Durham E-Theses

Holistic philosophy and spiritual well being in people facing life-threatening illness

Hanley, Elizabeth

How to cite:

Use policy

Holistic philosophy and spiritual well being in people facing life-threatening illness

Name: Elizabeth Hanley

Title: Holistic Philosophy and Spiritual Well Being in People Facing Life-threatening illness

Abstract

This research study was carried out to establish the significance of a holistic philosophy to the spiritual well being of people facing life-threatening illness. A phenomenological framework was adopted to conduct the research and the subjects were drawn from the Northumberland Cancer Support Group, which is affiliated to the Bristol Cancer Help Centre. Seven individual accounts are presented as part of the organisational case study, six of which concern people directly affected by cancer and one related to the carer of someone who has received a cancer diagnosis. The individual accounts are presented first as phenomenological description and are then subjected to phenomenological analysis. The significance of a holistic philosophy to the spiritual well being of the subjects is determined as part of this approach.

The research was conducted to gain insight into the everyday reality and lived experience of the participants. The overall themes which emerge are the alterations to senses of self of the subjects directly affected by cancer as a result of receiving this diagnosis and the associated change from a naïve to a scrutenising perspective on life and mortality. The importance of mundane routines and activities, which had previously been taken completely for granted, in maintaining purpose in life and reinforcing social roles and senses of self is also evident. Holism's contribution to spiritual well being is associated with the capacity for this approach to address every aspect of the person and to increase the individual's capacity for self healing. The human to human aspect of holism is of particular significance to the research participants and it is clear that the support group provides a therapeutic environment and shared universe of meaning for them.

07 DEC 2005

Holistic philosophy and spiritual well being in people facing life-threatening illness.

Introduction

The context of the study

Although knowledge of many areas of human life continues to increase, some subjects remain more or less a mystery, and such is the meaning and significance of death and dying. Since nobody knows with certainty what happens after death and since the process of dying is experienced but once by each person, scientific discoveries and technological progress alone are less than effective in providing answers in this field of enquiry. The individuals studied here will be described as 'facing life-threatening illness', rather than as 'dying', since everyone can be said to be dying, in that all face death at some point and, with improvements in treatments and technology, it is no longer possible to predict accurately when a person will die, even if illness is very severe and advanced. However, when a person is given a diagnosis of an illness likely to shorten their life span, they will go through the experience of facing the possibility of premature death and will require all of the support as if they were dying. It has also been stated that the term 'life-threatening' rather than 'terminal' illness 'gives a sense of possibility' and, therefore, hope to the sufferer and avoids negative labels being ascribed to the subjects (King 1990:16).

This study has been designed to investigate the impact of the application of a holistic philosophy on the spiritual well being of people facing life-threatening illness. Therefore, a group of people in this situation has been identified and the

1

ways in which they perceive themselves, their bodies, life and death are the focus of enquiry. This enables the researcher to discover how their illness experience and situation have contributed to the construction of their perceptions, and facilitates an assessment of the significance of holistic care in this context. The extent to which holistic care has been perceived by the subjects to have contributed to their capacity to experience increased peace, happiness and well being is taken as the indicator of spiritual well being and will be analysed using interpretative methods. These issues will be contextualised not only by the data obtained from field research, but also by their consideration with respect to the extensive literature and previous research on related subjects. A case study will be constructed, the focus of which is the Northumberland Cancer Support Group, which will be made up of individual accounts compiled from information provided by members of this support group.

The first contact people suspected of having a life-threatening illness have is usually with a member of the Primary Care Team, with the diagnosis, when confirmed, given by a hospital consultant. This medical approach to management judges potential success and failure of interventions in terms of the projected chances of physical recovery, which is demonstrated through scientific means, such as reduction in tumour size or changes in the person's blood picture. The likely prognosis of each individual is generally given in a direct, and often blunt, way and whilst honesty in relation to the diagnostic findings is to be commended, this can be perceived as denying the person the possibility of hope with respect to the future. Since a person's illness history can span several years and the quality of the total illness experience during this time can be very variable, it is inadequate to

limit enquiry simply to the time of diagnosis. That is, the total illness experience may consist of care received at home, in outpatient departments, as a hospital in-patient, in respite care facilities and in a hospice. There may also be long periods of remission when the person's quality of life is such that to call this time part of their 'illness experience' would not be accurate and when 'care' is not required. Accordingly, the way in which people live their 'normal' lives following a diagnosis of life-threatening illness, and particularly the experience of illness, will form a crucial part of this research study.

Although holistic palliative care is said to be seen as a priority with respect to commissioning services within the NHS, the statutory services in Britain are still provided around a medical model which concentrates on the type of cancer the person has and the best perceived medical treatments with which to deal with it. An example of this phenomenon can be seen in the increase in the number of 'site-specific' medical and nursing posts within oncology over the last decade. The multidisciplinary approach promoted by those organising and providing care, which has been promoted as an answer to the institutionalisation of death, may be seen as evidence of the continued professionalisation of the issues surrounding death and dying, rather than indicating a holistic framework of care (Walter 1994:193). The National Council for Hospice and Specialist Palliative Care Services (Occasional Paper, June 1998) and, more recently, *The NHS Cancer Plan* (DoH 2000) have recommended that palliative care be extended to the care of those suffering from non-malignant life-threatening illness, but the existing services in Britain are still geared towards cancer care. As is explained in chapter one, the subjects of this

study are affected by cancer, but they would still have been eligible for inclusion had they suffered any other life-threatening illness.

In the present environment within health care, which embraces open accountability, efficiency, audit and the setting of targets for service delivery, it is expected that care and services be justified on empirical grounds. Whilst this is a positive development from the historical practice of health care, which has been described as being 'founded on tradition, assumption and precedent', it makes it difficult to promote some aspects of holistic care, such as addressing spiritual needs (Hicks and Hennessy 1997:595). As holistic care is represented in the literature, and by those supporting the philosophy, as encompassing every aspect of a person, including physical, psychological and spiritual, it was chosen as the approach to care against which other frameworks would be measured. The people who have been given a diagnosis of a life-threatening illness will be at the centre of the study, rather than any particular group of health professionals or informal carers, as it is hoped that this will help to reduce preconceptions and allow for a clearer view of the subjects' experiences to emerge. Whilst a review of the literature completed on associated subjects shows that many aspects of this research have previously been pursued as discrete studies, this thesis benefits from an investigated synthesis. Some of the literature discussed relates to the study of health care professionals, but many of the conclusions can be applied to both formal and informal carers.

It is acknowledged that in any study which has holism as its basis the researcher needs to be sensitive to the differences between social categories, such as class

and ethnicity, as these play an important part in the extent to which people engage with this kind of philosophy. For example, holism can be seen as having a religious dimension by some people, which they may find problematic, or be seen to indicate a poor prognosis which the individual may not be prepared to face. In view of these possible perspectives, the subjects involved in the study have participated voluntarily and have expressed an interest in, and a regard for, a holistic philosophy by joining a support group for cancer sufferers, the Northumberland Cancer Support Group, which is affiliated to the Bristol Cancer Help Centre. Throughout this study the terms 'man' and 'mankind' will be used as generic terms to include men and women, that is humankind.

The content of the thesis

Chapter one details the method and context of the research study and establishes the appropriateness of interpretative methods, as opposed to positivist methods, in this case, with particular reference to phenomenological theory and to ethical considerations. The research design is presented and the theory behind conducting case study research is detailed. The ways in which the associated research methods, such as carrying out interviews and completing diaries, produces meaningful results is also analysed and the context of contemporary research discussed. Overall, this chapter sets the scene for the case study, made up of individual accounts, which are presented in chapter six and analysed in chapter seven.

The next three chapters of the thesis constitute background chapters which include a review of the literature associated with the many and varied subjects which are

relevant to it. The first of these, chapter two, reviews and examines the literature associated with death, dying and mortality. For example, the ways in which death is perceived in Western society, the medicalisation of death, whether or not death is considered as taboo in contemporary Western society and cancer as a metaphor for death are areas which are explored. With respect to dying, theory associated with the process of dying, fear of death and philosophies concerning grief and loss are examined. This helps to provide the context for the revelations made by the subjects with respect to living with a life-threatening illness as revealed in the individual accounts.

Chapter three also provides background to the case studies, as it examines the concept of spirituality, its expression and aspects of spiritual care. The difficulty of defining spirituality and how it differs from religion are discussed with particular reference to spirituality as it is perceived in contemporary society. Other theories associated with spirituality are also presented, such as concepts of self and self-identity, hope, quality of life, well being, healing and inner spirituality. The context of spiritual care for people with life-threatening illness is also set and the chapter concludes with a discussion of possible ways in which spiritual needs may be identified and addressed.

Chapter four presents a discussion centring on holism in its theoretical and practical contexts, in particular as it relates to health and theory associated with psychoneuroimmunology. The approach to health promoted by the Bristol Cancer Help Centre (BCHC) and the way in which the Northumberland Cancer Support Group (NCSG) adopts this philosophy are also presented as examples of the holistic

movement in practice. The ways in which health, illness and holism are linked are also examined and different theories of health and illness are considered, for example traditional and conventional. The medical model of health care is analysed in detail, as it has a significant impact on the subjects, and is compared and contrasted with complementary and alternative approaches. In addition, models of health behaviour and the sick role, issues relating to quality of life and well being and theories of the causation of cancer are discussed.

In chapter five, background theory relevant to the research study is revisited, as is the methodology associated with it. This chapter also deals with additional theory with the aim of locating the NCSG as the case study and to establish how the individual accounts contribute to its analysis. In chapter six the data gathered from the individual accounts is presented in the form of phenomenological description, with each subject's case detailed under their ascribed first name. Seven individual accounts are detailed, six of which are constructed around the illness experiences of people who have received a diagnosis of cancer and one which is based upon the experience of a carer of a person in this situation.

The penultimate chapter of the thesis provides an overall analysis of the case study and provides a discussion of the common essential features of the subjects' experiences. This includes how the Northumberland Cancer Support Group provides an environment for meaning making for the subjects as they try to come to terms with living with the effects of life-threatening illness. Areas of experience which emerge as central to the thesis are the sense of the preciousness of time relating to changes in expectations of life course, alterations to concept of self as a result of

illness, the perceived inadequacy of conventional medicine, reactions to perceived loss of control and benefits derived from engaging in the holistic philosophy in this context.

The final chapter constitutes the conclusion of the thesis and provides a review of it and a summary of the research findings. Overall, the change from the naïve approach to life which the subjects display prior to their diagnoses is in sharp contrast to the scrutinising perspective they adopt following the explicit recognition of their mortality. In addition, although the subjects employ a variety of therapies and approaches within a holistic framework, human to human connection emerges as the most important aspect of holism with respect to promoting spiritual well being. Following conclusions as to the wider applicability of this research study, recommendations for future research are also outlined.

Chapter 1

Method and context of research

This chapter presents the theory underlying this thesis as well as the practice involved in pursuing the research itself, including relevant ethical considerations. The research process is considered from the proposal stage to the final drawing of conclusions from the results. The complex nature of the data involved also makes it necessary to consider some of the influences that are exerted on research of this kind carried out in contemporary society.

The context of the research

Contemporary Western society can be described as 'postmodern'. Modernism is generally taken to refer to Western culture from the time of the Enlightenment and the Industrial Revolution (Sheldrake 1998:8) and this modern era is associated with striving to establish a definitive set of standards for what was considered to be civilisation and to judge how society measured up to these standards. The emphasis of this judgement lies in 'materialist and technological achievement' and, in contrast, postmodernism denies that such standards can exist in an objective way (Griffin 1988:81). Thus, postmodernism questions the conviction placed in human reason to establish truth and to solve problems, as all truth in this context is open to interpretation and, therefore, subject to partiality and cultural influences (Sheldrake 1998:8). As a concept, postmodernism has been described as a 'specifically Western rather than a universal phenomenon' and is associated with the perceived fragmentation of modern Western culture (King 1998:2). There are several theories of postmodernism, but in general, it is said to be characterised by

a 'suspicion of dogmas and ideologies' and a 'rejection of any kind of literalism' (Sheldrake 1998:9).

In relation to research, the modern, scientific perspective has been described as 'alienating', as it attempts to achieve objectivity, whilst the postmodern viewpoint, at least in its holistic mode, allows for a contextual research methodology which is able to understand and respect the 'unbroken unity of all life' (Dacher 1997:68). The phenomenological framework employed in this piece of research will allow the research participants to reveal their perceptions of reality in relation to their experience. This research study was conducted through participant observation, which is the best known method employed in anthropological research and involves the sustained involvement of the researcher with the subjects in an attempt to generate a comprehensive and in-depth report of the relevant group or organisation. Participant observation is not a single method and can encompass many ways of obtaining information through different forms of observation. This research method was developed in order to address and make the most of the 'special character' of people as the objects of research and to reduce the researcher's inclination to impose inappropriate conceptual frameworks on them, thereby facilitating the development of an in-depth and comprehensive account of the subjects in question (Bryman 1988:45,48,3,5). In this case, semi-structured interviews were conducted which involved minimal guidance from the researcher, and the subjects' diaries can be considered as part of participant observation, in that they reveal their perceptions of the world and reality. Details of the methods employed to conduct this research will be provided later in this chapter.

The anthropology of the body

A theoretical perspective described as 'the anthropology of the body' has been put forward which focuses on human biology, sociology and evolution. This term has been used since the 1970s and involves the perspective of the body as an object of analysis and as the 'source of symbols' which is identified in cultural discourse (Csordas 1994:4). As part of this theory man is not viewed in a dualistic way and it is argued that people experience themselves simultaneously 'in' and 'as' their bodies, and phenomenologically speaking, are not aware of their bodies, except when 'disease, distress or dysfunction' occur, when the person can experience a 'vivid but unwanted consciousness' of their bodies. Even when a person's body confers some kind of advantage on them, the body is perceived as 'an object of exchange' rather than an independent agent (Csordas 1994:54,52, from Merleau Ponty). The research subjects directly affected by life-threatening illness react to the associated significant changes to their bodies and to the ways in which these changes affect those close to them, as will be revealed through the individual accounts which make up the case study. The subjects' search for meaning in their illness experience demonstrates an attempt to transcend their bodies and the physical world, for example by gaining access to the spiritual domain through healing or prayer, which will be analysed through the case study, using a phenomenological approach.

Phenomenology

In order to apply a phenomenological framework to the analysis of the data gathered during this research study, it is important that the theory behind

11

phenomenology be understood. The word 'phenomenon' is of Greek origin and translates as 'to flare up' or show itself (Moustakas 1994:26). Phenomenology is the name given to the study or description of phenomena, with a phenomenon being 'anything that appears or presents itself to someone', thereby not needing to be in any way extraordinary (Hammond 1991:1), and thus 'causing us to notice features that we ordinarily fail to notice' (McQuarrie 1973:10). As a philosophy related to sociological themes it was 'first explicitly formulated' by Edmund Husserl (1859-1938) and has been defined as a philosophical 'method' rather than a philosophical 'doctrine' (Bettis 1969:5). Phenomena have been identified as the foundation of experience and knowledge:

> In a broad sense, that which appears provides the impetus for experience and for generating new knowledge. Phenomena are the building blocks of human science and the basis for all knowledge (Moustakas 1994:26).

Religion, morality, law, economics and aesthetics have been identified as the 'principal social phenomena' and as 'ideals', since they are made up of systems of values. An ideal reflects both the true state of society or a social phenomenon and its aspirations or potential (Durkheim 1965:96;xvi). Social facts, as identified by Durkheim, can be seen as a clustering of ideas and phenomena which reflects substance and meaning within a society, for example the beliefs and customs associated with parenting and child-rearing. Social facts can be seen as 'norms' in terms of rules and expectations which exist within society prior to an individual's entrance into that society, and if these norms are ignored a state of 'normlessness' or 'anomie' occurs (Garbarino 1977:39). In addition, it is argued that social

12

phenomena should be considered in themselves as distinct from the way in which individuals conceptualise them mentally and that the function of a social fact should be sought in terms of its being a means to a particular social end (Durkheim 1938:28;110,111). The main aim of sociology is that the 'principle of causality' be applied to social phenomena (Durkheim 1938:141).

Interpretative social science research is concerned with how reality is constructed and perceived by individuals and groups within society. Reality has been defined as 'a quality appertaining to phenomena that we recognise as having a being independent of our own volition' and knowledge as 'the certainty that phenomena are real and that they possess specific characteristics' (Berger and Luckman 1996:1). Reality has also been defined in terms of being 'an intersubjective world of culture', and social reality as:

> the sum total of objects and occurrences within the social cultural world as experienced by the common sense thinking of men living their daily lives among their fellow men, connected with them in manifold relations of interaction (Schutz 1962:53).

This definition highlights the ordinariness of reality in an everyday context. The theory has been put forward that the reality of 'everyday life' is the most 'real' as it 'imposes itself upon consciousness in the most massive, urgent and intense manner' and, therefore, subjectivity need not detract from this reality (Berger and Luckman 1996:21). Thus, reality is made up of 'common sense constructs of everyday life', whilst social scientists make 'constructs of constructs', which

creates distance from the observed reality (Schutz 1962:6). Different 'planes of conscious life' have also been defined, which correspond to specific tensions of consciousness. For example, the highest plane of consciousness relates to action carried out in 'full wakefulness' and the lowest to dreaming (Schutz 1970:68). All phenomena relate to one of these worlds and the average mind thinks of all of these subworlds 'more or less disconnectedly' and individually (Schutz 1962:240,207). These 'planes of conscious life' are termed 'spheres of reality' by Berger and Luckman (1996), and as 'finite provinces of meaning' by Schutz, as meaning is perceived as constituting reality (Schutz 1962:210).

Thoughts continuously change and have, therefore, been compared to a river or stream. Individual experiences are not clearly differentiated in the personal stream of consciousness and a person cannot be truly aware of experience whilst being 'immersed in the stream'. Therefore, reflection on experience is required to elicit meaning, in that meaning is 'merely an operation of intentionality' which can only be perceived retrospectively. Behaviour which is taking place has been defined as 'prephenomenal experience' and behaviour which has taken place as 'phenomenal experience' (Schutz 1970:57,61,63,67).

The individual experiences life and acts 'as the working self in the present', and as the 'total self', whereas on reflection on this activity the self can be said to have taken on a 'role', that is of only part of the self. In this way, a person finds himself at any time in a 'biographically determined situation', which includes a physical and sociocultural environment, within which he has a place (Schutz 1970:70-1). The individual takes part in the social world by taking on roles and it is through

internalising these roles that the world becomes 'subjectively real' to him or her (Berger and Luckman 1996:74). The sense of self of each subject emerges as a strong theme throughout the individual accounts and will be analysed in relation to each of them.

As an approach to anthropological research, phenomenology has been credited with an ability to synthesise the 'immediacy of embodied experience with the multiplicity of cultural meaning in which we are always and inevitably immersed' (Csordas 1994:vii). Phenomenology focuses on the individual's consciousness and experiences of the environment which are perceived through the use of the senses (Layder 1994:75). Merleau-Ponty argues that utilising a phenomenological method is a way of describing, as opposed to explaining, and that the aim of the phenomenologist is to describe the 'essence' of a phenomenon, not to 'locate' it (in Bettis 1969:6,10). Similarly, the Husserlian tradition of transcendental phenomenology seeks to discover the subjective essence of a phenomenon (Wright 2001:4). Phenomenologists also argue that there are no such things as 'facts' since, 'All facts are from the outset facts selected from a universal context by the activities of our minds' (Schutz 1962:5). Thus, all thoughts are characterised as being 'consciousness of something' and the 'personal environment' is a reality for the person rather than a real world 'in itself'. In addition, in this sense there can be no such thing as fear, fantasy or remembrance per se, as they are all thoughts or feelings of something or someone (Schutz 1970:4,28,103).

For analytical purposes the phenomenologist has, from one perspective, to 'suspend belief' in the existence of the world, to disregard any previous knowledge and

conceptions of this world and to transcend the everyday world which would normally be taken for granted. This has been termed 'phenomenological reduction' (Schutz 1962:104) and enables the researcher to dissociate subjective experience from the unchallenged acceptance of its character and substance through which such experience is 'filtered', which Husserl called the 'natural attitude' (Bryman 1988:51). 'Epoche' is the term used to indicate refraining from judgement and to see what 'stands before our eyes' (Moustakas 1994:28).

The 'personalistic sphere' of reality is characterised by communication and an idea of the reciprocal understanding of and by others. However, the first indubitable fact the analytical phenomenologist starts from is that a personal consciousness exists. In order to determine the foundation for all certain knowledge, Descartes propounded the theory that the mind had to be emptied of all thoughts associated with the senses, empirical perception and metaphysical beliefs. He presented the summation of his theory in the phrase 'cogito ergo sum', in that he considered the thinking self as the one true certainty (Bradshaw 1994:21). Thus, the 'personal self' rather than the thought is seen as the 'immediate datum in psychology'. (Schutz 1970:72,57). The way that phenomenological experience is verified by other people has been called the 'phenomenological nod', which indicates that the experience in question is recognised as one which the other person could have (Van der Zalm and Bergum 2000:212).

Phenomenology is concerned with wholeness and with:

'examining entities from many sides, angles and perspectives until a unified vision of the essences of a phenomenon or experience is achieved (Moustakas 1994:58).

This characteristic of phenomenology makes it the method of choice when studying holism and its effects. For the purposes of this research, Husserl's phenomenological approach will be used predominantly as the aim is to capture the absolute essence of phenomena and essential features of associated experience by analysis of experienced reality as it is presented to the consciousness of the participants. By the process of phenomenological reduction the researcher will focus on the experience of the subjects in search of its essence and this will enable reflection on the functions which allow this essence to become conscious. However, the complete 'bracketing' of a researcher's perceptions and cultural knowledge, which is desirable in the attempt to achieve phenomenological reduction, may never be possible as these perceptions are located both historically and culturally. In addition, as previously mentioned, it is argued that consciousness is always consciousness of something, so a degree of interpretation is always implicit in dealing with data. Merleau-Ponty's approach to phenomenology will also be drawn upon, grounded as it is in bodily behaviour and perception. Embodiment is a very important concept in relation to this research as embodiment is the grounding of all perception, and as embodiment shifts, for example due to illness, the world we perceive shifts with it. The aim of this research is to show if and how engaging in the holistic philosophy contributes to the experience of spiritual well being. In relation to this aim, the aspects of phenomenology which are most pertinent to the case study are the subjects' perceptions of reality, the shared environment for

meaning making which is provided through the support group, the phenomenological description provided by the participants throughout their illness narratives and the importance of the body of knowledge which they share.

Other methodological approaches were considered with respect to conducting this research study, such as grounded theory. Although grounded theory may have been appropriate in terms of being able to generate a theory which is specific to the characteristics and circumstances of the research focus and a theory which is grounded in actions and interactions of the participants, it would not have been appropriate for the following reasons. A feature of grounded theory is that several visits are required to the 'field' until saturation of data is attained. This process also involves theoretical sampling, as the research is conducted in order to establish a sample which helps the researcher to formulate a theory and also incorporates continuous comparison of data and emerging theory (Robson 2002:190-193). The subjects of this research study participated voluntarily and, due to the sensitive nature of the subject matter and the stage of illness of some of the subjects, it would not have been appropriate to have returned to the group in order to obtain more volunteers or to approach the same subjects more than once. Each subject was able to provide information collected over a period of several weeks in relation to their overall illness experience and attempts to analyse this data continuously, including comparing it to that of other participants, would not have achieved the aims of the research. As the support group is the case study and focus of this research, it is still possible to analyse the individual accounts with each other and with established and emerging theory, but continuous comparison and theoretical sampling would have involved systematic interpretation of the data

which could have detracted from the presentation of the subjects' experience from their points of view. The specific methods employed within the phenomenological framework will now be discussed.

The research proposal

The research proposal for this study was sent for consideration to the two relevant local Research Ethical Committees, that is Newcastle and North Tyneside and Northumberland. As the purpose of developing a research proposal is to outline the rationale behind a proposed research study, details were provided concerning what the research aimed to achieve, why the research needed to be carried out, why the researcher was suited to the particular study, how the study was to be carried out and what resources would be required (Greenfield 1996:16). The research question developed for this thesis arrived at its present form after discussion with the Northumberland Research Ethical Committee as part of the process of obtaining ethical approval, as detailed later in this chapter. It was considered most important for the question to incorporate the purported holistic philosophy of the support group and the effects of engaging in this philosophy. Issues to be explored included whether achieving spiritual well being is a shared goal of the group members and if maintaining positivity in the face of death is intrinsic to the group. *Please see appendix 1 for copy of research proposal.*

Ethical considerations and method

Any sociological, nursing or medical research which seeks to obtain subjects from the 'patient' population needs to be cleared by at least one Local Research Ethical Committee (LREC). The notion of ethics is related to morals, the treatment of

moral questions, moral correctness and honour (The Shorter Oxford English Dictionary 1993:856). The idea is, therefore, also concerned with the rights of individuals, such as the rights not to be harmed, to privacy, to self-determination and to dignity (Couchman and Dawson 1991:126-7). Scott draws attention to the increased content of ethical and philosophical theory in, and its perceived importance to, nursing and medical courses since the 1980s (2000:3). The formal internationally recognised code of medical ethics has its origins in the post-war Nuremberg code, which highlighted the need for proper consent, the avoidance of needless physical and mental suffering and the prohibition of unnecessary and aimless research. It was also acknowledged that subjects who have given consent have the right to withdraw that consent at any point during the research process. Ethical Committee review as it is known today had developed by the 1970s, which coincided with an explosion in clinical research activity (Evans and Evans 1996:1-2). The 'moral springboard' for the local Ethical Committee's responsibilities and concerns has been said to have its origins in the 'special vulnerability of all clinical research subjects'. Special groups have also been identified in terms of particular vulnerability, such as children, the mentally ill and the terminally ill (Evans and Evans 1996:1,15,18,68).

As the potential subjects to be involved in this research could be perceived as being particularly vulnerable, in that they are people who had been given a diagnosis of a life-threatening illness, ethical considerations were held to be of particular importance. In this case, Ethical Committee approval was required from both the Newcastle and North Tyneside and Northumberland Committees as the group meets in Northumberland but the subjects, in the main, were under the care of physicians

in Newcastle and resident in Newcastle, North Tyneside or Northumberland (*Copies of the application forms to Newcastle and North Tyneside and Northumberland LREC are included as appendices 5 and 6 respectively*). The researcher was not advised to apply for multiple centre research approval because the group members all had a General Practitioner or physician based in either Newcastle or Northumberland. Also, a form had to be completed to obtain indemnity from Newcastle City Health Trust to carry out the research, as the researcher was employed by this Trust at the time the research was carried out.

Both LREC applications required similar information from the researcher in order to assess the potential effects on the subjects of being involved in the research. Verification of the identity of the researcher, supervisor and the supporting organisation, in this case Newcastle-upon-Tyne University and Newcastle City Health Trust, were requested in order to establish that the research was being carried out legitimately. The researcher transferred to the University of Durham after the fieldwork was completed and both LRECs were informed of this change to the initial information submitted. Questions regarding the location of the study and the General Practitioner (GP) and/or the physician of each subject were included. It was explained that the interviews were to be carried out at the venue most suitable for each subject, for example the person's home or the Adult Learning Centre at Hexham, where the support group met, and that the Adult Learning Centre was designated as the central place where the researcher would introduce the research, contact subjects during the study and collect diaries from them. Telephone contact was also to be utilised between the researcher and the subjects to arrange interviews and meetings and to provide support during the diary-keeping

stage. The relevant GP or physician of each person was not notified by the researcher prior to each subject becoming involved in the research as people attended the group voluntarily, were capable of making an informed decision and were keen to participate in the research, which, in view of the research design, could have had no effect on their medical treatment. That is, group members take part in many activities and therapies which do not require medical permission at meetings and the research would have no more effect on medical treatments than one of these.

Possible psychological distress was the only potential 'inconvenience or danger' *(see Q.9, Newcastle form, included as appendix 5)* to the subjects, which could have occurred due to the type of data to be obtained. One of the support group's Committee members had been approached and arranged counselling support, to be instituted should the study have resulted in any such distress for the subjects. The researcher agreed to stop the interview if a subject showed any signs of stress or anxiety and alert the counsellor, but none of the subjects exhibited any such signs during the fieldwork. The subjects were to be given information about what form the completed study would take, and who would have access to it. They were to be assured that their anonymity would be maintained in the thesis and that only the researcher would know their true identities. Informed consent was to be obtained from each participant prior to taking part in the study and the subjects were offered access to a copy of the thesis when complete. *Copies of the consent form, 'information for subjects' sheet and 'guidance for diary keeping' are included as appendices 2, 3 and 4 respectively.*

The subjects were not going to be involved in clinical trials or categorised for the purposes of the research, for example by age or gender, but to be taken as volunteered, so controls and healthy volunteers were not required. As the proposed study was to be a discrete piece of research, it was not necessary to guard against the subjects being entered into repeated studies or trials. It was not planned to make any payment to the subjects as the researcher agreed either to attend the subjects' home or meetings that they had already planned to attend, and supplied each subject with a journal, so that no extra expenses would be incurred by them as a result of taking part in the research. The researcher was required to give information regarding funding arrangements, which were that funding was partly provided by Newcastle City Health Trust and partly met by self-funding and copies of the research tools to be used were requested and supplied.

The initial applications were given approval after further information was supplied. The Newcastle Committee required a copy of the letter from Newcastle City Health Trust giving the researcher indemnity to carry out the research, a copy of the research proposal with the associated bibliography and assurance that any audio tapes used would be bulk-erased after transcription. However, audiotapes were not used as the researcher felt that the interviews were more informal without and, therefore, more conducive to the collection of information in a relaxed and open manner. Similarly, the subjects were happy to keep a written record in the form of a diary. The researcher was also advised to inform the Northumberland Ethical Committee of the proposed study.

In addition to the information required on the Newcastle Committee's application

form, as detailed above, the Northumberland Committee considered the proposal at another two meetings following the Committee's request for a clarification of a number of issues. At the first referral the Committee felt that the support group would not provide generalisable data, appeared to have assumed that 'facing life-threatening illness' meant that a person was terminally ill, requested a list of references of associated literature and saw no reason why each subject's GP should not be informed. The researcher addressed these concerns by letter, pointing out that the term 'terminal illness' had not been used. The reasons for choosing the sample, including potential biases and limitations, were also acknowledged. Revised copies of the interview schedules and guidance to diary-keeping were provided which had been modified to make the process of care of each subject more explicit. A list of references was also included together with a copy of the letter from the Newcastle and North Tyneside Committee giving the researcher permission to carry out the research. The researcher informed the Committee that there was no reason related to the proposed research study to inform the GP of each subject and that the GP would only be informed if the subject requested this to be done.

After the second referral of the application the researcher went to see the consultant of Public Health, who was the Chair of the LREC, to discuss the reasons for referral. The researcher had been told that there was 'no attempt to identify in a structured way what the process of care received had been', that committee members felt that there had been inadequate definition of 'holistic care' and how its significance would be determined. It was also identified that the Committee felt that the researcher used the term 'holistic' as equivalent to 'complementary' and

that the research question and design appeared to prejudge the outcome. It was much easier to elaborate on information previously given and to clarify confusion over issues face to face than by letter. The interview schedules were again modified to ensure that questions relating to the person's illness history were clear and the research question was expanded so that the interest and situation of the subjects, that is that they had sought out and attended a group professing to work within a holistic framework, was clear. The methods to be employed in order to establish the significance of holism to the subjects were detailed in the research proposal and the misunderstanding of the Committee concerning the terms 'holism' and 'complementary' was cleared up. This information was subsequently provided by letter to the Ethical Committee and after the third meeting at which the proposal was considered it was given approval, with the proviso that the Committee is informed of any minor changes to the study. The following section will provide background theory relating to how the research study was carried out and the individual accounts developed.

Case study research

Research which focuses on case studies has been said to be suitable to answer questions concerning a set of events over which the researcher has little or no power and, therefore, allows the phenomena to be studied in their 'real life' context and can be particularly helpful when 'the boundaries between phenomenon and context are not clearly evident' (Yin 1994:9,13). This research study was completed through the analysis of a case study, due to the complex and sensitive nature of the subject area chosen and to the rich quality of the data that can be obtained by employing this approach within a phenomenological framework. The

Northumberland Cancer Research Group (NCSG) is the focus of the overall case study and is made up of the seven individual accounts.

Many potential problems of constructing case studies as part of the research process have been identified, for example it has been argued that they are anecdotal and may be unrepresentative of the wider population. However, this perspective is founded on the accepted theories of sampling, which are themselves based on the supposed representativeness of selecting a sample and the associated ability to make generalisations about a population from it (Bergan and While 2000:927). In other words, it is virtually impossible to include every member of a potential subject group in a research study, and any attempt to choose a representative sample is open to bias in the same way that case studies are. It has been suggested that if the number of case studies is increased, or more than one researcher analyses the same case studies, the results will be less anecdotal and more meaningful. The choice of cases which are 'typical' of a certain collection of characteristics, which are then examined by other researchers in the light of other groups of characteristics, is also likely to improve the credibility of research findings (Bryman 1988:88-9). Another potential limitation to the value of creating case studies is their subjectivity, as the information provided by the subjects can be described as 'their picture of the world as they see it', given in a way in which they are prepared to impart it and given that it is also very difficult to put feelings and emotions into words (Dean and Whyte 1969:105-6). However a case study can be seen as a 'significant communication device', in that the detail of analysis can convey a wealth of information about more general phenomena and, thereby, widen the audience of the research findings (Yin 1994:130).

Overall, the case study approach was employed to conduct this research in order to broaden the consideration of holism and spirituality by focusing on the role of the support group in providing both a source of meaning making and of support which is not available to group members from elsewhere. This group is made up of two types of people, those who are directly affected by cancer, and those who care for someone in this situation, the latter making up a smaller proportion of group members. By focusing on the support group as the case study, individual accounts from both sufferers and a carer can be incorporated to provide a more comprehensive picture of the effects of living with life-threatening illness and caring for someone in this situation. In view of the small number of individual accounts presented in this research, viz seven, their significance may be questioned, but the large amount of data provided through the case study gives valuable and in-depth insights into the phenomenological experience of people affected directly and indirectly by life-threatening illness and indicates key themes which can be given a more general application. By constructing narratives it is possible for the subjects to reveal their everyday world as the text alludes beyond its obvious content and context. The methods employed to construct the individual accounts making up the case study upon which this research is based will now be considered.

How the subjects were approached
Having spoken to the group secretary and another Committee member, the researcher planned to speak at a group meeting of the NCSG to introduce the research, after Ethical Committee approval had been given. Approximately twenty-

five people attended the scheduled talk in February 1999, at which information about the study was given *(see copy of 'information for subjects', appendix 3)*. Group members were shown consent forms and guidance for diary-keeping sheets *(appendices 2 and 4)* and asked questions to clarify what participation would involve. It was agreed that the information sheets would be circulated via the mailing list planned for May 1999 if enough volunteers had not been obtained by then. At the first meeting, five people were keen to be included, four sufferers and one carer, one person was given the information by another group member and contacted the researcher and another expressed an interest in taking part at the second meeting. The carer who volunteered was included as she was keen to take part and it was thought that the data collected would complement that gathered from the other subjects. The subjects who participated were all articulate and literate and were, therefore, able to be involved fully in every aspect of the research process.

Constructing the case study

As previously stated, the following case study was compiled from data gathered from seven subjects, six female and one male, which is roughly proportionate to the gender mix of the NCSG at the time when the fieldwork was carried out. The data from which the individual accounts themselves were constructed will be presented as an amalgamation of that collected through interviews and diaries so that themes are allowed to emerge and expressions, words and phrases may be demonstrated in a more comprehensive way. In addition, analysing the data collected in their complete form allows for ideas introduced at the preliminary interview stage to be developed through journal keeping and be evaluated at the

follow-up interview. In this way, each individual account will be written in a comprehensive format to facilitate the identification of their similarities and differences and will be presented as a balance of description, analysis and direct quotations in chapters six an seven. As mentioned above in relation to applications made to obtain Ethical Committee approval, the interviews were not taped as the researcher felt that it would reduce the informality of the context of the interviews. As each word was not required to elicit central themes and important aspects of each subject's experience, the researcher kept the interviews to a pace at which the information given could be recorded in note form. Taping interviews can be perceived as intrusive in informal interviews and the analysis of relevant passages and words is sufficient in the vast majority of studies, rather than analysing every single word transcribed from each tape (Robson 2002:289). In addition, had tapes been used, transcription of them would have been time-consuming and costly, without the benefit of adding anything to the information collected in written form. That is to say that more detailed and considered information was elicited from the subjects' journals. The researcher drew the headings under which the data are recorded from the themes which emerged from the interview data and journal contents as a way of presenting the data in a cohesive and meaningful way

A preliminary interview was carried out with each subject, followed by diary keeping and then a follow-up interview. The follow-up interview was carried out so that the researcher could clarify any issues which were unclear in the diaries and to give the subjects the opportunity to clarify or discuss anything in relation to the research process or their associated experience. (*Please see appendices 4, 10 and*

11 respectively for copies of the guidance for diary keeping, preliminary interview schedules and follow-up interview schedules).

In both the interviews and diaries, the subjects were invited to talk around subjects such as how they would describe their illness, how they feel about their illness and situation and any perceived stages of their illness. Personal definitions of holistic care, what it has to offer, approaches used and how these relate to notions of spiritual well being were also sought. The ways in which the participants have dealt with previous problems in life and what life and death means to them, in terms of what is valued about life and beliefs about what happens after death, were also included in the interview schedules as areas relevant to the research. This latter can be summarised as trying to establish how the participant's illness experience has affected how they view life and death. Themes emerged naturally from the individual accounts, some of which were surprising to the researcher, as will be discussed in chapter seven. As will be discussed in chapter four, the group does not have any brief as such, but it is clear that some areas of illness experience and coping mechanisms are common to group members and these may have contributed to their reasons for joining the group.

It has been argued that diaries kept by subjects can 'secure substantial amounts of data that otherwise would be inaccessible' (Clarke 1991:110), as they are kept over a period of time and contain the private thoughts and feelings of the subject, and can, therefore, be seen as a type of participant observation (Bell 1987:81). The type of subject able to be involved in this kind of data collection may be limited,

as the person has to be of a certain educational standard to understand the instructions and to keep the diary (Bell 1987:81,82,87). As with all qualitative research, subjects bring with them their own assumptions and orientations, which can influence the results and potentially cause bias (Clarke 1991:77). Also, because the subjects are keeping a diary, they become aware of their activities and this self-consciousness may affect their actions and what is recorded (Bell 1987:80). However, having had the main areas upon which the research was to focus introduced at the preliminary interview, diaries were employed in order that the subjects could record their thoughts and feelings relating to the research areas and their own experience over a designated period of time. This allowed them to expand on information given at interview and to consider their experiences in this light. Overall, it was not thought to be relevant to distinguish which information was derived from each method as the detail of the combined information was considered to be most important as it provides comprehensive insights into the everyday reality of the research subjects, as previously discussed.

It was decided that each subject would keep a diary for four to five weeks and would record their illness experience retrospectively and any other significant feelings and thoughts. The researcher planned to contact the subjects approximately half way through the period set aside for diary-keeping and they were given a contact number for the researcher in case they experienced difficulties or needed to have any aspect of the research process clarified. Only two subjects contacted the researcher in such an event, but the other five welcomed telephone calls from the researcher during the diary-keeping stage of the process as they wanted clarification of what they were supposed to be including in the

diaries.

As qualitative methods alone were to be employed, the researcher was advised that statistical support and analysis would not be needed and it was anticipated that the fieldwork would be carried out over one year. The research subjects will be referred to by a first name only, which has been changed from their own, in order to protect their anonymity.

The sample

As the potential subjects for this piece of research were identified through the Northumberland Cancer Support Group (NCSG), which is affiliated to the Bristol Cancer Help Centre, the sample for this study was purposeful, in that it was chosen as a means through which to obtain significant information whilst being of a manageable size. It was convenient in the sense that the support group was located in Northumberland, making it accessible to the researcher, and consisted of people suffering from potentially life-threatening illness. As the group is very open to new ideas and situations, the research proposal was well received and subjects were more than willing to volunteer. This became a small example of a snowball sample, as other potential subjects contacted the researcher having heard about the project by word of mouth within the group, or by receiving written information about it from other group members or through the mailing list.

The study was not initially to be limited to people suffering from cancer but as the Northumberland Cancer Support Group was able to provide subjects who fitted the research criteria, this group was approached as no such group for non-cancer

sufferers who were facing life-threatening illness was identified. The study of people suffering from other illnesses may have yielded different information, for example, HIV sufferers may have contrasting illness experiences influenced by the stigma associated with the disease by some people in society and illnesses such as multiple sclerosis and motor neurone disease may not be classified as immediately potentially life-threatening as is cancer. In addition, people who join support groups may not be typical of the whole population of potential members, which can influence the results. The voluntary nature of participation was always a major priority in view of the sensitive nature of the information required and it was recognised that this would limit the range of people participating in the study to those comfortable with talking and writing about the topics constituting the research and meant only involving people with the level of articulation and literacy required to achieve this. On the other hand, those prepared to participate were keen to become fully involved and to provide the highest quality of data possible, which was indicative of their commitment to the holistic philosophy. Indeed, their interest and belief in holism was a key part of the research process and analysis of the results.

This chapter has provided details concerning the theoretical influences on this research study and their practical application. That is, the research process and design have been explored and relevant ethical considerations examined. The context of the research study has also been analysed, in addition to the particular appropriateness of qualitative and interpretative methods to it. Particular attention has been focused upon phenomenology as a framework for the research and how

this is especially pertinent to case study research. Having considered these issues, it is necessary to explore in depth other subject areas which are relevant to the thesis. The next chapter focuses on issues relating to mortality, death and dying to provide background to the information provided by the subjects as detailed in the individual accounts.

Chapter 2

Death and dying

Having discussed in detail the methodology associated with this research, the next three chapters will focus upon background theory as presented in the relevant literature. A wealth of literature exists relating to death and dying but this section will only focus on those sources which can be considered most relevant to this thesis. The quality of care for the dying was a major focus of the literature in the 1960s and 1970s, which can be said to have contributed to the development of the hospice movement, as it is known today. The literature reveals many problems with the care of the dying at this time, not least of which was the perceived medicalisation of the dying process and of death itself. Six of the participants of this research study have been affected directly by a diagnosis of life-threatening illness, and one is the carer of another person in this situation and, therefore, death and dying take on a new, personal significance for them. They are trying to find meaning in their situation which is characterised by an explicit awareness of their mortality or that of somebody very special to them and, as a result, they are reviewing all aspects of their lives in this context. The first section of this chapter will deal with death as it relates to the subject matter of this research and the second section to dying and facing death and will also deal with the issue of anticipatory grief which is a significant feature of the case study material.

Death

The types, boundaries, nature and meaning of death are extensively discussed in the literature where a common theme emphasises that death can be experienced

on different levels and that it has 'religious, social, spiritual and individual ramifications' (Laderman and Roseman 1996:319). The types into which death has been divided are physical, psychological and spiritual. Physical death has been defined as the irreversible cessation of all bodily functions, whilst psychological death manifests as 'emotional deadening', or living as if one were already dead, and spiritual death is described as incorporating the end or transformation of previous roles and identities with the potential to include the birth of a new self (Kramer 1988:13,18,23). Medicalisation of death is exemplified in the process for certification of death in the United Kingdom, which has to be carried out by a medical doctor and by conventional medicine establishing its own definitions of death, such as the phenomenon known as brain death, which is used to establish if life support may be withdrawn following a number of tests.

Personal mortality is not something which is easy for people to explicitly acknowledge, particularly in Western society, an argument which Feifel attributes to an inbuilt mechanism to survive, stating:

> death, as a cessation of being, involves aspects of reality inadmissible to the omnipotent and narcissistic self and for this reason strong defences are developed against its recognition (1959:26).

Therefore, to have a conception of death, particularly one's own death, may be regarded as 'absurd' (Kearl 1989:48). This idea has been described elsewhere as society being geared towards denying death and retarding the ageing process (Pietroni 1990:126). Bauman goes further and purports the theory that human

beings live as if they were immortal and deny that they are going to die, presenting death as a contradiction, in that 'Death does not just defy imagination: death is the archetypal contradiction in terms' (1992:15). Death is thus presented as the inversion of rationality to people whose instincts and reason constantly impel them to survive, in that:

> death blatantly defies the power of reason: reason's power is to be a guide to good choice, but death is not a matter of choice. Death is the scandal, the ultimate humiliation of reason...Reason cannot exculpate itself of this ignominy. It can only try a cover up. And it does. Since the discovery of death...human societies have kept designing elaborate subterfuges, hoping that they would be allowed to forget about the scandal; failing that, hoping that they could afford not to think about it; failing that, they forbade speaking about it (Bauman 1992:15).

There are, perhaps, two threads to the same argument here, as Bauman appears to see the subconscious denial of death as a universal human phenomenon which enables people to carry on with the routines and aims of everyday life, and the idea that this is supported more overtly by Western societal norms. The uniqueness the subjects feel when facing a possible premature death bears out this argument, as they have always been mortal, as all human beings, but this particular threat to their implicit feelings of immortality highlights Western society's overt denial of death in every day life.

If, then, human beings live in a state of consciousness which does not include an

awareness of death, this state may be temporarily disturbed when people are affected closely by death, for example through bereavement, or, as in the case of the research subjects, receiving a diagnosis of a life-threatening illness. This is borne out by the individual accounts which reveal that, prior to their diagnoses, the six directly affected subjects had lived without an overt awareness of their mortality, although rationally all people know that they are mortal. Bauman sums up the culture created by people without this awareness of their own mortality as collectively living 'as if we were not going to die' which he describes as a 'remarkable achievement' and a 'triumph of will over reason' (Bauman 1992:17). This helps to explain the discomfort some people feel around dying people and the perceived lack of support bereaved and dying people can experience.

