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ABSTRACT

Geoffrey William Martin - Education, Empowerment and The Dying Patient

Nurse education has focused, in recent years, on the need for students to translate theory into improvements in practice. This thesis has used this idea to examine the concept of empowerment and the dying patient. Nurses involved in post-registration education have been asked to examine their practice and produce written reflections on critical incidents related to empowerment. These have then formed a basis for the examination of the strategies and barriers which effect the care of dying patients and their right to self-determination. A new paradigm approach to the research has been adopted in an effort to involve the subjects of the study (the nurses) in defining and controlling the outcomes. The data has been analysed, in the main, by employing 'thick description' advocated by Geertz to attempt to discover intentions and meaning which organise actions.

The thesis has examined five areas of concern:

1. The need to change the culture of care surrounding the dying patient.
2. The role that ritual action takes in limiting the options open to patients.
3. Strategies and barriers, linked to the communication process, which effect patient empowerment and come to light by an examination of the data.
4. The value of the nurse as patients' advocate and its effect on the process of empowerment.
5. Examination of the concept of reflection in practice and within the educational process as a way forward.

The conclusion highlights the difficulties that nurses have with ideas of change and attempts to emphasis positive aspects around nurse/patient communications, which may point the way forward for greater autonomy for patients. The need for further research is highlighted, which would examine the effect on practice of reflection on critical incidents and enquire into ways of ensuring that change results which moves towards the reduction of disempowerment for vulnerable dying patients.

Education, Empowerment and The Dying Patient.

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PREFACE

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Preface

I would like to thank all the students on the ENB 931, 934 and Death and Dying modules for their help with this study. I would also like to thank all my colleges at work who have listened to my ideas, particularly Gordon Mitchell and the library staff at Bishop Auckland Education Centre. I would especially like to thank my supervisor Professor Bill Williamson at Durham University without whose help this study would never have been written and finally I would like to thank my partner Steve Bamlett for his help and support, as always. They are not in any way responsible for the faults, those are all my own work.

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Chapter 1 Introduction

There remains in the health service many areas where standards and patient care could be improved. Over the last ten years reforms have taken place that have begun to show improvements in the way that patients' autonomy and self-determination have been realised. There is, of course, still a long way to go. People who have mental health problems or learning difficulties will need to put continual pressure on the health service to meet their requirements in ways that take account of their wishes. However, it could be argued that such groups are now being listened to and a level of empowerment is apparent. There are still large groups of people who have not yet achieved even these small measures of success. Older people, people with dementia and dying people are just three groups that very often have decisions taken for them. Recent studies have painted a bleak picture of the quality of care they receive. (Field 1989, Hockey 1990, Katz and Sidell 1994, Kitwood 1995, Katz 1996)

However, some improvement around care for the dying patient is apparent. The move to value the role of palliative care and the Macmillan nursing service have brought about changes that were fundamental to patient care in these areas. What this study addresses is the slow pace of change occurring in settings other than the hospice. It will examine the change of emphasis that care of the dying has faced over the last hundred years but particularly in the recent past. Discussion will address a new culture of care that values the role of the patient based around the work carried out by Tom

Kitwood (1995) and others in the area of dementia care. Factors affecting working practices which reduce the ability of the nurse to act as advocate and so reduce empowering opportunities will be discussed. Issue, such as empathy and advocacy will be examined as processes of empowerment to understand the problems nurses have when addressing the care of dying patients. The role of nurse education will be considered at relevant points in the discussion. The final chapter will examine the value of reflection as a central concept which underpins the research and has the potential to become a pathway to change.

Life expectancy in the United kingdom has changed dramatically over the last 70 years. In 1910 expectancy was 53.4 years which had risen to 73.7 by 1980. The majority of people who die in Britain now are older people, 79 per cent of deaths in 1986 were people over 65 and 55 per cent were over 75 (Seale 1993). Table 1 shows the causes of death in England and Wales for 1987.

Deaths by underlying cause: England and Wales, 1987

<u>Causes</u>	<u>Male</u>	<u>Female</u>
Neoplasms	74,325	68,126
Mental Disorders	4,140	8,297
Circulatory	132,599	138,462
Respiratory	29,712	27,363
Digestive	7,414	10,255
Injury or poisoning	10,991	6,832
Other causes	15,871	26,039
Total	278,172	285,374

Table 1. (Source OPCS 1989 Table C)

The largest cause relates to diseases of the circulatory system (heart attacks and strokes) these account for 47 per cent of all male deaths and 49 per cent of female deaths. As can be seen from the figures, death from cancer accounts for just 26 per cent of all deaths even though most of the literature tends to focus on this area (Victor 1993). Similarly many of the improvements in care of the dying patient have also been focused on the care of the cancer patient. Improvements such as the hospice movement, initially, concentrated on care of the cancer patient. Marie Curie and the Macmillan Nursing Service still tend to focus their care on this area. In recent times, however, they have considered the care of a broader range of patients, including people with HIV/AIDS.

The vast majority of deaths in Britain take place in hospital. Around 60 per cent in all, with higher figures in urban areas. The percentage of deaths at home remains at about

25 per cent, still higher than many other countries (1993 p.58) but low when considering the situation in the first half of the century. The pattern changed fairly rapidly from the late 1940s when most deaths took place at home. (These changes may now be slowing down, however, given the current emphasis on community care options.) According to Cartwright and Seale (1990) most of the **care** of dying patients still takes place at home or in settings other than the hospital. In 1987, 12 per cent of those who died had spent some time in a nursing or residential home and this number is increasing. This study will include research from all of these areas, by considering the role of the community and nursing home nurse as well as nurses from hospital settings.

Research results based on work carried out with students on relevant post registration modules will be utilised throughout the main discussion to inform the theoretical debate. These results will give a sound basis to the arguments, and enable analysis of the core issues of empowerment, empathy and advocacy pertinent to patient care. Some of the material that arises is directly relevant to nurse education. Hence recommendations will be offered, resulting from analysis of that material, that ensures that these core themes remain central to the development of nurse education. Findings which show a failure to take account of the oppressive nature of care will also be highlighted. Conclusions will attempt to bring together the arguments and point the way forward for further research and improvements in practice.

