least I read the situation as that.... (That incident) put me off in many respects informing patients... and I wish now that I'd stuck to my guns and told lies. I will often tell lies, white lies, sometimes quite bluntly, more often than not I will try to do it by telling lies". 

(Dr.Xi) (6.7)

But whether or not lies are told

"...I'm sure a lot of them know long before the end, but they don't particularly want to know". 

(Dr.Xi) (6.8)

and,

"...you know, it hurts sometimes, that's maybe one of the reasons I don't tell patients. I don't tell patients. I don't know, perhaps I'm too big a coward, I don't think so. I mostly keep that back because I think that it would be detrimental to the general progress. It depends upon the nature of the patient, obviously I've only had a limited number of terminal patients so far. I've got a lot more to face me, and their attitudes are going to be dependant on the particular situation. As I said, I don't have any fixed ideas". 

(Dr.Xi) (6.9)

Asked about the criteria he used for picking the right opportunity for telling a patient, he replied:

".... it's probably not very easy to identify the criteria, you see. A relaxed setting, sometimes a formal question from the person toward you makes it easy to give it. Sometimes there's a bit of a family crisis... But I don't have any set criteria. Very indecisive, aren't I"?

(Dr.Xi) (6.10)
Instead of a strict policy to tell or not tell patients X seems to depend on an ability to get on with people, to sense the right moment and the right way to convey information. For X the solemn announcement of impending death is as much out of place as it is for V and Z, although unlike Z he does not hint that knowledge on the patient's part might always be harmful. He depends on his sociability to judge the appropriate moment to give information, and to give it in a way that will not jar with the jocular relationship he normally builds up with patients.

W was different from the others and if Z and V are at the negative pole on a continuum of telling W is to the positive end.

"I was involved in a lot of the early audit study groups... who studied bereavement. Before that I believed that I only told patients that I thought could cope with death, but they were dying so I told no one. I finished the audit course and I understood the process of bereavement, the phases that people go through, and developed skills to cope with arrested bereavement and probably bereaving, you know bereaving impending death; and I said to myself, I decided that I won't tell people who I don't think can cope and I've told everyone. So I think that what the doctor does in bereavement is largely dependent on his own skills. If he has got to cope with a process that he doesn't understand then he doesn't tell. If he understands then he tells".

(Dr.Wi)

(6.11)

While other g.p.s see treating the terminally ill, especially how to communicate with them, as not having a
satisfactory solution, and perhaps peripheral to their professional concerns, W regards the problem as a challenge. His procedure is consciously, almost self-consciously, one of counselling, and it is the language of counselling that he used to describe the approach.

"Like most things I would explore what is their perception of themselves and then having asked them what it is they think they have got then they will always ask me what I think they've got, and it is one of these things that sort of comes out. If... you write the script then they will take the lines, if you cue them in then they will ask the questions... It may take me three or four consultations. Quite often you will tell them and they will deny it when they come back".

(Dr.Wi)

(6.12)

Thus it appears that similar to V's stated policy, Dr.W tells patients only when they ask. But unlike V, who has told only the one patient in hospital, W asserts that he has told every patient since completion of the bereavement audit, since he elicits the questions from his patients whereas V does not.

"...usually if there is a growth I ask them, "what do you think you've got" and if they say no, I say, "come on, what do you really think you've got". "Well have I got cancer?" "Yeah". And then try to put it into time, talk to the family... try to leave the problem in the family, not the individual."

(Dr.Wi)

(6.13)

Dr.W is the only one of the g.p.s whose stated policy was always to inform his patients when they were dying. Yet he did not see it as a simple problem of conveying information to a patient, but as part of his total
approach to patient care within the family. He recognised that a patient does not always take in fully what the g.p. is intending to convey and hence he was able to select patients for the terminal group without knowledge. We now turn to the interviews conducted with the patients and the g.p. case history interviews, in order to consider the way that stated polices are implemented.

Patient Awareness of Illness and G.P.s' Assessments of Patients' Awareness.

In Chapter 5 we saw that the g.p.s were able to allocate patients to groups reliably. And yet only one g.p. reports regularly telling patients about the illness. The other g.p.s only seldom discuss the illness with their terminal patients. If these findings are correct, on what were the g.p.s basing their judgements of patient knowledge of illness when allocating patients to groups and how accurate are g.p.s' judgements in relation to patients' expressions of knowledge during interview? Below we consider the individual members of the two terminal groups in turn.

Terminal Knowing

In the case of the terminally ill who know about their illness the most obvious basis of a g.p.'s judgement is discussion of the illness with the patient. But only Dr.W reports routinely doing so and in his case the two patients in this group reported receiving information from him.
"I had a feeling that there was something, em, well that I was advanced then... and I just wanted someone to tell me what, you know. The surgeon, Dr Smith, well they don't discuss things with you, at the bottom of the bed they'll talk to themselves, but you, the patient, are the last one to know anything. But I thought, well, when I get home I'll ask Dr W, you know and he'll tell me the truth.... And when Dr W came out I asked him and he told me."

(Pt.09)  (6.14)

Yet even in this case the patient claims that she was aware of the fact that she was severely ill before she had spoken to W. She may have gained overt recognition of her illness from W, but she had suspicions before talking to him. Of his other patient in this group (Pt.19) W explains that although reportedly told in hospital he ensured that she did in fact know about her illness as soon as she was released home.

"She was told by the gynaecologist. When I went out to see her, I reconfirmed it."

(Dr.Wii)  (6.15)

The patient confirms that she was told by the hospital consultant explaining that he told her because she was a widow with no adult relative whom he could inform.

"Mr Atkin said that it had been a hysterectomy and he'd taken everything away... Next week... he said he had some bad news to tell me. And he got round to telling me that I had cancer of the womb, and of course you can imagine what a shock it was. After I had steadied myself a little bit while he started to tell me the treatment... (and that there was) no reason why I shouldn't, em you know, come through the treatment alright."

(Pt.19)  (6.16)

The patient's hesitation and the negative way in which she
phrases her remark at the end of this quotation suggests an awareness of prognosis. This is confirmed later when she describes W's visit immediately after her release from hospital.

"He was very reassuring and very friendly. In fact going out he patted my arm and said, "What else can you get now?" But he says, don't despair we'll help you along... It wasn't a definite cure. He couldn't say that after the treatment it's cured, it's gone. He wouldn't say that, but definitely he said it would prolong life and that's all you want isn't it?" (Pt.19) (6.17)

It is thus clear that the patient knows that she has cancer and that the treatment cannot guarantee cure. It is probable that she takes this one step further and recognises that the refusal of both Mr. Atkin and Dr. W to guarantee cure, implies that she will eventually die from her cancer, but that the treatment will stave this off.

One may expect that a consultant would base a decision to tell a patient about his or her illness on attributes of the patient that marked the patient out as psychologically equipped to benefit from such information. Yet in this case a consultant, who according to Dr. W, does not usually tell patients, told Pt.19 on the basis of the characteristic that there was no other adult relative. Although she would not normally have been told, Pt.19 has not reacted adversely to the information and it appears that it has been beneficial to her, especially with reference to her two adolescent sons.

"Some people say that they don't worry but of course
There's a lot of things I've got to see to if I'm going to leave the boys alright and therefore I've got to face things. I've got to be able to say well look it is my responsibility to see to them and noone else's. I think we've all drawn a lot of strength from that really... life has got to go on."

(Pt.19) (6.18)

And

"I talked to the oldest son and he says, "well mum dad was never afraid... we've done it once and come through with it, so I don't see why we can't come through again". So I thought for a young lad that is a good attitude to take and that's the attitude I've got to take."

(Pt.19) (6.19)

W confirms that in his opinion Pt.19 is coping quite well.

"I think she's tough enough and well enough integrated to cope at least initially on her own with her impending death... I see the problem lying with the boys... I see the boys (during my counselling session) this weekend... Her coping mechanism... is to stick within the family and relate to her sons and try to work the thing through with an essence of privacy. I think she is coping quite well... trying to work the whole thing out and to communicate to her boys."

(Dr.Wii) (6.20)

Although Pt.19 may be coping well now, at first she was unable to talk about her illness.

"When I first got to know I couldn't say the word. If I was talking to the boys or to the doctor I'd just say well, "I didn't get a good report back (from the hospital)." And I never actually say what it was, you know cancer. And I was really upset and I cried to myself all the time when the boys were out. But since talking to Dr. W, I've been able to say the word and not be so distressed at it... I'll just have to take things as they come."

(Pt.19) (6.21)
However natural it may be to be upset about and unable to talk about having cancer, it caused W concern for both the patient and how her reaction might effect her sons. He thus set about the task of changing the way Pt. 19 related to her sons.

"She seemed to me blocked by her need to mother her sons... I wanted to go into the family and do something, because... She was quite into the angry sort of I don't really understand phase and she wasn't allowing herself to express it. She obviously hadn't expressed her feelings to anyone and it was getting on top of her. So I was encouraging her... to talk about their father and how she coped with it (his death). If anything happened to her, what lessons she could teach them (the sons). I feel that this led, will let her free to get on with real feelings and emotions... She's teaching them, imparting to them what has happened to her, letting them learn from her, but at the same time beginning to work through the bereavement part herself, as well as preparing them to face life without her. Because sometimes it is easier to die than to have someone die on you... And I probably won't do anything more until I see what is the next crisis, or if one feels from what the boys say that things are going wrong. Then I will take it from there."

(Dr. Wi) (6.22)

The relatively matter of fact way that according to these reports Pt. 19 is now approaching her illness and preparing herself and her two sons for her impending death is thus not purely a result of her own resilience or the family's previous experience of bereavement. It is probably also a result of the reassurance proffered by W and his open truthful approach. The approach in taking on and attempting to solve a patient's problems, also suggests to the patient that the problem is fairly routine and thus inspires confidence. W's method is interesting in that he manipulated the situation by
getting the mother and sons to talk about their father's
death, but using this as a metaphor for her own death.
The aim is to prepare the sons for the loss of their
mother and while maintaining the mother role for the
patient, in so far as she is advising her sons, enable
her to release suppressed emotions and come to accept her
fate. It seems thus that his approach is of benefit to
the whole family. Pt.09's explanation of how she learnt
of her illness from W, perhaps provides further evidence
for the benefits of his approach.

"I can talk to him, that he can tell me the truth... I
can just ask Dr W and he will just give me the truth.
He has told me an awful lot of things, more than what
the hospital had told me. Anything I've wanted to know
he has told me exactly, and I asked him to give me a
promise he would, and he has done and when he has got
word from the doctor from the hospital he has come out
and told me immediately what was in the reports and
things you know and has been quite honest with me and
I think I have been quite honest with him. But when I
packed the drink in, I became much calmer, I came to
terms with it more, I had time to sit and think about
it properly and then I thought, I don't know if I
brainwashed myself but you know, I thought I'm no
different from anybody else, there's just something
going off in my body that is not going off in other
people and after all, as I said before, we've all got
to die, some of us earlier than others and that has
helped me to settle down. I don't know, I certainly
don't want to die. I've sometimes felt, well I think
if I were just to sit and brood over it I could, I
could be a little anxious again about it".

(Pt.09) (6.23)

Such explicit discussion with their patients of either
prognosis or diagnosis is not to be found in the cases of
the other g.p.s, which tends to confirm the analysis of
g.p. interviews presented earlier.

Dr. X describes his relationship with Pt.15 and although
both doctor and patient know about the illness and know that the other knows, they do not routinely discuss it.

"... that man has accepted very well the diagnosis and he's accepted what it means to him and he's using his life to the full. He has got full intellectual capacity and he's another one really where a lot of the interview is spent socialising, and chatting about the history of the area, botany, insects. He's got a son, a grandson who is interested in butterflies apparently and he's got a photograph of the son and the butterflies on the wall and, well you know I did some entomology earlier in life and we talk about mutual interests in that a lot...".

(Dr. XII) (6.24)

In the patient's own words they talk about

"...anything that crops up, but not politics and not religion. Those two things are taboo. Well they should be taboo, anyway, because they're peoples private thoughts... I could say to Dr X if he were sitting where you are now, I could say now look here, doctor, let's not beat about the bush. You know how long I've had this terminal cancer don't you? And I would get a straightforward answer 'cause he's a straightforward young man. But I sort of ease it under that, under the wave, I don't upset him in my way and he doesn't upset me".

(Pt.15) (6.25)

If the illness is not discussed by the two men how do they know each other knows, and how did the patient find out?

One day Dr. X called to make a routine visit on Pt.15 and describes what happened as follows.

"His wife knew the diagnosis and he didn't and they sat down one afternoon on the settee and held hands and told each other and since then it has been very easy to deal with him.... They certainly discussed the diagnosis. And I went in one day wanting to do my general act, and they said, you know, he knows now so you can talk to him doctor. And I expected all hell to break loose, but it didn't... My immediate impact was hell what are we going to have to cope with now... I must admit I feared the worst, but then was immediately assured because we all sat down and had a
long talk... He knew the full extent and ... if his number was up his number was up."

(Dr.Xii)

(6.26)

Thus X's judgement is based on at least one discussion with the patient even if it now remains unsaid between them. It is interesting to note that again the patient claims that he was aware of the nature of his illness before being told.

"I knew, I knew even from the beginning, I told my wife what I had and they all pooh-poohed it."

(Pt.15)

(6.27)

The patient's claim is supported by the spouse.

"It wasn't discussed... anyway one night he was asking that many questions. He knew... oh he said somebody's not telling me the truth... It was building up on me. I knew. I was a bag of nerves... they said, whatever you do mum don't let dad know. And I said oh well... and I told him everything. And I think he's took it better that way..."

(Sp.15)

(6.28)

and the patient reaffirms his point:

"Oh I needed this confirmation, that was all... it was no surprise."

(Pt.15)

(6.29)

Another overt method by which a g.p. can base his judgement of a patient's awareness of illness is through communication with the consultant or other doctor who has informed the patient. In an example quoted above (6.15) Dr.W was informed by the hospital that Pt.19 had been informed of her illness. Likewise, Z bases his
judgement that Pt.23 knows about her illness primarily on a letter from the Department of Surgery at the local hospital which he read out (in precis form) during the case history interview.

"This is the registrar who is writing this letter as opposed to the surgeon, Mr Smith. And it says, em, "I presume her condition has been explained to her when she was seen, em surgically at the clinic. As she was not accompanied when I saw her. I did not mention her diagnosis to her myself. There is nothing further we can do for her...""

(Dr. Zii) (6.30)

Thus Z's judgement is based on that of a hospital doctor, although the evidence for the latter's judgement, at least as revealed within the letter, appears to be tenuous and does not really merit the conclusiveness that Z seems to accord it. Unlike W, Z has not taken steps to confirm with the patient that she does in fact know about her illness. But he does explain that he has other evidence for this belief that she knows.

"She's had quite a long spell of not seeing anybody and I think largely because she didn't want to. Now I've classified her as a "knows", knows that she has got this, although I have never actually mentioned it to her, but I think her attitude is I've got this and nobody can do anything for me... so I won't worry, I won't have the doctor.... (Int. What gives you the impression that she knows?).... I'm just wondering. There's no mention in this letter of him saying anything, of him saying I have told her. Just the fact that she didn't want the doctor to call. This suggests to me that she thinks she has got, or she knows she has got something for which there is no cure."

(Dr. Zii) (6.31)

Such evidence is at best circumstantial, but the impression that she knows about her illness is one that
was shared by the interviewer as witnessed in his field notes. Although the patient herself never mentioned cancer as such, the interview revealed that she probably recognised that this was what she had and that she would die from it. In the following quotation "he" refers to a registrar who examined her as an outpatient post-operatively.

"He said, "what did they tell you after the operation?" I said, "they told me I'd had two parts of my stomach taken out and the hernia done". And he said, "didn't they tell you anything else?" And I said "no". So he said, "when we opened you up we found that there was an ulcer too near to your heart and we couldn't do anything". "Oh!" He said, "well the last thing don't worry... you'll be alright." And I said, "Oh it's alright I've got past worrying, I take each day as it comes."

(Pt.23) (6.32)

and later in the interview,

"And then sometimes I think to myself, you're going to get a shake up that you're not looking for that, well when it happens it happens, but I'm accepting each day.... Well I don't know, something's got to happen hasn't it, you know."

(Pt.23) (6.33)

Pt.23's exclamation of "Oh" above suggests that she recognised the implicit meaning of the registrar's explanation of her illness, but whether or not she did, it is clear that she recognises that death may occur at any time. To be fair however we must remember that she is an elderly lady, who obviously recognises that her health is failing and death is inevitably approaching. The way in which the medical profession have approached Pt.23 is interesting in another way. Her case constitutes the
clearest example in these interview data of doctors maintaining the sort of "team performance" described by Goffman (1971), and conforming to the analysis of the medical profession forwarded by Freidson (1970a), as the following quotations reveal. Pt.23 had been receiving treatment for arthritis for some years prior to developing cancer symptoms. One of Z's partners used this to explain away her symptoms, by saying "some of these drugs cause a little ulceration", although the cancer diagnosis had already been made. Later an orthopedic surgeon, who also knew about her cancer, suggested postponing a hip replacement operation, reportedly saying that he would:

"keep in touch and as soon as I had got stronger he said he'd send for me and he'd do the operation."

(Pt.23)

(6.34)

Z confirmed the impression that this was said so as to maintain her morale:

"This sort of hope, she's looking forward still. I think it would be a mistake to say forget about your hip operation, you're going to die of cancer... It would take the joy of living that is left for her out of her... Why spoil it?... But I think she knows there is something seriously amiss... she knows what the score is."

(Dr.Zii)

(6.35)

Pt.23 holds on to the hope that she may be able to have her hip replacement but is basically content to still be alive and lucid.

"There's some poor old folk that haven't, but I've still got all my faculties and I can carry on. And I
enjoy each day more than I have ever done in my life.
You may not believe that and fuey.."

(Pt.23)
(6.36)

She was certainly very lucid and definitely resented the fact that some doctors treat her as if she were not. This in itself lends support to the notion that she saw through the machinations of the medical profession to conceal the severity of her illness from her. During one period of hospitalisation a house-officer came to test her cognitive functioning and she played a joke on him that almost backfired. Just prior to the following she has recalled the W.A.I.S. questions used by the house-officer and explained how she answered them correctly:

"Then they'd say, "what hospital are you in?" and I said Cherry Knowle, (laughs) and that's the madhouse and I never thought they'd believe. And the doctor said, "no, no,"... And I said, "Oh alright then Northton General Hospital". ...Guess I can't say anything unkind or anything, it's just that well...

(Pt.23)
(6.37)

While there may be uncertainty about Pt.23's knowledge of her illness, there is none for Z's other terminal knowing patient (Pt.27), who unequivically knows she has life threatening cancer, and talks explicitly about it during the interview. However, like Pt.15, she does not discuss it with the g.p., as respectively Z and the patient herself reveal.

"Well she definitely knows she has got cancer... I don't think she has accepted she is going to die from it. I think she still reckons... well that she is in with a chance... (Int. And you haven't discussed that
with her or have you?) No, no, no, I think we've just both assumed that we both know what she's got. She said something to me last time I went in. She said something about, about beating it. If it's possible to beat it I will beat it, that sort of, well words to that effect. So she's trying very hard." (Dr.Zii) (6.38)

And the patient:

"I think we both realise what it is, you know, and I don't think there's really been any, any need for deep explanation because, you know, I knew what was wrong and I think we appreciate that I did know what was wrong. I don't know, I mean I may be wrong with this." (Pt.27) (6.39)

She continues to say later during the interview:

"The cancer... it's affected not only my lungs, not only my joints, but liver, gall and kidney. But I'm not aware of anything else it's affecting. I don't want it to appear anywhere else. Please God let's hope that the chemotherapy kills all the disease. I've got to pray and hope for that. But no, no, ...Dr.Z has, you know, never, presumably he knows that I know... I'm presuming that possibly, possibly, he may feel that, the specialist will have told him therefore he may not want to discuss it in case it's painful to me. I don't know really. But er, no we've never mentioned it, cancer at all we've not er, we just seem to dwell on my aches and pains... But of course I don't know, I don't know if he knows that I know or not... I know from the specialist and therefore he may not want to saddle me by mentioning the word cancer, because let's be honest, as soon as the word cancer is mentioned people (say), "Oh my god I'm going to die". You see we are all going to die eventually... But one has got to come to terms... with it... I think you've just got to get on with living from day to day and pray... that science and doctors can help you one day and cure a person and keep them going... Because I'm a great believer in when, when death is due, death you can't avoid it. That when it's time it's time, and nothing and no-one can prevent it."

(Pt.27) (6.40)

As can be seen from these quotations the patient assumes
that Z has been informed that she is suffering from cancer and that she herself has been informed by the hospital. But since they have not discussed the issue the patient also expresses uncertainty about this. Dr. Z's reticence to talk to her about her illness is reasonable in her eyes, and interpreted as his concern to protect her from distress. Thus he does not say anything explicit in case it upset her. The quotations may represent evidence for Dr. Z's assessment that, although she knows she has cancer she does not acknowledge that it will kill her. However, it is just as likely that she does recognise that there is a very high probability that she will die from cancer yet maintains her own morale by holding onto the hope, however slim, that she could be cured. But there is another explanation that we must consider. While she does not reportedly talk to Z about her illness and recognition of impending death, she does do so with the interviewer. This is inconsistent with an explanation implying she is not willing to acknowledge the illness and death. Hence we surmise that she does not talk to Z about these subjects out of deference to the g.p.'s desire to avoid these subjects.

Pt. 27's explanation of her illness and communication with the g.p. takes for granted that she has been told by a specialist in hospital. This is so implicit in what Pt. 27 says that she assumes that Z has been informed and knows that she knows. However this is misleading, because the suggestion that she has been explicitly told
by the hospital specialist turns out later during the interview to be unfounded.

"The specialist came to me, examined me and said, "You know what I'm going to have to do?"... I said "Yes, I know"... (Int. Can you remember what the specialist said to you, his exact words?)... He said, "You realise what you've got do you?" I said, "I think so". He said, "You realise what I'm going to have to do?" and I said, "Yes". He said, "Right, we'll leave it at that", and that was it. But none of the other doctors have mentioned it, cancer or anything like that."

(Pt.27) (6.41)

If this account of what occurred is correct, the patient has never actually been told that she has cancer per se, although she understood the surgeon's comments to mean this. Such an understanding may have been confirmed by the fact that the surgeon performed a radical mastectomy, and she immediately started an intensive course of radiotherapy. These would have been highly meaningful indicators to Pt.27, who had earlier during her life worked as a nurse. It seems that her relatively sophisticated medical knowledge, may initially have been used by the hospital to obscure her diagnosis from her.

"The lump... I had no pain with it... you can have it and not realise it. First I was told it was the mammary gland lymph vessels, and I just accepted it was all connected to my back trouble".

(Pt.27) (6.42)

The explanation that the problem was in the lymph vessels of the mammary glands only specifies the site of the disease. These lymphatic nodes frequently enlarge during infective processes implicating the upper part of the back
and shoulders, as well as due to malignant disease (Warwick and Williams, 1973: p.734). Pt.27's cancer had first come to notice when the rheumatologist, who was treating her for degenerative lumbar spondolosis, had her chest X-rayed. Thus it may be that by specifying the lymph vessels of the mammary glands it was hoped to initially imply that the problems were directly connected to those with her back, rather than being an unrelated cancer, at least until this diagnosis was confirmed by histology.

The remaining three patients in the terminally ill knowing group resemble patients we have discussed above. V's two patients (Pt.01 and Pt.04) are similar in many respects to Z's Pt.23. There is in both cases certainly ambivalence about how much they do in fact know about their illnesses, and although V places them both in the knowing group, he does not talk to either explicitly. For V, "knowing" about the illness must be judged relative to other patients, who in his view do not know. Thus V's "knowers" may be less aware than another g.p.'s terminal ignorant patients. For V knowing of the illness seems to consist of knowing something about the diagnosis, whether that information is inexplicit, imprecise, or even highly misleading. V explains, firstly about Pt.01:

"It was a chronic illness. It was very gradual in onset and the cyst could have been benign and the rest arthritis. But she knows about the cyst, and she half suspects. But I say nothing... She thinks they
have taken the cyst out. She's lingering on, because she has been in a lot of pain and wants it to finish."

(Dr. Vii)
(6.43)

and about Pt.04:

"She had a breast removed for cancer.... She has the problems of an old person who is chronically ill with multiple illness.... But the cancer this is the thing which is causing her the damage.... but might cause, like kidney failure, or might lead to her death.... I think she knows, but she also knows that there are a lot of things wrong with her not only one."

(Dr. Vii)
(6.44)

The interviews with both patients reveal that V's is a fairly accurate assessment of their knowledge, at least to the degree that each is willing to talk about the illness. Firstly Pt.01:

"I went with this pain in my stomach... and it was a cyst on the ovary. Well they took it out... then I was in pain with my back, and he did the operation... I was still in pain... and he (surgeon) said he'd gone as far as he dare... he was frightened, you see, if he went any higher... I would lose control of my hands and things. But he told me he had done as much surgery as he could... And he told me, he said it was either a cyst or a tumour on my spine... Turned out to be just a cyst. What do you call it? a ratenoid (sic) cyst... (Int. Can you remember the very words he said to you when he was describing what was wrong with you?) No I can't... I think I was too poorly... for anything to register really... (Int. Did you understand what he meant?) Well I did to a certain extent then he told my husband and my son... I took it from them better than I did from the doctor."

(Pt.01)
(6.45)

And Pt.04 explains

"I've got what they call a diverticular (sic) disease.... There was something wrong, which was dramatically wrong you know. And they gave me treatment up there (at hospital) which was terrible.
Oh it's the things they do with you, you know. There's this machine, there's this thing. Oh I can't, I cannot think of it... If only I could have been operated on... Oh I don't know hinny, it was funny 'cause the doctor didn't want to do it."

(Pt.04) 6.46

In comparison to V's other terminal patients, these two patients are relatively informed about their problems. They both possess labels for their illnesses, which are reasonably related to the disease, and as the quotations reveal appear to comprehend some of the implications.

The final patient to be considered here is X's Pt.12 about whose diagnosis there was still a degree of clinical uncertainty at the time of the study. As X explains:

"The diagnosis hasn't been fully established... but he suffers from chronic bronchitis and he has had some suspicious changes. But the doubt must remain as to whether or not he has got a bronchial cancer."

(Dr.Xii) 6.47

but

"Perhaps I have given the nod that things perhaps are a little bit worse than they might have at first realised. But he knows jolly well that he could go the next week or the week after. Or at least I think he does... He's been told that there is nothing more that I can do for him, that I can't tell him exactly what is wrong."

(Dr.Xii) 6.48

The patient seems to confirm X's assessment that he knows or at least strongly suspects that he has more than a simple bronchitis.
(Pt.12) "Up to the day I retired... I'd been to the doctor's six times... But since I retired I've lived at the doctor's... with just ordinary bronchitis, you know... I mean they mentioned that they can't cure me, never been cured, never will be."

(Sp.12) "That's what he told him, he has chronic bronchitis... Just keep it at the chronic bronchitis."

(Pt.12) "He's treating me for chronic bronchitis. What the hell can I do if there is something else wrong with me!"

The last sentence of this quotation exploded from the patient in a loud and angry manner. During the interview this outburst was the only indication to the interviewer that this patient may be anything but a chronic control. Only once the interview transcript was undergoing analysis did the spouse's remark which preceded (and possibly caused) it attain any significance. It seems clear from the spouse's desire to "keep it at bronchitis" and the patient's response, that both are aware that bronchitis is only part of the problem. The nature of any further problem is not enlarged upon, and the source of any such information about the illness is not clarified. It is thus not possible to be more specific than to point to the agreement of all concerned that the doctor has said the patient is not curable and that any information indicating the case to be more complicated than bronchitis has been passed in some vague way by the g.p., which X expresses with the phrase "given the nod". However this may be, it appears that X's perception of Pt.12's awareness of his illness is accurate, since he expresses suspicions of there being a more serious problem.
Terminal Ignorant The first patient to be considered from the terminal ignorant group is Pt.24. Z's rationale for his assessment of her awareness closely resembles that of one of his "knowing" patients (Pt.23). In the latter case Z explained that he believed that she knew, because she kept away from doctors. In the case of Pt.24, Z described his patient's reticence in presenting her cancer symptoms to the doctor, and gave a detailed case history based on the patient's medical records. However in this case the fact that she avoided telling a doctor about her cancer symptoms is taken as evidence that she does not know what is wrong and does not wish to know either.

"She saw Dr. Brown in October 1980 and all she wanted was a hearing aid... then she saw Dr. Black in March... and she didn't mention anything about haemorrhoids or bleeding or anything like that... Further... she has also had diarrhea... which she did not mention to me before. She's been holding that back... To Mr Loftus... she gives a year's history of bloody mucoid watery diarrhea... She was having symptoms for a year really before she sort of took the plunge and told anyone about it."

(Dr.Zii)
(6.50)

Recently the patient asked Z about her illness.

"She said, "what's wrong with me?" and I said, "you've got some fluid in your tummy and they'll need to take it off." And she was obviously relieved that it was just fluid in her tummy, you know, and she accepted this and seemed quite ecstatic almost. I think she suspects that there is something seriously wrong... But as I say I don't think she wants to know. If she has got fluid in her tummy, this is great by her sort of thing."

(Dr.Zii)
(6.51)

The patient herself had obviously realised that something
was seriously amiss for some time. She described the following discussion with a friend which occurred during the period of a year or so before telling the doctor about her symptoms.

"I was ironing and she says, "You look jiggered." I says, "Jiggered, I feel it." And she said, "You should have a doctor." "Oh!" I says, "if I had a doctor I would be sure to go to hospital and I don't want to go."

(Pt.24) (6.52)

At the time of the interview the patient was very ill and although lucid, she occasionally appeared to be struggling to maintain consciousness. The only description of the nature of her illness that the patient gave, followed on from the spouse telling the interviewer about the illness during a lull in her talk when her concentration appeared to drift.

(Sp.24) "He cut a growth out of her you know... I don't know what it was, whether it was a cancer or what it was. But that's what I suppose it'd be." (Pt.24) "They operated on my tummy to clean it out."

(Pt.24) (6.53)

The spouse spoke within the patient's hearing and made no attempt to prevent her overhearing. The patient showed no surprise at what was said and just appears to confirm it. Whether the patient was still a social being in the eyes of her family is unclear and so it is not possible to assess whether the husband spoke knowing she would hear or as if she was not there.

Pt.26 also did not say much about his illness during the
interview and although he also delayed in going to the g.p. when he became ill, Z neither cites this as evidence that he knows, nor that he does not know. The patient says,

"I would say 3 or 4 months.... Now I kept putting it off until I got worse and worse. I just don't like going to the doctors... It was my own fault really, because I put it off and put it off you know. I should have been there afore."

(Pt.26)

(6.54)

Z is certainly aware that the patient delayed in seeking medical attention.

"That is quite a long time to have laryngitis... so you think. "Ah, there's a bit of something wrong here". So I made a little note of that... I then gave him a course of anti-biotics on the assumption that it was a straight forward laryngitis and that it would be dragging on a bit longer than average.

(Dr.Zii)

(6.55)

Z explains that he thinks that Pt.26 believes that he has an ulcer, and that this belief is based on information from the hospital.

"In one of the letters they actually said he has been told that he has an ulcer of the larynx and (in his notes) I have written down and underlined carcinoma in brackets. So they have told him he has an ulcer, so I don't know whether he still believes this or not."

(Dr.Zii)

(6.56)

Later he continues,

"as far as he is concerned he's being treated for an ulcer of his larynx and his life is still unfolding in front of him."

(Dr.Zii)

(6.57)
Pt.26 does indeed speak of his illness as an ulcer. During the interview, nothing was said that in any way implied that he did anything but accept this term at face value, even if he remonstrated himself for not seeking medical advice more promptly.

"They took a piece out to analyse it and they found it was an ulcer."

(Pt.26)  
(6.58)

Pt.26 gave one of the shortest interviews of the series, with a transcript length of 15 pages. This mostly consists of the interviewer asking the questions and probing, and the patient responding with short or yes/no answers. The reasons that Pt.26 says so little overall during the interview are complex and probably reflect more than just an ignorance of his illness. Dr.Z's assessment of Pt.26 is reasonable and agrees with points made in the interviewer's field notes. The following point is probably the most important, in so far as it explains Pt.26's reaction to his illness, at least in part.

"I think he's a down to earth pitman type, who has more brawns than brain, without, you know, being derogatory. But I think he's just the sort of lad that gets on with things and doesn't make a fuss. And I think his throat probably does hurt after talking at any length and that he probably does find that offputting."

(Dr.Zii)  
(6.59)

As stated earlier, V's policy is one of passively waiting. Yet he is aware that in some cases the patient will know what is happening. During the case history interview he said of Pt.05, who had died three days after
being interviewed,

"... he was sliding down and I think he knew he was sliding down.... Well, I didn't tell him that he had cancer. I didn't mention that, but I did mention what was done to his stomach, but not that there was cancer, understand. If he wanted to take that in, probably he might have thought that it was cancer but it was not told to him.... He must have known in his heart that he was not going to get any better, because he knew that we were not going to do anything about it, except I go and have a chat and talk to him about food and diet and pain and I give him some medicine. It is quite clear if someone is sensible enough, to know what doctors can do about it, and what it is then".

(Dr. Vii)
(6.60)

Thus V is aware that the patient may know the truth, but nevertheless categorised him as a terminal patient who did not know. V also indicates that information may be communicated by the g.p. himself by the nature of the treatment given, or as in this case the lack of any curative treatment. What appears to be held back by V in this case is not necessarily the information itself, but an explicit formulation of it as part of a routine encounter between g.p. and patient. There are a number of ways in which g.p.s can control and/or prohibit the flow of such explicit formulations of information during a routine interaction with a patient. The mechanisms by which any control is achieved, may be intrinsic to a g.p.'s style of doctoring (appearing in analogous forms in his consultations with non-terminal patients) and the g.p. may not be aware of this influence and control over interactions. On the other hand they may be "strategies" and include the intent that this word implies. It is likely that in fact V goes further than
merely awaiting a question, blocking potential questions from patients. The ways in which this may occur are described in the next chapter.

Even if V's stated policy is not as extreme as it could be, since it allows for telling in response to a direct question, in practice such questions never seem to be asked of him. It is clear, as we have seen, that V does not encourage questions, but accepts a patient's confidence and expectation that information will not be given, as indicated by what Pt.05 has to say.

"No, no they didn't tell me nothing, you see this is the idea of where that confidence comes in, isn't it?"

(Pt.05) (6.61)

and

"Well, when you've had an operation... they don't tell you what they've done do they?"

(Sp.05) (6.62)

Thus Z is not alone in his uncertainty about how aware patients are about their illnesses, for there is also ambiguity as to how much V's terminal ignorant patients know. Pt.05 has not been told about the nature of his illness and the operation he received, but perhaps suspects that he is seriously ill and dying. That Pt.05 was suspicious, is acknowledged by V in what he has to say about the patient (6.60). These suspicions were most clearly stated by Pt.05 during the interview when he said.
"I wish he had told us more. (Int. Why?) Why well, well he couldn't make no difference could he? Well I couldn't make head nor tail of it. (Int. Would it have made you any happier do you think?) Well, it's not necessary to make you happy, is it? (Int. What do you mean?) Aye, aye, it could be the reverse... well maybe that's why they don't tell you isn't it?"

(Pt.05) (6.63)

About Pt.08 the situation is more clear cut. During interview Pt.08 explained that she was suffering from anaemia and was run down as a result of an operation to remove a bleeding stomach ulcer. Her continuing anaemia would settle down in due course as she got over the illness. V explained her beliefs very similarly.

"She never even gave it a second thought... she was told at the hospital that she had had an operation, she was anaemic because she had an ulcer, which was taken out."

(Dr.Vii) (6.64)

V, like Z, bases his assessment of patient ignorance about the illness on multiple indicators. Again there are problems in the meaning that is ascribed to individual indicators by the g.p., some of which are nebulous, and open to alternative interpretation. Of Pt.05 V says,

"I'll see him depressed or pessimistic all the time which I feel was probably due to because he didn't know what was wrong with him. I didn't tell him."

(Dr.Vii) (6.65)

In the case of Pt.08 (6.64). V has either been in contact with the hospital or he bases his assessment on what she says the hospital told her. In addition what the patient's sister said when she visited the surgery, is
accepted by V as further evidence that Pt.08 does not know.

"I haven't spoken to her about her illness as such... She doesn't know it was cancer and I haven't told her anything about it.. The sister with whom she is living... came to see me and said "Doctor I haven't been told by anyone what is wrong with her... though I think probably it is cancer". I said yes... and then she said "Well I am glad that my sister does not know about it."

(Dr.Vii)  
(6.66)

A further indicator accepted by V is the patient's demeanour.

"I think she does not know because she is quite cheerful and she is thinking in terms of going shopping and buying new clothes for herself. So I am quite pleased for her that she does not know what is wrong with her."

(Dr.Vii)  
(6.67)

There is inconsistency in V's criteria, since in the case of Pt.05 (6.65) it is the patient's unhappiness that V takes as indicative of his not knowing, while for Pt.08 (6.67) it is her happiness which is indicative of her not knowing.

For X the patient's happiness is explicitly reason for not telling, as well as an indicator that the patient does not know, as is revealed in comments about Pt.13.

"He's the laughing one. He thinks he's been cured and I haven't enlightened him on that... I have no intention of telling him the nature of the illness... because he's happy. I wouldn't want to upset him... I think he'd be going through mental hell if he knew... so I think it would be cruel to tell him."

(Dr.Xii)  
(6.68)
And yet X entertains the idea that Pt. 13 may not be totally in the dark.

"Men of his age are normally quite sensible and... perceive that they have got a nasty illness."  
(Dr. Xii)  
(6.69)

In spite of this X's overall impression of Pt. 13 is that he does not know about his illness, an impression consistent with that of the interviewer. The interviewer left with the misapprehension that the patient was a chronic control, that is until the patient's wife whispered to him on the front doorstep.

"It wasn't a gallstone you know. They found a cancer, but he doesn't know. Just ask Dr. X, he'll tell you all about it."

(Sp. 13)  
(6.70)

On the other hand although the patient realised both that he had been very ill before the operation and that his life may have been in danger, this was now all in the past. In his view the operation had been even more successful than his doctors had expected and he was on the road to recovery.

"Yellow jaundice that was the complaint... and gallstones they had to take out... When I went down there (operating theatre) it was touch and go. It was either put you through alright or goodbye. It was 9 times out of 10 goodbye... I've had no pain since I came out of hospital... I've done remarkable well."

(Pt. 13)  
(6.71)

And this is consistent with X's assessment, although X
expresses a degree of uncertainty about how much either of
his "ignorant" patients know about their illness.
However of the two he is more sure about Pt.13, with
the unspecific assertion about "men of his age" being the
only time he suggests that Pt.13 may have any inkling of
what is going on. But, X seems far from certain about
how much Pt.17 knows or does not know. Because of this
he allocated her to the study only after another patient
had been found to be unsuitable.

"I think this one was put in in place of J.L., it was
one I considered early on and rejected. She is a woman
I have mixed feelings about and... I rejected. You
know, because I thought it was a bit difficult to
define really as to whether we had discussed things or
not."

(Dr.Xii)
(6.72)

X's uncertainty about how much Pt.17 knows, seems to
result from an uncertainty about how truthful he himself
has been to her.

"She has had a bladder tumour, she is under regular
review at the hospital and she does not like it. She
knows, I think, she has got a bladder tumour. But she
is one that I didn't tell initially. She was told by
inference. She has got a bit of angina and she is
anxiety prone, and she has had a fear of cancer and
she had the bladder tumour removed... and she goes up
for yearly checkups and she wanted to know why she had
to keep going. What was wrong? Did she have cancer?
And I think initially I probably said no, or I told
her a little white lie, and I went round the question
because she wouldn't have accepted it very well at
all... She wouldn't have accepted cancer very well,
but there is transitional cell tumour and she has had
radiotherapy and I am sure that she understood the
significance of radiotherapy but, well, she didn't
seem to let it hang out, you see".

(Dr.Xii)
(6.73)

Thus although it is clear the patient suspected she may
have cancer, since she asked, X has confused the issue by not answering this question straightforwardly. This he justifies by relating that she would not accept the truth anyway, and pointing to her "anxiety proneness", implicitly suggesting that such bad news could worsen her angina. It seems reasonable to suggest that X in fact felt uncomfortable in admitting his deception, for he reiterated his reasons (that the patient was anxious and unaccepting) on more than 4 occasions during discussion of the case. To some extent, X's version of what occurred, is confirmed by the patient herself, when she explains how she became aware of the nature of her illness.

"I had a tumour in my bladder... they sent for me to go and have, is it a biopsy?... I was sent to the General (hospital), as I thought for a deep X-ray and as X-ray goes I thought it was just X-ray, you see. But I found out it was radium they were doing. The nurse said, 'cause I was upset, the nurse says, "what's the matter?" I told her. She says, "how did you find out?" I says, "because you sent me to the same place as the other women that has got cancer, you see". And if they'd kept me on the other room the first day I went down I wouldn't have tumbled it, maybe I would in the end. But I wouldn't have tumbled to it so soon... As soon as they sent me into that room I tumbled right away, it was radium... It's just the thought of having it, what it's for." (Pt.17)

Later during the interview she describes her discussion of the illness with X.

"I just went (to see X) and said, "I think you and me better have a little talk". Well he says, "I was just thinking about that myself." He was just waiting for the opportunity to talk to me, to see when I would be alright to talk about it. So we talked about it and I said to him I said it was cancer. He says, he didn't say that... And of course I had the talk with him and I said what I thought it was. He says, "mind I didn't say that, you did." He says, "we don't call it that."

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We call them tumours. They are either malignant or they're not malignant you see." But he still didn't say that it wasn't malignant, you see. But I still say it was. Of course the doctor doesn't tell you these things to save you all this worry you see".

(Pt.17) (6.75)

X's account of their discussion corresponds to that of the patient.

"I think more recently we've had the opportunity to talk about things. And well I'm sure if I have used the word tumour, I think I have tried to define that from cancer, tried to infer that, well that this doesn't mean that her throat has been cut... But I am sure I have used the word tumour, that is a word that I would use and it does not necessarily have the same significance for them... And mostly it is reassurance she is looking for... But I have placated her and she is happier now and understands that she has got to go for the yearly checkup.... I've tried to explain it to her that it is something that can recur. But I don't think we will ever use the word cancer... She needed a great deal of reassurance and we have had to tell some white lies. One is perhaps trying to cloud the diagnosis and not make it fully clear... I think she understands the significance of it all now... I think in more recent times we have become a little more frank about it and we've talked about tumours and things. But whether tumours and cancer mean the same thing to her I just don't know.... There's a tension that comes across... She says I think there's something seriously wrong here, tell me... but I don't want to know at the same time."

(Dr.Xii) (6.76)

Thus X's account of what has been said, corresponds closely to that of the patient. From what Pt.17 says it is clear that he is correct to question how successfully he has clouded the diagnosis and made the somewhat artificial differentiation between cancer and tumour. Even if, when Pt.17 describes X's distinction, her words in transcript form leave room for ambiguity in meaning, the intonation with which they were uttered clearly
indicated that she did not believe a word of it. Later during the interview Pt.17 expands on the reasons why she felt X had not explained to her about her cancer more forthrightly, perhaps indicating that X was indeed correct not to do so.

"If it hadn't been for what it was, I would like to have been told, been explained more to me. My sister-in-law, they explained exactly what she, she had, hiatus hernia... So of course they explained everything to her. But with cases like mine, I preferred not to be explained to, you see". (Pt.17)

Towards the end of the case history interview, X admits that his perception of the patient as being anxious was only part of the problem. He feels that the way in which she had initially become aware of the nature of her illness in itself exacerbated the problems he faced.

"She literally did take it badly that she had had radiotherapy. I think that she did recognise the significance of it and didn't react very well to it. And it was a difficult problem actually, because, obviously the outlook wasn't too bright for her..." (Dr.Xii)

The patient also considers that the way she had come to know about her illness had upset her, asserting that she would have preferred to have been forewarned.

"I was very very upset when I got to know I was getting radium, because it never dawned on me... If they told me in the beginning... I would have sort of accepted it and I would have got over the shock. But with finding out myself I think it was a bigger shock." (Pt.17)
The hospital staff then attempted to disguise the reason for taking the patient to the radiotherapy room, by referring to her weight and saying that she was too big for the table in the other room (in the X-ray department). Whatever her reservations about finding out in this way, Pt.17 considers the hospital staff were well enough intentioned.

"Well they do these things for the benefit of the patient. I don't know if it's right that a patient finds out that way, but I got over it and I had a few weeks without knowing. So I mean it saved me that worry for that period of time."