In so-called primitive and developing societies, death occurs within communities and is perceived as part of everyday life, whereas in the West it is argued that death has become institutionalised (Manning 1983:20-1) and is no longer considered as a common occurrence within communities (Elias 1985:8). It seems that in the West, death started to disappear from communities, in this sense, from the time of industrialisation, as dying in the seventeenth century has been described as a 'leisurely affair', taking place at home and involving visitation by family and friends. In other words, the dying man was 'still at the centre of activity, presiding over the event as in the past and determining the ritual as he saw fit' (Ariés 1976:38). It has been argued elsewhere that by the nineteenth century medicine had gradually separated 'natural' death, which was 'conceived as the indwelling condition of life' (Hockey 1987:103) and as occurring without previous sickness or obvious cause, from 'abnormal' death, for which a medical reason had to be given

38

(Pietroni 1990:129). Thus, the role of family and friends in the care of the dying can be said to have been taken over to a large extent by paid professionals. Hockey argues that death and dying were excluded from the 'domestic space of the home' during the twentieth century in the West, with sixty per cent of deaths taking place in institutions such as hospitals and nursing homes by the mid 1960s (1994:2). This implies that death has become medicalised and that, consequently, medicine has the power to postpone death in many cases due to developments in medical technology, but this can be at the expense of the involvement of family and other carers, who provide much needed emotional, psychological and social support (Hockey 1993:71,46).

Taking this idea further, the National Health Service has been termed a 'death prevention service' (Pietroni 1990:129), as many health care professionals still consider that they have failed if a patient in their care dies. Within the medical model the decision to allow a person to die can be very difficult or impossible to make, as what has been called the 'technological imperative' implies that if the technological capacity exists to treat health problems, then they should be treated regardless of the context (Freund and McGuire 1991:253,255). Although the care of dying people has improved and there is a move towards providing palliative care in a patient's home, hospice or community hospital, Western society is still geared to letting doctors take the lead on issues relating to death and dying. For example, it has been argued that the increased expertise of professionals in relation to death can be seen as the 'further professionalisation' of death in our society (1994:201). The proliferation of palliative care professional posts and cancer specialists bear out this theory, but there is also an ongoing rise in voluntary organisation and

support group provision of practical, emotional and social support to people who are affected by life-limiting illness.

It is clear that exposure to death through the media is a developing phenomenon, so our opportunities to experience death vicariously have increased, but this has been said to go alongside a denial of death in the private sphere (Berridge 2001:5). For instance, since the advent of television, images of death and dead bodies have included the real deaths of strangers and the fictional deaths of actors and consist of 'flickering and transitory images' through which death can become familiar to viewers (Gibson 2001:308). There also appears to be a new trend for writers and artists to treat their life-threatening conditions as material, for example Ruth Picardie, writing in *The Observer* newspaper of her breast cancer (1996-7) and John Diamond in *C* (1998) writing of his experience of terminal illness. In addition, Diamond (1998:172-3) refers to Picardie's writing, which moves him to tears, and to others in the media who have written about their experiences of cancer. This almost cross-referencing of experiences is unique to contemporary society.

The additional effect of receiving a diagnosis of cancer is evident in Diamond's work, entitled simply *C*, as in our society, cancer seems to have become a metaphor for death and the initial fear of death on receiving a diagnosis of cancer is the result of knowledge accumulated prior to diagnosis, through direct contact with cancer sufferers and through sources such as the theatre, literature and music (Armstrong-Coster 2001:287). Although the research subjects involved in this study could not have been described as 'dying' when they participated in the research, it is clear from the information they provide that cancer and its potential effects

have symbolic meaning for them, as associated with a premature and unpleasant way of death.

Research studies into death and dying have been carried out in a variety of contexts. An example of this is a study carried out by Hockey (1987) through participant observation in three care settings which employed an anthropological approach focusing on the meaning and experience of life and death for those studied. In another project, Munns (1990) studied the factors that contribute to the quality of life of terminally ill people and analysed the changes in medical and nursing care throughout history. The findings of such social studies demonstrate the complexity of the issues associated with facing death and the negative associations with death which are implicit in our society, as does this research. However, this may change as more and more people live longer with chronic and terminal illness, and society and culture may undergo a shift so that they become less negative in relation to death (Young and Cullen 1996:2-3). The demographic context of contemporary society, wherein there is an increasing number of older people and a decreasing number of younger people, may also help to change attitudes towards death and dying as an increasing number of people live with an awareness of their own mortality (Berridge 2001:20).

A good death

In cultures where belief in life after death exists, death ritual can be seen to transform the boundary between life and death into 'a mediating link with future life, either in this world or the next' (Hockey 1993:54). Throughout history until the age of 'scientific progress' people accepted the idea that existence continued in

some form after death, since the idea was common to the 'ancient religions' and Christianity (Ariés 1981:95). However, although an intellectual worldview has developed in Western society, many people still believe in life after physical death, which may simply be a 'deep but vague and unexamined assumption within their own culture' or more formal beliefs associated with religion or spirituality (Saunders et al 1981:68). Alternatively, it has also been argued that through the study of philosophy, psychology and the natural sciences 'new, secular conceptualisations of finitude' have emerged, which form part of the 'American death system' (Kearl1989:11). Thus, the belief that suffering in this life will incur some future reward is no longer widespread and this meaning associated with suffering is, therefore, no longer assumed. Accordingly, the 'life at any cost' philosophy is being rejected and palliative care which aims to maximise the quality of life is increasingly sought as the framework within which the dying are cared for (Fallowfield 1990:16).

The individual accounts demonstrate that the subjects have a variety of beliefs relating to life after death and that they fear the way of their dying more than death itself, which suggests notions associated with a good or ideal death. Braun and Zir (2001) conducted focus groups in order to determine what constituted a good death in contemporary society. Aspects associated with this phenomenon include the effective management of pain and other symptoms, the avoidance of prolonging life inappropriately and having family presence and support. In addition, it is thought to be important to enable the dying person to resolve conflict and to address spiritual and existential issues. The main perceived barriers to a good death are fighting death and the existence of conflict, for example within the family or

with the health care system (Braun and Zir 2001:691-5). The case study will reveal that notions of a good death contribute to the meaning making of the subjects in relation to their illness experience.

The individual accounts will reveal that the way of dying is something specifically feared by the research participants and has implied links with notions of s 'good death', as touched upon earlier in this section. A research study conducted through the use of focus groups made up of people who have experienced death in their personal or professional lives in order to determine what constitutes a good death reveals six main themes. These include the recognition of the need for symptom management, clear decision making, preparation for death, the facility for completion and the ability to contribute to life with others, for example by sharing understanding. Overall, the groups feel that people should be affirmed as whole people in the context of their whole lives and not just seen and treated as a disease (Steinhauser K.E. et. al. 2000:825). In another study involving hospice patients, Lawton concludes that although the prospect of dying prematurely can be very upsetting for patients, what disturbs them most is the possibility of experiencing a 'drawn-out period of dependency, decline and social disengagement prior to death' (2000:171). Thus, it is clear that the pursuit of what is considered to be the gold standard in the care of the dying continues with cultural and historical variations.

Dying

Hutchings (1991:30) presents terminal illness as a 'time of uncertainty, transition and relinquishment' and Ainsworth-Smith describes it as a time during which:

The person who is dying grieves for the impending loss of their own life, in proportion to their awareness of what is happening (1982:64).

Possible reactions to realising that one may be facing premature death include feelings of loss, in particular of belonging, which can result in bitterness towards those close to them (Hinton 1967:88-89). Although those people who believe themselves to be terminally ill may at some stage in their dying be said to fight death, for example by undertaking what Glaser and Strauss (1965:131) describe as 'intensive living' or taking part in some related experiment, Hinton argues that people may possess an 'instinct' for death and once the person has accepted their dying as inevitable, that they can demonstrate a 'quiet enjoyment of the relaxation', now that the struggles for life are over' (Hinton 1967:44,107, from Freud). In addition, Kübler-Ross observed an increased need for sleep in dying people as the person's 'circle of interest diminishes', for example in relation to activities and visitors (1970:99,100). Dying is presented as a process by many authors and Kübler-Ross puts forward the theory that this process is made up of several stages, which has become the focus of debate in the literature.

The 'stages' of dying

In her work as a psychotherapist in the hospital setting, Kübler-Ross observes that people who are dying go through what she terms the 'stages' of dying and grief, that is, anger, denial, depression, bargaining and acceptance (1970:44,34,76,73,99). Although Kübler-Ross's work has had a profound effect on how death and dying are perceived by professionals and the public, it has been said that her theories were not accepted for their 'intrinsic strengths', as they have not

been confirmed in terms of validity and reliability (Corr 1993:72). Kubler-Ross's work is very limited and neglects the influences of several aspects of dying, including the type of illness suffered, the treatments experienced, personality traits, ethnic and religious factors and socio-environmental data. In addition, it has been argued that the acceptance of the 'stages' theory has discouraged research as it has been taken as 'all anybody needed to know' (Kastenbaum1989:221). For example, despite its limitations and flaws, Kübler-Ross's work has been adopted in health care practice and education as key texts, and health care professionals have been said to have applied the 'stages' theory too rigidly. That is to say that they have been adopted as representing normality and any departure from them as representing the pathological (Littlewood 1992:17).

However, Kubler-Ross's work draws the reader's attention to the impact of this work in bringing death and dying into the 'public arena' and it should be remembered that she was working in the late 1960s and early 1970s when such work was limited. Kübler-Ross also recognises the importance of hope to the dying, a theory which will be developed in chapter three.

Facing death

People react in different ways when faced with an explicit awareness of their own mortality, in that some remain calm, demonstrating acceptance, and others are seized by a significant fear of death, which they may feel unable to express (Elias 1985:9). The fear of dying has been the subject of much discussion and has been attributed to the fear of pain, loss and the unknown (Ainsworth-Smith 1982:26-7; Elias 1985:33). Stedeford draws attention to the universality of existential fear,

that is, the fear of 'ceasing to be', which may not be conscious, since it is 'almost impossible' to imagine oneself dead (1984:69). With obvious parallels to the work of Bauman (1992), as discussed in a previous section, Stedeford proposes the existence of 'existential denial' as a safety mechanism to prevent anxiety caused by dwelling on the possibility of death (1984:76). Hinton (1967:82) expresses the theory that existential fear may manifest as anxiety over a relatively small issue when the person finds 'the major fear too overwhelming to think of'. Craib (2003:286-7) provides personal experience of receiving a diagnosis of a brain tumour and reports the most memorable emotion at this time as fear, felt as 'intense anxiety' and 'abject fear'. The author goes on to say that the sociological literature associated with death and dying falls short of recognising the intensity of fear experienced by people facing a life-threatening illness, and attributes this omission to the individual's denial of the extent of the fear they suffer, which is described as:

> a panic which recurs and is suppressed regularly over the period from the first hint of diagnosis to some time after the operation and, less often, up to the present. If everything within the personality tries to escape from an emotion, a researcher with an interview schedule is not going to draw it out ... I want to suggest that this fear is a permanent human possibility belonging to our animal existence; I suspect that we have engaged in a life-long struggle of greater or lesser intensity to avoid experiencing it (Craib 2003:289).

It has been put forward by Manning that the seemingly universal fear of death in humans has its origins in the fear of losing control, in that death symbolises that which is outside of human control (1984:23,24). Duda (1982:15) states that death is feared because developed societies make physical security the ultimate goal and it is notable that in seeking meaning in their new situation those affected by premature death embrace non-material things, as will be shown through the individual accounts. Control and its loss are central themes in the case study and will be analysed in relation to it.

Walter concludes that a change has taken place in post-modern society as a result of progress and the development of insight into death and dying, in that:

> Those facing life-threatening illness are no longer being advised to turn their heads to the wall but to get on with living in the light of their mortality (1994:196).

The idea of living with, rather than dying from, a terminal illness is a very strong theme which runs through the individual accounts and will be presented in more detail in chapters six and seven.

Many manifestations of psychological, emotional and spiritual problems can be described as normal reactions to dying. For example, preparatory depression is often experienced and is thought to enable the dying person to get ready to leave the physical world. Alternatively, reactive depression may be associated with a loss of function, such as physical and social ability and with material loss, such as

financial. These phenomena were identified by Kübler-Ross (1970:76) and have links to theories associated with anticipatory grief.

Anticipatory Grief

Receiving a diagnosis of life-threatening illness has been said to intensify the sense of time for the patient and family and to make the threat of loss 'more critical than any other life stress' (Sourkes 1982:3). In this way, grieving may begin before death due to the awareness of a future loss and this phenomenon has been called 'anticipatory mourning' (Rando 2000). Rando presents anticipatory mourning as encompassing several operational aspects and functions, including 'grief, mourning, coping, interaction, psychosocial reorganisation, planning, balancing conflicting demands and facilitating an appropriate death', in the context of experiences of loss and trauma (2000:51). Anticipatory mourning is triggered by an awareness of life-threatening illness in the person so affected or in any significant others and can be associated with perceived losses in the past, present and future (Rando 2000:51). The context of anticipatory mourning associated with the experience of life-threatening illness can include:

> (a) exposure to horrific stimuli, (b) multiplicity and chronicity of illness-induced losses and traumas, (c) creation of secondary traumatic stress, (d) inherent generation of helplessness and conflicting demands during times of strained resources (Rando 2000:202).

This description suggests a process which can have a profound effect on the individual as a result of significant changes in their situation and outlook. When

48

anticipatory grief is experienced in relation to the expected death of someone close, some people cope with the impending loss by intensifying their relationship with the dying person, whilst others may start to withdraw from the relationship. The former approach may help the dying person, whilst the latter is more likely to help the survivor (Littlewood 1992:11-12). Some features of this theory will also be seen to apply to the research subjects directly affected by a diagnosis of life-threatening illness, who exhibit a variety of responses to the awareness of their own potentially premature deaths, including 'intensive living' (Glaser and Strauss 1965:131) and one participant who demonstrates withdrawal from some aspects of life.

The hospice movement

The major review of the services for the dying which took place in the 1960s was the point at which the modern hospice movement began to develop as we know it. Hockey (1993:180) argues that the hospice movement represented a challenge to the curative medical model of care within which the care of dying people was subsumed and describes the phenomenon of creating hospices as representing the spatial separation of the living from the dying (1993:155-6). In addition, the increased emphasis on the concept of the individual self, and its links to notions of holism, is also identified as a driver in the development of this movement (Lawton 2000:12-13).

The current context of palliative care in the UK is detailed in *The NHS Cancer Plan (2000)*, which aims to improve services and the care of patients suffering from cancer. Palliative care is no longer seen simply as care received in the end stages of

illness, rather it is increasingly being provided alongside treatment services and should be 'holistic' and 'patient-centred' and apply across all conditions and all settings. Although improvements have been made, the report identifies that the patient experience remains variable. Increased funding is also promised in order to make services more accessible and acceptable to minority ethnic users (DoH 2000:6-7,12,14,66-8). However, this still indicates that care is being planned and provided within a medical model, for cancer patients only and with a strong emphasis on service and treatment. McNamara argues that the growth of palliative care as a medical discipline and the incorporation of palliative care into mainstream practice 'indicate a movement to reinstate the medical focus of terminal care', leading to what she calls a 'salvational view of medicine' and promoting 'empire building' within the speciality (2001:124). This is, of course, at odds with the philosophy of the original hospice movement, which promotes the view that death is a part of normal living, an idea echoed as part of the holistic philosophy.

As the first of four background chapters, this section of the thesis has presented detailed theory relating to death and dying, particularly with respect to how these phenomena are perceived and dealt with in contemporary Western Society. The next chapter focuses on spirituality and spiritual care which is said to be an integral component of holistic care and, in particular, of holistic care as provided to those facing life-threatening illness.

Chapter 3

Spirituality

This is arguably the most central of the theoretical chapters as it will show why spirituality is important to the subjects, what it means to them conceptually and how it is bound up in the concept of holism. As an extension of this, chapters six and seven will reveal and analyse what the subjects perceive spiritual well being to be and how holism contributes to this. As spirituality is openly identified as being central to the philosophy of and approaches associated with holism by support group members, this concept has been given central place in the thesis as it constitutes one of the main areas of meaning making within the support group. As there is more than one concept of spirituality, the research will focus on what spirituality means for the research participants, particularly within the context of the support group and as associated with holism in practice.

Overall, this chapter will help to define spirituality, to determine if it is a universal phenomenon, linked to a need for transcendence of the human condition, and if it has meaning outside of a theological , religious or other faith-related context. A significant proportion of the literature related to spiritual care pertains to conventional health care contexts, so only that which is relevant to the principles of spiritual care as part of a holistic approach will be discussed in relation to the research subjects. The overarching aim of the research will be to determine the essence of spirituality and spiritual well being as perceived by the subjects, by allowing them to express their thoughts, feelings and beliefs, within a phenomenological framework and in relation to associated contemporary opinions. An attempt will also be made to ascertain the essence of spiritual care, or the

approaches which promote spiritual well being and reduce spiritual distress and feelings of meaninglessness. Whether there are generic elements to spiritual care will also be determined, as will any associated difficulties with providing spiritual care or addressing spiritual needs. Although the degree of spiritual well being experienced is difficult to measure, the phenomena of spiritual experience can be used as indicators, such as the thoughts, perceptions and feelings of the research subjects.

Defining spirituality

Just as there is an extensive literature on death and dying, as presented in the previous chapter, so, here, we encounter a similar prevalence of material relating to spirituality. Many authors express difficulty in defining what is meant by the term 'spirituality', but indicate that it is a broad concept which goes beyond, and can incorporate, the physical, psychological and emotional domains of human beings. The terms 'spirit' and 'spirituality' have their origins in the writings of St. Paul, having clear associations with 'life according to the Holy Spirit', and spirituality gradually developed from meaning the 'common experience of all Christians' to mean a way of life adopted by those striving for perfection of the soul, which incorporated 'individual, interior practise of special spiritual exercises' under the supervision of experts (Kornonchak et al 1987:972). However, spirituality is no longer restricted to Roman Catholic, or even Christian contexts, as it is now used in relation to other faiths and in non-religious contexts (Schneider 1986:257).

Therefore, there are acknowledged difficulties in defining and categorising spirituality and it is acknowledged that as a concept it has changed over time,

being characterised by a broadening of meaning and the capacity for representing different things to different people (Schneider 1986:254). That is, to some people it is closely associated with prayer and that which relates to 'inner life', to others it is linked to faith-related experience and can be connected to experience as a whole by yet others. In addition, spirituality can be interconnected with commitment to social and political change. Although the preceding discussion concerning the development of spirituality does not represent a strict progression over time, interpretations and analysis of spirituality do indicate a progressive expansion as a concept (Schneider 1986:253-4). In conceptual terms, spirituality can also be defined as a dimension of human beings or the lived experience which 'actualises' this and can be said to 'denote experience' per se in contemporary usage, seen as it is as integrating all aspects of human experience in this context (Schneider 1989:678, Schneider 1986:265). Therefore, in its widest sense spirituality can be perceived as 'all-embracing', with the capacity to encompass all aspects of life, including how people behave and what motivates that behaviour (Sheldrake 1998:57). However, this generic notion of spirituality is identified in the literature as having the potential to result in a 'dumbing down' of the concept, leading to the potential of reflecting a 'sterile, non-located' spirituality which offers nothing of substance, especially to people who face critical issues in life (Griffin 1988: 14).

The pervasive notion of spirituality has been described as 'integrative energy' by Goddard (1995:813) which indicates that spirituality is not simply a component of people but that it 'vitalises' and integrates every dimension of the person (Swinton 2001:16). This energising capacity of spirituality is perceived as what gives human

existence a sense of meaning and purpose and which prompts a search for these phenomena when they are perceived to be absent (Swinton 2001:14). Therefore, in the sense that spirituality is seen to provide purpose to life, it is essential throughout life, rather than just when death is faced (Aldridge 2000:35). It is also possible to talk of *spiritualities* as the concept changes depending on the context and also in the singular as an ideal, concerned with perfection, wholeness and transcendence (King 1998: 96).

In addition to the effects spirituality has on how a person's life is lived and the beliefs they hold, the 'meanings given to life and higher levels of existence' are also closely involved with notions of spirituality (Barnum 1996:104). The idea that aspects of spirituality can transcend this life and be concerned with a superior being, or beings, allows for the belief in such things as God, or Gods, and in life after physical death. Self-transcendence has elsewhere been identified with 'ultimacy in some ongoing and transforming way' (Shneider 1986:266). That is to say that spirituality exists in any experience that involves searching for or acknowledging associations with the 'ultimate ground of existence' through thoughts and feelings and is expressed through any cultural activity which has a dimension of 'ultimacy' as part of human experience and of the spiritual quest (Fuller 1996:227-8).

The self and inner spirituality

With a long philosophical history, notions of the self also have specific sociological, psychological, emotional and spiritual aspects. It appears that the idea of the existence of a self-concept developed more concretely in psychology in the 1920s

and can be seen in terms of being an 'inner authority' which the individual seeks to live up to (Freund and McGuire 1991:108). In Western society the 'self' is often expressed in popular culture in terms of how an individual perceives him or herself as an individual and how they are perceived by others.

The ability of a person to reflect on their actions and existence and to compare them with those of others characterises self-hood in sociological terms (Murray-Parkes 1996:93) and the reflexivity of the self allows for the individual to make sense and meaning of itself and of the world (Nerken 1993:4). Laderman and Roseman (1996:100-1) conceptualised the self as a 'repertoire of capacities for orienting in and engaging in the world' which suggests that the self can be seen as the starting point from which one makes sense of life as one takes part in it. This ability to experience ourselves as 'unique and distinct persons' is mainly developed through socialisation and the way people respond to and treat us, for example, in affirming our sense of self and our place in society (Freund and McGuire 1991:107).

One subdivision ascribed to spirituality itself as part of the attempt to define it is 'inner spirituality', which is presented as the 'immaterial' part of man, the soul or that which renders the individual capable of 'knowing sure from within' (Pietroni 1990:162). Inner spirituality would be engaged in a personal search for meaning and in relationships with transcendent beings and equates with the idea of the 'self'. For example, the concept of 'soul', interpreted non-theologically, has been defined as:

> the geist, spirit, inner self or essence of the person, which is tied to a

55

greater sense of self-awareness, a higher degree of consciousness, an inner strength and a power that can expand human capacities and allow a person to transcend his or her usual self (Watson 1988:46).

The 'usual self' in this context would appear to be the 'self' so often discussed in popular culture, as mentioned above. The capacities of the inner self have been detailed further by Watson as including the ability to:

transcend time past, present, future, through introspection, creative imagination, meditation, visualisation and the projection of the self in a series of experiences, as well as in sleep, dreaming and fantasies, including unconscious and possibly supra-conscious processes not yet known or fully explored (1988:48).

The New Age movement is also concerned with the inner self and has been perceived as a means through which the human race is 'reasserting its right to explore its spirituality in total freedom', as the 'constraints of religious and intellectual ideology are falling away' (Bloom 1991:149). As the self is defined by a variety of changing relationships, it cannot be said to exist as a complete self (Sheldrake 1998:13), and, therefore, a person can lose their sense of self if they are removed from their particular interpersonal network. Toulis identifies the concept of 'presence' as 'a sense of self where persons are conscious of their own autonomy and instrumentality, where they can perceive themselves to be the authors of their intentions, actions and definitions of self' (1997:127). A 'crisis of presence' is said to occur when the person loses the ability to determine and reflect upon their own

actions, for example when they are too engrossed in worldly affairs (Toulis 1997:127). Csordas (1994:5) describes the 'essential existential condition' of human beings as the 'grounding of the self in embodiment' and spirituality may be seen as making the self complete, particularly when associated with notions of transcendence and meaning. Embodiment will be discussed further in relation to holism in chapter four and self-identity and change will be discussed more fully in chapter seven, as part of the overall analysis of the case study.

Although each of the research subjects has their own way of engaging in and expressing spirituality, overall, this broad concept of spirituality, as it relates to what can be called holistic experience, has the most relevance to this research. For this reason, spirituality in theological and strictly faith-related contexts will be discussed only briefly. As part of this discussion, spirituality will be compared and contrasted with religion in the next section.

Spirituality or religion?

Spirituality can be confused with religion, but the literature reveals spirituality to be a larger concept than religion, in that although religious practice is one way of entering into and appreciating spirituality (Dyson et al 1997:1184), it does not necessarily allow for the breadth and range of spirituality, such as a potential to search for meaning. Some derive the word 'religion' from the Latin 'religio', which means to tie up, and therefore indicates life being tied up or linked to a deity or god (Strang et al 2002:50). Religiousness has been defined as 'a state of increased personal meaning attached to a system of beliefs and practices' (Meraviglia 1999:25) and a 'social institution in which a group of people participate' (Steiger

and Lipson 1985, cited in Dyson et al 1997:1184). This suggests that religious practices, such as church going, do not necessarily mean that the person involved actively believes in the symbolic meanings of the practices or that they are made fully aware of their spiritual domain and needs through religion. It has also been suggested that religion and the rituals associated with it may have the effect of inhibiting an individual's spirituality, by reducing such an all-encompassing phenomenon to a limited number of beliefs and practices (Dyson et al 1997:1184).

However, Toulis argues that religious worship involves belief which has its origins in 'spiritual rebirth' and, therefore, goes deeper than ritual and practice, as discussed in relation to pentecostalism (1997:123,121). It is also argued that spirituality is distinguished from doctrine in that faith itself is not the central focus, but the reaction that faith engenders in a person's religious consciousness and religious practice (McGunn and Meyendorff 1986:xv). However, religion, as part of spirituality, is often pursued in an attempt to gain 'answers to fundamental human problems' (Firth 1996:10) and it would seem, then, that depending on the beliefs and outlook of the individual, religion can be a way into the spiritual domain which allows for collective support and search for meaning. In addition, Walter argues that the terms 'spiritual' and 'spirituality' should only be used with respect to those people who themselves would use them, and that, although an increasing number of people personally embrace these concepts, they are not adopted by people who can be described as 'traditionally religious' or 'irreligious' (2003:133). The debate around spirituality has been described as fundamentally an 'Anglo-American' debate which is peculiar to the English-speaking world (Walter 2003:134) and the term 'worldview' can be said to be more helpful than 'religion' today when

secularisation and religious pluralism are widespread, particularly in the West.

A person's worldview incorporates all aspects of how reality is constructed and their concept of nature, self and society (Geertz 1975:127). It could be argued that the modern intellectual worldview in the West originates from a scientific and materialistic perspective, characterised by growing consumerism and a reliance on physical things, such as wealth, for security. It can be seen in its own right as a progression towards understanding life and meaning through rational means or as a reaction to the decline of organised religion, which involved a degree of reliance on superstition.

Spirituality in anthropological contexts

As discussed above, spirituality is now a concept used in a generic way to suggest a capacity to transcend the components of traditional religions and has its origins in experience, exploration and questioning (King 1998:96). Post modernism has been discussed in chapter one and the associated concepts of individualism and consumerism have been touched upon. It has been argued that the contemporary increase in interest in spirituality in a broad anthropological sense is in response to a perceived sense of fragmentation and is part of a search for wholeness in order to find meaning and community in this context (Schneider 1989:696). This suggests a link with the theory that postmodern spirituality is embodied, in that human beings are capable of communing with all aspects of nature and history through both biological and social experience (Holland 1988:50). For example, it has been argued that contemporary Western society manifests 'a group sense of the interdependence and sacredness of all life, and our special relationship to the

whole world and the cosmos' which results in a related need to develop a 'holistic, integral spirituality' (King 1998:108). Therefore, the contemporary approach to spirituality within an anthropological context shows spirituality as intrinsic to humanity and has been described as 'facilitating the resurgence and renewal of spirituality within a secular context' (King 1998:102). Holistic medicine has been identified as an example of 'secular' spirituality and the 'genuinely spiritual aspect' of this approach has been attributed to the 'affirmation that health requires release from a falsely mechanical concept of self' (Van Ness 1996:10).

As previously stated, although spirituality can be experienced at any time, it is often at the particularly good and bad times of life when one's awareness of it is likely to be most acute (Smucker 1998:96), such as when a death is perceived as being untimely. It has been suggested that people search for spirituality out of a fear of 'meaninglessness' in life rather than from a fear of death itself (Gelven 1990:239). As each person's experience of life is different, there is often a search for meaning in suffering and injustice as well.

As previously mentioned, individualism can be demonstrated through New Age spirituality as it involves listening to an 'inner voice' in order to create a personal spirituality through the selection of aspects of many world religions and folklore (Walter 1994:28). It has been argued elsewhere that spiritual 'truth' in contemporary Western society is perceived as 'what works for me' and people may have what they believe to be 'spiritual' experiences without having to hold specific religious beliefs (Heelas 1998:5). Heelas (1998:5) goes on to suggest that such 'individualised, deregulated religion' can be interpreted as a phenomenon of what

has been termed post-modern society and may be supported by the consumer culture of that society.

In addition, authority in the post-modern era may be said to 'rest with the person' rather than from 'authority and legitimacy resting with established orders' (Heelas 1998:2-4). Engaging in the NCSG can be seen as a manifestation of individualism and exercising choice and will be discussed in relation to the holistic health movement in the next chapter. For the purposes of this study, the concept of spirituality which is most relevant is that which is found in the ordinary aspects of experience associated with everyday life, as presented by Stanworth (2004:25) and not as a separate aspect of human beings, which can otherwise be described as an 'add on' to their physical, psychological and emotional components. Hope is integral to holism and the nature of spirituality associated with this philosophy by the subjects and the next section of this chapter will examine hope and its relationship with health and healing.

Hope and spiritual well being

The aim of this section is to present a sociological and anthropological discussion of the significance of hope, with particular reference to the role of hope in a person's will to live, their life force and personal quest for meaning. Hope has been defined as 'an anticipated sense of continued availability, endurance and persistence of an activity which will provide meaning over time' (Barton 1977:34). In addition, six 'dimensions' have been identified as comprising hope, that is affective, cognitive, behavioural, affiliative, temporal and contextual. The affective domain involves the emotions and feelings associated with hoping, such as desiring a particular

outcome. Cognitive skills, such as imagination, interpretation and judgement, will be utilised when people weigh up the realistic outcome of a specific hope and individuals may act in a way to improve the chances of achieving the desired outcome, which is an example of the behavioural dimension of hope. Affiliative aspects of hope include those which go beyond the individual, such as social interaction and relationships with God. For example, the individual may hope that certain relationships improve, that their love of God may increase or that a physician may be able to improve their condition. The person's experience of past, present and future time in relation to hope constitutes its temporal dimension and the contextual dimension is made up of the circumstances which bring about, activate and test hope (Default and Martocchio 1985:381-8).

Hope has also been identified as an important component of spirituality and, as such, depicted as 'a motivating force or as an inner readiness to reach goals' (Wilkinson 1996:659). Hope can be either 'generalised' or 'particularised' and the former is related to a sense of a future, expected advantage which helps to provide meaning and prevent despair when the individual does not have particularised hopes. The latter is associated with specific 'hope objects' and sought for results, which may be 'concrete or abstract, explicitly stated or implied'. Particularised hope enables the person to determine what they find most important about life (Default and Mortocchio 1985:380-1).

The ways in which health services and professionals can foster or reduce hope in patients and their carers was studied by Woods et al (2000). In this relatively small study (fifteen patients and ten carers) it was found that doctors were agents of

hope when they were able to offer potentially effective treatments, but individual doctors could also become 'the person who took hope away' in the absence of such treatment options (2000:317). Perceptions of hope varied from subject to subject and for each subject at different times. For example, although most participants defined hope in terms of realistic quality of life goals, many also expressed hopes of gaining extensions in the quantity of their life. This may explain the subjects' willingness to comply with hospital treatments which they perceived as representing the hope that something more could be done, although those involved in the research still accepted the 'inevitability of the end' (2000:318). The value of this kind of hope, which could be perceived as unrealistic, may be questionable, but the authors argue that 'some participants were denied the kindling of it from the outset' due to the way that their diagnoses were given (2000:318). This could be seen as an example of the nocebo effect, the opposite of the placebo effect, which will be discussed later in this section. In another study which focused on terminally ill adults, Herth concludes that for the subjects hope is 'an inner power that facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being' (1990:1250). From this research threats to hope are identified as isolation, pain, and the 'devaluation of personhood', but the results also show that increasing physical deterioration in itself is not a threat to hope.

Like healing, hope is not generally associated with terminal illness as, when related to illness, 'there is a strong tendency to link hope with cure' (Nekolaichuck and Bruera 1998:36). It can take time for a person to accept this change to the focus of hope and a period of denial may be required to facilitate the adjustment (Wilkinson

1996:659). For instance, the dying person may seek to 'confirm his aliveness' by trying to maintain his or her personal and social lives (Barton 1977:48). Positive *life* hope has been explained as that which enables a person to cope with the reality of the situation and negative hope as that perceived by professionals as false hope resulting from a mistaken viewpoint of the prognosis by the dying person (Wilkinson 1996:660).

'Hopelessness' can be the result of long-term or frequent encounters with unavoidable situations when the outcome is not within the control of the individual, even when the situations are not serious or life-threatening, and has been demonstrated in both animal and human studies (Ross 1994:440). This suggests that it is important for people facing life-threatening illness to feel that they remain in control of their lives in order to maintain hope and to promote their spiritual well being. Therefore, it is not just medical and scientific findings which need to be taken into account when establishing diagnoses and prognoses. If people receiving palliative care are perceived as 'hopeless', in the sense that cure is not an option as a goal in care, this 'experience and acceptance of helplessness may be a crucial bridge between hopelessness and hope', which can be achieved through quality palliative care (Husebo 1998:46). In other words, a lack of hope can be the impetus needed for regaining hope, since 'sometimes those who face complete meaninglessness find meaning' (Burnard 1987:380) and by facing the 'blankness' of spiritual pain the healing process can be facilitated (Burnard 1987:380). This can be seen as an effect of losing control over life and personal circumstances as a result of receiving a diagnosis of life-threatening illness and will be discussed in relation to the individual accounts. Healing in relation to dying would appear to be a

contradiction, since the healing process is usually associated with recovery from illness, but as the physical deterioration which precedes death is irreversible, it is the spiritual sphere which is the focus of healing so that 'death becomes easier to accept and face' (Lee 1985:23). Healing and spiritual care with respect to people facing life-threatening illness will be discussed later in this chapter.

The nocebo effect

The placebo effect, which is linked to theories of self and spontaneous healing, in relation to health and the presence or absence of hope will be discussed in the next chapter. The 'nocebo effect', which is perceived as the opposite of the placebo effect, has been identified as the phenomenon of the expectation of sickness resulting in sickness due to the cultural environment of the therapeutic encounter, with the response varying from culture to culture (Hahn 1997:56). For example, if a person is told that there is no cure for their illness, or even that they will live only for a specified period of time, the individual may give up hope and their death may be seen as a direct result of the prognosis they were given and the related power of suggestion. Alternatively, when a viable drug is given for a problem, but the doctor indicates that it will not be effective, the nocebo effect may result in the patient not responding to the said treatment (Chopra 1989:150). The nocebo effect can be due to subjective as well as objective conditions and it may be transient, chronic or fatal (Hahn 1997:56). The 'head and the heart' are identified by Chopra (1989:157) as the two centres where medicine can act and if the heart is not engaged the nocebo effect 'can run wild', for example the body will be 'flooded with negative emotions' which will greatly reduce its healing capacity. This phenomenon was highlighted over sixty years ago by Cannon in a work focusing on Voodoo death,

which was noted by 'apparently competent observers' in primitive societies in 'widely scattered parts of the world'. Possible explanations of why men can be 'brought' to death simply by predicting it are given as reactions to the power of suggestion or profound terror, with the associated physiological changes (Cannon 1942:169,170-1,176-7,180). Myers argues that physicians need to be aware of the potentially negative effect receiving bad news has on people, stating that:

> Physicians must create an accepting emotional space for the patient's lament by compassionately communicating the truth to their patients about their condition and then being willing to endure the discomfort that may follow. This includes curbing the temptation to use ambiguities of procrastination or premature discussions about available treatments to rescue both self and patient from what can often be an overwhelming experience of anxiety that begs relief (Myers 2003:384).

However, the author acknowledges that bad news will produce different reactions in individuals, but recommends that physicians should establish an environment that 'confirms for their patients the reality that they have received news that has profoundly changed their lives' and also helps the person to maintain hope (Myers 2003:384).

The power of hope in helping to prolong the lifespan of people suffering from life-threatening illness is demonstrated in a study conducted by Berland (1995). This qualitative study involved thirty-three people with a 'terminal' prognosis, but who had survived their expected lifespan of five years from diagnosis, and sought to

discover why the subjects believed this had happened. The methods employed to conduct the research were self-reports and in-depth interviews and the findings indicate that the most significant factor associated with increased survival rates is the support of family and friends, rather than conventional and non-conventional treatment. Eighteen of those involved attributed their 'healing' to a 'spiritual and existential shift in their perspectives about life' which resulted in changes to their attitude towards life and living. All of the subjects were described as having undergone a 'profoundly altered sense of self' with indications that their 'lives and well being' depended on their remaining committed to this new sense of self and associated priorities. The participants felt that, as a result of this, they had become more happy and satisfied than they had felt possible at diagnosis. Many also indicated that their experiences had made it impossible to turn back to how they had lived before. The researcher acknowledges that this is the result of interpretation, as the subjects did not all recognise that what they were saying directly related to the concept of self (Berland 1995:5-14). This phenomenon will be examined more fully in connection with the analysis of the individual accounts. Hope also has strong links to holism and quantum healing and will be discussed in relation to these concepts in chapter four. The next section will focus upon addressing spiritual needs through what is called in the some of the literature 'spiritual care'.

Promoting spiritual well being in people facing life-threatening illness

The context

As alluded to previously, the discussion which follows draws upon theory as it relates to issues and approaches concerned with the promotion of spiritual well

being in people living with life-threatening illness. For people in this situation, their established self is challenged, resulting in fragmentation and a re-evaluation of the self, life and its meaning which is more in keeping with the 'anticipated temporal framework' associated with their situation (Barton 1977:44). In a study involving hospice patients, it has been shown that some people became more religious as a result of experiencing life-threatening illness, whilst others turned away from their previously held beliefs (McGrath 2003:894). Overall, the researcher concludes that those experiencing such serious illness 'develop their own spiritual frameworks from their life-experience' rather than maintaining 'preformed religious worldviews'. These new frameworks embraced a broad concept of spirituality which incorporated 'a sense of personal connection and a focus on the here and now' which was felt to be as important as 'philosophical meaning-making' (McGrath 2003:895). Much of the literature relating to spiritual care relates to care in the conventional sense, that is that provided by health care professionals. However, the principles of care can be applied to the context of the support group and the ways in which the research subjects make meaning from their experiences.

The goal of spiritual care is the promotion of spiritual well being, which has been defined as an 'affirmation of life' which fosters the ability of the individual to develop a relationship of completeness with him or herself, God, others and the environment (Meraviglia 1999:25). Other principles of spiritual care include the affirmation of life and communicating and connecting honestly with another human being. It is broader than what is usually meant as 'care' in that it is about empowerment, healing and the promotion of a life-affirming life-style, as promoted by the NCSG and adopted by the research subjects.

Spiritual care has also been described as 'therapeutic understanding' which is implicit in the carer's ability and willingness to enter into the individual's experience and 'communicate understanding, compassion and empathy' which in turn facilitates some measure of healing. 'Interpathy' is an extension of this empathy and involves 'thinking with' and 'feeling with' a person whose culture is very different (Swinton 2001:140,142-3). This definition of spiritual care is particularly relevant when analysing the case studies, as this approach is manifest in encounters within the context of the support group.

Spiritual needs can be said to include a search for meaning, a sense of forgiveness, hope and love and such spiritual values can sustain a person as the physical body deteriorates (Conrad 1985:416). Spiritual needs in a non-religious context can include values and structures of meaning, notions of transcendence, affective feeling, communication and relationships (Swinton 2001:26). Overall, spiritual needs relate to the essence of living as a human being with respect to meaning and happiness (Swinton 2001:53).

Determining spiritual needs
A framework for the assessment of spiritual needs is provided by Stoll, who suggests that the person's concept of a God or deity should be determined, including how religion and prayer is felt to be significant to the individual, and what, if any, religious practices are valued. The reasons why these practices are believed to be important and the effects of illness on them should also be ascertained.   In addition, information regarding the individual's sources of hope and strength should

be identified, which can be achieved by asking who they see as the most important people in their life, whom they turn to for help and how this help is given. Stoll recognises that 'Relationships of trust and mutuality are one of the principal sources of hope and strength' to people when they are ill (1979:1575). In this way, the author argues that the person's beliefs in relation to life, meaning, relationships and illness need to be taken into account when conducting an assessment of their spiritual needs. Examples of the questions which should be asked as part of this assessment include:

What has bothered you most about your situation?

What do you think is going to happen to you?

Has being sick made any difference to your feelings about God or your faith?

Is there anything especially frightening/meaningful to you now? (Stoll 1979:1576).

However, a patient may not perceive his or her needs in the same way as the carer, so it has been proposed that the patient's own spiritual framework should be established as the starting point for the assessment of spiritual needs (Dawson 1997:288). An ideal for spiritual care has been proposed which should constitute a response 'to the uniqueness of the individual; accepting their range of doubts, beliefs and values just as they are' (Stoter 1995:2). This would seem to be of particular importance to those facing the stressful situation associated with life-threatening illness when belief systems are reviewed in response to the related challenges.

<u>Meeting spiritual needs</u>

A model for the spiritual care of patients who are experiencing suffering has been put forward by Emblen and Pesut (2001) and is summarised below. The model consists of five assessment strategies which are balanced by five suggested interventions:

1. To establish what authority exists for the person's beliefs: The individual is questioned to explore their beliefs about suffering and illness and how these beliefs may have changed as a result of the illness experience.

The suggested interventions include therapeutic listening and guidance with the aim of replacing negative thoughts with life-affirming ones.

2. To establish how the person describes and feels about their spirituality: The individual is asked about their experience of suffering and any coping strategies which have been employed. This should help to identify sources of hope and courage for the person.

Comfort may be given through art, nature or music.

3. To establish what support networks are available to the person: Enquiries are made into who supports the sufferer through the illness experience and how these significant people can be contacted and involved in the planned care.

Nursing presence should be employed and a connection established with the 'therapeutic support' persons.

4. To establish if any rituals and practices are significant to the individual: The

person is questioned about the existence and nature of significant rituals and practices and how these can be facilitated for them in their current situation. Examples of such practices which the carer may help with are prayer, meditation and reading.

5. To establish how the illness experience has affected how the person fulfils their duties and responsibilities: Enquiries are made to determine which duties may still be met and how limitations may be accommodated.

Interventions include discussing and identifying ways in which the individual's duties may be carried out and addressing limitations (Emblen and Pesut 2001:43-53).

A number of approaches are available to those providing for the spiritual needs of others and include giving full attention to the person, 'being with' them rather than 'doing' for them and developing an honest and trusting relationship with them. The behaviours implicit in these approaches are allowing the individual to express themselves in order to find meaning in their situation and facilitating the recognition of spiritual pain through prayer, reading and music (Elsdon 1995:642-3). Godkin identifies presence with holistic care:

> Holistic nurses grasp the essence of presence when they are available to their patients with physical presence, cognitive presence and spiritual presence. Going beyond the scientific data involves commitment and a covenant within; in other words, the holistic nurse upholds a promise to herself and to the patient- a promise to be vigilant to signals even when the

scientific data give no warning (2001:11).

It has been said that spiritual care is not a separate aspect of overall care but is 'implicit in everyday practice' in that 'There is spiritual comfort in being enveloped in efficient care and knowing that such care will continue as long as necessary' (Hopper 2000:60,61). Hopper continues to argue that as the 'means and ends are inextricably linked' in holistic care, in that as the way that carers and professionals work and speak have holistic effects, holistic care is best provided through practical, caring action (Hopper 2000:61-2). This idea is supported by Scott (2000) who argues that:

> It is activity of the moral imagination that enables the practitioner to connect with a patient at a level of human understanding and compassion...an important relationship between art and nursing or medicine is therefore one that enables the moral imagination of the practitioner to be stimulated and developed in such a manner that sensitive, constructive care is the likely result (2000:6).

Strang (2002:50) states that in order to provide holistic care the care giver needs to be a good listener, to respect the patient and their beliefs and to establish a 'contemplative' environment. Spiritual care has been defined elsewhere as a quality which pervades care as a whole, in other words, spiritual care is a 'humanistic' act and its success relies on the 'delicateness of the process and interactions between human beings' (Shih et al 2001:36). It has been said that spiritual care can be difficult to differentiate from 'sociopsychological-emotional'

care, although its advocates argue strongly against this theory and its being synonymous with religious care (Walter 2003:133).

As spirituality is associated with both 'religious and humanistic perspectives', these perspectives are dependent upon various aspects of the human encounter. In other words, a person's spirituality may depend on the ability to give and receive touch, to listen to other people or to 'committed presence'. The appreciation of other aspects of human life may also affect a person's spirituality in the sense that they stimulate meaning in the individual, for example food, music, literature, humour, relationships, and suffering (Oldnall 1996:139). This suggests that spiritual needs should be addressed as part of the whole human to human contact or encounter, rather than being viewed as a separate area of need. This approach may not be recognised specifically as spiritual care by those involved and that may be the point, in that it may only be possible to give truly holistic care when the care giver is not aware of it in itself. That is, in this context the nature of nurses' and other carers' actions is 'naïve' in a positive sense and involves the power of unreflective endeavour, a concept at odds with the post-modern condition, which can be characterised by over analysis. This can be seen as an example of the phenomenology of the naïve action of the everyday world.

However, it is argued elsewhere in the literature that spiritual care needs to be tailored to the needs of the individual and that more attention should be paid to the 'differences between and among patients and staff'. This argument presents dying as a journey and spiritual care as accompaniment on that journey, concluding that:

there will be no clear prescriptions for who can accompany whom...and should relieve each member of the team of the burden of feeling obliged to accompany each and every patient (Walter 2003:138).