Historical Perspective

To bring about change we must first understand the process of past change and the power structures and cultural diversities which were once in place. Aries, according to Walter (1992 p.296), argues that we are the heirs both of Victorian romanticism, which made the loss of loved ones unbearable, and twentieth century denial, which forbids mention, or at least hides death (Aries 1974, 1981). Aries thesis has been criticised for ignoring the death of women (Smale 1985) and the working class (Walter 1992). However his central premise remains valid; the death of Victorian romanticism has reflected cultural resources which have left denial, or secrecy, as the norm for the experience of death and dying. Covering all the changing factors of the last hundred years is not possible but from consideration of a few we can begin to see how such change may have emerged.

According to Aries the nineteenth century clearly took a different perspective on the process of death and dying from the twentieth century. The cultural resources available to the nineteenth century which facilitated a socialisation of death and dying, included popular literature of the time such as Dickens (the death of Little Nell for example) and the widely read poetry of Wordsworth, Byron and Tennyson. These writers' images of death and dying could have given a meaning to death and a model that people could use to structure the dying process, or even the way that death, and social responses to it, were managed. Dicken's idealisation of Little Nell's death is a

means of generalising its emotion so that it becomes a social fact, enabling death to be confronted across the range of human diversity.

and still her fairer self lay there, unaltered in this change....., at the door of the poor schoolmaster on the summer evening, at the still bedside of the dying boy there had been the same mild lovely look. So shall we know the angels in their majesty, after death. (Dickens 1978)

This passage attempts to unite a number of diversities in human life (gender, class, spirit/body and time). There would also have been the importance of religion and religious ceremonies. The arrival of the priest at the bedside would have been an important sign that the dying process was ending. At this stage the patient would be expected to act out the role accordingly, abandoning any illusion that they may have held of recovery. Aries agrees that at this time, death was a public affair in which the whole community was involved.

Even into the twentieth century, in some village communities, this level of involvement survived. David Clark (1982) illustrated this in his study of Staithes in North Yorkshire in the 1950s. He describes rituals that had not changed for many years and gives examples of a high degree of community and family involvement in the arrangements following death. Local women would layout the body, which remained in the family home until the funeral. Relatives and friends would pay visits to see the corpse. The funeral organisation occupied several people (mainly women) in the village, each involved in specific ways. In this way the management of death was a communal event.

At the time that Clark was describing, change in the social organisation of death and dying had been taking place in Britain and other western societies, be it slowly, for about fifty years. It was around the middle of the nineteenth century that these changes began. The introduction of the legal requirement that deaths should be recorded resulted in a new public awareness of every death and its cause. Gradually, over the intervening years, a change of focus occurred. Aries (1981 p550) identifies this as a new way of speaking about death. Discourse became removed from the 'whispering neighbours, relatives and friends' to the medical and administrative authorities who controlled the range and function of the discourse. Gradually the locus of the rituals of death altered to reflect that change of control. The community context was replaced by the administrative, mainly medical, context with its emphasis on diagnosis and infection control. Death became professionalised and the role of the local women vanished replaced by, the mainly male, undertaker (Clark 1982 p.137). Factors such as the requirement of a death certificate, weakening community bonds, smaller families, greater mobility and changing values were all instrumental in reinforcing the change. It is important not to overemphasise these changes as care of the **dying** was more subtly altered. More people were admitted to hospital and statistics show that more than 50% died there. However, around nine out of ten people still spent most time at home in the last year of life. (Cartwright et al. 1973)

By the end of the nineteenth century, the rules and regulations about public hygiene had ensured that the professionals were in control. The processes involved in the management of death and dying were mystified by professional bodies, which served to remove those processes further from their traditional place in the community. The

rules of hygiene, suggests Armstrong (1987 p652), labelled the body as unclean and 'nauseating' not suitable for the respectable family front room. Going hand-in-hand with this were the rules of the medical profession, that served to withhold information about prognosis and take a paternalistic control of the management of the dying patient. The continuing advances in treatments, coupled with wide ranging social changes, all played their part in removing the experience of death from everyday life. This situation dominated the management of death for almost one hundred years (Aries 1981). From the middle of the nineteenth to the middle of the twentieth century, people were screened from the processes of death and dying. As with the nineteenth century, twentieth century cultural resources remained mainly in literature, and latterly mass entertainment. For example, 'Camille', based on an Alexander Dumas book, was filmed seven times between 1912 and 1936, before producers decided it belonged to a bygone age, dealing as it does with death from tuberculosis. (Halliwell 1977 p124) However one of the major successes of 1970 was 'Love Story', a piece of abject thirties sentimentality, about a young woman dying without losing a shred of beauty (1977 p.46). These popular films portrayed death as romantic, painless and noble giving an acceptable model to people unfamiliar with dying, in a similar way to the death of Little Nell described above.

However, it can be argued that by the 1950s and 60s a new discourse had begun to emerge around disclosure and openness (Armstrong 1987 p.653). Slowly, this discourse began to challenge the 'conspiracy of silence' that had arisen, and by the late 1960s, change was occurring. Until this time it was the human body that was scrutinised, guarded and categorised; now it began to emerge that the person who

inhabited that body was allowed to speak. The sixties have been identified by several writers (Armstrong 1983, Walter 1992) as the turning point. They link this period to the emergence of the 'counter culture' and liberation movements that demanded to be valued. Simultaneously new innovations in health care were having an effect and most deaths were of older people. Blauner (1966 p.380) believes that, although such deaths were sad, the individual's roles had long been replaced and hence they were missed less than younger people. Elaborate rites of passage were no longer necessary. Meaning had become fragmented and death became non-threatening for the young. Popular culture played with ideas of death and a crop of 'death' songs were popular such as 'Tell Laura I Love Her', 'Leader of the Pack', 'Ebony Eyes'. These could be enjoyed without the fear that they held any reality for young people of the time.

The dying person began to be listened to and psychological needs as well as physiological needs began to be addressed. The emergence of the nursing process and models of nursing placed greater emphasis on communication with the patient. According to Armstrong (1983 p.459) this did not come about without problems. Nurses used this improved level of communication to reinforce the sick role by use of the power vested in the process of interrogation. They could use the products of that interrogation to define the needs of the patient according to the **nurse's** agenda. While the new regime of truth is to be welcomed, it must be seen within the context of a mode of control. The cultural impoverishment of the patient as far as models of dying were concerned, may have lead to disempowerment of the patient with little or no knowledge of the 'correct' procedures. A situation that allowed the professionals to take control. Not until the hospice movement began to have a major influence on care

and control did empowerment become central to patient care. Patients were, at last, allowed some measure of involvement in care decisions.

Professional Discourse

It is useful at this point to consider some recent nursing textbooks, insofar as they reflect a 'damaging' professional discourse, to assess to what extent they also reflect a change of direction. Particular note will be taken of any discussion of patient participation in decision making and advocacy by nurses.