(Pt.17)

(6.80)

Although the patient clearly revealed knowledge of her illness to the interviewer, X remains uncertain about how much the patient knows. This uncertainty is probably indicative of X's sensitivity to the problems involved in communicating with patients. He finds it difficult to assess the functional significance for a patient of what he has said. He notes, with reference to Pt.17, in a section previously quoted:

"If she knows she has had the cancer treated or not I wouldn't like to define... whether tumours and cancers mean the same thing to her I just don't know".

and more generally

"tumour, that is a word that... does not not necessarily have the same significance for them"

(6.81)

The use of language of this sort, when describing illnesses to patients, is something to which we will return. It suffices to say at this point that X is not
unique in reporting language behaviour of this sort. However he is unique for this set of g.p.s in that the use of such linguistic devices seems to result in a real feeling of uncertainty about how much information he has communicated to the patient.

While X, in common with V and Z, described a policy during interview 1, which did not routinely result in disclosure of information about illness to terminal patients. W described one which allowed for just such disclosure. But whilst ostensibly W's policy is one of informing everyone, he was still able to allocate patients to the study, whom he considered not to know about their illnesses. He was able to do this by virtue of his recognition that a distinction can be drawn between telling a patient about his or her illness and the patient understanding and/or accepting what he or she has been told. The latter is exemplified in the case of Pt.06 who early during her interview said to the interviewer:

"I am on the road to recovery. You know I feel much better than what I did... in the past when I was really ill"

(Pt.06) (6.82)

The interview continued with the patient apparently happy to answer the interviewer's questions, until the following exchange occurred (approximately half way through the interview transcript).

Int. "Has the doctor described the illness to
you or not?"
Pt.06 "Oh yes, yes."
Int. "Could you tell me about it?"
Pt.06 "I've got a colostomy."
Sp.06 "It was cancer of the bowels."
Pt.06 "Cancer of the bowels and well they take all
the bowels away." (Patient bursts into tears.)

The patient cried for some minutes before gaining control
of herself and continuing with the interview. She then
reveals that she had been told about her illness by a
doctor at the hospital, and that:

"He said I would have a fairly good span of life, you
know."

This incident makes sense in the light of what the g.p.
has to say about the patient, for W asserts that the
patient tends to deny the seriousness of her illness.

"She did very well to begin with, she coped extremely
well, felt that she had been cured, was aware that it
was a growth, a cancer... They were told it was a
growth and that it had been removed and that it might
have been successful in 1979... She gives the
impression that she is probably cured, but hasn't come
to terms with her colostomy... I think she has to feel
that, because I don't think she can cope with the
illness.... And now that the symptoms are coming back
again she realises that she, she knows that it is
getting worse and worse. But I think she still tells
herself that she had the thing taken away."

Dr.Wii

W has thus allocated a patient to the terminal ignorant
group who is in comparison to some of the patients we have
considered above highly knowledgeable. A major
difference between Pt.06 and W's two terminal knowing
patients is that whereas they are able to accept what
they have been told to the degree that they are able to talk about it calmly, Pt.06 is not able to do this. Furthermore the other two patients may recognise that the chances that treatment will cure them are slim, but nonetheless cure remains a morale maintaining possibility. Whereas the expectation of cure held by Pt.06 is unrealistic, in so far as she asserts that she is "on the road to recovery".

The final terminal patient to be considered is W's Pt.20 who like Pt.06 has been told about her illness. However the reasons for which W has allocated her to the ignorant group differ from those for Pt.06. While Pt.06 is considered by W to deny the nature of her illness, Pt.20 is in the words of W;

"not a very intelligent woman... She probably told you she'd got a bone disease. And you could tell her anything, but she would just come away with a bone disease."

(Dr.Wii) (6.86)

Disregarding the question of whether or not it is a function of her level of intelligence, the patient had in fact described her illness in terms confirming W's prediction.

"The trouble is I've got a diseased bone in the middle of my back... It started off with a pulled muscle didn't it? (Sp.20. You started off with a pain in the back, let's put it that way.) No! The pulled muscle Henry. It started when I pulled that muscle bending."

(Pt.20) (6.87)

The disagreement between husband and wife on the aetiology
of the illness may be evidence for W's low intelligence theory, or it may represent a defense mechanism for the patient. But, this causal misattribution is neither unusual nor indicative of low intelligence, in the light of Herzlich's (1973) research into lay concepts of illness causation. Overall, however, it is again not a simple question of the patient just not knowing about the nature of her illness. W certainly allowed for the possibility that she was aware that she suffered from a life-threatening disease, at least in the past.

"Originally she knew it was a fatal disease, now she has got used to living... (She is) in a status quo, in an equilibrium... with life and death... And she has moved from waiting to die, to living."  (Dr.Wii)  

(6.88)

The patient herself is probably aware that she suffers from an illness that is more complicated than just having a bad back. The husband at one point explains how the consultant told him about the illness, and that he had discussed what the consultant said to him with Pt.20. The consultant, according to the husband, said;

"It's a blood disorder that's causing a softening of the bones... But don't worry it can be treated by pills... I know what you are going to ask me next, is it cancer? Definitely not, so you can forget all about that."  

(Sp.20)  

(6.89)

This is in fact not completely true, since Multiple Myelomatosis (MM) is a malignant disease of the plasma producing cells of the bone marrow (see Portlock and Goffinet, 1980; pp215-217). Dr.W unequivically
described the illness during the case history interview as a "cancer". The patient herself expresses an awareness of the nature of the illness when she says:

"There are limits I suppose for treatment and they are holding it and that's just about it. As far as complete cure, oh I think age is against you for a start."

(Pt.20) (6.90)

Although she refers to her age as being against her, how aware she is of the life threatening nature of her illness is never made explicit. However, numerous remarks made during the interview could be interpreted as indicative of her awareness of mortality, although expressed in a veiled manner. The following quotation is presented by way of example.

"I had a little walk around the cemetry and it ended I had to use a headstone to rest on you know. So it proves, it's there as a witness, I know I've got what I've got."

(Pt.20) (6.91)

Such an expression would be interpreted in some analyses (e.g. Hockey, 1981) as a clear though disguised expression of awareness of impending death from illness. The present author is more guarded in his interpretation and wishes merely to point out this possible interpretation.

Chronic Controls Whereas the terminal patients revealed considerable diversity in the level of and degree to which
they expressed knowledge of illness, both within and between groups; the chronic controls show a great uniformity in knowledge. All but one of chronic patients interviewed knew exactly what was wrong with them, could report the nature of the diagnosis and expressed understanding the implications thereof. The one exception (Pt.07) is a special case, resulting from the criteria used by her g.p. (Dr.W) when allocating her to the chronic control group. We will thus consider this case separately at the end of the following discussion of the rest of the chronics. The chronic controls further differed from the terminals in the sources from which they learnt about their illnesses and the nature of the communications by which they gained that information. While few of the terminally ill group learnt about illness through explicit discussions with doctors, all chronics gained their information in this way. The following is typical of the chronic group.

"I asked the doctor, 'well it's arthritis isn't it?' and he told me that was right... So I says, 'well will it get worse then,' and he says... it all depended, but I would get stiffer and I'd have to take these drugs to keep it from getting bad quickly." (Pt.03) (6.92)

Thus all four g.p.s were able to be extremely accurate in their assessments of these patients knowledge. Even if, as was common, the g.p. himself had not been the one who actually initially gave the patient the information about his or her illness, they had always discussed the illness with the patient at some time in similarly
"He's a proper workingman's doctor and he talks with you not at you, no bombasting... (One day) he says you've got a terrible chest George. Well I knew that to start with... well bronchitis is chest trouble isn't it... and emphysema it's hardening of the arteries"

(Pt.16)

(6.93)

Another feature by which the chronics differed from the terminals is that even if a terminal patient had suffered from poorly defined aches and pains for some time before presenting to the g.p., there was clearly a point during the previous year or so at which they had become ill. On the other hand many of the chronics had been regularly seeing their doctors about the complaint for years. The most extreme example of this is Pt.02 who first experienced symptoms of his bronchitic condition during the 1930s. At that time his, long since retired, g.p. said:

"It's chronic bronchitis. And I said I've got no bronchitis, and he said well that's what you've got... well at that time they didn't know anything about the coal dust, you know pneumocosiosis..."

(Pt.02)

(6.94)

This extended period of poorly differentiated ill health has a number of implications. Firstly it appears to influence the way both patients and g.p.s approach consultations. Thus the behaviour during consultations, both as reported by the participants and as witnessed through the explicit knowledge possessed by patients (itself obtained via overt discussion) is changed by
the expectations that g.p.s and patients bring with them to interactions. Chronic patients had learnt of and learnt to live with their illness over a period of years. As Pt.02 goes on to say:

"One of the young fellows there (in the village) has got it. And I felt sorry for him and I says it's hard being a young fellow like him with that, never thinking that I had the same and had lived with it 40 year... (One day V said) take it easy... don't go running about. And I says, laughing like, I cannot walk let alone run doctor, or I'd be out there with a dog every morning."

(Pt.02)

Although a patient, depending on the nature of his or her illness, may have either experienced a long slow degeneration or periods of relative stability marred by crises, the dominant subjective pattern was similar. Both processes resulted in restriction and reduction in function. The dominant feature of both processes is long periods of apparent stability from the patient's point of view. In some cases, such as Pt.02's, this includes periods of apparent health, during which the underlying physical disorder impairs everyday activities to only a limited degree. Thus while chronic controls talked about diagnosis eloquently (and as seen in Chapter 5 frequently), they did not have so much to say about prognosis. Since the chronics' experience of illness was not one in which perceptible changes predominated, this lack of talk about prognosis reflects the long term nature of being chronically ill. Whereas in terminal cases there is a clearcut prognosis, whether or not the patient recognises this and/or talks about it, for the chronics
there is a very real sense in which there is no prognosis. This is possibly best expressed by Pt.22, who says about the way she sees her illness progressing:

"Oh more of the same I suppose. Slowly getting worse 'til I'm a bedbound old woman I suppose. Nothing much just years more of the same."

(Pt.22) (6.96)

But other patients have similar points to make.

"I've always understood that once you got this... then there's nothing they can do for you. And that kind of thing is always with you until you bow out."

(Pt.02) (6.97)

"I'm a creaking gate really I think... I'm sort of hanging on longer than some people who appear to be healthier... Well it's just old age, put it down to old age."

(Pt.21) (6.98)

The long term nature of chronic illness affects the way in which g.p.s and patients conceived of consultations. This differed fundamentally from the way that consultations with terminally ill patients were considered. As Z says concerning his consultations with Pt.21:

"I go in once a week or so on average... and there's not a great deal of active treatment really. It's just a sort of frail old person living on her own and you know she needs a bit of support... There's not really a great deal I can do for her. We can talk to each other and we get on quite well, it's a social visit really and she sort of accepts that a lot of things she has got to live with and that I can't cure her."

(Dr.Zii) (6.99)
Z makes a very similar point about his visits to Pt.22 and more generally of all chronic visits. Furthermore, V, W and X make similar points about their chronic consultations. First, V concerning Pt.02

"We get on alright, nothing very exciting but its social... like many other patients and normal routine."

(Dr.Vii) (6.100)

X says about Pt.16, in response to questioning about the nature of the relationship.

"Oh very good... a majority of consultations are regarding not his illness, but his past-times... He is one where I just pop in when I'm passing, a regular tea stop."

(Dr.Xii) (6.101)

And W says concerning Pt.10.

"It's a bit of a social visit and the active medical intervention has disappeared a bit"

(Dr.Wii) (6.102)

However, W does maintain the psychotherapeutic language and rationale for his chronic patients that we saw in conjunction with his terminally ill patients.

"The treatment planner is to try and anticipate the next disability... and do something about it... She'll have to demonstrate her independence because if I feel there is any loss of independence she'll be confronted with it... I insist the patient appreciates the truth, and encourage them to solve problems themselves, to become independent all the way through, despite their increasingly crippling disorder."

(Dr.Wii) (6.103)
The patients also see the visits in social terms, rather than predominantly medical ones, whether the g.p. is acting upon them as a psychotherapeutic agent or not. Of Dr. X is said:

"He's a nice person, a very nice person indeed... Of course we have similarities you know. He likes music and I like music, brass bands and all."

(Pt.16) (6.104)

While Pt.10 says of Dr. W:

"Well he's quite pleasant when he comes in but that's all it is... he doesn't do anything."

(Pt.10) (6.105)

That the g.p.s recognised that they could not cure chronics should perhaps result in them approaching chronic patients and terminal patients, whom they also could not cure, in a similar "social" way. Yet of their consultations with terminal patients only one case is talked about in these terms, Dr. X's visits to Pt.15. For both terminal and chronic patients the medical intervention which g.p.s offer, revolves around controlling symptoms and maintaining function, in a word palliation. Yet the consultations apparently differ greatly, at least in terms of the subjective experience reported by patients and g.p.s.

Finally to turn to the aberant chronic control patient (Pt.07). She is suffering from chronic lymphatic leukemia, which was identified by a screening program. Dr. W explains that:
"she is fortunate to be alive. She is in a symbiosis with death really... I wouldn't call her terminal... despite the fact that she has been terminal for the last 5 years. It's terminal though frustrated by the fact that even her cancer cells are not strong enough to kill her off."

(Dr.Wii)

Thus although the patient is suffering from an illness which might normally result in her being categorised as terminal, leukemia is not what he expects will eventually result in her death.

"Oh, I expect that I'll end up writing something cardial on the certificate. You know, a general systems failure from old age, rather than leukemia."

(Dr.Wii)

Because of this W has never completely explained the nature of the illness to Pt.07. We leave it to W to explain his reasoning.

"She knows that she has had chronic anemia. She knows that she has got a blood disease, but I haven't used the word leukemia because she knows it is a fatal illness... But it is so important for her to be the strong one, that it seemed to me the word, the label, leukemia was too strong for what she has. Blood disease is a better label and that is one of the few cases in which I prefer to be explicit rather than explicit... To give her the word leukemia could have been too much for her to cope with... the illness is secondary to her other roles. The sick role was less important than the other role of being the elder sister (who cares for the other sister at home) and to maintain the roles of being a leukemia patient and a strong sister would have produced an intolerable situation I think."

(Dr.Wii)

The patient herself never used the word "leukemia" during the interview, although she was able to explain about her
illness.

"Well he (W) seems to know what the matter with me is, after all that is what matters isn't it?... I feel confident in him in that I suppose. He does know what is the matter with me and he is in contact with the blood specialist... I know that it was 1977 when he told me the results of the tests. He said I wasn't making red corpusles and the white corpusles were becoming too prominent. They understand these things I don't."

(Pt.07)

Pt.07 then has been allocated to the chronic control group on the valid grounds that she is chronically ill and the doctor does not consider that the leukemia will result in her death. And yet since it is an illness normally associated with death he has not told her the exact diagnosis and she never indicated that she knew it. This results in a situation in which W who reports telling all terminal patients about their illnesses, has not told a patient suffering from an illness which often kills. Further this is not because she is curable but because she is in his view more likely to die of "old age". This case is a good example of potential differences between g.p.s stated policies and how things can work out in practice.

Summary
Only Dr.W states that he regularly tells patients when they are suffering from a terminal illness. Dr.V and Dr.Z say that they never tell, although perhaps allowing for the possibility that there may be circumstances in which they would do so. Dr.X prefers not to tell
patients, but forms an active, personal and friendly relationship with the dying patient, with which the solemn acknowledgement of impending death is normally incompatible. Patients expressed degrees of awareness about their illnesses consistent with their classification in groups. Thus, the "terminal knowing" group expressed more explicit acknowledgement of having cancer and dying, than did the "terminal ignorant" group. But this does not mean that patients in the latter group are totally ignorant of their illness, merely that their awareness is couched in terms of suspicions, denials, and the like. All "chronic controls" expressed knowledge of illness explicitly. Finally, there are indications of difficulties in the relationships between g.p.s and patients, where the patient "knows" (be this explicitly or a strong suspicion), but the g.p. refuses to talk about it. But these problems are not a simple function of level of knowledge and/or explicitness of communication, since some patients are satisfied with the allusions and social chat that fills their consultations. A fuller discussion of these points is to be found in Chapter 8, in which we also consider the typology of communication, to which we now turn.
CHAPTER 7

A typology of methods used by general practitioners and terminal patients to control the communication of information about illness.

"She spoke with calmness: he knew that calmness -it meant they had reached the quiet centre of the storm: always in this region at about this time they began to speak the truth to each other. The truth he thought has never been of any real value to any human being -it is a symbol for mathematicians and philosophers to pursue. In human relations kindness and lies are worth a thousand truths. He involved himself in what he always knew was a vain struggle to retain the lies."

Graham Greene  The heart of the matter.
From the interviews it was possible to develop a typology of ways by which g.p.s attempt to control the exchange of information with terminally ill patients. It is also clear from the analysis of the interviews presented in Chapter 6, that patients are not purely passive objects over whom a g.p. exerts complete control. Patients regularly attempt to obtain information about their illnesses, and use a variety of methods in order to do so. Moreover patients experience symptoms and may pick up information from a number of environmental sources. The typology is thus extended to consider the ways in which patients obtain, or attempt to obtain, information about their illnesses. The typology is not exhaustive and represents the methods identified from analysis of the interviews with the four g.p.s and their patients only. It is based on careful readings of what patients and g.p.s said about their communications with one another during interview. Thus, although we write in this chapter of the ways in which g.p.s and patients behave during consultations, such behaviour has not been directly observed. The typology is presented under 4 headings. The first two sections consider the ways in which g.p.s attempt to control information, withholding or conveying it. The third and fourth sections consider the ways in which patients obtain information, by actively seeking it or less actively acquiring it.
G.p.s' Methods of Withholding Information

A terminally ill patient is not always informed about the illness from which he or she is suffering. Although it is not necessarily the case, this may require that the g.p. actively withholds information about the illness diagnosis and/or prognosis from the patient. Below we consider a number of ways in which g.p.s attempt to attain this end. We start by considering methods by which g.p.s actively attempt to withhold information. We then progress to methods which require less visible effort on the doctor's part, and to those which withhold information through control of the agenda of the interaction by the g.p.

Denial Denial appears always to occur as a result of a patient's question or the voicing of some suspicion by the patient. The purpose of denial would seem to be to avoid causing the patient pain. Since denial is only necessary when the patient has revealed some suspicion or asked a question, it requires more, in the g.p.'s view, than mere negation. Thus the g.p. will often offer some reassurance, thereby affording some degree of reversal of the patient's worries. Denial can be seen in two forms.

(a) The outright lie. In quotation 6.7 Dr. X talks about lying to patients. He also explains his response to Pt.17's enquiries about her illness. This is the most explicit discussion of lying in our interviews. However, it is by no means unique. Asked by Pt.17 if she was suffering from cancer, X reported:
"I think that initially I probably said 'no'."
(Dr.Xii)
(7.1)

This sort of denial most commonly occurs when the patient asks the question in the negative, as Pt.17 reportedly did. The g.p. interprets this negative as a plea for reassurance and answers untruthfully.

(b) The "white" lie. The other sort of lie told is what g.p.s like to call a "white" lie. That is to say not telling an untruth but not telling the truth either. The "white" lie may consist of an omission, or more blatantly of what in propaganda terms is called disinformation. Here information is given which in itself is truthful, but it is not, in spite of appearances, the required information. Thus, if successful, it gives a false impression to the recipient. X, for example, continued the discussion of the exchange between himself and Pt.17 (6.76) to say:

"...Or (I) told a little white lie and went round the question... I don't know if I used the word tumour. I think I probably used the word and tried to define that from cancer, tried to infer to her that well that this doesn't mean that her throat has been cut and she's going to bleed to death any minute."
(Dr.Xii)
(7.2)

As we saw earlier, the patient's version of this episode concurs with X's, and to some degree X appears to have succeeded in his deception. What X said was perfectly truthful in itself. "Cancer" is not a medical word, but a general description of a group of diseases. X thus
attempted to differentiate "cancer" from the more correct
description of a tumour, that may or may not be malignant.
Yet from the perspective of the patient, "cancer" is
exactly what she did have, and the g.p. has clouded the
issue. However, he did not merely obscure the issue,
because he later offered reassurance.

Reassurance  Reassurance often appears to be associated
with denial. But it is a distinct category and has a
different function to denial on its own. When used
successfully with denial, and other information
withholding techniques, reassurance takes a form similar
to the following example.

"Well I basically would say 'no' and try to make it
clear that it will be alright... I sort of said it
was a common problem and it would be alright... we'd
get him to see a specialist who treated this sort of
thing all the time."

(Dr. Zi)  (7.3)

Of course reassurance can also be used in conjunction with
information conveying. But while reassurance is often
associated with denial, it appears to seldom complement
evasion.

Evasion  Evasion can be seen in the example quoted
above when X says he "went round the question". This
particular evasion required his deception about tumours
and cancers, and it is not completely clear how effective
it was in terms of keeping the truth from the patient.
There may be more subtle versions of evasion. One sort of
evasion may be to ignore a patient's question completely. Byrne and Long (1976) report this sort of evasion in their direct observations of consultations. But the versions of evasion reported by Byrne and Long are likely to be somewhat transparent in consultations with the terminally ill. Thus the most successful evasions require not only that discussion of the to be evaded subject is avoided, or better still precluded, but also that the evasion is itself relatively "invisible" to the patient. It is this feature of the successful evasion that results in evasion and reassurance not appearing together, since to offer the patient reassurance would be to enter the arena of the topic to be avoided. Thus, to offer reassurance would be to signal that the topic had entered the agenda of potentially acceptable items for discussion. Furthermore to offer nothing but reassurance alone would be "to protest too much".

Given that the onus is on the patient to ask the question in the first place, and that this can be difficult at the best of times, it may be that in order to avoid questions about terminal illness, all a g.p. has to do is fail to manoeuvre a patient into asking, or fail to give a patient an opening to ask a question he or she is trying to summon up the courage to ask. In cases of this sort one would expect the g.p. to fill the consultation with other talk and behaviour. The interactions that reportedly occur between Z and Pt. 27 conform to such an analysis. Moreover, in this case both g.p. and patient know about
the nature of the illness and are aware that the other knows. As we noted previously, Z says of Pt.27

"Well she definitely knows she has got cancer... but no I think we've just both assumed that we both know what she's got."

(Dr.Zii) (7.4)

The patient explained that she considered this to be because.

"He may not want to discuss it in case it is painful to me, I don't know really. But, er, we've never mentioned it, cancer, at all. We just dwell on my aches and pains and that, you know."

(Pt.27) (7.5)

To this patient Z fills consultations with talk, which does not reveal the nature of the illness, an example of a g.p. controlling the agenda of acceptable items for a consultation. It is also possible that Z goes further in his evasion with this patient, in that it seems that he avoids going to see her as far as possible. But this may be because he does not get on with her very well.

"She tends to rub me up the wrong way I think as a person... I try and remain objective because she is an ill woman... but she's not one of my favourite patients, shall I put it like that."

(Dr.Zii) (7.6)

It is clear that g.p.s do use evasion during their consultations. This is probably usually (and most effectively) achieved by their control of the agenda of the consultation, to stop questions of the sort they do not wish to answer getting asked.
Euphemism

An euphemism is defined in the O.E.D. as "a figure by which a less distasteful word or expression is substituted for one more exactly descriptive of what is intended". Death is a subject about which people often speak in euphemistic terms; a clear example being when "dying" is referred to as "passing on". However, not all euphemisms are as commonly understood as this example. Thus euphemisms do not always convey the same amount of information as the phrase that is replaced. Euphemism is widely used by the g.p.s when speaking about both diagnosis and prognosis. For example X says:

"Basically he is walking a tightrope and that Saint Peter might send for him... it's a phrase that's, sort of, I tend to use to soften things you know."

(Dr.Xii)  
(7.7)

When euphemistic terms referring to diagnosis are used, the reduction of precision that the euphemistic phrase entails can be used with the intent of making the diagnosis opaque, perhaps thereby withholding information. Dr W says of Pt.07,

"She knows that she has had chronic anaemia. She knows that she has got a blood disease, but I haven't used the word 'leukemia' because she knows it is a fatal illness... it seemed to me the word, the label 'leukemia' was too strong... Blood disease is a better label and that is one of the few cases in which I prefer to remain implicit rather than explicit.... To give her the word 'leukemia' could have, it could have been too much for her to cope with."

(Dr.Wii)  
(7.8)
Euphemistic phrases are so implicit to the g.p.s' repertoires that they were even used when describing diseases to the interviewer. In these cases it is clear that the g.p. is not attempting to shield the interviewer from bad news, but that the euphemism is used as a synonym for the more precise word(s) that it replaces. It is thus likely that euphemism may be used when communicating with patients in the same way. That is the g.p. may use an euphemistic phrase while talking to a patient with the intention of communicating information to the patient. But unless the patient understands the euphemism as standing in place of another referent the communication will fail.

Hints

Hints appear on occasion to be used to convey information, but in such a way as to put the onus on the patient to make an interpretation of the hint. Earlier, X said that he had "given the nod" to Pt.12, that he had cancer (6.48). It seems that he consciously hinted to the patient for the patient said:

"I'm only upset about one thing... He's told us I won't live until I'm a hundred."

(Pt. 12)

(7.9)

The g.p., it seems, hinted to the patient about death by mentioning the patient's mortality, albeit in a jocular manner well in the future. It is difficult to assess what the patient makes of this comment. However, that the patient said that it was the only thing that upset him suggests that the hint had hit home. Thus by hinting X
is able to convey information to a patient, but indirectly. It is done in such a way as to permit the patient to interpret information that he already has in his possession, by as it were pointing to the possible meaning of the symptoms that the patient is himself experiencing.

Prompting Prompting may perhaps represent another form of hinting, but it is correct to differentiate it from hinting, since it differs logically. The prompting of a question by the g.p. is revealed by Dr.W (6.12 and 6.13). Patients, however, never report that a g.p. has prompted them to ask a question. But unless a g.p. prompts a patient very overtly and in the face of resistance from the patient to ask the required question, it seems likely that such behaviour would be hardly noticed by the patient.

Patient Methods of Seeking Information
Patients are not the goffmanesque puppets during general practice consultations that they may be on hospital wards. They are not simply passive recipients of g.p.s’ communicative largesse, but will often set about finding out about their illnesses and it is to the techniques that they employ that we now turn.

Asking the g.p. Perhaps the most obvious way by which a patient can attempt to obtain information about his or her illness, is to directly ask the g.p.. In our sample
of terminal patients only one patient (Pt.09) had actually ever done so and received a straightforward answer to such an enquiry (6.14). Other terminal patients (e.g. Pt.17) may have asked their g.p.s questions, but they did not succeed in receiving such an honest response. It seems likely, however, that more often than not some information is gleaned via this approach, even if this requires the patient to read between the lines of what is said (or not said) by the g.p.. It is of interest to note that even when a g.p. lies to a patient, and says that he/she does not have cancer when in fact he/she does, this seldom satisfies a patient who suspects that cancer is what he/she has and genuinely wants to know about it. On the other hand, if the patient is actually seeking reassurance, then such a response from a g.p., being exactly what he/she is after, does satisfy and to some degree allay fears. Z's response to Pt.24's enquiry (6.51) that she had some fluid in her tummy, is a clear example of an enquiry which was placated by a misrepresentative answer, at least according to Z's version.

When faced by a patient's question about illness, the problem from a g.p.'s point of view, is to differentiate between the genuine enquiry for information (however unpallatable) and the enquiry which seeks reassurance. This distinction, however, is to some extent fallacious, since it does not allow for the shades of grey in between. Even though some patients append
conditions to questions, to define the range of acceptable answers, for the g.p., this just seems to represent the proverbial thin end of the wedge. But even patients who overtly knew their diagnosis and prognosis, and talked about them in explicit terms expressed the tensions involved between wanting and not wanting to possibly receive bad news.

"I always said if anything was wrong with me I would want to know. But there again, once you do get to know you think to yourself, "Oh my goodness! I wish I hadn't been told," deep down."

(Pt.19)

An expression of this tension was to be found in every interview with a patient who overtly knew and talked about his or her illness.

Asking another medic Clearly patients seek information from medical personnel other than g.p.s and we now consider these other medical sources of information. While the possibility remains that hospital consultants, registrars and house-officers do receive questions, and on occasion answer them, in our interviews there are no evidence that any overt information gained from hospital personnel was the product of patient initiated questioning. In the words of Pt.09,

"They don't discuss things with you. At the bottom of the bed they'll talk to themselves, but you the patient are the last one to hear."

(Pt.09)

Similar points were made on a number of occasions by
patients and their spouses during interviews. If information is to be conveyed to patients in this way, it seems that in the case of information conveyence by hospital doctors it is initiated by the medic him or herself. In every case which we have identified it was the doctor who approached the patient having presumably already decided to tell. Of the three patients told by hospital personnel in our sample, two were single women (Pt.19 & Pt.27) and the third (Pt.06) was married to an old school friend of the surgeon concerned. Thus in all three cases the circumstances if not unusual, were not routine. Pt.27, like Pt.19, was told by her surgeon because there was no adult relative to whom he could turn to tell. Pt.06 was reportedly told in the presence of her husband by the consultant because, "he could not leave her out being an old friend of the family," although thereby the surgeon "literally blew it.." (Dr.Wii).

Nurses, both those in hospitals and the district nurses who care for patients at home, may also be asked questions. Research indicates, however, that nurses do not routinely divulge information to patients in either situation (c.f. Cartwright et al, 1973; Field, 1983) and this is not contradicted by the present interview data. Pt.17 was alone in reporting an interaction with a nurse, which appeared to be a source of information. But this was only in so far as what the nurse said confirmed the patient's suspicions (6.74).
Asking a relative Patients may often seek information from relatives, most frequently the spouse. We saw previously (6.26 to 6.29) that Pt.15 asked his wife about his illness and that eventually she decided to tell all. Obviously to ask a relative about one's illness presupposes that the relative knows the answers to the questions. Thus such an approach may be based either on a culturally pervasive knowledge or expectation that, although cancer patients themselves are not told, their next of kin are; or on cues picked up by the patient which reveal that the relative knows, or a combination of both of these. In the case of Pt.15 it is clearly possible that the spouse unintentionally indicated to the patient that she knew by her emotional state, since in her own words she was "a bag of nerves" and by her previous attempts to avoid his questions. The effect of knowing about a spouse's cancer, while the patient him/herself does not, probably causes anxiety in all cases. Some of the clearest examples of these anxieties and the tensions aroused within the marital relationship by such an inequality of knowledge are revealed by V's comments about Pt.05 and his spouse and the analysis of interviews with Pt.05 and Pt.12. Such tensions are hardly surprising given the pretense that is required for their maintenance, especially in relationships in which secrets are not the norm. What is perhaps more surprising is that more couples do not discuss the illness from which one is suffering, but about which the other has been informed Consideration of an analogous situation perhaps provides
insight into what may be happening here. Let us posit a situation in which one marriage partner is involved in an adulterous affair. The faithful partner may wonder what the spouse does every Tuesday evening. He or she even suspect adultery, but never asks since the relationship continues the remaining 6 days of the week, there are the children to think of, financial security etc.. Such a conspiracy of silence, then, permits a semblance of normality to be maintained, although at a price.

It is also clear that g.p.s recognise that patients turn to relatives for information and all 4 g.p.s mentioned this in one form or another during interviews. For example

"I'm sure that some couples sit down together and talk about this and have a good cry together."
(Dr.Xi) (7.12)

Blinds The most devious way in which a patient can gain information that we have identified, is by the use of a blind. "Blind" is used here in the sense of "a pretence, a pretext, to conceal one's real design" (O.E.D). Dr.X recounted the story of a female patient with lung cancer. She had not been told the nature of her illness until one day he visited her and;

"She was saying more or less, "Well you can't pull the wool over my eyes mate"... The exact phrase was... "It's alright you needn't kid me any more, I know all about it.""
(Dr.Xi) (7.13)
At the time X accepted what she said and changed his approach to her accordingly, so as to overtly reveal the nature of the illness. However, X considers that he was duped by her, that he "misread the information", and consequently, "I wish now that I had stuck to my guns and told lies", since she reacted badly (in his view) to being informed. He took her reaction to indicate that she had not in fact previously known about her illness.

In order for a patient to use such a trick, he or she must first have suspicions. However, such suspicions may be either about the nature of the illness, or that he or she is not already in possession of the full facts and that something is being withheld. One might expect of most patients, that for them to resort to a blind they must not only suspect that information is being withheld, but also believe that it could not be obtained by a more honest approach. In the blind described above, the patient's device was to pretend to be knowledgeable, thereby to obtain information about her illness. Unfortunately for her perhaps, she did not obtain good news, and her reaction to the bad news alerted X to the possibility that he had been deceived into revealing information which he had previously withheld. Although this is the only blind identified in the present data, it does not require a particularly perverse imagination to conjecture other similar ways of attaining the same result. However machiavellian, such events are a common currency of social life. What is perhaps required of a
person who pulls off a successful blind, is that he/she possesses the fortitude to maintain the ruse in the face of unpleasant revelations. Since X's patient failed to conform to this implicit social norm, X discovered that he had been mislead. What remain unknown (and perhaps unknowable), are the blinds used by patients who succeed in following them through without permitting the deception to be discovered. But subjectively, once confirmed, the information obtained via use of a blind, has been known all along and thus no deceit ever existed.

Patient Methods of Information Acquisition

We now turn to some methods by which patients gain information, without necessarily initiating it. "Acquire", "acquisition" etc. are used to imply a less active process, but not necessarily a passive one. The patient must be at least alert to the possible meanings of environmental events in order to make sense of them. In most cases the patient has got to think out or deduce the meaning of what is observed, heard or felt in relation to other information that he or she already possesses. It is conversely also possible for a patient to refuse to do this and thus remain ignorant, although such ignorance must be continguent.

Deduction Some patients infer from general remarks and information from their doctors etc. the nature of their illness and its implications. In some ways deduction is the opposite side of the coin to hints. But whereas
"hints" implies that the "hinter" intends the patient to understand something, this is not the case here. Since it was g.p.s, rather than relatives, whom we identified as hinting we consider that whereas hints are g.p. centred and initiated, deductions are patient centred. Quotation 6.60, in which Dr.V is talking about Pt.05, is an example of this. The g.p. is aware that he has supplied the patient by his actions with all the information required for the patient to come to the logical conclusion that he has cancer and is dying. However, V does not imply that he intended Pt.05 to understand this, but he recognises that such an understanding is almost inevitable from treatment (or more properly lack of treatment) of the illness. How correct is this belief? In the previous chapter we concluded that Pt.05 almost definitely suspected what was going on, even though noone ever talked about it. This knowledge (or suspicion) was almost certainly acquired by deduction. The following exchange that occurred during the interview of the patient tends to confirm this.

Int. "Do you feel happy with the treatment you have received or not?"
Pt.05 "Up to a point you know, but it's been ignorance of the facts... I'm fed up with it, fed up with it all together.... I wish he had told us more."
Int. "Why?"
Pt.05 "Why? Well, well he couldn't make any difference could he? Well I couldn't make head nor tail of it could I?"
Sp.05 "He couldn't."
Int. "Would it have made you happier do you think?"
Pt.05 "Well it's not necessary to make you happy is it."
Int. "What do you mean?"
Pt.05 "Aye, aye it could be the reverse.... well maybe that's why they don't tell you isn't it."
(Pt.05)
This exchange reveals something of potentially great significance, namely that for the patient the fact that he has not been given explicit information about his illness is in itself information upon which knowledge may be based.

**Unguarded comments** The unguarded comments of medical personnel can also reveal much to a patient. Pt.09 became aware of the severity of her illness in hospital, although it was not until she talked to W that she learnt explicitly about her cancer.

"And of course I asked them if I could go home. And well it was just something that Dr Smith said. He said, "well under the circumstances I think she should spend as much time as possible with her family".

(Pt.09) (7.15)

That Pt.09 remembers and reports this incident is proof enough of the significance it had for her at the time. Yet we must not forget that this was not the sole information upon which she based her judgement about her illness and that she already had a cognitive set within which to interpret this remark. Such a set is to be expected for patients who have undergone major surgery. In her case this would have been further reinforced by her awareness of the potential significance of her symptoms. After all, it was her awareness that breast lumps may be indicative of breast cancer that drove her to the doctor in the first place.
Recognition of treatment We have already seen how Pt.17 explained to a nurse that she discovered that she had cancer, "because you sent me to the same place as the other women that has got cancer" (6.74). Pt.17 had not been told of her diagnosis before she went to hospital for radio-therapy. Yet she was in a ward with other women who knew they had cancers for which they were receiving radio-therapy. Furthermore, this was discussed openly on the ward. Thus when Pt.17 discovered that she was being sent down to the same room as women who went for radio-therapy she was able to infer that she was receiving the same treatment for the same illness. This is the only case in this series of interviews in which a patient mentions that patients discuss their illnesses together. However, Pt.17 never suggested that she learnt about her illness by comparison of symptoms with those of other patients. Thus although it is clearly possible for a patient to seek information by initiating discussion with other patients, we have no evidence that this is done by patients. But Molleman et al (1986) do report such processes in a sample of hospitalised cancer patients. It is perhaps surprising that the present set of patients apparently acquired very little information by recognising treatment. Pt.26, for example, was happy to describe the course of radiotherapy which he was receiving as treatment for an "ulcer", and there was no suggestion that he took this to be anything but "an ordinary ulcer".
Recognition of symptoms There are numerous examples of symptom recognition in the interviews, albeit with attached caveats. One cannot always accept a patient's report of symptom recognition as evidence that he or she thus knew the nature of the illness at the time, since this may be a post hoc rationalisation made once the diagnosis has become known to the patient in some other way. The interviews suggest, however, that patients do not overstate their cases in this way. Patients may say that they recognised a symptom to be indicative of something seriously wrong, which may be cancer. But they do not claim unequivocal recognition of the symptom(s) to mean cancer. A good example is Pt.15 who, although earlier quoted as saying he knew from the very beginning (6.27) qualified this by saying,

"You don't get a swelling like that for nothing do you? ...So there was only really one answer to that... but I would have been quite happy to have been wrong." (Pt.15) (7.16)

Of the three women with cancer of the breast, (Pt.04, Pt.09 and Pt.27) two had initially presented to their g.p.s as a result of discovering lumps in their breasts. Only Pt.04, who did not express any explicit knowledge of her cancer, had not presented in this way. Given the wide publicity over recent years of the importance of breast self examination, it is not surprising that this particular symptom and form of cancer is widely recognised. However, as both women implied during the interviews, they hoped that their lumps were benign. As
is clear from what we have said elsewhere, it was other factors that indicated to them that these hopes were unfounded.

Summary This analysis of interviews reveals that g.p.s attempt to control the flow of explicit information about illness to terminal patients in a number of ways. The methods employed by g.p.s can be broadly divided under two categories on the basis of the intentions which underlie them. The first attempts to withhold information from the patient, while the second aims to convey information to the patient. Patients gain information in a number of ways. Whilst some of these represent positive efforts on the patients' part to find out, information seeking, others are more passive. Thus a patients' discovery of information can be a consequence of treatment or picked up from the environment to which they are necessarily exposed. These are summarised in Table 7.01 below.
Table 7.01
Summary table of g.p. information withholding and conveying and patient information seeking and acquisition typology.

**G.P.S**

<table>
<thead>
<tr>
<th>Information withholding</th>
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<tbody>
<tr>
<td>i  Denial</td>
</tr>
<tr>
<td>(a) outright lies</td>
</tr>
<tr>
<td>(b) &quot;white&quot; lies</td>
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<tr>
<td>ii Reassurance</td>
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<tr>
<td>iii Evasion</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Information conveying</th>
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</thead>
<tbody>
<tr>
<td>iv  Hints</td>
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<tr>
<td>v   Prompting</td>
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<tr>
<td>vi  Euphemism</td>
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<table>
<thead>
<tr>
<th>PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information seeking</td>
</tr>
<tr>
<td>i  Asking the g.p.</td>
</tr>
<tr>
<td>ii Asking another medic</td>
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<tr>
<td>iii Asking a relative</td>
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<tr>
<td>iv  Blinds</td>
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<table>
<thead>
<tr>
<th>Information acquisition</th>
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</thead>
<tbody>
<tr>
<td>v  Deduction</td>
</tr>
<tr>
<td>vi Unguarded comments</td>
</tr>
<tr>
<td>vii Recognition of treatment</td>
</tr>
<tr>
<td>viii Recognition of symptoms</td>
</tr>
</tbody>
</table>

The mechanisms by which any control is achieved may be intrinsic to a g.p.'s style of doctoring, and may appear in analogous forms in his/her communications with non-terminal patients. The g.p. may not be aware of his or her methods of influencing and controlling interactions with patients. Alternatively she or he may do this consciously and intentionally. It is clearly possible that any particular method may be used by only one g.p. or patient, but it may be more widespread. However, that it has been identified from the present interviews suffices to show the possibility of use, which is our purpose. It will remain for future studies to ascertain the level
of use of these methods, to identify any specific situational or individual factors which promote their use, as well as to add to the list.
CHAPTER 8

Resume, prospects and design of longitudinal study of g.p. terminal patient communication.
This chapter is something of a hybrid, but serves the purpose of bridging between the previously reported study and further studies. The first half of this chapter comprises of a discussion of the findings of Study 1 and their implications for further research. The second half then details the program of research, which arose on the basis of these findings and the changes made to the basic research design described in Chapter 4. It then reports some problems that arose which influenced the performance of the proposed research, thus changing the scope and emphasis of the ensuing analysis.

Resume and Discussion of Study 1

The results of the statistical analysis of patient interviews presented in Chapter 5 were summarised as follows. The three groups of patients, terminally ill with knowledge, terminally ill without knowledge, and chronic controls, differed in frequency of expression of knowledge about the illness, the terminally ill with knowledge group showing the most, terminally ill without knowledge the least. The terminally ill with knowledge group were relatively more likely to get knowledge from "other sources" (usually a hospital), the chronic control group from the g.p.. The transcript lengths of the terminally ill with knowledge group were longer than those of the other two groups, possibly reflecting a greater willingness to talk about aspects of their illness and treatment. The frequency of "complete knowledge" utterances was positively correlated with transcript
length in the terminally ill with knowledge group, negatively in the chronic control group. The groups did not differ on either Trait or State Anxiety Scale scores. However in the terminally ill without knowledge group (but not the other groups) Trait Anxiety and age were correlated positively with transcript length and (most clearly in the case of age) with frequency of "complete knowledge" utterances, negatively with frequency of "not known" utterances. Finally men were more variable in frequencies of complete knowledge utterances than women.

Some of these results could be simple consequences of the difference in degree of knowledge between two terminally ill groups. This is true of the differences between frequencies of utterances categorised as "complete knowledge" and "not known", (Figure 5.04), a result which serves to validate the content analysis, and to show that g.p.s are indeed able to classify patients in the way required. If "suspicion" lies in between the extreme categories on a dimension of degree of knowledge, then the absence of a difference here is not surprising. The difference in "denial or disbelief", with the chronic control group using this category the least, terminally ill with knowledge group the most, can also be explained. Such utterances are unlikely to occur in chronic patients who have been living with their illness for some time, and it can really only be expressed as a reaction to knowledge.
Some of the remaining group differences may be accounted for by the conversational possibilities offered to members of the three groups by the interviewer. Anyone dying is likely to be preoccupied by the fact, and inclined to talk to someone who offers the possibility. The more preoccupied they are, the more they will talk and the longer the transcript. Hence, if utterances categorised as knowledge of diagnosis or prognosis can be taken as expressing preoccupation, this would explain the positive correlation between "complete knowledge" and transcript length. For the chronic patients also the interviewer will have offered the opportunity for conversation about their illness, but such conversation is not likely to have been encouraged in the past. In return for continued willing companionship, the patient may well have learnt to talk about other things, or to remain silent. There would thus be a negative correlation between preoccupation (as expressed in "complete knowledge" utterances) and transcript length.

The lack of group differences in anxiety revealed by S.T.A.I. scores is surprising, since the g.p.s gave anxiety as a reason for not being frank with certain patients. But some patients, at least, are likely to be prompted by anxiety into probing questions, both in hospital and with their g.p.s. In this way they will acquire more information, especially as we have found that g.p.s report that they wait until they are unequivocally asked before telling a patient he or she is dying (Chapter
6). Such factors may balance the effect of an intention not to tell the more anxious patients. Another reason why the lack of group differences is surprising is that there have been consistent reports of correlations between anxiety levels and cancer (c.f. Chapter 1). Specifically, researchers at King's College Hospital (Greer and Morris, 1975; Greer, Morris and Pettingale, 1979; Greer and Silberfarb, 1982; Pettingale, 1983) report differences between cancer patients and non-cancer patients on anxiety levels measured by S.T.A.I.. Therefore, as all terminal patients but only one control patient suffer from forms of cancer one may expect group differences in line with those of other researchers. There are a number of possible reasons for the differences between the present findings and those of the King's College group. Differences in sampling procedures and the populations the samples represent is the most parsimoneous explanation. Our findings refer to both male and female patients suffering from terminal cancers and being treated at home. This is a very different population to that studied by Greer and associates.