Although it is acknowledged that traditional religious practices as part of spiritual care may not fulfil the needs of someone with New Age beliefs, and vice versa, the connection between human beings as the basis of any spiritual care, as described above, emerges as the most important aspect in the debate.

Spiritual well being and recognised spiritual problems

It appears that indicators of spiritual well being include the experience of peace and acceptance of the situation and is described as manifesting itself 'by a sense of inner harmony' that is, as the opposite of 'despair, apathy and meaninglessness' (Goldberg 1998:839), which can be described as spiritual distress. Spiritual distress can also be expressed as the failure to invest life with meaning (Burnard 1987:377) or the loss of belief in a person's value system (Nolan and Crawford 1997:290). Walter argues that spiritual pain in the dying can be attributed to what he calls 'biographical' pain, which can result from the sense that a person's life has not met their expectations and impending death means there is no time for this situation to change (2003:138).

Many systems for the treatment of spiritual pain and distress have been established, for example, catharsis, the homeopathic approach, New Age healing practices (Burnard 1987:379) and consciousness therapies (Pietroni 1990:168). A search for meaning approach can also be used and may be undertaken by any

member of the caring team, regardless of their faith, as it aims to help the individual to find their own meaning (Walter 1997:25). Spiritual healing, which has been discussed briefly earlier in this chapter, also presents opportunities to address identified spiritual problems.

Spiritual healing

The aim of spiritual healing is to bring about a change in the person's consciousness which allows them to rise above their current situation and the effects depend on this situation, for example somebody facing death may be helped to find meaning or somebody experiencing distress may experience peace (Aldridge 2000:53). Finding sufficient meaning in this context can help to keep individuals going through very difficult times (Swinton 2001:57). This change is believed to be brought about by the transformation of divine energies from the spiritual level which produce a positive effect on the 'energy field' of the individual (Aldridge 2000:4).

Spiritual healing has been defined as:

> the channelling of universal energy to a patient by thought processes to bring about an overall state of energy balance and harmonisation at all levels, thus stimulating the body's natural defence system to deal with disease. Healing quickens the body's natural healing process at all levels (Neate and Neate 2001:122).

Spiritual healing can take a variety of forms and may be atheistic or religious, for example the Charismatic movement within the Christian church has a spiritual healing component. According to spiritual healers, the most important aspect in the spiritual healing process is that those involved believe in its potential effectiveness. That is, the individual needs to believe in the ability of spiritual healing 'to evoke powerful imagery, especially of body parts and aspects of the spiritual cosmology and to loosen blocked emotions' (Kearney 1978:24,37)'. It is also argued that in order to be effective, healing has to be undertaken when the person is in a position to focus their attention and healing energy on it. For example 'Whilst the body is in pain, little healing can take place, as all one's energy goes into dealing with it' (King 1990:1148).

The term 'shamanism' can relate to any form of non-medical, folk or mentalistic healing and is classified as either traditional or neoshamanism. There are several types of mentalistic or folk healer. Faith healers attribute healing to the faith of the healer or sufferer, spiritual healers believe that by healing the spirit and mind that the body can be healed, psychic healers work by calling in spirit guides and natural healers believe that a universal healing force can be tapped in almost anybody (Eagle 1980:13).

The theory has been put forward that in order to be an effective healer, it is necessary to be flawed or 'wounded'. The impetus or 'call' to become a healer or Shaman may be the result of serious illness, which can be linked to the concept of the wounded healer which is discussed in the next section. For the subjects of this research study who became spiritual healers, their experience of life-threatening

illness was the impetus for their taking on this role. A near death experience can also be considered an ecstatic, shamanic 'initiation' (Money 1997:132).

The wounded healer

This myth, expressed in terms of the 'wounded healer', is said to have originated in the fight, due to intoxication, between the centaurs Heracles and Chiron which resulted in Chiron sustaining an incurable injury to his leg. As Chiron was immortal he could not die, but neither could he be cured, so he taught many heroes his great knowledge of healing which he gained from his own experience (Dossey et al 1995:66). Although a very skilled and powerful healer, the wounded healer is also a weak figure, but this duality is not generally recognised by doctors who 'heal' in Western medicine. Instead of recognising their own weakness and helplessness, there are those who argue that doctors project these characteristics onto their patients, which increases the weakness of the patient whilst making the doctor more powerful. However, as this implies that there is a 'patient' component in every healer, it follows that there should be a 'healer' component in every patient and it has been said that unless these components are acknowledged by each, effective healing will not take place (Fox 1993:98). The diagnosis and experience of cancer prompted some of the research subjects to become spiritual healers and they can, therefore, be seen to have adopted the role of wounded healer.

Nouwen (1994:82) analyses the concept of wounded healer in relation to Christ, in that he who was wounded was also prepared to heal the wounds of others. As a worker in Christ's place, Nouwen goes on to relate the role of the Christian minister to that of wounded healer (1994:84-6). He describes the 'loneliness' of the

minister's role, in that, although he wants to 'touch the center of men's lives' he often remains on the periphery, unable to enter. Loneliness is here seen as a 'wound' and can be turned from a weakness to a strength, as the minister can offer his own experience as 'a source of healing to those who are often lost in the darkness of their own misunderstood sufferings'. By accepting the 'wound', ministry can become a healing service. This is not a sharing of superficial personal pains but a 'constant willingness to see one's own pain and suffering as rising from the depth of human condition which all men share'. Therefore, when people become fully aware that they do not have to escape their pains, but that they can be transformed into a 'common search for life', these pains can change from being 'expressions of despair' into signs of hope (Nouwen 1994:87-8,92-3). With respect to loneliness, hospitality enables a unity to develop based upon the shared acceptance of our 'brokenness' and a shared hope. In this way, the degree of loneliness can be made more intense in the context of the hospitality which seeks to remedy it and, in turn, increases the quality of the relationship forged. In summary, Nouwen (1994:94) argues that in Christianity:

> wounds and pains become openings or occasions for a new vision. Mutual confession then becomes a mutual deepening of hope and sharing weakness becomes a reminder to one and all of the coming strength.

The sharing of experience and human to human contact characterised in the relationships of the research subjects with their healers and 'healees' demonstrates the principles of the wounded healer in a post-modern context. In addition, it is made clear in the case study that engagement in the support group has similarities

to the Christian ministry described by Nouwen, through sharing and, thereby, reducing, the loneliness the subjects experience following the changes in their situation.

Psychotherapeutic theory is closely associated with spiritual care in some contexts, such as pastoral, but was not an approach used by the subjects of this research. The aim of psychotherapy is to change an individual's behaviour and is, therefore, remedial in nature and employed to help those whose 'level of adjustment' is fairly severe and the support group members did not display this level of disturbance. Counselling refers to a similar process employed in non-medical and pastoral settings, for those whose psychological problems are less severe (Willows and Swinton 2000:90). One of the research subjects states that she feels she would have benefited from counselling following diagnosis and counselling was made available to the participants in case engaging in the research process resulted in any emotional and psychological distress.

This chapter has provided an analysis of spirituality as presented in the significant amount of literature available on the subject. Difficulties in defining spirituality, the debate concerning the differences between spirituality and religion and concepts of inner spirituality have been incorporated into this examination. Healing and hope were also discussed with respect to spirituality and theory associated with the spiritual care of people experiencing life-threatening illness has been presented. Although much of the literature refers to research in the contexts of medicine, nursing and religious practice, the principles of the findings can be applied beyond these contexts. Much of the support and 'care' received by the

subjects is provided outside the health care environment and within the broader context of their social relationships and overall lifestyle and engagement in the NCSG. Although it is recognised that defining the concept of spirituality is difficult, it is possible to describe its effects (Swinton 2001:15), so the individual accounts will be analysed in relation to the phenomena of spiritual experience. As stated earlier in this section, spirituality as an all-pervasive and encompassing concept is the definition of spirituality which will be demonstrated through the experiences and perceptions of the research subjects. Holistic care has been touched upon in the earlier discussion relating to spiritual care and will be discussed more fully in the next chapter. Concepts of health and illness and the variety of approaches to healing in contemporary society will also be presented.

Chapter 4

Holism and health

This chapter takes up the complex issues of holism and holistic philosophy in relation to health and well being, and in so doing will also explore the concepts of health, illness, disease, quality of life and different models of care as they relate to health. Appropriate literature will be reviewed selectively in order to illustrate the themes which are most relevant to the context of the case study.

Holism: a discussion of the concept

Much literature exists on the subject of holism and the term is used to represent an approach to analysing and addressing a wide variety of potential problems and issues. The term 'holistic' has been in popular usage and has constituted a category in library catalogues from the 1980s onwards (Power 1991:6). Health and healing are examples of the areas where it has been claimed that holism, as a philosophy, has a significant part to play, due to its purported ability to encompass all aspects of a person, of life and of nature and is often contrasted with an attitude of scientific fragmentation. As fully explored in relation to method, the significance of this philosophy to health care will be determined through the analysis of the relevant literature, the beliefs and aims of self-named holistic centres and groups and from the perceptions and experiences of the members of one such group.

It has been said that since holism cannot be described as 'a single unitary concept' the term 'holisms' should be used in order to encompass the many types of holism defined in the literature and understood within society (Owen and Holmes 1993:1688). Indeed, the holistic health movement 'encompasses divergent

82

philosophies, religious doctrines and psychological theories', so that being a 'holist' can mean that a person can have a 'diverse group of views developed to varying degrees of scope and sophistication' (Kolcaba 1997:290). The heuristic holist may work with the concept of a whole by breaking it down to its constituent parts, their properties and how the parts are organised and, in this way, can deviate from strictly holistic ideas if demanded by the particular enquiry. For example, constituent parts of wholes can have properties which the whole lacks and Kolcoba argues that the summation of the 'vast array of descriptive predicates' which each part possesses 'would be of a magnitude that is far in excess of the predicates true of the whole', thereby emphasising the importance of analysing parts, as 'this is where vast bodies of detail reside'.

The three types of 'whole' identified by Kolcoba are a system, made up of interrelated parts which together perform a function, an organism, characterised by an actualised genetic code, and a person, defined as a 'self or agent which owns a body' (Kolcoba 1997:293). Persons have also been defined as 'experiential beings' who possess the ability to gain knowledge and are able to use knowledge to develop a concept of self and an understanding of each person's place in the 'scheme of things'. Concepts of self have been discussed in detail in chapter three, and such insight into the self differentiates the study of persons from that of systems and organs. However, the heuristic holist can take any of these 'wholes' as 'units for enquiry and treatment', whilst the whole person holist contends that anything less than looking at the whole person is inadequate when studying human beings. Conversely, when much of modern medicine is understood at the cellular or systems levels, whole person holists have been criticised as being unable to 'ground

a science, let alone an experiential science of health recovery and maintenance' (Kolcoba 1997:293).

With respect to health care, holism is said to be concerned with the inseparability of every aspect of the person and to contribute to the unique concept of self of each person, since it incorporates the 'mind, body and spirit within the context of the family, culture and ecology' (Patterson 1988:290). This reflects the theory that 'an integrated whole has a reality independent of and greater than the sum of its parts' (Dossey et al 1995:6) and that 'the cure of the part should not be attempted without the treatment of the whole' (Hippocrates, cited in Pietroni 1990:160). Although seemingly at odds with the earlier argument that different parts of wholes are capable of yielding more detail than the wholes themselves, it is the sum of all of this detail which comprises the whole for holists in health care. Holistic medicine has also been defined as an example of applying the 'General Systems Theory' to the practice of medicine, in that no aspect of the person or care should be studied in isolation, as everything and everyone is an interactive part of a system (Pietroni 1990:25:20). The holistic health movement sees physical illness as the 'organic manifestation' of an imbalance at a higher level of the human Gestalt and that the uniqueness of each person makes it necessary that any treatment is not targeted at any particular subsystem of the body, but is focused on the person as a whole (Lyng 1990:85,91). An example of the opposite of holism as applied within health science may be seen in the Human Genome Project, which has been described as the 'ultimate reduction of man to the sum of his parts', as it attempts to decipher the genetic code and its effects within each cell of the human body by 2075 (Berridge 2001:8).

Complementary and alternative approaches can be classified as examples of non-conventional medicine (BMA 1993:6) and have been defined as approaches which recognise that the 'mind, body and spirit are interlocked' (Lee 1995:20-1). The holistic philosophy, which is claimed to be incorporated in many non-conventional approaches to care, has also been linked with the theme of self-responsibility and to the idea of renewal or human transformation (Lyng 1990:56; Lee 1995:23). The terms 'alternative', 'traditional' and 'holistic', are either used interchangeably or to contrast with each other, depending on which text is consulted in relation to health care (Power 1991:51). Certainly the term 'holism' is becoming synonymous with 'complementary' in popular usage, but holistic health care can include conventional and non-conventional healing approaches, as it involves an open-minded perspective and a willingness to consider all possibilities in relation to treatment and healing (Patterson 1998:288).

Spiritual care has been examined in detail in chapter three and, as previously stated, the spiritual domain of human beings is the most difficult to assess and measure, therefore an approach to care with the capacity to encompass all domains within and outside the individual, such as holism, is most likely to enable the care-giver to meet a person's spiritual needs effectively. It is therefore the spiritual aspects of holistic care which are the focus of this thesis and will be analysed in relation to the individual accounts in chapters six and seven, as the holistic philosophy promoted by the Bristol Cancer Help Centre puts spirituality and healing at its centre. The concept of spirituality in this context is that of an all-encompassing phenomenon which incorporates other aspects of the person and the

additional capacity in human beings to go beyond the physical, psychological and emotional domains.

With respect to science, many texts dealing with the theory of holistic medicine claim that it is based upon new science, such as New Physics, perhaps in an attempt to make it more acceptable in the scientific arena (Power 1991:54). The next section will examine research into the physiological phenomena which support the theory that the body is linked throughout by various substances and systems, as examples of the scientific aspects of holistic theory, followed by a discussion of quantum theory and its association with holism.

Molecules of emotion and embodiment

One example of the importance of integrated systems of body-the and the related human response is furnished by Candice Pert in her book *Molecules of Emotion* (1997), which demonstrates through doctoral research that the systems of the human body, including the nervous and endocrine systems, are integrated with each other and with the whole body at a molecular level. Her work formed the basis for a thesis aimed at finding peptide receptors in the brain, which started with a search for opiate receptors in the brains of rats. The existence of the opiate receptor suggested that the body must make its own opiates, as a receptor to an external chemical is unlikely to occur naturally in animal brains. Three years after this receptor was found, endorphins were discovered in pigs by researchers in Aberdeen and throughout the twentieth century various peptides, including hormones, have been detected in animal and human studies in many sites of the body, regardless of where they have been manufactured. The animal and human

brain have receptors for a wide variety of these peptides, which are known as 'neuropeptides' (Pert 1997:47-71).

In another work, Pert also refers to the effects emotions have on the whole organism or person in terms of physiological and behavioural responses, which she describes as 'literally transforming mind into matter' (2000:174). That is, she found that the same peptides present in the brain were also discovered in the immune system, which indicated that the nervous, endocrine and immune systems are 'functionally integrated in what looks like a psychoimmune-endocrine network' (Pert 1997:171). This theory became the basis for the emerging field of psychoneuroimmunology. Pert sums up the interconnected systems of the human being as the 'mobile brain' which is made up of the 'psychosomatic network through which intelligent information travels from one system to another' (1997:188). Communication between the brain, endocrine glands, spleen, bone marrow and lymph glands is via peptides and messenger-specific peptide receptors and occurs below the level of awareness (Pert 2000:169-70). The theory of embodiment also involves concepts of integration and holism and its main characteristic has been defined as 'the collapse of dualities between mind, body, subject and object' (Csordas 1990:5).

As already intimated, 'embodiment' is a concept demonstrated when people experience themselves simultaneously 'in' and 'as' their bodies, and phenomenologically speaking, are not aware of their bodies, except when

affected by disease and its associated dysfunction, when the person can experience a 'vivid but unwanted consciousness' of their bodies (Csordas 1994:54,52). Lawton sums up the theory of embodiment as 'the body as it is lived', which represents each person's view of the world, as the body is the 'vehicle for seeing' and for forming and maintaining personal relationships (2000:87). Therefore, the role of the anthropologist can be seen to be 'to experience others' bodies' through his or her own body (Blacking 1977:5).

The individual in Western society has been said to have a 'bounded sealed body' and is only considered to be complete in this state Lawton (2000:139). For example, children are initially incontinent and attaining continence is considered as one of the requirements for being considered a complete person. Similarly, incontinence in a terminally ill adult may be the trigger for admission to a hospice or hospital in order for the unbounded body to be removed from society, as bodily deterioration is associated with approaching death and can be seen as a sign of the body's loss of control. In this way, the dying person takes on a new identity related to terminal illness which can be characterised by an inability to control bodily functions and powerlessness to explain their situation due to a loss of life and of self (McNamara 2001:57,63). Therefore, deterioration of the body and social networks can be seen as interconnected and each can lead to the disintegration of the person's sense of self (Lawton 2000:141-2,185). The profound effects that suffering life-threatening illness has on the subjects is often seen as a reaction they, or significant others, have to changes in their bodies, as will be revealed through the individual accounts. In addition, the subjects' search for meaning associated with their illness experience can be seen as an attempt to transcend

their bodies and the physical world, for example by gaining access to the spiritual domain through healing or prayer. An explanation for the physiology of self and spiritual healing is provided by quantum theory and will be presented in the next section.

Quantum theory

There are those who put forward the argument that quantum theory can explain the healing processes within human beings, as only a fraction of physical laws are understood in terms of applying established logic and computational laws. Those who endorse theory related to the quantum world, that is of the atom or the unseen world, believe that laws which apply to the atom, as the microcosm, also apply to the human being, as macrocosm. In this context, quantum leaps are possible beyond the limits of current scientific beliefs. The word 'quantum' describes the smallest unit which can be defined as 'particle-like' and translates from Latin as 'how much?' (Chopra 1989:18). Quantum theory, which is otherwise referred to as the 'New Physics', involves aspects of science which do not fit easily into the 'mechanistic, reductionist and deterministic' view of the universe generally adopted in the West by the nineteenth century (Graham1990:29). Classical Newtonian physics had lost popularity by the end of the nineteenth century due to discoveries related to the atomic structure of matter, as these units behaved in random, uncontrolled ways. Thus, a new physical theory, called the 'quantum theory', was developed between 1900 and 1926 (Pagels 1982:19).

Einstein, as a New Physicist, presented the theory that the speed of light was the independent variable to which everything else is 'relativised' and which determines

the 'arrangement of the world'. It is argued that if the motion of an object changes, then its reality changes, such as its mass, energy, space and time in order for the speed of light to remain constant. Increases in speed are associated with increases in mass and energy and decreases in space and time. Such changes are negligible in 'everyday' reality, but become more significant the closer one gets to the speed of light (Utke 1986:137). At the time when the theory of quantum physics was developed, five levels of matter were known, that is subatomic, atomic, molecular, macroscopic and macrosomic objects. The 'quanta' associated with these levels of matter were classified as electrons, protons, atoms, molecules, macroscopic objects and macrosomic objects. The senses of human beings are only able to detect macroscopic and macrosomic quanta, therefore the 'wave-like, unpredictable nature of the sub-atomic and atomic realms' is not perceived. For this reason, perceived 'reality' tends to be characterised by 'substance' and, at this level, is associated with the Newtonian principles of absolute 'causality, predictability and determinism' (Utke 1986:139). In addition, the human brain is only able to take in a minute amount, estimated as one part per billion, of the 'total energy vibrating in the environment' (Chopra 2001:198).

Atoms, protons and electrons exist as particles, but their characteristics, such as their momentum and energy, 'exist only on a contingency basis' and an atom's specific energy level has, therefore, been compared to the theory of card playing in relation to the probability of a certain hand being created (Pagels 1982:80,181). It has been argued that subatomic particles are capable of making quantum leaps from one 'orbit' to another, without leaving any clear evidence of having done so. Therefore, matter has been said not to exist at this subatomic level but to show a

'tendency to exist' and the associated activities, or atomic events, can only be expressed mathematically as abstract possibilities in terms of the likelihood that they may happen. This phenomenon is known as the 'Uncertainty Principle' and goes directly against the idea of the existence of an observable and fixed reality, which is encompassed in the notion of a 'measurable objectivity in science'(Graham 1990:36-38). Phenomenology has obvious similarities in this respect to quantum theory, particularly since it has been proposed that what is 'there' depends partly upon what the individual chooses to see and is, in this way, partly created by the observer (Pagels 1982:65). The expression 'quantum leap', which indicates a distinct jump between levels of functioning, has been said to be implicit in the healing mechanism when a seemingly spontaneous cure takes place, as briefly mentioned above (Chopra 1989:17).

There are also similarities in the way in which energy is perceived by the New Physics and the philosophy of ancient mysticism. For example:

> Both conceive this energy not as some underlying substance or 'stuff' but as dynamic patterns of activity, movement and change (hence the Greek *energeia*: activity) to be understood in terms of vibrations, pulsation, flow, rhythm, synchrony, resonance and relative to time (Graham 1990:185).

In summary, at all levels in the human body healing can be said to involve an infinite number of coordinated processes and the extent to which these are manifested in different people depends on the individual's ability to activate them. It has also been argued that modern medicine only has a knowledge of the major

aspects of the healing process and that this knowledge is often superficial (Chopra 1989:18-19). The theories put forward in the New Physics appear to demand a 'new concept of order' in that a wholeness is indicated in which 'all parts of the universe, including the observer and his instruments, merge and unite in one interdependent totality' (Graham 1990:38). With respect to human beings, quantum healing is said to demonstrate 'the ability of one mode of consciousness (the mind) to spontaneously correct the mistakes in another mode of consciousness (the body)', which has been described as a 'completely self-encased process' (Chopra 1989:257). Such theories can be seen as either an attempt to provide a scientific basis for the holistic approach, and for spiritual healing in particular, or simply as an explanation of their effects.

It is clear that aspects of some approaches within the holistic philosophy can be supported by research into their physiological effects. However, there are many and varied approaches which draw on the holistic philosophy, including some which have no demonstrable scientific bases. This research will focus on the overall effects and perceived effects of engaging in the holistic philosophy with respect to health, rather than investigating the specific effectiveness of individual approaches via a scientific framework. Membership of the Northumberland Cancer Support Group (NCSG), which promotes the philosophy of the Bristol Cancer Help Centre (BCHC) is key to the research subject's illness experience, how they deal with it and how they make meaning from it. The holistic philosophy as practised by these organisations will form the basis of the discussion which follows.

The holistic philosophy in practice

It has been said that since the 1960s, Western society has been characterised by a growth of individualism and is gradually replacing paternalistic government and welfare systems with 'an enterprise culture based on individual survival' (Howarth 2000:130). The growing interest in and influence of holism in a wide variety of areas, from gardens to health care, may be seen as an example of this phenomenon, in that the mood of a particular culture can affect every aspect of it. In this sense, 'holism' appears to be used in an increasing number of contexts as an all-embracing word to indicate an inclusive and broad view of whichever issue is in question. Holism in relation to health can be seen as an ideological movement, in that it may be sought in a proactive, rather than reactive, way to the perceived reductionism of conventional medicine. In this sense, the sociology of holism may be said to start from a positive point, as it is employed as a way of expanding and complementing existing and dominant care systems, rather than rejecting them. The growth of consumerism is cited in the literature as one of the main drivers of the holistic health movement and sociologists also offer dissatisfaction with conventional medicine by an increasingly well-informed public as another reason for the emergence of the holistic philosophy. The increasing professional development and 'outgrowth of the counterculture' are also implicated (Power 1991:63,66). It appears that it is people as individuals who generate and drive the holistic health movement, rather than institutions and that hope, which has been explored in detail as a concept in chapter three, is also presented in the literature as an important driving force, particularly with respect to life-threatening illness (Thompson 1989; Chopra 1989). Examples of the ways in which the holistic philosophy may be employed in practice will now be presented and the drivers for

93

the research participants to becoming involved in the holistic health movement will be revealed through the case study.

The Bristol Cancer Help Centre

The holistic approach to care has been the focus of increased interest in recent years and, in relation to cancer, the Bristol Cancer Help Centre has established itself as a major centre for offering and promoting this philosophy. The Centre was created in 1980 with the overall aim of 'enhancing and maintaining optimal health through a state of harmony between the mind, body, emotions and spirit, within an ever changing environment'. It was initially run from a private house by Penny Brohn, who had suffered from breast cancer, Pat and Christopher Pilkington, who ran a healing group in their parish, and Alec Forbes, a consultant physician who had contacted Penny looking for a setting in which to put his ideas about holistic healing into practice. Initially, it opened one day per week on a voluntary basis but, as its fame increased, it outgrew the premises and large permanent accommodation was bought through a loan, fundraising and patient payment. A bursary fund still exists for those who cannot afford to pay (Thompson 1989:14-16).

A complementary and patient-centred approach is employed which targets 'the disease at all levels of mind, body and spirit', so that care is said to 'complement the highly technological and specialised environment of modern healthcare'. An education programme is provided consisting of courses and workshops geared to the needs of professional and voluntary carers, with a separate support programme for sufferers. The formal teaching offered covers the place and purpose of many complementary approaches in holistic care, such as aromatherapy, healing, touch,

94

massage, visualisation, healing foods and relaxation, as well as sessions concerning

support and care for carers, including bereavement support. A selection of more in-

depth sessions is also scheduled, such as the exploration of the

psychoneuroimmunology of the mind/body interaction.

The Bristol Cancer Help Centre also has extensive nutritional and

mind/body/cancer databases which individuals and organisations can pay to have

access to (Introduction to Educational Programme, spring 2002). As previously

stated, the Bristol philosophy does not suggest that conventional treatments should

be avoided. Rather, the Centre's approach is promoted as complementing orthodox

care so that the best approach for the individual is determined and utilised. *(See*

appendices 7 and 8 for information relating to holism provided by the BCHC and

NCSG).

In 1999 Macmillan Cancer Relief commissioned a study *(Complementary Therapies*

in Cancer Care:2002) to find out what role these treatments play in the care of

patients in the U.K. The study found that complementary therapies were embraced

by patients for the psychological benefits and relief of symptoms they bring.

Patients and their carers reported reduced anxiety, less depression, greater

relaxation, better sleep and improved sense of well being after complementary

treatment. In addition, health professionals were canvassed and revealed that the

majority were asked by patients for information about complementary therapies.

As a result of this study, a directory was developed entitled *Directory of*

Complementary Therapy Services in UK Cancer Care (2002), to provide up to date

information about non-conventional approaches available to cancer patients and

their carers in the UK. Although this directory acknowledges the benefits of complementary therapy, as detailed above, it also recommends that cancer patients consult with their key health care professional before starting any complementary therapy. National guidelines for the use of complementary therapy in supportive and palliative care have also been produced by the Foundation for Integrated Medicine and the National Council for Hospice and Specialist Palliative Care Services. This document was produced in response to the request for such guidance by approximately five hundred providers of palliative care in the UK, as no clear standards existed with respect to the use of complementary therapies. These guidelines are for complementary therapies only, that is those used alongside conventional medicine, rather than as alternatives to it, and consider related issues, such as the recruitment, qualifications, training and supervision of therapists. The evidence base for each therapy is considered, but it is acknowledged that a 'lack of evidence is not necessarily evidence of a lack of effectiveness'. (Tavares 2003:11-13). In addition, guidance on improving supportive and palliative care for adults with cancer was produced by the National Institute of Clinical Excellence at the end of 2003 and includes guidance on the use of CAM.

The Northumberland Cancer Support Group

For those who are interested in holistic care, a number of support groups have been established which are affiliated to the Bristol Cancer Help Centre. One such group is the Northumberland Cancer support Group, which provided the subjects for this piece of research. This regional group meets weekly from 7-10pm at Cancer Bridge at Hexham, has approximately seventy members and a usual attendance of between twenty and forty members at each weekly meeting, of which three to six

were men at the meetings attended by the researcher. People can refer themselves and the initial contact is often made through the information about the group provided on cards and leaflets which are circulated to doctors' surgeries and hospital out-patient departments and by word of mouth. *(Please see appendix 8 for copy of information leaflet)*. After the first call to the Secretary or one of the therapists, the person can either meet a committee member informally at an agreed venue, at the group, but away from the other members, or be taken to a meeting and introduced. The amount of participation in the activities, discussions and therapies is entirely up to the individual, as is how often the meetings are attended.

The Bristol philosophy of healing is considered to be the cornerstone of the group and facilities and activities offered through the group include discussion groups, talks from specialists, such as healers and therapists, the provision of complementary therapies, access to counselling and the organisation of social outings. There is also a library for both consultation and borrowing and the chance to purchase dietary supplements at cost price. Home visits can be arranged from therapists for people who are unable to attend the group meetings and one therapist gives therapies in her home one day per week, seeing four people during this time. This group was identified through an enquiry to the Bristol Cancer Help Centre regarding the existence of such groups in the North East of England.

Although therapies provided through such support groups are free, there are economic and social implications to be considered by those eligible to join. For example, the financial costs of obtaining dietary supplements and of transport to

group meetings may be prohibitive to some people. In addition, residential courses and group sessions offered at the BCHC also involve costs in terms of time and money. The connotations associated with holism may also be off-putting to some people, particularly if the spiritual aspect is perceived in terms of spiritualism or religion. Gender and ethnicity may also act as barriers to becoming involved in this movement and it could be said that people below a certain level of education and articulation are less likely to become fully involved, or even to approach the group, than more confident and better-educated individuals. It has also been argued that the holistic approach may not appeal to people who are not prepared to change their lifestyle or who have a scientific worldview (Thompson 1989:195). The ethnography of the NCSG will be discussed in more detail in chapter five to contextualise the case study and further information relating to the development of support groups in general will also be given. As the NCSG meets at Cancer Bridge, details of this organisation and its facilities will be provided in the next section.

Cancer Bridge

In 1986 the wife of one of the Cancer Bridge Trustees developed breast cancer and spent some time at the BCHC. She and her husband felt that there should be a similar centre in the North of England and started to raise money with the aim of establishing the Cancer Bridge Centre at Hexham in Northumberland. The premises are set in a secluded area which used to be a monastery where the sick were cared for. The Cancer Bridge Centre opened in June 2001, approximately two thirds of the time into this study, having been equipped as a holistic cancer help centre. Formal courses have been running since September 2001 and the Centre offers a variety of sessions, residential and non-residential, which follow the Bristol

philosophy. For example, a range of personal support therapies and education are offered and information is provided about the holistic philosophy. The NCSG has held its meetings at the Cancer Bridge Centre since it opened, and at the Adult Training Centre in Hexham prior to this, but functions independently from it. *(See appendix 9 for information concerning Cancer Bridge).*

Health and its association with holism

Since an improvement in health and well being is put forward in the literature as the main aim of holistic care, it is useful to consider what is meant by health and illness and how they relate to a holistic philosophy. Health, like death, has been defined and perceived in a variety of ways. The word heal is derived from the root word 'hael', which means 'to facilitate movement towards wholeness or to make whole at all levels' (Dossey et al1995:59). Hence, in this sense, the word health can be said to be synonymous with holism, as illustrated by Dossey et al:

'Healing is a lifelong journey into understanding the wholeness of human existence' in order 'to open what has been closed so that we can expand our inner potentials' (1995:xxvi,85).

Philibert (1998:1) also defines health in holistic terms, that is 'To the degree that well being is diminished or damaged, some aspect of illness is involved' and that to be 'fully alive', requires 'peace of soul'. Elsewhere, health has been presented as the 'successful development of the vital forces' which results in 'the perfect adaptation of the organism to its environment' and morbidity as anything which causes a disturbance in this adaptation (Durkheim 1938:50). Psychological health

99

has been said to have a positive correlation with basic need gratification, particularly when striving to meet one's higher needs, such as aesthetic and self-actualising needs (Maslow 1970:67).

Despite such broad definitions of health, in reality the measurement of health usually starts from the negative point which is reflected in the degree to which disease and illness are detected (Aggleton 1990:19). Foucault (1976:13) argues that 'No measurable mechanics of the body can, in its physical or mathematical particularities, account for a pathological phenomenon' suggesting that biomedical techniques of diagnosis are limited when employed in isolation. In addition, illness is not just experienced by the physical body but as suffering by the whole person and it is often alleviation of this suffering which is sought, for example through symptomatic relief, rather than a cure of the illness itself (Freund and McGuire 1991:151,180).

Thus, the literature reveals that health is an abstract concept open to subjective interpretation and that it is not a static or constant phenomenon. For example, there are various stages in-between health and illness, such as 'becoming ill and getting better' (Seedhouse 1986:55). Continuing in this vein, Pietroni discusses the concepts of 'comparative' and 'acceptable' health, which are dependent upon the context and culture in which the person is living (1990:177). For example, the functional model of health embodies the theory that health enables the individual to fulfil their social roles and to perform expected tasks effectively within society, regardless of whether pathology is present or not (Talcott Parsons 1951, cited in Morgan et al 1985:83). The view that health is a 'reserve of physical and mental

strength' which gives the person the 'ability to adapt' to changes in circumstances, such as illness, can also be seen as part of this model (Seedhouse 1986:39). It has been argued that illness can be potentially damaging to the self, because it may result in the inability of the person to manage their life in terms of planning and action due to the associated loss of control (Freund and McGuire 1991:155,157). For example, illness or pain can result in the body 'ceasing to be a vehicle for the expression of the self' (Davey et al 1996:142) and illness can take the form of a 'felt incongruence' between how the self is perceived and experienced (Watson 1988:48).

Individuals have been said to develop a 'system of ideas, values, experiences and behaviour' about the healthy body and disease which affects how messages from the body are interpreted by each person (Blacking 1977:88-9). For example, Grimby presents health and illness as a 'continuum' and argues that if an individual perceives their position on this continuum as providing them with 'autonomy, self-respect, successful social interaction etc.', then medical diagnoses will be of limited significance to them (1995:20). Therefore, the theories of the causes of illness used by lay people are not necessarily 'bioscientific', but are established through the types of empirical evidence to which they have access or exposure. Serious problems of communication and understanding could, therefore, occur when the individual's theories and feelings are ignored or disproved by health professionals, as professional interpretations of health and illness in most modern societies are usually respected more than those of lay people (Freund and McGuire 1991:247,180). It follows that the beliefs and theories held in relation to health by individuals and societies can influence the approaches employed to identify and

address health needs and the next section of this chapter introduces a selection of the philosophies underpinning traditional and conventional approaches to health and illness.

Traditional and conventional approaches to health

Traditional approaches to health, such as Ayurvedic and Chinese medicine, are promoted as being holistic in nature. In Ayurvedic medicine, which is still practised throughout the Indian sub-continent, health is defined as a balance between the three 'humours', which are wind, gall and mucus, and is usually achieved when there is equilibrium between the person as a whole and with the environment. In this way, treatments for diagnosed imbalances, or illnesses, take the form of a combination of herbal remedies, changes in lifestyle and diet and meditation. Chinese medicine is based on the principle that the person is made up of six humours which constitute life energy, or chi. Health and well being are attained when the two opposing energies of the body, yin and yang, are balanced and when 'Harmonies between the cycles of the individual and those of the universe' are achieved (Aggleton 1990:56). Disease is believed to result from the interruption of the flow of chi through the body and so treatment is given to help to re-establish the flow of this energy (Aggleton 1990:54-6).

On the other hand, the Western tradition of disease and illness can be said to have its origins in the Eden myth, in that sickness was imputed to sin and purification, or healing, came through suffering. The roles of priest and healer were in this way combined, for example when the apostles in the New Testament healed the sick (Dawson 1997:284). Indeed, all of the major religions, for example the Jewish,

Islamic and Hindu, were concerned with healing and health and 'several of the earliest *medical* text books are to be found in the great scriptures of the day' (Pietroni 1993:304). It has been argued that the separation of the art of healing from its spiritual base originated with the early Greek thinkers, since philosophy was concerned with the examination of the mind and the body rather than the spirit (Dawson 1997:284). However, the early Greek physicians, such as Hippocrates and Empodocles, worked within a holistic model in that health was thought to occur 'when there was a balance between four basic humours: blood, phlegm, yellow bile and black bile' (Aggleton 1990:56). Hence, the physician had to determine which humour was out of balance and institute treatments in an attempt to re-establish equilibrium within the person and between the individual and the environment, for example changes in diet, rest, exercise and 'bleeding' (Aggleton 1990:57).

From the fifteenth century health and illness in the West have come to have a more specific meaning 'associated with control and cure' (Hockey 1993:58-9), as conventional medicine is primarily concerned with physical illness and disease (Giddens 1992:9). Perhaps because of the effectiveness of medical models in controlling such illnesses it is the physical aspects of illness which are focused upon, but 'the exclusion of the broader range of dimensions encompassed by the more traditional concept of healing' (Hockey 1993:61), such as spiritual aspects of care, may result in their being marginalised. The predominant view in conventional medicine in the West is that health has come to be regarded as a commodity and is dependent on the absence of disease (Seedhouse 1986: 45). This concept of health may have been developed as a result of the social and political influences on health

making it an 'ever-distant promise to which one is entitled by virtue of social justice' (Illich1975:58).

Since the 1950s in the West screening of populations for various health problems has been carried out, which has been said to have extended biomedicine's control over society. For example, Berry identifies such epidemiological study with the potential result that 'all aspects of bodily and mental experience, as well as behaviour, could fall under the purview of medicine's calculating gaze' (1998:6). Elsewhere, the medical model of care has been called 'reductionist' (Helman 1994:104) and Philibert (1998:3) argues that although the improvements in science and technology associated with modern medicine have enabled doctors to identify and treat disease in a 'systematic way', this had led to the alienation of the patient. Although this model aims to explain and control illness in a rational and scientific way, the individual and group variations in practitioners and patients make this impossible. Hence, the universality of the medical model has been challenged, in that 'There is more than one version of the biomedical model, just as there is more than one popular or folk model' (Currer and Stacey 1986:23).

As indicated earlier in this chapter, and as believed and promoted by the research participants, the holistic philosophy aims to combine traditional and conventional approaches to health and illness. In this context health goals can be individual and peculiar to different groups, which may be a driver in the development of 'healthcare pluralism', a phenomenon demonstrated in 'modern urbanised societies' where different models of health care are used alongside each other (Helman 1994:63). Within a society where there are wide variations in the concepts

of and approaches to health there are also different theories relating to illness and disease, which will now be discussed.

The concepts of illness and disease

As concepts of health in the West are often defined within the biomedical model in terms of illness, it appears that outside of this model illness and disease are conceptualised in relation to health. For example, in the New Age Movement , 'disease' relates to the opposite of 'ease' (Heelas 1998:81) and Easthope (1986:18) argues that disease results from a 'disharmony' within the individual, interrupting the physical, mental or spiritual homeostasis'. Boyd (2000:9) provides an esoteric definition of disease, that is as the absence of ease or 'elbow-room', which results in 'an impediment to free movement'. Similarly, the word 'illness' is said to have derived from 'evil' and was used up until the eighteenth century to express a concept which incorporated unpleasantness, immorality and depravity. In addition, Boyd argues that as the Latin word 'valere' means to be in good health and that as the English word 'value' is derived from it, good health is held in high regard within Western society (Boyd 2000:10). The terms 'disease' and 'illness' are sometimes used interchangeably but have distinct meanings in relation to biomedicine, in that 'diseases are indicated by signs that can be detected by medicine and recognised as abnormal and illnesses are subjective experiences of pain and discomfort' (Seedhouse 1986:28). Outside of the medical model disease can be perceived in a positive way, in that it is seen to have a role in enabling personal growth and in re-patterning and expanding individual consciousness (Barnum 1996:127). Some societies still attribute the onset of illness to retribution for wrongdoing and, in this way, have recourse to supernatural forces for explanations of it (Aggleton 1990:15).

Concepts and perceptions of health, well being, illness and death can be seen as largely socially produced and every society has different levels of common ideas about the body, including scientific and non-scientific, as indicated earlier in this chapter (Freund and McGuire 1991:3). Human beings learn ways in which to monitor the processes of their bodies and develop verbal and non-verbal systems through which they communicate changes, such as illness, therefore, all symptoms depend upon 'local knowledge about the body and its pathologies' (Kleinman 1988:13,23). Doctors in the West deal with signs and symptoms of diseases and, compared to such empirical evidence of disease, lay interpretations of illness can be seen as having lost importance in our society (Lupton 1994:84). However, the initial diagnosis of 'illness' is still usually made by the patient (Currer and Stacey 1986:227) and includes the way in which a person experiences ill health together with the 'meaning he gives to that experience' (Helman 1994:107). The types of feelings and incidents which lead a person to define him or herself as 'being ill' include perceived changes in the appearance of the body, changes in the senses, 'unusual emotional states', 'changes in regular bodily functions' and 'unusual bodily emissions' (Helman 1994:109). As illness is, then, a subjective experience, it may or may not accompany disease, since a person may be suffering from a disease and not be aware of it (Aggleton 1990:6).

When illness is experienced, three sectors of health care, popular, folk and professional, have been identified through which care and help can be sought. The popular sector, where 'ill-health is first recognised and defined and health care activities are initiated', is made up of lay people and includes health related action

such as self-help and self-medication. The folk sector involves healers who 'specialise in forms of healing which are either sacred or secular or a mixture of the two' and occupies a position between the popular and professional sectors. The professional sector comprises the organised, legally sanctioned healing professions, such as those who work within modern Western scientific medicine (Helman 1994:64,67,75,67). Whilst people may use all three sectors, most health care is provided in the home, either by the individual or the family, which results in only a fraction of ailments being brought to the attention of a health professional (Freund and McGuire 1991:185).

Human beings respond to perceived illness by trying to make sense of it, for example by giving it physiological, psychological and social meanings (Kleinman 1988:14). Serious illness is likely to take the search for meaning further through the different stages of illness, for example by trying to find meaning in life itself and facing the moral aspects of illness (Freund and McGuire 1991:157). The reflexivity which humans are capable of with respect to themselves and the condition of their bodies results in their suffering not only from a disease, but from their experience of it. Kleinman (1988:250) suggests that the care of chronically ill people should be organised around the 'phenomenological appreciation' of illness experience. With respect to serious illness, such as that experienced by the research subjects, the experience of illness leads to a profound search for meaning and can be revealed through a phenomenological framework, as employed to conduct this research. As spiritual well being is a central focus of this thesis, the concepts of quality of life and general well being will now be discussed.

Quality of life and well being

Health and well being have been presented above as mutually dependent concepts and well being can also be described as being unique to each individual, associated as it is with their ability to live life to their potential (Burrows 1993:19). Spiritual well being, as examined in chapter three, has been defined as 'an affirmation of life in a relationship that nurtures wholeness with God, self community and environment' (Meraviglia 1999:25) and is, therefore, closely related to holism (Grainger 1999:20). In Western society quality of life is promoted as a concept which incorporates well being and appears to have originated in the U.S. after World War II to imply comfort in material terms or the 'good life'. This concept has since broadened to become a 'multifaceted phenomenon', including the psychological, social, occupational and physical domains and good health has been identified as a prerequisite to achieving a good quality of life (Fallowfield 1990:18-20).

Grimby offers a broad concept of what constitutes quality of life, defining it as a state of mind and body which allows the person to live in a self-determined way in the pursuit of individual desires and enables them to 'reach out to others' (1995:43). The changes in definitions of 'quality of life' have been attributed to changes in social circumstances in the West, in that as material poverty has decreased for many people, other aspects of life have been included, such as personal development and feelings of spiritual satisfaction (McDowell and Newell 1987:204-5).

Although cure rates for illnesses such as cancer remain relatively poor, people are living longer with such diagnoses, which results in more associated chronic illness, and this has led to an increase in quality of life research in these areas. However, much quality of life research is still visualised in terms of function and is based around the conventional medical model, which fails to address fully the experiential, social and personal aspects of illness. More recent studies, however, have considered the existential and spiritual aspects of adapting to living with cancer, not least because spirituality is often cited by research respondents as being important to their quality of life (Efficace and Marrone 2002:747). It is argued that effective quality of life research should attempt a more sophisticated methodology, including the employment of interpretative methods, in order to achieve 'contextual understanding', rather than simply reductionist measurement (Schou and Hewison 1999:6,19). Such research could assist in the provision of effective palliative care, where the aim is to add 'health and life to years' rather than the promotion of longevity alone (Higginson 1997:2).

Measurement in relation to health has been discussed in chapter one and this section of the thesis will examine the types of health and quality of life measures and scales which exist, in an attempt to demonstrate their strengths and weaknesses. The main aims of quality of life measurement have been specified as the identification of people who may require special attention, to screen people for psychosocial problems, to monitor patients' progress, particularly those with chronic illnesses, and to assist with decisions when choices between treatments have to be made (Fitzpatrick et al 1992:1074). Quality of life measures in health care have been divided into four categories, that is disease specific, generic,

dimension specific and those which focus on items peculiar to a study. Generic instruments leave the research open and allow for unexpected phenomena to be discovered, but they may be too broad to provide useful data in some cases. Therefore, advantages of disease specific instruments include their ability to yield data only in relevant areas and increased compliance by subjects due to the relatively reduced amount of information required. However, generic and disease specific instruments may be combined in a study to complement each other. Examples of instruments include 'The structure of sickness profile', which is generic, 'The arthritis impact measurement scale', a disease specific measure, and 'The profile of mood states' which is a dimension specific tool (Fletcher et al 1992:1145,6).

In health care research, quality of life measurement is usually defined as consisting of six dimensions, which are physical function, emotional function, social function, role performance, pain and other symptoms (Fitzpatrick et al 1992:1075). In an attempt to establish a standard measure of output in health care the 'Quality adjusted life year' (QUALY) has been developed and is used when the rationing of resources results in decisions having to be made on behalf of a group of patients in terms of worthiness for treatment, for example when an organ becomes available for transplantation (Spiegelhalter 1992:1205). However, it has been demonstrated that the judgements of health care professionals and those of patients differ considerably, which further complicates the decision-making process (Fitzpatrick et al 1992:1074). An element of bias is always possible in employing any quality of life measure, as it is very difficult, particularly in terms of time and expense, to apply it to a wide population (McDowell and Newell 1987:15). It has been recommended

that research concerning length of life and quality of life should be conducted separately so that any conflict is highlighted (Fletcher et al 1992:1147). It may also be significant that some people do not respond in quality of life research or drop out of a study in which they were taking part before its completion (Fletcher et al 1992:1147).