To assess change, consideration of an early text book on the subject, edited by Raven (1976), may provide a base line. Raven's book contains various chapters which address aspects of the care of dying patients. It is general in nature but approaches the issue from a 'problem management' perspective. It does address the need to interact with the patient. It points out that patients, 'do require above all else from their nurses...an atmosphere, however spurious, of leisured personal interest in their problems' (p.24). This detached approach, which avoids the concept of involvement by the nurse, except on a fairly superficial level, fails to value the role or the 'personhood' of the patient. It advocates communications merely as a technique rather than a way of valuing and encouraging a patient-centred approach.

If we compare this with a more recent book for P2000 students by Kenworthy et al. (1992) we can see evidence of a change of emphasis. Kenworthy et al. (p.315) suggest

the nurse follows the person's own agenda 'to give him [sic] a sense of achievement and control'. There is still discussion of control of information by the medical team. Disclosure of bad news is felt to be best 'controlled' by the doctor. Advocacy is addressed briefly, but only in relationship to children. This book is wide-ranging in subject matter only covering care of dying patients in chapter 17.

A book written specifically to address the management of terminally malignant disease is a collection of essays edited by Saunders and Sykes (1993 3rd ed.). It starts with a chapter entitled 'communications' which covers the notion of self-determination but only 'within the limits set by the legitimate interests of others'. The author adds that such an approach requires a 'sharing of information and joint decision making'(Sheldon 1993 p.17). Little more is said about this but it is clearly progress on earlier texts.

The concept is also included in a further specialist text book 'The Quality of Dying'(Bender et al. 1990). They state in the preface that what makes the book unusual is that it stresses the importance of both physical and psychological care. Later they emphasise 'the importance of staff encouraging residents to make their own decisions... even if the staff are not totally in agreement with these decisions'(p.7). It is an accessible book that avoids jargon. Despite its promising start it tends to focus on what nurses should do in a practical sense rather than illustrating a partnership approach.

A widely available text is the 3rd edition of Robbins and Moscrop (1995). It contains a series of essays on a wide range of issues relating to care of the dying patient. The first chapter is disappointing in that it concentrates on the 'gentle quiet approach' with the nurse being a good listener and conveying warmth and a positive attitude. Although these are essential qualities, they do not give any scope for an individualised approach that allows the patient to define the caring relationship. The result may be to stereotype patients and so confine them to the passive role of receivers of care. The specific chapter on communications is better. It starts with the statement, 'It is important to give the patient a feeling of being in control' (Faulkner 1995 p.9). Later in the chapter there is some backtracking, when it is felt that the patient does not need 'the whole unpalatable truth' and that they 'generally suspect all is not well and arrive at the truth themselves'(p.12). These views tend to undermine the idea of control and allow the nurse to avoid confronting issues of truth and information giving, should this become important to the patient. Ellwood (1995 p.232) in a later essay acknowledges that nurses find it difficult to come to terms with giving bad news. He does not address how this problem might be addressed or what effect it has on the patient.

One final important text book widely used by students and registered nurses is 'The Elements of Nursing' by Roper et al. (1996 4th ed.) This was the only book in the set that addressed advocacy in any detail. Some findings from Mills et al. (1994 p.408) were quoted which showed that dying patients were usually alone for three quarters of the time and, as death approached, this increased. They emphasised the need to move away from doing things for patients towards an approach that respected autonomy,

self-direction and empowerment of the client, (p.128) clearly a step forward from earlier texts.

There have been a number of non-nursing books and papers in recent years that have looked in-depth at the issue of empowerment. Many address the concept from a particular stand point: i)Social work (Ward and Mullender 1990); ii)Groupwork (Mullender and Ward 1991); iii)Parents and children (Gibson 1995); iv)Multiple Sclerosis (Miller 1993); v)Women (Sheilds 1995); vi)Older people (McWilliams et al. 1994); vii)Community Care (Jack 1995). Several papers explore the concept in a general way (Skelton 1994; Gilbert 1995; Kubsch 1996.) There are a few studies that have linked empowerment and dying; two of these are worth consideration here.

Bailey (1990) looked at the subject from the perspective of the hospice patient and family. He emphasised the importance of the family unit as not only the unit of care but also the leader of the health care team. A basic framework of empowerment is outlined and this is then applied to the clinical setting. A few case histories are given as examples of how the process can work. It is a useful paper that includes a practical model for use in the clinical area. Ray (1996) has produced a shorter paper that identifies seven ways to empower dying patients. They include body language, voice tone and the importance of valuing the patients' abilities and strengths. Overall it is useful as a first step towards understanding the concept and applying it to practice.

The literature that has built up around hospice and palliative care contains the general consensus that patients should be fully involved in their care and fully informed

throughout. (Denise 1987, Martyn 1989, Saunders 1990) Otherwise there is little specific material that addresses the issue in depth.

This short selection of books and articles illustrates the beginnings of a new approach to care of the dying patient that includes consideration of the patient's wishes and involvement in decisions. Less recent books tend to concentrate on the nurse's role rather than patient involvement as an equal partner. While there is clearly a small body of literature that takes a new approach this is not fully reflected in the standard text books available.

Change is, therefore a slow process and change in approaches to health care can, perhaps, be linked to social changes which began to have an effect in the late 1960s. The various liberation movements of the time demanded to be heard and so the users voice, which had been largely absent until then, began to be heard. The new radical right in politics had grown in strength by the early 1980s and adopted a similar approach from a different ideological base. One result was focused around various users charters, the most relevant being the patients' charter, the implication of which will be considered in later chapters.

It is important to now consider what is meant by the term 'empowerment' before looking at the research findings in detail.

Chapter 2 Empowerment - a review

The model of empowerment discussed in this study relies, in the main, on the interpersonal communication processes which arise between the nurse and the patient. If we consider this relationship we may be able to identify the pattern or model which provides the most open and flexible environment in which empowerment can develop.(figure 1).

Relationship Model

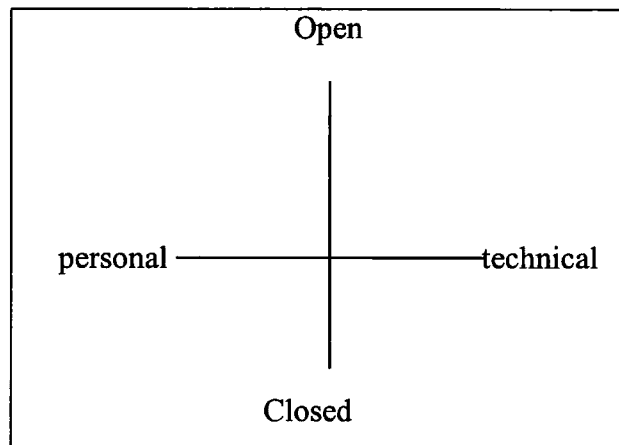


Figure 1.