In spite of no group differences in anxiety, there were correlations within the terminal group without knowledge between Trait Anxiety and age on the one hand, frequency of "knowledge" utterances and transcript length on the other. To explain these correlations, we surmise that the attempts by terminally ill patients without knowledge to talk about their illness will have been politely
deflected. Persistence in the face of such opposition will tend to be sensitive to individual differences, and therefore correlations emerge with frequencies of "knowledge" utterances. Anxiety increased the frequency of "complete knowledge" utterances and determined "not known" utterances. Increasing age neutralised this tendency, perhaps because the prospect of death is not so incongruous, and there is less need of a public struggle to come to terms with it. Anxiety also increased transcript length, but independently of the effect upon expressions of knowledge, which suggests that these expressions have a different meaning in this group compared to the others. Talking as such, and talking speculatively about the illness in a way categorised as "complete knowledge", may be alternative expressions of preoccupation.

It is not surprising that patients in the terminal group with knowledge were relatively more likely to indicate "other sources" (usually the hospital) as their source of knowledge, while in the chronic controls it tended to be the g.p. Chronic patients will have relied upon their g.p. as the principal source of medical advice, with visits to hospital usually for routine monitoring of treatment rather than diagnosis. Terminally ill patients on the other hand will have had the probably novel experience of several inpatient visits to hospital, with the express purpose of invasive diagnosis. Thus whatever they hear from their g.p., the hospital is likely to be
perceived as the original source of the information.

Finally the sex differences in willingness to talk (as manifested in variability in transcript length) may certainly be of importance, but are likely to be of complex origin, reflecting interactions of only local validity between socio-economic status, gender and language behaviour. They anyhow seem unrelated to those differences which depend on the nature of the illness and the patient's knowledge, which have been the main concern of this investigation.

The qualitative analysis of the g.p. interviews can be summarised as follows. The g.p.s generally agreed on the meaning of terminal illness. All expressed the aim when treating terminal patients of keeping them comfortable and at home until they died. But when it comes to what to tell patients their opinions diverged. Only one of the four g.p.s (W) stated that he regularly tells patients when they are suffering from a life threatening illness. Two of the g.p.s (V and Z) say that they never tell, although perhaps allowing for the possibility that there may be circumstances in which they would do so. The remaining g.p. (X) prefers not to tell patients, but forms an active, personal and friendly relationship with the dying patient, with which the solemn acknowledgement of impending death is normally incompatible. Dr.X will answer a patient's questions if he considers (a) the question to be asked in such a way
as to represent a genuine enquiry rather than a disguised plea for reassurance and (b) that a truthful answer which revealed bad news not to be detrimental to the patient physical or psychological state. However whether the g.p.s themselves tell or not, they also recognised that patients often find out indirectly.

Our qualitative analysis of patient interviews reveals that for the most part the g.p.s' assessments of patient knowledge do reflect features of the patients in a coherent way. The patients of each g.p. classified as terminally ill with knowledge certainly exhibited greater insight into their illnesses than did those classified as terminal without knowledge. However, one cannot assert that all knowing patients knew, whilst all those without knowledge were totally ignorant. Amongst the terminally ill with knowledge it is clear that patients 09 (W), 15 (X), 19 (W), and 27 (Z), knew that they had cancer and that death was "on the cards", since they explicitly spoke about these subjects. Amongst the remaining knowing patients there was, however, little such explicit talk. But, the analysis reveals there are many less direct indicators that the patients did indeed recognise what was going on: as in Pt.12's angry exclamation, "He's treating me for chronic bronchitis. What the hell can I do if there is something else wrong with me!" (6.49); or when V's patients mention the possibility of a tumour (Pt.01; 6.45); or that there is something "dramatically wrong" (Pt.04; 6.46) and alluding to the significance of
treatment (or lack of it); or Pt.23's comments (6.32) about making the most of her life. The accounts given by these terminal patients conform substantively to those given by their g.p.s. Thus we find that although Pt.27 explicitly knows about her illness she never talks overtly with Z about it (6.40). But there are hints that this situation is not totally satisfactory from her point of view and that Z avoids the issue to some extent unilaterally. X, on the other hand, is a "personable young man", upon whom Pt.15 does not impose. Thus the lack of explicit talk about the illness appears to be based on mutual consent (6.25).

Turning to the terminally ill without knowledge group, we found clear signs indicative of patients' suspicions about their illnesses. In these cases there were often reasons to believe that patients denied the nature of the illness or at least were unwilling to explicitly talk about the subject. Thus these patients may have avoided presenting their symptoms to doctors in the first place, or when they did so putting their confidence (perhaps unrealistically) in the medical profession. Pt.17 is probably more overtly knowledgeable and accepting than the rest of this group, but clearly X attempted to cover up the nature of the illness from her. Certainly it was the interviewer's impression that the interview with Pt.17 was probably the frankest discussion she had had to date with anyone about her fears.
All but one of the chronic control patients knew exactly what was wrong with them, understood the implications and were able to talk about it. The one who did not know exactly, lacked the specific diagnostic label, but was able to describe the basic features of the disease process. Whilst the other chronics described their consultations with the g.p. as predominantly social in nature, she saw them as medical, placing her confidence in the doctors' medical skills. This is as one might expect given that she alone amongst the chronics was receiving visible and active medical intervention from her g.p.

The description of the interviews proffered here reflects the results of the statistical analysis fairly faithfully, especially given the two analyses were carried out independently. Focusing on the degree of patient knowledge, we find that the qualitative analysis maps onto the quantitative analysis presented in Figure 5.02 quite accurately. The qualitative analysis suggests that the patterning revealed in Figure 5.02 may reflect group trends comprising of g.p. and/or g.p. by group interactions. But such influences on patient knowledge may be too subtle to pick up quantitatively in such a small sample, especially since they would often be vitiated by other sources of information with which patients come in contact.

In Chapter 7 a number of ways in which patients can find out either by trying to discover what is going on or by
simply picking such information up from their environment (both internal and external) were identified from the g.p. and patient interviews and presented in the form of a typology. A contrasting typology of the ways in which g.p.s attempt to control the flow of information to patients was also proposed. On occasion the g.p. is conscious of the way he exerts control over the information flow, but this is not necessarily the case. Some ways in which g.p.s talk about terminal illness appear to be routine and are also noted in the way the g.p. talked to the interviewer, when presumably there was no intention to conceal the nature of the illness. These ways of talking are thus probably closely associated with styles of doctoring (c.f. Chapter 2) and the sorts of recurrent patterns of expectations and behaviours, which are identified in social psychological research as indicative of roles (c.f. Chapter 3).

In our discussion of the statistical findings of patient interviews we posited that differences between groups may be explicable in terms of the conversational potentials offered to patients by the interviewer. The qualitative analysis suggests a compatible explanation, but suggests a shift of emphasis to a consideration of the role of patients and g.p.s. In this the role complement expectations of interviewee differs to that of the interviewee qua patient, notably in terms of what the patient/interviewee believes he or she can reasonably say without fear of upsetting the hearer. Thus we find that
patients quite openly talk to the interviewer about aspects of their illness, which they do not discuss with their g.p.s, whether or not they know the g.p. to know or not know. We now pursue this line of argument further, considering firstly the g.p.s' roles in the light of our findings so far.

Occasionally during interview, although not questioned about this issue, g.p.s said things which can be interpreted as direct references to their concepts of the role of doctor during terminal care. For example, Dr.Z revealed that he considered that his task may differ considerably from that of a doctor working in a hospital, when dealing with terminal patients.

"They (hospital) are treating her vigorously certainly... I don't quite know what the attitude is of the radiotherapy department, but they may be aiming at a cure. I don't know. But from a g.p. point of view, we don't seek for cures... we don't actively do much treatment you know. They go to hospital and they get radiotherapy and they go to see the surgeon and get it cut out you know. Em, this is more or less a hospital orientated treatment rather than a g.p. treatment. We tend to come into the picture when all else has failed you know. The really terminally ill, we treat them at the end, you know treat them at home."

(Dr.Zii)

As we have seen, Z has a policy of not telling, unless directly asked and that, furthermore, he does not discuss the illness with patients who overtly know. How does this relate to his notion of his role? The story of his embarrassment as a trainee faced by a patient who told him there was nothing Z could do for him (6.6) reveals the conflict Z experiences when faced by terminal patients.
That the story is recalled by Z some 3 decades after it occurred, is indicative of the importance of the incident to himself and the formative influence it had. Z recognises he cannot cure, (unlike the radiotherapists) but also that if he acknowledges it as such to patients, his role of doctor qua physician is lost. This would go some way in explaining why explicit statements are to be avoided. Yet when knowledge is there but not acknowledged, the respective roles of physician and patient are not openly threatened. Whatever the merits of this policy it is easier to assert that the reason for not telling is that it is bad for the patient to know, rather than bad for the physician patient relationship. The problem with this is, of course, that it leads to inconsistencies when the g.p. recognises that patients often know. Hence, he does not unequivocally admit in specific instances that this is the case, giving further reason not to allow the subject to come up during consultations.

V's policy is very similar to Z's and again we find expression of ambiguity as to how much patients know and what to do. X is in some ways similar to these two, but in others quite different. For him the solemn announcement of impending death is as much out of place as for V and Z, but he does not imply that knowledge on the patient's part may actually be harmful. X forms an active, friendly and jovial relationship with his terminal patients, but still prefers not to tell them when they are
dying, or explicitly acknowledge the fact even when the patient knows. It seems that X is also struggling to maintain his role as a physician by such avoidance, although his style and the demands of his version differ from those of V and Z. He espouses a belief in an informal professional style at all times, but there is evidence that he becomes even less formal and more like a cheerful friend than a doctor when his patients are dying. In the interview with Pt.15 the wife commented on how friendly X had become saying, "It's Bill now", referring to X's use of the patient's first name. In this role the g.p. does have more to offer than just pain relief, but it is not compatible with acknowledgement of impending death and private thoughts are taboo in the relaxed, lighthearted relationship, as the patient recognises. But even if on the surface relationships are relaxed, tensions still subsist as revealed by the outburst of anger and confusion of another of his patients (6.49). This is hardly surprising given the grave nature of the problems for both g.p. and patient (recalling Freudian formulations of the relationship between humour and the repressed). On a theoretical level this points to the existence of some form of role strain (ambiguity, conflict, discontinuity, overload etc.). One way of looking at X's friendly role is to see it as an attempt at role innovation by use of role extention (Brim, 1958, 1960). Thus the actor is inclined to use behaviour learnt from other roles in the present role, since "we do not set up locked compartments and forget all other roles when we
are playing a particular one” (Heiss, 1981: p.114), especially when the role in question is proving problematic.

W on the other hand is more critical of the value of the traditional physician role and hence it is suggested more able to give it up, or perhaps more correctly, to coherently modify it to fit the circumstances.

"Doctors preserve life, I'm not convinced that we should. I want to conserve the process of living, rather than the outcome. But sometimes it comes over wrongly, if you see. To say it explicitly, (traditionally it's a matter) of conserving the method of the doctor who treats, who cures."

(Dr. Wii)

What is more he explicitly connects the nature of the role played with the communicative competence of the player when dealing with dying patients.

"A surgeon... will never tell, or very rarely will tell the patient they are not going to succeed, they are going to die. They find it very very difficult, because the surgeon, well he's a cutter. He's a technician and to admit to failed technology is. is terrifying, or seems to be. And they are very bad at telling, particularly the older ones."

(Dr. Wii)

One way in which a g.p. can talk about impending death without threat to his medical role, is by expanding the role to include counselling. W has trained as a counsellor and for him facing death is a patient's problem like any other and capable of solution. Thus he expresses none of the uneasiness of the other g.p.s, but welcomes the challenge to his counselling skills. The psychological problems of the terminally ill have been
assimilated into W's normal practice, and it is significant that he speaks of them using a technical language not used by the other g.p.s. Telling patients is thus a matter of course as part of an approach towards the solution of their problems. Whatever the merits of this approach from the patients' viewpoint it appears to be a most satisfactory solution from that of the g.p., at least in a practice like W's with a high proportion of middle class patients.

We posit, then, that the g.p.s are trying to deal with a difficult human problem, while retaining the traditional role as healer within the doctor-patient relationship. The avowed purpose of the role is to bring comfort by curing illness, and this is expected by patients. But news of impending death is small comfort and a denial of cure, so the traditional role loses its purpose, except to reduce pain, or to keep alive the hope of cure, however small. This hypothesis will be central to our analysis of g.p. interviews in our further studies. But what of the patients? It is possible that the articulate and explicit acknowledgement of W's patients conceals an anxiety that would be better off in the open; while the lack of explicit acknowledgement between X and his patients may facilitate an ironic detachment. However, none of the data we have collected is capable of casting light on this subject.

The status of the patients' roles is also unclear and we
can only point to general principles. For the patients that explicitly know that they have terminal illnesses the dying role formulation posited by Noyes and Clancy (1977) is probably appropriate. Thus we find that these patients have had wills drawn up and started to make arrangements to pass on their social responsibilities to others. The chronic patients on the other hand seem to fit the sick role formulations as modified for chronic illness, (c.f. Chapter 3) learning to live with the restrictions imposed on their former lifestyles with varying degrees of success. The terminally ill patients who do not explicitly know, are a more problematic group. Some clearly still fit the sick role formulation, awaiting treatment to be effective and engendering a return to health. This is probably truest of Pt.26, who appears to be totally naive as to the diagnosis. But others appear to be less well situated in the sick role. For them it appears that although they hang on to the sick role there is a recognition that it is not totally appropriate, and anger, frustration, confusion, or tears appear (e.g. Pt.06, Pt.12). How this is to be resolved is by no means clear. But one thing that is clear about all of these patient roles is the absence of overt conflict that exists between the doctor and patient. The roles, as described by Parsons, are defined by the authority of the physician, a point that is not contended in the reformulations we have considered. Patients seem to accept the roles allocated of them by that authority and none of the knowing patients insist on talking to a g.p., who does not
first bring up the subject. But patients do come to
know they are dying and this does not necessarily
undermine the g.p.'s authority, even if it does alter the
role relationship between them.

The main factor that makes it impossible to evaluate the
effects of knowledge on our patients and their role
relationship with their g.p.s is the possibility that
different patients are at different stages of their
illnesses. Thus whilst one patient died within 3 days of
interview others were still alive at 6 month follow up.
What is more g.p.s' responses to questions in the
follow-up questionnaire made it clear that whilst some
patients had become more cognisant of their illnesses,
others had not, but there was no clearly discernable
pattern to this. However, the design of further studies
was such as to investigate the factor of change over time.
We thus turn now to consider the design of further
studies.

Changes in Basic Design of Study
Although the results of study 1 give us a general
indication of the way in which g.p.s and terminal
patients interact, the design was unable to take into
account factors associated with the stage of the patient's
illness. Specifically the methods of controlling
information flow described may well be associated with
different periods of an illness. Thus, while denial
associated with reassurance may be a useful way for a g.p. to handle a patient early during terminal illness, it may be of little use towards the end of the illness. Another important point is that the sample size of the previous study was small and needs to be extended if valid generalisations are to be made. The approaches to terminal patients identified in the previous set of g.p.s may be highly specific to these four, or they may represent more widespread ways in which g.p.s deal with communication with terminal patients. There may also be other ways of communicating, which we have not identified in this set of interviews? Another important point relates to the validity of the interview data already collected and such data to be collected in future. That is how do the accounts of behaviour in consultations between g.p.s and terminal patients match up to actual observable behaviour? The studies to be considered in the second half of this thesis were designed to address these problems. The explicit objectives were formulated for our applications to ethical committees for permission to carry out these studies. These protocols are reproduced in Appendix 3.

Design of studies

Two parallel and complementary studies were carried out which were based on the core methodology described in Chapter 4, modified to suit the new designs.

Study 2 A group of randomly selected g.p.s were
interviewed on the way they treated terminally ill patients, using a semi-structured interview schedule. This schedule was a modification of the one used in interview 1 of the previous study, retaining the same basic structure but rephrasing certain questions, dropping others that had proved to be redundant and introducing new ones as appropriate. Again interviews were audio-recorded for verbatim transcription. G.p.s were then requested to allocate all newly terminal patients who came to their notice over a period of 3 months from the day of the interview. Since on average a g.p. sees 5 terminal patients each year (Gambrill, 1973), this 3 month allocation "window" should result in g.p.s allocating a mean of 1.25 terminal patients each. At the time of allocating the terminal patient the g.p. was also required to allocated a chronic control patient matched for age, sex, socio-economic status and site and severity of symptoms. Clearly such matching could not be rigorous but should attempt to be as complete as possible. The example of patient matching used for the previous study was again given to g.p.s when describing matching in this study.

Each patient would then be interviewed "blind" using a modified interview schedule (Appendix 3) and S.T.A.I. administered. Patients would then be followed up for a 6 month period from initial interview or until such time as interviewing was no longer possible (i.e. patient was admitted to hospital, died, or withdrew from the study).
This follow up consisted of two aspects. First, patients would be reinterviewed at 2 monthly intervals. These interviews would consist of readministration of S.T.A.I., proffering of a resume of the previous interview for negotiation of meaning (Harre and Secord, 1976) and interview following the schedule and focusing on any changes since last interview. The second aspect was an attempt to monitor consultations between g.p. and patient during the period of study by use of consultation questionnaires to be filled in by g.p. and patient after each consultation. However, as only one g.p. completed this study and successfully recorded consultations the results are not reported in this thesis. Informal analysis of video-tapes failed to falsify the analysis presented in subsequent chapters.

After completion of each series of patient interviews, the g.p. was again interviewed and patient case histories collected. As in study 1 aspects of the communicative relationship between g.p. and each patient were investigated during this interview.

Study 2: Two g.p. volunteers took part in this study. The design was identical to study 2, except that in addition to the previously described procedures these two g.ps were requested to video record all consultations that took place with study patients in the surgery. Thus as well as g.p. and patient accounts of consultations, and consultation questionnaire responses, we were able to collect a behavioural record of the consultations.
Similar procedures to those described for study 1 were adopted to protect patient confidentiality and to ensure that patients gave informed consent without coercion for both of these studies.

Performance of Study 2

A number of unforeseen problems arose in the performance of these studies and these will be briefly dealt with here.

(i) Ethical committee permission. As with the first study permission to undertake these studies was required from Local Health Authority ethical committees. However, at the time such permission was being sought the Health Services Act: 1980, (H.M.G., 1980) was being implemented. This removed the Area (A.H.A) tier of the N.H.S. hierarchy, which had previously been responsible for granting such permission, devolving responsibility to District Health Authorities. Durham A.H.A. thus declined to give permission for the studies and D.H.A.s had to be approached. The D.H.A.s took some time to appoint staff and committees and to set up the necessary infrastructure for processing ethical applications. This resulted in a 9 month delay before approval was finally obtained from 3 of the 4 relevent D.H.A ethical committees.

(ii) Patient allocation. The cooperation of a sample of g.p.s was secured, however this sample failed to allocate
patients to the study at the rate or in the quantities anticipated. G.p. refusal to take part in the study and the patient allocation rates of those who did are dealt with in Chapter 9. However, the upshot of this was that it proved impossible to obtain a large enough sample of patients to fulfil the original research design's goals and subject patient interview data to statistical analysis. Thus patient interviews are used purely for qualitative analysis to augment the analysis of g.p. interviews. Thus the main body of data to be reported from this study derives from the series of interviews conducted with g.p.s and it is to this that we now turn. The following chapter reports the results of the quantitative analysis of g.p. interviews and Chapter 10 the qualitative analysis.
CHAPTER 9

Quantitative analysis of study 2 g.p. interviews.
In this chapter we report the statistical analysis of interviews carried out in Study 2, commencing with consideration of the selection of g.p.s, and thereby the representativeness of the sample to the more general population of g.p.s and their patients. The second section presents the analysis of the reliability of the g.p. interview content analysis coding, specifically reporting intercoder and test-retest reliabilities for the content analysis. The subsequent analysis of the interview data presented in section three then focuses on an examination of the factors which are involved in, and perhaps influence, g.p.s reported communicative behaviour when faced with terminally ill patients.

Selection of G.p.s

G.p.s were randomly selected from the list of those registered with the Durham Family Practitioner Committee (Durham F.P.C., 1980) and practicing medicine in the 3 District Health Authority areas from which ethical approval of the study had been obtained. The g.p.s were initially contacted using a standard personalised letter of introduction (Appendix 3).

Refusal rate: In order to obtain a sample of 20 g.p.s, letters were sent to 40 g.p.s; a refusal rate of 50%. The most common reason for declining to take part in the study proffered by the 20 g.p.s who refused was that he or she was "too busy" (9 cases). However, 4 g.p.s said they were worried about the research "upsetting
patients", 3 refused without explanation, and 2 declined since they were due to retire during the study period. One of the remaining two refused saying that he thought "research of this sort should be done by a medic", whilst the other (a junior partner) initially consented to take part, but then declined, reportedly at the behest of his senior partners.

In order to check for differences between g.p.s who refused and those who consented to take part in this study, the entry in the G.M.C. register (General Medical Council, 1981) for each doctor was consulted and the date of qualifying to practice medicine thereby obtained. The group of 20 g.p.s who participated in the study had been qualified for a mean of 15.6 years (s.e. 2.3), whereas those who refused had been qualified for a mean of 25.1 years (s.e. 2.2); a difference which is statistically significant (t=2.886, d.f.=38, p<0.01, 2 tailed test). This difference in the number of years each group has practiced medicine probably reflects an age difference between the two groups. Age data however are not readily available for the refusing group, but in the case of the participating group there was a high correlation between age and number of years qualified (Pearson's r=0.95). This lends support to the hypothesis that age was an important variable in deciding to take part in the study, as does the fact that 2 of those who refused, declined, reporting that they were approaching retirement.
The study sample thus comprised of 20 volunteers who had been randomly selected from the population of g.p.s practicing within 3 D.H.A. areas. In addition to these 20 g.p.s, there were two g.p.s who were taking part in a video/audio recording of consultations study: Study 2a (see Appendix 3). Thus 22 g.p.s in all were interviewed.

The group of 22 g.p.s had a mean age of 40.6 years (s.e. 1.9) and had qualified to practice medicine a mean of 16.4 years previously (s.e. 2.2). The personal information supplied by individual g.p.s was checked for accuracy against that published by the F.P.C. and G.M.C.. All personal responses conformed substantially to these official sources, the only difference being a tendency to round up/down the number of patients registered with the practice as reported verbally.

Table 9.01 below presents information about the g.p.s. derived from the interviews. Dr.03 and Dr.11 are the two females included in this sample, whilst Dr.05 and Dr.08 are the two video study g.p.s. Seven of the sample worked in partnerships based in L.H.A. health centres, and 15 in privately owned practice accommodation. All except Dr.21 saw patients in the surgery on an appointment system. The g.p sample is thus similar to the national norm and even more closely resembles the regional norm for these general characteristics (C.S.O., 1983b).
Table 9.01

The g.p. sample: Age, years since qualification, years at present practice, number of full-time principals in partnership, membership of the R.C.G.P. and number of patients per doctor registered with the practice (part-timers = half).

<table>
<thead>
<tr>
<th>Doctor No.</th>
<th>Age</th>
<th>Years since qualification</th>
<th>Years at present practice</th>
<th>Number of full-time principals</th>
<th>Member of Royal College G.P.?</th>
<th>No of patients per Dr. x1000</th>
</tr>
</thead>
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<tr>
<td>01</td>
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<td>11</td>
<td>6</td>
<td>5</td>
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</tr>
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<td>02</td>
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<td>15</td>
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<td>4</td>
<td>N</td>
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</tr>
<tr>
<td>03</td>
<td>38</td>
<td>15</td>
<td>3</td>
<td>4</td>
<td>N</td>
<td>2.25</td>
</tr>
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</tr>
<tr>
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</tr>
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<td>6</td>
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</tr>
<tr>
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<td>4</td>
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<td>5</td>
<td>4</td>
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</tr>
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</table>

InterCoder and Test-Retest Reliability of Content Analysis

To permit the calculation of reliability statistics all interviews were content analysed by the researcher and at least one other independent coder using the content analysis schedule described in Appendix 2. Coder 1 (CJT) coded all interviews in a random order and recoded 25% of interviews selected at random 3 months later (coding 1a). Independent coding of interviews was carried out by 7 coders on one complete set of interview transcripts allocated in random groups of 3 interviews.
and in 1 case 4 interviews (coding 2). All coders completed coding of one practice transcript, which was discarded, before commencing coding of their allocated interviews in a preassigned random sequence. 25% of interviews selected at random were recoded by the same coder 3+ months after the original coding (coding 2a). 55% of interviews were content analysed by another set of 4 independent coders using the same procedure (codings 3 & 3a). Intercoder and test-retest mean Kappa (Cohen, 1960) values are reported for the content analysis codings in Table 9.02 below.
Table 9.02
Reliability of content analysis of g.p. interviews: Mean Kappa values of the intercoder and test-retest comparisons carried out.

<table>
<thead>
<tr>
<th>G.P. Number</th>
<th>Intercoder comparisons</th>
<th>Test-retest comparisons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1vs2</td>
<td>1vs3</td>
</tr>
<tr>
<td>01</td>
<td>0.76</td>
<td>0.73</td>
</tr>
<tr>
<td>02</td>
<td>0.71</td>
<td>-</td>
</tr>
<tr>
<td>03</td>
<td>0.61</td>
<td>0.67</td>
</tr>
<tr>
<td>04</td>
<td>0.51</td>
<td>-</td>
</tr>
<tr>
<td>05</td>
<td>0.57</td>
<td>-</td>
</tr>
<tr>
<td>06</td>
<td>0.70</td>
<td>0.75</td>
</tr>
<tr>
<td>07</td>
<td>0.59</td>
<td>0.66</td>
</tr>
<tr>
<td>08</td>
<td>0.65</td>
<td>0.83</td>
</tr>
<tr>
<td>09</td>
<td>0.63</td>
<td>-</td>
</tr>
<tr>
<td>10</td>
<td>0.68</td>
<td>0.75</td>
</tr>
<tr>
<td>11</td>
<td>0.58</td>
<td>-</td>
</tr>
<tr>
<td>12</td>
<td>0.62</td>
<td>0.70</td>
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<tr>
<td>13</td>
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<td>0.67</td>
</tr>
<tr>
<td>14</td>
<td>0.68</td>
<td>-</td>
</tr>
<tr>
<td>15</td>
<td>0.66</td>
<td>0.73</td>
</tr>
<tr>
<td>16</td>
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<td>-</td>
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<tr>
<td>17</td>
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<td>0.64</td>
</tr>
<tr>
<td>18</td>
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<tr>
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<td>-</td>
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<td>-</td>
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<tr>
<td>22</td>
<td>0.66</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL MEAN</td>
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<td></td>
</tr>
<tr>
<td>KAPPA</td>
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<td>0.71</td>
</tr>
</tbody>
</table>

These values of Kappa indicate a reasonable level of both intercoder and test-retest reliability. Inspection of the category values of Kappa from which the means were calculated, reveals the lower values (<0.60) to be the product of lack of total agreement between coders rather than disagreement. As with the results of the patient interviews content analysis reported in Chapter 5, a weighted Kappa (Light, 1971; Fleiss, 1971, 1973) would take into account this sort of close but not perfect agreement. However, for the same reasons as expressed in
our patient interview content analysis (Chapter 5), the use of such weights was precluded by the nature of the coding scheme. Be that as it may, the obtained values of Kappa are if anything conservative in their estimation of agreement. It is thus safe to conclude that there is good intercoder and test-retest reliability and therefore that the content analysis is an objective measure of the interview content. We may thus confidently base subsequent analysis of interview content on the coding of one coder (coder 1).

**Normalisation of raw data** Since transcript lengths vary widely, the raw number of utterances is not an appropriate measure of differences between doctors. Thus mean frequency of utterance per page is used. This normalisation is achieved in the same way as that for patient interview transcripts reported in Chapter 5.

The content analysis scheme permitted coding of utterances in a large proportion of categories as referring to either diagnostic or prognostic information. However, only 18% of all utterances were coded as referring to prognosis. Since treatment of prognostic utterances distinct from diagnostic utterances would result in low or zero values in many cells, utterances coded as concerning prognostic information were summated with those concerning diagnostic information for each cell of the content analysis to give a single "information about illness" score. It is on these scores, normalised
for interview length, that further analysis is based.

Finally, before turning to the analysis proper, it is prudent to remind the reader of two terms we defined in our description of the content analysis schedule. Utterances about the communication of information to patients may indicate either that such information is given or withheld from patients. One of the first decisions a coder has to make when coding the interview material is mutually exclusive and concerns whether the to-be-coded item refers to giving or withholding information. In this chapter "given" and "withheld" are used specifically to refer to this dichotomous dimension of the content analysis. Other terms, such as "telling", "not telling" etc., will be used when no direct reference to this dimension of the content analysis is being made.

Analysis of G.P. Interview Content

The data were subjected to an exploratory data analysis (Tukey, 1977) so that relevant patterns in the data may be extracted for further confirmatory statistical analysis. One most striking pattern revealed by this E.D.A. has been singled out for immediate attention, since it influenced all subsequent analysis of the data.

The qualitative analysis of interviews, which was carried out independently of the content analysis and some 9 months later resulted in the positioning of the g.p.s on a dimension of positive disclosure to positive concealment
of illness. This dimension is described fully in Chapter 10, but briefly consists of a continuum ranging from the extreme of positive efforts being made by the g.p. to reveal to the patient the nature of his or her illness, to the opposite extreme of positive efforts being made to conceal the nature of the illness. The central region of this dimension, in which a large proportion of the g.p.s were placed, can be described as that in which the g.p.s responded to patient demands for information. For the purposes of the present discussion it is important to note that this discursive analysis and the positioning of the g.p.s on the continuum is based on an holistic reading of interviews, on overall impressions generated by total interviews, rather than specific items of interview content. G.p.s were positioned on the continuum as a hermeneutic device to aid interpretation of specific actions reported.

The g.p.s positioning on the disclosure continuum as an ordinal scale is used as one axis for the E.D.A. plot presented below (Figure 9.01). On the abscissa, and plotted on an interval scale, is a measure of g.p. communicativeness developed from the content analysis data. This is composed of the individual g.p.'s frequency of utterance per page of transcript for total number of utterances coded in all categories refering to giving information about illness minus the total number coded in withholding information categories.
Figure 9.01
Plot of qualitative analysis of positions of G.P.S on continuum of actively disclosing illness to patients vs actively concealing illness from patients against individual mean frequencies of giving minus withholding information utterances of content analysis.
In Figure 9.01 two groupings of g.p.s are clearly distinguishable, one centring roughly around Dr.15 and located towards the active disclosure pole of the informing continuum (Group 1); the other around Dr.03 and located towards the active concealment end of the continuum (Group 2). This clear split was used to define 2 groups of g.p.s. and further analysis consisted of a search for differences between groups in their talk about ways of approaching terminal patients.

In order to investigate the split revealed by Figure 9.01, cluster analysis was performed as an exploratory technique (Everitt, 1974, 1978). Scores from individual content category cells were pooled for each g.p. to give a set of summary scores for the following: telling patients about illness; not telling patients about illness; social, psychological and family factors used to assess patients when deciding whether or not to tell; responsiveness to patient requests. The total length of interview in pages and the total number of utterances coded for each g.p. were also entered into the cluster analysis. Thus the cluster analysis was computed purely on the basis of data derived from the content analysis of individual g.p.s' interviews. An hierarchical cluster analysis was performed using the SPSS-X "Cluster" program as implemented on the Numac computing service at Durham University (SPSS Inc. 1983, 1986). The analysis was performed with g.p.s entered as cases and data entered unweighted into a stepwise
analysis using Ward's method for the amalgamation, the distance between cases being measured in Euclidean space.

**Results of Cluster Analysis** The dendrogram produced by this cluster analysis is reproduced in Figure 9.02 below, and clearly reveals 2 main clusters of g.p.s. The allocation of g.p.s to the 2 clusters exactly mirrors the grouping revealed by Figure 9.01, except for Dr.02 and Dr.20 whose group membership is reversed. Thus in general terms the cluster analysis confirms the existence of two groups in the sample. Moreover, that the result of the cluster analysis so closely resembles the split revealed by Figure 9.01, whilst being based purely on summary statistics generated from the content analysis of interviews, suggests that underlying the two groups identified by Figure 9.01, there are differences, which are reflected in the interview content per se.
Figure 9.02
Dendrogram produced by the hierarchical cluster analysis of unweighted content analysis data from the 22 G.P.s.
Analytical procedure  The analysis of interview content focuses on extricating the differences between these two groups. Group scores for content categories were plotted and on the basis of the patterning revealed, the data were subjected to confirmatory statistical analysis as appropriate. These consisted of t-tests (Robson, 1973), Fisher exact probability test (Siegel, 1956; Finney, 1948) and focused comparisons by analysis of variance (Rosenthal & Rosnow, 1985). The latter were calculated using the SPSS-X "Manova" program with a contrast option (SPSS Inc., 1983, 1986).

Analysis of Interviews

Personal characteristics of g.p.s and general features of interviews. Figure 9.03 presents group mean data on 3 basic dimensions of the interviews. Clearly there were no significant differences between groups on the dimensions of total number of pages of interview transcript, total number of utterances coded per g.p. or frequency of utterance per page of interview transcript. There is also no significant difference between groups in their ages (t=0.8314, d.f.=20, p>0.05; 2 tailed test). Group 1 has a mean age of 39.1 years, while Group 2 were aged 42.4 years.
Figure 9.03
Group mean number of pages of interview transcript, mean number of utterances coded and mean frequency of utterance.

However, the 2 groups do differ in membership of the Royal College of General Practitioners. On the basis of the importance placed by the R.C.G.P. on communicative skills for effective practice (R.C.G.P., 1972), one would expect more R.C.G.P. members in Group 1 than in Group 2. Ten of the g.p.s held the M.R.C.G.P. qualification, of whom 8 were in Group 1 and 2 in Group 2. This is a significant difference between groups as tested by Fisher exact probability test (p=0.0379; 1 tailed test).
Another interesting difference between groups is in their rates of allocation of patients to the study. As previously described (Chapter 8 and Appendix 3) the study design required g.p.s to allocate all patients identified as becoming terminally ill during a 3 month 'window', and a sample of 30 terminal patients, each with a control was expected. However, patient allocation was much lower than expected even though the allocation window was extended. To exacerbate this problem, it appears that the life expectancy of patients allocated was much lower than had been the case in Study 1 since at least 10 patients died after being allocated to the study by their g.p.s, but before a first interview could be arranged. A further 5 patients were hospitalised and 2 patients moved out of the study g.p.'s area (to stay with relatives) during the same period. A further 3 terminal patients refused to take part in the study at first contact with the researcher. Thus 20 allocated patients were lost from the study without being interviewed. This resulted in only 10 terminal patients being interviewed at least once. Of these 10 only 6 completed 3 interviews, 3 dying after completing 1 interview only and 1 dying after completion of 2 interviews. Controls were interviewed on a similar schedule.

Although a total of 30 terminal patients were allocated to the study, only one third were successfully interviewed. Whilst 11 of the Group 1 g.p.s allocated patients to the
study, only 4 members of Group 2 did so, a statistically significant difference (p=0.015 by Fisher-Yates exact probability test). Of the 30 patients allocated, 26 were allocated by Group 1 g.p.s, but only 6 of these died before they could be interviewed at least once. On the other hand all 4 patients allocated by Group 2 g.p.s died before interview. This is a statistically significant difference between g.p. groups (p=0.008 by Fisher-Yates test).

**Interview Content**

**Information communication.** Figure 9.04 presents individual normalised scores for the various categories of the content analysis concerning the communication of information about illness (c.f. Appendix 2). Scores plotted to the left of the abscissas are those of members of Group 2 (noninforming) and to the right are those of Group 1 (informing).
Figure 9.4A: Stem and leaf plots of scores on the various categories of the content analysis of E.P. interviews. (See text for details.)
Figure 9.04B
Stem and leaf plots of scores on the various categories of the content analysis of g.p. interviews. (See text for details.)
Figure 9.04C
Stem and leaf plots of scores on the various categories of the content analysis of g.p. interviews. (See text for details.)
1. Total number of utterances.

301 individual utterances were coded as concerning talk about the communication of information about illness. The members of Group 1 (informing) talk nearly twice as much about giving information to patients than do those in Group 2 (noninforming), a result that is statistically significant ($t=3.866$, d.f.=20, $p<0.01$, two-tailed test). On the other hand, for the withholding of information from patients, Group 2's mean frequency of utterance is approximately twice that of Group 1's, a result which again is statistically significant ($t=4.269$, d.f.=20, $p<0.01$, two-tailed test). These differences between the two groups in frequencies of utterance of giving and withholding information categories are highly compatible with the grouping of g.p.s revealed by Figure 9.01 and subsequently confirmed by the cluster analysis in Figure 9.02. The present findings confirm that an important dimension on which the two groups of g.p.s differ is the degree to which they report informing terminal patients about illness and therefore verifies our provisional naming of the two groups. We will henceforth identify the two groups as informing and noninforming g.p.s.

2. Form of communications (Figure 9.04a)

The giving and withholding utterances were also coded as to how overtly information was communicated or not. 50% were categorised as concerning explicit giving, 20% as implicit giving, 19% as explicit withholding and 11% as
implicit withholding of information.

Within groups there is a significant simple effect of information giving compared to withholding for the informing group \((F_{20,1}=35.66, \ p<0.01)\) but not for the noninforming group \((F_{20,1}=0.86, \ p>0.05)\). There is a significant simple effect of explicit vs implicit information communication, for informers \((F_{20,1}=11.19, \ p<0.01)\) and also for noninformers \((F_{20,1}=6.88, \ p<0.05)\). There are significant group by information giving \((F_{20,1}=4.99, \ p<0.05)\) and information withholding \((F_{20,1}=5.41, \ p<0.05)\) interaction effects. However, there are no significant group by explicit/implicit information giving/withholding interactions \((F=1.90, \ p>0.05)\).

The informing group, then, make utterances about giving information more frequently than about withholding it. Also they talk more frequently about giving information and less about withholding it, than do the noninforming group, who talk with similar frequency about both giving and withholding information. Both groups make utterances about giving or withholding information explicitly more frequently than they do implicitly and they do not differ in the ways they do this.

3. Nature of information given and withheld (Figure 9.04b)
125 (41.5%) of the 301 utterances coded under information giving or withholding went on to specify what sort of information was communicated to the patient. The 2 groups
differ significantly in their frequencies of total utterances for these content categories in terms of the specific information given to patients \((t=3.005, \text{ d.f.}=20, p<0.01, \text{ 2 tailed test})\), but not in terms of specific information withheld \((t=1.118, \text{ d.f.}=20, p>0.05, \text{ 2 tailed test})\). Of particular interest are the differences between information giving and withholding for each of the 2 groups, with a significant difference between groups \((t=2.954, \text{ d.f.}=20, p<0.01, \text{ 2 tailed test})\). Thus the informing group talked more about giving specific information and less about withholding it, whilst the noninforming group talked more about withholding such information and less about giving it and significantly so in relation to one another.

To facilitate analysis of the specific information given or withheld categories they were summated to form 2 superordinate categories: information about the disease entity (site, severity, time, symptoms and cause), and information about aspects of treatment (treatment, cure, incure and fatal) (c.f. Appendix 2).

Disease entity and treatment information

Frequencies of giving and withholding disease entity information are both relatively low, and there are no intergroup differences for giving or withholding information about the nature of disease. Thus neither group makes frequent mention of giving or withholding descriptive information about the illness. However, the informers make utterances
about giving treatment information significantly more frequently than the noninformers (t=2.772, d.f.=20, p<0.05, 2 tailed test). But for withholding treatment information there is no significant difference (t=1.382, d.f.=20, p>0.05, 1 tailed test) between groups. Thus the important difference between groups is the degree to which they talk about treatment available to the patient. The informing g.p.s talk more about giving this sort of information than do the noninforming g.p.s.

4. Style of information communication (Figure 9.04c)

(i) Information conveying modes. The informing group report giving information significantly more frequently in this way than do the noninforming group (t=2.636, d.f.=20, p<0.05, 2 tailed test). Occasionally it appears that information is being withheld rather than given by use of conveying modes. The small degree to which this does occur is accounted for by the intentional use of vague euphemisms and technical language by the g.p.s, but there are no differences between groups in their frequency of utterance in this way.

(ii) Information concealing modes. Whereas information conveying modes may on occasion be used to withhold information, the information concealing modes are never used by members of either group to give information. The noninforming group use these modes to conceal information more frequently than do the informing group and
significantly so (t=-2.269, d.f.=20, p<0.05, 2 tailed test).

The informing group use information conveying modes to communicate more than the noninforming group. Conversely, the noninforming group use concealing modes more than the informing group. Moreover, whilst some modes of communicating with patients (e.g. euphemism and implication) are relatively widely used by both groups, the use of steering questions is limited to the informing group and never mentioned by a member of the noninforming group. Evasion on the other hand, although used by both groups of doctors, is very infrequently mentioned by the informing group, but very frequently by the noninformers. This can be most readily understood if we consider that there is a sense in which evasion and steering questions are opposites; the latter attempts to cajole a patient into asking relevant questions about illness and the former sidesteps any such relevant questions.

(iii) Reassuring patients and responding to patient questions. Responding to patient questions is the only mode of communication content category for which there is an entry in every g.p. cell. 42% of the utterances coded as concerning the communication of information include reference to responding to patient questions. Offering reassurance, whilst not mentioned by every g.p. is the second most commonly coded mode of communication category of the analysis, with 20% of utterances
including an item or items so coded.

The noninforming group make utterances related to offering patients reassurance twice as frequently as the informing group, a difference which is statistically significant ($t=-2.246$, d.f.=20, $p<0.05$, 2 tailed test). This difference between groups probably reflects the already noted relationship between offering reassurance and denial; that is that a large proportion of reassurance is offered as a corollary of denial. Thus the difference between groups in their use of denial also results in a difference in the frequency of the reported use of reassurance. Inspection of the individual interview transcripts and their content analysis coding sheets reveals that the informing group report using reassurance in tandem with giving information about treatment in 68% of cases of their overall use of reassurance.

There is no difference between groups in the frequency of utterance of the responding to patient questions category. This probably reflects the widespread assertion by g.p.s that if asked they would tell. What g.p.s report they would be willing to tell and how assertive a patient's question has to be, to qualify in their eyes as a "real question", are however not dimensions clarified in our analysis.
The g.p.s' talk about their patients

1. Patient factors considered in decision to tell or not

We now turn to the sorts of patients and the patient centred variables that the g.p.s maintain influence (or would influence) any decision to tell or not to tell a patient about his or her illness. Scores for patient types told and not told (Appendix 2) were summated to give 4 decision factors as presented in Figure 9.05.

There were no significant differences between groups for total frequency of utterance of the 4 patient factors overall, nor for the patient psychological state, request, or social relations factors individually. The patient illness factor is only mentioned by members of the informing group, which is a statistically significant result (p=0.005 by 2 tailed Fisher exact probability test). Thus the only patient variable that distinguishes between groups relates to the patient's illness. The informing group report considering this factor when coming to a decision to tell the patient, whilst the noninformers never report considering the patient's illness when deciding if the patient should be told or not.
Figure 9.05
Patient characteristics considered by g.p.s in decisions to tell or not to tell a patient about his or her illness.
Figure 9.06
G.p.s' aims in telling or not telling patients about their illnesses.
2. Aims in telling or not telling patients. (Figure 9.06)

The informing group make utterances describing their aim in telling patients about illness approximately 3 times more frequently than the noninforming group, a difference which is statistically significant (t=3.673, d.f.=20, p<0.01, 2 tailed test). On the other hand the noninforming g.p.s make utterances about aims in not telling patients about twice as often as the informing group (t=-2.778, d.f.=20, p<0.05, 2 tailed test). Thus whilst the informers state aims in telling patients, the noninformers state aims in not telling patients. What are the stated aims of the 2 groups in telling and not telling and do they differ?

Patient happiness The most frequently mentioned aim, for either telling or not, was the maintenance of patient happiness. 63% of all aim utterances included a reference to patient happiness and 21 of the 22 g.p.s mentioned it at least once. While the informing group more frequently stated patient happiness to be an aim in telling than not telling patients, the noninforming group almost equally more frequently stated that this was an aim in not telling rather than telling patients; a difference in mean frequencies of aims in telling and not telling that is statistically significant (t=3.729, d.f.=20, p<0.01, 2 tailed test). Thus while keeping the patient happy is seen as an important aim by both groups of g.p.s, the way in which they go about attaining it is very different. The informing group see telling patients
as the way to keep patients happy, whilst for the noninforming group not telling is the way to attain the same aim.