As the majority of medical research into quality of life is specific to health care, there is a lack of data regarding life satisfaction or living standards, which is reflected in the terms used within quality of life research, for instance 'subjective health status' and 'functional status' (Fitzpatrick et al 1992:1074). However, there are those who argue that in assessing quality of life medicine is attempting to influence aspects of life which should stay under the control of the individual (McDowell and Newell 1987:206). Fallowfield (1990:26,76,108) observes that health is 'noticed more by its absence than by its presence' and that a person's quality of life can be seriously impaired by receiving a diagnosis of a life-threatening illness, due to the number and variety of problems they face. Whilst quality of life obviously contributes to and can incorporate spiritual well being, it is not captured in these methods of measurement. Therefore, this research study is important in establishing the effect of experiencing serious illness on this aspect of well being.

The Individual accounts, making up the case study, will reveal that how health and illness are perceived is strongly influenced by cultural and intellectual factors, as they are complex phenomena. The participants' experiences of conventional medicine will demonstrate many of the aspects of experiencing illness and choosing approaches to its treatment. The next section of this chapter will introduce the

main models of health care employed in our society and will go on to analyse the medical model of care which predominates in the West.

Models of care in the West

A model of care, or a 'system of medicine' has been defined as 'a set of ideas, values and practices concerned with health and disease involving adepts whose special competence is recognised by at least a section of the population at large' (Blacking 1977:85). The concept of a medical system is much greater than what is perceived as conventional medicine in the West and can include treatments or preventatives which aim to act at a distance and 'charms and counter charms' which may be used to help in a wide variety of illnesses and life situations (MacLean 1978:162). The ideologies, which have been said to form part of all medical systems, vary in nature according to the structure of each society (Freund and McGuire 1991:216). Conventional medicine in the West has been defined as 'Treatment delivered by a medical practitioner' (BMA 1993:7). The terms 'complementary' and 'alternative' approaches to healing are often used interchangeably, constitute non-conventional approaches and are defined as those approaches not included in the traditional medical undergraduate programme (Pietroni 1990:179) or not standardly available on the NHS (BMA 1993:6) and can be applied as complete alternatives to the established model, or as additional therapies and treatments to the conventional model.

The medical model

The dominant, or conventional, model of health care delivery in the West is the medical model and its history and development is comprehensively covered in the

literature. Most schools of European medicine have their origins in the Greek systems, which sought to explain illness in terms of the general physical and mental dispositions of the individual (Porter 1986, cited in Giddens 1992:603). The family was the main institution dealing with sickness until approximately the eighteenth century and until this time ideas of health, sickness and treatments were similar globally (Giddens 1992:602). Prior to the rise of modern medical systems, theories of disease causation were either 'personalistic', where the sick person is perceived as the object of intervention from a supernatural being, such as God, or 'naturalistic', which were believed to be the effect of a lack of balance between the basic body elements (Morgan et al 1985:11-2). In this way, illness was seen as 'moving between bodies and environments (as in humoral medicine) without ever stopping to be analysable' (Armstrong 1993:55). However, the development of such techniques as dissection revealed that internal lesions could result in the external appearances of illness.

Although the medical model is now considered as the orthodox approach to care in the West, until the scientific revolution it was only one of many approaches to healing, with any orthodoxy in healing provided through the Church (Pietroni 1990:160). For example, in England during Medieval times caring and welfare were mainly the responsibility of the monasteries, due to the shared religious beliefs across society, which gradually disappeared following the Reformation (Munns 1990:20). Conventional medicine was originally termed 'allopathy' and defeated astrology by the turn of the eighteenth century to become the orthodox approach to healing due the triumph of 'science over ignorance' (Easthope 1986:35). Allopathy appears to have fitted more easily into the developing rationalistic and

individualistic worldview at this time. The introduction of Descartes' theory of mind-body dualism helped to develop the idea of physical reductionism where the concept of illness is limited to disordered bodily functions and, in turn, the body is perceived 'as the proper object of regimen and control' (Freund and McGuire 1991:226). Descartes' theory had separated the mind from the body, or the physical from the metaphysical, and, therefore, man from God, creating an accepted method of 'establishing verifiable knowledge' and introducing the idea of body as machine (Pietroni 1990:12). For example, the 'adoption of the germ theory of disease' resulted in a system which reduced patient involvement and increased the professional status and autonomy of practitioners, which was reinforced through the associated patient dependency (Morgan et al 1985:117). Physicians had previously been dependent on the patronage of the rich and powerful, but with their new scientific knowledge the balance of power began to swing towards the doctor (Morgan 1985, cited in Munns 1990:22). As the technical skill and knowledge required to practise medicine increased, the medical doctor can be said to have taken on 'the role of the shaman: mysterious, powerful and frightening' (Pietroni 1990:71).

The Industrial Revolution is identified in the literature as a major influence on increasing the demand for effective treatment and the medical profession's ability to provide it. For example, urbanisation increased geographical and social mobility and resulted in a breakdown in traditional communities and associated ideas. There was also an associated growth in experimental science and technology, which allowed hypotheses to be tested systematically and reduced the reliance upon the clinical experience of individual practitioners (Wallis and Morley 1976:11). The

scientific approach to the world from this time included advances in medicine which resulted in an increased knowledge of nature, disease and treatments and medicine was thus perceived as having the power to diagnose and cure an increasing amount of conditions. Modern methods of diagnosis and treatment date from the early nineteenth century, as does the establishment of hospitals as we know them (Giddens 1992:603). Western medicine has also been credited with improvements in health from the eighteenth century which could be more accurately attributed to advances in public health and improvements in the environment, such as developments in sanitation and increased access to improved nutrition (Illich 1975:15-6)

Consequently, through this specialised role and knowledge the Western doctor provides a 'cognitive system' of applied science to eliminate the 'chaos of fear' experienced by sufferers, this being one of the most distressing aspects of illness (Laderman and Roseman 1996:314). This 'coherent story' or 'medical narrative', having the support of medicine, is generally accepted in the West as a description of the illness situation and frequently overcomes the individual's illness narrative (Davey et al 1996:140). Thus, power has been acquired by medical staff over the users of the health care system, who are classified as 'patients', perpetuating the myth that only one system of care can be effective against illness and disease.

The growth of interest in the humanistic and psycho-social issues associated with improvements in medical technology has been said to be partly at the expense of spiritual care (Barton 1977:3-5) and conventional medicine has been held responsible for what has been termed 'the medicalisation of life events', including

birth, the menopause, and death, which had previously resided within the domain of the community and the clergy (Barton 1977:3-5,200). Such 'medicalisation' of what had been natural events can be said to have reduced the 'adaptive ability' of individuals, thereby promoting 'passive consumer discipline' in relation to health care (Illich 1975:39). However, there has been a reverse in the medicalisation of some situations, for example, homosexuality is no longer defined or treated as a disease (Bury 1997:101).

Medicine has been defined as being 'either preventative or curative' (Hockey 1993:63) and those endorsing it have been described as having dismissed the idea that the body may follow a 'spiritual, emotional or associational rather than a purely mechanical logic' (Bordo 1993:66). Hence, although conventional medicine is recognised as being responsible for some major improvements in health, such as the eradication of certain diseases, it has been argued that new problems have emerged which require the employment of a holistic philosophy in order for them to be addressed effectively (Alder and Mukherji 1995:142). As Hippocrates argued that medicine should assist the body's own powers for self-healing, by creating the best environment for this process to take place, there is an obvious irony in modern medicine adopting Hippocrates as its founder (Graham 1990:23).

There are many behaviours associated with the experience of illness in different societies. For example, adopting the sick role is a sociological phenomenon associated with conventional medicine and will be discussed in the section which follows in relation to the theory which underpins it and the perceived limitations to its applicability to all illness experience.

Health behaviour and the sick role

Sociological classifications of approaches to health and illness are discussed in the literature (Lupton 1994; Helman 1994), and include, for example, the functionalist and the social constructionist perspectives. From the functionalist perspective, a consensualist society exists in which order is maintained by members of society performing certain functions through defined roles. In relation to health, the sick role is an example of this, which will be discussed later in this section. The perspective of political economy gives health a political dimension in relation to the person's control over access to material and non-material resources which are required to establish and maintain health. Struggle is seen as a component of health from this perspective and poverty is an example of a barrier to be overcome in the pursuit of health by individuals. Medical knowledge from the social constructionist perspective is perceived as 'a series of relative constructions' which are constantly changing and which vary from one socio-historical context to another (Lupton 1994:6,8,11). The changing nature of late twentieth century society and the growth in consumerism has been said to have resulted in a culture of 'body maintenance' and the overall interest in and pursuit of a healthy lifestyle for many people in the West (Scambler and Higgs 1998:11). Thus, health behaviour is influenced by a person's beliefs about the cultural aspects of health and structural influences, such as power relationships within the system (Freund and McGuire 1991:4).

In order to understand these phenomena within a social context, models of health behaviour have been developed. The perceived benefits of having access to health

care is one factor affecting health behaviour and Becker and Rosenstock developed this theory into the 'Health Belief Model' (1984). The main element of this theory is that the perceived severity of the condition and its relation to the potential benefits of action are calculated by the individual, who then acts accordingly. In addition, a person cannot usually 'be ill' in Western society, without being aware of the need to account to others for the change in their situation (Bury 1997:2) and the benefits to be gained from health and illness also play a part in health behaviour. For example, signs of illness will almost always be played down by a person whose employment depends on passing a medical examination and, conversely, in compensation cases signs of illness may be enhanced (Blacking 1977:95).

Parsons (1951, cited in Bond and Bond 1986:211-3) developed the theory of the sick role, as part of the conventional medical model of care, which is adopted by those categorised as ill with a view to their recovering. The sick role enables the person to have their illness made legitimate by a doctor, who acts as the gatekeeper to health services, thereby establishing the illness as being serious enough for the person to be made exempt from normal duties, such as work. The sick person is expected to comply with treatment with the aim of overcoming the illness. This role involves the assumption of rights and responsibilities and the power within the relationship lies mainly with those who have control over legitimising and curing illness. Thus, within the medical model, it is argued that the main function of the sick role is to control the disruptive effect of illness within society (Morgan et al 1985:83).

However, Illich (1975:58) argues that the sick role fits only a limited number of conditions and situations, highlighting the fact that it does not allow for those who are not yet ill, those who are unlikely to get better, such as people in the end stages of illness, and those whom conventional treatments cannot help. In addition, everybody cannot be fitted into the two categories of 'the healthy' and 'the sick', therefore any value or boundary which divides such categories has to be arbitrary (Blacking 1977:85). Elsewhere it is argued that Parsons' sick role 'understates the moral judgement and social control aspects of sickness', for example sickness is sometimes considered as the sufferer's responsibility, as in substance misuse and some cases of HIV infection (Freund and McGuire 1991:137). The source of stigma associated with certain illnesses is not inherent in the disease but arises when a 'negative association' is given to it within society, which indicates a moral aspect of the concept of sickness (Freund and McGuire 1991:139). For example, in some societies such stigma has a religious significance and the sufferer of certain conditions may be seen as sinful and evil (Kleinman 1988:159). In order for stigma and deviant behaviour to occur, a society has to have basic agreements about what constitutes normality, which enable people to demonstrate which social group they belong to (Davey et al 1996:12). Therefore, it seems that the influence of labelling on illness has been studied comprehensively in the literature, with illness perceived as a form of deviance and health as the norm. Medicine has contributed to the development of labels for certain conditions and in this way has been seen

to encourage the reinforcement of illness behaviour. For instance 'Certain behaviours or conditions are given medical meanings and thus medical practice becomes the appropriate vehicle for their elimination or control' (Levinson 1998:75). An element of the creation of dependence upon medicine and upon the self-perpetuation of its practitioners is indicated in this theory. In addition, the power to label someone as sick can also be seen as the power to discredit that person in the eyes of society and treatment, or therapy, may be offered as the process through which the 'deviant' individual is socially reintroduced (Freund and McGuire 1991:143,144). However, socialisation has also had an effect on illness behaviour since patients sometimes seek to gain a label for a certain disorder or symptom when doctors are reluctant to provide one, for example in the case of Chronic Fatigue Syndrome (Bury 1997:101). Overall, it is recognised that the sick role, within the context of biomedicine, gives a 'temporary safety valve' to reduce pressure in such areas of society as the family and workplace (Freund and McGuire 1991:132,146).

As there are different ways in which health and illness are perceived and meaning made from them, so there are a number of theories held relating to how illness and disease are caused. These include immediate causes, which illustrate how diseases come about, and ultimate causes, which explain why they occur. Concepts of disease may be described as endogenous, for instance when illness is attributed to the 'magical capture' of a person's

soul, or exogenous, when illness is put down to the introduction of an object, either actual or symbolic, into the individual's body (Morley and Wallis 1978:3). Theories of the causality of illness have been seen to influence the kind of treatments which people seek when they experience ill health, for example making decisions between conventional and non-conventional approaches (Kearney 1978:23).

Experiencing cancer

As an example of a life-threatening illness, cancer and its associations are central to this thesis and theories relating to its causation will now be presented. Although the subjects of this study need not have a diagnosis of cancer, as explained in chapter one, the fact that they are in this situation has specific implications for them, as cancer has certain associations in our culture. For example, McNamara identifies that the 'symbols' of cancer are as debilitating for sufferers as the symptoms of it, as cancer is associated with 'pollution, uncontrollable and overwhelming growth and with evil' (2001:29). McNamara goes on to argue that cancer has become a metaphor for the 'feared death' in contemporary society, which leads to the loss of the healthy image of self sufferers have prior to diagnosis and to the related ability to 'express similarity and solidarity' with other people, which in turn results in social isolation and physical restriction (2001:30;36). Elsewhere, Diamond takes up this theme, entitling his book about cancer simply as 'C' and stating that, although there are many different types of cancer, 'the one thing that everyone knows about cancer is that it kills' (1998:37).

Cancer is still the commonest cause of death in the UK, being responsible for approximately one quarter of all deaths, and lung, colorectal, breast and prostate cancer have been called the 'biggest killers' within this context. Although there are significant variations associated with different types of cancer, it is very common for people to survive a cancer diagnosis by five years, and discrepancies in outcome also exist between treatment centres in the UK and countries around the world (Wilkinson and Hatfield 2002:15). Many factors have been implicated in the causation of cancer, although it is usually acknowledged that a combination of factors come into play when a person develops cancer. Cancer risk increases rapidly with age and the length of time some carcinogenic substances take to provoke a noticeable change in a person's health status needs to be taken into account (Lynge 1992:18). In general, approximately one third of cancers have been attributed to tobacco consumption and thirty per cent to nutritional factors (Heller et al 1992:56-7). Hill presents the theory of diet having a role to play in preventing cancer, pointing out that research has shown that trace elements and vitamins help to prevent cancer developing (1992:61-2). For example, vitamin C and beta-carotene appear to protect against gastric cancer and vitamin A against lung and oesophageal cancer. Other causative factors include exposure to ultraviolet light, contact with carcinogenic materials, such as asbestos, genetic predisposition, ethnicity and alcohol consumption (Wilkinson and Hatfield 2002:20-21).

Hormones also have a part to play in the development of some cancers. For example, prostate cancer is thought to be androgen dependent, as it is not seen in eunuchs and responds to castration or the administration of oestrogen (McPherson 1992:107). In addition, animal studies suggest that breast cancer is dependent on

oestrogen and women who have advanced breast cancer have been observed to go into remission after having their ovaries removed (McPherson 1992:109). A document produced by the health Development Agency in 2002, *Cancer Prevention*, links with the *NHS Cancer Plan* and details the main recognised risk factors associated with developing cancer. Smoking, diet and nutrition, obesity, limited physical activity, alcohol consumption, exposure to sunlight and contact with Radon are identified as the main contributory factors associated with the risk of developing cancer (Health Development Agency 2002:1). It is particularly interesting that the government's recommendations warn against taking beta-carotene supplements to protect against cancer and advise caution in using 'high doses of purified supplements of other nutrients' (Health Development Agency 2002:27), which is in direct contradiction to the Bristol Philosophy with respect to diet.

In addition to the accepted scientific theories relating to the causation of cancers, individuals, groups and societies may have different theories. An example of this can be seen in the particular theories of cancer causation which are alluded to by the research subjects in the case studies and which will be discussed in chapter seven.

Non-conventional models

Although biomedicine is considered as the dominant approach to health care in the West, globally most people subscribe more closely to traditional and religious ideologies with respect to health, illness and healing (Murdoch 1980:3). In many areas, traditional healing systems are utilised in conjunction with modern medicine

and different aspects of both systems may be adopted concurrently or at different times for a particular problem (Kearney 1978:23).

As previously mentioned, 'alternative medicine' is a term used in the literature as synonymous with 'non-conventional medicine'. The latter is more common in the more recent literature and indicating complementary and holistic approaches to health to a greater extent than systems and treatments which aim to be substitutes for conventional medicine. Non-conventional approaches can be employed in the place of conventional medicine and comprise complete systems of healing, such as acupuncture, diagnostic methods, for example kinesiology, and therapeutic modalities, which include massage. Self-help measures, such as meditation and relaxation techniques, can also be included as part of this approach (Pietroni 1990:181). A common element of alternative healing systems is the 'life force', or 'chi' or 'vitalism', which is thought to be an essential element of health and healing (Salmon 1985:265).

It has been argued that within the framework of the biomedical model, a person, whilst 'healthy' need only concern themselves with the functioning of their bodies and, therefore, may ignore other aspects of their existence (Lyng 1990:101). Non-conventional and holistic approaches to health attempt to include all aspects of the person and environment in concepts of health and illness. Historically, the Medical Act (1958) ensured that only those practitioners registered with the then recently created General

Medical Council could practise conventional medicine or surgery. In addition, the NHS Act (1946) did not detail what form of treatment should be made available on the NHS, leaving doctors to decide the matter (BMA 1993:7). Conventional medicine enjoys the reputation of being 'scientific' and, as the official approach to health care in the West, has the power of the law behind it. Therefore, given that non-conventional medicine is not the 'established' system in the West and is funded independently, it does not have an equal chance of uptake and demonstrable effectiveness as traditional medicine, although against this can be set its associated gains in freedom from bureaucracy (Sharma 1992:119). The medical profession may have some genuine causes for concern with non-conventional approaches, such as the possible generation of false hope in users of their effectiveness, but it has been proposed that the attitude of medical practitioners in relation to them is 'essentially protectionist' (Lee 1995:21-2). In addition, the fact that medicine makes a significant contribution to corporate profit also needs to be considered when analysing the provision of health care and the associated alternatives (Salmon 1985:4). The orthodoxy of modern medicine has been defined as being in the 'narrow political sense' only, since its cultural orthodoxy, in the sense of being the approach in which the general public has most confidence, may be questioned (Sharma 1992:24).

As previously stated, it is possible for conventional and non-conventional approaches to be used together so that a truly complementary framework

for care is achieved. For example, Western medicine can provide a diagnosis for a person to give to a non-conventional healer or can give treatment for simple injuries or infections to support complementary healing programmes. In addition, conventional medicine has retained some aspects of alternative medicine, such as immunisation, which has its basis in the principles of homeopathy (Easthope 1986:37). It has been put forward that many of the effects illnesses respond to the attention and suggestion of the non-conventional therapist (Eagle 1980:32), although the value of giving patients sufficient time, of touch and of the importance of including patients' spiritual and emotional concerns in care have been recognised within orthodox medicine as well as non-conventional approaches (BMA 1986:78).

Organisations focusing primarily on holism have emerged since 1982 in Britain (Power 1991:180) and the increased interest in alternative and complementary therapies has been said to 'bring back into our care system simplicity, safety, individual responsibility and autonomy' (Aakster 1993:92). Sharma and Clark argue that complementary and alternative medicine should promote health at all levels of the human being, that is 'from the subtle field of molecular interaction, through the levels of cellular function and organ system function to the physiologic functioning of the whole individual', involving aspects of quantum theory (1998: foreword). It is argued that conventional approaches, such as drug therapy, are not able to work with the whole person in this way, since they are alien to the body. This concept is illustrated by Chopra, through metaphor, as 'a man-made drug is a stranger in a land where everyone else is blood-kin' (1989:14). However, when

facing serious or life-threatening illness, people will take their chances with a risky cure, which could be said to be unethical since the individual is almost being blackmailed in order to accept the established treatment in serious illness (Chopra 1989:14).

When considering different approaches to healing, it has been recommended that certain questions be asked about the system in question. That is, questions relating to the focus of the healing approach should be asked, for example to establish if it is a whole body or whole person approach, and to determine its rationale and scientific method. The role of the expert in the model of medicine and its implications for the user-practitioner relationship also needs to be ascertained. Finally, questions should be asked to elicit the nature of the proposed therapeutics, how it is claimed that healing takes place and which authority is referred to (Power 1991:87). In addition, the term 'healing' is very broad and it is more helpful to specify which type of healing is in question, which healers, the setting and the timing of the healing (Salmon 1985:140). Non-medical approaches to healing are often concerned with the 'placebo effect', which will now be discussed.

The placebo effect
This phenomenon has been defined as 'a physical change that happens in the absence of any known or accepted medical intervention' (Achterberg 1985:84) and has elsewhere been described as the part of the behavioural change which can be attributed to the 'symbolic effect' of the placebo in question and the placebo response as the behavioural change itself (Spiro 1997:49). The use of placebos in double blind medical research trials has been common since the early 1920s

(Shapiro and Shapiro 1997:20) and the term 'placebo', from the Latin meaning 'I please' (Achterberg 1985:84), entered the medical vocabulary in 1811, used to indicate that placebos were a 'kind of gratifying fraud', in that they were 'pleasant but useless' (Morris 1985:186). This idea has continued, in that from the perspective of orthodox medicine, placebos are usually defined as 'sham treatments' which are given to placate anxious or 'unsuitable' patients (Harrington 1997:1). This indicates that the placebo effect has often been associated with stigma in that it has been considered either as a sign of 'patient neuroticism' or of 'clinical quackery'. However, it has been argued that all treatments, with or without known active properties, have a psychological impact when taken by a conscious person (House of Lords 2000:27). For example it has been found that the physiological effects of drugs are largely dependent upon 'the interaction between the pharmacologic action of the drug and the psychobiological state of the individual into whom it is introduced' (Ader 1997:139). In addition, the person's 'psychobiologic state' is influenced by countless factors which range from the person's genetic makeup to environmental factors (Ader 1997:139). This suggests that the individual has a significant part to play in the effectiveness of any form of treatment and that the effects of drugs, for example, are often assessed in isolation, which does not give anything like the whole picture.

A definition of what can constitute a placebo beyond the context of conventional medicine is given by Shapiro and Shapiro (1997:12) as:

> Any therapy prescribed knowingly or unknowingly by a healer, or used by laymen, for its therapeutic effect on a symptom or disease, but which is

actually ineffective or not specifically effective for the symptom or disorder being treated.

Thus, if the artificial stimulus were removed, it has been proposed that the process could be started at will and, in this way, the active properties of drugs could also be overcome by the imagination (Achterberg 1985:84). In other words, it is the belief in the substance which appears to give it its power, and this suggests that the body has a considerable capacity for self-healing, with the potential to be fostered and cultivated (Pietroni 1990:39). Achterberg develops this point further, arguing that the placebo can be seen as 'actually granting permission to heal' to the body (1985:85).

Cultural differences affect the way in which placebos are defined, since what is considered as a therapeutic agent in one context will be considered a placebo in another (Spiro 1997:39). Indeed, Shapiro and Shapiro put forward the theory that if everything were known about the phenomenon we call the placebo effect, the term would be replaced by a 'hugely powerful megapsychotherapy', but concludes that our current knowledge is far from this point (1997:29). Historically, useful drugs and other medical treatments have been developed in an erratic way and at irregular intervals and it has been argued that, because of this, interest in the placebo effect is stronger at some times than at others. For example, interest in this phenomenon is likely to decrease at times of medical breakthrough and to increase when people's expectations in available medical treatments are unfulfilled (Shapiro and Shapiro 1997:12,27). This idea is supported by Spiro who asserts that 'the ascent of science during the nineteenth and twentieth centuries did away with the need for magic and mystery in medical practice' (1997:39). The role of hope as part of spirituality, healing

and the will to live has been discussed in chapter three, as has the nocebo effect, which can be seen as the opposite of the placebo effect.

A number of reviews of Complementary and Alternative Medicine (CAM) have been carried out, including a comprehensive report compiled by the House of Lords Select Committee on Science and Technology, and an account of the associated findings are detailed below.

Comparisons between conventional and non-conventional medicine

A review of non-conventional medicine carried out by the BMA acknowledges that therapists give more time to clients, appear to show more compassion and employ touch to a much greater extent than conventional therapists. The main criticism in the report is that alternative medicine is perceived as 'unscientific' in this sense (BMA 1986:78), but it can also be said that conventional medicine is unscientific as the patient is also involved in a belief system, since they do not always fully understand the effects and implications of illness and treatments (Morley and Wallis 1978:15). However, the BMA (1986:78) does reinforce the close relationship between body, mind and spirit and elsewhere in the literature both the art and science of medicine are recognised as important aspects of practice (Fallowfield 1990:16).

As mentioned above, the House of Lords Select Committee on Science and Technology also produced a report in 2000 on the effectiveness of complementary and alternative medicine (CAM). This report was the result of consultations, through public hearings, with forty-five organisations, including the Department of

Health and the main CAM associations. It is acknowledged by this enquiry that the use of CAM is widespread and that this is increasing across the developed world. As there is such a wide range of therapies and care delivery systems incorporated by CAM and the relevant organisations have failed to come up with a single definition of CAM which is agreed by all concerned, the report divides CAM into three groups. The first group is defined as including the most organised professions, for example, acupuncture, herbal medicine, homeopathy and osteopathy. The second group is classified as those which most complement conventional medicine and as approaches which do not claim to 'embrace diagnostic skills', some of which are already available on the NHS. Examples include aromatherapy, massage, counselling, flower remedies, meditation and hypnotherapy. The third group are described as consisting of long-established traditional systems of health care, such as Chinese herbal medicine, and other alternative disciplines, for example crystal therapy and iridology, and which are said to lack a credible evidence base, favouring a philosophical approach to healing (House of Lords 2000:7).

A number of reasons for the increasing popularity of CAM are suggested in the report, not least the increased information available to the public about their health options, for example through newspapers, magazines and the internet. In addition, there are many common conditions for which conventional medicine and surgery can provide no outcome completely satisfactory to all patients, such as arthritis, low back pain, asthma and some forms of cancer. Previous research has identified that doctors now act in a more cautious way as a result of the recent increase in the threats associated with perceived malpractice and patients feel that doctors are more reluctant to share information with them. In contrast to this

environment, CAM consultations tend to take longer and the therapist uses more active listening skills in order to find out about the client's whole life, not just their physical health. This holistic approach has been shown to provide the user with a way in which to make sense of the illness in a more understandable and personally relevant way (House of Lords 2000:25,10,26,24).

One of the main findings of the enquiry is the considerable diversity of standards and the 'unacceptable' fragmentation of some therapies, especially those in Group two, and a recommendation is made to consider regulation by statute in some cases in order to protect the public. For example, it is difficult to determine which herbal products are licensed, which do not require a licence and those which can be sold as food supplements. The report also recommends that the existing regulatory bodies of each health care profession develops guidelines on competence and training in CAM for their members and on the position taken to their members' involvement in CAM. In addition, each health care professional should also become familiar with the potential uses of CAM therapies and their main weaknesses, or dangers, so that they can advise patients accordingly. In addition, the suggestion is made that each CAM discipline should develop one professional regulatory body which would be responsible for supervising all training and develop core competencies for each therapy. Guidelines for the public are also needed so that they can find out which therapies work, which do not and what is safe for them to use, through information which is evidence based and not aimed solely at selling the therapy (House of Lords 2000:7-8,101).

The enquiry finds that very little truly persuasive research into the effectiveness of CAM exists, for a number of reasons, such as a lack of training available for practitioners with respect to the principles and methods of research. In addition, there is a lack of funding and a poor research infrastructure in this area and there is also the general belief in CAM circles that conventional research methods are unsuitable for research into CAM. The report recommends that a central mechanism for co-ordinating, increasing the availability of and advising on CAM research should be developed through government and charity funding, which would enable CAM to establish a credible evidence base, for example by conducting Randomised Control Trials. It is anticipated that the therapies which make up Group one would command the highest proportion of research resources and that the National Institute for Clinical Excellence (NICE) could have a role to play in evaluating the existing CAM research (House of Lords 2000:8,32).

Overall, the House of Lords Select Committee recommends that CAM should be integrated with NHS services through the development of a culture in which doctors inform their patients about and refer them to CAM and that CAM practitioners encourage their clients to see a conventional doctor if this is appropriate. The report advocates that doctors, particularly GPs, should be the gatekeepers to CAM which is provided on the NHS, in order to minimise the risk of failing to diagnose serious health problems. That doctors should also be aware of all the treatment each patient is receiving and record this in the patient's records is also advocated. These recommendations can be summarised in encouraging communication and collaboration between practitioners of CAM and conventional medicine (House of Lords 2000:110).

Summary

This chapter has presented and discussed a variety of concepts and theories which are relevant to this research study. Holism is a complicated concept and can be viewed and engaged in within many different contexts. For the purposes of this research, holism will be analysed as it applies to health care and, more broadly, as associated with lifestyle to promote health. How the research participants see and engage in the holistic philosophy are key to this study as they have joined self-named holistic centres in order to do this. That is, it is their belief that they benefit from their involvement in the holistic movement and why they value this philosophy, including the identified drivers for joining, will be revealed through the research process.

It is clear that the subjects and the group as a whole see spirituality as an integral part of the holistic approach, and spiritual well being as a positive outcome of their involvement in this approach. Indeed the openly spiritual approach to health promotion and to healing is what attracted some group members to join. Spirituality is openly spoken about by group members and at group meetings and it is perceived differently in conceptual terms by different group members, as will be shown through the analysis of the case study. It is clear, then, that spirituality is given central place in the ethos of the support group by the group members and is part of their agenda. This is revealed through the overall philosophy, the group's library and workshops offered by the Northumberland Cancer Support Group (NCSG) and the Bristol Cancer Help Centre (BCHC). In view of these issues being so important to the research subjects, this research was designed to determine what

holism means to them and how spirituality and spiritual well being are addressed and achieved through their engagement in the group and its philosophies.

A large amount and a wide variety of literature have been presented relating to holism, health, illness and disease and the aim of this has not been to analyse critically each piece. Rather, the aim has been to provide background to the case study and, particularly, to the broad spectrum of theories and approaches which are associated with holism and health. An attempt has also been made to present theories which aim to justify how and why the holistic approach to health is perceived to work with the aim of providing possible scientific explanations for the phenomena described in some of the individual accounts.

Within the overall research question, the areas of enquiry which will be more specifically pursued through the research process are if and how engaging in the holistic philosophy promotes spiritual well being and how the concept of spirirituality is associated with this philosophy by the research subjects. The next chapter will discuss further some of the issues already touched upon in the background chapters and will present additional theory which is relevant to this research framework and process.

Chapter 5

Framing the case study

At this point in the thesis we recall several of the theoretical and methodological issues discussed earlier, as part of the transition into the presentation and analysis of the case study, constructed from the individual accounts of people who have experienced living with the effects of cancer, six of whom are affected directly and one indirectly, being the carer of her mother who suffered from cancer. The overall purpose of creating the case study is to demonstrate how people affected by a diagnosis of a life-threatening illness make meaning from the associated changes to their perceptions and related experience and to address the research question in this context. As discussed in the chapter relating to method, the individual accounts will be presented as an amalgamation of data collected from semi-structured interviews and personal journals, as ideas and issues raised at the preliminary interview stage were frequently developed more fully in the subjects' journals and this resulted in the development of more comprehensive and meaningful information. As a result of this the majority of the direct quotations were derived from the journals and it is not thought that anything is to be gained by identifying which were initial thoughts expressed at interview stage and which represent ideas developed over time whilst constructing the written account. The results are displayed in the next two chapters under headings that best reflect the main themes which evolved from the case study, some of which will be shown to apply to the group members collectively and some to individual subjects. For example, it is clear from the individual accounts that there are common essential features to the participants' experiences and that this experience is made up of multiple realities for them. Examples of themes revealed in the individual accounts

which are common to some of the participants only, and then to varying degrees, include the relationship between knowledge and control and the sense of life course, including ideas relating to what life events should happen when and how much life each person should get. In addition, there is lots of material about the body, such as the body in history, which is linked to health beliefs and theories of illness causation, the body as the container of cancer and feelings of loss associated with changes to the body as a result of illness.

The everyday activities, feelings and worldview of each subject are key to this study and, for this reason, their sense of everyday reality, and how they construct this reality, is central to the research process, as phenomenology captures the immediacy of embodied experience. In this sense, the individual accounts will reflect the experiential, everyday and personal aspects of living with cancer, which will involve drawing upon anthropological theory, including that which underpins the anthropology of the body. As the subjects were allowed to speak and write freely around the subjects introduced as part of the research process, the main themes which emerged have been drawn straight from the phenomenological description of their experience, with no attempt at interpretation from the researcher, in order to capture the essence of this experience. The researcher maintained an objectivity from the information gathered and bracketed off personal beliefs, assumptions and the influences of previous experience, as far as is possible, in order to achieve phenomenological reduction. As stated in relation to method, the subjects will be referred to by first name only, and that not their own, in order to maintain their anonymity. Each individual account will be presented as

the narrative of each subject under the heading of their designated first name in chapter six.

The research question and associated aims and objectives were derived from the philosophy of holism, as incorporated in the Northumberland Cancer Support Group, (NCSG) and what, if any, added value is achieved by those who engage in this philosophy in terms of spiritual well being. Spirituality, as an aspect of being human and of promoting health and, thereby, affirming life, is explicitly put forward as a key feature of the holistic philosophy and as a phenomenon which complements conventional approaches to health care, as discussed in chapter four. Therefore, the individual accounts will be analysed to determine if engaging in the holistic philosophy results in increased spiritual well being for the group members and, if so, to what extent. As it is the NCSG which provides a therapeutic environment for the members within which to make meaning of their experience, this group is the focus of the case study and it is within this context that spirituality is analysed. In this way, issues relating to the group can be grounded in data relating to the group itself, for example what is discussed when they meet. Having gained ethical approval to conduct the research, as detailed in chapter one, no ethical problems were encountered throughout the research process. That is, each subject volunteered readily, gave informed consent prior to taking part in the research and no apparent distress was caused to the subjects as a result of participating.

Overall, the individual accounts demonstrate how people adapt to living with life-threatening illness in terms of how they respond to the effects of change, particularly with respect to physical and social changes and alterations to their

senses of self. This includes revelations relating to how embodiment shifts as a result of the effects of illness and how perceptions shift accordingly, since all experience can be said to be grounded in embodiment. A new awareness of their own mortality affects how the subjects view their illness, illness in general and their own potentially premature death. How the subjects deal with the changes to their situation includes embracing holism, in particular through the Northumberland Cancer Support Group (NCSG).

The isolation and devastation experienced by the subjects as a result of receiving their diagnoses may have its roots in how death is perceived and conceptualised in postmodern society. In summary, it has been argued that death in this context is medicalised, professionalised, made taboo, denied and comes to represent that which cannot be controlled. In addition, cancer is perceived as a metaphor for death. Theories of grief and bereavement are discussed in chapter two and are particularly relevant to the case study as anticipatory grief is evident throughout them, as when the subjects worry about how their deaths will affect their loved ones.

Spirituality provides a thread throughout the thesis as it forms part of each of the individual accounts and is an important component of the participants' lives, as well as being central to the research outcomes. The theory related to spirituality has been discussed with respect to the similarities and differences between spirituality and religion and the move towards individual spirituality in contemporary society. Spirituality as it relates to healing is of particular significance to the thesis, especially as it links to the subjects' role of shaman or

wounded healer. Hope emerges as the driving force of spirituality and is central to the concepts of the placebo and nocebo effects. Spiritual distress and spiritual care are also analysed as these phenomena are central to the subjects' search for meaning in their experiences and changes to senses of self. The theories relating to spiritual care, especially that of human to human contact, help to give background to the data provided by the participants relating to their particular circumstances. As previously stated, 'care' is taken in the broad context of lifestyle and social relationships, rather than being specific to health care.

Theory relating to concepts of health and illness and models of health care provide the basis for the discussion of how the subjects perceive and live with the effects of illness and how they are treated by others within the health care system and elsewhere. This includes an analysis of health behaviour and the sick role and their shared knowledge base, which includes commonly held theories of cancer causation.

Chapter four outlined the theories underpinning holism and some of its practical applications, making links to the philosophy of the Bristol Cancer Help Centre (BCHC), the NCSG and Cancer Bridge. Spirituality is linked to holism through hope, individualism and by holism's capacity to embrace spirituality. Healing theory has been further expanded in chapter four, incorporating the theory of 'molecules of emotion' as applied to human physiology, upon which the belief in the health promoting behaviours exhibited by the research participants is based.

Overall, the background chapters have presented theory and discussed issues which locate a particular set of contemporary Western beliefs about how it is acceptable to negotiate illness and death within this particular historical and cultural context. This provides the basis for the discussion of the NCSG and its philosophy as embraced by the research participants, who are part of this society which is rooted in this historical and cultural context, as an example of how this nexus of beliefs is being lived on an everyday level. Before providing a discussion of the ethnography of the NCSG, the phenomenon of support groups in general will be now be presented.

Support Groups

A network of approximately six hundred local cancer support groups and self-help groups exists across the United Kingdom, most of which were created in the last decade. This is perhaps surprising in a post-modern society which appears to be increasingly moving towards individualism (McNeill 1999:13-14). In 1992, *Cancerlink* (a charity which provides support through self-help and giving information to people affected by cancer) carried out a survey entitled *Celebrating Groups*. A questionnaire was distributed to three hundred and fifty groups, professionally and non-professionally-led, and two hundred and twenty-four responded. The survey showed that the majority of groups were started by someone with cancer or who had a relative with cancer. Forty per cent had professional involvement and meetings were held in a variety of places, including hospitals, hospices, health centres, hostels and members' homes. Meetings were held mainly weekly or monthly, with regular attendance between ten and thirty members. In addition to meetings, a variety of services are available to members through the groups, such

as telephone support, access to a library, home and hospital visiting and information about living with cancer (Urben 1997:27). Non-professionally-led self-help groups are founded on the principles of self-determination and member empowerment, democratic decision-making, sharing a common experience and the free donation of services (Gray 2001:53). Other characteristics include providing the means to reduce isolation and stigma, the provision of emotional support and sharing information (Urben 1997:26).

Several benefits associated with being part of a support group have been identified in the literature, including finding commonality with others and the chance to talk about difficult issues (Gray et al 1997:20). Self-help groups encourage the 'face-to-face social interactions' of members and it is expected that they assume personal responsibility for the group (Van den Borne et al 1986:368). Support groups can also provide the opportunity to some members to recreate some aspects of their previous work, which may lead to a rebuilding of the person's self-respect and give meaning to their lives. This phenomenon was evident in research carried out by Gray et al (1997:20), which involved men who were suffering from prostate cancer, and in Mary's individual account.

Small concludes that such groups as bereavement support groups are formed because members experience social exclusion and are committed to the 'authenticity of personal experience as a source of knowledge' (2000:114). In other words, people relate to others who have shared a similar experience and this experiential knowledge can help with the 'cathartic and empathetic' dimensions of self-help groups. In addition, self-help groups can offer social ties which members

feel they have lost in their own social circle and this enables them to address feelings of 'loneliness and uniqueness' by developing a feeling of community within the group (Stewart1990:1060). This idea will be developed in the next section as it relates to the anthropological theories of liminality and communitas and the new loneliness experienced by some of the research participants as a result of the changes in their circumstances.

The literature also provides criticism of some aspects of support groups, such as volunteerism, which is associated with amateurism (McNeill 1999:13). In addition, as self-help groups are self-selected, their usefulness to those who fit in may be magnified and their uselessness to others may also appear to be exaggerated (Walter 1994: 130). Support groups are not representative of society as a whole in that more women than men attend self-help groups (Urben 1997:26) and they have been found, in the main, to be made up of people from non-minority ethnic groups and who have had more than average education (Gray 2001:54). Physicians have expressed concerns about self-help groups which are not professionally led, which include the possibility of members receiving misinformation, potential negative effects of association with the very ill, unnecessarily dwelling on illness, destructive doctor 'bashing' and the cultivation of false hope (Gray et al 2001:55).

As there are so many different types of self-help and support groups, it is very difficult to draw clear evidence of their effectiveness from the literature. The effect being a member of a support group has on an individual depends upon their situation, so it is difficult to make generalisations. For example, a person's family and friends may provide the support which others receive from the group. It is also

possible that some people will experience deterioration in their well being after attending a peer support group. For instance, Helgeson reports that two women involved in a research study who were happy with their social network prior to joining the group were affected by the negative experiences and illness narratives of other group members (2000:212). This resulted in their reevaluating their own relationships in the light of the experiences of their peers. The members of the NCSG identify a variety of benefits associated with their involvement in the group, which will be discussed in the next section.

Ethnography of the Northumberland Cancer Support Group

The gender ratio of subjects who took part in the study is roughly proportionate to that of the attendance at NCSG meetings, that is three to six men at meetings of twenty to forty people, which is roughly six women to one man. There are specific rituals associated with joining, attending and leaving the group, which were explained by the Support Group secretary. In order to join the group, individuals contact one of the three Committee members, whose telephone numbers are detailed on the promotional literature. Prospective members usually indicate by telephone when they will attend their first meeting and often take someone with them to it. If they prefer to attend alone, or are unable to bring a friend or family member, one of the Committee members offers to meet them and take them into the meeting.

The Northumberland Cancer Support Group may be said to provide its members with an alternative reality and environment from that inhabited by their families and friends, from which they have been removed following their change of

situation. Lawton develops this argument stating that the new environment provided for her subjects by the hospice day unit, where they were studied, enabled them to construct an 'autobiography of self' which was dissociated from their 'current state of atrophied personhood' (2000:68). Lawton also found that the subjects used the phrases 'in the same boat' and 'kindred spirits' to describe why they felt a closeness to their fellow patients which they no longer felt with their families and friends (2000:46).

In addition, there are parallels with the theory of communitas, as put forward by Turner (1995) in relation to rites of passage or transition. Communitas is characterised by three phases, that is separation, margin, or limen, and aggregation. Separation marks detachment from a set of cultural conditions and movement into the 'liminal' period before being reincorporated into the new state (Turner 1995:94). In the case of the research subjects, their movement from pre-illness to post-illness sense of self is an example of this phenomenon and their search for a therapeutic community which addresses their changed needs characterising the time in which they could be described as 'liminal entities', on the threshold of a changed state. The resulting communitas, in this case as it pertains to membership of the support group, develops a structure from the initial 'free relationships' between individuals and changes them into new 'norm-governed' relationships within the altered structure (Turner 1995:95;132). Oliver provides an example of communitas as it relates to life on a hospital ward, which is described as a 'community of pain' as a result of residents experiencing 'common misfortune and threat of personal danger' (1986:64). In this case the pre-liminal stage equates to pre-hospitalisation, the liminal period to the period of

hospitalisation and post-liminal to the individual's return to the community on discharge. The main argument is that, although the way people are admitted to hospital varies, their admission constitutes an absolute new status for them. That is:

> The patient becomes a member of the ward community under authority, under the will of his superiors, in the company of many others and subject to rituals associated with the routinisation of medical care (Oliver 1986:65-66).

There are obvious similarities between the liminality and communitas of hospitalisation and Lawton's theories associated with the hospice day unit which can also be applied to the environment of the NCSG.

When a group member deteriorates and is unable to attend the meetings a number of options are available through which support can be given. Some people completely withdraw from contact with the rest of the group at this point, but the majority prefer to maintain links. Group members offer to give therapies in the person's home, in hospital or in the hospice according to their wishes. In addition, group members who have developed relationships with the person whose condition has deteriorated make visits to them, telephone them or write to them, depending on their mutual wishes and extent of intimacy.

If the person's deterioration continues and results in their death, a number of rituals are available to mark the event. The Committee keeps in touch with the

person throughout their illness, if they have no objections to this, and the group are kept informed of the condition of members who can no longer attend meetings. Similarly, when the person dies, the group is informed and they decide on the most appropriate action in each case. The group secretary stated that a group member always attends the funeral on behalf of the group and a letter of condolence and card, which is composed at a group meeting, is sent to the person's partner, friends or family, depending on their circumstances. Other group members may send cards and flowers as individuals if they feel particularly close to the person who has died. A tribute may be paid to the deceased person at a future meeting if the group feels that this is appropriate. The support group secretary felt that the questions she was asked about the rituals surrounding the deterioration and death of a member were appropriate as she said that dying and death are a 'huge part' of running a group like the NCSG as, due to the nature of this support group, it is inevitable that members will witness the deterioration of fellow members as time elapses. Therefore, the group has developed its own way of acknowledging and coping with this situation, aspects of which will now be discussed.

Effects of deterioration of other group members on the subjects

Some of the subjects are obviously affected by the deterioration of their peers, but references are also made throughout the individual accounts of the positive aspects of living with the threat of premature death and of spending time and building relationships with people in a similar situation. A number of similarities in groups sharing experiences in this way also highlight this aspect of being affected by life-threatening illness. For example, the results of a research project conducted by Quinn (1996) highlight the perceptions of cystic fibrosis sufferers with respect to

147

death and dying. For example, one participant states 'outside cystic fibrosis I'd never talk to anybody about dying. We're all in this together'. This indicates that the close network of fellow sufferers provides a safe environment within which their shared concerns can be aired. Thus, when one of this group dies, the loss is shared and felt on a number of levels, the first of which is the loss of someone known to them and to whom they may have become very close. On another level, this brings into focus the awareness of their own potential deterioration and death and, finally, there will be the 'cumulative impact of a number of deaths from cystic fibrosis over a period of time'. However, it is acknowledged by the subjects that the situation allows them the capacity to discuss death and dying in relation to themselves (Quinn 1996:86).