The relationship can be characterised to range from an open, personal approach, characterised by emotional involvement and empathy, to a closed technical approach marked by emotional neutrality and distancing, depending on which point of the diagram the relationship falls. It will be argued throughout this study that it is through the former that patient empowerment is most likely to arise. The latter can only lead to a less involved relationship in which there is less scope for empowerment by virtue of the control that the nurse maintains within it. A closed relationship can result in the

nurse avoiding the patient, for whatever reason, and their relationship never having the potential to become an empowering one.

Awareness context and the dying trajectory

The question must be addressed as to why nurses adopt such avoidance behaviour? Consideration of Glaser and Strauss's (1965) 'awareness context' may point to one possible reason. They identified four types of awareness context. (The reaction by the parties to the realisation that death is inevitable and relatively imminent.) In brief the reactions are as follows;

- 'Closed' context, when the patient is not aware of his/her terminal condition although the staff and other carers are.
- 'Suspicion awareness' context, when the patient suspects he/she is dying but any attempts to confirm this are rejected.
- 'Mutual pretence' context, when both patients and staff know the prognosis but agree either implicitly or explicitly not to discuss it.
- 'Open awareness' context, which hold the potential for free discussion of the situation as all parties are aware of the prognosis.

By considering these four contexts it is possible to see that the first two could lead to a greater avoidance by nurses. They must face the dilemma of answering difficult questions or lying and therefore are more likely to avoid any situation that may bring this about. These first two contexts were very much the norms in the past. High (1989 p.6) reminds us that in the 60s and 70s the term a 'conspiracy of silence' arose related

to the situation of the terminally ill. He feels, however, that there is evidence that the attitudes of professionals, especially towards terminally ill patients, may be changing. If this is the case, are we seeing a change in the way nurses relate to patients and an increase in the level of empowerment?

This issue is addressed by May's (1993) study which confirms that distancing may still occur. He found that non-disclosure rendered interactions between nurses and patients highly stressful. He quotes one nurse, who felt that, when patients knew their diagnosis, their care was much easier to manage. This begs the question of whether disclosure is always done to benefit the patient if the nurse is more comfortable working in an open awareness situation.. It may sometimes make the nurse's job easier and less stressful and so benefit the nurse. However, a closed awareness context may also help the nurse, depending on that nurse's ability to talk to patients about death. A nurse who feels uncomfortable in such situations will welcome a closed context as he/she will not then be fearful of the patient wanting to discuss the subject. Strategies that would be difficult in an open awareness context can, as a result, be employed to avoid the subject.

Nurses in May's study felt that patients had the right to know their diagnosis and that relatives had no right to prevent this happening. This view while appealing, fails to consider the wishes of the relatives, partners or carers of the patient, who may know the person better than the medical staff and may constitute an important network through which patients come to decisions. Some cultures, for instance place high value on family network involvement. There is the danger that the open awareness

rule could be applied across the board without taking into consideration individual and cultural diversity and so lead to a disempowering situation developing. However May found that, when the patient was elderly, the wishes of the next of kin often prevailed. Inconsistencies to the nurses' stated rule do therefore, in fact, occur. The whole issue of disclosure and awareness has a bearing on communications between nurse and patient and needs to be taken into account when looking at ways of enhancing the empowerment of patients.

May also found that confirmation of the 'trajectory' of a disorder allowed the nurse to match their nursing practice to it rather than the patient's individual needs. The notion of a 'dying trajectory' has been researched by Glaser and Strauss (1968 p.10). They found that the nurses' definition of the patients' illness and its prognosis, affected their behaviour towards those patients. Such definitions are made by nursing staff, possibly in concert with others, based on their experience of nursing similar patients. The nurse will decide whether the patient will linger, die quickly or approach death at some pace between these extremes. This process of predicting the course of death can give the nurse the ability to plan care over the long or short term, depending on the perceived trajectory. In this way, a standard approach to care is developed which could serve to restrict options for the patient even though it meets their projected medical needs. It may lead to a stereotyped approach to the professional assessment of care needs, based on subjective observation of the length of time the patient is likely to be in need of care rather than the perceived needs of the 'here and now'.

One example of this is the standard practice of moving patients, who are likely to die quickly, into a room on their own. This is done, on the face of it, to benefit the patient by allowing privacy and open visiting but it may also have the effect of isolating patients. Nurse/patient interaction could, as a result, lead to further distancing, owing to removal from the ward environment and the nurses' regular field of vision. Glaser and Strauss found that work time with a given dying patient, depends on that patient's dying trajectory and there **was** a strong tendency to isolate patients during their last days. Strauss (1971 p.7) emphasised that trajectories are **perceived** courses of dying rather than the actual courses themselves. When they go according to expectations, then nurses are able to work to a prepared format. They can plan care without problems and they can plan the ward and bed state management to meet desired targets. As highlighted, the problems occur when the trajectory does not go as planned.

Glaser and Strauss (1965) also argue that nurses have a concept of the 'death ratio'; that is the proportion of patients on the ward who are likely to die. In an area where the chances of a sudden death are low, nurses become involved quite freely with the patients and empowerment may then be at its optimum. However, on wards where there is a high death ratio, they found there was more limited involvement. They call these differing levels of involvement the 'sentimental' order of the ward. This order is defined by what is perceived as the appropriate level of involvement in, and attitude towards, the patients. Each nurse's composure is vital to the maintenance of that order. Sentimental order therefore, is behaviour expected from the nurses that ensures the smooth running of the ward. The nurse may be in fear of becoming too upset

when caring for dying patients and so may 'lose control of herself'; in other words, lose professional 'composure'. In order for this not to happen, the nurse develops strategies, such as avoiding the dying patient or, what the authors call, the 'general defence strategy'. This is used to maintain composure when caring of patient who are dying. The strategy includes ways of talking with the patient, collective support from other nurses and, as a result, reduced personal involvement with the patient who is approaching death.