**Patient relationships**  The continuation of normal relationships between patients and other people (including the g.p.) is the second most frequently mentioned aim for telling or not telling patients and 34% of the aim utterances including mention of this. There is no significant difference (t=1.994, d.f.=20, p>0.05, 2 tailed test) in the frequency of utterances between the 2 groups for this category overall. However, the patterning of responses was different for aims in telling and not telling. Both groups reported that maintaining patients' relationships with other people was an aim in telling them about the illness more frequently than not telling, a difference that is statistically significant for the informing group (t=3.092, d.f.=11, p<0.01, 2 tailed test) but not for the noninforming group (t=0.836, d.f.=9, p>0.05, 2 tailed test). There is no significant difference between groups in their differences of use of this reason for telling and not telling (t=2.042, d.f.=20, p>0.05, 2 tailed test).

**Patient management**  22% of the aim in telling or not telling utterances contained reference to patient management. There is a significant difference between groups with the informing group mentioning patient management as an aim in telling, more frequently than the
noninforming group (t=2.532, d.f.=20, p<0.05, 2 tailed test).

Other aims The remaining aims in telling or not telling (patient financial considerations, family happiness, etc) were relatively little used by the g.p.s in their descriptions of their aims as identified by the content analysis. Hence a number of very different sorts of aims have had to be placed together under the catch all of "other aims" to facilitate analysis. There were, however, no statistically significant differences (t=0.0533, d.f.=20, p>0.05, 2 tailed test) between groups in the frequencies of utterance for these other aims for either telling or not telling patients.

G.P.s' Assessment of Patient Knowledge of Illness

Levels of patient awareness of illness. 157 g.p. utterances were coded as containing mention of patients' awareness of illness. These are coded as being on one of three levels; (1) no accurate knowledge or denial, (2) partial knowledge or suspicion, and (3) complete and accurate knowledge (Figure 9.07). 80% of the utterances referred to patients having some degree of knowledge of illness. Only 20% of utterances referred to patients not knowing at all what is/was wrong with them.

Perhaps surprisingly the informing group spoke more frequently than the noninforming group about patients having no knowledge of illness, a result which is
statistically significant \( (t=2.505, \ d.f.=20, \ p<0.05, \ 2\ \text{tailed test}) \). But although as may be expected the informing group also speak more frequently than do the noninforming group of patients having complete knowledge this is not a significant difference \( (t=1.905, \ d.f.=20, \ p>0.05, \ 2\ \text{tailed test}) \). There is also no significant difference \( (t=1.249, \ d.f.=20, \ p>0.05, \ 2\ \text{tailed test}) \) between groups in their frequency of utterance of talk about patients having partial knowledge of or suspecting the nature of the illness.
Figure 9.07
Patient levels of awareness of illness
This patterning of results makes sense once one considers the implications for the g.p.s of the different levels of patient awareness of illness. For a doctor who does not inform patients about their illnesses a patient, who has no knowledge or suspicion of his or her illness presents no real problem. The patient does not know and thus the g.p.'s approach to the patient can remain the same. If the patient has complete and overt knowledge of his or her illness the noninforming doctor may not relish the situation, but he is faced with a 'fait accompli' and again this requires no new action on his part. However, the patient who suspects or partially knows about his or her illness confronts the g.p. who prefers not to tell with a problem; namely how to prevent the patient from learning about the illness or whether, after all, in this case to tell? In such a case the doctor is constantly facing a patient toward whom he must act with care if he is not to let slip the nature of the illness etc. Seen in this light, it is not surprising that the noninforming g.p.s as a group are preoccupied with patients who have only partial knowledge or suspicions about the illness from which they are suffering, and thus speak more frequently about this group. On the other hand for the informing g.p. a gradual shift of patient's knowledge from none, through partial to complete knowledge is the normal aproblematic course of events. This process of gradual revelation is desired, and partial knowledge is but a transitory stage between complete ignorance and overt knowledge.
Sources of patient information

105 utterances were coded as indicating sources of patients' knowledge or information about illness. Of these only 12% reported the g.p. himself as a source, whilst 26% concerned other medical sources and a further 9.5% mentioned family and friends as sources of information. Thus in excess of 50% of the utterances did not refer to persons as sources of patient information.

23% of source of information utterances made reference to treatment per se. Of these approximately one third specifically mentioned the requirement that terminal patients make continuous return visits to the doctor as being the salient feature of treatment which revealed information. A further 20% of utterances pointed to self diagnosis as an important way in which information is acquired, whilst the remaining 10% referred to other sorts of ways in which patients gleaned information from their environment. There were no statistically significant differences between groups in their talk about patients' sources of information.

Reasons for telling or not telling patients

It is in the g.p.s' reasons for telling or not telling that we find one of the clearest dichotomous distinctions between groups in the whole analysis. In total 54 utterances were coded as containing items giving reasons
for g.p.s' reported behaviour. Of these 24 referred to reasons for telling and 30 for not telling. Of the former all but 4 were made by g.p.s in the informing group, whilst of the reasons for not telling all but 3 were made by noninforming group g.p.s. All except one of these 7 utterances were, however, posed as hypothetical arguments. For example, one noninforming g.p. indicated that contemporary literature on the subject of terminal care recommended telling patients about their illnesses. This was in his opinion a good idea in theory, but in practice he would find it very difficult.

On the basis of these considerations it is reasonable to consider the two groups as expressing diametrically opposed ideas. Thus, the informing group express reasons for telling, while the noninforming group reasons for not telling. Because of the relatively low overall frequency of utterance for the various reason categories of the content analysis, to facilitate analysis the expressed reasons for telling or not have been amalgamated into 2 categories: technical/medical and ethical/personal reasons (Figure 9.08).

(i) Technical/medical reasons are made up of all the content analysis categories referring to clinical considerations. (e.g. technical and managerial consequences or advantages), and are grounded on scientifically justifiable criteria and knowledge. Thus this category can include items relating to medical school
training and post-graduate education as these refer to the transmission of the corpus of medical knowledge, reading papers in scientific and medical journals, clinical experience and the like.

(ii) Ethical/personal reasons are made up of those content analysis categories which centre on ethical judgements, (e.g. a patient's right to know), and affective responses rather than being in the domain of empirical science. Again it is of course possible that these reasons have their origins in formal training, reading and the like but in practice this is less likely and there is a tendency for such notions to be couched in a less explicit language.
Figure 9.08
G.p's reasons for telling or not telling patients about their illnesses.
The 2 groups of g.p.s differ in the sorts of reasons that they give to explain their communicative behaviours. The informing group express their justifications for telling patients considerably less often in terms of the technical and medical than the noninformers, a difference which is significant \((t=3.061, \ d.f.=20, \ p<0.01, \ 2 \text{ tailed test})\). On the other hand the informing group express ethical and personal reasons in the order of twice as frequently as the noninforming group, again a significant intergroup difference as tested by Mann-Whitney test \((U=18 \text{ for } N_a=12, \ N_b=10, \ p<0.05, 2 \text{ tailed test})\).

The difference between groups in their expression of medical vs ethical reasons is statistically significant \((t=5.022, \ d.f.=20, \ p<0.01, 2 \text{ tailed test})\). The noninformers express their reasons for not telling patients about their illnesses predominantly in technical/medical terms and only very infrequently in ethical/personal terms. In the case of the informing group although they express reasons for telling patients in terms of the technical/medical model \(^\land\) they do so at less than half the frequency of the noninformers. Furthermore the informers comparatively more frequently express their reasons as ethical or personal.
Summary

Since the length of interview, the total amount said, and frequency of total utterances did not differ significantly between groups it is safe to conclude that further intergroup differences are not simply a function of these characteristics of the interviews. But whilst the two groups of g.p.s do not differ in the aforementioned gross characteristics of the interview nor in age, Group 1 contains both absolutely and relatively more g.p.s who hold the M.R.C.G.P. qualification than Group 2. Furthermore, Group 1 allocated more terminal patients than Group 2 and patients allocated by Group 1 lived longer than those of Group 2. This suggests that more pervasive differences between the g.p.s are being reflected by placing them into these two groups. On the basis of differences in their information giving and withholding the 2 groups can be dubbed "informing" and "noninforming" respectively. In order to clarify the differences revealed by the analysis, we summarise the findings as they relate to the two groups of g.p.s, by way of describing the reported behaviour of a hypothetical typical member of each group.

Informing group: The typical doctor in this group is a member of the Royal College of General Practitioners, aged 39 and allocated terminal patients to the study. He talks more about telling patients about their illnesses than his counterpart noninformer. He tells patients explicitly rather than implicitly, gives rather than
withholds information and in particular he tells patients about treatment. The strategies and tactics he adopts differ from those of noninformers in that they are information conveying rather than concealing. He conveys information by using steering questions to manoeuvre patients into asking relevant questions which he then answers; something noninformers never do. He also uses euphemisms, hints and implications to convey information and only infrequently evades patients' questions. When telling patients about their treatment he more often than not attempts to reassure them as well. In coming to a decision to tell a patient our typical informer will, like any other g.p., take a number of patient centred variables into account. However he will give more weight to patient illness factors than will his noninforming colleagues. His aim in telling is most cogently characterised as that of keeping the patient happy, and maintaining his or her relationships with other people and himself. For our informing g.p. the patients who are problematic are those who have no idea or deny what is the matter with them. When faced with patients of this sort he must initiate interactions with the intention of making them aware of the nature of the illness and its implications, often in the face of resistance from the patient. When discussing reasons for informing patients, although he entertains medical and technical reasons, the typical informing g.p. feels these are of lesser import than would his noninforming counterpart. On the other hand ethical considerations are more important.
Noninforming group: The typical noninforming g.p. is not a member of the Royal College of General Practitioners. Aged 42, did not allocate a patient to the study, but if he had done so the patient would have died before being interviewed. This g.p. positively withholds information from his terminal patients to a far greater extent than an informing colleague. Information withholding is mostly achieved by a greater reluctance to volunteer information than is the case for an informing g.p.. The communication strategies and tactics utilised reflect this. Denial and evasion are used more commonly than they would be by an informer, denial often being accompanied by placatory words of reassurance. Although euphemisms and the like are reportedly used by the typical noninforming g.p., steering questions do not form part of his reported behavioural repertoire. Thus his assertions that he responds to patients' questions are fairly vacuous, since questions (at least the important ones) do not get asked. In a way similar to his informing counterpart, a major aim for the typical noninforming g.p. is to keep his patient happy. Yet he believes that the way this aim is best achieved is by not telling the patient, the antithesis of the informing g.p.'s approach. If he must tell the patient his aim is more likely to be to maintain the patient's relationships with other people. His reasons for not telling patients are predominantly expressed in terms of a medical
rationale.

Discussion.
It is clear that by splitting the g.p.s into 2 groups on the basis of the qualitative analysis of interviews (Figure 9.01), we have revealed a myriad of differences in the content of g.p.s' interviews. Central to our understanding of these differences is the finding that whilst one group reports telling patients about illness, the other conceals a considerable amount of information that would be required by patients, if they were to have a thorough understanding of the illness from which they are suffering. It is important to note that the differences between groups are not simply that informers tell all and noninformers tell nothing. For example, both groups report giving patients descriptive information about the disease entity to similar extents, and withhold similar small degrees of such information. In other words, both groups talk about talking relatively openly with patients about symptoms and the like. However, when it comes to explaining treatment to patients the two groups diverge in their willingness to be frank. The informing group withhold little information and tell patients about the treatment, which they already receive or may in the future be offered. The noninformers, however, express great reticence in telling patients about treatment, and withhold as much as they give.

One explanation of these differences points to the
informative value to a patient of the two sorts of information: disease entity and treatment descriptions. In many ways, talking to patients about symptoms experienced etc. is giving little or no new information to the patient. If the patient experiences the symptoms, then he or she of course knows of their existence. That the doctor talks about the symptoms with them may reduce patient anxiety about the said symptoms, especially if the g.p. maintains a matter of fact manner, for it merely reveals that they are known and to be expected manifestations of the illness. If the g.p. tells the patient of symptoms he or she can expect to experience this will reduce the shock of experiencing them when it occurs, again they are routine and thus less likely to provoke anxiety.

On the other hand, telling patients about treatment does give patients information. Most importantly perhaps, by definition the terminal patient is beyond curative treatment. Any description of treatment, which is in any way truthful, would have to include at the very least an expression of doubt as to its curative efficacy. Even if the doctor does not admit that treatment aimed at cure is hopeless, he would be bound to have to admit that he cannot guarantee the treatment will work, a point to be taken up again in the qualitative analysis (Chapter 10). Thus, whereas it appears that the informers are willing at least to express such doubts, the noninformers are not. On those occasions when the noninforming g.p. is

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tempted to talk to patients about treatment, when, for example, it is likely that such and such a treatment may provide benefits at least in the short term, he may well remain mute for fear of opening a proverbial Pandora's box. Such an explanation, with the specific variations required by each sort of information under consideration, probably goes far to explain many of the various differences in talk between the two groups. If there is a boundary to the information one is willing to impart about some topic, one is better never to allow that topic to become one with conversational possibilities during an interaction. Thus, although there were no differences between groups in the degree they expressed willing to respond to patient questions, this probably reflects a conventional answer being given by g.p.s to the question, rather than what happens during interaction with patients. Such an interpretation is supported by the finding that the noninforming group talked significantly more about evading and denying patient questions and reassuring patients, than the informing group.

When deciding whether or not to tell patients, the two g.p. groups took similar factors into account, except that the informing group consider the patient's illness when deciding to tell, whilst the noninforming group never report considering this factor. There is stark contrast in the aims of the two g.p. groups in respectively telling or not telling patients. Both groups aim at maintaining patient happiness, but the informing group attempt to
achieve this by telling, the noninforming by not telling. Consideration of the g.p.s' talk about patient knowledge revealed that the two groups had different preoccupations. The noninforming group were most concerned about patients with partial knowledge, but the informing group did not differ in the extent they talked about any particular level of patient awareness. For a noninformer, a suspicious patient is probably problematic, since the g.p. must be more guarded in his approach, if he is not to let slip crucial information, which he would prefer to withhold. But such a problem does not exist in the case of patients, who have no idea about their illness or patients who already know. For the informer the level of patient knowledge represents a sort of continuum, and if the g.p. is to tell a patient, he must guide the patient from ignorance through suspicion to unambiguous knowledge. The reasons expressed by the two g.p. groups for telling or not telling patients, reveal a major rift in the groups' perspectives. The informing g.p.s justified telling in ethical or personal terms, whilst the noninforming justified not telling in terms of the effects knowing might have for patients' medical condition and management.

The patterning of results suggests that g.p.s develop specific views and maintain a particular perspective on whether or not patients should be told. But stating the situation in such dichotomous terms is somewhat misleading, and it is to this aspect of the interview
results that we concentrate in Chapter 10, drawing out the subtleties of g.p.s' approaches to terminal patients. However, before turning to this we have to consider one further aspect of the results, the patient allocation rates of the two groups of g.p.s.

The 22 g.p.s were requested to allocate patients to the study as they became terminally ill. We expected to obtain a sample of approximately 30 such patients, who could be followed longitudinally over a period of 6 months. But, the number of patients successfully followed was a fifth of the number initially expected, even though the length of the allocation period was extended. Whilst problematic in terms of the initial objectives of the study, the failure of the design to produce the expected rate of patient allocation is in itself an interesting result. In Study 1 the 4 g.p.s reported no problems in identifying and allocating patients. Yet a relatively minor change in the definition of the requisite patients resulted in the failure of all but a minority of Study 2 g.p.s to identify and allocate suitable patients. How can we explain this? Although it is possible that there was a dearth of terminal patients amongst the g.p.s at the time of Study 2, there is no obvious reason to believe this was the case. We must assume, therefore, that the failure of the g.p.s to allocate patients was a function of the patient identification procedure used, rather than reflecting a statistical fluctuation within the patient population.
In Study 1 each g.p. undertook to find 4 terminal patients for the study on agreeing to cooperate with the research project. But in Study 2 the g.p.s were asked to identify an unspecified number of patients as they became terminal over a specified period of time. What seems to have happened in Study 2 is that the less rigid criteria given to g.p.s, rather than being easier to fulfill, had the consequence that many g.p.s deferred allocating patients. Therefore they did not label patients as terminal until it was too late for the purposes of this research. Thus it seems that many g.p.s are unable or unwilling to identify a point at which patients move from being "cancer patients" to being "terminally ill". Thus in 15 cases by the time the g.p. allocated a patient, that patient was so ill that he or she died or was hospitalised before he or she could be interviewed. These 15 patients were allocated by 12 g.p.s, but 7 g.p.s failed to allocate any patients whatsoever to the study. These 7 g.p.s were all members of Group 2, the noninforming g.p.s, whilst those g.p.s who successfully allocated patients were informing g.p.s. Those g.p.s who unsuccessfully allocated patients to the study (i.e. allocated patients who died before completing interviews) are scattered across the central region of passive response of Figure 9.01. Although all g.p.s gave textbook definitions of terminal illness during interview, this patterning of patient allocation suggests that individual g.p.s differ in the degree to which they are
willing to acknowledge that a patient is terminal. These differences in willingness to accept that a patient is terminal are generally consistent with g.p.s' communicativeness. A g.p., who is willing to label a patient as terminal earlier during the illness, and thus successfully allocate patients, is also likely to attempt to actively disclose the nature of the illness to the patient. Other g.p.s defer acknowledging the patient's terminality until later during the illness, and this is associated with a more passive response strategy (Figure 9.01). A final set of g.p.s, who tend toward actively concealing the nature of the illness from patients, never allocated patients to the study, perhaps because they never themselves acknowledged that the patient was terminally ill. This interpretation of why these g.p.s failed to allocate patients is of course only one of many possibilities, albeit one that is consistent with the statistically significant differences found between the two groups of g.p.s. Alternative explanations include the possibilities that, the noninforming g.p.s genuinely had no suitable patients, that they only took part in the study half-heartedly, or perhaps they did not inform the researcher of suitable patients for fear of the consequences to their patients' wellbeing. But, although it is clearly impossible to totally discount such explanations, they do not parsimoniously account for the overall patterning of our results. Moreover, as we shall see in Chapter 10, consideration of the role formulations of the g.p.s supports the hypothesis that the
noninforming g.p.s resisted acknowledging that their patients were terminally ill, whilst others accepted this more straightforwardly.
CHAPTER 10

Roles, strategies and tactics in g.p. communication with the terminally ill: A qualitative analysis of g.p. interviews.

"Verbally I don't learn anything definite, since in discussing tuberculosis... everyone drops into a shy evasive glassy eyed manner of speech."

Strategies and Tactics

In Chapter 7 we wrote of "methods" and "ways" by which doctors and patients attempt to exert control over the exchange of illness related information. At times these terms may have appeared somewhat strained in their use. It may also have occurred to the reader that a word such as "strategies" would be more appropriate. This class of term was avoided so as to prevent confusion with the way they are used in this chapter.

A number of previous authors, the most notable of whom is McIntosh (1974, 1977), have considered the communicative behaviours of doctors and patients in terms of "strategies". In a wideranging review of cancer and communication McIntosh wrote,

"Few studies exist which can shed light on the information seeking strategies used by patients... For example, one ploy used by patients is to.... No one has specifically examined the information seeking strategies used by cancer patients and their relatives... Medical personnel have developed a number of tactics for controlling the amount of information which a patient receives. One previously mentioned tactic is for doctors and nurses to avoid interaction with patients whom they wish to maintain in a state of closed awareness. Although this strategy is used in the case of dying patients, it...."

(McIntosh, 1974; p.178)

McIntosh uses the words "strategy", "ploy" and "tactic" as if they were synonyms. The only obvious difference in their use is that whilst patients tend to implement "ploy"s, medical personnel implement "tactics", which perhaps connotes more consciously thought out intentions. However, there is no consistency in use and we also
find patients using "tactics". "Strategy", moreover, appears to be used as a synonym for all the other terms. McIntosh is by no means alone in using these terms so loosely. McClenahen and Lofland (1976), for instance, use them in exactly the same way. "Strategy" and "tactic" are however not synonyms and their use as such is imprecise.

During the 1830's, Clausewitz in his treatise "On War" distinguished strategies from tactics.

"The conduct of war, then, consists in the planning and conduct of fighting... (which) consists of a greater or lesser number of single acts, each complete in itself... called engagements... This gives rise to the completely different activity of planning and executing these engagements themselves, and of coordinating each of them with the others in order to further the object of the war. According to our classification, then, tactics teaches the use of armed forces in the engagement: strategy, the use of engagements for the object of the war.... The first is concerned with the form of the individual engagement, the second with its use. Both affect the conduct of marches, camps, and billets only through the engagement: they become tactical or strategic questions insofar as they concern either the engagement's form or its significance... Tactics and strategy are two activities that permeate one another in time and space but are nevertheless essentially different."

(Clausewitz. 1976; pp.128-132)

Further "the analysis must extend to the ultimate objective," (p.159) which permits a distinction to be made between ends and means. This distinction allows an action, such as marching, to be considered in terms of the part that it plays in the overall structure of the activity. We will use these terms in a way that reflects this classification in our analysis, although
obviously adapting it to the more peaceful activities that occur during interactions between g.p.s and patients. Such an adoption of military terms is moreover consistent with the conflict model of the doctor patient interaction now ascendant over the reciprocity and harmony of the traditional Parsonian formulation (c.f Chapter 3).

**Definition of Terms**

As Clausewitz points out, in order to understand the individual activities, one must first clarify the overall objective, which he, perhaps contentiously, identifies in the case of waging war as the attainment of peace. Thus, we must consider the objectives of the interactions that occur between doctor and patient, and place further analysis within this context. **Objectives** refer specifically to the stated objectives of the g.p.s and as such will be based on the explicit responses of g.p.s to interview 1, question 5: "When treating someone with a terminal illness what is your aim?" An objective may consist of a number of goals, in the same way as the objective of "attaining peace" may require the attainment of the goal of victory in battle. **Strategy** refers to the overall plan and mode of approaching a patient adopted in order to attain the objective. Strategies normally have a temporal extension of weeks or months of repeated consultations. They are recognizable and explicitly stated styles of interacting with specific patients or groups of patients. **Tactics** refer to behaviours used (normally) in single consultations to attain specific positions within the
overall strategy. Thus a strategy such as disclosure over a period of time requires the doctor to withhold information during a consultation early in the series (a strategic consideration) and thus adopt a tactic intended to avoid disclosure at this point. However, later during the series of consultations the doctor may have to change his or her tactics and confront the patient so as to actively disclose the nature of the illness, as part of the strategic approach.

Analysis of Interviews
G.p.s' Objectives The stated objectives of g.p.s caring for terminally ill patients can be broadly subsumed under the general heading of palliation in all cases. Some g.p.s speak explicitly of the inherent contradictions encompassed by the notion of palliation. Others make no reference to these problems and refer to the relief of physical pain only. The stated objectives of the 22 g.p.s are presented in Appendix 5, but it is clear from what the g.p.s say that a central objective in all cases is a desire to keep the patient comfortable, painfree and happy. Thus the technical side of the medical care offered relates to pain control and relief of symptoms. Yet a major objective in many cases is to keep the patient human by maintaining his or her dignity. This is clearly expressed by Dr.01, Dr.07 and Dr.08, for example, but reference by some g.p.s to "mental comfort" and "mastery" is also indicative of a preoccupation with patient dignity. This aspect of the g.p.s' stated
objective stands in stark contrast to the typical (sick) role of the patient. The objective is an expression of returning to the patient autonomy of action, which is normally relinquished when entering the sick role. The g.p.s are as such describing their objectives as ushering the patient out of the sick role and into the role described by Noyes and Clancy (1977) as the dying role. While these g.p.s put the emphasis on dignity, rather than the physical suffering and pain of the patient, this is not to say they do not concern themselves with looking after the physical side of things. For them pain relief etc. is a prerequisite for the attainment of the real objective; death with dignity. There is, of course, no absolute way of judging the g.p.s' objectives. Different patients may feel more comfortable under different regimens and we do not have sufficient data to identify whether the patients' preferences tally with the individual g.p.s' objectives.

Strategies of Communication
The description of strategies used by g.p.s is drawn from explicit utterances made during interview, normally in response to questions enquiring whether or not the g.p. tells patients about their terminal illness. Careful reading of transcripts revealed three sorts of strategies adopted by the g.p.s, which effectively range across a spectrum of disclosure to patients.

-361-
Strategy 1: Passive response to patient  Many of the g.p.s are ambivalent about what to tell patients and in a sense abdicate responsibility for making a decision. Central to the strategy is the assertion that the g.p. only responds to patient initiated queries. Dr.11 and Dr.01 are typical:

"No aim (in telling) at all except that if they ask, if I felt that they genuinely wanted an answer then what is the point in telling lies... You become fairly important to the patient because it is what you give them that eases the pain... I mean you've got to do what the patient wants... I don't see any virtue in truth for its own sake... (it's) initiated by the patient... Basically the way you treat them is geared to what they are like when you go to see them... I don't have a coherent policy... telling and not telling is a one off thing with each person and you probably only decide what you're going to do when you are with them, confronted with what they ask you."

(Dr.11) (10.1)

and

"I don't make a determined effort to tell, or I don't go and think I am going to tell this patient today... The telling usually evolves after the looking after them. It doesn't come as a separate phase, it evolves and sometimes it is done, sometimes not... So you've got to accept if that's the way they want to play it. You've got to play it by ear... There is absolutely no rule, no technique or anything else. It just evolves on the spot, purely thinking on your feet so far as I'm concerned... If they want to know they let you know and you've got to decide there and then what and how to tell them, or more likely you play for time."

(Dr.01) (10.2)

But there is wide variation amongst the g.p.s who assert they respond to patient questions. Some clearly respond more readily than others. Dr.07's position clearly differs from that of Dr.01;
"Usually you just carry on with your usual relationship as before. Most of them you've seen over the years... I don't decide to tell them, it's when they ask... look me in the face and say "I've got cancer, haven't I?"... but very few of them say that... I would only tell if they asked me. And if they ask me, it's in a way they've forced me into it, into telling them, you know what I mean. I often feel it's a, it's such a negative thing."

(Dr.07)

During interview all the g.p.s expressed willingness to answer patient questions. However, they differed in the sorts of caveats placed around their expressed willingness to respond to these questions. This suggests that there are variable thresholds at which g.p.s accept a patient's question as a genuine enquiry. Dr.09 for example explained:

"If they looked me straight in the eye and said, "have I got cancer?" then the answer would be yes... I don't think I've ever been asked by a patient and told a patient... It doesn't work quite like that."

(Dr.09)

Whilst Dr.17 says:

"So I prefer to play along and at some stage of the illness I think they all turn round and say "I'm dying aren't I?"... It's just that I've never come to a system whereby I can tell them earlier... I play it by ear... I don't know if I leave too much up to them but I find it very difficult and it's probably a fault I should think."

(Dr.17)

And Dr.15:

"I let the patient make the enquiry, unless you can tell they were, you know, waiting to know and you can sometimes without them actually putting it into words... It's as if you had antennae which pick up
vibrations. You can sometimes see that someone is
dying to ask you something and you can tell them. But
I mean that is a question which is not voiced by the
patient but it is a question nonetheless."

(Dr.15)

(10.6)

Stated most cogently, the differences between the g.p.s is
to be found in their attributions to patients of
preferences for knowing or not knowing about the illness.

Strategy 2: Active disclosure Some g.p.s report actively
telling patients the nature of the illness. The most
extreme version of this is to be found in Dr.08's
transcript when he says:

"The decision to tell them is a decision of principle.
I can only work with the patient when I'm telling the
truth and I can't maintain a lie in a relationship
with a patient... I tell everyone... Instead of just
being brutally forthright about anything I prefer
people to more or less ask me... but if they're still
fencing, that is if I feel they are still being
defensive, not asking when prompted... I will state
it quite emphatically."

(Dr.08)

(10.7)

The strategy of passively responding to patient questions
does not normally differ so very greatly from that of
active revelation in one important way. As Dr.08 says, he
prefers people to ask. Thus only an apparently minor
modification need be made to the passive response
strategy: that of actively prompting patients into asking.
Paradigmatic of this active revelation strategy is Dr.19's
description:

"I have a clear policy, it's to develop perhaps a
closer relationship with the patient than I had
beforehand in order that I may tell them their
diagnosis and discuss with them how we're going to manage their terminal illness and that is basically how I handle the terminally ill... with the aim of developing a trustful relationship, so that they will tell me the truth and I can tell them the truth... It normally takes me between a month and 2 months from first regarding that patient as terminal, building up a different relationship to the relationship you had with them before, so you can discuss more fully with them their prognosis... By the time you've built up the relationship, at the end of it, it comes naturally, and you know you are going to do it before you go into the house. Therefore, it's not difficult once you've built up this relationship."

(Dr.19)

This g.p. manipulates the patient towards mutually and explicitly formalised acknowledgement of illness by a gradual and progressive increase in patient awareness. This permits the g.p. to gauge the pace of revelation via feedback from the patient.

The strategy of revealing to patients is one in which the doctor prompts the patient into asking and thus reveals progressively more about the illness, until the patient overtly knows. Thus the strategy of responding to patient questions merges into that of actively revealing information in two ways. First, there are the differing individual thresholds to patient demand for information at which the g.p. is willing to impart information. Second, g.p.s can initiate patient questioning, but only Dr.08 reports that if this does not result in the patient asking the relevant questions that he will force the situation. The others follow Dr.05 who says:

"I'm a great believer in letting them (patients) dictate the rate at which things go ahead... It's the timing of this that I think is the most difficult.
On the whole I think it is better if the patient knows, but I would certainly not force it on them. But I would want most patients to know before the end, before they died."

(Dr.05)

(10.9)

Strategy 3: Active concealment The converse of actively revealing to patients the nature of the illness is to actively conceal this information. One aspect of this is that although some doctors report that they respond to patient questions, they also make it clear that the patient has to overtly ask or even force them into answering. We saw hints of this in the quotations from Dr.09 and Dr.07. Even more extreme is the strategy in which questions posed are not answered and attempts are made to vitiate information already acquired.

"I never tell them what they have got. And even if the hospital has told them, I try to avoid it. I try to find out what has been told them, and get out of it, because I think it is cruel to tell them that. So I always try to find a way to get them to see it different... that they didn't understand it right... You know, get it out that it is another very common problem, that it is not terminal, it will clear up. Because I don't believe to tell the patient that he has got cancer and that he has a few weeks to live or a few months... I'm just against it... I wouldn't like anyone to tell me... I try to avoid it, I just keep quiet... I haven't ever mentioned it to a patient even if it is not terminal... even if we catch it early and they are alright. No way, because they (would get a) fright... I would never tell them... I change the conversation."

(Dr.20)

(10.10)

Clearly he acts both to conceal information from patients and to actively mislead patients who are in possession of accurate information about their
illnesses. How this g.p. specifically attempts to do this, and discussion of how successfully he may negate patient knowledge of illness, must be left over until we consider tactics, although tactics (e.g. changing the subject of conversation) are revealed by this quotation.

Individual G.P.'s Strategies

As a hermeneutic device to facilitate further analysis and comprehension of interviews, g.p.s were ranked on the basis of the strategies described. Rank 1 was assigned to Dr.08 as the most radical actively information disclosing g.p. and rank 22 to Dr.20 as the most actively concealing. The rank position of the individual g.p.s was then graphically represented on a continuum of disclosure with Dr.08 and Dr.20 placed at the two extemities and the central region representing the passive response strategy (Figure 10.01). Since the strategies described by some g.p.s allowed for a range of possible behaviours, this is indicated on the continuum. Although the ranking was based on an holistic reading of interviews, extracts from interviews indicative of how each g.p.'s position on the continuum was ascertained are given in Appendix 5. G.p.s' positioning on the vertical axis has no significance, but is merely in order to permit overlap of individual's positioning. The scale on the horizontal axis is ordinal.
Figure 10.01
Qualitative plot of g.p.s' strategies of communication with terminal patients.

This diagramatic representation of the g.p.s' strategies places Dr.08, Dr.05 and Dr.19 close to the actively revealing end of the continuum, whilst Dr.09, Dr.20 and Dr.22 are close to the actively concealing end. In the central region the g.p.s respond to patients questions, but as one moves toward the revealing end they respond more readily. In the region occupied by Dr.04, Dr.14, Dr.12 and Dr.15 g.p.s are beginning to take more active steps to permit the patient to ask relevent questions so
that they may answer them. Conversely, whilst they may not positively discourage patient questioning, Dr.10 and Dr.18 certainly do not encourage them. To the right of the region occupied by Dr.10 and Dr.18, g.p.s are beginning to take more active steps to block questions.

On the basis of this analysis of the g.p.s' strategies we consider the tactics they report implementing when interacting with terminally ill patients. Specifically, we will be looking to see if different strategic approaches require the implementation of different tactics of interaction, or whether similar tactics are reported by g.p.s regardless of their strategies. This will be done by considering in turn each of the tactics reported by g.p.s. A plot on the strategic disclosure continuum of those g.p.s, who are identified as using each tactic, is presented at the beginning of the discussion of each tactic. After consideration of the use of individual tactics we turn to discuss the ways in which g.p.s' strategies, tactics and objectives interrelate. To this end we draw upon the rationalisations for their behaviours proffered by the g.p.s.
Evasion tactics are reported by 11 g.p.s, only one of whom (Dr.02) is positioned towards the revealing side of the continuum. This g.p. expresses reservations about the use of evasion, but indicates that on occasion it may be appropriate.

"Sometimes patients just don't want to know and once that is clear you just don't discuss it... It would cause panic and for their sakes you just don't mention it, don't let it come up."

(Dr.02)  
(10.11)

Some more centrally positioned g.p.s also make similar points.

"I might digress if I really thought that it would hurt their psychological wellbeing. I might skirt around it. I'm not entirely inflexible either way, most times I try and tell the truth... but some patients they just don't want to know any more, they're refusing and it's best not to go too far. With them I wouldn't elaborate and I wouldn't let it go any further in that direction."

(Dr.21)  
(10.12)
These g.p.s then use evasion passively. When in their words "patients just don't want to know" they just don't bring it up.

But other g.p.s are more active in their use of evasive tactics and may use them to prevent patients, who are expressing interest in knowing, from finding out. We identify a number of different ways in which these tactics may be used. One is to evade the question by the verbal response given. This seems to be particularly favoured by g.p.s in the central region of the continuum and it may be used to check if a patient really wants to know.

"If they ask I might be very naughty and turn the question back on them, which is a trick I picked up in hospital... 'Well what do you think you've got?' You put the ball back in their court again, and most leave it at that. But it depends on the personality of the patient if you confirm what they suspect, but most leave it at that. If they really want to know they'll come back to you for more."

(Dr.07)
(10.13)

Yet some g.p.s located in this central region reject the use of evasion. They prefer to take patient questions at face value, even though their strategy is not actively revelatory since:

"You don't do your relationship with the patient any good by evading the issue, because they know perfectly well you're evading it. If they're that sort of person... who really wants to know, they ask. Then you talk about it quite openly... they know when you're evading it anyway so you might as well be quite open."

(Dr.11)
(10.14)
This quotation also exemplifies the main reason given by the more actively revealing g.p.s for not using evasion.

The g.p.s on the borders of passive response and active concealment appear to evade answering patient questions more generally, not just as a test of patient desire to know.

"I don't give a proper answer to that, you know. We slip away or we say 'Oh, forget about that'."  
(Dr.10)  
(10.15)

"I might start to answer the question, for appearances, but then I might digress."  
(Dr.18)  
(10.16)

"I'd certainly evade the issue, if they're asking by emphasising what can be done and not mentioning what things cannot be done for them."  
(Dr.13)  
(10.17)

Moreover, a second aspect of evading becomes apparent in this area of the continuum and is often mentioned by the g.p.s: the necessity to avoid the subject matter altogether. This requires a g.p. to carefully monitor his or her own performance, so as not to say anything which may either draw the patient's attention to the to-be-avoided subject or allow it to become a permissible topic of conversation. This must all be achieved without alerting the patient to the fact that the topic is taboo, which in itself would indicate that there is a problem.

"You have to be careful not to mention it casually in conversation in any form whatsoever."  
(Dr.18)  
(10.17)
The more active concealers are in many ways similar, but tend to take their evasions further, and appear to use evasion routinely in their interactions with patients.

"I just don't give it away... I always try to avoid answering it... I always try to find a way out of the answer, you know, you say non-committal things... or I try to be cheerful and I change the conversation."

(Dr.20) (10.19)

"I normally just skirt around it. I don't find it difficult"

(Dr.03) (10.20)

As with the borderline concealers they recognise the need to avoid the subject matter all together for the tactic to be really successful:

"It is more difficult being more guarded in what you say and what you do, but if you do it properly and never let it come up, I think can get away with it. You have to be careful."

(Dr.06) (10.21)

The most extreme version of evasion was described by the most extreme of the active concealers. In these cases physical evasion of the patient is used and Dr.20 explains that he had dealt with situations which became problematic for him in this way on more than one occasion.

"I didn't tell this woman anything... In fact to get out of it I sent one of my colleagues to go instead of me, because she'd put me in a corner. She wanted to know what's happening, and I couldn't say she would get better... So I sent my partner, you know, and that worked 'cause she didn't know him. I told him I couldn't tell her that she had cancer and she wanted to know, so he went... I don't think he told her anything, she wouldn't have asked him. But I never saw
The reported use of evasion as a tactic is thus highly congruent with the strategies adopted by the g.p.s. Evasion is a preferred tactic for the avoidance of revelation, but to be really successful it requires not only evading the issue but doing so covertly. Some g.p.s consider this feature of evasion to be problematic and that the risk of failure mitigates against its use. Others reject the use of evasion on the grounds that it is incompatible with their strategic objectives of revelation.

**Denial**

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14 g.p.s report the use of denial and as in the previous series of interviews two forms of denial are apparent: the "outright lie" and the "white lie". None of the g.p.s clearly positioned in the revealing area of the continuum report ever lying to patients. Report of the
use of denial first occurs on the border with the passively responding region, and Dr.21 is typical.

"I'm usually strictly honest, but I don't perhaps tell the whole truth... Well if you tell them a direct lie, you know you start down a difficult road because you can't ever go back on that or they may perhaps feel you are not very good at your job or that you are deliberately misleading them. So sometimes I might, well, on one or two occasions I have not told the whole truth, because I didn't think the patient could cope with it... I try to assess the patient's needs and I might be a little more optimistic than is perhaps justified. You know, give the best case not the worst case (analysis)."

(Dr.21) (10.23)

These "white lies" are in fact the only form of denial reported as being used to the left of centre of the continuum. But at the centre some of the g.p.s do suggest that on occasion they may tell the odd outright lie, but this is not routine.

"You know when it is right to say, 'good lord no!.. of course you haven't, what a silly idea!'"

(Dr.07) (10.24)

As we move to the right of this central region the outright lie becomes more commonly reported as routine and it appears the lies become more excessive. The following quotations exemplify this progression towards more outright lying, although, of course, the "white lie" does not die out.

"If he does ask, I have to sit and talk with him quite at length. I am telling them about what the thing is and mostly we have to tell him much more about the prognosis, at least the better parts of it, or they will be better but it'll be some time."

(Dr.10) (10.25)
"I leave it entirely up to the patient to ask, I would not volunteer it to anybody... if somebody asked me did he have such and such well fair enough but I would try and paint a relatively bright picture... I don't routinely tell I'd be optimistic about the outcome, about what can be done, emphasizing what can be done, not mention things that cannot be done... Sometimes I might take that further, although they were obviously terminal to say there are positive therapeutic steps you can take."

(Dr.13)  (10.26)

"If they ask, I only answer their questions really. Well it depends, that's not really true... Well I don't tell people I think it is unfair to tell them... so you give them peace of mind if it is possible really. Suggest that perhaps it is not physically as black as all that... (One patient) said he wanted the truth and I said I didn't know exactly what it was, he would have to have an x-ray... but it would probably be an ulcer. In all probability it was a tumour but I didn't say that... And he had an operation... so during his illness we played it along like this all the time. We talked about how he was going to get better... but that after the operation that it was going to take a long time to get better because of his age, and he would be tired and weak because of the operation... and he never knew the truth."

(Dr.03)  (10.27)

"They will ask things like, 'doctor do you think I will benefit from going to the hospital?' I say 'yes, my you will benefit' even if I don't think they will... No, I do not tell them... I may tell lies like I say, 'we have got a letter from the hospital that they are hoping you will be alright within the next few months or so, but you need to get over the operation.' I don't know I might be wrong but it pleases the families."

(Dr.20)  (10.28)

Treatment in itself can be used as an adjunct to verbal denial as revealed by what Dr.09 has to say:

"I mean I have even gone to the stage of lying to patients and saying I've given them treatment for this condition, when what I'm doing is giving them placebos so that they don't think that I've just given up trying to cure them... I would rather tell a lie to a patient to let them think you are doing something constructive."

(Dr.09)  (10.29)
This is the only occasion on which a g.p. admits to administering a placebo as a supposedly curative treatment to terminally ill patients. But other g.p.s admit, giving similar reasons, to reluctance in curtailing radio-or chemo-therapies, even though they recognise that these treatments are having little or no effect. Moreover, many of the g.p.s. who did not express information revealing strategies, blur the distinction between palliative and curative treatment when communicating with their patients.

"We would certainly not be saying there is nothing more we can do for you. These two things are entirely different."

(Dr.01)
(10.30)

"I tend to be optimistic with these chaps. I always tell them there is some hope and it's not entirely a lie, because most of them do have some form of treatment."

(Dr.17)
(10.31)

"In some diseases they are really happy that you are going to be able to do something for them, the patient. And some we know that this patient is going to die anyway. I can see it in front of my eyes and the only thing I can do is to give some analgesics you know and narcotics, to knock the pain out, but there is nothing I can do by way of curative treatment. So you say nothing about the different medicines... or you say you will be alright with this medicine and you will be better."

(Dr.10)
(10.32)

From the quotations describing denial it is clear that it is often associated with the use of uncertainty, a category of communicative tactic not identified in our
previous set of interviews, but included in the content analysis on the basis of findings from other research. It is to uncertainty that we now turn.

Uncertainty

Uncertainty is a tactic which was not reported by the g.p.s in our previous study but 13 of the 22 g.p.s in this set of interviews report using uncertainty in their interactions with terminal patients. The majority of these g.p.s are to be found in the passive response to patient questions region of the continuum. We consider the use of uncertainty by the active concealers first. Both Dr.03 and Dr.20 use uncertainty as a way to get out of answering patient questions.

"I just said I am sorry I don't have the full (report of the) investigation from the hospital yet."

(Dr.20)

(10.33)

The use of uncertainty in this way resembles the evasive
response to a patient question. In the specific case referred to by Dr.20 (10.33), it was true that he did not have the report back from the hospital, and this expression of uncertainty was not a lie as such. However, Dr.20 is also willing to lie about his uncertainty and in these cases it is clear that uncertainty is used as a form of denial:

"I would just say well they haven't finished their tests and investigations yet. And sometimes I tell a lie that I am still waiting for the letter from the hospital... (In one case) I said I will get the report in due course but I already knew the report, but that is one way to get out of the house."  
(Dr.20)  
(10.34)

Finally Dr.20 expresses uncertainty as a way in which to persuade the patient to attend a hospital clinic to see the consultant, without revealing to the patient that he is particularly concerned about her or his health.

"A lot of patients I tell them we are sending them to the hospital for a second opinion."  
(Dr.20)  
(10.35)

Again this is not completely untrue, since his primary diagnosis is only a hypothesis and he has not got the technological facilities to hand to carry out the tests required to confirm or refute it.

Dr.03 also reports using uncertainty in cases where the patient has been told the diagnosis by someone other than herself, and is now enquiring about the prognosis. Under these circumstances she reports she would say;
"We can't predict exactly what the course will be and it is possible it will remain just as it is for quite a long time and treatment may put it back a long way... If they asked how long they had to live I think I would have to say you can't be accurate and you could be proved wrong over and over again... I think you have to say you can't see into the future."

(Dr.03)

Thus these doctors are conveying restricted information in their interactions with patients by their use of uncertainty tactics. They use uncertainty as part of their information concealing strategies. It is also noteworthy that Dr.03 speaks in the conditional and at no time during her interview does she indicate that she has ever had to face the hypothetical situation of a patient asking how long he or she had to live. This suggests that she does not let the situation arise in which a patient was pressing for such information.

Dr.15 speaks very similarly to Dr.03 about the use of uncertainty, pointing out that he is only talking in terms of prognosis and that he really is unable to answer the questions. But whereas Dr.03 may be attempting to make the future appear more rosey and is speaking hypothetically, Dr.15 merely indicates that it is impossible to predict the time course with any accuracy. Furthermore, he is clearly speaking about a situation which regularly occurs.