Two research studies, using the Hospital Anxiety and Depression scale, indicate that patients who witness the death of fellow patients in the hospice setting display less depression than patients who do not. The first study involved eleven people who had shared a room with another person who had died and were compared with nine who had not (Honeybun et al 1992:67-9). A larger study, in which sixty-nine people participated, was carried out by Payne et al and also showed that those who had witnessed the death of a fellow patient were less depressed than those who had not (1996:1792). These studies indicate that the effects of deterioration and death in one's peers is a complex phenomenon which offers potential for personal growth and increased understanding of the human condition. The explicit awareness of potential deterioration and death on a personal level appears to bring with it a new sense of the preciousness of what time an individual has left and is a strong theme of the case study.

Preciousness of time and intensive living

As discussed in chapter two, the concept of intensive living was identified by Glaser and Strauss and classified as one of three forms of 'fighting behaviour' which dying people may engage in (1965:131). The other two types of behaviour which indicate that the person is fighting death were observed to involve visiting marginal doctors or quacks and participating in an experiment. 'Intensive living' appears to be adopted in an attempt to hold death off by 'living life to the full', but may also enable the dying person to prepare actively for death by 'increasing the patient's fullness of life before he dies' (Glaser and Strauss 1965:131). The research subjects demonstrate a variety of forms of 'intensive living' in that quantity of experience is sought by some, such as Beatrice, and quality by others, such as Anna and Susan. The fact that the subjects are living with an awareness of their own potentially premature death appears to have prompted their 'intensive living', although they could not accurately be called 'dying' at the time the fieldwork was carried out. A contemporary interpretation of 'marginal doctors' and 'quacks' could be taken to include non-conventional doctors and therapists who work within a philosophy which complements and may offer an alternative to what conventional medicine has to offer. An example of this can be seen in Rachel's willingness to try anything which may improve her condition and prognosis. Notions of being an individual and attempts to regain control over their situation through such changes in activity are also linked with the phenomenon of 'intensive living' for the subjects. This individuality takes different forms, such as in the loneliness felt following diagnosis and the individualism associated with New Age approaches to spirituality and senses of self.

In addition, Lawton identifies that the future becomes problematic for people who live with a life-threatening illness, as the perception of time for most people is associated with planning for the future (2000:47-9). Lawton's hospice day unit patients were observed to concentrate on past and present concerns in order to avoid confronting an uncertain future, a phenomenon which is described as living in a 'present-orientated temporal framework'. Their families, on the other hand, were found to seek as much information as possible about their relatives' prognoses as they wanted to plan for the future.

Control, knowledge and power

As previously discussed, research has shown that people facing life-threatening illness value being treated as individuals rather than as a number or case and that the main types of information they feel they need are related to medical treatments, life management and what has been described as information about 'big issues', such as dying (Macmillan Cancer Relief 1999). However, it is evident from the literature that it is professionals who have control over information in health care and this is not always given in a way which responds to the changing information needs of the individual (Van der Molen 2000). This may contribute to the development of a lack of real communication between patients and health professionals, as indicated in some of the individual accounts. Individual beliefs concerning the causality of disease have been said to influence the type of treatments people choose when they experience ill health and make decisions between conventional and non-conventional medicine (Kearney 1978:23) and this

150

potential breakdown in communication can alienate people further from the conventional health system.

The attempts made to regain control over their situation by all of the subjects appears to be an attempt to reduce the negative effects on their defences caused by stress and helplessness. A research study carried out by Stanworth also reveals the phenomenon that people experiencing life-threatening illness feel helpless in the face of their destiny and in losing control over their situation (Stanworth 2000:342). Toulis (1997:127) argues that when people lose control over their actions and thoughts they experience a 'crisis of presence' and they become 'passive and ineffectual' as a result of this, as discussed in chapter three. Research has identified that when individuals and families have sufficient information about the condition in question they are more able to make sense of the situation, accept the illness more easily and are able to manage it successfully (Boise et al 1996:80).

Leydon et al conducted a small study, involving seventeen people, in an attempt to establish the nature of cancer patients' needs (2000:910-2). It was found that all of the subjects wanted information about their diagnoses, treatment options and possible side effects of treatment. However, the preferred timing of this information varied, as did its content and detail. Although the author of this study concedes that the sample cannot be considered as statistically representative, sufficient information was gathered to suggest that information needs vary from person to person and the way in which information is given should be flexible, taking into account the individual's coping strategies and choices. Macmillan Cancer Relief undertook a major survey of cancer patients' views as part of its 'A voice for

life initiative', inviting participants through newspapers, magazines, self-help groups and the Macmillan information line and web site, which resulted in 3,046 responses, subsequently analysed by the British Market Research Bureau. Participants were asked to provide information regarding: *The one thing that made, or would make, a positive difference to my experience of cancer.* In total, 130 different issues were raised in the received responses, but one common theme emerged. That is, people replied that they wanted to be 'treated as a person, not a number' and stated that information, care and support should be provided how and when *they* needed them. Another important issue raised was the importance to the participants of early diagnosis and prompt test results and treatments (Macmillan Cancer Relief 1999).

The main concerns of people suffering from cancer are summed up by McNeill (1999:13), who states that:

> In discussions with people with cancer, there is seldom a demand for state of the art drugs or access to world experts, but rather clear, timely information, delivered with some empathy as well as sensible approaches to involving close family members and friends. People deserve respect as whole human beings with lives beyond hospital and a recognition that cancer does not reduce the individual to 'symptoms on legs' as one friend with prostate cancer said recently.

It is evident from the individual accounts that obtaining accurate, relevant and timely information is very important to the subjects and that their involvement in

decisions relating to their health is very important to the majority of the subjects. Being treated as a whole person is also valued by the research participants and it is in search of this end that members join the support group in many cases. The relationship between knowledge, control and holism will be discussed in the next section.

Perceived benefits of holism

The subjects indicate several benefits to them of adopting the holistic philosophy of care. Touch from therapists is valued, especially when the subjects experience changes in their body and self-image. One subject says that healing gives hope to the 'healee' and gives the healer the opportunity to help others (the term 'healee' is used by the subjects but is not an accepted form of the root word 'heal'). Support from other group members is seen as valuable in maintaining hope and promoting a therapeutic environment. The case study indicates that within the holistic health movement the individual is seen as the key to their own success and the aim of the holistic philosophy is to promote health and to increase the individual's resistance to illness and disease, for example by strengthening the immune system and learning how to deal with, or avoid, stress. This often results in significant changes to lifestyle in order that health-promoting activities can be incorporated and stress avoided. These findings help to support theories in the literature which identify the growth in consumerism, dissatisfaction with conventional medicine and a better informed public as the main drivers of the holistic health movement in Western society (Power 1991:63).

Our society has a strong emphasis on consumerism and choice through which individuals are able to control how they live their lives. The subjects attempt to regain control over their lives by searching for information about their illnesses and particularly about possible treatments. They all undergo conventional treatments, but in addition they make choices about what complementary and alternative treatments are available to them to promote health and reduce the effects of their illness. The range of complementary approaches used is considerable, including the Alexander Technique, homeopathy, Bach flower remedies, spiritual healing and the use of crystals. The effects of economic constraints in terms of limiting choice have been identified in the individual accounts, particularly in relation to Rachel, but all of the subjects had sufficient financial resources to attend the support group and have access to facilities such as the internet. Although not the focus of this thesis, the sociological effects of material poverty on people suffering from chronic or life-threatening illness is an area which merits further research. The individualism reflected in the subjects seeking information and exercising choice is at odds with the strength they get from being part of the support group. However, it seems that through the group their knowledge is increased and their choices of non-conventional approaches extended, for example by providing all of the treatments free at the meetings or in members' homes.

It is evident from the group that a shared body of knowledge exists relating to illness causation in general, and of cancer in particular, which leads to a set of beliefs relating to how those affected should be treated in an attempt to facilitate a cure of the condition or to alleviate symptoms. In addition, the promotion of

overall well being, which includes that of the spiritual domain, is also a specific aspect of the philosophy of the NCSG.

Shared body of knowledge relating to living with the effects of cancer

Although the group librarian does not keep an index of publications which are available for group members to borrow, she was able to give information about the categories of books which are included and the most popular subject areas. As indicated above, texts are kept which are concerned with cancer causation and its treatment. Books about diet and recipes, particularly the diet promoted by the Bristol Cancer Help Centre (BCHC), are very popular and the library has a significant selection of books on this topic. The rest of the library is made up of self-help publications, particularly those which provide guidance concerning visualisation and meditation, biographical works written by or about people who have had a cancer diagnosis, material concerning non-conventional medicine and books based on quantum theory and its relation to healing. In addition, a selection of relaxation tapes is kept and there is a section of the library devoted to death and dying.

Other than Mary and Gill, all of the subjects refer to books which are held in the support group library and demonstrate that this literature has an effect on how they perceive their illness and its causes. It is clear that some of the subjects have read Getting Well Again by Simonton et al (1980) as its theories on how illness, and in particular cancer, is caused are reflected in the individual accounts. This book is a step-by-step self-help guide to overcoming cancer for those affected directly and their families. Statistics are given to support the theory that improvements in

prognosis occur as a result of using a whole person approach and several factors are identified as contributing to the development of cancer, such as genetic predisposition, diet and exposure to carcinogenic substances, such as radiation. The authors acknowledge that these factors alone are not the direct cause of cancer, as many people who would be considered to be at risk do not develop cancer, but that other characteristics, particularly deficiencies in the immune system, are also required to allow it to develop. In addition, Simonton et al observe that on receiving a diagnosis of a life-threatening illness the person gains a new perspective on the world and on their problems and may make a conscious decision to alter their behaviour and to become a different kind of person (1980:76-7). This is the opposite to feeling a victim, as it involves a conscious attempt to regain control of their lives and aspects of their illness experience. This change in worldview can also have an effect on their physiology in that the immune system becomes strengthened and they feel 'weller than well'. This change in perspective is usually also accompanied by changes in body image and sense of identity, which will be discussed in the next section.

Self-identity and change

Carpenter et al identifies several aspects of experiencing a life-threatening illness which can have a significant effect on the person's sense of self, either positively or negatively (1999:1403). These include physical changes which occur as a result of the illness or its treatment, the inability to fulfill one's roles within society and the psychological and spiritual processes which help the person to find meaning in the experience. This research, involving breast cancer sufferers, indicated that the process of transformation of the self begins with an increased self-awareness which

is brought about by a 'sudden awareness of personal mortality' (Carpenter et al 1999:1405). The subjects of Carpenter's research were found to make changes in their lifestyles, relationships and work which were more in line with their new self-identity (Carpenter et al 1999:1406).

Facing a life-threatening illness can also lead the person to disengage from their interpersonal ties and social networks, which has elsewhere been identified with a 'debasement and erosion of personhood', and can be compounded by physical deterioration (Lawton 2000:42). Lawton's observations are made as a result of research carried out in a hospice which indicate that the 'alternative reality' of the hospice day unit gives the subjects the opportunity to 'reinstate' their sense of self in a new environment which allows for the change in their situation. The environment of the NCSG can be said to provide such an alternative reality for the research subjects, as previously noted. There is also a lot of material in the individual accounts about the body and changes as a result of illness which will be analysed in chapter seven.

A personal narrative of living with breast cancer also supports the theory that identity is adversely affected by a diagnosis of life-threatening illness (Gee 1992). The author expresses a wish for her family not to be directly involved in her personal care when she deteriorates physically, as she says that 'Even in death and dying I want to continue as wife and mother' (Gee 1992:60). However, although she states that her sense of self has changed as a result of her diagnosis, in that she feels she is a 'different person now', she asserts that she does not want to return to her old self, saying:

I fear drifting back into an old oblivion where life was taken for granted and routine removes you from much of the vividness of nature' (Gee 1992:71).

Following a review by her doctor which confirms that her illness is in remission, the author expresses a gratefulness for being alive which she would never have felt prior to her illness. She states 'After leaving his office I felt a fresh exuberance about being alive, a clean awareness of the day' (Gee 1992:118). In summary, Gee (1992:28) describes cancer and its effects on sufferers as:

A net thrown over their most intimate thoughts, fears and dreams. It is a web so persistent and present that its grip becomes familiar, a given part of daily existence.

The all-encompassing nature of the disease summed up in this comment is a theme which is evident in the individual accounts.

Diamond also picks up the theme of change in self-identity as a result of experiencing life-threatening illness when discussing his return home with his wife the evening before he is to be admitted for surgery, saying 'we drove home and lay together in our bed for what was to be the last time as the couple we had been for eight years' (1998:144). In addition, at a later point in his illness experience, he hears a recording of a radio programme he had made before his illness and describes this experience as 'coming unexpectedly upon' his 'pre-cancerous self',

who 'didn't know he was living' due to taking things for granted (Diamond 1998:209).

Staton et al (2001) reports on a piece of research which followed nine people who had been diagnosed as terminally ill until their deaths and carried out at least one visit to their families after the death of each subject. The subjects suffered either heart disease, pulmonary disease or cancer and this study aimed to provide a continuous record of the lived experience of dying and care giving. The author argues that life itself is embodied in a person's daily activities which involve the body and that this is part of being human. Therefore, people who are dying fear that when they are unable to continue with these activities they may become isolated and 'inhuman' whilst still alive, and so mundane activities may take on a symbolic significance for the dying person. This was found to be the case, as those who took part attempted to maintain connections with people and activities they considered meaningful, which allowed them to maintain a connection with society and culture (Staton 2001:135-7). The main themes which emerged from the study were attempts to maintain control and the assertion of independence through carrying out as many daily activities as possible. By these efforts, the subjects felt able to maintain their identity and continued existence. Examples of the activities valued by the research participants include visits, watching television, eating, outdoor activities, spending time with pets, reading and listening to music (Staton 2001:169-72). The theme of the importance of maintaining normality was also manifested in Stanworth's research with hospice patients, where normality was defined as 'traits or activities unrelated to a person's illness which are associated with expressions of self' (Stanworth 2000:442). There are also obvious parallels

with the individual accounts which involve an appreciation of simple, normally taken for granted, activities and aspects of life.

People experiencing life-threatening illness have been seen to manifest the desire to appear 'normal' and to go unnoticed within society, as they did before their illness. However, their family and friends are often reluctant to be seen with them, particularly if signs of serious illness are visible, which can result in alienation of the sufferer due to being stigmatised by society and those closest to them (Lawton 2000:44-5). However, the case study will reveal that the subjects who have completed their treatment and who display no obvious signs of illness, such as Rachel and Beatrice, express frustration at being treated as being back to normal by their family and friends. It seems that their pre-illness identity developed into another identity as a result of illness and that a second transformation takes place after their immediate sense of danger is over. In other words, they have an initial sense of self, then a sense of self associated with their illness and a third sense of self which is distinct from their original sense of identity. This reasoning shares elements of Bloch's theory of 'rebounding violence', which he explains as the response provoked in individuals by undergoing certain rituals which change them from fulfilling the role of victim to that of vanquisher, or from 'prey into hunter'. In other words, the power gained by the people in this situation through an encounter with some transcendent dimension precipitates a desire to change others and a biblical example is given in Abraham's willingness to sacrifice his son, where his submission to God's will 'was followed by a return to a successful mastery of the world, in this case through a most explicitly sanctified productivity' (Bloch 1992:2,93). Therefore, although the experience of the subjects in relation to facing

a life-threatening illness would not have been chosen by them, they do express that they feel they have benefited from it in terms of gaining inner strength and personal growth which enables them to regain an element of control over their individual situations .

The individual account as illness narrative

The creation of 'stories', which may take the form of individual accounts, has been endorsed as a legitimate and powerful research method, as it gives the author the chance to give insights to the reader into their experiences:

> Stories, when well crafted, are spurs to the imagination, and through our imaginative participation in the created words, empathetic forms of understanding are advanced (Koch 1998:1183).

The increasing amount of information available about various illnesses and treatments from a variety of sources, particularly in relation to chronic illness, has contributed to the questioning of medical authority (Bury 2001:269). As illness narratives constitute part of each of the individual accounts, one of the contributions they make to the research is to act as devices which can be used to challenge cultural meta-narratives (Sakalys 2000). The scientific meta-narrative which underpins the conventional medical model is challenged explicitly by six of the seven individual accounts. The perceived limits to what is available to the authors of the narratives from the conventional healthcare system is one of the reasons which leads them to seek help through the Northumberland Cancer Support Group (NCSG) and, thereby, become involved in the holistic health-movement.

Van der Molen (2000) analyses six illness narratives produced by three men and three women, between the ages of forty-five and sixty-five years, who each suffered from a different kind of cancer. Each person's brief was to 'tell the story of their cancer experience from the point when they felt their experiences began' (Van der Molen 2000:49). It was found that each narrative started with the description of the symptoms which had prompted the person to suspect that something was wrong. The time of diagnosis appeared to provide the most intense memories, but other events were not always clear, particularly in terms of chronological order. The participants identified that they were overwhelmed by some information, but not given enough in other areas. For example, comparatively more information was given before treatment than afterwards, when the authors felt they would have benefited by knowing what had happened to their bodies. Other strong themes which emerged from the narratives were the effects of altered body image and anxieties and fears associated with death and dying (Van der Molen 2000:49-53). All of these issues feature in the individual accounts which make up this case study.

This chapter has revisited background theory relevant to the research study and summarised the methodology associated with it. Additional theory has been presented in order to locate the NCSG as the case study central to the research process and to establish how the individual accounts are crucial in contributing to the analysis of the case study. The next chapter will present the individual accounts as phenomenological description as the first step in analysing them in relation to the case study.

Chapter 6

The Case Study: phenomenological description

Anna

This individual account involves a forty-nine year old woman who worked as a tracer, which she explains involves drawing up plans for building projects, before having children, when she became a housewife, and was diagnosed as having ovarian cancer in 1997. She shall be called 'Anna' for the purposes of this study.

Anna was screened and given prophylactic medication for breast cancer, as she has a strong family history of the condition and, consequently, she never expected to live until old age. When she reached the age of forty she thought that she may have escaped developing cancer, but she was diagnosed as having ovarian cancer at the age of forty-seven. Although she always thought that she would develop cancer, at diagnosis Anna admits to feeling angry:

> Initially I was disappointed for my family and children because I lost my relatives at an early age and don't want my children to go through this.

Anna mentions that she was angry at her diagnosis and when asked by her family and friends if she was angry at God, she replies that this was the case, but on reflection she realises that she was 'most angry with other people'. She acknowledges that this 'sounds horrible' but elaborates, saying:

> I resented people being well, and still do sometimes, because, without realising, people are always talking about the future.

She qualifies this frankness with: 'Not a very nice trait, but unfortunately I do do this.'

Anna underwent radical surgery, followed by a course of chemotherapy, a year after which she suffered a relapse in her condition. No treatment was offered on the NHS and she paid to have a course of chemotherapy in the private sector. The differing results she has had throughout her illness experience have been a source of great worry. For example, she describes her blood tests for the tumour marker as being:

> all over the place. Very low and very high, so I just don't know where I am. Worry is still always there, niggling away- the only way around it is to keep busy, pray a lot and have therapy sessions.

Anna feels that this situation is:

> very disconcerting and hard to handle mentally...The worst position to be in with illness is not knowing where you are.

Anna explains that she sleeps well at night, but the first thing she thinks of on waking is her illness: 'Sometimes I feel really bad about it and I usually pray and then I am asleep again'. Prior to this episode of serious illness she had been fairly well, suffering only from what she describes as 'women's' problems and troublesome pregnancies.

Anna states that she is glad the research study focuses spirituality, as she feels that it is her spirituality which has given her contentment throughout her illness:

> I was very pleased to find it (the research) was basically about spirituality and support with my illness (my cancer) as it is my spirituality that has given me most contentment and peace throughout my illness backed up with the support of the cancer support group.

Anna describes herself as a Church of England Christian. When asked what she understands by the terms 'spirituality' and 'well being' she replies that all she can do is say 'what it means for me', as, to her, it has to be an individual thing. Personally, she feels that she has 'always been spiritual in a Christian sense and it has brought me well being'. She demonstrates an acceptance of her lot when she says 'what will be will be. I am in God's hands'. Anna gives an example of what she believes the effects of spirituality feel like when she says:

> In a distressing situation turning to someone to talk through spirituality, then something happens (small or large) and not always immediately, the situation changes. It is as if the desperation is going to be taken care of by your letting it go. It always works. Spirituality gives the same feeling mentally as when you are on morphine, i.e. everything around you feels o.k.

Anna equates the power of spirituality with prayer and obviously sees prayer as one way in which access to spirituality can be gained. Although Anna feels that she

benefits from the support she receives from the support group she does wish that it had a more 'spiritual side'. She has experienced healing through the group, but remarks that it was 'spiritual rather than Christian'. However, she finds Reiki relaxing, as she likens the feeling it produces afterwards to 'walking on air'.

Anna makes references to information and knowledge relating to illness on several occasions. For example, her husband has a degree in medical physiology and has gathered information and statistics about cancer for and with her. She states that at diagnosis 'if I had the knowledge that I have now I would not be in this position' in that she was not screened for a specific tumour marker (CA125) which could have detected the cancer early. However, since she did not then know about it she feels that 'I will probably lose my life because nobody would screen me'. Anna acknowledges that the good thing to come out of this is that her daughter will now be screened regularly for ovarian cancer from her twenty-fifth birthday.

Anna strongly asserts that a person facing a life-threatening illness should be allowed hope when she says:

> the worst thing the medical profession can do is to take away hope and say 'that is that'- to me they have to keep giving you hope (even if it is a bit false) because then you don't lose the will to fight. The fight should only be over once we have decided to give up, not doctors...if a patient wants to fight they should be given every help possible.

Anna believes that she joined the Northumberland Cancer Support Group (NCSG) because she is 'that sort of person'. She states that she felt isolated following her diagnosis and wanted to meet people in a similar position. These feelings of isolation surprised her since she had grown up with 'cancer all around' her but she still felt that she was 'the only one in the world with it' at diagnosis. She says that her husband does not understand her need to seek support outside the family and asks 'Am I not enough for you?' He expresses cynicism about the group but does not object to Anna taking part in it.

Holism to Anna means that individual needs are met through a caring environment: 'Whatever the individual needs, the group will try to meet them'. She knew what some of the therapies available at the group involved before she joined and found the additional therapies a bonus. She has tried many therapies, which she describes as relaxing and which give a 'feeling of well being' which lasts for a day or two afterwards. During the therapies Anna says that she talks to god, which she feels helps to calm her mind whilst the therapy calms her body.

Anna finds the questions about death the most difficult to answer because they bring back:

> All the bad memories of the deaths of people close to me, so in turn that worries me about my death and the suffering it will have (sic) on the people left behind close to me.

The realisation that her illness is life-threatening is summed up in her saying: 'I know I'm not going to reach old age' and her situation has, therefore, made her 'look at life and death more closely and immediately'. She has never felt that she can look forward to the future and says 'I don't think beyond tomorrow. I always was a bit like that'.

However, it is not death that Anna fears, but the way in which she may die: 'I'm worried about a possible horrible end. I'm frightened of pain and other symptoms'. When asked about her beliefs concerning life after death she asserts that she does not know, as there 'is no proof of anything'. However, as a Christian she knows what she is 'supposed to believe' and personally feels that there 'has to be something', but not Hell and damnation, as she feels that 'This is Hell- what we are going through now'. Anna feels that 'it doesn't matter if there isn't anything and great if there is'.

Beatrice

The second individual account focuses on a woman who was diagnosed as having breast cancer in 1998 when she was fifty-three years old. Her breast cancer was detected on a routine mammogram. When she walks home after being given her diagnosis, she thinks, 'Yesterday I was a healthy person and today I am about to die', which indicates that she feels an extreme change has taken place in how she perceives her health status before and after being given the diagnosis. Following a mastectomy, Beatrice stayed in hospital for five days and was offered an adjuvant course of cytotoxic chemotherapy. Beatrice's first language is Polish and, although

she does demonstrate a good command of the English language, her word order and expressions sometimes sound a little odd.

Beatrice states that she is trying to find out lots of information relating to her illness:

> I had read lots on my condition after diagnosis. I asked a lot of questions about chemotherapy etc- we have two shelves of books now on cancer...I'm trying to regain control over the illness and my life.

Having worked as a freelance interpreter for 'vulnerable' people in hospitals, she feels that she is no longer overawed by the hospital environment and states that:

> With hospitals it's like with car mechanics- the more you know the more they tell you.

Beatrice expresses displeasure at having to 'visit doctors all the time' and says: 'I hate being a patient', because she feels that control is taken away from her in relation to her illness. She gives details of a particularly bad consultation she has with a gynaecologist, to assess her continence problem, whom she describes as 'all knowing and patronising'. In response to his advice that she should not question everything, she states:

How can I not? I reply I have two degrees which taught me to question things. I am not going to stop now. He does not even shake hands or say goodbye. I may have given him inaccurate answers as a result of his manner.

Beatrice describes her treatment options as an 'insoluble dilemma' when she states that she 'secretly' wishes that she had not had cytotoxic chemotherapy, because she does not like to expose her body to chemicals. However, she feels that she had no choice, because the cancer may have spread had she not had it.

Two theories concerning the cause of her cancer are put forward by Beatrice, which are taking Hormone Replacement Therapy (HRT) and experiencing stress. With respect to HRT she states:

I believe it was the first three months of high oestrogen pills which started the whole process just days after going on pills (sic).

Beatrice continues to endure physical problems, such as lymphoedema and continence problems, even though her treatment for cancer has been completed. Although she says 'On the whole my body feels o.k.' she makes several references to physical symptoms and worries that she thinks may indicate a new tumour or a new tumour site. Examples of such references include:

I do not like right leg swelling above ankles- I wonder if it is related to cancer. After massage I pray it will go away.

I do wonder where my cancer is now- has it really gone or is it simply hiding, waiting to strike again?

Now that her treatment is finished, Beatrice appears to feel that people think she is fine and do not, therefore, know how it affects her day to day. For example, she indicates that her energy levels are easily depleted and other people's problems 'impinge' on her 'stamina and well being'.

Beatrice identifies that it is hard to structure her days 'without the stimulus, and reward, of paid work' and feels that this causes continuous stress for her. However, due to her commitments and the pressures on her time, she finds it difficult to fit complementary therapies, such as practising the Alexander Technique, and other health-promoting behaviours, into her day.

The uncertainty she feels about the future also makes her feel that she cannot plan ahead as she would have previously. For example, she states:

Life is not really the same, life with cancer. It is sort of tentative, uncertain, unpredictible. Can't really plan ahead (sic)- yet it is wise to plan a little.

Doubts about the eventual outcome of her illness are also expressed when she is writing her journal on what she describes as a 'yummy, gorgeous day', observing:

171

Thoughts of last year drift in. I often sit here wondering how chemotherapy is going and what will happen next...It is hard to live not knowing whether there will be many more summers to come or not.

Beatrice identifies that she must make best use of her 'precious time' and declares that she intends to reduce stress in her life:

I have to take more care of myself and less of others. I think is a flaw in my character (sic), which perhaps allowed cancer to develop.

She identifies areas of her life where future stress needs to be reduced so that she can reduce its ill effects on her health and well being, such as being taken for granted by her family. Her family's expectations of her are exemplified through her reflections on a trip she makes, whilst keeping the journal, to see her pregnant daughter in Paris. Beatrice goes straight to the hospital to see her daughter, who has been admitted with toxemia, as soon as she arrives in Paris and is disappointed that neither her daughter nor son-in-law enquire how she (Beatrice) is. She is also disappointed that her daughter accepts an epidural for the delivery of her baby and beta-blockers to treat her high blood pressure. Beatrice finds it difficult to visit her daughter in hospital as she associates all hospitals, even maternity ones, with cancer.

Towards the end of her diary she feels that her resolution to be more assertive is starting to pay off, since her husband becomes more affectionate and understanding, which she calls a 'small miracle', and states:

But in the end it is good for me to be VISIBLE and not just 'nice'. I *do* matter'.

Due to suffering bereavements throughout her life, including the deaths of her mother and father, Beatrice has regularly thought about life, death and meaning. Her second husband gave her a book about death *(How we die)* when her father died and she states that 'I don't like this book since I was diagnosed'. Evidence that she associates having cancer with death is provided by her reference to Cardinal Hume's experience of cancer when she asks 'how long he had to live with a death sentence' (sic). She gets upset when people say 'but you're alright now' because she feels that 'you don't know if you'll ever be alright'. The deterioration in health of other members of the Support Group affect her.

I found it shocking that people's conditions changed in the group. I have seen other people die, that's what upsets me.

Beatrice does express a belief in the immortality of the soul, which she knows is what she should believe as a Roman Catholic:

At times of trouble I pray to my mother. I think the soul lives on 'somewhere'. I have to- I'm a Catholic.

Beatrice observes that 'I've always wanted to live for a hundred years for as long as I can remember'. She also appears to derive a great deal of pleasure from news of new life:

> Read my mail- fantastic news...babies everywhere...My illness is almost incidental in context.

Holism has interested Beatrice since the 1960s and she has read a lot about the subject, particularly in relation to childbearing and childbirth. She was given the number of the NCSG by her breast care nurse and was interested in joining the group, even though 'it was a bit far' from where she lives (approximately twenty miles). She attends group meetings as often as she can and has taken her husband and children to meetings with her.

Beatrice was initially skeptical about some of the treatments but now has them to help with various symptoms, such as a painful wrist and stress. For example, she has partaken of a creative writing course, aromatherapy massage, Reiki and the Alexander Technique (AT). Beatrice also takes vitamin C and vitamin B complex supplements daily. In addition, she eats a diet recommended by a Dutch biochemist, consisting mainly of fruit. Reiki helped her during cytotoxic chemotherapy:

> I experienced something even though I didn't know what it was- I wanted it regularly. I have taught myself the technique... I can feel the energy moving around.

Of all the complementary therapies she has tried, she appears to rely on the Alexander Technique to help her cope with stress day to day:

> Spent forty minutes allowing myself into now familiar Alexander supine position. No matter how busy I am or what pain I experience...after twenty minutes of AT I feel renewed, energised, happy to carry on hoping, living. I enjoy listening to music whilst doing Alexander- allowing the tiniest muscles in my body to stretch and to relax ...Decided to do AT twice each day- that means I spend minimum 1 ½ hours meditating and listening to my body (sic)...I can't do without it.

Beatrice believes that complementary therapies should be available to everyone so that each person can choose the right approach for them and values the fact that they are offered free of charge at the Support Group.

Beatrice summarises her beliefs in holism in the phrase: 'If the body is happy the spirit follows' and states that she feels she is a 'bad Catholic' as she only started to attend church regularly after her diagnosis and turns to God most in times of trouble. It is obvious that she gets a lot of strength and support from her faith and religious practices. For example, during a time of family troubles she says:

> I went to church hoping for a confession, but found out there was a lovely concert coming. So I went, prayed during it. Reacted to music, candlelight.

Beatrice's belief that suffering and endurance are part of Christian life is made explicit in her statement:

> Anger is bad for you spiritually. Coping with it is part of Christianity and helps me relieve the tension.

James

James is a sixty-nine year old man who was diagnosed as having prostate cancer in November 1996. As James had not considered that his symptoms may have been caused by anything as serious as cancer, his initial reaction to the diagnosis is one of numbness. However, when this has worn off James recognises that:

> being the type of person that I am my next thoughts were 'How long have I got? What can I do about it?

This led him to look around for a support group and from those available he felt that the NCSG would be best suited to his needs.

James reflects on the possible causes of his cancer and offers two possible theories. The first is a sustained greater than average alcohol consumption throughout his adult life and the second is stress. James attributes this stress to the facts that he and his wife lived with his in-laws for one year when he was a full time student, having left the RAF, and then working in a stressful lecturing job when he had completed his course.

The continual search for knowledge and answers and the exploration of possibilities for self-help have helped James to cope with his diagnosis:

> I feel much calmer now I've revived my determination and plan of attack. I feel that I am the key to my success or otherwise. The medics can only offer Zoladex or radiation. I don't want the latter.

Although he was initially devastated by his diagnosis of cancer, James states that he sees his illness as a challenge which has afforded him opportunities which he otherwise would not have had. For example he says, 'Thank you cancer, as through this I have developed my spirituality'.

James describes himself as 'affiliated to Church of England' but elaborates that he does not adhere to any formal religious practices. He explains that this is because he needs to have 'some intellectual proof and logical reasoning' to support his beliefs, which led him to decide that the established church is 'not for me'. However, James demonstrates an absolute belief in spiritual things, describing love as the 'central force' of spirituality. His spiritual beliefs reinforce his lack of interest in material things, in that he sees the body as a 'carcass in the earthly plain' and, therefore, unimportant in itself. His believes in the indestructibility of energy stating 'I believe our field of energy can go on when we throw away our carcass- or die'. This belief has enabled him to find 'great peace of mind' so that he is 'no longer afraid of death'.

James feels that the development of his spiritual side is attributable to his experiences as part of the NCSG:

> The atmosphere of the Group meetings was very strong, in a spiritual sense...The spiritual input really made me feel in control and at peace. I no longer feared death.

He also values the library at NCSG as he has discovered Quantum and nuclear energies theories which he finds to be:

> dead in line with theories of mystics from thousands of years ago. It all clicked mentally into place. I now fully understand the basis of life.

James defines spiritual well being as 'Achieving a harmony with the order of unseen things' and he has been involved in many activities which aim to promote this state. For example, he attended a course at the BCHC on spiritual healing and remarks that it 'changed my life', in that he has now become a spiritual healer. James feels that 'It's wonderful to be able to help others' and to pass on his knowledge to others. He has also undertaken a Reiki attunement session and benefits from group meditation at the NCSG. To summarise, James feels that:

> This constant seeking for greater experience must be developing my spiritual awareness and leading me to the pathway. *(To spiritual fulfilment).*

It is apparent even in everyday activities that James is aware of the potential contribution to his spiritual well being of health promoting activities. For example:

> I feel catharticised (sic) after exercise. My body feels purged, my mind alert, and I get a spiritual feeling which makes me feel wonderful. I feel I am keeping myself young.

However, unlike him, his wife and daughter have not yet 'awakened themselves spiritually', according to James, which is a source of regret to him as it 'does make for lonely travel' on his 'spiritual quest'.

Central to James' ideas related to holism are the theories of the New Physicists, which he sums up as: 'Life is energy and energy is life. Quantum energy makes up the Universe.' Holism is defined by James as the body, mind and spirit making up 'one unified whole' and, to him, holistic systems 'don't divorce the mind, body and spirit'. James sees nurses as the holistic link in care and states that engaging in the holistic movement has helped him to develop his female side, which he calls his 'yin' component.

As a practical example of the power of spiritual healing, James recounts that through spiritual healing he significantly reduces his PSA (Pituitary Specific Antigen) reading and his consultant is unable to see any other reason for this dramatic improvement. He thinks that this fact, in addition to him looking so well, gives 'credibility' to his work in spiritual healing. To James, the most important quality a healer should have is to be 'sensitive beyond normal'. He suggests the brain's

ability to produce peptides in response to spiritual healing and the beneficial physiological responses to meditation, such as lowered blood pressure and brainwaves, as reasons why physical improvements can be achieved through such holistic approaches. In addition, he mentions the beneficial effects of transcending the conscious world through spiritual healing which allows for healing to take place through 'harmonizing our mind and body and spirit'.

James has also used other complementary approaches to health promotion, such as reflexology (which resulted in an improvement in his urinary symptoms) and adhering to the BCHC diet. In summary, James sees holism as an overall system within which 'everyone helps', in that doctors give him the appropriate drugs, his family give him love and support, books give him knowledge and the NCSG aids him in his spiritual development.

James feels that counselling should be available 'immediately from diagnosis' to help the person cope with coming to terms with having a serious, life-threatening illness:

> I'm not fearful of death. It's just as well, because one is very much left to coming to terms with one's own cancer.

Thus, in James' case, it seems to be the dying process which concerns him, rather than death itself, as he again says: 'I'm not afraid of death anymore, I am afraid of the way I might die'. He mentions incontinence and pain as examples of symptoms which he particularly dreads.

James understands that his illness could result in premature death, but, having been told by his consultant that his cancer was a comparatively 'good' type, he was given hope that he would have time to find out what he could do to treat or contain it. Although James perceives medicine as positive in offering him the latest available drugs and treatments, on the negative side his consultant stresses that there is no outright cure and setbacks in treatment can occur. James feels that giving such information in a truthful but brutal way can be 'destructive mentally', which he sees as an example of the nocebo effect, to which he says thirty per cent of deaths in America can be attributed. On the other hand, dietary supplements and complementary therapies give hope to people and he cites spiritual healing as an example of this:

> As a healer I give hope to the people I serve...from which they begin to believe in their ability to heal themselves. In helping others in this way I feel I am also helping myself.

James elaborates on the positive effects of hope and the placebo effect related to complementary approaches to healing when he says: 'The effect is beyond belief. Specialists just ignore spontaneous remissions'. In contrast he believes that 'All drugs are toxic'.

James sums up his beliefs in what happens after death as being:

Difficult to answer in specific terms, but energy is indestructible, it can only change its form. People are full of electricity/life force energy. Because there are so many ordered structures in people (DNA etc) life cannot be random, therefore there must be a great power which started the world off and now has limited control. We can call on the energies of the Universe to help ourselves in various ways. We have to, after death, go on in terms of energy. I can see a vague link to notions of reincarnation. Nothing is absolute- everything is grey. Everything is possible.

James demonstrates feelings of anxiety at having to wait six months to see his specialist, which is made worse by his sometimes only seeing a junior doctor who does not know his case when his appointment comes around. He lacks confidence in his General Practitioner's knowledge of his condition, as he is not a specialist. Therefore, he states:

I feel I have to look after myself. I rely upon my positive attitude, meditation, exercise and love from my family.

This helps him, as he can only 'chug along' between appointments. In addition, he feels that people do not take the trouble to find out what he is really thinking and feeling, as they accept his 'normal, carefree and joyous' expression and attitude at face value.

Waiting for the results of blood tests for PSA is identified as a particular source of stress for James, which he describes as: 'Time stands still. It must be on a par with

waiting for the jury's verdict'. James also finds it difficult to cope with any fluctuation in his urinary symptoms as he worries that they may be a sign that his drug therapy is losing its effectiveness or his tumour is growing. Although he does have times when he feels negative about the outcome of his illness, he is careful to check such thoughts as: '...this is the start of depression, which inhibits the immune system'. James summarises being affected directly by life-threatening illness as living 'with a time bomb'.

At diagnosis James is told that with drug therapy he may live for five to ten years and that radiotherapy may be an option for the future. The only other advice he receives during this encounter is, 'If you need counselling see your doctor or Macmillan nurse'. During subsequent consultations, the consultant expresses skepticism about the advice and treatments offered by James' healers and therapists. James concludes that the consultant: 'is a good man, just overly reliant on science. If it's not scientifically proven he doesn't want to know'. Of doctors themselves he argues, 'They are also specialists and do not take into account the unity of the mind, body and spirit'. He also includes an anecdote about a consultant at a conference who was 'rubbishing' complementary therapies, saying that if they couldn't be scientifically proven they couldn't be accepted. James asked him if he believed in love, to which he replied 'yes'. James countered, 'show me the research'.

James' urinary symptoms and pain from osteoarthritis have a negative effect on his quality of life. A short remark from James reflects a profound source of concern to him as he lives with his illness. That is: 'I don't want to feel old. It takes my

enthusiasm for life away'. However, when symptom-free he can enjoy his retirement and partakes in golf, squash, going to the gym, playing the guitar and writing poetry. To promote his capacity to enjoy life James endeavours to 'try to keep peaceful and calm'

Mary

This individual account is based upon the experiences of a fifty-one year old woman who was diagnosed as having lung cancer in 1993 and adrenal gland cancer in 1995, which were both part of her overall diagnosis of 'multiple primary tumours', the positive side of which, she was told, is that metastases ('secondaries') are unlikely to develop. Mary describes the period of time surrounding her first diagnosis as consisting of a 'stream of visits to the hospital for tests and scans and biopsies'. However, she describes her state of mind at the time as 'calm', as she perceived her illness as 'a nuisance' rather than 'devastating'. At her second diagnosis her overall feeling was of 'not again', but she did not think that her life was in any immediate danger, as she had faith in the available medical treatments.

At the time of her operations Mary has worries that her husband will find her unattractive as a result of her scars. However, she remarks on another occasion that she sees her scars as her 'war wounds' and that sometimes she feels proud of them. After her first operation it takes Mary eight months to feel better and after her second she does not feel well for approximately one year, during which time she feels as if she has 'flu. Even now, she feels that people do not realise the effects her surgery has had on her:

I wish I could get people to understand that I'm not physically strong to do what I used to. I don't think they understand the extent of my surgery...They seem to think I'm tired because of my age.

An example she gives of a long-term symptom of her cancer treatment is breathlessness on slight exertion as she had one of her lungs removed.

Mary appears to have a significant amount of unresolved negative feelings about her illness and the lack of external signs of what she has been through, stating:

> Today I think about my cancer and the awful ops (sic). This is said IN CONFIDENCE TO THE WHOLE WORLD but most women seem to have breast cancer and they have some chemotherapy or radiotherapy and seem to recover so quickly- shopping within one week of op (sic). I feel bad having to think like this. Perhaps they think I had it easy.

Mary identifies the lack of counselling at diagnosis and throughout her illness experience as the cause of her continuing negative feelings. For example, she refers to an occasion when a specialist nurse in lung cancer gave a talk at the support group, saying:

> I'm always afraid I say too much and people think I'm a hypochondriac...but I never really talked about my illness. I would have liked counselling. I think in situations like this I let off steam.

Mary feels that she has suffered from emotional and psychological stress since her first diagnosis and is continually frustrated by her inability to be as active as she was before her initial operation. This stress leads her to say 'I make a fuss over silly, trivial things', although she feels that she copes well in the face of more serious problems.

Mary was employed as a secretary in the past but has now not worked for several years and enjoys being the secretary of the Support Group. Her reason for taking on the role is that she misses working, which is also expressed when she says 'I wish I could work. I'd love to have a job again'.

On her return from a holiday in a friend's cottage with her husband Mary indicates that she associates being at home with her illness experience when she says:

> Today we came home and it is good to see the girls (her daughters), but I cannot understand that when I am away I do not think of my illness.

Mary indicates that she values her family, animals and friends and that, in relation to what life means to her, she does not look further than that. When she was first ill she thought from time to time that if she died 'everybody else would enjoy themselves' when she had gone. Her response to being asked what she thinks happens after death elicits this response:

> I don't know...I don't really believe that we go to heaven...something does happen but I don't know what.

She also has doubts about human beings having a soul and what happens to it after death, asking 'When does the soul leave the body? When we die, at the funeral, when the body is committed?'

Mary states that she has never given her spiritual beliefs a lot of thought. She describes her religious denomination as 'loosely' Church of England, but she is not a practising Christian. She feels that she does not have time to think about religious or spiritual issues. Mary did not know about the holistic philosophy until she joined the NCSG, stating that 'I just joined the group for support'. She had tried two other support groups which had been recommended to her by her Macmillan nurse, but they seemed to be more suited to bereaved people. She was visited by a member of the NCSG after her first operation and after that attended the group regularly. Now she is a member of the NCSG Committee and feels that she gets most out of the group in terms of love and support.

In her case, the cues for the use of complementary therapies came 'purely from the group' and she elaborates that 'I do not believe in some of the treatments, but would not force this view on others'. Mary has tried aromatherapy and reflexology, which she enjoyed, but she does not see them in terms of healing, rather as relaxation treatments which lead to physical well being. She also values the 'one to one' nature of the treatments. However, Mary believes that therapies which involve touch, such as reflexology, would have irritated her when she felt unwell, stressed or in pain. She does not feel comfortable with spiritual healing but finds Reiki relaxing and feels that the therapist also benefits from treating other people.

Susan

Susan was diagnosed as having breast cancer approximately one year before she became involved in the research, when she was forty-eight years old and underwent a mastectomy and removal of lymph nodes. She states that she felt as if she had been 'spun into another world' at diagnosis and:

> as if everything was far away...like being in a vacuum...I was frightened, then sad, then really angry. Angry at myself for not being more assertive with doctors when I first began to feel unwell.

In the period between receiving her diagnosis and having the tumour removed, Susan experiences some very negative feelings about what is happening in her body and the effect her illness is having on her family:

> I began to feel unclean knowing there was an uncontrollable tumour growing in my breast. I felt ashamed, and felt not only that I had been let down but that I had let my husband and family down. I felt a great need to express how sorry I was to them for inflicting this upon their lives and a feeling of guilt set in. I wanted this uncontrollable thing out of my body as soon as possible. It made me very nervous and afraid.

Susan did not tell her family of her diagnosis for two weeks after she received it, as she felt that it was never the right moment, and says that at this time she knew what it was to be lonely. She continues to say:

It doesn't matter how much love and support there is, it is a journey you have to take on your own. Sometimes I would prefer to be on my own than with sympathetic people...It is very difficult to carry on as normal when someone keeps looking at you with every expression of their face portraying sympathy.

She also feels responsible for the worry which her family experience as the result of her illness and explains that she ends up supporting her family, and in particular her husband, rather than receiving support from them:

this is not helpful at all because it makes me feel guilty for having had the disease, for the disruption I have caused in so many other people's lives, guilty because I keep having scares after the treatment etc. etc.

Susan feels that her family would like things to be the way they were prior to her illness, but she knows that this is not possible and welcomes the change:

I don't want things to be as they were, I feel the need for change, this is something I think my husband finds hard to accept.