If a patient, who is thought to be lingering, suddenly dies, this can affect the nurse's composure and consequently effect the sentimental order of the ward. Similarly a patient who is expected to die but lingers, will also disturb the nurse's composure. The nurses may become distressed to see the patient suffering when they feel that there is little they can do. They may also put pressure on the senior nursing staff and doctors to give more pain and symptom control, whether the patient needs or wishes it or not. If the nurses cannot see the patients discomfort, they will feel happier and composure will return. The effect of more pain relief can be more sedation and all the accompanying physical problems. However the nurses are able to carry out routine tasks without having to feel empathy for the distress the patient is experiencing. The resulting situation is managed by the nurse to avoid the stress involved in caring for the dying patient but it also denies the patients' rights to make decisions about care and treatment.

Occasionally the patient's trajectory can be redefined and, if they are comfortable, be considered as 'lingering' until there are obvious signs of dying, such as cheyne-

stokes respiration. Through the process of redefinition and reappraisal of the patient's condition, based on notions of comfort or distress, the nurses can fall back on their role of carers as defined by the UKCC (1996). In this way they can still fulfil their role of advocates for the suffering patient, who at this stage in their illness may be too ill to make decisions for themselves.

The roles the nurse adopts, as can be seen, are dependent on a number of factors. Awareness context has its effects, as the patient will experience interactions with the nurse depending on their awareness of their prognosis. The dying trajectory will also affect the way that the nurse relates to the patient, dependent on the perceived length of the trajectory and the sentimental order of the ward. Factors which serve to limit or extend the scope of interaction that is permitted between the nurse and the patient.

For nurses to act as empowerers, they must adopt a new approach, outlined in Chapter 3. This approach depends for its success on the capacity of nurses to be prepared to work with patients at an empathetic level, that overrides aspects both of paternalism and professionalism. Davis et al. (1996) found in their research that there were surprising numbers of terminally ill people who did not seek advice for symptoms. They concluded that the extent of expressed need is likely to be far less than that of felt need (1996 p.519). Nurses must attempt to overcome disempowering situations such as these, despite the pressures imposed upon them to conform to the accepted definition of their roles. The concepts of dying trajectory and the awareness context isolate some variables which effect the levels and quality of communication. Without

them, it appears that the nurse would be unable to focus on the level and nature of involvement required by the patient.

The nurse, patient and other health care professionals are faced with a complex set of interlocking relationships within which communication takes place. The analysis of the nurses' situation can be evidenced by looking at the relationships in which their practice is situated. (Figure 2.)

Nurse/Patient/Doctor - interlocking relationship

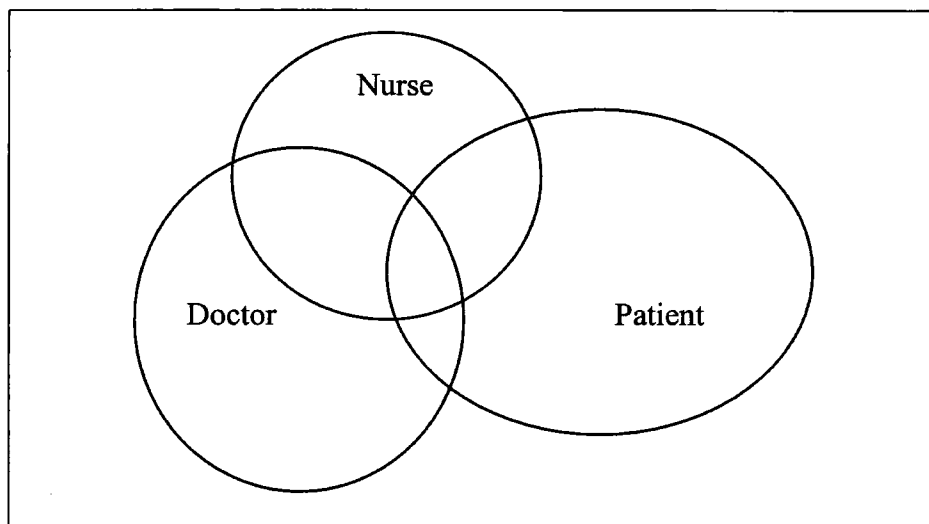


Figure 2

There is an area of shared knowledge among all three main parties. (For simplicity just three have been identified) Each of the participants has **special** knowledge that is not fully shared by all parties. For example the nurse and doctor have knowledge that is not shared with the patient based on experience and training. Similarly the patient may share confidences with the doctor that are not shared with the nurse and will, almost certainly, share confidences with the nurse that are not shared with the doctor. The overlap shown in figure 2 indicates the possible extent of such shared knowledge. The patient and doctor, for example, may have only a minimal amount of overlap

while the nurse and patient may have a larger proportion. The overlap among all three is the lowest level of knowledge which can be shared. Each party will have control over certain information that they will feel a need or a compulsion to keep to themselves. Some of these boundaries are tactical in that they can be used to keep control over the situation and so allow the individual to retain a measure of power. Awareness of diagnosis and prognosis for example is just one such area. The extent of control will depend very much on their relative status. The doctor, is likely to have the greatest control over the situation (Ballinger 1997). For patient empowerment to occur the balance must shift. It can be argued that it is the nurse who is most able to bring about this shift, by insuring the patient's boundaries of knowledge and control are extended.

This shift can be seen as a cultural change, similar to that outlined by Kitwood (1995) for people with dementia where the emphasis is placed on valuing the 'personhood' of the patient. The discussion must be focused on this change of culture and routes to such a change identified. A number of areas in which change can occur can be isolated but only four will be considered in detail in this study. They are ritual action, empathy, advocacy and education. Issues of communication will cut across all these concepts and will be addressed in the light of the overall discussion. Together, these areas of concern will be understood as barriers to, or strategies towards, allowing the patient a greater control of the management of their own care. The discussion will highlight both barriers and strategies, in an effort to move the debate forward towards an empowering cultural change. It is important to address not only the ways that change is prevented from happening but also the ways that change may best occur.

Empowerment

It is useful at this point to explore in more detail what is meant by the term empowerment, which some have called a 'fashionable' concept, whose weakness is that it can mean different things to different people. The UKCC's (United Kingdom Central Council) Code of Conduct, has until recently avoided the word empowerment but directs nurses in language that leaves little doubt of what is required. It states in clause 5 that nurses must;

work in an open and co-operative manner with patients, clients and their families, foster their independence and recognise and respect their involvement in the planning and delivery of care. (UKCC 1992)

This clause implies empowerment of patients, yet is vague enough to allow an interpretation that could fall far short of this. Keeping in mind the other demands put upon the nurse by the Code of Conduct, it is easy to see how they could be met, while still rendering the patient powerless and remote from the decision-making process.