"The ones I'm visiting at the moment all know exactly what they've got. We don't discuss how long they've got, because I've made it clear I can't really say. One of them asked me, 'am I like your other patients like this or am I worse or am I better?' you know this
sort of thing. All you can say is: 'Everybody is different, someone might have a nasty breast cancer or simply a weak heart, and the heart which doesn't look like a real problem might get them before the person with cancer.' Or something like that."

(Dr.15)  
(10.37)

Dr.05 and Dr.19 also report the use of uncertainty, but they both assert that it is only used early on during the illness, for example, when the diagnosis still requires confirmation or before the illness is clearly not responding to treatment. Thus their use of uncertainty expresses a real clinical uncertainty. They both recognise that the expression of the probable, but still tentative, diagnosis plays a specific function within their strategies of active revelation.

"If there is going to be some treatment, well then obviously the sooner that you institute the treatment the better... So initially you send them for tests. And quite often you can see it is going through their minds, is it cancer? And then you can say it might be, but we'll have to see, we need to do some tests, it may be one of a number of things. But when that happens it's sometimes easier later on, because if the tests are positive it's clearly not such a shock. I don't know that I've ever had anyone who has either broken down or reacted hysterically. They may be surprised but in a way it is sometimes much easier than you'd think."

(Dr.05)  
(10.38)

It is amongst the passive responding doctors that the different functions of the uncertainty tactic are most clearly revealed. The use to which they put uncertainty is slightly different to doctors such as Dr.20 and Dr.03 and even Dr.15. For them, it seems, the main function of uncertainty is to take the edge off of the information, which they are revealing in response to patients'
questions. Although both diagnostic and prognostic information is referred to by these g.p.s, it is the diagnostic information which they talked about most and clearly the prognostic questions are less routine. Dr.21 describes quite cogently the typical use of uncertainty.

"I might use some of that uncertainty to my advantage and say 'We've done this and we've taken samples, and we're awaiting the outcome of the tests.' I don't think that is unreasonable. I think people understand today that one has to do considerable further investigation and that is a reasonable lead into the diagnosis. 'I'm afraid there are some suspicious cells there and we won't know until the tests.' I mean I don't blunder in and say, 'yes, it's cancer...'. I use it to lead them into it."

(Dr.21)

(10.39)

In summary, the g.p.s' use of uncertainty is similar to that described by Davis (1960), but the g.p.s have considerably more scope for its use than did the doctors on Davis' polio ward. First, the g.p., as a generalist, can legitimately claim ignorance about a specialist area of knowledge and thus decline to answer a patient's questions. This is an option which is not open to a specialist without casting doubt on his or her competence qua specialist. Second, the g.p. does not have direct access to the technology of diagnosis and treatment, and the lines of communication between g.p., consultant and laboratory are for the patient of unknown reliability. There is, for example, inevitably delay between a test being carried out and the result being communicated to the g.p.. Most patients have little idea of how long laboratory analysis takes and what is a reasonable delay before a g.p. is informed of the result of a test or the
outcome of treatment. G.p.s are aware of their patients' lack of knowledge about these lines of communication and can use this so as to extend the period during which uncertainty can be claimed. Uncertainty can thus be used by g.p.s functionally to avoid giving information to patients, as is done by g.p.s inclined to concealment. On the other hand, the uncertainty expressed by revealers normally reflects real clinical uncertainty. To the degree this has a functional significance, it serves a different purpose, that of breaking the news more gently to the patient.

Prompting

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The use of prompting, or steering questions, is reported by 7 of the 22 g.p.s, all of whom lie to the left of centre of the continuum. The following quotations typify the way in which prompting is used by g.p.s, and the way that the degree of prompting changes as one moves in towards the central passive response area of the
continuum. Dr.19, for example, prompts patients more overtly than does Dr.01. The latter uses the failure of the patient to take up his prompt as evidence that the patient does not ‘want to know, and therefore makes no further mention of the issue to such patients.

"I generally ask them what they have been told because quite often they are attending hospital or have attended hospital. And I say, well take a carcinoma of the lung recently. He said he'd been told that he had this infection of this lung and it isn't getting better. I said, it's getting worse isn't it? He said, yes. I asked do you know why it's getting worse. And he said I've got an idea. I said well do you want me to tell you? and he said well yes. So I said it's because the infection... that underlying this infection, why the infection is still there is because you have a cancer of the lung which is stopping us effectively treating the infection."

(Dr.19)

"Generally I don't just tell, but I always tell them if they ask. I like to be in a situation ultimately where everybody is being honest and everybody knows... so ultimately I like all patients to know, so what I meant was I wouldn't tell everybody straight out early on, you need to build it up, and make it clear they can ask when they're ready."

(Dr.14)

"If they suspect they have cancer, then under those circumstances I think they tend to get very anxious... then I'll try and lead them into it by, you know, saying certain things, like is there anything you want to ask me, or some sort of leading question like that. And that often brings them you know to asking me... In the vast majority of occasions I'll try and get them to introduce the word cancer. If they do then obviously it's easy, you can take it from there, and just say, 'yes I'm afraid I think it is cancer'... If they don't introduce the word then it is more difficult."

(Dr.04)

"Some patients if you've been able to talk to them and find out what they would want to know, okay. Others they've resisted a few vague attempts to bring up the subject and you'd say they were not interested, they don't want to talk about it and so obviously they are not pushed any further."

(Dr.01)
Dr. 04 reports using this tactic quite routinely to permit the patient to ask relevant questions. Specifically, he uses open ended questions to permit the patient to ask open questions or to express their own suspicions, which he would then answer or confirm as appropriate. This use of the tactic is not as positively revelatory as Dr. 19 who points out relevant aspects of the illness to the patient to precipitate discussion of them. However, it is more positive than the versions of the tactic typified in the reports of Dr. 14 and Dr. 01, which are fairly vague or merely make it clear that such patient questions will be answered.

Hints

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9 g.p.s report the use of hints, and the patterning of its use is very similar to that of prompting patient questions, except that Dr. 22 appears to report hinting.
However, what he more properly reports is awareness that patients can acquire information by deduction. He has this to say on the subject:

"When you visit people quite often who are ill they obviously think, 'what is going on here?.. I must be quite poorly.' All these sorts of things tend to have meaning to people, who if they have any reasonable sort of sense will understand what is going on... There are all sorts of things which I would think really would imply some serious illness, patients will pick up little things like, well like 'I'll see you next week, if we're all here,' things which you don't say to everybody of course but, if you know the person who you are seeing, you know you can get away with these sorts of things and patients will say themselves whether they expect the doctor to say it. Some do say when you say 'I'll come and see you next week' they say 'If I'm still here.'"

(Dr.22) (10.44)

The other g.p.s use hinting in a way which parallels their prompting of patient questions, as the following exemplifies.

"Put them a little more in the picture, hinting that maybe there was a little bit more to it than that. And that I hope would lead into a discussion of the nature of the illness. You know I would point to the sort of condition they had and hope they cotton on so that we can talk more about the sorts of things we can do for it."

(Dr.12) (10.45)

As with prompting, those g.p.s situated in the central region drop their hints and if they are not taken up by the patient, this is accepted as evidence that the patient does not want to know and the subject pursued no further. G.p.s closer to the extremity of active revelation make their hints more firmly and see them as veiled references on the way to full acknowledgement and open discussion of
Euphemism as with our previous sample is widespread, with 18 g.p.s referring to their own use of it. The two most extreme revealers report that they avoid the use of euphemism since, in the words of Dr.05.

"I think the sensitivity is important, not only the way you tell but the time. I think it is wrong to be too mealy mouthed and use euphemisms, because, you know, people can deliberately not hear the euphemisms. But equally I think that to be too bold about it is just as bad."

(Dr.05) (10.46)

While Dr.17, who is one of the two passive responders who report not using euphemisms, has the following to say on the subject:

"I wouldn't say I always tell them, in fact I tend to, probably because it is easier, to leave it up to them to ask. Then if somebody asks and obviously wants to know if they've got cancer or not, it's obvious to them and then I tell him yes... More often than not they undergo some sort of operation and
they're told that they have some inflammation or something... I know this idea of inflammation and stuff when they come out. But I think if they ask, they want to know. And if they don't, they don't want to know... I think they know but they just, for a number of reasons, do not want to be told, either to fool themselves or more often to fool the families, to keep the families going... If they ask I tend to be quite blunt about it, because there is no point in beating about the bush, maybe... maybe not kind of thing. But the fact is that the chap has got cancer and he seems to want to know about it just by asking you, so you've got to respect that and be straightforward."

(Dr.17)  
(10.47)

Euphemism is used differently depending on whether the g.p. tends toward revealing or concealing information.

For the g.p.'s whose strategy is to progressively reveal information to patients, euphemism is essentially a station on the road to full and frank discussion.

"I think I probably avoid using the word cancer, at least initially, by saying something like, a rather unpleasant illness... or not responding to treatment... That's a vague opening gambit which would perhaps prepare them for something they were half expecting, but didn't really want to hear... an inoperable condition perhaps... And if they then ask me, is it malignant or is it cancer doctor? I would say, yes I am afraid it is."

(Dr.12)  
(10.48)

This waystation use of the tactic is apparent in an earlier quotation from Dr.19 (10.40), who makes it clear that he only uses euphemism on occasion and for very particular reasons:

"For example in that case I used the word infection (because) I didn't want to destroy the relationship that he'd built up with the hospital, because they had told him it was an infection."

(Dr.19)  
(10.49)
But for those g.p.s who are inclined to conceal, euphemistic reference to the nature of the disease represents the zenith of revelation.

"If they want more information, and ask, well, I'd say I'm afraid that, you know, this condition you've got is not just a simple condition... As I said most patients don't want to know, and if they don't want to know I don't tell them."

(Dr.06)
(10.50)

From the present set of interviews we have identified a number of different euphemistic devices. Some of these devices are clearly more communicative than others, and it seems likely that their use differs in a way correlated with the communicative strategies of the g.p.s. However, a larger number of instances of each would be required in order to assert this with any certainty. Below our original typology is supplemented by the identification of various figures of speech used in the euphemistic communication of information.

Euphemistic understatements of the nature of the illness depend on being unspecific about the diagnosis. Examples of such imprecision include, "not just a simple condition", "it's not nice and simple", "there's something more serious going on", and "you're very very ill". When giving information a word which is regularly used is "tumour". Although this is a fairly transparent euphemism, as discussed in Chapter 7, it is a word which the g.p.s report can be differentiated from cancer per se. But because some euphemisms are so potent and generally
understood some g.p.s avoid their use. For example Dr.09 explains that two words he always avoids using when talking to terminally ill patients are "spread" and "recurrence" since they are so associated with cancer.

A regularly used set of euphemistic devices are derived from the manifestations of the disease process as revealed by the clinical gaze (Foucault, 1973). Amongst the most common are phrases such as "opacity on the lung", "shadows", "masses", and "suspicious looking cells". Other euphemisms refer to patient fears and suspicions and thereby signal more information than is actually said. Typical of this sort of device are: "you've got a bit more than you thought", and "it's what you expected". Some euphemisms call upon lay knowledge about cancer to carry the meaning as in the following: "'it's an illness not ammenable to treatment' and that means cancer to them" or "a disease which isn't going to get better and we're not looking for a once and for all cure". This latter figure of speech is more properly an allusion.

Another figure of speech used by g.p.s in their communication of information to patients is the synecdoche, for example, "the diagnosis was that there were some cells there". Tropes are very common amongst the g.p.s who tend to conceal information, as in the use of the following all reported to be used to mean cancer when talking to terminal patients: "ulcer", "absesses", "warts", "gallstones", "swollen glands", 

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"inflammation", "a bit of a twisted bowel", "a bit of an infection", and "nerves".

As this brief resume of euphemistic devices reveals, the range and accuracy of phrases available is vast. Whilst some phrases may be easily understood by patients, others are less comprehensible. The incomprehensibility of medical language to even the more sophisticated patient permits, perhaps paradoxically, the g.p. to use this language with the intention of transmitting little information. The clearest specific example of this is Dr.02's discussion of a control patient with multiple sclerosis (M.S.). The patient was told that he had disseminated sclerosis (D.S.), so as to avoid the use of the better known term M.S. and its implications. He was likely to die of "old age" long before the disease became functionally serious. Such use of technical language may occur with terminal and cancer patients also. Dr.01 made it clear that he had told a patient of her Hodgkin's disease, and assumed this would not be recognised as a form of cancer. Other g.p.s indicated, less specifically, that terms such as "sarcoma", "melanoma" and "myeloma" were not as taboo as "carcinoma" and "cancer".

Euphemisms and other figures of speech, then, are in widespread use, but again are largely used in ways which accord with the strategic approach of the g.p. For a g.p. who conceals, the euphemistic reference represents the zenith of his or her information giving, whilst for
the revealing g.p. it is used as an early waystation in the process culminating in more full and frank acknowledgement. For the g.p. who responds to patient demands, the euphemism can similarly be used to allow the patient to set the pace, since the patient has some option in how to hear what is said.

Humour

Only 2 g.p.s report the use of humour in their interactions with their terminally ill patients. They lie at opposing extremities of the continuum. Dr.22 does not specifically report what he does and given his general approach one cannot but wonder at the veracity of the following comment.

"There's one patient who I've maybe mentioned it to jokingly, you know, in an off the cuff sort of way."

(Dr.22) (10.51)

The other report is highly specific to an individual patient. In this case information was transmitted by use
of shared knowledge. Because of the information shared by g.p. and patient the message has a special meaning, one which it would not have to an outside observer who did not, as it were, share the key to the code. Dr.19 told the story of his relationship with a patient who had died some weeks previously.

"He kept asking how long had he got. I said to him until England win the World Cup... He said I'll hold you to that one and it became a standing joke. We both knew it was a standing joke."

(Dr.19) (10.52)

This makes sense once the content of previous discussions about soccer is revealed. The g.p. and patient assessed the England team's chances of "surviving" the early rounds of the competition as low. Thus the notion of England winning the World Cup was untenable. Presumably, their discussions implied either that the patient would die soon, (like England's chances of winning the World Cup) or that the patient would be alive in another four years, which given his condition was unlikely. Whether this story is actually humourous is problematic. Yet the g.p. found relief in being able to laugh with the patient about the state of English soccer, whatever the personal ramifications.
All but the 3 most extreme revealing g.p.s report the use of reassurance in their interactions with terminal patients. The reasons why these 3 do not use reassurance are similar, and the essence of their argument is that giving reassurance implies that what is said is not actually the case or completely justifiable. Thus, in their view, the offering of reassurance implies some form of lying and as such is incompatible with the strategy of actively revealing the truth to the patient. Dr.05 describes this view cogently.

"I think a very important part, particularly of the doctor patient relationship, but also I think of any caring relationship, is honesty and trust. And I have been very impressed by people who have been told. It's much easier for both themselves and the relatives who look after them, than if they hadn't been told... They can make preparations and plans to do what they will before they die... one often wants to clarify relationships with people... and if they are going to make decisions about treatment and the like... then you have to lay the cards out in front of them. I think it is terribly important the dying person must make their own decisions. So they need to know and it would be wrong to make promises we could not keep, to say yes this treatment may give you x years more when
All the other g.p.s report that they offer patients reassurance. In Chapter 7 reassurance was described as a method used by g.p.s to withhold information from patients, a method frequently used in conjunction with denial. However, analysis of the present series of interviews suggests a different analysis, or at least a different emphasis to the analysis. Reassurance is associated not only with denial, but also with other tactics of interaction. Reassurance occurs with some form of information transmission about which the patient is to be reassured. As such, is a stylistic device in the sense described by Norton (1983).

"Any message system can draw a distinction either by literal meaning or by stylistic means... One message system gives form to another when the literal meaning of one system is reinforced or changed by another... Form giving messages can be antecedant to, simultaneous with, or subsequent to another message."

(Norton, 1983; p.281)

In the analysis of the previous set of interviews we identified the way in which reassurance was used to modify denial, by reinforcing it. But reassurance can also be used with a transmission of correct information so as to modify the meaning of the message as, for example, in the following case.

"There are people who have cancer and they have the operation and the surgeon seems fairly confident that it has been removed. In which case if they ask whether they had got cancer, then you can tell them that. You can also tell them how encouraging it is, that there are people walking around who had the
operation for cancer years ago... Yes, I think you ought to tell them that, even if the surgeon is not completely sure."

(Dr.11)  
(10.54)

Thus the confirmation to a patient, that he or she did indeed have cancer, is linked with the surgeon's report that there is no obvious secondary spread and that the primary has been removed. The information that the patient had cancer is modified by the reassurance, that there are others who have had the disease and survived. In this case the information the g.p. is giving is based on the truth of the situation. This example is one in which reassurance is used to modify overt information transmission about diagnosis in response to a patient question. As such, it is fairly typical of all of the g.p.s, who use reassurance as a way to, as it were, take the edge off of what is being said to a patient. The main difference between individual g.p.s in their use of reassurance is to be found in the other tactics with which reassurance is associated, as the following three quotations reveal.

"When the diagnosis has been confirmed... I would be seeing the patient to explain what is happening. That is the time when things would start to be unfolded... And later on depending on their actual clinical state at the time, presuming you are treating them in that terminal phase and that it is a prolonged illness, I would be saying that from their present stage it is going to stay as it is and possibly get worse. I would admit that, but generally I would not say much more. Be as supportive as I can, but I would not try to deliberately mislead them... You can make it clear that you will be there and that there is lots you can do to make them comfortable, and there is no need for them to suffer pain."

(Dr.16)  
(10.55)
"If they went on and said, 'is that cancer and is it going to kill me?' then my answer would be, we are treating it with the intention of trying to stop it doing you serious damage and we'll go on treating it. If it recurs we will treat it again. That's the way I do it, so that they do not think that the treatment had just been stopped, even if it's a lie. But I don't think I've ever been asked by a patient or told a patient that clearly."

(Dr.09) (10.56)

"Whereas the ones who really want the reassurance, you can tell from the tone of their voice and the look in their face that they are desperate for you to tell them they haven't got cancer. Well you might say this is something that everyone worries about but the tests don't show that you have or that it hasn't been proved or something like that to avoid giving them their (diagnosis). I always tell them that there is some hope. And it is not entirely a lie, because most of them do have some form of treatment and... because of course there is always uncertainty in these cases."

(Dr.17) (10.57)

At one end of the spectrum we find that a more actively revealing g.p., such as Dr.16, uses reassurance in conjunction with tactics congruent with his revealing strategy. On the other hand, Dr.09 uses reassurance in conjunction with evasion (since he does not actually suggest he would answer the patient's question). In the central region reassurance is used, as in quotation 10.57 for example, although there is less real uncertainty in the sort of situation that Dr.17 is reporting.
Tactics, Strategies and Objectives: A Discussion.

Overall the patterning of results suggests that individual g.p.s have developed specific views about terminal illness, maintain a particular perspective on whether or not patients should be told permitting them (reportedly) to act reasonably consistently. Although there may be grounds for making a dichotomous distinction between telling and not telling, it is somewhat misleading. Whilst it is true that when asked whether or not they told terminal patients, some g.p.s answered "Yes" or "No", all except one went on to qualify this (see Appendix 5). Those who answered "Yes" generally made it clear that telling, if it occurs, is a gradual process, and that they only tell in answer to a question by the patient. And those who answered "No" qualified this by adding "unless explicitly asked" (or words to that effect). As it stands this would be no difference at all, but more detailed analysis does reveal different strategies, and these differences form a continuum rather than a dichotomy. Thus g.p.s agree that most patients come to know in one way or another, so it is not simply a matter of whether or not to communicate information, but of whether or not to acknowledge openly the nature of the illness.

Although a minority of g.p.s may prefer to defer to the more sophisticated equipment, regulation of care and higher technical proficiency available to patients in hospital, at least on occasion, most consider terminal
care to be well within the domain of general practice. What is more, some g.p.s see terminal care as one of the few classes of illness in which they are able to exercise their clinical skills in an interesting way, rather than deal with the "trivia" of everyday practice, or act purely as agents of referral to hospital specialists (see Appendix 5). Central to the objectives of all the g.p.s is a desire to keep the terminal patient comfortable, painfree and happy. Most prefer to keep the patient at home whenever possible, given the resources available to him or her. This gives scope for the exercise of the technical skills of pain control and symptom relief in the home care of the dying. But it is in terms of what it means to keep a patient happy that the g.p.s objectives diverge most strikingly. The two extremities of this are captured in the notions that on the one hand, "ignorance is bliss", and on the other that "happiness can only be achieved in association with the dignity afforded by autonomous actions based on informed choice". Naturally, between these two extremes lie many shades of grey. For many g.p.s happiness is to be maintained by not unduly "rocking the boat". Since these g.p.s are uncertain in individual cases as to whether to tell or not, they prefer to take no active stance, short of maintaining the status quo. These objectives underlie the ways in which g.p.s reportedly communicate with their terminal patients, and the analysis distinguishes between the strategies and tactics adopted by g.p.s to approach terminal patients. Strategies refer to
overall plans and modes of approaching patients, whilst
tactics refer to specific behaviours (reportedly) used
during an interaction. Three distinct strategies and a
number of tactics used by g.p.s in the attainment of their
objectives were identified from our interviews.

Some g.p.s report adopting the strategy of actively
disclosing the nature of the illness to patients by
manipulating the situation toward mutual and explicit
formalised acknowledgement, normally over a series of
consultations. Other g.p.s report adopting the opposite
strategy of actively concealing the nature of the illness
from the patient. These g.p.s routinely gear their
approach to the terminal patient so as to avoid
acknowledgement of the illness, to ensure the patient
never finds out or even to contradict suspicions the
patient may harbour. Between these two poles lie the
majority of g.p.s, whose reported strategy is to passively
respond to patient demands, allowing patients to set the
pace and provide the cues to which they may respond
accordingly. These three strategies represent landmarks
on a continuum of strategies, rather than clearcut and
exclusive categories by which individual g.p.s may be
classified. Hence, individual g.p.s who adopt a more
central passive strategy differ. Some are more inclined
towards a preference for disclosure, while others prefer
concealment.

When facing individual terminal patients the g.p.s report
using specific tactics. These are normally congruent with their strategies, in the sense that, for example, g.p.s who have a strategic approach of revealing tend to use tactics one would naturally associate with such revelation, such as prompting the patient to ask relevant questions. Where tactics and strategies are associated, which do not on the face of it appear so congruous, closer consideration reveals that either the tactic has been cleverly adapted, or more usually, that it is being used with the specific purpose of attaining a goal within the overall strategy. The latter is most commonly and clearly involved in the strategy of revelation. Since revelation is a gradual process, early during this process a g.p. may prefer to avoid revealing information, which later he or she would quite willingly reveal.

The most widely reported tactic is reassurance and it is used by all but the most extreme revealers to modify information conveyed. As such it may often be more correct to consider reassurance as a stylistic device used in association with other reported behaviours, rather than a distinctive tactic in its own right. Euphemism is apparently used by g.p.s across the complete range of strategies. But whereas g.p.s, who aim at revelation may use euphemistic phrases as a waystation on the road to more explicit disclosure, for those who tend towards concealment an euphemistic reference represents the zenith of revelation. Uncertainty is also apparant across the whole spectrum of strategies, but the nature of the
uncertainty used differs in ways similar to those described by Davis (1960). Thus, some g.p.s clearly would use uncertainty functionally to avoid giving bad news. Others only express uncertainty when it is clinically justified, and in these cases it seems that the g.p.s intend the uncertain information to constitute a graduation towards more complete revelation. Expression of uncertainty, it seems, is particularly suited to general practice as a tactic, since both the g.p.s and patients recognise that diagnostic tests and the like are carried out by specialists in hospitals. Thus a g.p. can express uncertainty either on the basis that he or she is not a specialist, or that the report has not yet been received. How long after tests have been carried out such a claim can be convincingly maintained may be dubious. But it seems likely that all but the most persistent patient would give up asking before a tenaciously concealing g.p. would feel forced to admit to knowing the results.

Denial and evasion, although predominantly associated with the concealment strategy, are also common amongst those g.p.s who passively respond, especially when they are undecided about a patient's desire for information. However, under certain circumstances evasion is also reportedly used by g.p.s pursuing a strategy of revelation. Two such circumstances are, first, early during a series of consultations when the g.p. judges that it is still too soon to be forthright with the
patient. And second, in circumstances when the g.p. judges that the patient is asking questions in bad faith and does not really want a truthful answer. By comparison, prompting questions and hinting are tactics almost exclusively reported by g.p.s favouring revelation. Only one g.p. who adopts the strategy of concealment talks about using hints, and in this case the hints are such as to imply that the illness is not as serious as the patient may fear. All other g.p.s, who say they use hints or prompting questions, do so to promote awareness in their patients.

What this analysis reveals is an intentionality underlying actions not clarified in previous research that does not distinguish strategies from tactics. In part this may reflect the greater autonomy of the g.p. in comparison to hospital doctors, such as those studied by McIntosh (1977), who were implementing ward policy decisions. What is clear is that although individual tactics may be adopted on the basis of the features of a specific interaction with a patient, they are also conditioned by the g.p.'s strategic approach, itself subservient to the g.p.'s objectives. Thus, strategies define the parameters of, from the g.p.'s point of view, the acceptable tactics at any point during the care of the terminal patient. Hence, we argue that if a social scientist is to validly interpret behaviours observed during interactions, then those observations must be contextualised within the framework of the consultation as one of a series, the
objectives being pursued by the g.p., the strategic approach adopted and the position within the overall strategy at which a consultation occurs. Such an approach to doctor patient communication research is lacking in the literature, which predominantly consists of analyses based on single consultations (c.f Chapter 2).

One way of interpreting these different reported behaviours and intentions of g.p.s is in terms of their roles, as we discussed in Chapter 3. Recourse to such concepts is particularly suitable as it is congruent with the action theory approach of Parsons, by which behaviours are related to objectives (Heritage, 1984). It also reflects the way the g.p.s themselves on occasion speak, when justifying themselves. We now turn to the role descriptions made by the doctors during interview.

G.p.s' Roles during Terminal Care
During interview the g.p.s made spontaneous reference to what they considered the work of the g.p. during terminal care to be. All g.p.s also described how they themselves reacted to the prospect of treating a patient as terminally ill. Taken together these constitute descriptions of roles during treatment of the terminally ill. Many g.p.s' descriptions of the role stressed the violation of the ideal typical physician role of doctor as technically equipped curative agent, since the patient is dying. Many of the role descriptions also reveal emotional responses on the part of the g.p., at odds with
the ideal typical feature of maintaining affective neutrality toward patients. Three main variants are discernable in the role formulations derived from these descriptions.

Abandonment of the traditional curative role

A small number of the g.p.s seem to be able to abandon the curative role with relative ease, replacing it with another role. Two versions of the role appear to be in use. The first is to replace the physically curative feature of the ideal type with that of some form of psychotherapist, to complement the dying role of the patient.

"My patients are people... I am much happier in a consultation with my patients if they love me or are crying... If they get me crying with them that's good too, so if we have a burst of tears it's not bad... It's at odds with the traditional view of the doctor, the applied scientist who is a medical man certainly... I enjoy terminally ill people. I enjoy any sort of illness that will get me close to the patient. I don't really enjoy tonsillitis. I am much more at home with a crisis... If I want to treat someone I use another member of the family to do this, it's indirect therapy and I allocate therapeutic roles to different folks without them realising it, I give them my therapeutic role. Therefore I am dealing at many different planes, at many different logical times, well it is a multidimensional matrix, a rubic cube of therapy... The linear model, the medical model, is non applicable... because scientifically I apply general systems theory to everything... (I want patients to) take back some sort of responsibility for the process of dying, rather than abdicating everything and lying back and letting everybody else do it all. The problem is making death as important as living... In fact classically the doctor operates, I suppose, is taught to operate by not sharing himself with people, but by being a therapist at a distance. And I believe in sharing myself.

(Dr.08) (10.58)
The role, however, is not the only one in his repertoire. As well as redirecting his healing ability from the soma to the psyche to help the patient to prepare for death, he hints that in some cases he abandons the doctor role to offer spiritual succour.

"I am a practising Christian... which means I want them to know of me not as a foggy therapist, but I am quite prepared to get involved... Some of my patients will come along and say I can talk to you, well as a pastor. They look to me as the local priest, because I will let them and make it quite obvious to them that I am a Christian. I suppose what I am saying is that I operate at a level of completeness and my Christian faith is not an uncommitted faith. If God says he heals, well he heals... We use not only therapy, but we do use the doctor as the drug."

(Dr.08)

Such an explicit replacement of the doctor role with such a role is unique in our data. The other g.p.s, who abandon the curative role in favour of an alternative one, do so less self consciously, perhaps, than Dr.08. They talk in terms of friendship and human rather than spiritual care, but there are nuances that they too consider themselves to be counsellors.

"Everyone you get on terminal care should be someone that you think about and you care for... I think if you get concerned and you care, that goes a long way... I make no claims to have any spiritual involvement, perhaps they just want to talk about it from the spiritual side with their priest... It is very hard sometimes in a way because the relationship isn't only doctor/patient... but I think the general practitioner has a role to play here because he may have known the patient for some time and he's going to know the relatives a while... So help them with fear, loneliness, because they can be very lonely dying... and concern of what is going to happen to the people that are left behind, as well as keep them comfortable
in the actual process of dying... So one takes more care... one thinks more of the emotional aspects of what one is doing... I am likely to try harder to be nice to people because I think they are probably undergoing sufficient discomfort, emotional and physical. For some physical illnesses you can say this is the treatment get on with it. Perhaps in a way people who are dying, you have to tailor things more carefully, individually, see them as people. I just wondered whether like Avis we try harder when they are dying rather than when they are living. That sounds terrible doesn't it?... Medicine is, well rationally the number of diseases that we can actually alter for the better, that we can actually modify the pathological process is relatively limited. I believe a doctor's work is to make life more alive, as tolerable as possible. That is why I believe more and more general practitioners will get involved in counselling and things such as terminal care."

(Dr.05)

and

"The better sort of relationship to have rather than the formal doctor patient relationship is more of a friendship, when they accept you as a friend who happens to be a doctor, who can treat their pain or help their symptoms rather than the straightforward doctor relationship. And that's what I aim for I think... There's no real reason why you should, but mentally you tend to treat them slightly differently... The relationship I build up with them is closer than with normal patients. And in that way as I say you are more of a friend who happens to be a doctor, rather than a doctor. In that way you handle them, and you talk to them is different to how you handle and talk to other patients... You know you can't cure them, so what you have got to do is make their lives better. So I develop a closer relationship with the patient, than I had beforehand in order to tell them their diagnosis and discuss with them the way we're going to manage their terminal illness and that is basically how I handle terminal illness. Sometimes you can't do that, but that's the aim and to keep them comfortable... Sometimes medicine does not do them any good, but you see them regularly for medication, mostly for pain, and for advice."

(Dr.19)

(10.60)

Abandoning the role of doctor and becoming a friend to the terminal patient may not be easy, but is clearly accomplished by these two. Other g.p.s stress a variant of their own professional roles as healers to
guide them during treatment of terminal illness. These g.p.s consciously replace the curative feature of the physician role with one of technical excellence of symptom control. Thus, these g.p.s transform their role, but continue to emphasise the maintenance of a high level of technical competence. The focus of this competence is changed from diagnostic and curative skills to those relating to the technical control of symptoms; palliative competence.

"From a medical point of view supervision of terminal care is one of the most sad, typically challenging and medically challenging things that you have got to do. Nothing else really can have that intense working with people, with at the same time the purely technical problems of overcoming pain, vomiting, constipation, death rattles, you name it. You have got to physically overcome all of them, and as such it's an interesting field."

(Dr.01) (10.61)

A number of g.p.s make comparable comments during interview, indicating that the problem solving skills required in treatment of the terminally ill, although different from those required in treatment of other patients, are not totally alien. In many ways the skills required are not dissimilar to those oft employed in the treatment of chronic illness, and thus emphasis is given to management over treatment (Gallagher, 1979). Hence, the care of the terminally ill can be rewarding to the g.p. since it does permit the exercise of clinical skills and decision making. This is reported by a number of g.p.s as a "paradox", since there are frustrations attendant to the impossibility of cure of which they are
well aware, but at the same time they indicate that
treatment of the terminally ill is to them by no means
an onerous task.

Role ambiguity

Most g.p.s report some degree of conflict between
their expectations and the fulfillment of the ideal type
of the physician role in the situation they face with the
terminally ill. This is cogently expressed by Dr.13.

"So I would find it very hard telling patients that
they had something for which modern medical science
couldn't offer a cure... I presume I started off
with the most ideal expectations of medicine, perhaps
false expectations of medicine, thinking I'd go
round literally administering healing and curing and
that kind of thing. The reality is a little
different and it's always disappointed me a bit,
especially at first, people used to have conditions
that I couldn't intervene in. It still does
disappoint me to some extent, but not nearly as much
as it did. I presume the lack of prospects for
positive intervention used to distress me a bit, I'm
not sure why I just don't like it."

(Dr.13)

(10.62)

Another aspect of the tension created by the situation
relates to the observation, reported by numerous g.p.s,
that terminal patients are suffering from "real"
ilnesses, whilst a lot of patients in general practice
present with poorly defined minor ailments and
irresolvable social problems. Thus:

"You should really keep going, do you know what I
mean. You never know what is going to turn up, do
you. I mean in medical science itself, so that it
might just fit the bill for this particular patient so
you shouldn't give up. Although I suppose half your
brain has given up already do you know what I mean?
If you've already got them down as terminal in your
own book, you must still soldier on with your role as
a doctor to that patient, yes. And you give them everything you can. So I'm not one for telling the patients that they have got a terminal illness."

(Dr.07)  

(10.63)

"There's a problem if they lose faith in you, so I think that if they know that you can't wave a magic wand and make them better, then they value your approach and guidance more... But my job is to try and make them better. I suppose I feel that somewhere along the line they've failed themselves by the habits they have taken up, or we've failed them by not spotting something sooner... (One) worries patients will ask us to work a miracle for them and we haven't got one. No perhaps it's a deeper down instinct that we can't come up with the goods this time. I suppose that is the basic feeling that makes me uncomfortable... Earlier (in my career) I perhaps used to get more emotionally involved and mention it at home to my wife and start to look down and get grumpy."

(Dr.12)  

(10.64)

"I suppose you'd have to break them down and call them medical problems, sort of social and family problems really, and they are entirely separate... Considering you can't cure the cause, all you can do is take care of any physical needs they may have, discomfort physical discomfort. And then there are the usual things like helping the family cope, and apart from nursing care this sort of thing isn't really my province... You certainly treat them differently if they are dying. Sometimes I find it frustrating. I think possibly because you can't do a great deal for them except make them comfortable. You do your best to make sure they are comfortable."

(Dr.17)  

(10.65)

Above we use the word "conflict" in describing what the doctor experiences here. But, analytically the term ambiguity is, more appropriate, since what is being experienced here is not so much a conflict between two well established roles, but a situation in which normal role expectations are being violated, so that the role to
be performed is not properly specified. These g.p.s.,
then, recognise the inherent contradictions in the ideal
type of the role and their practice. But they manage to
live with the resultant ambiguities, even if they
are never totally resolved and are felt to be
frustrating. Other g.p.s., however, do not manage to
accept these ambiguities and will go, on occasion at
least, to some lengths to avoid them.

Maintenance of curative feature of the role
Some g.p.s attempt to maintain their traditional role as
healers, while dealing with terminal patients.

"You see terminal doesn't necessarily mean in my book
stopping treatment. A patient may be terminal but I
would still ask the radiotherapy department to shoot
some rays at it. But you wouldn't be pursuing the
sort of chemotherapy which may make them ill... We'll
go on treating it, if it recurs we'll treat it again.
That's the way I do it so that they don't think that
it's just being stopped... I'd rather tell a lie to
let them think that you are doing something
constructive... Even if it were just a placebo,
knowing that it was not going to do any good, but it
won't do him any harm and he may feel that I am doing
something constructive... You can't cure the patient
but it stops everyone being terribly upset... I think
it's our job."

(Dr.09)
(10.66)

Although exhibiting considerable tenacity to the curative
role, this quotation also reveals that Dr.09 partly
recognises that there is little, if anything, he can
actually do by way of cure for the patient. Hence, one
might expect that a doctor taking this position will
experience cognitive conflict, since although recognising
that the patient is terminal, he still wishes to entertain
the possibility that treatment may help. Dr.09 copes with this partially by a refusal to give up all treatment. Furthermore, as long as the patient does not recognise that he or she is terminally ill, the g.p. is able to continue to go through the motions of the curative role, conform to role constituting expectations held by the patient and thus continue interacting with the patient in a way complementary to the sick role. This is justified as follows:

"Because you don't like giving a death sentence to somebody and that is what it amounts to if they are terminally ill. You are telling them you can not get them better... It's an upsetting subject really to all concerned, the doctor, the patient, the relatives... Life is very precious."

(Dr.06)
(10.67)

Such tenacity to the curative role does have its drawbacks and may result in role strain for the doctor. Admission by a g.p., even to himself, that he, and more generally the medical profession, is unable to cure may result in anger, frustration and the like.

"Recently I had two cases of ovarian tumours which both died. And I feel anger and frustration there because we can't sort of detect these things early enough to do anything and that's the main problem with this situation... I was relieved when she died, in fact I was pleased, not relieved. I was getting a bit rough myself seeing this poor woman and not really being able to help much... because I felt so helpless. I had various consultants to see her... but no matter what you did for her you just couldn't help... So I felt frustration towards the medical profession for not devising some sort of test which would detect these problems earlier, so that by the time it is found it isn't so far spread that the prognosis is obviously not good, there's nothing we can do."

(Dr.22)
(10.68)
Hence, the maintenance of the curative role may be associated with little personal satisfaction. But such a role enactment, while permitting the continued interaction with patients in a routine way, may have other implications. One striking example in these interviews is the following reversion to a stylised role enactment, a coping strategy that is predictable on the basis of role theory. (Heiss, 1981).

"to show them that we are not neglecting them, on the whole, if you don't send them into hospital and they have something seriously wrong, they would say doctor you haven't sent me into hospital, and they think I am not doing my job. And that is why I make use of the hospital, they can't do anything. The other reason is because of pain and change of atmosphere. Tell me is what I do wrong?"

(Dr.20)

It is noteworthy that Dr.20 adds as an afterthought that he has a medical reason for using the hospital (i.e pain control). This in itself reinforces the analysis that the behaviour has become stylised or ritualistic. Even though Dr.20 puts it in terms of fulfilling patient expectations, we must remember that this is actually an attribution of expectation on his part, thus revealing his own expectations, rather than those of the patient.

Discussion of g.p.s roles during terminal care
During the interviews g.p.s expressed three distinct sorts of roles for themselves during terminal care. Some attempt to maintain a role conforming to the Parsonian ideal typical physician, whereby they continue with
treatment aimed at cure, or at least its semblance. Their reported interactions with terminal patients can be characterised by the need to avoid revealing to the patient that cure is not possible. This is justified to themselves by these g.p.s in terms of the possibility of cure still existing. To the extent that they feel uncomfortable about not telling, it is excusable in terms of putting the patient's immediate interests first (c.f. Tuckett, 1976b). In these terms the objective is to protect the patient from the unpleasant experience of knowing he or she is dying. This refusal to acknowledge death to the patient has the "advantage" of allowing the g.p. also to avoid upset. And so we find that g.p.s, who maintain the curative role, express strategies of communication towards the concealing end of the continuum.

A few g.p.s abandon the curative feature of the physician ideal type in favour of one that emphasises counselling, itself another professional activity. While one g.p. expressed his role explicitly in terms of counselling, others talk in terms of friendship. But their underlying preoccupation is with psychological problems, fear, depression, anxiety and the other problems of living, which can be alleviated with care. This role then does not so much give up on cure, but refocuses on the psyche as a legitimate object for treatment, rather than the soma of traditional medical practice. Other g.p.s change the emphasis of the curative feature in a different way. They emphasise palliation, aiming for palliative
excellence, especially in physical and technical terms, but recognise that good palliation requires an humanitarian orientation rather than being motivated by a scientific one. In line with these abandonments of the traditional curative ethic, the g.p.s express revealing strategies of communication. These they justify by recourse to patients’ longer term interests being served by having knowledge, permitting informed choice.

The majority of g.p.s experience ambiguity between what they face in terminal care and the physician ideal type. That is their normative expectations are violated, so that the role to be played is not properly specified. Such g.p.s express frustration at themselves, the profession and patients. Clearly they do not find the task before them easy. They attempt to fulfill the role of physician, offering what treatment and advice they can, especially since the patients are "really ill". To the extent that these g.p.s have a routinised response to terminal patients, it is to allow patients to take the lead. They respond to patient demands for information, rather than actively conceal or reveal it. Their objective is to keep patients happy in terms of not "rocking the boat".

These role descriptions correspond to what one might predict on the basis of role theory. Heiss (1981) in a recent review of role theory literature points out that the instability caused by role ambiguity will be handled
and can be resolved in a number of ways. One way to resolve role ambiguity is to draw on other roles within one's repertoire, and using features from them, modify the ambiguous role, so as eventually to create a new stable role for the situation. Another is to put up with the ambiguity in the present situation, because the role is sufficiently valid for the majority of performances and the disruption caused is not catastrophic. This, however tends to be a short term solution. A third way to handle role ambiguity is to allow the role partner to take the lead, and supply cues as to how the role should be played. A fourth method is to refuse to recognise the ambiguity and hold on to the role tenaciously. However, the resultant behaviours from this approach tend to be disfunctional and stereotypical in nature.

Which solution to the role ambiguity problem an individual g.p. will take is hard to specify. But the solution pursued must be related to the individual's personal experiential history, the role models to which he or she has been exposed, his or her own ability to innovate, as well as more general societal demands. Some solutions will achieve the required equilibrium within the social system and survive to become normative. Others will not prove fit and either die out or find another niche.
CHAPTER 11

Conclusions: The role of the g.p. during terminal care
By way of introduction to this concluding chapter, we offer a resume of the major deductions from the interview material. These are under two headings, patient and g.p. centred.

Patients
Although in Study 1 the g.p.s initially expressed pessimism about their ability to allocate patients to the required groups, they proved capable of fulfilling the task. As confirmed by both statistical and qualitative analyses the terminal knowing group of patients were more knowledgeable about their illnesses than the terminal group without knowledge, at least as revealed by their talk. But a rudimentary level of awareness of illness was apparent for all terminal patients. Chronic control patients all had clear knowledge of their illnesses and the implications the illness had for their lives.

Whilst all patients considered they had good relationships with their g.p., who was seen as a good doctor, the g.p.s differed in the extent they acted as sources of knowledge to the groups of patients. The chronic controls gained most information from their g.p.s. the non-knowing terminals the least. Sources other than the g.p. are of importance for terminally ill patients, and they report gaining much of their awareness during visits to hospitals. But this should not be taken to suggest that the g.p. plays only a minimal informative part.
since the g.p. tends to supply information which is confirmatory and supplementary in nature. Such information from the g.p., when this occurs, is probably of considerable importance to the patient, since it consists of an overt and explicit formulation of what was previously a suspicion, or imprecise knowledge. Analysis of interviews reveals that awareness of the nature of the illness may have been gleaned from a number of sources, in the ways considered in our typology of patient information seeking and acquisition. Patients are by no means the passive objects acted upon by doctors so often represented in the literature (Chapter 2). Patients report that they find out about their illnesses in many ways. Some of these may be intentional acts of information seeking, which usually consist of asking doctors (including g.p.s) and relatives. But although this direct approach does not always result in an explicit honest response, the answers reportedly given will provide an inquisitive and persistent patient with sufficient information to comprehend what is occurring. Other ways reportedly exist for obtaining information, but these require the patient to be more confrontational and/or deceptive than is usually the case. One striking example revealed by our analysis is the reported case of the "blind", by which a patient feigned more explicit knowledge than she actually possessed, thereby tricking her g.p. into more open acknowledgement of illness than he would otherwise have made. But such violation of implicit rules of interaction are seldom reported, and in the
vast majority of cases it seems that the inexplicit hints and euphemisms proffered by g.p.s suffice. In addition there is the information patients overhear when others talk about them "at the foot of the bed" or "on the front doorstep", to say nothing of the significance of being excluded from such discussions. As well as the linguistic communications of those around them the patient's environment contains other potentially rich sources of information. Treatments and symptoms are not semiotically vacuous, but themselves have meanings which are regularly reported as being recognised by patients. What is added by language is explicit acknowledgement of these meanings.