Susan has always believed in God and prays weekly ('like talking, not asking for things') and finds comfort in her belief in god. Compared with what the support group has to offer, Susan feels that conventional religion is very limited. For

example, through the group she has been made aware of a variety of approaches to addressing spiritual needs, such as Buddhist meditation and Hari Krishna chanting.

Since her diagnosis Susan has had one or two new symptoms which could have indicated a return of her cancer. She says at such times that 'I felt as if I was in prison waiting for a sentence' and that, even when her results are normal, that it can take her months 'to get back up to the psychological strength prior to the shock'. After finding a lump under her arm, which turns out to be a false alarm, Susan remarks that she finds it very difficult to remain positive about the future at such times of uncertainty:

> When things are going smooth (sic) it is reasonably easy to be positive but the moment there is the slightest doubt it is easy to fall into the depths of despair and see only the negative side of everything.

Susan's worries about her body image start before her operation and she states:

> My head was full of what would never be again. How would I look at myself with one breast? How would my husband look at me with one breast...would he look at me again undressed? Would he want to look at me? How will he feel touching me?

After her operation Susan feels relieved that the 'uncontrollable growth' has gone, but still 'cried like a baby' at her loss:

I knew I had lost something very dear to me, a part of my body which I liked very much. I then started feeling guilty forever wanting it removed.

Susan agrees to look at her scar two days after her operation and a male nurse helps her to remove the dressing after her shower:

> It was quite an ordeal, but not as bad as I had thought it would be...Whilst I was looking at the void in my body I kept looking at his face and eyes for any tell-tale signs of disgust, revulsion, dislike etc. but saw only care and compassion from the young male nurse.

Susan applies a holistic philosophy to all aspects of her life and interprets many and varied phenomena in a spiritual and holistic way. For example, she sits in the garden watching a bird which is singing and comments:

> I sat and watched and listened to that little bird with wonder and amazement. Not that I haven't heard a bird sing before...but today it seemed special, it was as if it was trying to tell me something so I sat quietly and listened to what it had to say...I thought the little bird would burst if it did not stop singing its song. As I watched and listened it became apparent to me that this small bird was alive and pleased to be so...It helped me to realise that the present is the most important part of our lives.

In addition, Susan reveals that she gets more strength and support from her two year old grandson than from anyone else, as he has taught her 'the meaning of

living in the moment' and 'not to live each day as if it was my last but to live everyday as if it were my first'.

Summarising why she sought help from a support group she says: 'I had been looking for extra help because hospitals don't give any hope'. Susan also experiences stress as a result of what she describes as fighting for financial benefits and she feels that this has a negative effect on her spirits and that this compounds the other stresses related to living with a life-threatening illness. She feels that at the support group she is treated like a person, not as a patient and therefore:

> you can discuss how you feel, see how others react, feel safe; it's like a family and you can behave how you feel and be honest.

Susan values the fact that 'The Group doesn't stand still', in that there is a constant exchange of ideas by the members and she enjoys mixing with such positive people. She believes that the many activities and therapies available through the Support Group are beneficial to herself and others, particularly as they are provided free of charge. Susan has also searched for information about her illness and possibilities for support on the Internet and in journals and books, as she feels that hospitals do not help to 'enhance your prospects'. She summarises her approach to her situation as follows:

> I try very hard to help myself and not rely on other people and feel I have lots of things in place which I have researched and sorted out for myself to give me support. A few of these are diet, vitamins, minerals , herbs, yoga.

Tai Chi, meditation, Reiki, visualisation, doing more creative activities...the Support Group, Iscador, Tamoxifen and the list goes on.

Susan particularly appreciates the one-to-one therapies she has received at the Support Group, such as Reflexology and aromatherapy:

At first it was lovely to have a caring unpaid person to spend time with me and to touch me. All therapies I have tried to date have been helpful in some way to my psychological needs.

Visits to the Krishna temple are referred to several times by Susan, and she states after one visit:

I felt as if I could move a mountain. The Krishna temple and devotees never fail to inspire me. It was wonderful and once again I felt so energised I couldn't believe it...I do hope the effects of this boundless energy stay with me.

Susan finds that people talk more openly to her about God and religion since her diagnosis and says:

it is amazing how all of a sudden people want to talk to me about God, giving me their theories and asking mine. I don't mind this type of conversation at all, in fact I welcome it, because I still have a lot of unanswered questions.

In her search for answers to questions such as 'Who am I?' and 'What am I here for?' Susan has read lots of books about spirituality.

Rachel

Rachel is a fifty-one year old woman who was given a diagnosis of breast cancer when she was forty-eight years old. Her breast lump was detected by a practice nurse during a well woman check and resulted in Rachel undergoing a mastectomy and a course of chemotherapy. She previously worked as a university lecturer and now works part-time as a personal tutor.

She describes her reactions and the process she went through as 'stages' of her illness and presents them as a list:

I can't believe that this is happening to me. It felt like having a lead weight inside.

Half of you is angry and half of you vulnerable. One writer said that cancer patients are hopeless and helpless.

(Referring to the differences between the concepts of curing and healing): this is where the spiritual quest comes in.

When the cancer moved to the bone- preparing myself spiritually for the next stage.

Able to distance myself from it: where I am now.

Two years after her diagnosis a bone scan identified bony metastases and at her review it was found that the metastases had shrunk significantly, but Rachel is unsure whether to attribute this improvement to her conventional or non-conventional treatments:

> One or all of them might have contributed to my survival so far, so the first dilemma arises, as one does not know any test results from complementary therapies...one is working blind and can't drop any of them as the one dropped might be the one keeping me alive.

Rachel believes that there is a link between the way in which a diagnosis is given and a person's prognosis. She states that a diagnosis which is given in a tactless or blunt way 'can condemn some people to death', which she compares to 'pointing the bone by the witch doctor' which occurs in other cultures. She feels that the medical model is not sufficient to address all of her needs and so seeks other approaches with which to complement it:

> I researched the subject and had less faith in doctors, as when you know about statistics etc. you can't fool yourself about the prognosis.

After diagnosis, Rachel went to the Bristol Cancer Help Centre (BCHC) to find out about the 'cancer diet', but was surprised at how many other options were offered, as she says:

> I was introduced to the world of holistic care and the variety of treatments and approaches available'.

It was at Bristol she found out about the NCSG and she has attended weekly for the last two and a half years, of which she says that 'it offered me hope and kept me going'. In addition, she feels that being involved in the support group helps her to cope more effectively with stress.

Rachel gives a clear definition of how she perceives holism when she says that the word:

> means the whole- it comes from the same word as heal. It means keeping things in and trying to get balance, i.e. balance of mind, body and spirit. Emotions affect the equilibrium- everyday hurts put you out of balance, therefore it is a huge job to stay in balance. Holism draws on the Eastern view of illness. Holistic care keeps you well.

She says of holistic care that it helps to keep her 'focused on something other than imminent mortality' and, therefore, gives her hope. Rachel is also a spiritual healer, in that she practises the laying on of hands and Reiki. She appears to benefit from helping others, and she explains that she believes this is one way in

which she can pay back the help she has received. This is one example which she gives of good things which have come from her having cancer. However, Rachel asserts that she would love to see a cure for cancer and demonstrates the dilemma she feels exists for her between what living with cancer has taught her and what she really craves saying:

> It's time this thing was tackled with more money by the country. Complementary therapies are useful and give one some control and input into doing something to try to help one's survival chances, but it would really be great to have something that was proven to mitigate or cure this terrible disease. It hits so many people at a young age and whilst I feel better and grateful even for the opportunity cancer thrust at me to learn these things- yoga, Tai Chi, Reiki, a spiritual path- nevertheless, the chance of survival to pursue such things is what I ultimately seek, as does everyone who uses complementary therapies.

Rachel gives a substantial list of treatments and approaches she has tried since joining the support group, including aromatherapy, homeopathy, Reiki, spiritual healing, past life regression, kinesiology, counselling, dream interpretation and Iscador injections. Homeopathy is the approach she uses to the greatest extent and she has a close relationship with her homeopath, whom she calls her 'homeopathic doctor'. She sums up her approach to treatments when she states, 'If I can afford it I'll try it, if it's not harmful'. Rachel demonstrates a great interest in the role of crystals in healing but cites the cost of the courses (£440) as a barrier to finding out more.

Rachel describes herself as an Anglican and a 'committed Christian' and elaborates on this subject, saying:

> Before I contracted cancer I was what I now call a 'passive' Christian, now I am an active one and my faith helps. As I live alone, there are times when there is no one to talk to when I am frightened about dying or the cancer: and then I need God. ...there are times when I cannot cope on my own and he is there. I feel almost a physical presence when I need it- like someone putting their arms around me for comfort.

Rachel also has very clear ideas about what constitutes spiritual well being, defining it as:

> A goal...the further you get along the path you realise that it is a huge achievement. As it cannot usually be possible in one lifetime, perhaps reincarnation exists. The journey to spiritual well being may continue in the afterlife along a continuum...People may have a simple faith through which they attain spiritual well being without realising it.

Rachel owns two houses which she rents to university students and she makes several, lengthy references to the amount of time she devotes to these students and the profound stress she experiences as a result of her confrontational relationship with them. Rachel resents this stress as she associates it with a deterioration in her physical and psychological well being. For instance, she gives

an example of how her dealings with the students interferes with her health promoting activities:

> I am worn out and very stressed. Left alone I try to meditate and do my Reiki, but it's no use, the house is cold and unwelcoming and I give it up... I am supposed to have regular meals and no stress, both of which have gone by the board today... Before I'd have gone in all guns blazing on my own behalf, but years on and aware of the dangers of stress, I do not. Aggression is as bad as stress and financial worry and I know it is this sort of thing that can trigger off the cancer... Spend a miserable day which puts me off making the sort of food I should be eating.

Rachel indicates that her family now think she should get on with her life and put her illness behind her, citing an occasion when her sister was busy when she was trying to arrange something with her:

> I love my family very much and in the past I, like them, was always busy. The trouble is, for them there is a tomorrow when they can do things, there may not be a tomorrow when they can see me... as it is three and a half years since I was diagnosed and I seem well to them (they don't see me enough to see some days I'm so tired and off colour that I do nothing but lay on the settee) and cheerful... so they think everything is o.k. and they sometimes put the terminality of my life away from them. If the doctors said tomorrow that I'd be dead in three weeks' time, I know they'd drop everything and stay with me, but that doesn't help now...I want and need to

put everything I would have put in a life of eighty-odd years into one of fifty plus, and that includes time and relationships.

Rachel believes the theory that certain personality types are prone to developing cancer, describing her predisposing personality trait as her 'capacity to be easily hurt'.

Rachel's illness experience has necessitated major changes in her lifestyle and this is highlighted in a meeting she describes with a friend who is now in a similar position to Rachel before her diagnosis:

> there she is, healthy (or as healthy as anyone knows...), earning very good money and with a good career- that was me before I was diagnosed with this dreadful disease...I still get a lot out of life, but in a different way now, and even when I've had a very enjoyable day, or done something fulfilling, or both, there is always the shadow of this rotten disease dogging me, waiting for me, the minute life becomes quiet again.

Rachel states that she wants to survive her illness, but she has 'made provision' in case she does not. Rachel believes that 'what is to come' is better than this life, but she still describes life as 'precious'.

It is apparent that Rachel has read extensively about reincarnation and out of body experiences before her diagnosis, but now her need for the belief that life continues in some form after death is greater:

Now I need the reassurance that there is something after death. A religious faith and assurances of an afterlife, be it Doris Stokes or St. Paul, I think are probably as important to me from the point of view of hope and help with the psychological suffering being terminally ill brings as the complementary therapies themselves. Before, death was something I could put on the back boiler for thirty years.

She sees the effects of death as 'damaging' to the lives of those left behind and believes that when somebody dies 'it makes everyone think what is life about/what are we doing here?' However, it seems that Rachel fears dying more than death itself, in that she states she particularly fears 'a loss of consciousness', the 'pain' and the 'way of dying'.

Gill

Gill is a thirty-year-old PhD student (Medieval studies) caring for her mother, who was diagnosed as having colorectal cancer two years prior to her taking part in the research, when she was sixty-four years old. Gill and her mother are very close as her father died suddenly when she was eighteen years old and she has no brothers or sisters. The researcher never met Gill's mother, who will be called Linda for the purposes of this study.

Linda was admitted to the local District General Hospital for tests having consulted her General Practitioner about her diarrhoea. Initially, staff thought that Linda may

have had constipation as they said her x-ray showed a 'bit of something' and that the diarrhoea was 'overflow'. However, when Gill returned to the hospital the next day she found that the attitude of the staff had changed markedly since the day before:

> I would definitely say the nightmare began for real this day- nurses who'd been chatty the previous night weren't readily available and nobody seemed able or willing to answer my questions about mum's condition.

One junior doctor told Gill that her mother had a 'blockage' and 'narrowing' of her bowel and mentioned the possibility that it was a colorectal tumour. Gill asked her what she meant by that, but the doctor refused to go into any detail saying 'I'm not getting into that'. Another junior doctor told Gill that her mother probably had a malignant tumour, drew her a diagram and said that this could not be confirmed until an operation had been performed. Gill made it clear that Linda was not to be told of these suspicions until after her surgery:

> I didn't want mum to enter the theatre with that knowledge. I knew she would never suspect it was cancer and would be better off not knowing until she had to.

Therefore, Linda was told that she would be having 'exploratory surgery' to determine the cause of her symptoms. She was very nervous at the prospect of this, but managed to remain in fairly good spirits. However, a number of people involved in Linda's care made it clear to Gill that they thought her mother should be told

the truth about her suspected condition. In response to all of the advice she received with respect to being honest with her mother, Gill states that she intended to be honest with her but felt that the time for giving her this information 'had to be when the diagnosis was properly established' postoperatively. Postoperatively, Linda said that she was glad that she had not known of the doctors' suspicions before her operation as she could not have been as calm. Gill feels that this is justification of her determination to keep the truth from her mother. The staff said that they were finding it a strain not being able to be totally honest with Linda and Gill suggested that carrying out the operation on time would have been a remedy for this and goes on to explain:

> Their alleged strain was of little consequence to me: what I wanted to do was to protect mum. She was my priority and I was not going to do anything to undermine her.

Linda's operation was delayed due to the operating list being lost and Gill was reassured by staff that delays at this stage would not make a difference to the outcome of her mother's illness. Further delay was caused due to out of hours emergency cover and a senior House Officer spoke to Gill about this and took this opportunity to ask Gill to reduce the number of family friends who were ringing the ward to ask how Linda was, as it was blocking the line for others to get through to the ward. The doctor illustrates his point by saying that when his father was in hospital recently he tried not to call the ward for this reason. Gill asks him why his father had been in hospital:

He thought I was softening at last, so told me he was having a bunion treated. I told him he wasn't comparing like with like and how dare he try to draw a parallel between our situations. I also asked if his father had had his operation on the date and time scheduled and he had to admit he had. He ended up looking rather silly and started to say he wasn't actually part of the surgical team, but had just been asked to step in and have a word. I said it was a pity they couldn't find someone relevant for me to speak to.

Following this, the staff became 'extremely cold' but 'superficially civil'.

Gill and her mother were then told that the procedure would be delayed for a further two days due to them having reached a weekend. Although this reduced her mother's anxiety about the immediate future, Gill explains that the extension of the wait was a great strain for them:

She was hungry, tired and fearful. I was going up the wall with stress... The hospital's lack of action added to the unreal, nightmare aspect of it all.

At this time, Gill feels as if they are 'living intensely' whilst living in a 'strange out of kilter world, out of step with normal reality':

It was strange thinking that just the previous week we'd been doing our normal, everyday stuff, then suddenly we were pitched into this horrible world... Being suddenly confronted with a life-threatening illness makes

everything spiral out of control really horribly and this is compounded by the unyielding, monolithic hospital system.

Aspects of the hospital environment also had a major physical effect on them:

> It also felt like our senses were continually being assaulted by continual yellow, sharp strip lighting; the noise of the buzzers and a patient's shrieking; the smell of over-boiled food, disinfectant and very unhygienic loos.

As the operation had been rearranged for Monday, Gill went home on Saturday night and had not planned to be in until late on Sunday morning. However, a nurse telephoned her on the Sunday morning and told her 'kindly and perceptively' not to panic and that her mother was going to theatre. Her mother also spoke to her and said that she was calm and ready to have the surgery. Gill expresses regret that she could not be with Linda at this time:

> It was unbelievable that after all these long days and nights by her bedside they were taking her down the one time we were apart... During the time mum was in theatre I sat under a hawthorn hedge outside and cried and prayed and held dad's watch... It rained constantly: I've never minded the rain before, but I still don't like it if it rains on a Sunday morning, as it momentarily transports me back to that day... I just wanted to be with mum.

It had been originally planned that Linda would spend some time immediately postoperatively in the High Dependency Unit, but she actually returned straight to the ward from the operating theatre. When Gill arrived she was shocked by her mother's appearance and makes further comments concerning the poor standard of care she receives and their lack of privacy:

> she was wearing a mask with all sorts of drips and tubes attached to her... Visitors passing our ward were gaping at mum, as were several of the people in the ward itself... the lack of organisation, foresight and consideration and basic care skills on the part of the staff impeded mum's well being.

One nurse always allowed Gill to stay whilst she carried out her mother's care, for example when she changed dressings, which prompts Gill to comment that:

> I would far rather that all the staff had been as emotionally honest and accepting of my presence as Deborah with the exposure to the blood and rawness of it, as uncooperative and cold as the rest of them, even if this kind of relationship does establish more distance between the carer and the gory, messy side.

Following Linda's surgery it took two weeks for the results of tissue samples to come back, which confirmed the diagnosis of cancer. Gill insisted that her mother was not told of her diagnosis until these results were obtained and she 'hand-picked' the staff who would be present when she was told, so that the information would be given in the most positive way possible. When her diagnosis was explained

to her Linda was 'emotional but not hysterical' and, as previously mentioned, said that she was grateful not to have known of the doctors' suspicions preoperatively, as she would have been very anxious.

Gill identifies that, in contrast with the staff on the surgical ward, the Chemotherapy Day Unit staff were 'really nice'. The oncologist and two nurses in particular were involved in Linda's care throughout her six months of treatment with 'mild' cytotoxic chemotherapy, which did not result in any particular side effects for her. Gill was anxious throughout this time, for example about the results of blood tests, stating that 'you never feel out of the woods'.

Gill defines holism as 'looking at a person on a variety of levels- psychological, emotional, spiritual. It is an approach to life, not just healing'. She found out about the NCSG from a dossier of healing groups in the waiting room at the local hospital. Gill and Linda knew what they wanted from the group before they joined, as they both already had a keen interest in holism. For example, Gill had suffered from chemical allergies, due to an immune system disorder, as a child and her mother had taken her for various treatments, including homeopathy. In addition, Gill admits that it would have been difficult to afford therapies outside the support group.

Gill has experienced foot massages, aromatherapy, AT, Indian hand massage, Reiki and reflexology. Her mother has been given healing, aromatherapy, therapeutic homeopathic medicines and Reiki. Gill incorporates complementary therapies and approaches into her daily life, such as taking Bach flower remedies to promote well

being when she is not eating and burning lavender oil to reduce stress. Gill remarks that the ward staff had a 'seen it all before attitude' and made her feel as if she were 'clutching at straws' when she mentioned the BCHC.

Gill had felt bitter about her father dying and at the prospect of losing her mother as well. However, she put the idea that Linda's life was at risk to the back of her mind in order to support her mother through her operation, until she was told of her diagnosis. Gill comments on the 'mystique' which surrounds cancer and the way in which many people, including health care professionals, associate it with a 'death sentence'. She says that health care staff should know better in view of the fact that they see for themselves that this is so often not the case.

Gill describes her mother as an Irish Catholic and herself as a non-practising Roman Catholic, stating that they both have a strong interest in healing and spirituality. Gill believes that the energy involved in spiritual healing is 'divine and spiritual'. Since her father's death, Gill says that she has had a 'feeling of impending doom' and a fear of becoming an orphan. She felt very bitter for a while after his death because most of her friends still had both parents and siblings. Her definition of spiritual well being is:

> A sense of the presence of God and being able to cope well with what life throws at you. The ability to come to a place where you feel at ease with yourself.

Whilst in hospital, a friend offered to give spiritual healing to Linda. As Gill suspected the ward staff would have reservations about this taking place on the ward, she describes the healer as a 'minister of religion' and asks if they could have a private room where he could see her mother. She and her mother felt that this healing was very 'powerful and peaceful', despite the surroundings and Gill elaborates, saying 'The atmosphere did feel special, as if there was a comforting presence or several presences in the room'.

In this chapter the individual accounts have been presented in the form of phenomenological description and as the first stage of their analysis. Several themes are evident from these narratives and will be analysed in the next chapter.

Chapter 7

The case study: Overall analysis

Chapter six presented each of the narratives of the subjects as phenomenological description and this chapter will present further analysis by linking the individual accounts with related theory presented earlier. As stated in chapter one, the researcher made every attempt to achieve phenomenological reduction by presenting the data as provided by the research participants and allowing essential features, and associated themes, of their experience to emerge directly from the individual accounts. The themes were identified in the context of considering the seven individual narratives as a whole and establishing common features and some differences. The NCSG will be presented as the case study as the group is the link between broader discussions of related theory and philosophy and the embodied experiences of the group members. The individual accounts which constitute the overall case study allow different realities to be revealed first hand and, when considered together, shared reality relating to the ways in which experience is interpreted.

The common essential features of the subjects' experience include perceptions of the NCSG as an environment for meaning making, perceptions of the preciousness of time and the all-encompassing nature of cancer. There is also a significant amount of material relating to the body and to issues associated with control, knowledge and power. With respect to those subjects directly affected by a diagnosis of life-threatening illness, a new loneliness clearly results from finding themselves in this situation and is associated with feelings of being out of step with those close to them in terms of living in the present whilst the latter are looking to

the future. It is also apparent from the individual accounts of this group that everyday activities and an endeavour to appear and to be treated as normal, in the sense of how they were before receiving their diagnoses, are important to them. Other related themes which emerge are the experience of powerful, negative emotions, such as anger and resentment, the latter focusing on people who are well and those who work in the established health care system. Each of these essential features will now be considered in turn in relation to data presented in the previous chapter.

Preciousness of time and life course

There is a strong sense from the individual accounts of what should happen when in terms of life course and how much life each person should get. For example chronological age is mentioned a lot, which links to notions of measuring how much life individuals get and feelings of being short-changed if some people do not get what they perceive to be enough. This links with Stanworth's research findings where the subjects reappraised their priorities when they knew they were dying and developed a new sense of the 'appropriateness of time, right times, wrong times' (2004:103). This reevaluation also involves the development of a temporal framework which is not synchronized with that of well people (Stanworth 2004:100), which links to Lawton's (2000) research involving hospice day unit members, as discussed in chapter two.

The majority of the subjects who took part in this research study display an awareness of the sense of the preciousness of time and the perceived anomalies relating to their situation and previously expected life course. For example, Anna

resents other people discussing their seemingly taken for granted future since, for her, the implicit aspects of ordinary life, such as planning ahead, seem to be lost in the explicit awareness she has of her own probable premature death and the limited time she feels she has left, which leads to her not thinking beyond the present. However, Anna acknowledges that her resentment of others is not a 'nice trait' and that it is something she thinks of only intermittently.

Even though we know we are mortal, the reality that our lifetime is limited is not normally made explicit within our society and does not seem to have been a major cause for concern to the subjects before they became ill, a phenomenon discussed in detail in chapter two and which will be further examined in relation to Beatrice. Anna gives the impression that she is withdrawing from life in the face of this awareness, which can be seen as the opposite of 'intensive living' in the face of death, as identified by Glaser and Strauss (1965:131). This withdrawal from life can be compared with the four life stages (*ashramas*) which are detailed in Hindu texts, each of which have distinct goals. The most significant stage for this comparison is the final stage of life and involves a full renunciation (*sannyasa*) of worldly things, including material possessions, the person's house and their spouse. Anna's withdrawal from life appears to be the result of much consideration and insight into her circumstances and it has taken a significant amount of time for her to come to this stage of awareness.

Since diagnosis Beatrice seems to have been living in the shadow of premature death and, like Anna, exhibits concern about her inability to plan ahead. For example, she refers to her 'precious time' and demonstrates a reluctance to waste

it, which can be interpreted as evidence of the phenomenon of 'intensive living', as indicated earlier in this section. In addition, her effort to spend time with her family and friends is also proof of her making the most of being alive.

As Susan says that she wants to make the most of any time she is now given, she can also be said to be displaying the phenomenon of 'intensive living' in the sense that she seeks quality of life experience, like Anna. For example, she appears to have slowed the pace of her life down in order to savour each moment and to appreciate fully the simple aspects of living in the present. She makes explicit that she now lives each day as if it were her first, rather than her last, which implies that she is making the most of her time rather than resenting its ebbing away from her. James' willingness to take part in research and to be involved in a variety of activities can also be interpreted as examples of this phenomenon, which Rachel's account also reveals by her attempt to pack as much experience and activities associated with healing as possible into her lifestyle. Linked to this heightened awareness of the preciousness of time and the related idea of life being of great value, Beatrice expresses pleasure when she receives news of babies being born, which represent new life.

The body

There is a variety of aspects to the material associated with the body as detailed in the individual accounts, including the body in history, which involves the family's predisposition to cancer, and is linked to theories of causality. The symptoms associated with cancer and its treatment are also relevant here as are the resultant changes to body image, feelings of being unattractive and an associated sense of

loss and changes to sense of self. As an extension of this, witnessing the deterioration of peers and witnessing other deaths are also relevant. The all encompassing nature of living with the effects of cancer, the new loneliness experienced by some subjects following diagnosis and the negative emotions expressed in association with this change in situation are also linked to embodied experience. The body is also seen as a container of or hiding place for cancer in this context. In terms of phenomenology, embodiment can be seen as the grounding of all perception, of the world and of reality, and this changes when embodiment changes, for example when illness is experienced, as discussed in relation to methodology.

Physical bodily symptoms are common to most of the subjects and have been presented as part of each individual account as examples of the phenomenological aspects of illness experience. For instance, Anna identifies that she suffers stress as a result of living with the uncertainty of her prognosis and the variability of her test results. She also finds the physical symptoms related to her ileostomy so intrusive that she is, at times, unable to concentrate on writing her journal. Beatrice makes constant references to symptoms which she fears may indicate a recurrence, such as lymphoedema and urinary symptoms. James's intermittent awareness of his body through his experience of urinary symptoms is another illustration of phenomena that can be interpreted through embodiment theory. In the same way, Mary's long-standing breathlessness following surgery to remove a lung can be seen in this context. Although Susan has worries about possible signs of recurrence, such as finding a lump under her arm, she is not troubled by symptoms or side effects of

treatment on a regular basis, but she does see her mastectomy scar as a reminder of her illness.

Beatrice attributes the cause of her cancer to looking after others at the expense of herself and believes that this self-neglect may have allowed cancer to develop. Taking Hormone Replacement Therapy (HRT) for a short time when she reached the menopause is also identified by her as a possible cause. Although, it is generally accepted in medical literature that breast cancer is hormonally related, HRT is only directly implicated when it is given in a high dosage and over a long period of time, when the increased risk is thought to be modest (McPherson 1992:109). Rachel assigns the cause of her cancer to her personality type and capacity to be easily hurt. She quotes that cancer patients have been described as 'hopeless and helpless' from *Getting Well Again* (Simonton et al 1980), one of the books held in the support group library. This refers to the theory that feelings of helplessness can result from continual encounters with situations over which individuals have no control, which has been shown in both animal and human studies (Ross 1994). In particular, Stroebe and Stroebe demonstrated this theory of 'learned helplessness' in humans through a major bereavement study (1987:69-70). As an extension of this theory, it is argued that the maintenance of hope is required in order to sustain control and maintain well being. Rachel expresses her belief in this reasoning when she states that when a diagnosis of life-threatening illness is given in a blunt way it may 'condemn some people to death'.

James relates the development of his cancer to a time of his life which was very stressful and tries to regain control of his situation by constantly seeking for more

knowledge about his condition and trying to maintain as much independence as possible.

Bodily changes and sense of self

The changes to her body image and outlook on life following diagnosis and treatment are the things which have the greatest effect on Susan. She is very frank about discussing the sexual side of her life and the sense she feels of being mutilated following her mastectomy is very powerful. It appears that her sense of identity and womanhood has been negatively affected by surgery, although she states that her husband does not find her any less attractive.

Mary appears to have joined the support group in order to meet people in a similar situation to herself, but she is bitter that people suffering from other cancers, such as breast cancer, get more attention and recognition than people in her situation. For example, she feels that breast cancer sufferers get more sympathy and this may account for her appreciation of her surgical scars, which she describes as her 'war wounds', since they are physical testimony to her physical illness. However, she expresses frustration at her symptoms, such as breathlessness, preventing her from getting on normally with life.

Beatrice's illness was discovered through screening as she had no symptoms and, because of this, she feels that she went from being 'healthy' to 'dying' in the time between having her mammography and receiving the results. This situation is only possible in societies where screening for abnormalities takes place, as in the majority of cases illness is recognised by the sufferer in the first instance and this

216

prompts them to seek help from the source they feel is most relevant. In addition, when cancer is detected without symptoms, it is the treatment of cancer which can be seen as the cause of problems to sufferers, rather than cancer itself, as expressed by Diamond (1998:115) who only feels he is experiencing cancer when enduring the side effects of radiotherapy.

Although most of the subjects believe that the holistic philosophy promotes health, they, including Beatrice, express disappointment that their families and friends do not give them sufficient attention once their initial treatment is over. Rachel expresses resentment at her family for not making enough time for her, stating that they should not spend so much time with other people who have more time at their disposal. Rachel does believe, however, that they would immediately see her if she had evidence of a recurrence, but is frustrated by their seeing her as being back to normal following her initial treatment. Unlike Rachel, Susan's family continue to be concerned about her although she seems to be clear from cancer, which is a source of stress for her, as she feels responsible for causing their concern. It seems that the subjects develop a self-identity after the initial stage of illness and treatment which is different from the self-identities they had before and immediately after diagnosis. It appears that their families and friends expect them to revert to their pre-illness sense of identity, as they do not perceive a significant outward change in them, which may contribute to the difficulty some subjects experience in adjusting to their pre-illness relationships.

New loneliness

The subjects appear to develop what can be described as a new loneliness as a result of being made explicitly aware of their potentially imminent death. This is revealed in references to conflict with family members over attending the support group and to changes in relationships following initial illness experience, as discussed in the previous section. In this context, the subjects seem to hold everyday aspects of life and mundane activities as having more importance than previously and want to be treated as before, perhaps in an attempt to regain closeness to their pre-illness sense of self and related relationships. Associated with this is the particpants' tendency to live in the present, rather than look to the future, which is uncertain for them. As discussed in chapter two, Bauman argues that human beings hide their own mortality from themselves as it is perceived as absurd in the context of their everyday lives (1992:15). However, receiving a diagnosis of a life-threatening illness breaks this illusion and appears to change the person's approach to life from what could be described as a naïve to a scrutinising approach.

James expresses regret that his family are not able to accompany him on his spiritual journey and develops new relationships at the support group. On the other hand, Gill's experience appears to have intensified her relationship with Linda and to have brought her feeling closer to her friends. Gill is obviously bitter at losing her father from a sudden illness and the possibility of losing her mother from cancer. She also puts a great deal of value on her relationship with her friends and they support her particularly when she is keeping the truth of the diagnosis from her mother. In turn, Gill is very supportive of Linda and could be said to have

reversed roles with her, in that she is behaving as a mother towards her. This concern and being actively involved in her mother's illness experience is in contrast with Beatrice's and Rachel's families who treat them as if they were no longer ill. However, this is how Beatrice and Rachel perceive things and we do not know that this is how their families feel as we have no information from them. Susan did not tell her husband as soon as she received her diagnosis as she wanted to protect him from it. This may also have had the effect of making the situation less real for her and, thereby, enabled her to protect herself from it until she was able to deal with it adequately.

All encompassing nature of cancer

It is clear from the individual accounts that the effects of cancer can be all encompassing, a theory expressed by Gee in a metaphor which presents cancer as a 'net thrown over the most intimate thoughts, fears and dreams' (1990:28). Susan uses a variety of idioms to describe what it is like to live with a tumour, including being in prison waiting for a sentence, to describe how it feels to wait for results, and, prior to treatment, being possessed by an 'uncontrollable thing'. These are very strong images which evoke the serious effect having cancer has on her life and how her body is perceived by her to be a container for cancer.

Rachel exhibits a strong belief that cancer damages the lives of everyone involved and makes them question what life is about and why they are alive. Gill feels that there is a 'mystique' surrounding cancer and that it is often perceived as a 'death sentence'. She states that health professionals help to perpetuate the idea that it is a dangerous and mysterious illness and suggests that they should speak of

'cancers', since the prognoses associated with different types of cancer vary dramatically.

Susan describes the residual effects of having cancer, and undergoing the associated treatment, as they affect other aspects of her life, that is physical, psychological and spiritual aspects. Having cancer has given James the opportunity to grow spiritually and this can be seen as an example of links between bodily and spiritual contentment. Beatrice associates hospitals, even maternity ones, with cancer as a result of her experience and finds the illness and death of public figures depressing, describing having cancer as living with a 'death sentence'.

Negative emotions

Related to bodily changes, body image and senses of self, there are a number of references to negative emotions, particularly anger, resentment and guilt. For example, Anna expresses bitterness and disappointment at the effect her death will have on her family and would like her children to be spared the experience she had of losing a parent at an early age.

As discussed with respect to changes to the body, Mary obviously has some unresolved bitterness about not receiving counselling when she was diagnosed as having cancer. Although Gill is not suffering from a life-threatening illness, her mother's illness experience has clearly had a deeply negative effect on her well being. It is apparent that Gill has great difficulty fitting her mother into the role of 'patient' and constantly questions and challenges the ideology of the health care system, as she makes numerous references to the limits of conventional medicine.

They suffer several set backs in hospital and a breakdown in their relationship with the staff involved in Linda's care. For example, keeping Linda's diagnosis from her until after her operation is particularly unpopular with the ward staff and Gill is made to feel that their belief in the holistic approach to health and illness is evidence that they are 'clutching at straws'. However, their experiences through Linda's chemotherapy are more positive as a result of the helpful and flexible attitudes of the health professionals involved in this part of her care. Gill's frustration and anger are palpable throughout the case study and it is clear that her mother is very precious to her.

Control, knowledge and power

There are clear associations in the research material between the concepts of control, knowledge and power. The subjects seek information relating to their illness experience in an attempt to regain control over their situation and to reduce the feelings of powerlessness indicated by some of the participants. The support groups allows the members to be part of a shared body of knowledge relating to living with the effects of cancer and of holistic health care. The sense that someone else is the location of knowledge intensifies vulnerability, as time and information are key resources which the participants feel they have been deprived of and, therefore, work towards gaining access to. By experiencing a life-threatening illness, some subjects have become isolated from their families and friends both literally and figuratively and it has been acknowledged that the feelings of loss of control related to this isolation can be made worse by those nearest to the affected person not acknowledging this (Stanworth 2004:123). Alternatively, some people in this situation may be overprotected by their

221

significant others, which can be as 'socially displacing' and promote perceptions of losing control as much as being ignored, as a source of power for the individual is being valued and acknowledged by others (Stanworth 2004:186, 121).

In Anna's case, knowledge is associated with empowerment, which she sees as a means of increasing her capacity to take control over her life and her illness. Woods et al (2000) have identified the ability of health professionals to give hope to patients, and to take it away. Anna recognises this power, particularly in doctors, and feels strongly that this does not give them the right to take hope from patients, even if it is considered false hope, as she makes a direct link between the nocebo effect and death. In addition, Anna's educational level and financial situation give her more control over her treatment choices. Anna would change her situation if she could, but she has learnt to accept it as being outside of her control.

Like Anna, Beatrice struggles to take control of different aspects of her situation through the employment of self-help techniques, her involvement in the Support Group and trying to gain as much knowledge as possible about her condition. Her reliance on and confidence in the Alexander Technique (AT) is made plain in her individual account, as is evidence of the strength she gains from her religious practice. However, Beatrice's approach to her illness is less accepting of the situation than Anna's and could be described as being more focused on reducing her symptoms and maximising her sense of well being. Beatrice gives details of extremely disempowering encounters with health professionals, states plainly that she hates being a 'patient' and feels that the atmosphere and power relationships experienced in her dealings with medical staff may have caused her to give

inaccurate information to them about her illness. The concepts of power and control are central to Beatrice's illness experience, and are characterised by her constant fight against the medical system. Susan also provides details of this struggle, which is extended in her case to battling with the system for sickness benefit.

Like Beatrice, James seeks to fight his illness through gaining more information about it, giving and receiving spiritual healing and using other complementary approaches to the treatment of illness. Rather than fit into the sick role, James does not accept his situation as unchangeable and directly challenges the conventional medical system and some of the cultural norms of our society, such as the reliance on and the value placed on material things. Susan also strives to regain control over her situation by searching for information relating to her illness. It is the perceived limits of medicine which lead Rachel to research into her illness and possible treatments for it. Following diagnosis she finds out about the Support group from her Macmillan nurse and is obviously very knowledgeable about holism and spiritual healing. Rachel acknowledges that she has learnt a lot through her illness experience but still expresses a desperate wish that a cure for cancer is found and, although she believes in the afterlife, she describes this life as 'precious'. Gill highlights two kinds of control which she feels she and her mother have lost. The first is control over their everyday lives, which was lost when Linda became ill, and the second is the control exerted over them by the hospital system, within the constraints of conventional medicine. Her beliefs about health and illness are obviously in conflict with those of the conventional medical system and she feels resentful that she and her mother have no choice concerning how, when

and where some aspects of her treatment are carried out. She appreciates being involved in her mother's care and, even though the 'rawness' of it may put others off, Gill feels that everybody should have the choice to become involved.

Perceived benefits of holism

All of the subjects actively participate in the Northumberland Cancer Support Group and, therefore, can be said to be engaging directly in the holistic health movement. The most significant feature of holism for Anna is her belief that holism can be adapted to the needs of the individual. Anna's view of holism reflects the need to see and treat each person as a whole and the potential for the individual's needs to be addressed through a holistic approach, which involves self-care and empowerment. The human to human contact within a caring environment inherent in the holistic approach is also important to Anna and the key link between holism and spiritual well being for her is hope. Although she expresses regret at not receiving the correct screening or treatment initially, Anna does not display any real disillusionment with, or resentment of, the conventional health system.

Overall, Beatrice indicates that conventional medicine alone is inadequate when dealing with whole people, demonstrating her belief in the fundamental theory of holism that a whole person is greater than, and has an identity independent of, the sum of the constituent parts (Dossey et al 1995:6). Her dislike of the effects of chemicals used in medicine, such as hormones, anti-depressants and cytotoxic drugs, reflects the disparity she sees between how conventional medicine and holism work. Beatrice is given the impression by health professionals that complementary therapies are options which may make people feel better, but

which have no real benefit in terms of treatment, an impression which is also expressed by Gill. Her involvement in holism is long-standing and is demonstrated by reference to her interest in natural childbirth and holism since the1960s. Therefore, it is possible that her interest in and the familiarity she has with the grammar and discourse of holism, makes a difference in scale to the impact the holistic philosophy has on her illness experience overall.

In addition to organising her life around treatments, such as AT, and taking a health promoting diet, Beatrice also incorporates an appreciation of nature, such as walking by the sea, into her holistic view of health and well being. This proactive approach to living with illness could be seen as adopting a role which is the opposite to the sick role (Parsons 1951), in that Beatrice appears to fight her illness and tries to optimise her potential for health. Therefore, in order to analyse the experience of people like Beatrice, who cannot be described as being ill in the conventional sense and who have long periods when they are also symptom free, it is clear that Parsons' sick role theory is inadequate.

James' whole lifestyle reflects the holistic philosophy, as he sees a benefit from all aspects of his care and from everyone who is important to him, including conventional medicine, the support of his family and the use of specific complementary therapies. However, like Beatrice, he describes disempowering encounters with the medical profession and recognises the limits to medical knowledge. He links the holistic philosophy to everyday activities, such as bathing and taking exercise, as they lead to feelings of rejuvenation, relaxation and spiritual well being. James describes nurses as the 'holistic link in care' as a result

of their 'attitude' to patients and such activities as holding a patient's hand, which is part of the human to human contact implicit in holistic care, which has been described as 'being with' rather than 'doing' (Elsdon 1995). James' lifestyle is also organised to promote the effectiveness of his immune system and to fight cancer, as shown by his determination to be stricter with his diet and exercise regimens. He also states that thinking of his inner self and his links to the Universe and developing his 'female side' has helped to make him complete. James believes in natural approaches to healing, which make the most of the person's potential for healing.

In general, as a result of her illness experience, Susan seems to have developed into a more independent person who has a broad idea of what holism is and how it can be applied to her lifestyle. For example, she sees its effects in everyday things and situations, such as flowers, a bird singing and taking a walk by the sea. Susan sees control as the central concept of holism and information as the key to control, which links to the discussion of control, knowledge and power earlier in this chapter.

As Rachel tries so many approaches to treating her illness, she expresses concern that she does not know what is keeping her well, which results in a fear of stopping anything in case that is the approach which is maintaining her equilibrium and promoting her health. Cost seems to be the only barrier to her willingness to try anything in the search for a cure, which is more of a problem for her since giving up work and, therefore, living on a reduced income. Financial constraints contribute to Rachel's stress, which is a central theme of this case study and it is directly

associated with negative effects on her physical, psychological and spiritual well being. Rachel is acutely aware of the effects of stress on her immune system and constantly acts to reduce this, for example through Reiki and paying attention to her diet. Her work as a spiritual healer, which she has been involved in since joining the support group, is a way in which she tries to help others as she has been helped herself.

Mary enjoys her practical participation in the group, perhaps because she had to give up her secretarial job due to illness and seems to see the holistic philosophy as a bonus rather than the main reason for her involvement in the NCSG, as she knew nothing of it before joining the group. Unlike the other participants in the research, Mary does not give the impression that living with a life-threatening illness results in continuous stress for her or in the fear that she may soon die. Mary's concerns are about her illness experience, which she sees as part of her past, and its effects on her physical well being then and now. Mary's individual account is comparatively short and provides a contrast to the others by showing another perspective on why people may join such a Support Group, that is to meet people in a similar situation and to be able to help themselves and others practically. However, this may indicate that the group's holistic philosophy still provides something for everyone.

Gill is not living with a life-threatening illness, but the support group has a membership which includes those directly affected by cancer and their carers. Gill's account provides valuable insights into how a carer can be affected by such changes in their situation and provides for a more comprehensive case study in

terms of the NCSG. Linda is ignorant of her diagnosis until after her surgery, but she receives her prognosis in different ways from the professionals involved in her care. Her surgeon is blunt and warns that a recurrence could result from one cell lying dormant following the original treatment. On the other hand, the oncologist and specialist nurse are more hopeful and gentle and offer chemotherapy as a precaution against recurrence. Gill chooses how and by whom Linda is given her diagnosis and, although she does this in order to reduce the negative impact of receiving this news on her mother's well being, it is clear that Gill suffers stress as a result of keeping this information to herself initially. Gill is very open about her ideas concerning spirituality and has a holistic perspective on life in general, which involves incorporating complementary therapies into her everyday life, such as the use of Bach flower remedies and crystals. Gill and her mother had a keen interest in holism before joining the support group and they could not have afforded therapies outside the group. This broader perspective on holism and the more pervasive incorporation of its principles and associated activities into their lifestyles is, perhaps, a feature of having a long standing interest in and experience of holism.

Spirituality and spiritual well being

It appears from the research material that the ill-defined, yet positive nature of spirituality allows a diversity of beliefs and positions to be encompassed within it. That is, approaches to spirituality range from religious to atheistic and embrace a wide-variety of life-affirming activities and beliefs related to what happens after death, including reincarnation. Anna's spiritual beliefs are primarily Christian and she makes reference to the power of prayer in her life, which indicates another

way in which she seeks to gain control over her life and situation. She appears to get more from healing within the Charismatic movement than from the spiritual healing offered at the support group. However, what she sees as the spiritual environment, the people and the therapies at the Support group give her much contentment throughout her illness and promote feelings of overall well being. Although Anna has strong beliefs in the afterlife, in line with Christianity, she has fears relating to the way in which she is likely to die. Beatrice experiences peace and relaxation through religious practice and describes the strength she gains from attending Mass, but she does not appear to experience spiritual well being for any sustained period. Beatrice's religiosity has increased since her diagnosis and she now attends church regularly.

James is obviously very well read and articulate and his definitions of spirituality and spiritual well being had been well thought through in advance of his interview and diary-keeping. James sees life as a path to spiritual fulfillment through a spiritual quest and gives more detail of the theories behind holism than Anna or Beatrice, which demonstrates individuality in his approach to finding meaning in his life and situation. Although he is a Church of England Christian, James expresses a belief in a spirituality which could be called atheistic, as it is non-religious and non-theological. That is, he has a New Physics view of energy which sees the spirit in terms of indestructible energy and sees spirituality as the uniting force of holism and that which links him to what he describes as 'unseen things'. The uncertainty and worry he experiences when waiting for the results of tests obviously has a negative effect on his overall well being.

James identifies meditation and visualisation as the most powerful and important healing approaches for him, sees spiritual healing as very potent and suggests possible physiological processes, including spontaneous healings which can be linked to the effectiveness of spiritual healing and meditation. He tries to give hope to the people he heals, as, like Anna, he recognises the damaging nature of the nocebo effect, in particular its potential to be 'destructive mentally'. In addition, James can be said to have taken on the role of 'wounded healer' in that his cancer experience led him to become a spiritual healer so that he could help others and learn more about healing in relation to himself.

Mary's practical nature is reflected in her lack of thoughts about spiritual well being or what she believes happens after death. She does not give the impression that she finds these subjects difficult or painful to talk about, rather that she is not used to thinking about them.