'Involvement' does not necessarily mean autonomy for patients. A disempowering culture would be one that maintained a task-orientated approach to care rather than an individualistic one and remained caught in a rigid hierarchical structure. The potential for devolved decision-making, and a holistic approach to patient care, would be impossible. Moves to reduce the disempowerment of patients would be difficult in such a culture, as individual nurses would be unable to take control of the work environment. The process may be more subtle than this, however, since day-to-day

working practices need to be examined to ensure that old attitudes do not undermine moves towards a participatory approach between patient and nurse.

Take the assessment process for example. By its nature assessment should involve the patient but it can lead to a disempowering situation, if approached from the perspective in which 'the nurse knows best'. It may therefore become merely an 'answer giving' exercise which encourages the patient to ask questions from a position of ignorance but does not inform the patient, to the degree that they are able to understand the alternative views of their current condition or the treatment appropriate to it. This situation denies them the very knowledge of alternatives required to participate, when going on to the planning stage. A questionnaire, piloted for this study, was completed by 18 registered nurses who were attending courses related to the care of the dying patient. They were asked to put in order of importance a list of factors that related to assessment of patients' care needs. The results were interesting (see Figure 3)

Hierarchy of assessment factors

1. Holistic approach
2. Listening skills
3. Patient-lead approach
4. Empathy
5. Accuracy
6. Activities of living
7. Accountability
8. Advocacy
9. Systematic approach
10. Consultation

Figure 3.

A holistic approach was considered the most important factor and advocacy only the eighth in the list of priorities. Consultation was surprisingly bottom of the list although 'patient-led approach' and empathy came fairly high. It could be that there was some ambiguity about the meaning of the term 'consultation'. However, it would appear that decisions made by the nurse on patients' needs, although considered holistically, would ignore the patient's views. A nurse-lead approach seems to emerge if these results are to be taken at face value.

It is clear that the assessment process may meet the needs of the Code of Conduct and yet may fail to meet the needs of the patient. Hence the code is offered as an example of patient involvement at a superficial level only. It is tempting to exaggerate Clause 5's demand to empower patients. (Although the document 'Guidelines for professional practice' has clarified the position, as explained below.) Pullen (1995 p.275) feels that the improved understanding of advocacy in practice implied by clause 5, has led to a new emphasis on empowerment. She interprets the wording of the clause to refer to the promotion of independence rather than merely patient representation.

Whilst agreeing broadly with this view, it may be that we are taking too big a leap. Pullen's interpretation allows advocacy to become a cure-all without taking on board fundamental changes that must occur in the nursing culture and nurse education. Her recommendation for the instalment of a specialist practitioner seems to put too much emphasis on the personal agency of one individual nurse. Pullen does go on to discuss problems related to her recommendation and concedes that 'nursing advocacy is inherently limited by the limits of the nursing role'. The solution to employ a

specialist nurse may not be the answer, therefore. Could it hold the pitfall of being seen as the **only** solution, whilst in reality becoming merely a complaints service paid for and monitored by the organisation that is the subject of the complaint. Pullen highlights another important consideration. The Code of Conduct also asks nurses to work in collusion with the medical profession as part of the multi-disciplinary team. The two demands lead to contradictions and dilemmas that are difficult to overcome given the power structures involved.

The 'Patients' Charter and you' (Department of Health 1995) also outlines the rights of patients, including among the definition of those rights,

... the right to ... have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it.

The patient is encouraged throughout to make their wishes known. The charter emphasises their role in decision-making and outlines what to expect from the health service. This approach is underlined in the UKCC document, 'Guidelines for Professional Practice' (1996), which devotes a section to advocacy and autonomy. It requires the nurse to respect the patients' autonomy and choices concerning their own lives. Both these documents bring together the recent discussions in nursing and other health journals about the rights of patients and clients. (Gibson 1991, Malin and Teasdale 1991, Skelton 1994, Wright 1995, Gilbert 1995, Rodwell 1996) What this discussion amounts to is, in effect, a call for the transfer of power from the health professional to the patient. This process, is defined by Rodwell (1996) as follows,

In a helping partnership it is a process of enabling people to choose to take control over and make decisions about their lives. It is also a process which values all those involved.(p.309)

It is useful at this point to explore these ideas in more detail in order to understand what it is we will be addressing with regard to the empowerment of dying patients.

Bailey (1990 p.17) uses May's categories of power as a way of introducing the concept. In summary they are;

- Exploitative -- power of one person over another with actual or implied use of force.
- Manipulative -- power of one person over another due to the inability of the subservient person to exercise freedom of choice.
- Competitive -- power of one person against another, as in athletic contests.
- Nutrient[sic] -- power for another as a parent for a child.
- Integrative -- Power with another.

By examining these categories it may be possible to see some of the problems that arise in the empowerment of patients. Just three of the areas are relevant to the discussion - manipulative, nutrient and intergrative models of power.

Within the manipulative model the health professional has complete power over the patient, particularly the critically ill or dying patient who may not have the physical resources to exercise freedom of choice. It is in this situation that the health professional will need to be particularly vigilant to ensure the patients' wishes are not

ignored or interpreted in a way that is not congruent with the actual aims of those wishes.

In the nutrient model the health professional exercises power on behalf of the patient, without that person being involved in the process. The health professional acts in the perceived 'best interests' of the patient; a form of advocacy without consultation.

The integrative model is closest to that of empowerment. It occurs when the health professional involves the patient in the process but, by virtue of their role, remains the party with overall power. The result is a partnership approach that strives for equality for both parties. The health professional remains in control and retains power to influence and even veto the joint decision making process.

Because this final category does not go far toward giving the patient overall control, it is necessary to add a further category to the list that can be called 'facilitative'. This arises when the health professional enables and allows the patient to make their own decisions. At the integrative stage a sharing of power is possible. However, danger lies in it not being clear who is able to interpret and control the process. If this remains with the health professional, then it will be limited in nature and restricted in focus to that health professional's agenda. Only at the facilitative stage can a transfer of power take place and the patient begin to become empowered.