The patient groups did not differ in either Trait or State Anxiety. If State Anxiety is an outcome of awareness, then we cannot conclude that knowing one has cancer and is going to die increases anxiety. However, the relationship between awareness of illness and anxiety may be complex. Greater anxiety perhaps drives greater information seeking, but faces greater doctor resistance. Such factors as age, sex, socio-economic group etc. are also associated with knowledge (as expressed) in a complex way. One may posit that g.p.s' perception of such factors is causally involved here.
G.P.s

In the first study we found that g.p.s make fairly accurate assessments of the degree of patients' awareness of illness, even if they do not themselves discuss the issue with their patients. We then proposed a typology of ways in which g.p.s attempt to exert control over communications with their terminal patients. This typology was later applied to the second set of g.p. interviews and we return to it later.

Informers and noninformers (Chapter 9)

G.p.s were divided into two groups. One group tended to be more inclined towards informing terminal patients whilst the other tended not to inform patients. The general characteristics of these two groups were very similar, although the informing group comprised significantly more Members of the Royal College of General Practitioners and allocated more terminal patients to the study than the noninforming group. Statistical analysis of the interview content based on these two groups, reveals that the informing group report giving more information to their patients, especially information about treatment. Furthermore, the noninforming group talked significantly more about evading and denying patient questions and reassuring patients than the informing group. However, there were no differences between groups in the degree they expressed willingness to respond to the patient's questions. When deciding whether or not to tell patients, the g.p. groups took
similar factors into account, except that the informing group consider the patient's illness when deciding to tell, whilst the noninforming group never report considering this factor. There is stark contrast in the reported aims of the two g.p. groups in respectively telling or not telling patients. Both groups aim at maintaining patient happiness, but the informing group attempt to achieve this by telling, the noninforming by not telling.

**Strategies and tactics (Chapter 10)**

In analysing the accounts of the g.p.s' approaches to communicating with their terminally ill patients, we drew a conceptual distinction between objectives, strategies and tactics. This distinction permits us to extend beyond previous analyses such as that of McIntosh (1974, 1977). Objectives refer specifically to the stated objectives of the g.p.s in their management of terminally ill patients and may consist of a number of specific goals. Strategies refer to the overall plan and mode of approaching a patient adopted in order to attain the objective. Strategies normally have a temporal extension of weeks or months over repeated consultations. They are recognisable and explicitly stated styles of interacting with specific patients or groups of patients. Tactics refer to (reported) behaviours normally used within a single consultation in order to attain a specific position (or goal) within the overall strategy. Below we consider the strategies and tactics of communication adopted by
Though it is possible to group g.p.s on the basis of stated intentions to give or withhold information, more detailed consideration of the strategies and tactics actually identified from interviews blurs this simple polarity. Whilst it is true that when asked whether or not they told terminal patients, some g.p.s answered "Yes" and some "No", all except one went on to qualify this. Those who answered "Yes" generally made it clear that telling is a gradual process, and that they only tell in answer to an explicit question by the patient. And those who answered "No" qualified this by adding "unless explicitly asked" (or words to that effect). As it stands this would be no difference at all but more detailed analysis does reveal different strategies. From this point of view the differences form a continuum rather than a dichotomy. Thus all g.p.s agree that most patients come to know in one way or another, so it is not simply a matter of whether or not to communicate information, but of whether or not to acknowledge openly the nature of the illness.

Central to the objectives of all g.p.s is a desire to keep the terminal patient comfortable, painfree and happy. Most prefer to keep the patient at home whenever possible, given the resources available to him or her. But the g.p.s' objectives differ subtly when we consider what it means to keep a patient happy. Stated most
extremely the differences are captured in the notions that, on the one hand, "ignorance is bliss", and on the other that happiness can only be achieved in association with the dignity afforded by autonomous actions based on informed choice. Between these two extremes lie many shades of grey. For many g. p. s happiness is to be maintained by not unduly "rocking the boat". Since these g. p. s are uncertain in individual cases as to whether to tell or not, they prefer to take no active stance, short of maintaining the status quo. These objectives are reflected by the ways in which g. p. s communicate with their terminal patients, but are not perfectly mirrored by them. Our analysis distinguishes between the strategies and tactics adopted by g. p. s to approach terminal patients. Some g. p. s (and they are all "informers") report the strategy of actively disclosing the nature of the illness to patients by manipulating the situation toward mutual and explicit formalised acknowledgement, normally over a series of consultations. Other g. p. s (all "noninformers") report the opposite strategy of actively concealing the nature of the illness from the patient. These latter g. p. s, it seems, routinely gear their approach to the terminal patient so as to avoid acknowledgement of the illness, to ensure the patient never finds out and even to contradict suspicions the patient may harbour. Between these two poles lie the g. p. s (some "informers", some "noninformers") whose reported strategy is to passively respond to patient demands, allowing patients to set the pace and provide
the cues to which they may respond accordingly. However, these three strategies represent landmarks on a continuum of strategies, rather than clearcut and exclusive categories by which individual g.p.s may be simply classified. Hence individual g.p.s who adopt a more central passive strategy differ. Some seem more inclined towards a preference for disclosure, while others prefer concealment.

A Taxonomy of Communication

Mcintosh (1974, 1977) (cf. pp.100-104 and pp. 357-358) described a number of ways in which hospital doctors attempted to exert control over patients’ awareness of cancer. The present findings can be seen as an extension of some of his ideas. Whilst Mcintosh’s results relate to the hospital context, the present results refer to the home context. One might expect the doctor to be able to exert more control over his or her patients in hospital than is possible at home. However, this is not necessarily the case since as we have seen the extended time periods and personal knowledge of the patient involved in home care may be used by the g.p. to advantage. It is important to note that in the ward studied by Mcintosh there was a policy of not telling patients the precise nature of their illness. This may be the reason why Mcintosh only observed and reported one strategy, concealment. Perhaps because of this Mcintosh never differentiates between tactics and
strategies and only describes the tactics of concealment implemented by medical staff (McIntosh, 1977: p.28). We have extended the analysis in two ways. First, we have added to the list of tactics used by doctors. This is not surprising given the very different contexts in which the two pieces of research were conducted and it is possible that future researchers will add further to the list. Second and perhaps more importantly, by placing tactics in relation to the strategic considerations involved, we reveal that the use of a specific tactic may at different times have a very different purpose. Thus we reveal that a tactic can have different meanings and accomplish different tasks depending on the part it plays in the overall strategy. This is important since we have revealed that different g.p.s have different strategies, ranging from active revelation of illness, through passive response to patients, to active concealment.

When facing individual terminal patients the g.p.s described using specific tactics. Tactics we have identified from our interviews include the use of evasion, denial, reassurance, euphemism, uncertainty, giving hints and steering and prompting questions. These are normally reported as being used in ways that are congruent with the g.p.'s strategy, in the sense that, for example, a g.p. who has a strategic approach of revealing tends to report use of tactics one would naturally associate with such revelation (e.g. prompting). Where tactics and strategies are associated, which do not on the face of it
appear congruous, closer consideration reveals that the tactic is deployed with the specific purpose of attaining a goal within the overall strategy. Thus, in the strategy of revelation, which is a gradual process, a g.p. may initially avoid revealing information which later might be freely offered. In conclusion, then, we argue that any future analyses of behaviours that include tactics must also consider the part the tactics play in the overall strategy being pursued.

Role Ambiguity

The way in which g.p.s allocated or failed to allocate patients to study 2 reveals an important point. Not only are the noninformers less willing to communicate information, but also it appears that they are more resistant to labelling patients "terminally ill".

In general the noninforming g.p.s attempted to maintain their roles as technically equipped curative agents. They were loath to admit to patients, or themselves, that there was nothing medical science could offer by way of cure, since this would undermine the basis of the complementary physician and sick roles, which guide behaviour during interaction. On the other hand there are the g.p.s who report routinely informing patients, and who also are most willing to admit that there is nothing they can do to cure the patient. These g.p.s have incorporated into their roles that of the counsellor. For them treating the dying
is not an onerous task, but one which requires a different set of skills from those of the traditional curer described by the Parsonian ideal type. These skills, and the role that underlies them, complement the dying role of the patient by emphasising care over cure. For them the patient is more than the set of organs of "scientific medicine", but a psycho-social entity with a diseased soma. Palliation of the somatic component affords relief to the psycho-social which is their central concern. The exercise of these caring skills is no less challenging than the exercise of the diagnostic and treatment skills required by the traditional physician's sick role complement.

While a few g.p.s express themselves explicitly in the language of counselling, others have less consciously taken up the professional role of the counsellor. They resort to another role in their repertoire, that of friend. This perhaps represents a transitional role on the way to the more formal counsellor or psychotherapist role. But a majority of the g.p.s neither resort to stereotypical role enactments mimicking the curative ideal type, nor simply abandon that ideal type in favour of counsellor. They clearly experience ambiguity in their role, which they resolve with different degrees of success. The most commonly reported ambiguity resolution is to allow the patient to take the lead. Thus patients provide the cues as to how they want interaction to proceed. Telling becomes a function of patient demand, at
least ostensibly, since individuals have different thresholds at which they will respond. Possibly these thresholds are themselves a function of the individuals' commitment to the physician ideal type.

How an individual g.p. will attempt to resolve the ambiguity faced during terminal care is uncertain. But they are likely to conform to the general predictions from role theory analyses such as those reviewed by Heiss (1981). Thus role innovations will involve the processes of creative modeling, role amalgamation, role assimilation and role extension (Heiss, 1981; p.114-116), as well as the formal role socialization to be found in training. An individual's role innovations will depend greatly on his or her personal history, personality and the models to which he or she is exposed. However, all future g.p.s will have the common experience of training, to which we return later.

We have considered the results obtained in the light of one major trend in contemporary social psychology - role theory. Thus our analysis has focussed on the roles of g.p.s and patients and we have taken utterances during interview to constitute accounts of expectations about behaviours and to point towards ideal types underlying roles. But other analyses may point in different directions. Yet our intention has been to use role theory as a vehicle, rather than it being a theoretical perspective to which the author is committed, to make
visible patterns within reports in order to further our understanding of what may occur during consultations. Our understanding can not be complete without consideration of the structures within which consultations occur. Role theory has been criticised for presenting an analysis based on individuals and their interactions, placing too little emphasis on the structures of the social system within which behaviours and expectations occur (c.f. pp.116-117). The authority (or power) of the doctor, for example, does not inher within the consultation, although it is displayed there. To redress any imbalance in this thesis we can merely point to the "macro" level of analysis, the social institutions within which g.p.s' roles have evolved. Analysis of the profession, its institutions and regulation within the wider social world and the limits thus placed on roles is a research endeavour in its own right and beyond the scope of the present thesis (cf. Friedson, 1970a; 1970b). Yet it is important to note that g.p.s who resist disclosing the nature of the illness to patients and maintain the curative role are not simply or necessarily maladaptive in role evolutionary terms. For one thing, adoption of the non-disclosing role as opposed to disclosing one may well depend on personality variables, an area which this thesis has not explored and which remains open to future research (see below). Furthermore, the non-disclosing and curative role that some g.p.s espouse is the role validated by the profession (cf. p.119 and pp.135-139). Thus it is the counsellors

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and friends who are deviants, or social mutations, whose roles’ future survival will depend upon the attainment of professional acceptance and probably dominance. The attainment of such dominance is likely to be a gradual (and perhaps almost imperceptible) process. It is likely to be influenced by changes in the habitat of medicine—the hospitals, the surgeries—as well as the changes in the niche itself engendered by the advent of terminal illness. Chronicling the changes in the professional structures and institutions and the ideal types they underwrite, would seem to be an important requirement for our future understanding of the roles of doctors and terminal patients. Thus explanation and prediction of the way a g.p. (and general practice as an entity) will resolve the ambiguity he, she or it faces during terminal care will depend at least in part on changes within the profession of medicine as a whole.

Our analysis of the communication between g.p.s and their terminally ill patients has focused on the social roles of the protagonists. Thus g.p.s' reticence to disclose the nature of the illness to a patient has been discussed in terms of g.p.s' tenacity to the curative physician role. However, such (reported) behaviour may be explained in a number of ways and although by no means exhaustive we now briefly consider other general approaches which could be of use in considering the data reported here. A Freudian analysis, for example, would be based on individuals' needs to protect themselves, and be protected from, the
unconscious irrational forces which the prospect of death would bring all too threateningly near. Such an analysis would be incomplete without reference to the social structures (e.g. the profession of medicine, hospitals) which perform the (disguised) function of defending individuals against the arousal of such deep rooted fears. In part then a Freudian analysis would return to the role concepts espoused here, considering them as a mechanism of defense. Whether one accepts the precepts of Freudian analysis or not, that many doctors find it difficult to talk to patients about impending death is hardly at issue. Talking about dying is a threatening experience for most people and an individual g.p.'s willingness to disclose information is likely to be a function of a number of personal factors, such as previous experience, training, personality and the like. That some doctors will find ways of avoiding telling patients if it is possible is self evident. This will probably depend on the complex factors alluded to above, as well as the roles, which are the central core of this thesis. The work of Lief and Fox (1963) is of relevance here since it points to such mechanisms as denial, distancing and objectifying patients into sets of organs as coping strategies developed early during medical careers to protect against the threat of death. Objectification, denial and distancing is exactly what the curative role can offer. Finally, the way in which a g.p. and a patient will behave during consultations and talk about their consultations is likely to be influenced by
personality variables and the g.p.s' willingness to disclose information. Thus, for example, on the basis of personality theory one would predict differences in personality traits between g.p.s who disclosed and those who did not. Such an approach has not been followed here but clearly there is room for research into these issues.

Methodological Considerations

In this section we consider a number of interrelated problems in the methods used in our studies. These have both practical consequences for the performance of the studies and implications for the generalisability of our results. First we consider the pilot study (pp. 150-154) and the use of role playing subjects. Role playing as a methodology has been criticised on a number of grounds (e.g. Freedman, 1969) and we considered some of these problems earlier (p.152). At the time the main perceived advantage of the role play method was the availability and accessibility of subjects. Yet inherent within this advantage is a problem, for it implies the expectation that securing the cooperation of g.p.s and their patients would itself be difficult. This was in fact the case. Had these issues been more directly confronted during the initial stages of the research, it is possible that they could have been more successfully overcome. It is suggested therefore that in future research of this kind, role playing should not usually be used as an alternative to actual occupants of the role.
Nevertheless, there may be areas, such as training, where role playing will continue to prove fruitful.

In Chapter 4 we briefly considered problems of interviewing g.p.s and patients. Little attention was paid there to the issues involved in attaining reasonable levels of subject cooperation. In Study 1 we recorded an initial g.p. refusal rate of 58%, which was exacerbated by one of the 5 g.p.s dropping out of the study. In Study 2 we recorded a g.p. refusal rate of 50% and although none dropped out, 7 failed to allocate any patients. This failure may suggest that these g.p.s only half heartedly cooperated with the study design, although the possibility that they had no suitable patients at the time cannot be totally dismissed. Refusal to cooperate can be equated with self selection by the g.p.s. What is more, the g.p.s who did cooperate selected patients and may have biased the patient sample in line with their own preconceptions. We consider these two points in turn below.

G.p.s were selected at random, but with so many refusals the sample can not be considered random. Nonetheless the samples of g.p.s who participated broadly resemble national and regional norms for general practice in terms of age and sex composition, and features of the practices in which they work. Thus the sample may have been representative. So whatever the problems with our procedure, it is an improvement on the usual sampling procedures that depend on the cooperation of
practitioners who are associated with medical schools and teaching hospitals. In one respect the sample in Study 2 may not be representative; 40% held the M.R.C.G.P. qualification compared with 32% of the national population of g.p.s [as calculated from data for 1986 reported in R.C.G.P. (1986) and D.H.S.S. (1987)]. As g.p.s who are members of the Royal College were found to tend more towards revealing, it seems likely that the distribution of g.p.s across the continuum of communication strategies (p.317) underrepresents the proportion who tend towards concealment. However, it seems likely that the range of strategies is represented in this thesis. We have identified g.p.s at one extreme of the continuum who report routinely revealing information to patients. At the other extreme we have g.p.s who report that they try to stop their patients from discovering anything about their illnesses and even physically avoid patients in order to conceal information from them. It is difficult to think of more extreme versions of the strategy of actively concealing than that implied by the tactic of physical avoidance, but future research may show them to exist.

As well as the problems associated with g.p. self-selection there are those related to the selection by g.p.s of patients for the study. These are of two sorts. First, the problem of whether g.p.s introduced bias by selecting patients on the basis of some other criteria than those specified. (e.g. by only allocating patients
they personally liked and got on with). Second, the problem in Study 2 that g.p.s failed to allocate patients in the numbers anticipated. We consider these two separately below.

During case history interviews each g.p. was asked why he or she had allocated the patient being discussed to the study (see Appendix 1). In Study 1 all g.p.s replied that the terminal patient had been allocated as the only one suitable for inclusion in that group. However, we cannot be certain that this was in fact the case, since on the two occasions during Study 1 when the originally allocated patient was not successfully interviewed, the g.p. found it possible to replace them (cf. Quotation 6.72 p.244). Thus it is possible that g.p.s' allocation of patients biased the results. One might expect then that g.p.s would choose patients to confirm their own accounts. Whilst this may have occurred, we can point to the existence of discrepancies between g.p.s' and patients' accounts (identified in Chapter 6) to show that at least the g.p.s were not completely successful if they were attempting to deceive the researcher. In Study 2 the level of patient allocation was very low, (discussed in Chapter 9; pp.353-356). As a result we were unable to present an analysis comparing the perspectives of g.p.s and patients as for Study 1 (Chapter 6), and have had to depend only on the g.p.s perspectives. The relatively few patient interviews that were conducted during Study 2 were analysed informally and no clear clashes in perspectives
were identified. This is better than nothing, yet it would clearly have been preferable to have had a full complement of patients. Moreover those patients who were assigned had unexpectedly high mortality rates. Thus only a minority of the relatively few patients allocated were actually interviewed, and so few completed the 6 months of the longitudinal study that formal analysis of these interviews was judged to be unproductive. The low level of success in interviewing patients as intended had the result that our analysis depends totally on accounts, except in the case of the one g.p. who supplied video recordings of interactions. However, careful viewing of the two and a half hours of video recordings collected, revealed nothing that did not conform to the accounts proffered by the g.p. and those patients that were interviewed (q.v. Appendix 5).

In terms of the original objectives of the research, the study designs were not overwhelmingly successful, although the g.p. refusal rates recorded are not unusual. The experience of problems in the present research can, however, be instructive and lead to a number of methodological recommendations for future researchers. These are now considered.

Reduction of g.p. refusal rates and improvement of patient allocation levels. We selected g.p.s at random from F.P.C. lists and contacted them by letter. These letters emphasised the research nature of the studies. This may
have caused disquiet to some g.p.s, since it is possible
that they perceived that an evaluation of their own
professional competence was implied. This may have
resulted in refusal to cooperate. Obviously care must be
taken in the wording of such letters. Specifically,
greater stress could be placed on the recognition that
communication with terminally ill patients is a highly
problematic situation for all doctors, so as to minimise
the individual g.p.'s self doubts about his or her own
competence in this field. Second, and perhaps more
importantly, there is a need to offer some form of
incentive to g.p.s to cooperate in research of this kind.
One possibility would be to offer feedback and training to
the g.p.s on the basis of involvement in the research,
thus making it a learning experience. Clearly if an
educational component were built into the design, it would
have to be undertaken at the end of the data collection
period, unless one was evaluating the effectiveness of the
training itself. It would probably also prove
advantageous for the researchers to have the backing of
the relevant professional bodies and institutions (e.g.
R.C.G.P./local medical school) rather than being based in
an institution with few clinical contacts.

The problem of low levels of g.p. allocation of patients
could be overcome in a number of ways. For whatever
reasons g.p.s in Study 2 clearly had difficulty in
identifying a point at which patients became terminally
ill. Given the "career" conception of terminal illness
(c.f. Chapter 3) outlined in this thesis, it would seem worthwhile to identify patients from as early as possible for longitudinal study. This could be accomplished by identifying patients at first presentation to their g.p.s. This, however, would require constant monitoring of large numbers of g.p.s., who would have to be persuaded to cooperate in the first place. A more feasible solution is to identify patients by referral to specialists. This would entail changes in the design to make it more "patient driven", so that rather than having g.p.s allocate patients, patients are used to identify g.p.s. For example, all new referrals to specialist clinics for cancer might be allocated to the study and contact made with the g.p. who made the referral. Such a design might result in reduction of the refusal rates if these are due to g.p.s feeling that they are being evaluated. Although first referral to the specialist is one possibility, permitting an almost complete career history, the length of many patients' careers as cancer patients prior to their becoming terminal patients (if they ever do) may make this method difficult in practice. Thus future researchers will have to consider carefully the entry criteria for such studies, perhaps accepting the more manageable time scale associated with recurrance.

A design that depends on patients being identified on the basis of referral to hospital requires four main caveats. First, a small minority of patients with cancer are never referred by g.p.s to specialists (c.f. Wilkes, 1964, 1965;
MacDonald, 1986). Such patients may be identified by cross reference to cancer registration. Second, it is possible that diagnosis and referral to specialists differ across g.p.s. This, for example, could be a function of g.p.s' diagnostic skills and orientation, or of some epidemiological factor related to the catchment area of their practice. Thus it will remain necessary to check the representativeness of the sample of g.p.s accessed via patient referral. Third, such a design is by no means a panacea for all the problems identified by our own research. The allocation of patients to a study by hospital consultants is not always a simple process and can be fraught with problems both in securing the cooperation of the hospital medical and nursing staff and in accurately allocating patients to the study (Addington-Hall, 1987). Finally, such a design equates terminal illness with cancer, or its recurrence, but there are other diseases which result in patients becoming terminal. The most topical example at present is Acquired Immune Deficiency Syndrome (AIDS), and it may be worthwhile to extend patient identification to include such patients.

Accessing g.p.s through their patient referrals, making the contact letter less professionally threatening and offering a quid pro quo for their cooperation by appending an educational component to the research are thus likely ways of reducing g.p. refusal and attrition rates, and the bias inherent in g.p.s' selection of patients. Such
changes may also permit greater demands to be made on the g.p.s. Thus the g.p. could be offered the opportunity of viewing video recordings of his or her interactions with cancer/terminal patients as part of the educational experience, which would at the same time provide the researcher with behavioural data as well as accounts.

Other extensions of the basic paradigm could include analysis of communications with professionals other than g.p.s and within the various settings of the patients' careers. Thus outpatient clinics should be accessible without difficulty. Inpatient stays may also be accessible and although the practical problems of recording behaviour on open wards may be prohibitive, useful data based on reports and medical and nursing records could be obtained. Thus it would be possible to collect data representing the complete history of the illness, from time of first referral for cancer through the terminal phase to eventual death.

Two further points about methodologies are worth stressing. First, our description of objectives, strategies and tactics reinforces the point made earlier that the study of the single consultation results in collection of impoverished data. Tactics are the behavioural dimension of the analysis and are to be found at the level of the single consultation. Yet the meaning of the tactic lies within the strategy of which it is a part. Normally, one would expect a strategy only to
become visible over a series of consultations. Thus observations made during one consultation need to be contextualised within the series of consultations for their meaning to be made clear. For example, the evasion of a patient's question early during a series of consultations, made by a g.p. pursuing a strategy of gradual disclosure, has a very different meaning to the evasion of a question made by a g.p. pursuing a strategy of active concealment. However, within the single consultation the two evasions may appear behaviourally identical and thus lead a researcher, who bases his or her research on single consultations, to draw spurious conclusions. It is also necessary to consider the tactics and strategies in the light of objectives, a dimension that only becomes manifest with accounts of intentions. Thus in future it is recommended that behavioural data be considered in relation to intentions, or the relationship between observed behaviour and accounts of actions. This is an issue not fully addressed in this thesis, since we were unable to collect substantial behavioural records of consultations. It is necessary to monitor series of consultations in conjunction with the collection of interview data from the participants. Whilst video recording of consultations offers a behavioural record, the consultation questionnaires developed for the present research (Appendix 4) should also prove a useful tool. These questionnaires were developed to provide a record of the g.p.s' and patients' impressions immediately after the
completion of a consultation. Thus whilst subsequent analysis of the video recording of a consultation may reveal, for example, a g.p. as utilising a specific tactic, the questionnaires would tap the g.p.'s and the patient's perceptions of what occurred and thus permit comparison of these varying perspectives. Thus the questionnaires were designed to provide further data on the consultation process, data that would provide us with insight into the protagonists' perspectives on what occurred (q.v. Appendix 5). Furthermore the completion of these questionnaires after consultations should provide us with data on consultations not accessed by video or audio recorders. Such an approach would appear to offer fruitful directions for future research. However, these questionnaires should be further developed to tap the intentions of the respondents; asking, for example, what it was hoped to achieve during the consultation, what was achieved, and perceived reasons for any discrepancies.

To summarise, the methodological inadequacies identified in the studies reported result in a number of problems. One is that aspects of the studies as initially conceived were not completed. In the second study we depended more heavily on g.p. interviews than intended, since we were unable to collect sufficient data from patients. This lack of patients also made it impossible to analyse the longitudinal components to consider how, for example, patient awareness changed over time. We were also forced to depend on reports of consultations without sufficient
behavioural data to confirm them. Second, the samples of g.p.s and patients may not be perfectly representative of the populations from which they were drawn. In terms of the continuum of communication developed here this bias in the sample suggests one major caveat. That is that the distribution of g.p.s along the continuum may overrepresent the proportion favouring active disclosure. We feel confident that the range is representative, since an extreme of non-disclosure is also revealed, but further research is needed to test this. We have also suggested methodological improvements to overcome the major flaws in design that we have discussed and consider the implications of our findings for future research later. Now however, we turn to consider medical training.

Implications for Medical Training

The results of these studies have a number of implications for the future training of medical practitioners. We can outline only general principles, and no attempt will be made to suggest specific changes to either undergraduate or vocational curricula. Changes constantly occur in curricula and some of those which have already occurred are in line with suggestions we would make. Thus, the report of the D.H.S.S. working party on terminal care (Wilkes, 1980) and the recently modified G.M.C. guidelines on basic medical education (G.M.C., 1981) both emphasise the need for medical students and vocational trainees to gain experience in terminal care, especially
"psychological aspects of dying... (and) techniques in counselling" (Wilkes, 1980; Para 5.3). However, the fruits of such recommendations may not be visible in the everyday practice of medicine for some years.

In Chapter 2 we reviewed numerous studies of the communication of information between doctors and patients. Many of these implied that communication can be improved by teaching doctors specific skills, be they the order in which to present information, or the way in which to elicit a good case history. But our research suggests that communication, at least during general practice terminal care, is inextricably intertwined with the role that the doctor plays. Thus exhorting doctors or trainees to tell patients in such and such a way, is of little use if the recommendation conflicts with their concepts of the role they play. Such problems can probably be overcome by exposure to alternative roles, complementary to the dying, and compatible with telling.

According to Wakeford (1983) the vast majority of the teaching of communication skills in medical schools is on an ad hoc basis. Clearly more systematic, early training in such skills would equip the g.p.s of the future with resources beneficial to their interactions with patients in general and terminal patients in particular. A striking feature of our interviews is that g.p.s, whilst explaining how they developed their approaches to terminal patients, invariably referred to clinical experiences as
formative. This is true even of those few g.p.s whose training included components explicitly aimed at teaching communication skills, and they all mentioned the overriding importance of clinical experience in moulding their approach. This is consistent with Freidson's (1970a) analysis of the "clinical mentality", whereby experience is weightier than the abstractions and generalisations taught or read about. The recommendation that this implies is that during training more careful control and monitoring of students' first interactions with patients, especially dying patients, could be used to set behavioural moulds in desired ways.

A specific feature of communication with the dying about which medical practitioners need to be made aware is that "telling" is not simply saying, "You have X and....". What needs to be recognised is that information is inherent in treatment regimens. Not only do patients recognise treatments and symptoms, but they are also capable of "reading between the lines" of what doctors say (or do not say) to them. Such meta-communication is an inevitable consequence of the sort of interactions necessitated by the medical task and cannot be divorced from that task. Furthermore, such meta-communication is largely inaccessible to conscious manipulation by a doctor, as such manipulation is itself signaled by/on this channel. But, by their very nature, meta-communications do not have to be acknowledged by the patient. Thus awareness that this channel of communication exists,
opens up for the g.p. an important possible mode of communication, to be used as part of an overall strategy. Another aspect of this is that most patients come to be aware that they are dying. Such a point is important, since once a student knows this, it vitiates against his or her (self) consciously suppressing information in the belief that patients can be prevented from ever acquiring it.

As is pointed out above, teaching communication skills is not enough. The general problems facing g.p.s in communicating with patients are exacerbated during terminal care by the contradiction which exists between recognition that the patient is terminal and the ideal type of the curing physician, into which students are socialised at medical school. Thus although training in communication skills may improve some aspects of g.p.s' communicative performance, such training will not in itself resolve the core dilemma. The resolution of the core dilemma rests on the exposure of medical students to alternatives to the ideal type of curative medicine. Clearly the introduction of communication skills training in medical schools is itself intertwined with a recognition that the medical task is more than mastery over pathological processes. Hence a correlate of communication skills training is exposure to alternatives to the historically dominant model of medicine, and its physician ideal type.
But although social skills training may have as a concomitant exposure to roles other than the classical curative one, for individual g.p.s (and medical students) the problem is not consciously one of learning new skills and changing roles to incorporate that of counsellor, so much as coping with their own emotional responses and attitudes. Social skills training may give doctors the "tools" for the job of informing a person that he or she is dying, but it does nothing to make the job more palatable. Training must thus also be aimed at changing deep rooted cultural attitudes towards death, and the fears they engender. Only by making the prospect of telling a patient that she or he is dying less threatening are g.p.s likely to both initiate revelatory strategies and maintain them. There are ample models in the persuasion and dissonance literature of attitude change to guide training programs here. Methods of coping with emotional responses to death require consideration during training, both in terms of showing emotions and in terms of tempering them. Longer term support may also be required, since regularly conveying bad news may itself have its toll on the g.p.. One approach that is gaining currency in other professions is the setting up of support groups for the carers themselves. Such an approach would not be distant from that advocated by Balint (1957). Clearly any changes in training will need to be evaluated, both in the short term and the longer term practice of future generations of medics.
There are indications in our research that, by default, changes are occurring. Our second study included 5 g.p.s who acted as trainers on g.p. vocational training schemes. These 5 g.p.s all held the M.R.C.G.P. qualification, and espoused revelation strategies of communication. Since these g.p.s (and not those who maintain silence and the Parsonian ideal type) are involved in the training of future generations of g.p.s, it seems likely that such strategies of communication will be passed on to their pupils, along with the caring role that is its concomitant. This, however, is an issue which will require research in the future. It is to directions for future research indicated by this thesis which we now turn.

Directions for Future Research

In Chapter 7 we forwarded a typology of the ways in which g.p.s and patients attempt to exert control over information exchange during terminal illness. This typology is further developed in Chapter 10, and presented as a taxonomy of g.p.s' strategies and tactics of communication. The results reported in this thesis are based on interview data from relatively small samples of g.p.s and patients and thus further research is needed to corroborate our findings. Specifically the samples should be extended, in the ways described in the previous section and as well as interview data, behavioural data should be collected. A study of a longitudinal nature, preferably
encompassing complete histories of cases from first presentation, would permit consideration of how tactics and strategies work out in practice, validating and developing our typology of tactics used during interactions.

Another issue in need of investigation is the degree to which patient wants and needs are met by g.p.s. One aspect of this would require that individual patients' preferences for information were identified early during the illness. Thus, by monitoring interactions and conducting interviews, it would be possible to see whether g.p.s respond to patients' preferences. This project, however, is fraught with difficulties as the measurement of communication preference in itself is by no means straight-forward, and patient needs are likely to alter over time. Any assessment will also have to consider the degree to which g.p.s respond to patient demands. Hence the study must contain some independent evaluation of patient demands, and whether g.p.s take into account both different needs of different patients and changes in the needs of a patient over time. It will be necessary to assess whether g.p.s are flexible in the strategies and tactics they implement, or whether they exhibit the same behaviours regardless of needs as suggested by Byrne and Long (1976). Analysis of behavioural and account data here will also reveal whether the g.p.s are consistent and coherent in their use of strategies and tactics. We also need to assess the effects that different strategies of
communication have on patients, relating these both to patient wants and outcome variables. A number of outcome variables seem germane, anxiety and satisfaction being amongst the psychological ones requiring urgent attention. It may also prove possible to extend these findings into the psychosomatic realm and consider illness outcome variables (cf. Greer, 1979).

In Chapter 2 we reviewed a number of studies, mostly based on questionnaire techniques, which sought to discover the proportion of doctors who informed patients that they had cancer and/or were dying. One implication of the research reported in this thesis is that results based purely on forced choice questionnaires do not validly reflect the actions of doctors, when facing the difficult problems involved in communicating with terminal patients. Future research must take into account the subtleties of communication rather than posing questions in all or nothing terms.

Whilst studies of behaviour during consultations are obviously of importance, actual behaviour has not been the object of enquiry of this thesis. Rather we have considered the expectations about and rationalisations of such behaviour. One point deserves particular emphasis. Our analysis of g.p.s' strategies and tactics of communication points to the way in which g.p.s plan actions over a series of consultations. The paradigm, which has dominated research into doctor patient
communication, has involved behavioural observations based on single consultations (Waitzkin and Stoeckle, 1972; 1976; Waitzkin, 1985). Whilst such a "snapshot" approach may be applicable to some illness treated in general practice, it is not suitable for illnesses like those we have considered, which result in multiple consultations. In order to understand what is occurring in such consultations one must consider the individual consultation in the context of the series as well as the doctor's and the patient's intentions.

In Chapter 8 (see also Appendix 3) we outlined a series of problems, which our later studies were to address. One was to carry out a longitudinal study on individual patients, but this was not successful. However, by modifying the sampling procedures and entry criteria for patients as described previously, there is no reason why the original aims of our studies could not be accomplished. Specifically, we would recommend that patients should be identified from first diagnosis of cancer. This may be done primarily via referrals to hospital, but must be supplemented in order to pick up those patients who are never referred to a consultant. Such a study would thus attempt to monitor a cohort of patients as they progress from first presentation to the g.p. until eventual death or cure (5 years without recurrence). A study of this sort is in fact now underway (MacDonald, 1986).
In conclusion then, McIntosh's (1974) review paper of communication associated with the treatment of cancer in hospital outlines 26 questions requiring urgent examination. It seems to the present author that these questions remain outstanding, and that they need to be extended to the less structured situation of patients receiving terminal care at home. Such an extension must also take into account the increased importance of the informal channels of communication open to the patient at home. In addition our differentiation between tactics and strategies, and the way these are associated with the role played by a g.p. opens up further avenues of research. Initially, at least, it remains to be ascertained how widespread are the tactics, strategies and roles we have identified. We also need to know whether there are other variants of the roles, strategies and tactics in use. Perhaps most pressing is a need to identify how g.p.s' roles, strategies and tactics relate to such variables as patient satisfaction and anxiety, so as to permit delivery of high standard home care to terminal patients of the future.

Finally in this section we note an implication of our findings which requires research. We have identified tactics and strategies implemented by g.p.s in communication with terminal patients. A pertinent question would appear to be to identify how these strategies and tactics were learned. Given that the strategy of actively concealing information from patients
may be maladaptive and at odds with the ethos of contemporary medical practice, we specifically need to identify aspects of training which inculcate such an approach into the medics of the future, in order to make changes to training. Such a project requires evaluation of both undergraduate and vocational aspects of medical training. We would suggest that of particular importance is the way that students' first interactions with the dying are managed. Such studies, in conjunction with studies of communication skills training and the effects of exposure to non-traditional medical roles would appear to us to be of the highest priority, if the medical practitioners of the future are to be equipped to provide high standard and humane care for the dying.

Concluding Remarks
One way of trying to interpret data such as those reported in this thesis is in terms of a single medical role, and the conflicts induced when the doctor is required to deal with situations where the role does not adequately prescribe appropriate behaviour. We saw signs of this interpretation in the quotations from doctors and researchers concerned with doctors' treatment of the dying, and in Chapter 8 we proposed that "... the doctor is trying to deal with a difficult human situation while retaining his traditional role as healer within the doctor-patient relationship." But analysis of the data collected during our second study suggests a different
interpretation, or at least a different emphasis. If role behaviour tends towards an ideal type which governs rationalisation, then the g.p.s' attitudes can be seen to revolve around two ideal types. One is that of the technically equipped curative agent, and complements the patient's "sick role" as outlined by Parsons (1951a, 1951b). The other is a "caring role", which complements the patient's "dying role" described by Noyes and Clancy (1977): it involves guiding the patient in the transition from sick to dying role, and then giving physical (through palliation) and psychological support. Apart from being palliative rather than curative, it differs from Parsons's physician role by giving weight to social rather than technical skills, and by relaxing the mask of affective neutrality. The involvement of relatives and the preference for keeping dying patients at home, suggests that the doctor's activity is toward the family and the wider social context, instead of being focused upon the isolated individual, which is the concern of the Parsonian physician's role. Far from being "no longer primary" (Noyes and Clancy (1977, p.18), the doctor in the caring role continues to be of major importance to the patient, albeit as part of a group which includes nurses and members of the family, rather than as the detached expert of the consulting room.

Roles and their ideal types presumably evolve and at any one time they may be in a stable or transitional state. One source of instability is likely to be conflict between
the ideals expounded and inculcated in the prestigious teaching and research institutions, and those found necessary by the vast majority of doctors who work in the comparative obscurity of general practice. This conflict has been documented by Friedson (1970a) (c.f. Chapter 3). Through publicity and teaching, the ideals of the curative role, which are appropriate to the goals of hospital doctors, have tended to dominate the expectations of patients and the practice of g.p.s where they are only partly appropriate. Thus many g.p.s experience role ambiguity which they often attempt to resolve by recourse to other roles in their role-set. But in recent years there have been moves to make general practice a higher status specialism in its own right. The task of the g.p. has been defined as that of providing "personal, primary and continuing medical care, (intervening) educationally, preventively and therapeutically." (R.C.G.P., 1972, p.1), which differs significantly from the more focussed curative role of hospital practice. We surmise therefore that the ideal type complementary to the dying role is in a transitional state, and that g.p.s sometimes experience ambiguity in mediating the demands of the physician ideal by which they are guided. The role ambiguity which results is especially marked in treating dying patients, and this would explain why the doctors in our study vary so much in their attitudes towards such patients. Some find them rewarding to treat and appeal to an ideal type in their common explanations of its satisfactions, although they also add personal reasons for their
attitudes. While a few doctors find treating such patients difficult and unrewarding, and give reasons suggesting that for them it fails to match the satisfying and clearcut skills of the curative role; such doctors, perhaps, are guided by the single role model, and have not yet begun to internalise the role model for dealing with dying patients.

This other caring role, so close to that of the counsellor or psychotherapist, cannot be foreign to the everyday experience of g.p.s., who have never played a simple curative role like that of a surgeon, dentist, or chiropodist. With the advent of terminal illness, as opposed to merely dying, the best g.p.s have not had to add the skills of a psychotherapist to their repertoire, for they have always been necessary, however neglected during medical training in favour of the more teachable techniques of physical medicine. This was recognised by Parsons himself when he wrote, "Modern psychotherapy has been built upon the role of the physician as this was already established in the social structure of Western Society." (1951b, p. 458). Perhaps when counselling and management practices are more firmly established in the training of doctors the role of curing the sick and caring for dying will be given equal weight, distinct but not conflicting, in the profession of general practice.


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ADDENDA


Appendix 1

G.P. Interview 1 Schedule

Section 1
1) How old are you Dr. . . . . ?

2) And when did you qualify?

3) And where was that?

4) How long have you been at this present practice?

Section 2
And now to turn to this practice and get some background information on it. Firstly:-

1) How many doctors are there in this practice?
   Are they all full time?

2) How is the practice organised, meaning are you all equal partners?

3) What is the catchment area of the practice?

4) How many patients over the age of 16 are included in the practice?

5) And how many of those are registered with yourself?

6) What are the physical resources of the practice in terms of consultation rooms, treatment rooms, office space etc?

7) What are the personnel resources of the practice in terms of attached district nurses, practice nurses, receptionists etc?

8) How are consultations arranged, do you have an appointment system or do you run an open surgery during certain hours? What hours do you keep?

Section 3
And now to turn to your patients. Firstly:-

1) How many patients do you see each day on average in surgery? And on house calls?

2) How long do you spend on average with each patient in surgery? And on house calls? (Does that include travelling time?)

3) Do you feel this generally suffices or not?

4) How many patients do you have on your books at present who are suffering from an incurable disease which you believe will be fatal?

   typical number for your practice; and in
Appendix 1

6) What are the major illnesses with this prognosis (death) that you meet?

7) Apart from the illnesses in the above group, how many patients do you have suffering from chronic illnesses?

8) How many of these do you expect to ever recover 100%?

9) What kinds of illnesses are we considering in the chronic group?

Section 4

And now to turn specifically to terminal illness and the way in which you approach this group of patients. Firstly:-

1) What do you mean when you speak of terminal illness?

2) Do you find that these patients have any special needs or not?

3) What resources are available in this geographical area for the treatment of the terminally ill at home? (Are there back up services on which you can call?)
   a) And in terms of hospital beds and their availability?
   b) And is there a hospice or terminal or special care unit?

4) When treating someone with a terminal illness what is your aim?

5) Do you find treating this class of patient, the terminally ill, any more or less difficult than treating any other class of patient? Could you explain that more fully, for what reason do you think that is?

6) How do you feel when you make a diagnosis of such an illness or when it becomes apparent that this is the likely outcome?

7) Do you tell patients when they are suffering from an incurable fatal illness, or not?

8) How do you decide to tell them or not? What sort of criteria do you use?

9) Do you ever tell other members of the family in preference to the patient?

10) What criteria do you use in this case?

11) Do you expect the person that you have told to tell the patient or not?

How to tell a patient, how do you tell the heir diagnosis and probable prognosis?
13) Do you find this difficult or not? Why do you think this is?

14) How do you think the patient takes it?

15) Have you ever regretted telling a patient? What happened and why?

16) What do you think are the major problems of the terminally ill patient?

17) Do you think the nature of the illness changes your feelings towards a patient or not? How?

18) How do you typically treat such patients - where do you think it is best to treat them?

19) What sort of criteria influence this decision?

20) Given adequate resources where should they ideally be treated? Why?

21) How do you feel when a patient dies?

22) Do you make any special efforts towards the family or is this unnecessary? Can you explain?

23) Does your treatment of such patients differ in any way subjectively from treatment of other patients?

24) Would you like to expand on anything you have said?

25) Have you any thoughts on the subject or experience to tell me about which we have not covered?
Appendix 1

G.P. Interview 2 Schedule

The following questions were asked for each patient interviewed.

1) How long have you known this patient?
2) How good a relationship do you have with this patient?
3) Why did you tell or not tell this patient about the nature of the illness?
4) How do you think this patient is coping?
5) What do you think this patient's needs are?
6) Do you feel happy about the way this patient is progressing?
7) How often do you see this patient?
8) Why did you select this patient for the study?
9) Which group is this patient in?

Patient Interview Schedule

After setting up and checking the audio recording equipment the interview was introduced as follows:-

"As I have previously explained, I would now like to ask you a number of questions about the way you treat terminally ill patients. The answers you give are for research purposes only, and will remain completely confidential. Any names you may use, or anything you may say which may identify yourself, your patients and where you practice will be removed from the tape before transcription. Thus your identity will be known only to myself. Firstly I would like to collect some background information about yourself and this practice, if that is alright by you?"

The patient was then requested to supply the following information

Full name
Date of birth
Place of birth
Marital status
Age and grade at which formal education completed
Patient's (or spouse's) occupation
Patient's religious affiliation
General practitioner with whom registered
How long registered with this doctor
Sex was assessed visually

Preamble I am going to ask you some questions about your doctor and the treatment you receive before asking you more specific questions
Appendix 1
about your present illness. Please answer the questions in
your own words and take as long as you wish to answer.

Section 1
1) Is there a doctor at the practice whom you think of as
your own doctor? Who?
2) How often do you see your doctor for treatment?
3) How often would you like to see your doctor?
4) Do you see him in surgery or does he visit you?
5) Do you think you relationship with Dr .... is (prompt)
   impersonal and businesslike
   personal and friendly
   businesslike but friendly
   other
don't know
6) How well do you think Dr..... knows you?
7) Do you find Dr..... easy or hard to approach?
8) Do you find Dr..... easy or hard to talk to?
9) Why do you think this is?
10) Do you think the doctor is interested in you as a
    person or restricts his/her interest to your medical
    condition?
11) Do you feel this is how it should be or not?
12) Do you feel confident in your doctor or not?
13) Do you feel the facilities made available to you are
    sufficient or not?
14) How would you like to see these improved?

Section 2
Perhaps you will tell me about your illness starting from
when you first noticed there was something wrong and going
through from then as accurately as possible. Who you saw?
What they said? How you felt? What was wrong with you etc?