Susan speaks openly of God, how she prays regularly and the benefits she gains from attending the Krishna temple and also remarks that people speak more openly to her about God since her diagnosis. She appears to have taken a step back from the roles she has had within her family and makes a conscious effort to reorganise her life in order to accommodate what she sees as health promoting and life-affirming activities based on her new beliefs. She feels that she has been put in this situation, i.e. experiencing cancer, for a purpose and believes in the principles of reincarnation.

It is clear that Rachel has a strong belief in God and clear ideas about what constitutes spiritual well being, which she describes as a goal on the spiritual journey and explains that she prepares herself spiritually for each stage of her illness, for example when the cancer spreads from her breast to her bones. Although Rachel believes in God, she searches for proof of His existence in the face of death. Rachel sees spiritual well being as not necessarily achievable in one lifetime, which links to the notion of reincarnation, and believes that people may not be aware of their spiritual needs.

Overall, the type of spirituality revealed inn the individual accounts can be defined as generic and all-encompassing, as stated at the beginning of this section. This spirituality is characterised by and all-pervasive energy which can be channeled to provide spiritual healing. There is also a link to notions associated with the inner self and New Age spirituality. Transcendence also constitutes part of spirituallity for the subjects, particularly those with religious beliefs and who engage in spiritual healing. In general, then, this spirituality can be said to have its origins in experience and is related to embodiment, which fits well into an anthropological framework.

Northumberland Cancer Support Group as an environment for meaning-making

An account has been given in chapter five of how this support group operates, which provides the context within which to analyse the group members' experiences. A number of issues have been revealed through the individual accounts, including why the research participants engage in the holistic health movement and what benefits they feel they gain as a result of this. The group

clearly provides an environment for meaning-making for its members in their new situation and acts as a therapeutic community. Two types of people make up the group membership, sufferers and carers and the group provides an environment where support can be obtained, which is not available in other areas or within relationships outside the group.

Communitas theory can be used to interpret how the group works, in terms of rites of passage or transition, separation and aggregation. However, it can be said that the communitas associated with being a member of the group moves people into a 'dying' identity whether they resist it or not, or at least to a post-illness identity. The group members welcome the positive feelings of calm and healing associated with being part of the support group and thereby engage in a process which turns them into 'the dying' as a social category. This helps to explain apparent contradictions in the individual accounts where the participants express anger, resentment and bitterness, yet speak positively about healing via various channels and of the personal insights they have gained.

Being affected by a diagnosis of life-threatening illness, either personally or through a relative who is in this situation, leads to the development of multiple realities linked to the social construction of reality of living with these effects. The collective roles and expectations of society have an influence on the subjects' experience, as society is made up of individuals and the specific reality which represents their association. There are obvious links to Lawton's (2000) work in the area of a hospice day unit, where people attending described other attendees as kindred spirits and in same boat.

Despite her close personal experience of the disease, Anna feels as if she is the only person with cancer when she is diagnosed, but she benefits from being part of the community of the Support Group. Although Beatrice's lifestyle is driven by the holistic approach, she has a real fear of dying and indicates a significant fear of her cancer recurring. The deaths of support group members profoundly affect Beatrice as they go against the life affirming and healing environment of the group. However, in view of the nature of the group, it could be argued that over time the deterioration in health and the death of some group members is inevitable.

Susan feels that the support group does not stand still and she is eager to increase her knowledge continuously and, in this way, appears to be trying to regain control over her situation. She states that she only feels completely open and at ease within the group, because of their shared experience and, therefore, shared environment for meaning-making. This is contrasted with a new loneliness she feels with family members, including her husband, and is another example of people who are important to the subjects having difficulty adjusting to their new self-image and perspective on life.

It is clear from the individual accounts that the subjects see holism as directly associated with the promotion of their spiritual well being and this approach offers them a great deal more than conventional medicine alone. The maintenance of hope, religiosity and control appear to be clear drivers of holism for the subjects. The main benefits associated with being part of the Support group can be seen as aspects of spiritual care. These include active listening, presence, self-disclosure,

acceptance, therapeutic touch, healing and meditation. In addition, the group members are able to express themselves through art and music if they wish. This approach may be summed up as 'being with' rather than 'doing' and as human to human contact, which may be naïve on the part of those involved.

The subjects try to maintain control over their lives and identities by obtaining and sharing appropriate information and incorporating aspects of the holistic approach into their lifestyles, in addition to undergoing conventional medical tests and treatments. As discussed in an earlier section, religiosity is seen as part of spirituality by the subjects, but they also demonstrate that spirituality is a larger concept which incorporates religion. For example, Beatrice and Susan take part in religious services and rituals, but also value the contribution made to their spiritual well being by spiritual healing and non-conventional therapies. The subjects also exhibit individuality in their spirituality and some appear to see religion as a refuge at times of crisis in their lives associated with facing life-threatening illness, perhaps as part of their search for meaning. As spirituality can be said to encompass religion, holism encompasses spirituality and makes it possible for each individual to use whichever means are available to assist them to live with the effects of a life-threatening illness and all of the physical, psychological and spiritual problems that this involves.

By establishing the Northumberland Cancer Support Group as the case study around which this thesis has been constructed, the data making up the individual accounts have been integrated into a framework which analyses them in the context of the group itself and the shared ways in which the participants interpret their

experience. This has also allowed for the different perspectives of group members to be incorporated, that is those suffering from a life-threatening illness and a carer.

The main findings of the research study and the overall themes which emerge from the case study will be discussed in the next and final chapter of the thesis. This will involve reviewing the appropriateness of the research design to the area of enquiry and identifying any weaknesses or problems associated with the research process in this case. The significance of a holistic philosophy to the spiritual well being of the research subjects will be determined and conclusions drawn from the research results, revisiting the main points of this chapter. Recommendations will also be made regarding potential areas for future research as indicated by the findings and outcome of this study.

Conclusion

As previously stated, this research study was designed to explore the degree to which holistic care has influenced the subjects' sense of spiritual well being by employing a phenomenological framework. This approach was adopted to allow the subjects to speak for themselves and thereby reveal the real, lived experience of the effects of life-threatening illness and how this affects the way in which they construct reality. Finding an example of holism in practice was crucial to the research as it was essential to explore non-conventional approaches, the philosophies behind them and how they are perceived by users. It was expected that this would then link in with how the subjects see themselves, their bodies, life and death and how the experience of illness has shaped these perceptions. In order to set the scene for the research and to establish what literature and research existed on associated areas, a comprehensive literature review was completed.

Ethical considerations were of the utmost importance when designing and conducting this research due to the sensitive nature of the area of enquiry and have been comprehensively discussed in relation to methodology. One of the areas of enquiry relates to care of the dying in a post modern context and it is clear that some aspects of this have improved since the 1960s and terminology modernised, such as the introduction of terms such as 'life-threatening' and 'life-limiting' illness. It is accepted that significant investment has been made in palliative care since the fieldwork was carried out, but the current literature reveals that experiences of contemporary health services continue to reflect similar problems to those revealed through the case study. For instance, quality of life continues to be measured predominantly in terms of longevity and positive physical outcomes, as

discussed in the main body of the thesis, and palliative care is still provided within a professional, if not medical, framework. In addition, it is not only the palliative stages of illness experience which are important and it is evident from the perspective of those research subjects living with a life-threatening illness that their conventional medical care alone was woefully inadequate in assisting them to live in the related circumstances. Before reviewing the overall findings of the research, the contents of the thesis will be briefly revisited.

Overview of the thesis

As holistic care is presented as the broadest framework with respect to health care and with the capacity to encompass all aspects of the person, including spiritual, it was chosen as the philosophy with which to compare and contrast other systems, particularly the conventional medical model of care. For the purposes of the thesis, health is seen in the broader context of the lived experience of illness and holistic care characterised by human to human connection. In addition to being examined as a philosophy relating to health, holism has been analysed as a sociological movement and, in the wider sense, as a worldview. Individual accounts were chosen as the media through which to present the research findings as they were used as effective communication devices within the context of the ethnography of the Northumberland Cancer Support Group.

The rhetoric and reality of theories relating to death and dying have also been examined as well as exploring spirituality, its expression and aspects of spiritual care. Concepts of self have also been discussed and picked up again in relation to the analysis of the case studies. Several authors have expressed difficulty in

defining spirituality, in part because some argue that it is an all-embracing concept, incorporating a wide variety of associated phenomena, such as hope and healing. It is clearly quality of life, rather than quantity, which is important to the research participants and exploration of this phenomenon has revealed some of the difficulties involved in identifying and measuring it, since, with respect to health, this concept is still bound up with the biomedical model to a large extent.

The individual accounts have been presented under each subject's assigned first name as phenomenological description and then analysed in relation to their shared experience, aspects of individual experience and methods of meaning-making in relation to these.

Research findings

Overall, the research design and phenomenological framework was deemed effective in capturing the phenomenological aspects of lived illness experience and to making sense of a large amount of data from a small number of subjects, gained through the individual accounts as part of the overall case study. These individual accounts communicated the detail of what it is like to live with a life-threatening illness in contemporary Western society and, through the frank disclosure of the research subjects, revealed powerful feelings and sentiments to the reader. It has already been noted that being party to illness narratives of a very personal, and sometimes harrowing, nature can have a negative effect on the researcher and this was found to be the case here, particularly with respect to Gill (Gilbert 2000). For example, it is clear from this case study that Gill's mother's illness experience has been traumatic and overwhelmingly negative in nature and the researcher's

interaction with Gill resulted in strong feelings of empathy regarding her experience. However, Linda's story is so disturbing in places that aspects of it stayed with the researcher and it was difficult to create this case study because of the necessity of reviewing its content at various stages of the research process. However, the researcher found, in the main, that interaction with the subjects was positive and yielded a significant amount of relevant information and was grateful for the quality of personal information they were prepared to share. Taking part in the research appears to have helped the participants to reflect on their experiences while the very act of expressing their feelings may have also produced a cathartic effect.

Holism is perceived by the subjects as having the capacity to address every aspect of the person and to stimulate the individual's capacity for healing by reducing stress and re-establishing balance. Spiritual well being is the overall aim of adopting these approaches by most of the subjects who seek to alter their lifestyles to incorporate life-affirming activities which are believed to stimulate the immune system. Spiritual well being is articulated in different ways by the subjects but is associated with a spiritual journey, peace, contentment and transcendence. Spirituality is revealed through the case studies in a variety of forms, from traditional Christian to atheistic, and three of the subjects have become spiritual healers since joining the group, taking on the role of wounded healer or shaman to help themselves and others to live with life-threatening illness. Spirituality in the context of the research participants' experience is embedded in their illness experience and in embodiment. Religiosity was more important for some subjects than others as part of holism, but spirituality in its broadest sense was crucial to six

of them. Holism in this sense involves post-modern notions of individualism and consumerism in relation to choice and control. This is characterised here by a search for information relating to cancer, its treatment and healing, for example through conducting research via the internet. Although individuality is implicit in the approach to holism as revealed by the subjects, it takes different forms. For example, it is revealed as a new loneliness resulting from feelings of isolation following diagnosis and in terms of individual spirituality, as incorporated in approaches such as the New Age movement.

Joining the support group may seem to be at odds with the individualism implicit in the holistic approach, but the group provides a focus and centre for holism in practice, providing opportunities for human to human contact, access to therapies, dietary advice and supplements and sharing information through personal experience, as well as providing access to an impressive library. All of these help to develop a shared body of knowledge relating to living with cancer, which is clear from the contents of the individual accounts. This knowledge is sought and obtained in an attempt to gain control over aspects of illness experience, such as treatment choices, as it is acknowledged by the subjects that loss of control over their situation and life is a potential source of stress. The illness narratives of the research participants include an attempt to challenge the powerlessness they feel by seeking alternatives to the medical model alone and educational attainment and financial power are also seen to affect an individual's choices. The group also fosters a sense of communitas for the members through a shared environment for meaning-making and enables new relationships to be forged to replace aspects of previous significant relationships which have changed since the subjects' diagnosis.

The result is seen in a reduction in loneliness and an increase in ability to face their new situation. There are various triggers to joining the group displayed by the subjects, including to gain access to holistic treatment and meeting people in a similar situation to themselves, and it is clear that the group and what it offers caters for a wide variety of need. A summary of the case study findings indicates that holism was of great importance to six of the subjects, but provided only limited benefit to one (Mary). Holism has been shown to have contributed to the spiritual well being of the participants, again except in the case of Mary, who is not used to thinking in this abstract way.

Although the subjects have employed complementary and alternative approaches to their health, it is obvious that they are also committed to their conventional treatments, such as cytotoxic chemotherapy and surgery, which suggests that holism can incorporate conventional and non-conventional medicine. Conventional medicine includes screening for illness and can detect it where symptoms are vague, minimal or absent. As a result, it is sometimes only when treatment has started that the person feels they have cancer, for example when experiencing the side effects of cytotoxic chemotherapy or radiotherapy, as alluded to previously. The limits to the sick role have been discussed and are revealed again through the variation in pattern and the length of illness experience of each subject.

The explicit awareness and declaration of mortality by the subjects following diagnosis is a major theme which emerges from the case study, as mortality is denied under normal circumstances by individuals and by society as a whole. This has been described as changing from a naïve to a scrutinising approach to life.

There is evidence that these changes are characterised by alteration to the participants' senses of self at different stages throughout their illness experience, which are linked to the reasons why the subjects joined the support group, as discussed above. There is tension between the feelings of wanting to be treated as normal and carry on with usual activities and roles and being recognised as needing special consideration as a result of the change in situation, even when treatment has finished and the prognosis favourable. There is also a sense of their feeling grateful to be alive and to have a chance to review life and meaning, although this is tempered by a concern and guilt associated with causing worry to family members and friends. Those affected by life-threatening illness have been shown to live in the present in order to avoid comparing this with their past, pre-illness self, or with an uncertain future. Conversely, their relatives and friends seek information about what the future holds in order to plan accordingly, which may go some way to explain the distance which develops between the subjects directly affected by life-threatening illness and those closest to them following diagnosis. Changes to body image, psychology and spirituality are manifest in the individual accounts as a result of experiencing illness. Tentative references are made by the subjects to the effects deterioration of fellow group members has on them, as this, perhaps, serves as a reminder of the eventual failure of all approaches to treating illness.

Everyday and mundane activities and phenomena, previously taken completely for granted by the research participants, take on significant importance to them following diagnosis in the face of a perceived premature death. It is clear that the subjects want to make the most of the time they have left and they exhibit the phenomenon of 'intensive living', which they interpret in terms of either quantity

or quality of experience. This reflects a desire to continue in social roles which were held pre-illness and serve to enhance the related senses of self and to maintain control. The desire to be engaged in such ordinary activities is at odds with the idea that dying people may want to take part in exciting activity or visit exotic places, which can be viewed in terms of unfinished business and unfulfilled dreams. In particular, James makes reference to everyday activities which he sees as part of the overall holistic approach he adopts to live with his illness. Aspects of embodiment theory are also revealed through the case study, particularly when the subjects experience physical symptoms of their illness or its treatment and, thereby, are aware of themselves as and in a body. It emerges from the research findings that the way of dying is feared by the subjects more than death itself and is seen in terms of physical deterioration and reduction in normal activity and function.

Limits to research design and recommendations

In retrospect, it is possible to identify certain constraints within the previous chapters as, for example, the fact that only people affected by cancer were involved and that only white, middle class people who had received above average education volunteered to become involved. The limits to the sample were discussed in chapter one, but, on balance, the amount of data provided has been more than adequate in addressing the research question. Although it was not appropriate to the research design to include a control group, the nature of the sample may have resulted in over-stating the value of holism to the participants. In addition the sample was very small, although the similarity of the themes which emerged suggests that a larger sample from the same group would also have revealed such

similarities. It is possible that some areas of the research could be refined and applied to a larger sample, for example concentrating on the time around diagnosis and comparing a group made up of individuals who have adopted a holistic philosophy and those who have not. However, it would be very difficult, and produce a temptation to over generalise, simply to increase significantly the size of the sample within the criteria for this study. Significant data may have been gained from involving the carers of all of the subjects and from explicitly asking the participants how they felt at the times when their peers deteriorated or died. However, the latter would not have been ethical and the subjects themselves may have died since the fieldwork was completed.

Overall conclusions

The research has established that engaging in the holistic health movement has had a positive effect on the subjects' capacity to experience spiritual well being. This was not explicitly expressed by all of the subjects, but it is clear that active membership of the Northumberland Cancer Support Group addresses recognised needs in the subjects and contributes to their quality of life and overall well being, which includes spiritual well being. Although studies focusing on the effects of holistic care and of the holistic movement in general have been carried out, for example in relation to the Bristol Cancer Help Centre, this research makes a valuable contribution to the knowledge base in a variety of ways. Firstly, it has established its primary aim of establishing how spiritual well being is affected by engagement in the holistic health movement, as already stated. Secondly, it has revealed aspects of living with a life-threatening illness which were not anticipated at the start of the research process. These include the changes in the senses of self of the research participants as a result of their illness experience and the related

phenomena of new loneliness, 'intensive living' and changes to the relativity of

time. Finally, the very ordinary activities and relationships which are usually taken

for granted take on a new importance for the subjects after their situation changes

and it is this mundaneness which they seek, associated as it is with their pre-illness

self. Although Gill is not directly affected by life-threatening illness, the potential

loss of her mother due to cancer changes her perspective on life and she also

demonstrates some of the essential aspects of the other subjects' experience, as

detailed in her individual account.

Bibliography

Aakster, C W. 1993. Concepts in Alternative Medicine. *In: Beattie et al (eds). Health And Well Being: a reader. (Pp.84-93). Buckingham. Open University Press.*

Achterberg, J. 1985. Imagery In Healing: shamanism and modern medicine. Boston. Shambhala Publications Inc.

Adams, A. 1996. My World Upside Down. *In: Goodacre, H (ed). Fighting Spirit: the stories of women in the Bristol breast cancer survey. (Pp.11-17). London. Scarlet Press.*

Ader, R. 1997. The Role of Conditioning in Pharmacotherapy. *In: Harrington, A (ed.). The Placebo Effect: an interdisciplinary exploration. (Pp.138-165). London. Harvard University Press.*

Adjeman, I and Mount, B.M. 1981. The Adult Patient: cultural considerations in palliative care. *In: Saunders, C et al. Hospice: the living idea. (Pp.19-31). London. Edward Arnold.*

Aggleton, P. 1990. Health. London. Routledge.

Ainsworth-Smith, I and Speck, P. 1982. Letting Go: caring for the dying and bereaved. London. SPCK.

Alder, L and Runi Mukherji, B. 1995. Spirit v Scalpel. Westport. Conn. Bergin and Garvey.

Aldridge, D. 1991. Spirituality, healing and medicine. British Journal of General Practice. Vol.41. Pp425-7.

Aldridge, D. 2000. Spirituality, Healing and Medicine: return to the silence. London. Jessica Kingsley Publishers.

Alter, J.S. 1999. Heaps of health, metaphysical fitness. Current Anthropology. Vol.40. Pp.43-66.

Angelo, J. 1991. <u>Spiritual Healing: energy medicine for today.</u> Shaftesbury. Element.

Appignanesi, R and Garratt, C. 1995. <u>Postmodernism For Beginners.</u> Cambridge. Icon Books.

Aranda, S. 1999. Global perspectives on palliative care. <u>Cancer Nursing.</u> Vol.22. No.1. Pp.33-9.

Ariés, P. 1976. <u>Western Attitudes Towards Death: from the middle ages to the present</u>. London. The Johns Hopkins University Press.

Ariés, P. 1981. <u>The Hour of Our Death.</u> Oxford. Oxford University Press.

Armstrong, D. 1993. The Problem of the Whole-Person in Holistic Medicine. *In: Davey, B et al (eds). <u>Health and Disease: a reader.</u> (Pp.33-6). Buckingham. Open University Press.*

Armstrong-Coster, A. 2001. A. In Morte Media Jubilante: an empirical study of cancer-related documentary film. <u>Mortality.</u> Vol.6. No.3. Pp. 287-305.

Arnason, A. 2000. Biography, bereavement story. <u>Mortality.</u> Vol.5. No.2. Pp.189-204.

Bagenal, F S, Easton, D F, Harris, E, Chilvers, C E D and McElwain, T J. 1990. Survival of patients with breast cancer attending Bristol Cancer Help Centre. <u>The Lancet</u>. Vol.336. Pp.606-610.

Bahro, R. 1986. <u>Building The Green Movement.</u> London. GMP.

Bailey, C A. 1996. <u>A Guide To Field Research</u>. Thousand Oaks, California. Pine Forge Press.

Bailey, P H. 1997. Finding your way around qualitative methods in nursing research. <u>Journal of Advanced Nursing.</u> Vol1. No.25. Pp18-22.

Baker, M R (ed). 2002. <u>Modernising Cancer Services.</u> Oxon. Radcliffe Medical Press.

Bannerman, R H, Burton J and Che'en W C. 1983. <u>Traditional Medicine And Health Care Coverage.</u> England. Macmillan.

Barker, P J. 1996. Interview. *In: Cormack D F S. The Research Process in Nursing. (Pp.267-234). Oxford. Blackwell Science.*

Barley, N. 1997. <u>Dancing On The Grave.</u> London. Abacus.

Barnum, B S. 1996. <u>Spirituality In Nursing: from traditional to New Age.</u> New York. Springer.

Barraclough, J (ed). 2001. <u>Integrated Cancer Care: holistic, complementary and creative approaches.</u> Oxford. Oxford University Press.

Barton, D. 1977. <u>Dying and Death: a clinical guide for care givers</u>. Baltimore. The Williams and Wilkins Co.

Bauman, Z. 1992. <u>Mortality, Immortality and Other Life Strategies.</u> California. Stanford University Press.

Bauman, Z. 1998. Postmodern adventures of life and death. *In: Scambler, G and Higgs, P. Modernity, Medicine and Health. (Pp216-231). London. Routledge.*

Beattie, A, Gott, M, Jones, L and Sidell, M (eds). 1993. <u>Health And Well Being: a reader.</u> Buckingham. Open University Press.

Beck, A T and Rosenstock, I M. 1984. The health belief model and preventive health behaviour. <u>Health Education Monographs.</u> Vol.2. Pp.354-86.

Bell, J. 1987. <u>Doing Your Research Project</u>. Buckingham. Open University Press.

Benor, D J. 1990. Survey of spiritual healing research. <u>Complementary Medical Research</u>. Vol.4. No.3. Pp9-33.

Bergen, A and While, A. 2000. A case for case studies: exploring the use of case study design in community nursing research. <u>Journal of Advanced Nursing.</u> Vol.31. No.4. Pp.926-34.

Berger, P L and Luckman, T. 1996. <u>The Social Construction Of Reality.</u> New York. Doubleday.

Berger, A S and Berger, J. 1995. <u>Fear Of The Unknown: enlightened aid in dying</u>. Westport. Praeger Publishing.

Berland, W. 1995. Can the self affect the course of cancer? <u>Advances.</u> Vol.11. No.4. Pp.5-19.

Berridge, V. 2001. <u>Health And Society In Britain Since 1939.</u> Cambridge. Cambridge University Press.

Berry, P and Wernick, A (eds). 1992. <u>Shadow of Spirit: postmodernism and religion.</u> London. Routledge.

Berry, R. 1986. <u>The Research Project: how to write it.</u> London. Routledge.

Bettis, J D. 1969. <u>Phenomenology Of Religion.</u> London. SCM Press.

Blacking, J (ed.). 1977. <u>The Anthropology Of The Body.</u> London. Academic Press.

Blank, R H. 2001. Technology and death policy: redefining death. <u>Mortality.</u> Vol.6. No.2. Pp.191-202.

Bloch, M. 1992. <u>Prey Into Hunter: the politics of religious experience.</u> Cambridge. Cambridge University Press.

Bloch, M and Parry, J (eds). 1982. <u>Death And The Regeneration Of Life.</u> Cambridge. Cambridge University Press.

Bloom, W. 1991. Extract from <u>The New Age: anthology of essential writings.</u> Rider. London. Pp.xv-xviii. *In: Wolfe (ed). The Growth of religious diversity: a reader. (Pp.149-152). Buckingham. Open University.*

Bloom, W (ed.). 2000. <u>Holistic Revolution: the essenetial New Age reader.</u> London. The Penguin Press.

BMA. 1986. <u>Altenative Therapy: Report of the Board of Science and Education.</u> London. The Camelion Press Ltd.

BMA. 1993. <u>Complementary Medicine: new approaches to good practice.</u> Oxford. Oxford University Press.

Boeve, L. 1999. Market and religion in postmodern culture. <u>Theology.</u> Vol.CII. No.805. Pp29-36.

Boise, L, Heagerty, B and Eskenazi, L. 1996. Facing chronic illness: support model and its benefits. <u>Patient Education and Counselling.</u> Vol.27. Pp.75-84.

Boman, L, Bjorvell, H, Langius, A and Cedermark, B. 1999. Two models of care as evaluated by a group of women operated on for breast cancer with regard to their perceived well being. <u>European Journal of Cancer.</u> Vol.8. Pp. 87-96.

Bond, J and Bond, S. 1986. <u>Sociology and Health Care.</u> London. Churchill Livingstone.

Bordo, S. 1993. <u>Unbearable Weight.</u> California. University of California Press.

Boston, S, and Trezise, R. 1987. <u>Merely Mortal: coping with dying, death and bereavement.</u> Great Britain. Methuen, in assoc. with Channel 4.

Bottomley, A. 1997. Cancer support groups- are they effective? <u>European Journal of Cancer Care.</u> Vol.6. Pp.11-17.

Bouma, G D and Atkinson, G B J. 1995. <u>Social Science Research.</u> Oxford. Oxford University Press.

Bourner, T. 1996. The research process: four steps to success. *In: Greenfield,T. Research Methods: guidance for postgraduates. (Pp.7-11).* London. Arnold.

Bowker, J. 1999. The Meanings Of Death. Cambridge. Cambridge University Press.

Boyd, K M. 2000. Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts. Journal of Medical Ethics. Vol.26. Pp.9-17.

Bradshaw, A. 1994. Lighting The Lamp: the spiritual dimension of nursing care. London. Scutari Press.

Braun, K L and Zir, A. 2001. Roles for the church in improving end-of-life care: perceptions of Christian clergy and laity. Death Studies. Vol.25. No.8. Pp. 685-704.

Bruce, S. 1996. Religion In The Modern World: from cathedrals to cults. New York. Oxford University Press Inc.

Bruce-Long, G. 1975. The death that ends death in Hinduism and Buddhism. *In: Kübler-Ross, E. Death, the Final Stage of Growth. (Pp. 52-72). New Jersey. Prentice Hall.*

Bryman A. 1988. Quantity and Quality in Social Research. London. Unwin Hyman.

Buckle, J. 1993. When is holism not complementary? British Journal of Nursing. Vol.2. No.15. Pp744-5.

Buckman, R. 1988. I Don't Know What To Say. London. MacMillan.

Bugental, E K and Bugental, J F T. 1984. Dispiritedness: a new perspective on a familiar state. Journal of Humanistic Psychology. Vol. 24. No. 1. Pp49-67.

Burkhardt, M. 1989. Spirituality: an analysis of the concept. <u>Holistic Nursing Practice</u>. Vol.3. No.3. Pp.69-77.

Burnard, P. 1987. Spiritual distress and nursing response. <u>Journal of Advanced Nursing.</u> Vol 12. Pp.377-82.

Burridge, K. 1979. <u>Someone, No One: an essay on individuality.</u> Princeton. New Jersey. Princeton University Press.

Burrows, R. 1993. <u>Holistic Approaches To Health and Well Being In Northern Ireland</u>. PhD. Queens University, Belfast.

Bury, M. 1997. <u>Health And Illness In A Changing Society.</u> London. Routledge.

Bury, M. 1998. Postmodernity and health. *In: Sc-ambler, G and Higgs, P (eds). <u>Modernity, Medicine and Health.</u> (Pp.1-28). London. Routledge.*

Bury, M. 2001. Illness narratives: fact or fiction? <u>Sociology of Health and Illness.</u> Vol.23. No.3. Pp.263-285.

Callahan, D. 1993. <u>The Troubled Dream Of Life: in search of a peaceful death.</u> New York. Simon and Schuster.

Cannon, W B. 1942. 'Voodoo' death. <u>American Anthropologist (ns).</u> Vol.44. No.2. Pp.169-181.

Carpenter, J S, Brockopp, D Y and Andrykowski, M A. 1999. Self-transformation as a factor in the self-esteem and well being of breast cancer survivors. <u>Journal of Advanced Nursing.</u> Vol.26. No.6. Pp 1402-1411.

Carroll B. 2001. A phenomenological exploration of the nature of spirituality and spiritual care. <u>Mortality</u>. Vol.6. No.1. Pp.81-98.

Cassidy, S. 1988. <u>Sharing The Darkness: the spirituality of caring.</u> Darton. Longman and Todd.

Cassileth, B R. 1999. Complementary therapies: overview and state of the art. Cancer Nursing. Vol.22. No.1. Pp.85-90.

Chan, A and Woodruff, R K. 1999. Comparison of palliative care needs of English and non-English-speaking patients. Journal of Palliative Care. Vol.15. No.1. Pp. 26-30.

Charles, R. 1996. Immune response. *In: Goodacre, H (ed). Fighting spirit: the stories of women in the Bristol breast cancer survey. (Pp.26-40). London. Scarlet Press.*

Charlton, R and Dovey, S. 1995. Attitudes to death and dying in the UK, New Zealand and Japan. Jounal of Palliative Care. Vol.11. No.1. Pp42-7.

Chopra, D. 1989. Quantum Healing. New York. Bantum books.

Chopra, D. 2000. Aging: ageless body, timeless mind. *In: Bloom, W (ed). Holistic revolution: the essenetial New Age reader. (Pp.198-206). London. Penguin.*

Cimprich, B. 1999. Pretreatment symptom distress in women newly diagnosed with breast cancer. Cancer Nursing. Vol.22. No.3. Pp. 185-194.

Clarke, R A. 1991. Studying Interpersonal Communication: the research experience. California. Sage Publications.

Clark, D (ed). 1993. The Future For Palliative Care: issues of policy and practice. Buckingham. Open University Press.

Clark, D, Hockley J M and Ahmedzai, S (eds). 1997. New Themes In Palliative Care. Buckingham. Open University Press.

Clarke, A. 1999. Qualitative research data analysis techniques. Professional Nurse. Vol.14. No.8. Pp531-3.

Clark, D. 2000. Palliative care history: a ritual process. European Journal of Palliative Care. Vol.7. No.2. Pp.50-5.

Cleiren, M. 1992. Bereavement and Adaptation. Bristol. Taylor and Francis.

Cobb, M. 2001. The Dying Soul: spiritual care at the end of life. Buckimgham. Open University Press.

Cohen, K P. 1979. Hospice: prescription for terminal care. Germantown Md. Aspen Systems Corporation.

Conco, D. 1995. Christian patients' views of spiritual care. West-J-Nurs-Res. Vol.17. No.3. Pp266-76.

Conrad, N L. 1985. Spiritual support for the dying. Nursing Clinics of North America. Vol.20. No.2. Pp415-25.

Cormack, D F S (ed.). 1996. The Research Process In Nursing. Oxford. Blackwell Science.

Cormack, D F S and Benton, D C. 1996. Asking the Research Question. In: Cormack, DFS (ed). The Research Process in Nursing. (Pp.53-63). Oxford. Blackwell Science.

Corr, C A and Corr, D M. 1983. Hospice Care: principles and practice. London. Faber and Faber Ltd.

Corr, C A. 1993.Coping with dying: lessons that we should and should not learn from the work of Elisabeth Kubler-Ross. Death Studies. Vol17. No.1. Pp69-83.

Costello, J. 2000. Truth telling and the dying patient: a conspiracy of silence? Int. Journ. of Palliative Nursing. Vol.6. No.8. Pp.398-405.

Couchman, C and Dawson, J. 1991. Nursing And Healthcare Research: a practical guide. London. Scutari Press.

Coulthard, M. 1977. An Introduction To Discourse Analysis. London. Longman.

Coward, R. 1995. The Myth of Alternative Health. *In: Beattie, A (ed). Health and well-being: a reader. (Pp.94-101). Buckingham. Open University Press.*

Coyne, I T. 1997. Purposeful and theoretical sampling: merging or clear boundaries. Journal of Advanced Nursing. Vol.26. No.3. Pp.623-30.

Craib, I. 2003. Fear, death and sociology. Mortality. Vol.8. No.3. Pp.285-295.

Critchley, S. 1997. Very Little...Almost Nothing: death, philosophy, literature. London. Routledge.

Csordas, T J. 1990. Embodiment as a paradigm for anthropology. Ethos. Vol.18. Pp.5-47.

Csordas, T J. 1994. The Sacred Self: a cultural phenomenology of charismatic healing. Cambridge. Cambridge University Press.

Csordas, T J. (ed.) 1994. Embodiment And Experience: the existential ground of culture and self. Cambridge. Cambridge University Press.

Currer, C and Stacey, M (eds). 1986. Concepts of Health, Illness and Disease: a comparative perspective. Leamington Spa. Berg Publishers Ltd.

Dacher, E S. 1997. Towards a post-modern medicine. Complementary Therapies in Nursing and Midwifery. Vol.3. Pp.66-71.

Davey, B, Gray A and Seale C (eds). 1996. Health and Disease: a reader. Buckingham. Open University Press.

Davies, D J. 1990. Studies in Pastoral and Social Anthropology. Dept. of Theology. University of Birmingham. 2nd edition.

Davies, D J. 1994. The social facts of death. *In: Howarth, G and Jupp, P C (eds). Contemporary Issues in the Sociology of Death, Dying and Disposal. (Pp.17-29). Basingstoke. Macmillan.*

Davies, D J. 1997. Death, Ritual and Belief. London. Cassell.

Davies, S T. 1989. <u>Death and Afterlife.</u> New York. St. Martin's Press.

Dawson, V. 1997. A reply to 'spirituality as integrative energy'. <u>Journal of Advanced Nursing</u>. Vol.25. No.2. Pp282-9.

Dean, J P and Whyte, W F. 1969. How do you know the informant is telling the truth? *In: McCall-Simmons, G J. Issues in Participant Observation: a text and a reader (Pp.105-115). New York. Random House.*

De Beauvoir, S. 1972. <u>The Coming of Age</u>. London. G P Putman's Sons.

Default, K and Martocchio, R N. 1985. Hope: its fears and dimensions. <u>Nursing Clinics of North America.</u> Vol.20. No.2. June Pp.379-91.

Dein, S and George, R. 2001. The time to die: symbolic factors relating to the time of death. <u>Mortality.</u> Vol.6. No.2. Pp.203-211.

Demopoulos, W and Marras, A (eds.). 1986. <u>Language, Learning and Concept Acquisition.</u> U.S.A. Ablex Publishing Corporation.

Denzin, N K and Lincoln, Y S (eds). 1994. <u>Handbook of Qualitative Research</u>. London. Sage.

Department of Health. 2000. <u>The NHS Cancer Plan</u>. London. DoH.

De Rosny, E. 1998. The longevity of the practice of traditional care. *In: Chaevet L.M. and Tonka M (eds). Concilium: Illness and Healing. (Pp.8-14). London. SCM Press.*

Diamond, J. 1998. <u>C: because cowrds get cancer too.</u> London. Vermillion.

Dickenson, D and Johnson, M (eds.). 1993. <u>Death, Dying and Bereavement.</u> London. Sage Publications, in association with the O.U.

Dirksen, S R. 2000. Predicting well being among breast cancer survivors. <u>Journal of Advanced Nursing.</u> Vol.32. No.4. Pp.937-943.

Doka, K J. 1989. <u>Disenfranchised Grief: recognising hidden sorrow.</u> Lexington, Mass. Lexington books.

Dollimore J. 1998. <u>Death, Desire and Loss in Western Culture.</u> London. The Penguin Press.

Dom, H. 1999. Spiritual care, need and pain-recognition and response. <u>European Journal of Palliative Care.</u> Vol.6. No.3. Pp.87-90.

Dossey, B M, Keegan L and Guzzetta C E. 1995. <u>Holistic Nursing; a handbook for practice.</u> Gaithersburg, Md. Aspen Publishers Inc.

Douglas, C. 1992. For all the saints. <u>BMJ.</u> Vol.304. Pp.579.

Draper, P. 2001. Spiritual coping strategies: a review of the nursing literature. <u>Journal of Advanced Nursing.</u> Vol.34. No.6. Pp.833-841

Dreyfus, H L. 1980. Holism and hermeneutics. <u>Review of Metaphysics.</u> No.34. Pp.3-23.

Duda, D. 1982. <u>Guide to Dying at Home.</u> Santa Fe, N M. John Muir Publications.

Durkheim, E. 1938. <u>The Rules of Sociological Method.</u> New York. The Free Press.

Durkheim, E. 1965. <u>Sociology and Philosophy.</u> London. Cowen and West.

Dyson, J, Cobb, M and Forman, D. 1997. The meaning of spirituality: a literature review. <u>Journal of Advanced Nursing.</u> Vol.26. No.6. Pp.1183-8.

Eagle, R. 1980. <u>A Guide to Alternative Medicine.</u> London. BBC.

Eagleton, T. 1991. <u>Ideology: an introduction.</u> London. Verso.

Easthope, G. 1986. Healers and Alternative Medicine: a sociological examination. Aldershot, Hants. Blackmore Press.

Edgar, I R. 1995. Dreamwork, Anthropology and the Caring Professions. Aldershot. Avebury.

Efficace, F and Marrone, R. 2002. Spiritual issues and quality of life assessment in cancer care. Death Studies. Vol.26: Pp.743-756.

Eliade, M. 1989. Shamanism: archaic techniques of ecstasy. London. Penguin Books.

Elias, N. 1985. The Loneliness of the Dying. Oxford. Blackwell.

Ellison C. 1998. Introduction to symposium: health and well being. Journal for the Scientific Study of Religion. Vol.37. No.4. Pp.692-4.

Elsdon, R. 1995. Spiritual pain in dying people: the nurse's role. Professional Nurse. Vol.10. No.10. Pp.641-3.

Emblen, J and Pesut, B. 2001. Strengthening transcendent meaning: a model for the spiritual nursing care of patients experiencing suffering. Journal of Holistic Nursing. Vol.19. No.1. Pp.42-56.

Ernst, E. 1997. Evidence-based complementary medicine. Complementary Therapies in Nursing and Midwifery. Vol.3. Pp42-5.

Evans, D and Evans, M. 1996. A Decent Proposal: ethical review of clinical research. Chichester. John Wiley and Sons.

Fallowfield, L. 1990. The Quality of Life: the missing measurement in health care. London. Souvenir Press.

Feifel, H (ed). 1959. The Meaning of Death. New York. McGraw Hill.

Feinstein, A. 1979. Personal mythology as a paradigm for a holistic psychology. American Journal of Orthopsychiatry. Vol.49. Pp.198-217.

Field, D, Hockey, J and Small, N (eds.). 1997. <u>Death, Gender and Ethnicity.</u> London. Routledge.

Fingarette, H. 1996. <u>Death: philosophical soundings.</u> Illinois. Open Court.

Firth, R. 1996. <u>Religion: a humanist interpretation.</u> London. Routledge.

Fitzpatrick, R, Fletcher, A, Gore, S, Jones, D, Spiegelhalter, D and Cox, D. 1992. Quality of life measures in health care I: Applications and issues in assessment. <u>BMJ.</u>Vol.305. Pp.1074-7.

Fletcher, A, Gore, S, Jones, D, Fitzpatrick, R, Spiegelhalter, D and Cox, D. 1992. Quality of life measures in health care II: design, analysis and interpretation. <u>BMJ.</u> Vol.305. No.6862. pp.1145-8.

Foltyn, J L. 1994. Dead beauty: the preservation, memorialisation and destruction of beauty in death. *In: Howarth, G and Jupp, P C (eds). Contemporary issues in the sociology of death, dying and disposal. (Pp.72-83). Basingstoke. Macmillan.*

Foucault, M. 1976. <u>Madness and Civilization: a history of insanity in the age of reason.</u> London. Tavistock Publications.

Foucault, M. 1989. <u>The Birth of the Clinic.</u> London. Routledge.

Fox, N J. 1993. <u>Postmodernism, Sociology and Health</u>. Buckingham. Open University Press.

Frankl, V E. 1963. <u>Man's Search for Meaning: an introduction to logotherapy.</u> New York. Washington Square Press.

Fraser, S J and Walters, J W. 2000. Death- whose decision? Euthanasia and the terminally ill. <u>Journal of Medical Ethics.</u> Vol.26. Pp.121-5.

Freund, P E S and McGuire, M B. 1991. <u>Health, Illness and the Human Body: a critical sociology.</u> New Jersey. Prentice Hall.

Froggatt, K. 1997. Signposts on the journey: the place of ritual in spiritual care. International Journal of Palliative Nursing. Vol.3. No.1. Pp42-6.

Fu-Chang Tsai, D. 1999. Ancient Chinese medical ethics and the four principles of biomedical ethics. Journal of Medical Ethics. Vol.25. No.3. Pp.315-321.

Fuller, R B. 1996. Holistic Health Practices. In: Van Ness, P H (ed). 1996. Spiirituality and the Secular Quest. Pp.227-250. New York. The Crossroad Publishing Company.

Furnham, A. 2000. How the public classify complementary medicine: a factor analytic study. Complementary Therapies in Medicine. Vol.8. Pp82-87.

Garbarino, M S. 1977. Sociological Theory in Anthropology: a short history. U.S.A Holt, Rinehart and Winston.

Gearin-Tosh, M. 2002. Living Proof: a medical mutiny. London. Scribner.

Gee, E D. 1992. The Light Around the Dark. New York. National League for Nursing Press.

Geertz, C. 1975. The Interpretation of Cultures: selected essays. London. Hutchinson and Co. Ltd.

Geertz, A W and Sinding Jensen, J. 1991. Religion, Tradition and Renewal. Denmark. Aarhus University Press.

Geertz, C. 1995. After the Fact: two countries, four decades, one anthropologist. Cambridge, Massachusetts. Harvard University Press.

Gelven, M. 1990. Spirit and Existence: a philosophical enquiry. U.S.A. Collins.

Gerber, R. 2000. Vibrational medicine. In: Bloom, W (ed). Holistic revolution: the essential New Age reader. (Pp.175-8). London. The Penguin Press.

Gibson, M. 2001. Death scenes: ethics of the face and cinematic deaths. Mortality. Vol.6. Number 3. Pp. 306-320.

Giddens, A. 1992. Sociology. Oxford. Polity Press.

Gilbert, K R. 2002. Taking a narrative approach to grief research: finding meaning in stories. Death Studies. VOl.26. No.3. Pp.223-239.

Gill, R, Hadaway, CK and Long Marler, P. 1998. Is religious belief declining in Britain? Journal for the Scientific Study of Religion. Vol.37. No.3. Pp.507-16.

Glaser, B G and Strauss, A L. 1965. Awareness of Dying. Chicago. Aldine Publishing Co.

Goddard, N. 1998. Spirituality as integrative energy. Journal of Advanced Nursing. Vol 22. Pp808-15.

Godkin, J. 2001. Healing Presence. Journal of Holistic Nursing. Vol.19. No.1. Pp.5-21.

Golberg, B. 1998. Connection: an exploration of spirituality in nursing care. Journal of Advanced Nursing. Vol.27. Pp 836-42.

Good, B J. 1994. Medicine, Rationality and Experience. Cambridge. Cambridge University Press.

Goodacre, H (ed.) 1996. Fighting Spirit: the stories of women in the Bristol breast cancer survey. London. Scarlet Press.

Graham, H. 1990. Time, Energy and the Psychology of Healing. London. Jessica Kingsley Publishers.

Grainger, R. 1999. Medicine and the meaning of life. Int.Journ.of Complementary Medicine. Vol.17. No.6. Pp.20-5.

Graves, N and Varma, V (eds). 1997. Working For a Doctorate. London.

Routledge.

Gray, R E. 1997. Interviews with men with prostate cancer about their self-help group experience. <u>Journal of Palliative Care.</u> Vol.13. No.1. Pp.15-21.

Gray, R E. 2001. Cancer self-help groups are here to stay: issues and challenges for health professionals. <u>Journal of Palliative Care</u>. Vol.17. No.1. Pp. 53-8.

Green, J. 1991. <u>Death With Dignity: meeting the spiritual needs of patients in a multi-cultural society.</u> London. Nursing Times Publication, MacMillan Magazines Ltd.

Greenfield, T (ed). 1996. <u>Research Methods: guidance for postgraduates.</u> London. Arnold.

Griffin, D.R (ed). 1988. <u>Spirituality and Society</u>. Albany. State University of New York Press.

Grimby, A. 1995. <u>Aspects of Quality of Life in Old Age: studies on life events, bereavement and health.</u> Dept. of Geriatric medicine, Vasa Hospital, Goteborg University, Sweden.

Guthrie, S E. 1996. Religion: what is it? <u>Journal for the Scientific Study of Religion</u>. Vol.35. No.4. Pp412-9.

Häggman-Laitila, A. 1999. The authenticity and ethics of phenomenological research: how to overcome the researcher's own views. <u>Nursing Ethics</u>. Vol.6. No.1. Pp.12-22.

Hahn, R A. 1999. The Nocebo Phenomenon: scope and foundations. *In: Harrington, A (ed.). The Placebo Effect: an interdisciplinary exploration. (Pp.56-76). London. Harvard University Press.*

Hall, S and Gieben, B (eds). 1982. <u>Formations of Modernity</u>. Oxford. Polity Press.

Hallam, E, Hockey, J and Howarth, G. 1999. Beyond the Body: death and social identity. London. Routledge.

Hammond, M, Howarth, J and Keat, R. 1991. Understanding Phenomenology. Oxford. Blackwell.

Harden, J. 2000. Language, discourse and chronotope: applying literary theory to the narratives in health care. Journal of Advanced Nursing. Vol.31. No.3. Pp.506-512.