Bailey (1990 p.19) makes the point that the goal to reach is that of integrative power in order to help the patient and family help themselves. This may indeed be all that is

necessary, in many instances, but the potential for a facilitative approach must be acknowledged if a fuller empowerment is to be realised. Salvage (1990 p.42) points to the 'ideology of partnership' as a way forward. She links this to the practice of accountability, primary nursing and 'nursing as therapy' that have the one-to-one relationship of the professional and client at their roots. She concludes that the concept of partnership holds contradictions but should not be discounted because of this. The question remains as to whether purely, via one-to-one relationships alone partnership could in reality, occur. Given the current practice and ideology dominant in the health care system, the process is not clear cut. At the micro level, changes may be possible but without similar changes at the macro level, (i.e. organisation and management of health services), they become unrecognised, unfocused and fragmented. The power that the health professional holds can be devolved, as outlined, to that of a facilitator with specialist skills. The nurse/patient relationship underpins and supports such change, but without the support and commitment at the macro level change is likely to be slow to come about, if possible at all.

Kieffer (1984) (quoted in Gibson (1991 p.355/6)) conceptualises empowerment in a developmental sense that includes both macro and micro considerations. He defines the four stages as follows:

- *Era of entry* - When the individual's participation remains unsure and unknown, even though authority and power structures at the macro level are becoming demystified.
- *Era of advancement* - When mentorship relationships begin to emerge and collaboration and mutually supportive problem-solving is possible. An

understanding of the situation is gained and mechanisms for action and choices occur.

- *Era of incorporation* - When the permanence and painfulness of structural or institutional barriers to self-determination are confronted, and organisational, leadership and survival skills are developed.
- *Era of commitment* - When the interaction of new personal knowledge and skills become part of the reality and structure of the day-to-day situation.

From this we can see that empowerment is just as much a process of helping individuals to develop a critical awareness of the causes of their powerlessness, as it is an enabling process. A readiness to act to facilitate and engage in the process of the redistribution of power is central to this awareness. As Gibson (1991 p.356) puts it, 'a revolutionary rather than a reformist approach to problem-solving' is needed which changes the structure of society rather than integrating change into the existing structure. Gibson concludes that intervention needs to take place at the macro level to the conditions that control, influence and produce health or illness in human beings. Nurses must be prepared, as part of this process, to be used as a tool for empowerment within the context of equal partnership with patients. They must become a 'resource mobiliser and advocate' to ensure that access to resources are available (1991 p.360) and the patient has the knowledge to make use of them.

An important subtext that needs to be acknowledged is the use of the concept of empowerment by the radical right in politics. They use it as a way to justify the dismantling of the state bureaucracies and advancing privatisation, competitive tendering and the separation of purchasers and providers. (Skelton 1994 p.416) They

stress the importance of individual rather than that of collective responsibility. Without a collective approach, the individual is inevitably thrown back on their own resources and so the weakest members of society suffer from lack of support. Empowerment becomes another word for neglect and the individual is expected to decide and provide, without the skills or finance necessary to do so effectively. In the context of nurse-patient relationships a radical right model of empowerment might be the withdrawal of overt coercion by the nurse to enable the patient greater autonomy, but a lack of overall support from the nurse to ensure that the patients' need were addressed.

A further problem is discussed by Skelton. Using an example from Quebec, in Canada he argues that the ideas can become merely rhetorical devices to reinforce the position of the professional. Middle-class professionals are able to improve their power base at the expense of more traditional social elites and so empowerment becomes secondary to these more pressing concerns. He concludes that it does not automatically follow that empowered professionals will extend an empowering hand to their patients. It is suggested that it is not possible to say that, merely because health professionals have greater autonomy, they will automatically value that of the patient. A cultural change is also necessary in which they are prepared to take seriously the patients' point of view. This change will, according to Skelton, require a number of strategies which he called 'voice' and 'exit' strategies. 'Voice' strategies can be linked to advocacy to facilitate a 'voice' for the user/patient, allowing them to express views about quality and provision of care. 'Exit' strategies allow the user/patient to leave the service

offered if dissatisfied. It is these voice strategies, which are also relevant to the role of the nurse, but Skelton asks,

What nurses may wish to consider is how they can effectively advocate democratic rights for the least powerful, whilst also bearing in mind that the “voice” of the collective may demand aspects of care which are of doubtful benefit ... and which because they are costly, will divert resources from less glamorous but more worthwhile areas. (1994 p.420)

The issue of ‘the nurse knows best’ comes into conflict with the wishes of the patient, as does the management of scarce resources, particularly when considering the needs of dying patients. Such issues of advocacy are explored more fully in later chapters.

We have looked at the main factors and problems associated with the concept of empowerment. It is now necessary to explore further the concept of power itself to assess the influence that power structures have on the ability of the health care worker to facilitate the empowerment of patients.

Power

It is not sufficient to recommend a set of tactics which, if put into practice, would bring about an empowering culture. Tactics such as information giving, listening skills, or allocation of a named nurse, while important in themselves, do not amount to the automatic empowerment of the patient in any real sense. Gilbert (1995 p.866) rejects two further approaches. He feels that a psychological model, that asserts that

personal growth can lead to personal power, is flawed. He agrees with Katz (1984) who maintains that the approach does not attend to socio-political obstacles to self understanding. Similarly the purely political model that calls on people to work together to bring about change, is also a problem. According to Gilbert, it can lead to romantic idealism that is not relevant to modern industrial society. Such ideas are based on the works of Paulo Freire (1972) which are themselves conceptually ambiguous and can be incorporated within both liberal and conservative ideologies.

As discussed later, it is the unspoken acceptance of social practices and roles that remains the problem. Change continues to be frustrated by the view that the status quo is the natural order and therefore unquestionable. According to Lukes (1974) it is at this 'dimension of power' that the real power is situated. Foucault (1984) takes this a stage further when he points to the way power operates to create new ways of seeing and speaking. This produces a consensus around what is considered to be the truth in a particular society (Gilbert 1995). Foucault's contribution to the debate centres around the concept of normalising judgement that compares the person to given norms and notes deviations. Individuals therefore become fixed within objectifying discourses such as medicine or psychiatry.

It could be argued that tactics such as care planning and the nursing process contain all the elements of this objectification (1995 p.868). Within these tactics the individual is encouraged to 'confess' to the professional to the extent that that individual defines him/herself within a particular discursive format, such as hysteric, deviant, or alcoholic. Records are then made (the care plan) and the individual is fixed

within, for them, an alien discourse. People who are considered to be low in the hierarchy, e.g. the mentally ill, the person with dementia, the dying person, have their knowledge disqualified. As a result the discourse of popular knowledge become marginalised and devalued. Nurse education, nursing culture and the operation of the health service, also demonstrate the process.