15) When did you first notice there was something wrong?
16) How long have you been seeing Dr about your
    complaint? (if time delay) So you waited some
    time before seeing the doctor? Why was that?
17) Has a doctor described the illness to you? Who?
18) Can you tell me what he/she said?
19) Can you tell me how he/she said it?
20) Did you understand him/her?
21) Has a doctor described the treatment to you?
22) Can you tell me about this?
23) Do you feel happy about the way he/she told you these things or not?
24) Do you feel happy with the treatment you have received or not?
25) Does your condition give you much pain or not?
26) Are there any aspects of your condition that you would like your doctor to pay attention to or not?
27) How restricted are you by your condition?
28) How do you cope with day to day living, meaning cooking cleaning etc? Who helps you?
29) Do you get out at all? (much)
30) How do you feel about you illness in general?
31) Would you like to add anything about anything we have discussed?
CONTENT ANALYSIS INSTRUCTIONS

When performing content analysis of doctor interviews you are seeking utterances by the doctor of 6 types. These utterances are about

1] Communications of Diagnostic Information
2] Communications of Prognostic Information
3] Types of Patient who are told or not told
4] The doctor's aims in telling or not telling
5] The doctor's reasons for telling or not telling
6] Patients knowledge about their illness as perceived by the doctor.

Any utterance of this type will then be categorised according to the categorisation scheme explained below.

Categorisation of utterances must be on the basis of the manifest content of the transcript only, that is reading of meanings into what is said which go beyond the information in the transcript should be avoided.

The categorisation of utterances should be based on the paragraph as a unit. That is within one paragraph an utterance of an idea is coded only once, but if the same idea is expressed again in the next paragraph it is recorded. Although often there may be only one utterance in a paragraph at other times there may be more than one. This occurs when there is a clear change in the subject matter being described. Such boundaries should be marked in the text by the coder. An example of a change in subject is: a doctor describes how he does something and then moves on in way of illustration to give a case history. The case history should be treated as a separate utterance. Another example may be where he describes one sort of patient and his treatment of them and then turns to another group and his treatment of that group. Words
such as 'whereas', 'but', 'on the other hand' may be useful indicators of boundaries under these circumstances.

Paragraphs are bounded by utterances of the interview of a substantial nature. In particular the non-directive reinforcing utterances of the interviewer [ie. u, hhuh, right] do not act as paragraph boundaries.

Categorisation Scheme

[1 & 2] Communications about diagnosis and prognosis are sub-classified in an identical way and will thus be described here together. In fact the coder's choices when faced with what he believes to be an utterance codeable in this section

1) to classify it either as a communication about diagnosis or prognosis if it is clear which of these it is,

2) to classify it in the 'communication of diagnosis/prognosis unclear' category, if it is unclear which is being described.

If the utterance is one describing both diagnosis and prognosis it should be coded in both of these rather than singularly under the 'unclear' category.

The first level of the analysis considers whether information is given to or withheld from the patient. [Patient will be used throughout but the coder should note that the top line of these categories coding sheet is for indicating who the recipients of information is, ie. patient or family.]

The given/withheld told/not told sub-categories are mutually exclusive throughout the content analysis scheme. [N.B. an utterance which appears to require coding in both of these sub-category positions is indicative of its being more than one utterance.]

The next level is that which generally describes the nature of the communication. That is, is it explicit or not, implicit, in the case of given information or refused in the sense of a deliberate
attempt to withhold information or fudged in a less overt attempt. The next level refers to aspects of the information given to or withheld from patients.

1) site(s): information referring to the site(s) affected by the illness.
2) severity: information referring to the severity of the illness for the patient.
3) time span: information referring to how long the illness will continue or how long it will take or could be expected to take, in its progression etc.
4) symptom: information referring to the symptoms of the illness and/or the meaning of those symptoms.
5) treatment: information referring to the nature of the treatment being received, to be received or potentially available and its meaning.
6) curable: information referring to the fact the illness is curable.
7) incurable: information referring to the fact the illness is incurable.
8) cause: information referring to the cause of the illness or making causal attributions.
9) fatal: information referring to fatalities from the illness or that the illness will result in the patients death.

The next level of the analysis refers to the means by which information is communicated or withheld.

MEANS

1) Hints: information is conveyed (N.B. in all cases it is possible that information is not actually conveyed by the strategy but withheld.) to patients about aspects of their illness by use of hints.

eg. If they don't take it up I'll push them a bit. I'll say things like 'are you sure?'
2) Implication: information is conveyed by giving pieces of information about the illness from which the patient may be able to logically deduce further information.

eg. Told him about his operation and another time pointed out his symptoms had not changed, so his may have worked out the operation was not successful.

3) French Humour: information is conveyed in a jovial or humorous way. A bit of a joke is made about the news being conveyed.

eg. I don't put on the black cap ha ha.

4) Fatalism: information is conveyed in a way expressing fatalism perhaps including aphorisms about the inevitability of the events.

eg. I'll say its just one of those things.

5) Euphemism: information is conveyed using euphemisms for the diagnosis or prognosis.

eg. suspicious cells, St. Peter may call.

6) Technical: information is conveyed using technical language or jargon. Information may not be conveyed because the level of technicality may be beyond the sophistication of the patient.

eg. malignant neoplasm

7) Denial: information is conveyed but then implications of the information or aspects of the information are denied. Patient knowledge expressed through questions or statements is denied by doctor.

eg. Pt "Have I got cancer doctor?" Dr "Oh no its not."

8) Reassurance: information is conveyed but reassurance is offered about the meaning of that information or used with denial after denying an aspect of patient knowledge etc., the doctor offers reassurance.

eg. We'll get it all cleared up.
9) **Evasion**: information is not conveyed by the doctors use of the way he manages the consultation to avoid allowing a patient asking critical questions or evading a question when asked or avoiding contact with patient to make questioning impossible.

10) **Steering Questions**: information is conveyed by steering the patient to ask pertinent questions. This is in a sense the opposite to evasion in that the doctor is managing the consultation to enable questions to be asked so that he may convey information.

eg. "So what do you think you've got?"

11) **Response to questions**: information is conveyed but merely in response to patient questions which are not necessarily provoked by doctor.

12) **Uncertainty**: uncertainty is used to either withhold information from the patient or to control the flow of information to the patient or to control the understanding of the implications of information. Uncertainty may be real or professed by the doctor to the patient.

eg. "I don't know the answer to that question as I have not yet received the reports on the tests carried out."

or

"Cancer is an unpredictable disease and we cannot say if it will stay dormant or not."
3) Types of Patient

The first level is again to decide whether the patient is told or not told. [this includes other means of conveying/withholding information].

Criteria upon which the decision is based to tell/not tell are then grouped under 4 main headings:

1) psychological
2) social
3) other patient attributes
4) aspects of the illness

Each of these has more specific sub-categories, the headings themselves being merely to aid the coders choice.

1) Psychological

1) anxiety: anxiety levels, or states or proneness as perceived by doctor, or previous history of anxiety is used by doctor in his decision [non clinical].

2) depression: depressive states, proneness or levels, or previous history is indicated as a factor in decision [non clinical].

3) neuroticism: neuroticism, neurotic state or proneness is indicated as a factor in decision [non-clinics].

4) intelligence: patient intelligence level as perceived by doctor is used as factor in decision.

5) clinical state: an abnormal psychological state of clinical proportions (e.g. requiring treatment) or a history of a clinical problem is indicated as a factor in decision [non organic].

6) organic state: an abnormal psychological state of an organic nature (e.g. damage from stroke) is indicated as a factor in decision.

7) unspecified: doctor refers to some ambiguous and unspecified
psychological state/indicator as being a factor in his
decision.

8) other: some specified psychological variable not covered by
the above [please specify].

2) Social

1) Financial: financial considerations for the patient is a
factor in the doctors' decision.

2) social status/class: the patients' social status or class
is a factor in the doctors' decision.

3) family wants: the desires of the family are taken into
account as a factor in the doctors' decision.

4) interpersonal relationships: the relationships the patient
has with others are a factor in the doctors' decision.

5) family per se: the doctor evaluates the family unit and
takes this evaluation into account in his decision.

3) Patient Attributes

1) patient knows already: the doctor takes into account the
state of the patient's knowledge about their illness in a
decision to give/not give the patient information.

2) patient wants to know: the doctor evaluates whether or not
the patient wants to know more about their illness. That
is the doctor makes some [subjective] evaluation of the
patient's desire to know beyond their asking.

3) patient asks: the doctor bases his decision on the express
enquiries of the patient.

4) patient knowledge inevitable: the doctor bases his decision
on a perception that the patient will find out anyway. That
is even if the doctor were to attempt to conceal information
from the patient the patient would eventually gain this
information from [eg] another source.

5) patient age: the patients age is taken into account as a
factor in the doctors decision.

6) patient other: any other aspect of the patient not covered by the above is taken into account in the doctors decision (please specify).

4) Aspects of Illness

1) sort: the sort of illness from which the patient is suffering is a factor in the doctors decision.

2) severity: the severity of the illness is a factor in the doctors decision.

3) time: the time during the illness is a factor in the doctors decision, eg. the doctors estimate that the patient will only live x weeks longer.
6) **patient other:** any other aspect of the patient not covered by the above is taken into account in the doctor's decision (please specify).

4) **Aspects of Illness**
   1) **sort:** the sort of illness from which the patient is suffering is a factor in the doctor's decision.
   2) **severity:** the severity of the illness is a factor in the doctor's decision.
   3) **time:** the time during the illness is a factor in the doctor's decision, eg. the doctor's estimate that the patient will only live x weeks longer.
4) Aims in Telling/Not Telling

The first level of this category of utterance is to specify whether the aim is to be achieved by

1) **telling** or 2) **not telling** (or in other ways conveying/withholding information) a patient about the illness.

The aim of telling/not telling a patient is:

1) **patient management**: that is to achieve technical ends with the patient, to, for example, secure the patient's cooperation in a regime of treatment, or to make the patient more docile and accepting of the doctors professional help.

2) **patient happiness**: to ensure that the patient is as happy accepting etc., or as minimally distressed as possible.

3) **family happiness**: to ensure that the family is as happy accepting etc., or as minimally distressed as possible - including for example the possibility of the family doing death work or preparing for the bereavement.

4) **own happiness**: the telling or not telling is to achieve a minimal level of distress for the doctor himself.

5) **absolution of self**: the doctor tells or does not to absolve himself of responsibility, or to make it clear to the patient/family that he has not been negligent in his duty as doctor to cure the patient.

6) **patient financial/organisational**: doctor tells/does not tell on the basis of his perceptions of the patient's need to have information in order to make financial arrangements or other organisational or official arrangements (ie. to set their affairs in order).

7) **patient relationship Dr**: doctor tells/does not tell patient in order to alter [improve?] or maintain his relationship with the patient.

8) **patient relationship others**: doctor tells/does not tell
patient in order to alter [improve?] or maintain the 
patients relationships with others [primarily family?].
5) Reasons for Telling/Not Telling

This category differs from the aims in telling category in that whereas the aims in telling category considers what effect on the patient the doctor is attempting to attain and therefore in a 'forward looking' category the reasons for telling category considers the reasons behind the doctor's adoption of his policy, his justification for his approach.

The first level is again to specify whether the doctor tells or does not tell his patients or otherwise conveys, or not to them.

The second level then delineates his general justification for his policy.

1) ethical: The doctor considers his policy is motivated by an ethical obligation. He has made a decision of principle. The patient has for example a right to know or a right not to know and the doctor considers this as a moral decision. This may sometimes be a paternalistic position.

2) medical: The policy is based on technical or medical considerations. His decision to tell or not is based on a belief that this can have advantageous/disadvantageous medical consequences [eg. patient turns his head to the wall].

3) Management: The policy is based on a belief that telling/not telling has management consequences, which make his job harder or easier. These are to be distinguished from the medical sub-category which consider physical effects of information on patients, whereas this category considers the effects information has on for example co-operation in a treatment regimen, or stopping patients going elsewhere for treatment.

4) psychotherapy: The policy is based on principles of psychotherapy and telling/not telling is part of a treatment regime to benefit the patient psychologically.
5) **personal feelings**: The policy is based on the personal feelings of the doctor which cannot necessarily be articulated.
The next level considers more fully the background to this position.

Background

1) **training**: the policy was adopted because of training received, either at medical school or during general practice training or from courses or lectures attended since that time.

2) **clinical experience**: the policy was adopted because of experiences during practice. This included specific case histories of patients treated by the doctor which were formative and are quoted as explanations or justifications for present behaviour or policy.

3) **reading**: the policy was adopted because of reading done by the doctor since he has been practising.

4) **talking doctors**: the policy was adopted because of conversations he has had with other doctors informally, for example, partners.

5) **talking others**: the policy was adopted because of informal conversations he had had with other lay persons or patients, or formal conversations with patients during consultations.

6) **apocrypha**: the policy was adopted on the basis of stories heard of unknown authenticity or origin. It is based on a professional folk lore or stories of incidents, that have occurred to other unknown doctors. Beware when using this category to distinguish from case histories of the doctor's own patients or those of partners or other verifiable stories of other doctor acquaintances.

7) **own feelings**: the policy was adopted on the basis of the doctor's own feelings or attitudes.

8) **no insight**: the policy was adopted by the doctor, but he is unable to account for his reasons.

9) **other**: the policy was adopted for reasons other than those covered by the above (please specify).
[6] Patient Knowledge

The first level is to specify whether the patient has knowledge of i) diagnosis or ii) prognosis or iii) this is unclear or iv) both diagnosis and prognosis in the doctor's opinion.

The next level is to specify the degree of that knowledge and consists of 6 sub-classes.

1) **complete:** The patient has complete knowledge of either diagnosis or prognosis etc.

2) **partial:** The patient has some knowledge of either diagnosis or prognosis but not complete knowledge.

3) **suspects:** The patient suspects their diagnosis or prognosis but does not know for sure.

4) **incorrect:** The patient has knowledge of their diagnosis or prognosis but this is in fact incorrect. Thus eg., a diagnosis of lung cancer is believed to be pneumonia by the patient.

5) **none:** The patient has no knowledge of their illness at all.

The next level is the source of the knowledge of the patient. These can be split into two sorts external sources, the knowledge has been given by an external agent, and internal sources, the patient has in some way worked out the diagnosis or prognosis for himself.

**Sources**

**external**

1) **g.p.:** The GP himself has given the information, which is the basis of the patient's knowledge, to that patient.

2) **GP other:** Another GP has given the information to the patient.

3) **hospital:** A doctor or other medic at a hospital has given the information to the patient.

4) **family:** A member of the patient's family (eg. spouse) has given the information to the patient.

5) **other:** Some other person not covered in the above has
given the information to the patient.

**internal**

1) **treatment**: The patient has recognised some aspect of the treatment that he is receiving which has given him information about his diagnosis or prognosis, eg. a patient recognises that he is receiving radium therapy which is for cancer ergo he has cancer.

2) **self diagnosis**: the patient recognises certain of his signs and symptoms, how he feels, etc., and is able to work out his diagnosis from these or noticing the way his illness is progressing works out his prognosis, eg. continuing deterioration will result in death.

3) **tacit**: the patient intuits his diagnosis or prognosis in a way that is not specified; he just knows.

4) **other**: the patient comes to know his diagnosis or prognosis in some way not specified in the above [please specify].

**Coding**

Each utterance that is to be coded should be underlined in the text and the boundaries of the utterance marked with vertical strokes. Each utterance should be numbered in the text and that number entered into each cell of the coding sheet to indicate that that content category/sub-category item is present in the utterance. Items present in one utterance in one category should normally be marked in one column, in order to facilitate scoring of coding sheets for analysis. As many category or sub-category classes as are present in one utterance should be coded. The only coding that is prescribed as mutually exclusive is the use of the tell/not tell sub-categories together. No other combination of codes is prescribed. Although some combinations are logically inconsistent, they may be used if necessary. Attempts at their use, could indicate miscodings (eg. combining more than one utterance) or inherent weaknesses in the content analysis scheme.
A manual for patient interview content analysis similar in style to the g.p. interview content analysis schedule was prepared. However, for reasons of brevity we limit the categories of this scheme, rather than present the entire training manual here. Thus coders read interviews searching for the following types of patient utterances.

1) Patient knowledge of diagnosis
2) Patient knowledge of prognosis
3) Patient source of knowledge
4) Patient's opinion of g.p. and relationship with g.p.

Patient knowledge of diagnosis or prognosis subcategories.
   i) Patient knows completely
   ii) Patient suspects
   iii) Patient expresses no knowledge at all
   iv) Patient appears to know but denies
   v) Patient disbelieves diagnosis/prognosis

Patient source of knowledge subcategories
   a) External
      i) g.p. (own)
      ii) g.p. (other)
      iii) hospital doctor
      iv) nurse
      v) spouse/next of kin
      vi) other (specify)
   b) Internal
      i) self diagnosis
      ii) recognise treatment
      iii) tacit knowledge
      iv) other (specify)

Patient's opinion of g.p. and relationship subcategories
   a) G.P.
      i) good
      ii) satisfactory
      iii) bad
   a) Relationship with g.p.
      i) good
      ii) satisfactory
      iii) bad
APPENDIX 3
Ethical committee protocols
1. **Title of project:**
Investigation of factors involved in the doctor-patient relationship during terminal care at home.

2. **Responsible Investigators:**
Dr. A.W. STILL: MR. C.J. TODD, M.A.
Department of Psychology, University of Durham.

The study is funded by the Social Science Research Council and the North of England Cancer Research Campaign.

3. **Summary:**

Empirical studies of doctor-patient relationships during terminal care at home are conspicuously lacking from the literature. Very little is known about how doctors and patients interact in this difficult situation and what strategies are most desirable in terms of patient wellbeing.

A pilot study has identified a number of strategies used by doctors under these circumstances.

Two complementary studies are proposed herein, which will further investigate the strategies used, specifically the extent of use of these strategies, how these change over time as the case progresses, factors that may influence the strategies, the efficiency of the various strategies and the validity of the accounts of behaviour against observable behaviour.

Both studies are longitudinal in nature. In the first, 20 GPs will supply all newly diagnosed terminal patients over a 3 month period, plus controls, who will then be followed for 6 months, being interviewed bimonthly. Doctors will initially be interviewed on their perspective on terminal care and again at the end of the study at which time case histories will be collected. Both doctors and patients will make records on consultations during the study period. Patient interviews will be run blind and the content analysis method will enable a double-blind design.
In the second study, two GPs will carry out the same procedures but in addition will tape-record consultations (and where available videorecording will also be used) to enable behavioural records to be checked against reported behaviour.

Normal procedures will be followed to maintain doctor patient confidentiality. The design also minimises the danger of adverse patient reaction but should these occur the researcher is trained in psycho-therapeutic techniques applicable for their management. Written consent is obtained from all patients.

4. Scientific Background

(a) Literature on care of the terminally ill

Numerous articles and books have been published on the psycho-social care of the terminally ill patient, and it is now generally recognised that their needs differ from those of other patients. However, many of the articles present the opinions of individual doctors and/or case studies of a few patients (e.g. Blake 1977; Dumphy, 1976). They call on the medical profession to attempt to treat these patients in a more humanitarian fashion, but lack the unambiguous empirical evidence that is necessary to support specific recommendations.

(b) Care of the terminally ill at home

Research to date has generally focussed on the care of the terminally ill in institutions (Kubler-Ross, 1970; Hinton, 1967; Lamerton, 1973; Cotter, 1971; Garfield, 1978). Studies of the care of the terminally ill at home are uncommon. The study by Cartwright et al (1973) of a sample of deceased patients reveals the problems of home care for GPs, patients and families both in terms of physical resources and of psychological stress. (Because of its retrospective nature this study, though important, is limited in value).

The report of the DHSS standing sub-committee on cancer (Department of Health and Social Security, 1980) recommends an integrated care system primarily based on GP care in the home, in order to improve the care of terminal patients within the financial constraints of the NHS. Already approximately 1/3 of deaths in Britain occur at home, and it is probable that given the present policies this will increase. Moreover, this figure conceals the fact that 83% of the deceased studied by Cartwright et al (1973) spent most of their last year at home, and that
66% will have been restricted for 3 month or more. Although these figures refer to all causes of death one can estimate that from the 130,000 or so people who die from cancer each year, up to 43,000 will die at home and receive most of their care from the primary care team and relatives (Cartwright et al 1973). Thus there is a large population of patients suffering from terminal illnesses, including cancer, who remain at home and receive treatment primarily from their GP.

(c) The doctor-patient relationship
Fitton and Acheson (1978), Byrne and Long (1976), and Ley et al (1976) have revealed the importance of the subjective relationship between doctors and patients in effective management of illnesses. The collection by Garfield (1978) reports aspects of this in relation to terminal care. However, information about the psychosocial care of the terminally ill at home in Britain is lacking, and little is known about the way GPs treat the terminally ill. Present practice is largely determined by extrapolation from institutional care or rules of thumb developed from practice by physicians. If social and psychological treatment of the terminal patient is to be improved more information is required.

(d) A pilot study of doctor-patient relationships has already been run in County Durham. Permission for this study was obtained from Durham Area Health Authority on 15 April 1981. The study was completed during October 1981.

Conclusions from pilot study
Exhaustive search of the transcript material has revealed a number of patterns in the data. These will be expressed in quantitative terms by content analysis (a technique for making inferences by systematically and objectively identifying specified characteristics of messages). This analysis will be complete during June 1982.

The analysis of the data to date have revealed a number of results of interest.

The doctors interviewed fit the national picture of general practice in terms of the number of patients registered with them, amount of time spent on each consultation and number of patients seen per day (these are within the normal range, approximating the means). That 4 out of 5 doctors interviewed, report not telling patients they are dying conforms to the figure of 80% reported by Hinton (1967). These doctors appear to use a number of strategies when communicating to their dying patients. These include the use of hints, implication, euphemism, trench humour, denial, reassurance and evasion. While some of these strategies may act to ensure that the patient does not discover
or come to suspect the nature of their illness and its prognosis, others (e.g. euphemism) appear to transmit the information to the patients.

The patients interviewed are similar to patients reported in other studies of terminal illness in age and demographic terms - although lower social classes are more highly represented, probably reflecting the geographical region of the study as well as the fact that previous studies have centred on institutional care, especially hospices, which may be expected to attract more middle-class patients (c.f. Mechanic, 1968).

The terminally ill patients are predominantly suffering from forms of cancer. The non-terminal chronic patients are suffering from diseases such as bronchitis emphysema, arthritis and pernicious anemia. The sort of problems dying patients have, are revealed by the following examples:

(1) A female patient who recognised radiotherapy as a treatment for cancer when no-one had told her of her illness diagnosis and she had been told that she was simply being X-rayed. This woman reported being initially very disturbed by her discovery but appears to accept the illness more calmly now. One result of the experience is a distrust of her GP and other doctors.

(2) A male patient who suspected he had a terminal cancer and whose wife eventually told him despite the doctor's recommendation that he was not to be told. The relationship between husband and wife was reported to have become very tense before she told him, because of the secret she was keeping from him. Since then the patient has, to quote the doctor "accepted very well the diagnosis and he's accepted what it means to him and he is living his life to the full".

(3) The female patient who suspected that she was dying from cancer who during the interview indicated she suspected this, then denied that she had ever had cancer and became very distraut when her husband mentioned she had had a colestomy. She appears to live in a world of half-knowing, denying and intense anxiety - she scored high on the state anxiety scale.

The dying patients appear to adopt complimentary strategies when communicating to the doctor. Thus in the case of the man told by his wife described above (2) the GP and patient never talk about the patient's impending death or that he has a malignant brain tumour, although both parties know this and know the other knows. The patient reported that he would be happy to talk about this with his doctor but never does because he would not want to 'upset him'.

Many of the dying patients appear to know or definitely do know the illness from which they are suffering and its prognosis. This is in spite of
the fact that doctors report that they have not been told. The ways in which patients come to know include self diagnosis, recognition of treatment and being told by some other (e.g. spouse - next of kin are told in all cases). However, there are also a sizeable number of these 'suspecting/knowing not explicitly told' patients for whom the information source appears to be the GP. That is, they are being covertly given the information by the GP using the strategies indicated above, even though the GP denies that they are told. These findings offer explanation to findings by Cartwright et al (1973) that 83% of patients who know that they are dying have never been told by anyone.

There are also indications in our data that not telling patients the diagnosis and prognosis is associated with stress in the patients. Problems in relationships between patients and spouses also appear to be exacerbated by the telling of spouse but not patients. This may result in adverse bereavement reactions on the part of spouses. Although at present our data is unable to answer this question doctor follow-up questionnaires will shed light on the issue, when analysed. Some of the strategies used by "telling" doctors - at least initially when preparing patients to be told - are similar to those used by "non-telling" doctors.

Although these results give us a general indication of how doctors and patients are interacting during this difficult time the design of the study is unable to answer questions concerning how doctors treat patients at differing stages of the patient's illness. This factor would appear pertinent. The small sample size needs to be increased in order to investigate the strategies further if generalisations are to be made. It is also most important that we check the validity of the accounts rendered by doctors and patients by collection of behavioural data if the research is to be able to make empirically sound recommendations concerning desirable strategies in the future. The studies proposed here will enable these problems to be overcome. In addition more meetings with each patient will enable the researcher to increase the rapport with the patients facilitating more complete data collection than in the first study.

5. Objectives

The studies proposed in this application have the objective of answering the questions which can be placed under the following headings:

(a) Extent of use: Are the strategies of communication already identified widely used by GPs and their terminal patients during their interactions or are they unique to the small sample studied? Do other strategies exist and to what extent are these used?
(b) **Time course**: Are different strategies used at different stages of the terminal illness or does a strategy remain dominant once initiated? What part does the progression of the illness play on the strategy/ies adopted by the doctor and patient?

(c) **Factors**: What factors influence the decision to adopt a strategy? What factors influence stability or change of a strategy? What cues do doctors pick up from patients that influence their decisions? What cues do patients pick up from doctors both in terms of knowledge about their illness and in terms of strategy adopted by patients? Are strategies doctor or patient driven?

(d) **Efficacy**: How effective are strategies adopted in securing the doctors goal, that is either concealing from or revealing to the patient the diagnosis and its prognosis? How effective are the strategies in terms of the psychological well being of the patient? To what degree are longer term gains set off against short term losses and the corollaries of this question?

(e) **Validity**: How well do accounts of behaviours proffered by doctors and patients match against observable behaviours? (Study 2 only)

6. **Design**

Two parallel and complimentary studies are proposed:

(i) **Longitudinal study of doctor-patient relationships during terminal care at home using interviews and written records**

(a) **Subjects**: Twenty general practitioners registered with the Durham Family Practitioner Committee will be selected at random and invited to take part in the study. Doctors will be requested to supply all their terminally ill patients upon diagnosis over a period of 3 months. Thus statistically, as a GP will see 5 terminally ill patients each year: one would expect a sample of 25 terminally ill patients, 1.25 from each GP. Each GP will also be requested to supply a control non-terminal chronic patient for each terminal of approximately the same age, sex, socio-economic group site and severity of symptoms diagnosed at about the same time. The study is thus essentially a cohort study of terminally ill patients diagnosed over a three month period.

Each patient will then be followed for a period of six months from their diagnosis or until their death.

(b) **Procedure**: Doctors will be initially interviewed about their ideas on terminal care and background information on the practice, training, etc. collected. (Interview schedule 1).
The study will then be fully described to doctors and they will be requested to ask patients when diagnosed to take part in the study (see below (f)). Those who agree will be interviewed initially by the researcher at home (Schedule 2). The state-trait anxiety inventory (Speilburger et al, 1970) will also be administered.

Patients will be re-interviewed and STAI readministered at 2 monthly intervals. These interviews will cover essentially the same information as the first except that points made during previous interviews will be followed up and questions asked about changes since the last interview, (Schedule 3).

Doctors will be requested to make notes on consultations with patients after each consultation on a standard form (form 1). These will be distributed to doctors at the beginning of the study and returned to the researcher monthly. These forms will be anonymous except for code numbers which are unknown to the researcher. This will control bias from knowledge of doctor-patient interactions while interviews are still being conducted.

Patients will also be requested to make notes on consultations after each consultation and these will be collected on subsequent visits (form 2). These will remain unexamined until completion of the study.

Upon completion of the interviews with patients the GPs will be re-interviewed and case histories and subjective assessments of the individuals collected. Individual code numbers will be identified.

The above procedure will give us the data to identify strategies of communication between doctors and patients, analyse the factors involved, how these change over time, and their efficacy, (objectives a-d).

(c) Additional work/cost: The study will require from each doctor approximately 2½ hours of time at his convenience for completion of interviews and writing notes on consultations. Postage costs etc. will be covered by the researchers.

(d) Benefit to patients: It is anticipated that most patients will benefit from taking part in the study as it is reported that in many such cases just having a concerned interested listener is helpful. The study will also reveal any problems that individual patients have and these can be reported back to doctor/care team, if the patient so consents. Future patients will also benefit from the study by the identification of desirable models of communication from doctors.

(e) Discomfort or danger: Patients will be required to give 1½ hours of their time at their convenience to take part in the initial interview and approximately 1 hour in subsequent interviews. The only possible discomfort would result from the disturbing topic of the interviews. However, the interviews
are designed to minimize this. Patients are not asked bluntly about their illness in such a way as to disturb them. The interviews set up the conditions under which patients can feel free to discuss the nature of their illness, their fears and knowledge about it. Patients will not be pressed to discuss disturbing aspects of their care and it will be made clear that they can terminate the interview if they wish. The researcher has been trained in counselling techniques necessary for dealing with any problems encountered and has experience in their use. The design of the study ensures that the researcher does not know details of the case during interviews and thus cannot reveal them to patients. Should a patient press for details the researcher will advise the patient to discuss the issue with the doctor, ensure the patient is satisfied and inform the doctor of the situation.

Great care will be taken to ensure all patients are happy about the interview at the end of the session. No patient will be left if there is any doubt as to the patient's state of mind.

This design proved adequate to ensure that there were no adverse reactions in the pilot study and thus no problems are foreseen for this study.

(f) **Explanation and consent:** A written general explanation (see attached letter) will be sent by the doctor to invite patients to take part in the study.

Patients who agree to take part in the study will be visited and before the interview is started the study will be explained in the terms described below and written consent obtained using the attached consent form.

"The study in which you are being asked to take part is a study of the relationship between doctors and patients receiving treatment for a chronic or long-term illness. Your doctor has put us in contact with you because you have been diagnosed as suffering from an illness the treatment of which will possibly necessitate fairly regular contact with your doctor over the coming months. This part of the study is investigating your views on the treatment you have received from the doctor. It is also investigating how you feel about your illness, how you are coping, what you feel could be done for you, what is good about the treatment you receive, and what, if anything, could be done to improve it. From this study we hope to find out what could be done, in terms of the communication between doctors and patients, to improve the care of patients within the National Health Service.

We guarantee that anything you may say will be confidential between you, and the researcher. Your identity will only be known by the researcher. Nothing will be said to your doctor or anybody else about anything that you may say."
You will be asked to fill in a self-evaluation form, and answer various questions about your illness, feelings, and relationship with the doctor in your own words. The interview will be tape-recorded for analysis but will be heard by no-one else than the researchers.

The researcher would like to have the opportunity to meet you again on later occasions at your convenience to discuss how your case is progressing. We would also like you to keep brief notes on what happens when you meet your doctor. If you are willing to do this I will describe exactly what is required later.

If you do not wish to answer a question you are under no obligation to do so. If you wish to change an answer or decide you do not want to continue you may.

We would also like your permission to talk to your doctor, and for him to be allowed to give us information relating to your present illness."

Patients would then be asked if they have any questions about the study and these answered. Then they will be asked to give written consent. It will again be stressed that the patient is under no obligation to take part in the study, but that the researcher is under obligation to protect the patient's interests for their co-operation in the study.

No special problems are anticipated in obtaining patient's consent.

All normal procedures for maintaining confidentiality of subjects will be followed.

(ii) Longitudinal study of doctor-patient relationships during terminal illness using interview technique, written records and recording of consultations.

Objective: The objective of this study is to check on the validity of accounts rendered by doctors and patients by comparison of behavioural records against these accounts. Furthermore these records will also enable analysis of the actual way in which strategies of communication operate in practice.

(a) Subjects: Two general practitioners on the Durham Family Practitioner Committee list have been approached and have indicated their agreement in principle to co-operate in this study subject to ethical approval.

The general practitioners will select patients in the same way as in the above proposed study to take part in the study.

(b) Procedures: Procedures for this study are identical to those in the above proposed study except that video or video recording of all consultations with the patients being studied will be made. Sony TCS-310, (a small inconspicuous
portable recorder) will be supplied for this purpose. Both GPs have indicated the possibility of video-recording consultations in surgery. Advantage of this facility will be taken when feasible.

(c) **Additional work/cost:** The study will require the same time from these two GPs as the above study, plus time for operating recorders and recording details of when, where and with whom the recording was made.

(d) **Benefit to patients:** As per above proposed study (Section 6.i.d).

(e) **Discomfort or danger:** As per above proposed study. (Section 6.i.e).

There is also the possibility that recording patient consultations with their doctor may be disquieting to certain patients.

However, this possibility is minimal as previous researchers also have used this method (e.g. Byrne and Long 1976, Balint and Novell, 1973) and report that patients are cooperative and that patients are on the whole unaffected by the presence of a tape or video recorder. Patients will be given the option not to take part in the study or if they wish the recorder can be turned off during the consultation. Expected refusal rate is low (5%). Furthermore such techniques are often used for teaching purposes without reported adverse effects.

(f) **Explanation and Consent:** Explanation and consent will be as for the above proposed study (Section 6.i.f). However, patients will also be requested to allow consultations with doctors to be recorded. It will be stressed that the recordings are for research purposes only and that their confidentiality will be strictly maintained.

British Psychological Society ethical guidelines for research will be followed.

Recordings of interactions during consultations made will be used for research purposes only. Strict confidentiality will be maintained and all recorded material will be destroyed at the end of the study.
REFERENCES


INTERVIEW SCHEDULES

The following schedules are guidelines to the questions that will be asked of doctors and patients during the study. The format will be strictly followed, as the ordering of topics of discussion is methodologically important. Topic areas will be introduced using verbatim questioning as these questions are designed to minimise sources of bias. As far as possible the questions will be asked as reproduced here, and in that order, as they both control bias and increase accessibility. However, flexibility must remain so that the interviewer can respond to the dynamics of the interviews. There are two major pragmatic reasons for this (as well as theoretical reasons within the paradigm in which this research is being carried out).

(1) That close adherence to the questions may result in poor information, and the interviewer would not be able to follow potentially fruitful turns in the informant's report.

(2) That because of the nature of the project's subject matter, a detached approach whereby the interviewer just asks questions reproduced verbatim without reference to the informant's emotional state would be inappropriate. It must be possible for the interviewer to respond to the informant's state appropriately.

Interviews with doctors are thus likely to stay more closely to these schedules because of both the factual nature of the questions and the lower emotional involvement.

Interview Schedule 1: General Practitioners

1) Personal Information
   1) Name?
   2) Sex?
   3) Age?
   4) When qualified?
   5) Where qualified?
   6) Specialised qualifications?
   7) How long at present practice?

2) Information about Practice
   1) Number of doctors in practice?
   2) Catchment area of practice?
   3) How is practice organized?
   4) Physical resources of practice?
   5) Personnel resources of practice?
   6) Number of patients registered with practice?
   7) Number of patients registered with doctor?
   8) How are consultations arranged?

3) Patients (general)
   1) How many patients do you see each day on average;
      i) in surgery?
      ii) on house calls?
2) How long do you spend on average with each patient;
   i) in surgery?
   ii) on house calls?

3) Do you feel this generally suffices?

4) What are the general sorts of illnesses that you treat in surgery?

5) What are the general sorts of illness that you treat at home?

4) Terminal patients

1) What do you mean when you speak of a terminal illness?

2) How many patients do you have on your books at present who you consider to be suffering from terminal illness?

3) Is this a typical number for your practice/from your experience?

4) What are the major types of illnesses with this prognosis which you meet? Are there others?

5) When treating someone with a terminal illness what is your aim?

6) Do you tell patients when they are diagnosed as suffering from a terminal illness or not?

7) How do you decide to tell them or not? What sort of criteria do you use?

8) How would you tell a patient who you decided to tell?

9) What is your aim in telling or not telling a patient?

10) Do you find telling patients difficult or not? Why do you think this is?

11) How do patients normally react to this information?

12) How would you like patients to react to this information?

13) How do you feel when you make a diagnosis of terminal illness, or when it becomes apparent that this is a likely outcome?

14) Do you find treating this class of patient any more or less difficult than treating other classes of patients? In what way?

15) Do you tell other members of the family in preference to the patient? Who?

16) For what reason do you tell this person in preference to the patient?

17) Do you expect the person you have told to tell the patient or not?

18) Would you say that you have a clear policy about how to talk to your terminal patients or not? Could you describe this? For what reasons did you adopt this policy?

10) Have you treated any terminal cases which stand out in your mind?
20) Why do you think these cases stand out?

21) Have you ever regretted telling a patient or not telling a patient (as the case may be)? What happened and why?

22) What do you think terminal patients’ major problems are?

23) What resources are available in this area for the treatment of the terminally ill?

24) How do you typically treat such patients – where do you think it is best to treat them?

25) What sort of criteria influence this decision?

26) Where would you ideally like to treat them?

27) Do you feel the nature of the illness changes your feelings towards a patient or not?

28) Do you make any special efforts towards the family or is this necessary? Can you explain?

29) Does your treatment of terminal patients differ subjectively in any way from treatment of other patients or not?

30) How do you feel when a patient dies?

31) If you were suffering from a terminal illness would you want to know? Can you explain?

32) Would you like to expand on anything you have said so far?

5) Control patients

1) Apart from patients in the above group how many patients do you have suffering from chronic illnesses?

2) What do you mean by chronic illnesses?

3) What kinds of illnesses are we considering in this group?

4) What is your aim when treating the chronically ill?

5) Do you tell these patients about the illnesses from which they are suffering or not?

6) How and what would you tell them?

7) What sorts of criteria do you use in this case?

8) Have you any thoughts on the subjects we have discussed or experience which you consider pertinent which we have not covered?

9) Would you like to expand on anything?

The rest of the study will then be planned with the doctor.
INTERVIEW SCHEDULE 2: Patients

1) General Information (to be completed at first interview only)
   1) Name?
   2) Sex?
   3) Date of birth?
   4) Place of birth?
   5) Marital status?
   6) Occupation?
   7) Age at which education completed?
   8) Time resident in area?
   9) Religious affiliation?
   10) With which doctor registered?
   11) How long registered?

2) Administration of S.T.A.I.

3) Reiteration of patient's right to decline to answer questions or withdraw from study, reaffirmation of confidentiality of answers.

4) Relationship with doctor
   1) Is there a doctor at the practice whom you think of as your doctor or not? Who?
   2) Are you seeing any other doctors or not? Who?
   3) How long have you been seeing Dr. ... for your present condition?
   4) How often are you seeing Dr. ... for treatment of your illness at present?
   5) Do you generally go to the surgery to see Dr. ... or does he come to see you?
   6) How often would you like to see Dr. ... for treatment?
   7) How well do you think Dr. ... knows you?
   8) Do you think Dr. ... is interested in you as a person or does he restrict his interest in you to your medical condition?
   9) Do you think this is as it should be or not?
   10) Could you describe your relationship with Dr. ... to me? (Prompts - How do you get on with him? How does he act when you see him? Is he perhaps businesslike but friendly, personal and friendly, impersonal and businesslike, serious or jovial, talkative or reticent?)
   11) Why do you think that is?
   12) Do you find Dr. ... easy or hard to talk to?
   13) Do you find Dr. ... easy or hard to understand?
   14) Do you feel confident in Dr. ...?
15) Have any facilities been made available to you by Dr. ... or not? What?

16) Is this sufficient or not?

17) Would you like to add anything to anything you have said so far?

5) **Present Complaint**

"I wish to turn now to the illness from which you are suffering at the moment and which Dr. ... is treating".

1) When did you first notice that there was something wrong?

2) Would you describe what you noticed and how you felt which made you go to see Dr. ...?

3) (If delay between noticing symptoms and going to see doctor - (q.3 above)) You said you noticed something wrong in ... but didn't see Dr. ... until .... why did you wait?

4) How did you feel about going to see Dr. ...?

5) What did you tell Dr. ...?

6) Did Dr. ... describe the illness to you? Can you tell me what he said? Did you understand him? Has any other doctor described your illness to you?

7) Can you describe how he said what he said?

8) Can you tell me in your own words what is wrong with you?

9) Can you tell me what treatment you are receiving?

10) Did Dr. ... describe how this treatment works or not?

11) Did Dr. ... say how long you would have to receive this treatment for? Did he say anything about the outcome of the treatment, or alternative treatments or not?

12) Did you understand Dr. ... or not?

13) In your opinion what is the most important aspect of your condition?

14) In your opinion what is wrong with you? Is this the aspect of your condition which is receiving treatment or not?

15) Do you feel happy with the way Dr. ... has described the treatment to you or not?

16) Do you feel happy with the treatment you have received from Dr. ... or not?

17) Are there any aspects of your condition that you would like Dr. ... to pay more attention to?

18) How does your condition restrict you if at all?
19) How do you cope with day to day living - cooking, washing etc.? Who helps you?

20) Are you able to get out at all?

21) Does your condition give you much pain or not?

22) How would you describe your general condition?

23) How well are you coping psychologically in terms of modes, feelings etc.?

24) How do you feel in general about your present illness?

25) Is there anything you would like to add to anything you have said?

Cues such as "Could you enlarge on that?", "Could you explain that?", "How", "What", "Why" etc. will be used as appropriate.

Questions to be asked in subsequent interviews will be essentially the same as those in the above schedule except that they will be modified to focus on changes since the last interview. Subsequent interviews will take the following format,

1) Administration of S.T.A.I.

2) Proffering of resume of previous interview for 'negotiation of meaning' with patient.¹

3) Conducting interview on basis of modified schedule questions and questions arising from negotiation.

SCHEDULE 3: Doctor interview 2 (case history collection)

Collection of specific details of medical condition of patients, how this has changed over period of study. Discussion of doctor’s rationale for communicative approach adopted with individual patients.

Identification of group membership.

In addition doctor's assessment of individual patients' psychological state and expected prognosis.

1) How long have you known this patient?
2) How good a relationship do you have with this patient?
3) How do you approach this patient?
4) Why have you told/not told this patient about the nature of the illness?
5) How did you tell the patient about the illness?
6) What do you consider this patient's needs to be?
7) Do you feel happy about the way this patient is progressing?
8) Why did you select this patient for the study?
Dear Sir or Madam,

We are carrying out an enquiry into medical care in the National Health Service. We are particularly interested in the attitudes of patients towards illness, the treatment they receive, your relationship with your doctor and your needs. Your opinions in this matter are very important as we are concerned with the views of patients to illness as well as those of doctors.

We have discussed the objects of the enquiry with your doctor and he has sent you this letter on our behalf. In order to protect your privacy the doctor has not informed us of your name and address. You have been chosen by your doctor because you are one of his patients whom he has recently seen and expects to see again in the near future.

There is a slip attached to this letter which shows a suggested time and date for the researcher to come and see you. The researcher will come and see you in your home in order to describe the research to you more fully and then if you are willing to take part, to conduct an interview which will take about one hour. If this is convenient please tick the box provided. If this appointment is not convenient for you but you are willing to take part in the study, please indicate a time and date which would be convenient in the space below. Please also print your name and address on the slip so that we know who you are and where to meet you. If you are not willing to take part please tick the 'no' box.

A stamped, addressed envelope is enclosed for the return of the slip. We would be most grateful if you would help us in this study as without the opinions of patients it is hard to improve the treatment received. We would be most grateful if you would post this back to us as soon as possible.

Yours faithfully,

C.J. Todd.
Amendments to application for ethical approval of research project.

1) **Title of project**

   Investigation of factors involved in the doctor-patient relationship during terminal care at home.

2) **Responsible Investigators**

   Dr. A.W. Still: Mr. C.J. Todd MA
   Department of Psychology, Durham University

   The following amendments should be made to the above named document submitted to the District Health Authority for ethical approval on 27 May 1982.

1. page 7 delete paragraph 1 and insert.

   "The study will then be fully described to doctors. Doctors will be requested to identify potential subjects at diagnosis and to tell these patients that there is a study of doctor-patient relationships being carried out by researchers from Durham University in their practice. The doctor will then ask the patient whether he would object to his/her name being submitted to the researchers so that they could contact the patient to describe the study and request them to take part. If the patient is agreeable the researcher will be informed of the patient's name and address and will be contacted with the letter of introduction supplied in the appendix. Patients who agree to take part in the study will be interviewed initially by the researcher at home (schedule 2). The state-trait anxiety inventory (Spielburger et al. 1970) will also be administered".