Harrar, S and O'Donnell, S A. 1999. The Woman's Book of Healing Herbs. Pensylvania. Rodale Press Inc.

Harrington, A (ed.). 1997. The Placebo Effect: an interdisciplinary exploration. London. Harvard University Press.

Harris, P and Rees, R. 2000. The prevalence of complementary and alternative medicine use among the general population: a review of the literature. Complementary Therapies in Medicine. Vol.8. Pp.88-96.

Harvey, L. 1990. Critical Social Research. London. Unwin Hyman.

Hayes N. 1984. A First Course in Psychology. Surrey. Thomas Nelson and Sons.

Health Development Agency, 2002. Cancer Prevention: a resource to support local action in deleivering the NHS Cancer Plan. London.

Heelas, P. 1996. The New Age Movement. Oxford. Blackwell.

Heelas, P (ed.). 1998. Religion, Modernity and Postmodernity. Oxford. Blackwell Publishers.

Heidegger, M. 1968. Existence and Being. London. Lowe and Brydone.

Helgeson, VS, Cohen, S, Schultz, R and Yasko, J. 2000. Group support interventions for women with breast cancer: who benefits from what? Health Psychology. Vol.19. No.2. Pp.107-114.

Heller T, Bailey L and Pattison, S (eds). 1992. Preventing Cancers. Buckingham. Open University Press.

Helman, C. 1994. Culture, Health and Illness. Oxford. Butterworth-Heinemann Ltd.

Hendrick, J. 2001. Legal aspects of clinical ethics committees. Journal of Medical Ethics. Vol.27.Supp.1: Pp.150-153.

Herman, J. 2001. Medicine: the science and the art. Journal of Medical Ethics: Medical Humanities. Vol.27. Pp.42-6.

Herth, K. 1990. Fostering hope in terminally ill people. Journal of Advanced Nursing. Vol.15. Pp1250-9.

Hertz, R. (Translated by Needham R. and Needham C.) 1960. Death and the right hand. Aberdeen. The University Press.

Hicks, C and Hennessey, D. 1997. Research evidence and practice. Journal of Advanced Nursing. Vol.25. No.3. Pp.595-601.

Higginson, I J. 1992. The Development, Validity, Reliability and Practicality of a New Measure of Palliative Care: the support team assessment schedule. PhD. London University College.

Higginson, I. 1997. Palliative and Terminal Care. UK. Radcliffe Medical Press.

Highfield, M F and Cason, C. 1983. Spiritual needs of patients: are they recognised? Cancer Nursing. Vol.6. No.3. Pp.187-192.

Hill, M. 1992. Nutrition and the prevention of human cancer. In: Heller et al, (eds). Preventing Cancers. (Pp. 59-67). Buckingham. Open University Press.

Hinnels, J R (ed). 1995. Dictionary of Religions. London. Penguin.

Hinton, J. 1967. Dying. London. Penguin.

Hinton, J. 1999. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. Palliative Medicine. Vol.13. Pp.19-35.

Hockey, J L. 1987. The Human Encounter With Death: an anthropological approach. PhD. Durham.

Hockey, J. 1993. Experiences of Death: an anthropological account. Edinburgh. Edinburgh University Press.

Hockey, J. 1994. The Ideal of Home: domesticating the institutional space of old age and death. Conference Papers. University of Teesside. 6th-8th September.

Hockey, J, Katz, J and Small, N. 2001. Grief, Mourning and Death Ritual. Buckingham. Open University Press.

Hofmann, B. 2001. The technological invention of disease. Journal of Medical Ethics: Medical Humanities. Vol.27. Pp.10-19.

Holland, J. 1988. A Postmodern Vision of Society. In: Griffin, D.R (ed). Spirituality and Society. (Pp.41-61). Albany. State University of New York Press. Albany.

Holmes, J. 1992. An Introduction to Sociolinguistics. London. Longman.

Holt, J. 2000. Exploration of the concept of hope in the Dominican republic. Journal of Advanced Nursing. Vol.32. No.5. Pp1116-1125.

Honeybun, J, Johnson, M and Tookman, A, 1992. The impact of a death on fellow hospice patients. British Journal of Medical Psychology. Vol.65. Pp.67-72.

Hopper, A. 2000. Meeting the spiritual needs of patients through holistic practice. <u>European Journal of Palliative Care.</u> Vol.7. No.2. Pp.60-2.

House of Lords Select Committee on Science and Technology. Session 1999-2000. <u>Complementary and Alternative Medicine</u>. HL 123. 6th Report.

Howarth, G and Jupp, P C (eds). 1996. <u>Contemporary Issues in the Sociology of Death, Dying and Disposal</u>. Basingstoke. MacMillan.

Howarth, G. 2000. Dismantling the boundaries between life and death. <u>Mortality.</u> Vol.5. No.2. Pp.127-138.

Howes, D (ed). 1991. <u>The Varieties of Sensory Experience: a sourcebook in the anthropology of the senses.</u> Toronto. University of Toronto Press.

Hughes, M. 1996. Interviewing. *In: Greenfield T (ed)*. *<u>Research Methods: guidance for postgraduates.</u> (Pp.169-177). London. Arnold.*

Humphreys, C. 2001. 'Waiting for the last summons': the establishment of the first hospices in England 1878-1914. <u>Mortality</u>. Vol.6. No.2. Pp.146-166.

Hunt, M W. 1994. <u>Dying at Home: its basic 'ordinariness' displayed in patients', relatives and nurses' talks</u>. PhD. Goldsmith's college, London.

Husebo, S. 1998. Is there hope, doctor? <u>Journal of Palliative Care.</u> Vol.14. No.1. Pp43-8.

Hutchings, D. 1991. Spirituality in the face of death. <u>The Canadian Nurse.</u> Vol.87. No.5. Pp30-1.

Illich, I. 1975. <u>Medical Nemesis.</u> London. Calder and Boyars.

Irish, D P, Lunquist, K F, and Nelsen V J. 1993. <u>Ethnic Variations in Dying, Death and Grief.</u> London. Taylor and Francis Inc.

Iwerson, J. 1999. Phenomenology, sociology and history of the New Age. <u>NUMEN.</u> Vol.46. No2. Pp.211-18.

Jeffrey, M A. 1995. Appropriate palliative care: where does it begin? European Journal of Cancer. Vol.4. Pp122-6.

Johnson, I S, Rogers, C, Biswas B and Ahmedzai, S. 1990. What do hospices do? A survey of hospices in the United Kingdom and the Republic of Ireland. BMJ. Vol.300. Pp791-3.

Johnson, M. 1999. Observations on positivism and pseudoscience in qualitative nursing research. Journal of Advanced Nursing. Vol.30. No.1. Pp67-73.

Jones, A. 1997. Death, poetry, psychotherapy and clinical supervision. Journal of Advanced Nursing. Vol.25. Pp238-44.

Justice, C. 1997. Dying the Good Death. Albany. State University of New York Press.

Kamm, F M, 1996. Morality, Mortality: Vol1: rights, duties and status. New York. Oxford University Press.

Kastenbaum, R and Kastenbaum, B. 1989. Encyclopedia of Death and Dying. Phoenix, Arizona. Oryx Press.

Kearl, M. 1989. Endings. Oxford. Oxford University Press.

Kearney, M. 1978. Spiritualist Healing in Mexico. In: Morley, P and Wallis, R. Culture and Curing: anthropological perspectives on traditional medical beliefs and practice. (19-39). London. Owen.

Kellehear, A. 1995. Dying of Cancer: the final year of life. New York. Harwood Academic Publishers.

Kellehear, A. 1999. Current perspectives on death, dying and mourning. Religious Studies Review. Vol.25. No.1. Pp29-34.

Kelsey, M T. 1973. Healing and Christianity. New York. Harper and Row.

Kim, M J and Moritz, D A (eds). 1982. <u>Classification of Nursing Diagnoses: proceedings of the Third and Fourth National Conferences.</u> New York, McGraw-Hill Book Co. P.314. *Cited in Conrad, 1985.*

King, P. 1990. <u>The Will to Live: a holistic approach to life-threatening diseases.</u> Wellingborough. Thorsons.

King, U. 1998. <u>Faith and Praxis in a Postmodern Age</u>. London. Cassell.

Kirkevold, M. 1997. Integrative nursing research. <u>Journal of Advanced Nursing</u>. Vol.25. No.5. Pp.977-84.

Kleinman, A. 1988. <u>The Illness Narrative: suffering, healing and the human condition.</u> New York. Free Press.

Koch, T. 1998. Story telling: is it really research? <u>Journal of Advanced Nursing</u>. Vol.6. Pp.1182-1190.

Kolcaba, R. 1997. The primary holisms in nursing. <u>Journal of Advanced Nursing</u>. Vol. 25. No.2. Pp.290-6.

Kornonchak, J A, Collins M and Lane D A. 1987. <u>The New Dictionary of Theology.</u> Dublin, Eire. Gill and MacMillan Ltd.

Kramer, K. 1988. <u>The Sacred Art of Dying: how world religions understand death.</u> New York. Paulist Press.

Krausz, E and Miller, S H. 1974. <u>Social Research Design</u>. London. Longman.

Kubler-Ross, E. 1970. <u>On Death and Dying</u>. London. Tavistock.

Kubler-Ross, E. 1975. <u>Death, the Final Stage of Growth.</u> New Jersey. Prentice Hall.

Kubler-Ross, E. 1982. <u>Living With Death and Dying.</u> London. Souvenir Press.

Kuppelomaki, M. 2001. Spiritual support for terminally ill patients: nursing staff assessments. Journal of Clinical Nursing. Vol.10. Pp.660-670.

Laderman, C and Roseman, M. 1996. The Performance of Healing. Routledge. London.

Lamerton, R. 1973. Care of the Dying. London. Penguin.

Lampe, G W H. 1977. God as Spirit. Oxford. Clarendon Press.

Lawton, J. 2000. The Dying Process: patients' experiences of palliative care. London. Routledge.

Layder, D. 1994. Understanding Social Theory. London. Sage Publications.

Lee, E. 1995. A Good Death. London. Rosendale Press.

Leibvicic, L. 2002. Medicalisation: peering from inside medicine. BMJ. Vol.324. Pp.866.

Levine, S. 1987. Healing Into Life and Death. Bath. Gateway Books.

Levinson, R. 1998. Issues at the interface of medical sociology and public health. In: Scrambler, G and Higgs, P (eds). Modernity, Medicine and Health. (Pp.66-81). London. Routledge.

Leydon, M, Boulton, M, Moynihen, C, Jones, A, Mossman, J, Boudioni, M and McPherson, K. 2000. Cancer patients' information needs and information seeking behaviour: in depth interview study. BMJ. Vol.320. Pp.909-913.

Little, M. 1999. Research, ethics and conflicts of interest. Journal of medical Ethics. Vol.25. Pp.259-62.

Littlewood, J. 1992. Aspects of Grief: bereavement in adult life. London. Routledge.

Lloyd, L. 2000. Dying in old age: promoting well being at the end of life. <u>Mortality.</u> Vol.5. No.9. Pp.171-188.

Lupton, D. 1994. <u>Medicine as Culture.</u> London. Sage Publications.

Lyng, S. 1990. <u>Holistic Health and Biomedical Medicine: a countersystem analysis.</u> Albany. State University of York Press.

Lynge, E. 1992. The importance of the social dimensions of cancer. *In: Heller, T et al. <u>Preventing Cancers.</u> (Pp.18-26). Buckingham. Open University.*

MacLean, U. 1978. Choices of Treatment Among the Yoruba. *In: Morley, P and Wallis, R. <u>Culture and Curing: anthropological perspectives on traditional medical beliefs and practice.</u> (Pp.152-167). London. Owen.*

MacLeod, R. 2001. On reflection: doctors learning to care for people who are dying. <u>Social Science and Medicine.</u> Vol.52. Pp.1719-1727.

MacMillan Cancer Relief Survey. 1999. <u>Open Spaces.</u> London. BRMB Social Research.

MacMillan Cancer Relief. 2002. <u>Directory of Complementary Therapy Services in UK Cancer Care.</u> Cambridge. Cambridge Publishers.

MacNutt, F. 1977. <u>The Power to Heal.</u> Indiana. Ave Maria Press.

Madge, J. 1965. <u>The Tools of Social Science.</u> London. Longman.

MaGee, P and Notter, J. 1995. <u>Research Appreciation</u>. London. Mark Allan Publishing.

Malpas, J and Solomon, R C (eds). 1998. <u>Death and Philosophy.</u> London. Routledge.

Manning, M. 1984. <u>The Hospice Alternative</u>. London. Souvenir Press.

Mansell-Pattinson, E M. 1977. The Experience of Dying. New Jersey. Prentice-Hall.

Martin, C J and McQueen, D V. 1989. Readings for a New Public Health. Edinburgh. Edinburgh University Press.

Martin, G. 1977. Healing: reflections on the Gospel. Michigan. Servant Books.

Martsolf, D S and Mickley, J R. 1998. The concept of spirituality in nursing theories: differing worldviews and extent of focus. Journal of Advanced Nursing. Vol.27. Pp294-303.

Maslow, A.H. 1968. Toward a Psychology of Being. USA. Litton Educational Publishing Inc.

Maslow, A H. 1970. Motivation and Personality. New York Harper Row.

Maslow, A.H. 1976. The Further Reaches of Human Nature. Middlesex. Penguin.

Mauss, M. 1979. Sociology and Psychology: essays. London. Routledge and Kegan Paul.

Mazer, T M. 1994. Death and Dying in a Hospice: an ethnographic study. PhD. Edinburgh.

McCall-Simmons, G.J. 1969. Issues in Participant Observation: a text and a reader. New York . Random House.

McDonnell, A, Lloyd-Jones, M and Read, S. 2000. Practical considerations in case study research: the relationship between methodology and process. Journal of Advanced Nursing. Vol.32. No.2. Pp.383-390.

McDowell, I and Newell, C. 1987. Measuring Health: a guide to rating scales and questionnaires. New York. Oxford University Press.

McGee, P and Notter, J. 1995. Research Appreciation. Salisbury. Mark Allan publishing Ltd.

McGinn, B.C. and Meyendorff, J. (eds). 1986. Chrstian Spirituality: origins to the twelfth century. London. Routledge and Keagan Paul.

McGrath, P. 1998. Role of a Buddhist philosophy in an Australian hospice. Journal of Mortality. Vol.3. No 3. Pp.251-63.

McGrath, P. 1999. Exploring spirituality through research: an important but challenging task. Progress in Palliative Care. Vol.7. No.1. Pp3-9.

McGrath, P. 2003. Religiosity and the Challenge of Terminal Illness. Death Studies. Vol.27. No.10. Pp.881-899.

McHaffie, H.E. 1996. Ethical Issues in Nursing Research. *In. Cormack, D F S (ed). The Research Process In Nursing. (Pp.32-40). Oxford. Blackwell Science.*

McKenzie, E. 2001. Healing Reiki. London. Hamlyn.

McNamara, B. 2001. Fragile Lives: death, dying and care. Buckingham. Open University Press.

McNeill, J. 1999. Cancerlink: helping people to help themselves. European Journal of Cancer Care. Vol.8. Pp.12-15.

McPherson, K. 1992. Hormones and Cancer. *In: Heller, T et al. Preventing Cancers. (Pp.106-111). Buckingham. Open University.*

McQuarrie, J. 1973. Existentialism. London. Penguin Books.

McSherry, W and Draper P. 1998. The debates emerging from the literature surrounding the concept of spirituality as applied to nursing. Journal of Advanced Nursing. Vol.27. Pp683-91.

Meraviglia, M.G. 1999. Critical analysis of spirituality and its empirical indicators. Journal of Holistic Nursing. Vol.17. No.1. March. Pp.18-33.

Merton, R K. and Kendal, P L. 1956. The Focused Interview. New York. The Free Press.

Mills S.Y. 2001. The House of Lords report on complementary medicine: a summary. Complementary Therapies in Medicine. Vol.9. Pp.24-9.

Money, M. 1997. Shamanism and complementary therapy. Complementary Therapies in Nursing and Midwifery. Vol.3. Pp.131-5.

Morley, P and Wallis, R. 1978. Culture and Curing: anthropological perspectives on traditional medical beliefs and practice. London. Owen.

Morgan, M, Calnan M and Manning N P. 1985. Sociological Approaches to Health and Medicine. London. Groom Helm.

Morris, C A. 1985. Self-concept as altered by the diagnosis of cancer. Nursing Clinics of North America. Vol.20. No.4. Pp.611-30.

Morse, J.M. 1992. Qualitative Health Research. California. Sage Publications.

Moustakas, C. 1994. Phenomenological Research Methods. London. Sage Publications.

Moynahan, R. and Smith, R. 2002. Too much medicine. BMJ. Vol.324. Pp.859-360.

Munns, B. 1991. What Factors Are Important to the Quality of Life of Dying Patients? PhD. University of Surrey.

Murdock, G.P. 1980. Theories of Illness: a world survey. Pittsburg. University of Pittsburg Press.

Murray Parkes, C. 1996. Bereavement: studies of grief in adult life. London. Routledge.

Myers, G. Restoration or transformation? Choosing ritual strategies for end of life care. <u>Mortality</u>. Vol.8. No.4. Pp.372-387.

Narayanasamy, A. 1993. Nurses' awareness and educational preparation in meeting their patients' spiritual needs. <u>Nurse Education Today</u>. Vol.13. Pp196-201.

The National Council for Hospice and Specialist Pallliative Care Services. 1997. <u>An Introduction to Palliative Care.</u> Occassional paper.

The National Council for Hospice and Specialist Pallliative Care Services. 1998. <u>Reaching Out: specialist palliative care for adults with non-malignant disease</u>. Occassional paper 14.

The National Council for Hospice and Specialist Pallliative Care Services. 1998. <u>Promoting Partnership: planning and managing community palliative care</u>. Occassional paper 15.

<u>The New Shorter Oxford English dictionary</u>. 1993. Oxford. Clarendon Press.

Neate, T and Neate, A. 2001. Healing the whole person. *In: Barraclough, J. Integrated cancer Care. (Pp.120-131). Oxford. Oxford University Press.*

Nekolaichuk, C and Bruera, E. 1998. On the nature of hope in palliative care. <u>Jounal of Palliative Care</u>. Vol.14. No.1. Pp.36-42.

Nerken, I.R. 1993. Grief and the reflective self: toward a clearer model of loss resolution and growth. <u>Death Studies.</u> Vol.17. No.1. Pp1-26.

Neuman, B. 1989 <u>The Neuman Systems Model.</u> Conneticut. Appleton and Lange. 2nd.edn. *Cited in Goddard, 1995.*

Nichol, K.M. and Devereux, J. 1999. Encounters with doctors: quantity and quality. <u>Palliative Medicine</u>. Vol.13. Pp.217-223.

Niven, N. 1989. <u>Health Psychology.</u> London. Churchill Livingstone.

Nolan and Crawford. 1997. Towards a rhetoric of spirituality in mental health care. Journal of Advanced Nursing. Vol 26. No.2. Pp.289-94.

Nouwen, H. 1981. The Way of the Heart. London. Darton, Longman and Todd.

Nouwen, H. 1979. The Wounded Healer. London. Darton, Longman and Todd. (This edition 1994).

Nuchtern, M. 1998/5. The criticism of scientific medicine and the attractiveness of Western 'alternative' methods of healing. Concilium: Illness and Health. SCM Press. London. Chaevet L.M. and Tonka M. eds. Pp.15-24.

Nuland, S.B. 1994. How We Die. London. Chatto and Windus.

O'Gorman, S M. 1998. Death and dying in contemporary society: an evaluation of current attitudes and the rituals associated with death and dying and their relevance to recent understandings of health and healing. Journal of Advanced Nursing Vol.27. Pp.1127-35.

Olarte, J M N. 1999. Care of the dying in eighteenth century Spain- the non-hospice tradition. European Journal of Palliative Care. Vol.6. No.1. Pp.23-7.

Oldnall, A. 1996. A critical analysis of nursing: meeting the spiritual needs of patients. Journal of Advanced Nursing. Vol.23. Pp.138-144.

Oliver, L. 1990. Liminality and the Hospital Ward: unity through adversity. In: Davies, D J. Studies in Pastoral and Social Anthropology. (Pp.64-74). Dept. of Theology. University of Birmingham. 2nd edition.

Oliviere, D. 1999. Culture and ethnicity. European Journal of Palliative care. Vol.6. No.2. Pp.53-7.

Orchard, H. (ed). 2001. Spirituality in Health Care Contexts. London. Jessica Kingsley Publishers.

Osuna, E, Pérez-Carceles M D, Esteban M A and Luna A. 1998. The right information for the terminally ill patient. <u>Journal of Medical Ethics.</u> Vol.24. Pp.106-9.

Owen, M.J. and Holmes C.A. 1993. 'Holism' in the discourse of nursing. <u>Journal of Advanced Nursing.</u> Vol.18. Pp.1688-1695.

Pagels, H R. 1982. <u>The Cosmic Code: quantum physics and the language of nature</u>. London. Michael Joseph.

Parsons, T. 1951. <u>The Social System.</u> London Routledge and Keegan Paul.

Patterson, E F. 1998. The philosophy and physics of holistic health care: spiritual healing as a workable interpretation. <u>Jounal of Advanced Nursing</u> Vol.27. Pp.287-93.

Pattinson, S. 2001. Dumbing Down the Spirit. *In: Orchard, H. (ed)*. *Spirituality in Health Care Contexts*. London. Jessica Kingsley Publishers.

Paton, D and Brown, R. 1991. <u>Lifespan Health Psychology.</u> London. Harper collins.

Paton, L. 1996. Complementary therapies in terminal care. <u>Am-J-Hospice-and-Palliative-care.</u> Vol.13. No.2. Pp.52-6.

Payne, S, Hillier, R, Langley-Evans, A and Roberts, T. 1996. Impact of witnessing death on hospice patients. <u>Social Science and Medicine</u> Vol.43. No.2. Pp.1785-1794.

Payne, S and Walker, J. 1996. <u>Psychology for Nurses and the Caring Professions.</u> Buckingham. Open University Press.

Penson, J. 1998. Complementary therapies: making a difference in palliative care. <u>Complementary Therapies in Nursing and Midwifery.</u> Vol.4. Pp.77-81.

Pert, C.B. 1997. <u>Molecules of Emotion: why you feel the way you feel.</u> London. Pocket Books.

Pert C. Psychoneuroimmunology: molecules of emotion. 2000. *In: Bloom, W (ed.). Holistic Revolution: the essenetial New Age reader. (Pp.169-174). London. The Penguin Press.*

Philbert, P.J. 1998/5. Transitions in the meaning of health and health care: a first world perspective. *In: Chaevet, L.M. and Tonka, M. (eds). Concilium: Illness and Healing. (Pp.1-7). London. SCM Press.*

Pietroni, P. 1987. Holistic medicine: new messages to be learned. The Practitioner. Vol.231. Pp.1386-90.

Pietroni, P. 1990. The Greening of Medicine. London. Victor Gollancz Ltd.

Pietroni, P. 1993. The Return of the Spirit. *In: Beattie, A et al (eds). Health And Well Being: a reader. (Pp.303-310). Buckingham. Open University Press.*

Porter, R. 1986. Patients and Practitioners: lay perceptions of medicine in pre-industrialised society. Cambridge. Cambridge University Press.

Porter, S. 1996. Qualitative Research. *In: Cormack, D F S (ed.). The Research Process In Nursing. (Pp.113-122). Oxford. Blackwell Science.*

Porter, S. 1996. Qualitative Analysis. *In: Cormack, D F S (ed.). The Research Process In Nursing. (Pp.330-340). Oxford. Blackwell Science.*

Poss, S. 1981. Towards Death With Dignity: caring for dying people. London. George Allen and Unwin.

Power, R M. 1991. The Whole Idea of Medicine: a critical evaluation of the emergence of 'holistic medicine' in Britain in the early 1980s. PhD. Southbank Polytechnic.

Presley, 1996. Common Terms and Concepts in Nursing Research. *In: Cormack, D F S (ed.). The Research Process In Nursing. (Pp.14-21). Oxford. Blackwell Science.*

Price, J L, Stevens, H O and La Barre M C. 1995. Spiritual caregiving in nursing practice. Journal of Psychosocial Nursing. Vol.33. No.12. Pp5-9.

Prickett , J.1980. <u>Death.</u> Guildford. Littlewood Educational.

Prior, D. 1999. Palliative care in marginal communities. <u>Progress in Palliative Care.</u> Vol.7. No.3. Pp 109-114.

Quinn, S. 1996. <u>Uncertain Lives, Untimely Deaths: experiences and psychosocial needs of the young adult with chronic illness.</u> Aldershot. Avebury.

Rabinow, P. (ed.) 1984. <u>The Foucault Reader.</u> London. Penguin.

Radice, S. 2001. Bach to Basics. <u>The Guardian *Weekend*.</u> September 1st. P.73.

Randall, F and Downie, R S. 1996. <u>Palliative Care Ethics: a good companion.</u> Oxford. Oxford University Press.

Randall, F. 1999. Reply to Farside's editorial: palliative care- a euthanasia-free zone. <u>Journal of Medical Ethics</u>. Vol.25. Pp.259-62.

Rando, T (Ed). 2000. <u>Clinical Dimensions of Anticipatory Mourning: theory and practice in working with the dying, their loved ones and their caregivers.</u> Illanois. <u>Research Press</u>.

Rankin-Box, D. 1998. Spirited approaches. <u>Complementary Therapies in Nursing and Midwifery.</u> Vol.4. Pp.153-5.

Reed, P G. 1986. Religiousness among terminally ill and healthy adults. <u>Research in Nursing and Health</u>. Vol.9. Pp35-41.

Reed, P.G. 1991. Preferences for spiritually related nursing interventions among terminally ill and non-terminally ill and well adults. <u>Applied Nursing Research.</u> Vol.4. No.3. Pp.122-8.

Reoch, R. 1997. <u>Dying Well: a holistic guide for the dying and their carers.</u> London. Gaia Books Ltd.

Richer, M.C. and Ezer, H. 2000. Understanding beliefs and meanings in the experience of cancer: a concept analysis. Journal of Advanced Nursing. Vol.32. No.5. Pp.1108-1115.

Rinpoche, S. 2002. The Tibetan Book of Living and Dying. London. Rider.

Robinson, M. 2000. Writing well: health and the power to make images. Journal of Medical Ethics: Medical Humanities. Vol.26. Pp.79-84.

Robson, C. 2002. Real World Research. Oxford. Blackwell (2nd edition).

Roman, E M, Sorribes E and Esquerro, O. 2001. Nurses' attitudes to terminally ill patients. Journal of Advanced Nursing. Vol.34. No.3. Pp.338-345.

Rosenberg, A. 1995. Philosophy of Social Science. Oxford. Westview Press.

Ross, A. 1994. Spiritual aspects of nursing. Journal of Advanced Nursing. Vol.19. Pp.439-47.

Russell, P and Sander, R. 1998. Palliative care: promoting the concept of a healthy death. British Journal of Nursing. Vol.7. No.5. Pp.256-62.

Sadala, M and Adorno, R. 2002. Phenomenology as a method to investigate the experience lived: a perspective from Husserl and Merleau Ponty's thought. Journal of Advanced Nursing. Vol.37. No.2. Pp.282-93.

Sainio, C, Lauri, S and Eriksson, E. 2001. Cancer patients' views and experiences of participation in care and decision-making. Nursing Ethics. Vol.8. No.2. Pp.97-113.

Sakalys, J.A. 2000. The political role of illness narratives. Journal of Advanced Nursing. Vol.31. No.6. Pp.1469-1475.

Saks, M (ed.) 1992. Alternative Medicine in Britain. Oxford. Clarenden Press.

Salmon, J.W. 1985. Alternative Medicines: popular and policy perspectives. New York. Tavistock Publications.

Sarvimaki, A. and Stenbock-Hult, B. 2000. Quality of life in old age described as a sense of well being, meaning and value. Journal of Advanced Nursing. Vol.32. no.4. Pp.1025-1033.

Saunders, C and Baines, M. 1983. Living With Dying. Oxford. Oxford University Press.

Saunders, C, Summers, DH and Neville, T. 1981. Hospice: the living idea. London. Edward Arnold.

Saunders, C. 1990. Hospice and Palliative Care: an interdisciplinary approach. London. Edward Arnold.

Scambler, G and Higgs, P. (eds.) 1998. Modernity, Medicine and Health. London. Routledge.

Schneider, S. 1989. Spirituality in the Academy. Theological Studies. 50. Pp.676-697.

Schneider, S. 1986. Theology and spirituality: strangers, rivals or partners? Horizons. Vol.13. No.12. Pp.253-274.

Schou, K C and Hewison, J. 1999. Experiencing Cancer. Buckingham. Open University Press.

Schutz, A. 1962. Collected Papers. Vol.1: The Problem of Social Reality. The Hague. Martinus Nijhoff.

Schutz, A. 1962. Collected Papers I and 111. The Hague. Martinus Nijhoff.

Schutz, A. (Edited by Wagner H.R.) 1970. On Phenomenology and Social Relations: selected writings. Chicago. The University of Chicago Press.

Scott, P. A. 2000. The relationship between the arts and medicine. Journal of Medical Ethics. Vol.26. Pp.3-8.

Searle, J.R. 1996. The Constuction of Social Reality. London. Penguin Books.

Seedhouse, D. 1986. Health: the foundations for achievement. New York. Wiley.

Sellers, S C. and Haag, B.A. 1998. Spiritual nursing interventions. Journal of Holistic Nursing. Vol.16. No.3. Pp.338-54.

Sen, A. 2002. Health perception versus observation. BMJ. Vol.324. Pp. 860-1.

Shapiro, A K and Shapiro, E. 1997. The Placebo: is it much ado about nothing? In: Harrington, A (ed.).In: The Placebo Effect: an interdisciplinary exploration. (Pp.12-36). London. Harvard University Press.

Sharma, U. 1992. Complementary Medicine Today: practitioners and patients. London. Routledge.

Sharma, H. and Clark, C. 1998. Contemporary Ayurveda. New York. Churchill Livingstone.

Sharpe, V.A. and Faden, A.I. 1998. Medical Harm: historical, conceptual and ethical dimensions of iatrogenic disease. Cambridge. Cambridge University Press.

Sheldrake, P. 1995. Spirituality and History: questions of interpretation and method. SPCK. Revised Edition. London.

Sheldrake, P. 1998. Spirituality and Theology: Christian living and the doctrine of God. Darton, Longman and Todd. London.

Shemmings, Y. 1996. Death, Dying and Residential Care. Aldershot. Avebury.

Shih F J, Gau M, Mao H, Chen, C and Kao Lo, C. 2001. Empirical validation of a teaching course on spiritual care in Taiwan. Journal of Advanced Nursing. Vol.36. No.3. Pp.333-6.

Simonton, O C, Matthews-Simonton, S and Creighton, J L.1980. Getting Well Again. London. Bantam Books.

Small, N and Rhodes, P. 2000. Too Ill to Talk. London. Routledge.

Smaje, C. and Field, D. 1997. Absent minorities? ethnicity and the use of palliative care services. In: Field, D et al. Death, Gender and Ethnicity. (Pp.142-165). London. Routledge.

Smith, K. Earth to Earth. Guardian. Society. 18.8.99. Pp.6-7

Smucker, C J. 1998. Nursing, healing and spirituality. Complementary Therapies in Nursing and Midwifery. Vol.4. Pp.95-7.

Sourkes, B M. 1982. The Deepening Shade: psychological aspects of life-threatening illness. Philadelphia. University of Pittsburgh Press.

Spiegelhalter, D J, Gore, S M, Fitzpatrick R, Fletcher, A E, Jones, D R and Cox D R. 1992. Quality of life measures in health care. III: resource allocation. BMJ. Vol.305. Pp.1205-9.

Spiro, H. 1997. Clinical Reflections on the Placebo Phenomenom. In: Harrington, A (ed.). The Placebo Effect: an interdisciplinary exploration. (Pp.37-55). London. Harvard University Press.

Stajduhar, K and Davies, B. 1998. Death at home: challenges for families and directions for the future. Journal of Palliative Care. Vol.14. No.3. Pp.8-14.

Stallibrass, C. and Hampson, M. 2001. The Alexander Technique: its application in midwifery and the results of preliminary research into Parkinson's. Complementary Therapies in Nursing and Midwifery. Vol.7. Pp.13-18.

Stanworth, R. 2000. <u>Sources of Meaning and Sense of Self in People Who Are Dying</u>. PhD. London, Heythorp College.

Stanworth, R. 2004. <u>Recognising Spiritual Needs in People Who Are Dying</u>. Oxford. Oxford University Press.

Staton, J, Shuy, R and Byock, I. 2001. <u>A Few Months to Live: different paths to life's end</u>. Washington D C. Georgetown University press.

Stedeford, A. 1984. <u>Facing Death: patients, families and professionals.</u> London. Heinemann Medical Books.

Steiger, N and Lipson, J. 1985. <u>Self Care Nursing: theory and practice</u>. Brady communications, Bowie, Maryland. *Cited in Dyson and Cobb, 1997.*

Steinhauser, K E, Clipp, E C, McNeilly M, Christakis, N A, McIntyre, L M and Tulsky, J A. 2000. In search of a good death: observations of patients, families and providers. <u>Annals of Internal Medicine.</u> Vol.132. No.10. Pp.825-832.

Stewart, M J. 1990. Expanding theoretical conceptualisations of self-help groups. <u>Social Science and Medicine.</u> Vol.31. No.9. Pp.1057-1066.

Stiles, M K. 1990. The shining stranger. <u>Cancer Nursing.</u> Vol.13. NO.4. Pp235-45.

Stoddard, S. 1979. <u>The Hospice Movement.</u> London. Jonathon Cape.

Stoll, R. 1979. Guidelines for spiritual assessment. <u>American Journal of Nursing.</u> Vol 79. No9. Pp1574-7.

Stone, J. 2000. Ethical issues in complementary and alternative medicine. <u>Complementary Therapies in Medicine.</u> Vol.8. Pp.207-213.

Stoter, D. 1995. <u>Spiritual Aspects of Health Care.</u> London. Mosby.

Strang, S, Strang, P and Ternestedt, B M. 2002. Spiritual needs as defined by Swedish nursing staff. Journal of Clinical Nursing. VOl.11. Pp.48-57.

Strauss, A and Corbin, J. 1990. Basics of qualitative research: grounded theory procedures and techniques. California. Sage Publications.

Stroebe, W and Stroebe, M S. 1987. Bereavement and Health: the psychological and physical consequences of partner loss. Cambridge. Cambridge University Press.

Stroebe, M and Schut, H. 1999. The dual process model of coping with bereavement: rationale and description. Death Studies. Vol.23. Pp.197-244.

Sudnow, D. 1967. Passing On: the social organisation of dying. New Jersey. Prentice Hall.

Swinton, J. 2001. Spirituality and Mental Health Care: rediscovering a forgotten dimension. London. Jessica Kingsley Publishers.

Tannen, D. 1984. Conversational Style: analysing talk among friends. Norwood, New Jersey. Ablex Publishing Corporation.

Tannen, D. 1989. Talking Voices: repetition, dialogue and imagery in conversational discourse. Cambridge. Cambridge University Press.

Tavares M. 2003. National Guidelines for the Use of Complementary Therapies in Supportive and Palliative Care. London. The Prince of Wales Foundation for Integrated Health and The National Council for Hospice and Specialist Palliative Care Services.

Taylor, A. 1989. Acquainted With the Night: a year on the frontiers of death. London. Fontana.

Thomas KJ, Nicholl JP and Coleman P. 2001. Use and expenditure on complementary medicine in England: a population based survey. Complementary Therapies in Medicine. Vol.9. Pp.2-11.

Thomson, R. 1989. Loving Medicine. Bath. Gateway Books.

Toulis, N.R. 1997. Believing Identity. Oxford. Berg.

Turner, V. 1995. The Ritual Process: structure and anti-structure. New York. Aldne de Gruyter.

Urben, L. 1997. Self-help groups in palliative care. European Journal of Palliative Care. Vol.4. No.1. Pp.26-28.

Utke, A.R. 1986. The cosmic holism concept. Ultimate Reality and Meaning. Vol.9. No.2. Pp.134-155.

Van den Borne, H W, Pruyn, J F A and Van DAM-de Meyk. 1986. Self-help in cancer patients: a review of studies on the effects of contacts between fellow patients. Patient Education and Counselling. Vol.8. Pp.367-385.

Vandendorpe, F. 2000. Funerals in Belgium: the hidden complexity of contemporary practices. Mortality. Vol.5. No.1. Pp.18-33.

Van Der Molen, B. 2000. Relating information-needs to cancer experience. 1: Jenny's story: a cancer narrative. European Journal of Cancer Care. Vol.9. Pp.41-7.

Van Der Molen, B. 2000. Relating information-needs to cancer experience. 2: Themes from six cancer narratives. European Journal of Cancer. Vol.9. Pp.48-54.

Van der Zalm, J and Bergum, V. 2000. Hermeneutic phenomenology: providing living knowledge for nursing practice. Journal of Advanced Nursing. Vol.30 No.1. Pp.211-18.

Van Ness, P H (ed). 1996. Spiirituality and the Secular Quest. New York. The Crossroad Publishing Company.

Wallis, R and Morley, P. 1976. Marginal Medicine. London. Peter Owen.

Walter, T. 1990. Funerals and How to Improve Them. London. Hodder and Stroughton.

Walter, T. 1994. Facing death without tradition. *In: Howarth, G and Jupp, P C (eds). Contemporary issues in the sociology of death, dying and disposal. (Pp.193-204). Basingstoke. MacMillan.*

Walter, T. 1994. The Revival of Death. London. Routledge.

Walter, T. 1996. Developments in spiritual care of the dying. Religion. Vol.26. Pp.353-63.

Walter, T. 1997. The ideology and organisation of spiritual care: three approaches. Palliative Medicine. Vol.11. Pp.21-30.

Walter, T. 1999. On Bereavement: the culture of grief. Buckingham. Open University Press.

Walter, T. 2003. Spirituality in palliative care: opportunity or burden? Palliative Medicine. Vol.16. Pp.133-9.

Ward, J and Wood, C. 2000. Education and training of healthcare staff: the barriers to its success. European Journal of Cancer Care. Vol.9. Pp.80-85.

Watson. 1984. Fear No Evil. London. Hodder and Stroughton.

Watson, J. 1988. Nursing: human science and human care. New York. National League for Nursing.

Weir, R F (ed). 1977. Ethical Issues in Death and Dying. New York. Columbia University Press.

Wengstrom, Y, Häggmark, C, Strander, H and Forsberg, C. 2000. Perceived symptoms and quality of life in women with breast cancer receiving radiation therapy. European Journal of Oncology Nursing. Vol.4. No.2. Pp.78-88.

Wheeler, I. 2001. Parental bereavement: the crisis of meaning. Death Studies. Vol.25. No.1. Pp.51-66.

Wilkinson, J and Hatfield, A. 2002. The epidemiology of cancer. *In: Baker, M R (ed). Modernising Cancer Services. (Pp.15-35). Oxon. Radcliffe Medical Press.*

Wilkinson, K. 1996. The concept of hope in life-threatening illness. Professional Nurse. Vol.11. No.10. Pp.659-661.

Williams, D. 1996. Research Proposals. *In: Greenfield, T (ed). Research Methods: guidance for postgraduates. (Pp.15-19). London. Arnold.*

Williams, D. 1996. Finding Funds. *In: Greenfield, T (ed). Research Methods: guidance for postgraduates. (Pp. 20-28). London. Arnold.*

Willows, D and Swinton, J (eds). 2000. Spiritual Dimensions of Pastoral Care: practical theology in a multidisciplinary context. London. Jessica Kinsley Publishers.

Wolfe, J. (ed.) 1994. The Growth of Religious Diversity: Britain from 1945. Buckingham. Open University.

Woodhead, L. and Heelas, P. 2000. Religion in Modern Times. Oxford. Blackwell Publishers.

Woods, S, Beaver, K and Luker, K. 2000. Users' views of palliative care services: ethical implications. Nursing Ethics. Vol.7. No.4. P314-26.

Wright, M. 2001. Spiritual Health Care: an enquiry into the spiritual care of patients with cancer within the acute hospital and the specialist in-patient palliative care unit in England and Wales. PhD. Sheffield University.

Yin, R.K. 1994. Case Study Research: design and methods. London. Sage Publications Ltd.

Young, M and Cullen, L. 1996. A Good Death: conversations with East Londoners. London. Routledge.

Zappone, K. 1991. <u>The Hope for Wholeness: a spirituality for feminists.</u> Conneticut. Twenty-third Publications.

Zimmern, R. 2002. Genetics and medicalisation. <u>BMJ.</u> Vol.324. Pp. 863-4.

Zucker, M B and Zucker, H D. 1997. <u>Medical Futility.</u> Cambridge. Cambridge University Press.

Research Proposal

Title

The significance of a holistic philosophy to the care of people facing life-threatening illness.

Research question

In what ways is the application of a holistic philosophy in care significant to the spiritual well-being of people facing life-threatening illness who have joined a support group which purports to promote a holistic philosophy?

Aims

The aim of the research is to determine the significance of holistic care to the spiritual well-being of people facing life-threatening illness.

Objectives

With this aim in mind, the objectives are to study a group of people who are experiencing a potentially life-threatening illness and to look at the ways in which they perceive themselves, their bodies, life and death, to discover in what ways their illness has contributed to these perceptions, and to assess the contribution made by holistic care in constructing these perceptions. The extent to which holistic care has been perceived by the subjects to have contributed to their capacity to experience increased peace, happiness and well-being will be analysed using discourse analysis and other interpretative methods. Finally, the significance of the data collected in field research will be considered with reference to the extensive literature and previous research on holism and holistic care.

Method

The term 'spirituality' will be used to encompass all aspects of the spiritual side of life, such as world views, personal outlooks and philosophies on and of life and the perceived meaning of life and death. Spirituality encompasses the physical, psychological and social spheres of life. This, and related concepts, will be discussed in detail in the preliminary chapter(s) of this thesis.

The data collected in field research will be analysed using discourse analysis and interpretive methods. The research is qualitative rather than quantitative.

The subjects

The subjects will be self-volunteered and have expressed an interest in what they perceive to be holistic care by joining a cancer support group which promotes the philosophy of the Bristol Cancer Help Centre. The 'actively' terminally ill will not be involved. Taking part in the research will be completely voluntary. The consent of the support group Committee will be obtained prior to starting the study and counselling support for the subjects will be arranged through the group in case this is required during the research, since this is such a sensitive area of enquiry.

Approaching the subjects

Ethical Committee permission will be obtained from the two area Committees relevant to the geographical locations of the study prior to the start of the research. The researcher will then speak at the meeting of the Northumberland Cancer Support Group and will send information to members of the group via the mailing list explaining how they can become involved in the study. **Written consent** will be obtained from each subject prior to their participation in the study and the most suitable venue for future meetings and interviews will be established.

The **diagnoses** of the subjects need not be limited to cancer, but it is acknowledged that, as subjects will be identified through a cancer support group the majority of them will have this diagnosis.

Each subject will take part in a preliminary interview conducted by the researcher, will keep a diary record for 4-5 weeks and will have a follow-up interview (see copies of consent form, information to be given to subjects, interview schedules and guidance for diary keeping).

Consent Form

I am conducting a research project and would be grateful if you would consider taking part in it.

As I have explained at the Northumberland Cancer Support Group meeting, participating in the research will involve two interviews with the researcher and the keeping of a diary recording significant information for a period of four to five weeks. This diary can be either written or take the form of a tape recording, according to preference. A tape recorder may be used during the interviews, for which your consent will be requested prior to starting the interview.

Taking part in the research is entirely voluntary and, if you decide to become involved, you have the right to withdraw your consent at any time without giving a reason.

Researcher: **Elizabeth Hanley**

I,   have read and understood the information detailed

above and consent to becoming involved in the proposed study.

Signature: **Date:**

Research project information

I am conducting a research project and would be grateful if you would consider taking part in it.

The **aim of the research** is to determine the significance of holistic care to the spiritual well-being of people facing life-threatening illness.

Taking part in the research is **entirely voluntary** and, if you decide to become involved, you have **the right to withdraw your consent at any time without giving a reason.**

Participating in the research will involve **two interviews** with the researcher and the **keeping of a diary** recording significant information for a period of **four to five weeks. You will be contacted by the researcher after two weeks so that any questions or concerns can be addressed.** The issues you will be asked to provide information about are your illness history, perceptions of illness and well-being, beliefs about life and meaning, perceptions of self and how the process and philosophies of your care have affected these.

The proposed research study will form part of a postgraduate degree thesis project, undertaken at Newcastle University.

The diaries will be transcribed by the researcher only. The researcher, her supervisor and those assessing the final thesis will have access to the data and results, but the identities of the subjects will be known only to the researcher. A copy of the thesis will be held in the University library after completion and may be consulted by other students involved in related projects.

If you are interested, please contact me at the number below.

Liz Hanley   Tel: 01669 620 856

Guidance for diary keeping

Please include any further details of your **illness history,** as discussed in the preliminary interview and **your perceptions of the quality of your care at different stages. Memories** of **experiences of care and treatments** can be recorded at any point in the diary. That is, this record is meant to be a record of **significant** day to day events, with it's main aim being reflection on your overall illness history over the specified time period.

Please continue to collect information related to the **themes discussed in the preliminary interview.**

Please record **any event which makes you think about your illness and its impact on the subjects discussed at your preliminary interview,** particularly personal views of self and comments in relation to this expressed by others in concrete situations.

Any aspect of your care found to be most helpful and most unhelpful should be recorded as close to its happening as possible, so that you are jotting down your reactions to situations as they are experienced.

Daily entries should be made, even if only to record that nothing significant happened on that particular day.

The record should be kept for **two weeks,** after which you will be contacted by the researcher, who will answer any questions and give you support as required. The diary should be kept for **a further 2-3 weeks.**

The diary will be collected prior to the second interview.