2. page 8 section f) paragraph 1 change "doctor" to "researcher".

2. page 7 append to end of section b) "General practitioners will be asked if nursing staff are visiting the patients involved in the study. In cases in which nurses are involved and if the general practitioner is in agreement, the nurse will be contacted at the outset of the study and a meeting arranged with the researcher. The study will be fully described to the nurse. Nurses will be interviewed in the same way as doctors, using versions of interview schedules 1 and 3 modified to their circumstances."

3. page 8 section e) append to end of paragraph 1 "During the initial explanation of the study to the doctor it will be stressed that patient welfare remains his responsibility, and that should there be any adverse reaction from the patient during the interviews that although the interviewer will use those skills available to him to calm the patient if the disturbance is too great the doctor will be called in. The general practitioner will be notified in advance of times and dates of all interviews with his patients."
4. initial letter of introduction to patients in appendix. Delete paragraph 2 and insert. "We have discussed the objects of the enquiry with your doctor and he has suggested that you may be willing to take part in the study. You are, however, under no obligation to do so. Your name was passed on to us by your doctor as you are one of his patients, whom he has recently seen and expects to see again in the near future. The treatment you receive from your doctor will not be affected by participation or non-participation in this study. Our study is into the views of patients on illness, treatment etc. and consists of a series of interviews requesting information on these. Any information you give us will be treated in confidence".

5. page 9 section b) change "video or video" to "audio or video"
PATIENT CONSULTATION QUESTIONNAIRE

Please answer questions in your own words or put tick to indicate answer.

Name of patient __________________________ Date ________________

Age ___ Occupations
(if retired or unemployed state previous occupation;
if married woman who has not worked, state husband's occupation)

How long did you spend with the doctor? ___ mins.

Did the doctor examine you physically? Yes ___

No ___

Don't know ___

What did he do? ____________________________________________

What did the doctor ask you? _________________________________

What did you ask the doctor? _________________________________

What did the doctor tell you? _________________________________

What did you tell the doctor? _________________________________

During the consultation did you find out anything new about:
(1) Your condition: Yes ___ No ___ Don't know ___
(2) Your treatment: Yes ___ No ___ Don't know ___
Will you describe this

__________________________________________________________

How did you get on with the doctor?
Very well ___  Well ___  Satisfactorily ___  Poorly ___  Badly ___

Did you get what you wanted from this consultation?
Yes ___  No ___  Don't know ___

What was this?

__________________________________________________________

Which words best describe the consultation (please tick any you feel are appropriate):
confusing ___  worrying ___  frustrating ___  accepting ___
close ___  non-committal ___  helpful ___  cold ___
warm ___  informal ___  dismissive ___  frank ___
reassuring ___  unhelpful ___  distant ___  satisfying ___
friendly ___  clear ___  serious ___  insecure ___
business-like ___  sincere ___  jovial ___  formal ___

Please make any comments on the consultation below

__________________________________________________________

__________________________________________________________

__________________________________________________________
APPENDIX A
G.P.-patient consultation questionnaire development
1. TITLE OF PROJECT:

Pilot study of effects of prior exposure to questionnaire on patient behaviour during consultation, and response to questionnaire.

2. RESPONSIBLE INVESTIGATORS:

Dr. A.W. Still, Mr. C.J. Todd, M.A.
Department of Psychology, University of Durham.

The study is funded by the Social Science Research Council and the North of England Cancer Research Campaign.

3. SUMMARY:

In a series of studies being carried out by the present researchers it is proposed to use the questionnaire method. Because of the nature of the proposed studies the design requires patients to be exposed to the content of the questionnaire prior to the consultation being investigated. Studies in cognition and social psychology suggest that this prior exposure may affect both patient behaviour during the consultation and their responses to the questionnaire.

The present study will investigate effects of the questionnaire on patient behaviour, recall for medical information and attitudes and opinions on the consultation.

72 patients making return visits to two G.P.s will be used. The study will be administered by the general practitioner's receptionists who will identify suitable patients, request their cooperation and give out and collect questionnaires. Informed consent in writing will be obtained from all subjects.

4. SCIENTIFIC BACKGROUND

Questionnaire techniques have been widely used in studies of attitudes towards various aspects of health service provision (e.g. Royal Commission on the National Health Service, 1978) as well as studies of patient recall for medical information (Ley 1977). In most of these studies patients are unaware at the time of the consultation that they will be asked to fill in a questionnaire after the consultation.

Experiments in the field of cognitive psychology indicate that subject knowledge that they will be required to answer a questionnaire after the experiment improves performance on the post-test, due to effects on memory coding for the information during the experiment, (Rothkopf, 1972).

Experiments in the field of social psychology indicate that knowledge of an experimental situation affects subject behaviour during the experiment (Rosenthal and Rosnow, 1969) as well as attitudes and belief about the experimental material.

The use of a questionnaire, to which subjects are exposed prior to the consultation, to investigate patient knowledge acquired during the consultation and attitudes and beliefs about that consultation may thus be expected to influence the object of study.
5. **OBJECTIVES**

In studies of doctor-patient relationships during terminal care at home to be carried out in Co. Durham we are constrained by the study objectives to allow exposure to a questionnaire prior to the consultation. (See Application also enclosed).

The present study is designed to investigate the effects of prior exposure to the questionnaire, to be used in further studies, on patient behaviour during the consultation, memory for information after the consultation, and attitudes toward the doctor-patient relationship. Information about any effects of prior exposure to this questionnaire is required if we are to make valid inferences in the other studies where this questionnaire is to be used. The present study is designed to investigate the nature of any gross effects enabling us to identify effects requiring fuller investigation by future studies.

6. **DESIGN**

**a) Subjects**

Subjects will be 72 adult patients making return visits to their general practitioner for consultations about any illness. All patients selected as subjects will have been registered with their general practitioner for more than 3 years. Two general practitioners will be used in this study.

**b) Procedure**

The receptionist of each general practitioner will be instructed to select the first suitable 36 patients making return visits to their general practitioner from the commencement of the study to take part in the study. Each patient will be allocated at random to one of three conditions. Receptionists will indicate to the doctor only that the patient is taking part in the study.

**Group 1 - prior exposure to questionnaire.** Subjects will be requested to take part in the study when reporting to the receptionist. Each subject will be given a standard form (form 1) explaining the study plus the questionnaire to be read before entering the consultation room.

**Group 2 - prior knowledge of study.** Subjects will be requested to take part in the study when reporting to the receptionist. Each subject will be given a standard form (form 2) explaining the study.

**Group 3 - naive subjects.** After leaving the consultation room subjects will be requested by the receptionist to take part in the study. Each subject will be given a standard form (form 3) explaining the study.

The receptionist will give each patient the questionnaire to complete before leaving (groups 1 and 2) or ask the patient to take part in the study and then give the patient the questionnaire (group 3) (see questionnaire attached).

All questionnaires will be completed by the subjects before leaving the surgery and sealed by them in an envelope supplied.

Should a patient refuse to take part in the study the receptionist will simply replace this patient by the next suitable patient on the...
appointment list until the quota of subjects is fulfilled.

General practitioners will at the end of each consultation with a patient taking part in the study judge to which group the patient had been allocated. If explicit reference to the study was made by the patient during the consultation he will note this down.

This design will give us data enabling analysis of the behaviour of patients in the consultation between groups and their responses to the questionnaire, while maintaining ecological validity.

7. ADDITIONAL WORK/COST

Each general practitioner's receptionist will be required to identify suitable subjects, and speak to each of 36 patients about the study. This should require no more than a total of 30 minutes of their time. Each doctor will be required to judge group membership of the patients and record this. Approximately 5 minutes in all will be required to fulfill this function.

8. BENEFIT TO PATIENTS

The benefit accrued by patients taking part in the study, if there is any effect of prior exposure to the questionnaire (group 1) or knowledge of the requirement to fill in a questionnaire after the consultation (group 2), will be in terms of improved memory for medical information. Improved recall of medical information communicated during a consultation has been shown to be associated with improved prognosis, mediated by adherence to treatment regime. (Ley 1977)

Benefit to patients in future will come from identification of desirable modes of communication from doctors. (See investigation of factors involved in the doctor-patient relationship during terminal care at home application enclosed).

9. DISCOMFORT OR DANGER

No discomfort or danger is foreseen for patients taking part in this study.

10. EXPLANATION AND CONSENT

Explanation of the study is given in writing to all patients (forms 1, 2 and 3). Consent in writing will be obtained from all patients.

11. CONFIDENTIALITY

Patient confidentiality will be maintained by subjects sealing their responses in envelopes. Responses of specific individuals will not be revealed to receptionists or doctors. All normal procedures for maintaining subject confidentiality will be followed.
REFERENCES


INSTRUCTIONS TO RECEPTIONISTS

The following instructions explain how the study of the effects of prior exposure to a questionnaire should be conducted. Please follow these procedures exactly as the study is being carried out in more than one surgery and the procedures must be identical in each.

1) Patient Selection

The first 36 patients who have made appointments to see Dr. ................ from the beginning of morning surgery on ...................... and who satisfy the following criteria should be selected to take part in the study.

a) The patient must have been registered with this practice for at least three years - that is before August 1st 1979.

b) The patient must be making a return visit to see Dr. ................ about their illness. That is the patient must have seen the doctor at least once before about this illness.

c) Pregnancy - pregnancy testing and normal ante and post-natal services should not be included, nor should consultations for prescriptions for oral contraceptives, vaccinations, insurance examinations etc. be included.

d) Patients should be adult (18+) and making the consultation for him or herself, not as proxy.

e) If you are unsure as to the eligibility of a patient for this study the particulars should be checked in the patient's records only. No reference should be made to any doctor in the practice. Should you be unable to confirm the patient's eligibility the patient should be assumed to be ineligible and not used in the study.

Procedure

Before surgery - As identified as eligible each patient's name should be placed in the order in which it appears on the appointment list on the sheets supplied.

Sheet 1 will indicate to which experimental group the patient has been allocated. The patient will be allocated to either the group which has complete knowledge of the questionnaire before the consultation (group 1) or the group that knows they will be asked to fill in a questionnaire (group 2) or the group which has no prior knowledge of the study (group 3).

This sheet should be retained by the receptionist. The doctor should under no circumstances see this sheet.

Sheet 2 only indicates which patients are taking part in the study. This sheet should be given to the doctor at the beginning of the surgery so that he can complete it during surgery.
During surgery - When patients report to reception to keep their appointment one of the three procedures described below should be followed depending upon to which group the patient has been allocated.

1) **Full knowledge**

Patients reporting who have been allocated to this group should be asked whether they would be willing to take part in a study of doctor-patient communication being carried out by researchers from Durham University. If they are willing they should be given Form 1 and consent form. They should be asked to read this carefully and completely before signing the consent form. Form 1 should be returned to the receptionist before entering the consultation room. Receptionists should reiterate that patients should not mention to the doctor that they are taking part in the study.

2) **Partial knowledge**

Patients reporting to the receptionist in this group should be treated in exactly the same way as group 1 except that they should be given Form 2 instead of Form 1. Again this form and the consent form should be collected before entering the consultation room. The receptionist should reiterate that the patient should not mention to the doctor that they are taking part in the study.

3) **No knowledge**

No mention of the study should be made to these patients before they go in to see the doctor.

**After Consultation**

When patients come out of the consultation they will return to the receptionist, having been asked by the doctor to do so. Patients in group 1 (full knowledge) and group 2 (partial knowledge) will be given the questionnaire to fill in. Each patient should seal his/her answered questionnaire in an envelope supplied and return this to the receptionist.

Patients in group 3 will now be asked whether they are willing to take part in the study and given Form 3, consent form and questionnaire. Patients should fill in the questionnaire and consent form and return the questionnaire in the sealed envelope.

Receptionists should write the patient number as indicated on sheet 1 on each envelope as it is returned.

Receptionists should countersign all consent forms.

**Refusals or non-arrivals**

Should a patient refuse to take part in the study, or not arrive at surgery to keep their appointment, the patient should be replaced by the next eligible patient on the appointment list after the last patient already allocated if the last patient allocated is to attend a surgery subsequent to the present one; or the first eligible patient of the next surgery if the last patient already allocated is attending the present surgery.
Synopsis of Procedure

For a 3 month period commencing and finishing, patients should be identified in two groups.

i) New terminal patients

ii) A chronic control for each terminal matched for age, sex, socio-economic group and site and severity of symptoms.

The researcher should not be told the group identity of patients until after the study is completed.

Each patient should be allocated a code number for the purpose of filling in the questionnaires (01, 02 etc. will suffice). Your own code number is in the envelope. This system has been adopted to enable analysis of questionnaires to be commenced before the end of the study. Completed questionnaires should be kept in the envelope provided and will be collected at intervals during the study.

Patients identified should be asked whether they would be willing for their names to be put forward for a study of doctor patient communication being carried out in your practice by researchers from Durham University and if they are willing their name and address should be forwarded to the researcher who will then contact the patient.

The records of patients who do consent to taking part in the study should be flagged and questionnaires placed in the records to be filled in. (This will probably depend on the practice - it is essential that questionnaires are filled in whenever a patient taking part in the study is seen and therefore whatever system will ensure this within your practice is acceptable.)

In the case of a patient dying or leaving the practice lists for any other reason please arrange a case history interview as soon as possible so that this can be conducted while patient records are still available.
Investigation of consultations with general practitioners

Dear Sir/Madam,

We are carrying out an investigation into aspects of consultations by patients with their general practitioner, as part of a series of studies into medical care in the National Health Service. We are particularly interested in the attitudes of patients towards illness, treatment and relationships with doctors. Your opinions in this matter are very important to us as without patient opinions it is hard to improve the treatment offered in the N.H.S.

The receptionist has asked you to take part in this study because you are making a return visit to see your doctor and he is therefore not a stranger to you.

Although the doctor you are going to see knows about this study and has given his permission for it to be carried out in this surgery he does not know exactly which patients are being approached to do this part of the study. This will ensure confidentiality.

When you come out of the consultation the receptionist will give you a short questionnaire to fill in. This will take about 5 minutes to complete. A copy of this questionnaire is attached to this sheet. Please read it carefully now so that you can decide whether you are willing to answer these questions after you have seen the doctor.

After you have filled in the questionnaire you will seal it in an envelope supplied. Neither the receptionist nor the doctor will see your answers. Your answers will be treated with the strictest confidentiality.

If you are willing to take part in the study please sign the consent form.

Please do not mention to the doctor during the consultation that you are taking part in the study.

If you have any questions the receptionist will be pleased to answer them.

Thank you in advance for your help and cooperation.

Yours faithfully,

C.J. Todd.
Researcher

Doctor.
Investigation of consultations with general practitioners

Dear Sir/Madam,

We are carrying out an investigation into aspects of consultations by patients with their general practitioner, as part of a series of studies into medical care in the National Health Service. We are particularly interested in the attitudes of patients towards illness, treatment and relationships with doctors. Your opinions in this matter are very important to us as without patient opinions it is hard to improve the treatment offered in the N.H.S.

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Although the doctor you are going to see knows about this study and has given his permission for it to be carried out in this surgery he does not know exactly which patients are being approached to do this part of the study. This will ensure confidentiality.

When you come out of the consultation the receptionist will give you a short questionnaire to fill in. This will take about 5 minutes to complete.

After you have filled in the questionnaire you will seal it in an envelope supplied. Neither the receptionist nor the doctor will see your answers. Your answers will be treated with the strictest confidentiality.

If you are willing to take part in the study please sign the consent form.

Please do not mention to the doctor during the consultation that you are taking part in the study.

If you have any questions the receptionist will be pleased to answer them.

Thank you in advance for your help and cooperation.

Yours faithfully,

C.J. Todd.
Researcher

Doctor
Investigation of consultations with general practitioners

Dear Sir/Madam,

We are carrying out an investigation into aspects of consultations by patients with their general practitioners, as part of a series of studies into medical care in the National Health Service. We are particularly interested in the attitudes of patients towards illness, treatment and relationships with doctors. Your opinions in this matter are very important to us as without patient opinions it is hard to improve the treatment offered in the N.H.S.

The receptionist has asked you to take part in this study because you are making a return visit to see your doctor and he is therefore not a stranger to you.

Although the doctor you saw knows about this study and has given permission for it to be carried out in this surgery he does not know exactly which patients are being approached to do this part of the study. This will ensure confidentiality.

If you are willing to take part in this study the receptionist will give you a short questionnaire to fill in. This will take about 5 minutes to complete.

After you have filled in the questionnaire you will seal it in an envelope supplied. Neither the receptionist nor the doctor will see your answers. Your answers will be treated with the strictest confidentiality.

If you are willing to take part in the study please sign the consent form. If you have any questions the receptionist will be pleased to answer them.

Thank you in advance for your help and cooperation.

Yours faithfully,

C.J. Todd.
Researcher

Doctor.
DOCTOR CONSULTATION QUESTIONNAIRE

Patient code no. ................

Doctor code no. ................ (if partner, name)

Date of consultation ................

Place of consultation: home ____ surgery ____ other ____

Did you conduct a physical examination? Yes ____ No ____

Did you conduct a verbal examination? Yes ____ No ____

How is the patient coping psychologically with the illness? Well ____ ____ ____ ____ ____ ____ ____ ____ ____ Badly

Does the patient know the nature of the illness? Definitely knows ____ ____ ____ ____ ____ ____ ____ ____ ____ Definitely does not know

Does the patient know the prognosis of the illness? Definitely knows ____ ____ ____ ____ ____ ____ ____ ____ ____ Definitely does not know

Was the consultation predominantly social or physical medicine? Physical ____ ____ ____ ____ ____ ____ ____ ____ ____ Social

How satisfied with the treatment is the patient? Satisfied ____ ____ ____ ____ ____ ____ ____ ____ ____ Dissatisfied

Did the patient request any medical information, treatment or facilities etc. during the consultation? Yes ____ No ____

What was requested? .................................................................
Did you learn any new information from or about the patient during the consultation?

Yes ___  No ___

What was learned? .................................................................

Did you give the patient any new information during the consultation?

Yes ___  No ___

What was given? .................................................................

What is the patient's understanding of this illness in your opinion?

.................................................................

What is the patient's major concern?

.................................................................

Further Comment
Please answer questions in your own words or put tick in box supplied to indicate answer.

PATIENT CONSULTATION QUESTIONNAIRE

Patient Name ........................................ Date ........................................

Doctor Name ........................................

How long did you spend with the doctor ............ mins.

Did the doctor examine you physically? (Please tick) Yes ☐

No ☐

Don't know ☐

What did he do? ..........................................................

........................................................................

........................................................................

What did the doctor ask you? ...............................

........................................................................

........................................................................

What did you ask the doctor? ............................

........................................................................

........................................................................

What did the doctor tell you? ............................

........................................................................

........................................................................

What did you tell the doctor? ............................

........................................................................

........................................................................

During the consultation did you find out anything new about

1) Your condition Yes ☐ No ☐ Don't know ☐

2) Your treatment Yes ☐ No ☐ Don't know ☐

Will you describe this ................................................

........................................................................

........................................................................

How did you get on with the doctor?

Very well ☐ Well ☐ Satisfactorily ☐ Poorly ☐ badly ☐
Did you get what you wanted from this consultation?  

Yes  
No  
Don't know  

What was this? ..........................................................  

..........................................................  

Which words best describe the consultation. (please tick any you feel are appropriate)  

confusing  worrying  frustrating  accepting  

close  non-committal  helpful  cold  

warm  informal  dismissive  frank  

reassuring  unhelpful  distant  satisfying  

friendly  clear  serious  insecure  

business-like  sincere  jovial  formal  

Please make any comments on the consultation below  

..........................................................  

..........................................................  

..........................................................  

..........................................................  

..........................................................  

..........................................................  

..........................................................  

..........................................................
APPENDIX 5
Supplementary interview quotations for Chapter 10.
G.P.S' OBJECTIVES

Dr. 01
"To get them to die with absolute pain relief and maximum dignity, peace and comfort at home."

Dr. 02
"To keep them as cheerful and as happy as is possible, to keep them painfree...as comfortable as possible. Keep them happy."

Dr. 03
"To keep them I suppose fairly mentally content...as comfortable as I can and to keep them painfree, physically comfortable."

Dr. 04
"To make them comfortable... To make them physically comfortable and mentally comfortable."

Dr. 05
"To keep them as comfortable and as normal as possible for as long as possible. To let them live a full, or as full, a life as possible. To minimise the distress to themselves and...to the relatives."

Dr. 06
"To make the patient comfortable and free of pain."

Dr. 07
"To die with dignity...(not with) tubes up every orifice...in control as well...warm and dry and clean, not stinking. You should have the family round you, if you want them there...er painfree."

Dr. 08
"Quality of life... I think that sums it up... Length of life is one dimension...you can fairly easily prolong life, painful life which has no value to it. Quality of life in relationships and relationships to make sure the family is communicating, making sure that they can maximise all their resources."

Dr. 09
"Purely to relieve pain and suffering. There aren't any other considerations."

Dr. 10
"To make them as comfortable as possible, don't have any pain... To make them live as happily, as happy as possible, as pain free as possible."

Dr. 11
"To make what remains of their life as comfortable as possible, particularly with regard to pain... To make that little while as reasonably pleasant as is possible."
"To make them as comfortable and as painfree as possible, even if it meant perhaps reducing total lifespan."

"Hopefully delaying the progress of the illness... but for the vast majority... relieve the suffering by any means possible... relieve physical suffering."

"The broad aim is to make them as comfortable and as pain free as possible... so that they can die as peacefully as possible."

"Obviously relieve any physical discomfort. That's your first aim. This can usually be done by drugs quite effectively nowadays. By and large people put up with the agony of the body rather well. It's the agony of the mind that gets people down... One tries to alleviate depression or anxiety symptoms with medication or simply by talking... Hopefully keep them in a comfortable state is the aim."

"Well basically that they are comfortable and enjoy what time they have left... That's the best wording of it really."

"Basically to make them comfortable, 'cause I know I can't cure them. I suppose that's it really. It's just to make them comfortable, painfree, see to their basic sort of needs."

"To keep the patient comfortable and see he is free of any pain at all... Try and make him to not think about all his suffering."

"Basically to make the death as painfree... not really painfree, as suffering free as possible... To make their suffering as little as possible... So that they can plan their lives ahead of them and in a way ready themselves for death... Some people have a creed or belief others don't, but you have to mentally prepare yourself for death and in these situations most people do in my experience prepare themselves very well for death."

"Just try to comfort them as much as I can... Make them happy as much as I can... Of course you give them pain relief... you're not going to let them suffer. You give them pain relief that's common sense."
Appendix 5

Dr. 21
"My aim is to prevent them having any pain... to allow them to still be their own master within their own home, so they feel psychologically happy and I keep spirits up."

Dr. 22
"My aim is to alleviate as much as possible any physical suffering and that's my prime concern really and any associated problems, any psychological problems that may arise from it, depression and things like this."
Dr. 01

"From a medical point of view supervision of terminal care is one of the most sad, typically challenging and medically challenging things that you have got to do. Nothing else really can have that intense working with people, with at the same time the purely technical problems of overcoming pain, vomiting, constipation, death rattles, you name it. You have got to physically overcome all of them, and as such it's an interesting field... It's always bandied about that 20% of general practice is trivia, or something like that. But a lot of that isn't trivia, there's a lot you can be doing which isn't life or death medicine... as such a lot of trivia tends to disappear."

Dr. 02

"I'm shattered inside, first of all, every time it happens because I know most of the people. You feel a shattering feeling inside when your investigation comes back... But it is very rewarding if you can support these people and go through it with them. That is of course accepting that we all have to die... (But) it hurts you when something like that happens, where you know you have not really got control of the case. Normally you get the case under control and you've got it all under control. But some stick out really because we never really got them under control. Relationships are very very difficult, sometimes you have known a patient for a while and you don't like them, and this sort of thing happens. When the chips are down you suddenly find a different personality to the one you thought was there... It becomes a very intimate relationship when somebody is dying... You get to know them, their family life, they ask about your family life, and it is not just medicine you see."

Dr. 03

"I think it is unfair to tell them, since you have got the knowledge and they have not. You are not really there to dictate to them what their lives are going to be after all. You are there to put over what knowledge you have in their interest to an extent and this is what you have trained for... You are to a certain extent their instrument... I don't find it difficult... I think it is not difficult for me because of the sort of doctor I am. I find some other things much harder, than treating terminally ill people. There are some highly technical things I find very very much harder... It is all going to be a relationship problem isn't it if you are looking after somebody who is terminally ill? A lot of it is relationship... and it is just the way I am really... I prefer people sort of with psychiatric or psychological problems."
"One of the reasons I've always been interested in cancer, the treatment of cancer, is because again going back to general practice you see so much minor rubbish in general practice. To a certain extent you feel that at least these patients are genuinely ill, and need your help. Whereas so many people really they shouldn't be coming... it's trivia. I try not to get too emotionally involved myself. One tends to put them to the back of your mind... you don't sort of dwell on the matter, whether it went well or not. Most of the time I don't feel too much because one has become immune to it over the years. I remember when I was a junior houseman getting very upset about people dying, but you can't go around being a doctor getting upset every time somebody dies."

"My belief is that death is not a frightening thing, and that relationships with relatives and friends can be in fact improved by not withholding information... People like to know what is going to happen, and they can make preparations and plans to do what they will before they die. So I think the doctor has a part to play here... Over the last few years I think I've become far less frightened of emotion and recognise it has a very potent part to play in life. So I think that it is going to heighten the quality of the remaining life, one hopes for all of the family... I suppose one thinks of diagnosis as an intellectual process, and that's a rather unemotional sort of thing. But it's only when you actually start to project that diagnosis onto the patient as an individual that you think 'oh god!'... But it can be rewarding to oneself. Because patients don't know what to do and they look to you as a doctor for guidance... and be helpful in fact in enabling them to die well, make the last few weeks, months worthwhile... I don't think I would be revealing any terrible secrets in that 90% of medicine that you do with 10% of your brain, so many things are automatic. This I don't think should come into it, everyone you get on terminal care should be someone that you think about and you care for... I think if you get concerned and you care, that goes a long way... I make no claims to have any spiritual involvement, perhaps they just want to talk about it from the spiritual side with their priest... It is very hard sometimes in a way because the relationship isn't only doctor/patient... but I think the general practitioner has a role to play here because he may have known the patient for some time and he's going to know the relatives a while... So help them with fear loneliness, because they can be very lonely dying... and concern of what is going to happen to the people that are left behind, as well as keep them comfortable in the actual process of dying... So one takes more care... one thinks more of the emotional aspects of what one is doing... I am likely to try harder to be nice to people because I think they are probably undergoing sufficient discomfort, emotional and physical. For some physical
illnesses you can say this is the treatment get on with it. Perhaps in a way people who are dying you have to tailor things more carefully, individually, see them as people. I just wondered whether like Avis we try harder when they are dying rather than when they are living. That sounds terrible doesn't it?... Medicine is, well rationally the number of diseases that we can actually alter for the better, that we can actually modify the pathological process is relatively limited. I believe a doctor's work is to make life more alive, as tolerable as possible. That is why I believe more and more general practitioners will get involved in counselling and things such as terminal care. Legally we're the only people allowed to deal with a lot of the drugs that are involved and I think they do have a role to play in dying. But a lot of the counselling, the supportive things, I don't think it matters two hoots whether the person who is dying fixes on the doctor or somebody else... Alright we've got to supply the drugs... as to who's the most important one to tell them, I don't believe it actually matters providing the person who knows, know that they know. And that comes back to us doctors more often than not."

"Because you don't like giving a death sentence to somebody and that is what it amounts to if they are terminally ill. You are telling them you can not get them better... It's an upsetting subject really to all concerned, the doctor, the patient, the relatives... Life is very precious."

"You should really keep going, do you know what I mean. You never know what is going to turn up, do you. I mean in medical science itself, so that it might just fit the bill for this particular patient so you shouldn't give up. Although I suppose half your brain has given up already do you know what I mean? If you've already got them down as terminal in your own book, you must still soldier on with your role as a doctor to that patient, yes. And you give them everything you can. So I'm not one for telling the patients that they have got a terminal illness."

"My patients are people... I am much happier in a consultation with my patients if they love me or are crying... If they get me crying with them that's good too, so if we have a burst of tears it's not bad... It's at odds with the traditional view of the doctor, the applied scientist who is a medical man certainly... I enjoy terminally ill people. I enjoy any sort of illness that will get me close to the patient. I don't really enjoy tonsilitus. I am much more at home with a crisis... If I want to treat someone I use another member of the family to do this, it's indirect therapy and I allocate..."
therapeutic roles to different folks without them realising it, I give them my therapeutic role. Therefore I am dealing at many different planes, at many different logical times, well it is a multidimensional matrix, a rubic cube of therapy... The linear model, the medical model, is non applicable... because scientifically I apply general systems theory to everything... (I want patients to) take back some sort of responsibility for the process of dying, rather than abdicating everything and lying back and letting everybody else do it all. The problem is making death as important as living... I am a practising Christian... which means I want them to know of me not as a foggy therapist, but I am quite prepared to get involved. In fact classically the doctor operates, I suppose, is taught to operate by not sharing himself with people, but by being a therapist at a distance. And I believe in sharing myself. Some of my patients will come along and say I can talk to you, well as a pastor. They look to me as the local priest, because I will let them and make it quite obvious to them that I am a Christian. I suppose what I am saying is that I operate at a level of completeness and my Christian faith is not an uncommitted faith. If God says he heals, well he heals... We use not only therapy, but we do use the doctor as the drug."

"You see terminal doesn't necessarily mean in my book stopping treatment. A patient may be terminal but I would still ask the radiotherapy department to shoot some rays at it. But you wouldn't be pursuing the sort of chemotherapy which may make them ill... We'll go on treating it, if it recurs we'll treat it again. That's the way I do it so that they don't think that it's just being stopped... I'd rather tell a lie to let them think that you are doing something constructive... Even if it were just a placebo, knowing that it was not going to do any good, but it won't do him any harm and he may feel that I am doing something constructive... You can't cure the patient but it stops everyone being terribly upset... I think it's our job."

"In some diseases you are really happy, that you are going to do something for the patient. But I feel sorry because we know the patient from the beginning you know, it must be in the situation, sometimes you know that this other patient is going to die in a way. I see it in front of my eyes and the only way I can help is to give the patient some analgesics or narcotics to knock the pain out. But then is nothing I can do by way of you know curative treatment and well you feel sorry about that and it is sort of unsatisfactory... It is different from treating the other sorts of diseases. It is not treatment of the pain or symptoms or the disease alone, but treatment of the whole family. And the patient is going to die, so I feel there is a lot of emotional things, you
know attached to this type of treatment of the terminally ill patient. It is not like other cases where you can go in, see the throat or whatever, write a prescription and come out and forget about the patient because you know the patient will be alright. But not in this sort of case, you have to sit and talk and spend time... But it is satisfying. I don't want to be called out for a headache, I would rather be called out for a terminal case... They become my friends actually, without realising it I move closer to them... So it is a dedicated work and you should understand about the agony the patient is undergoing... As a doctor we look at the illnesses all the same, but when we see the terminal cancer condition, we see the patient as well."

Dr. 10

"A lot of people say they don't like it because it's a failure of medical science, but I don't really think of it that way really. I'm more inclined to think of it from the personal point of view of what the patient's reaction is going to be... I feel sorry, but not in a deeply personal sort of way, you know how can you be?.. Really I don't feel a great deal, unless it's somebody I know particularly well, who is also a patient. That sounds heartless but you can't feel sorry in a committed way in general practice, we'd go round the bend, we couldn't cope. You can't get deeply personally involved with patients because if you are not detached you don't do your job properly. I mean if you treated everybody who was going to die like you'd treat your friends you wouldn't last would you. So you have got to be detached... It's a bit depressing, but I don't find it all that difficult, because it achieves a worthwhile object on the whole... if you deal with their medication so that they are reasonably comfortable, that's very useful. Therefore it has a satisfaction about it because a lot of what you do in general practice is not satisfying... Kids with colds and things... they don't even need a doctor really, that's frustrating. But you are doing something worthwhile even if all you can do is improve somebody's last days."

Dr. 12

"There's a problem if they lose faith in you, so I think that if they know that you can't wave a magic wand and make them better, then they value your approach and guidance more... But my job's to try and make them better. I suppose I feel that somewhere along the line they've failed themselves by the habits they have taken up, or we've failed them by not spotting something sooner... (One) worries patients will ask us to work a miracle for them and we haven't got one. No perhaps it's a deeper down instinct that we can't come up with the goods this time. I suppose that is the basic feeling that makes me uncomfortable... Also there is a bit more emotion in you have been seeing them more often... You them and you know very well you'll be coming
Appendix 5

out to see them dead sometime. Earlier (in my career) I perhaps used to get more emotionally involved and mention it at home to my wife and start to look down and get grumpy."

**Dr. 13**

"So I would find it very hard telling patients that they had something for which modern medical science couldn't offer a cure... I presume I started off with the most ideal expectations of medicine, perhaps false expectations of medicine, thinking I'd go round literally administering healing and curing and that kind of thing. The reality is a little different and it's always disappointed me a bit, especially at first, people used to have conditions that I couldn't intervene in. It still does disappoint me to some extent, but not nearly as much as it did. I presume the lack of prospects for positive intervention used to distress me a bit, I'm not sure why I just don't like it."

**Dr. 14**

"The worst part for me is getting attached to patients and then discovering that they have got something terminal. That's the worst part the discovery, that somebody that you perhaps get on well with as a fellow human being, you like them as a patient, it's depressing. You might find diagnosis a satisfying part of medicine, but it is not when you come up with something nasty, when you know the patient. It is different in hospitals, because you don't know them, whereas in general practice you do. You know the family, you probably know a lot about them, then you discover that somebody you have been seeing for years has in fact got cancer, that is the worst part... I find you have to be quite objective and detached about it you can't get totally involved in the sense of emotionally involved as you would with say a close relative. Otherwise, I don't think you would survive the job, you would crack up. I think you've got to get, what is the word, a sort of detached, distant almost hysterical, a 'belle indifference' (sic)... You've got to have the empathy I think... You've got to remain detached, or you don't sleep at nights, then you would not manage the job. One accepts that after doing the job for a while, that he is going to die anyway. I mean this is the thing, it just happens to be this illness that is going to kill him. You have got to make it as comfortable as you can for them, because there's nothing miraculous about any of it, medicine, it's all very real. So you've got to be fairly cool about it... It upsets me to think they are going to suffer and you know I don't really want them to die, even though I accept that it's inevitable. You become more or less conditioned to it... Perhaps I want to be upset every time, but I don't think I could take it. I have to survive so I condition myself, I have that I am not upset every time, otherwise I crack up. So in a way I'm protecting
myself, there is a lot of that in the job, protecting
yourself... It is more demanding than treating ordinary
people, but it is something I rather like... There are
certain situations medically where you have to devote your
time to them, I mean they are top of the list of
priorities. And terminal illness is one of them for a
general practitioner, in my opinion... I think the nature
of the illness changes my feelings about them as a person.
It's inevitable because of it being a terminal illness and
the nature of the involvement between doctor and patient.
It makes me closer to them so I get to know them as people
perhaps better than I get to know other patients. It can
be difficult to cope with."

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Dr. 15

"I suppose it largely depends on the age of the patient.
I mean I feel pretty depressed that I'm right over this
sort of thing (the primary diagnosis). I feel it affects
me deeply, but I mean I hope I have a certain professional
detachment to be able to cope with it. I think it is
difficult to deal with day by day... it's emotionally
draining... because it's not just the sort of case where
you rush into the house and say Fred has got measles or
this or that, take this and get on with it... You can't
help but have sympathy for someone you know is dying...
it affects me. I try to sort out all that can be done in
terms of home helps, meals on wheels or whatever... help
them to face the real difficulties of living... But I
mean one does it willingly. I think it is very much part
of a g.p.'s role. It's difficult after 20 years of being
a doctor to unthink yourself from medical knowledge you
know that is part of the trouble."

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Dr. 16

"Basically people have a right to know what is happening
to them... so that they can plan what they wish to do with
the time they've got.... I find it terribly difficult
though, and in terms of shying away from telling, possibly
a little training (would help), because well there's a
lack of it. It probably has altered considerably since I
qualified. I think things have changed since I was in
hospitals, but they do things differently in hospitals.
Obviously there's more personal medicine in general
practice, and you're dealing with the whole person, well
the whole family, when it's terminal... I think the
basic thing is, I believe that the person should be in
control of their destiny, and they can't do that if some
very important information is being withheld from them...
It can be one of the most difficult aspects in purely
medical terms."

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Dr. 17

"I suppose you'd have to break them down and call them
medical problems, sort of social and family problems
really, and they are entirely separate... Considering you
can't cure the cause, all you can do is take care of any physical needs they may have, discomfort physical discomfort. And then there are the usual things like helping the family cope, and apart from nursing care this sort of thing isn't really my province... You certainly treat them differently if they are dying. Sometimes I find it frustrating, I think possibly because you can't do a great deal for them except make them comfortable. You do your best to make sure they are comfortable."

**Dr. 18**

"A person is not interested in what he's got, what he wants is a cure. But here is an unfortunate thing because we can't cure it.

**Dr. 19**

"The better sort of relationship to have rather than the formal doctor patient relationship is more of a friendship, when they accept you as a friend who happens to be a doctor, who can treat their pain or help their symptoms rather than the straightforward doctor relationship. And that's what I aim for I think... There's no real reason why you should, but mentally you tend to treat them slightly differently... The relationship I build up with them is closer than with normal patients. And in that way as I say you are more of a friend who happens to be a doctor, rather than a doctor. In that way you handle them and you talk to them is different to how you handle and talk to other patients... You know you can't cure them, so what you have got to do is make their lives better. So I develop a closer relationship with the patient, than I had beforehand in order to tell them their diagnosis and discuss with them the way we're going to manage their terminal illness and that is basically how I handle terminal illness. Sometimes you can't do that, but that's the aim and to keep them comfortable... Sometimes medicine does not do them any good, but you see them regularly for medication, mostly for pain, and for advice."

**Dr. 20**

"Well we are at a stage at which nobody can do anything but later on we might be able to do something... I feel upset and my attitudes change completely towards them. I feel anything they ask for I will just get... No you live with them, we suffer with them when we find that they are dying and we can not do anything." (He also regularly arranges for patients to be admitted into hospital) "to show them that we are not neglecting them, on the whole, if you don't send them into hospital and they have something seriously wrong, they would say doctor you haven't sent me into hospital, and they think I am not doing my job. And that is why I make use of the hospital, they can't do anything. The other reason is because of..."
Appendix 5

pain and change of atmosphere... Tell me is what I do wrong?"

Dr. 21

"I don't think I find it difficult. I think it is part of the job and I think I get on and do it, when I am in full control and have knowledge of all the facts... It depends in some cases on how well you know them. Some patients you seem to have a better rapport with and you seem to share their illness much better than others. I suppose that's inevitable. The fact is that we're all human... Even if one hopes that they'll get better, I think that one has exactly the same thing if somebody's had a severe heart attack, they may get better... I suppose we don't know with certain illnesses whether we are going to cure them, but invariably we try."

Dr. 22

"Recently I had two cases of ovarian tumours which both died. And I feel anger and frustration there because we can't sort of detect these things early enough to do anything and that's the main problem with this situation... I was relieved when she died, in fact I was pleased, not relieved. I was getting a bit rough myself seeing this poor woman and not really being able to help much... because I felt so helpless. I had various consultants to see her... but no matter what you did for her you just couldn't help... So I felt frustration towards the medical profession for not devising some sort of test which would detect these problems earlier, so that by the time it is found it isn't so far spread that the prognosis is obviously not good, there's nothing we can do.

Corroborative evidence: Analysis of patient interviews, consultation questionnaires and video recordings.

As reported in Chapter 9, only 10 terminally ill patients were successfully interviewed and a total of only 22 interviews carried out with terminal patients during the second study. Because of the small number of terminal patient interviews carried out, they can not meaningfully be subjected to a statistical analysis along the lines initially conceived (Chapter 8). However these interviews are to some extent useful for the additional light they shed on the analysis of g.p. interviews analysed in Chapters 9 and 10. A characteristic feature of the the patients' accounts is that they were highly coherent and consistent. The second outstanding feature of the the patients' accounts is the degree to which they corroborate the accounts of the g.p.s and the analysis we have proffered. A careful search of the patient interviews was carried out in an attempt to identify statements which contradicted the g.p.s' accounts of how they handled the individual cases, as reported during the case history.
interviews, or contradictory to the general policies and abstractions vis a vis terminal care expressed by the g.p.s during their first interview. This search failed to identify any meaningfully contradictory evidence. Only minor aspects of patients' accounts deviated from those of the g.p.s, slight differences in trains of events, dates and the like accounting for the majority of these. Although there were clear examples of differences in the perspectives of g.p.s and patients as to the meaning of signs, symptoms etc. these were not inconsistent with the g.p.s accounts since these differences were often recognised and commented upon by the g.p.s. What is more such differences were often also recognised as historical entities by the patients themselves, who said things along the lines of "I didn't realise how serious that was at the time, but now I suppose I should have known".

In so far as they go the consultation questionnaires completed by g.p.s and patients are completely consistent with the accounts offered by both parties of their interactions. However, again because of the small number of patients involved in the study little of value can be gleaned from them. This problem is further exacerbated by the ways in which questionnaires were completed. Both g.p.s and patients tended to be somewhat vague in their descriptions of what was said and done during the consultation, the former in particular completing questionnaires in little more than shorthand notes. Thus a typical response to the question concerning what (if any) new information was given to the patient are the two words "serious pathology" written by one g.p. Thus although other researchers have used the consultation questionnaire technique to reportedly good effect (Russell et al, 1984), we can only conclude that this aspect of the study design was a failure, although holding out the hope that if greater numbers of patients and their consultations had been forthcoming statistical analysis of the Likert-scale items would have been productive.

Finally to consider the video-recording of consultations. As far as it is possible to ascertain from the videos the behaviours of the g.p.s conform substantially to the accounts they gave of their interactions with terminal patients. Tactics such as prompting questions, and using uncertainty were clearly discernible. In the case of the one patient who was videoed on more than one occasion the g.p.s strategic approach is confirmed. Early during the series of consultations he is more reticent than during a later consultation.
Appendix 6

Note 3.01 Compare Heiss (1981) with Biddle (1979) on the meaning of the role concept.

"...it is preferable to define role as expectations rather than as behavior. The ultimate dependant variable in social-psychological theory is social behavior, and if roles refer to actual behavior there would be little for roles to explain. Thus, for me, a role is a set of expectations in the sense that it is what one should do."

(Heiss, 1981; p.95)

"...we now define a role to be those behaviors characteristic of one or more persons in a context... Roles are behavioral. Involved in the definition of role are only those overt actions or performances that may be observed and that characterize the persons observed."

(Biddle, 1979; p.58)

Note 4.01 "Cancer" is used here in the same way as it is used for registration purposes and thus includes all malignant neoplasms classified in the International Classification of Diseases as ICD codes 140-208 plus certain other sorts of conditions (see Acheson, 1980).

Note 6.01 The main quotations (indented text) are numbered for easy reference within the text. The patient number or doctor identifier is given in each case. For g.p. interviews whether the quotation comes from the first or second (case history) interview is indicated by appending "i" or "ii" to the doctor identifier respectively. On a number of occasions the spouses of patients are quoted. They are identified as "Sp.+patient number". "Int." refers to the interviewer (CJT). All proper names used have been changed. The partners of the 4 g.p.s have been given surnames which are colour terms (e.g. Dr Black). Other persons (e.g. consultants) have been given pseudonyms chosen in such a way as to disguise but reflect essential characteristics of the original surname. Where necessary relationships between persons are clarified.

Non-verbal components of quotations The quotations are culled from verbatim transcripts. In the original interview transcripts all pause fillers, part word hesitations, grammatical errors, false starts etc. were reproduced from the audio-recordings. Where necessary the phonetic features of what was said were represented by the transcribers. In the quotations presented semantically redundant pause fillers have been removed. Pause fillers have been retained where they appear significant either because they modify the message or because they indicate something about the state of the informant. Quotations have been punctuated in such a way as to reflect the pauses of informants and thus do not always conform to the usual rules. Since speakers are
seldom grammatical and often depend heavily on context to clarify meaning, the quotations have been annotated and occasionally grammatically corrected in order to transfer their meaning to the written medium. While carrying out the qualitative analysis of the interview transcripts the author checked relevant sections of the original audio-recordings to ensure that vocal non-verbal features did not modify the verbal message. All ambiguous exemplifiers were rejected. Only one of the quotations presented depends on vocal non-verbal aspects of the message to modify its meaning and in this case the style of delivery is described separately.