It is, according to Foucault, 'specific intellectuals' who have power which can either benefit or destroy life. The nurse is part of this group, not able to take life as such, but able to define a person or allocate resources. However this, in itself, has been shown to have the potential to become an empowering situation. Gilbert (1995 p.869) gives a number of examples where popular knowledge may be used to confront existing discourse. People with learning difficulties, or mental health problems may require the nurse's support to form alliances with others to challenge prevailing forms of truth. Foucault (1980) therefore proposes that the analysis of the effect of power should focus on :

- Local forms of decision-making and the techniques involved.
- The identification of the processes of ongoing subjectification.
- The identification of individuals as the vehicles of power.
- The use of a bottom up rather than a top down approach.

This is different to Gibson (1991) who suggests a broader approach to bring about a change in the structures which control power at a macro level. Foucault's ideas cut across this by advocating the identification of these structures of power which, as a result of this awareness, can then be challenged and eventually changed. It may be true to say that the powerful are not going to relinquish their power voluntarily;

pressure to effect this will need to come from individuals and groups. Specific intellectuals and self-help groups would be central actors in any such process of change.

Rodwell (1996 p.310) identifies the antecedents that are necessary for the empowerment process to develop. They are in his view;

- Mutual trust and respect.
- Education and support.
- Participation and commitment.

If these factors are effectively in place, and people at the macro as well as micro levels, are committed to change, then there is the potential for the empowerment process to take place. In summary empowerment is clearly a significant concept within nursing and related professions. For empowerment to exist, nurses need both a management structure and educational process that supports and encourages the development of the essential attributes to sustain it (1996 p.311). There must also be a clear understanding of the ways in which power operates coupled with the realisation that the nurses' culture is the product of power structures both hidden and overt. Only through this understanding will the hegemony of the present cultural rationality be broken.

This study seeks to address some of the routes to empowerment that nurses and other health professionals can adopt in order to begin the process of change and so make the empowerment of the dying patient a possibility.

Anti-oppressive practice

Oppressive practice is not confined to specific groups within health care, it is more useful to think of oppression as the ability of a powerful group (health care professionals) to make decision for, and possibly against the wishes of, a less powerful group (patients). With this in mind there are certain well defined sections of the community who face oppression in situations both related, and not related, to health care. These groups could be seen to be doubly oppressed within the health care system. It is not possible to address, in detail, specific groups of patients who may face particular forms of such oppression. Groups such as women, black and Asian people, disabled people and lesbian and gay people all face forms of oppressive practice, which are sometimes hidden and therefore difficult to identify. (Ward and Mullender 1991) These specific oppressions are central to any discussion of empowerment and will be addressed when they arise in the research results.

The term empowerment is itself an ideological concept. It could be said to remain the property of the holder of power and therefore defined and manipulated in the interests of that group alone. As such the relationship between the health professional and the patient is a double-edged one consisting of elements of care and control, both potential empowerment and potential oppression. (Thompson 1993 p.10) Ideologies which maintain the responsibility for patient empowerment on professionals and not patients also legitimate a status quo in the unequal balance of power, justify, protect and reinforce current social arrangements of power. One means by which this is done is by the establishment of 'norms' which construct a notion of the 'normal', so

establishing a standard to measure deviance from that norm. The terms 'normal grieving', 'normal relationships', 'normal stages of dying', for instance, act as powerful ways of legitimating practice. Stereotypes of the 'abnormal' are therefore powerful tools of ideology and are thus significant obstacles to anti-oppressive practice (1993 p.27) It may be through the medical discourse that power relations are constructed so that the idea of an 'outgroup' of people, be they black, gay, old, etc., are defined in negative terms and assigned an inferior status. By way of example, Thompson points to the use of the terms 'dependency' and 'frailty', which imply a medical model which focuses on physical incapacity, decline and dysfunction of the person rather than their social diversity. Anti-ageist practice, he maintains, should focus instead on empowerment through advocacy rather than adjustment to infirmity. He concludes that,

Oppression is both a social injustice and a barrier to self-realisation and, as such, the removal, reduction and prevention of oppression are valid and legitimate aims... (1993 p.99)

There have been fundamental changes taking place in the care of people with AIDS and HIV in particular, which could show the way forward for others. Historically this particular group of people have been considered a special case, since they are thought to consist of both a younger population with an identifiable culture apparently already in place, at least so far as gay men are concerned. In some large urban areas, gay men were able to organise support through self-help and advocacy groups, such as Body Positive and Terrance Higgins Trust. In this way people were able to take control of information and expertise, a form of self empowerment. Recently this model of

empowerment has been questioned precisely because of its assumption that an homogeneous social group were affected. Specific voices have been raised in challenge to their exclusion from HIV/AIDS care; women (Doyal et al. 1994) older people (Kaufmann 1995, Nokes 1996) and black and asian people (BHAN 1991) in particular. Nursing literature has also reflected these factors by consideration of the needs of specific groups of people such as gay men and women (Getty 1990, Janes 1994, Weaver 1994).

However not all people have the resources to bring about change which results in their self empowerment and it is for this reason that Dalrymple and Burke (1995 p.42) believe that it is important to interrogate rigorously liberally generated values by using principles, such as empowerment and partnership, that inform anti-oppressive practice. By taking into account the power differentials involved in moving towards change such change is more likely to occur.

Chapter 3 A new culture of care for dying patients

Chapter one indicates that nursing care of the dying patient has undergone fundamental changes in the past 20 years alone. The hospice movement has served to redefine the role of the nurse. The emphasis on palliative care has allowed the nurse a greater measure of control over his/her working practices, as well as allowing the patient a greater say in care decisions. The major task now is to ensure that the control exercised by the nurse translates itself into a greater autonomy for the patient in all settings where nursing care is delivered. Examination of the literature seems to show that this is already a fundamental part of hospice care (Winn 1987, Twycross 1995).

This may not be the case in other settings where dying patients are found. (Hockey 1990, McWhan 1991, Field 1994, Hewison 1995) Nurses would appear to be stuck in a paternalistic approach that denies the value of the patient's involvement. Any limited patient participation, that is allowed, is likely to be ignored. Downie and Calman (1993 p.114) feel that this is the result of the professional's construction of the patient's wants, fears and anxieties a causal product of the illness, or as related to psychological factors centred on the dying process. Their opinions are therefore treated as symptoms rather than genuine desires. While this may be true, there is a more fundamental problem related to the environment of care that must be addressed. The culture, from which the care arises, needs to be questioned if we are to see any real and lasting change in nurse/patient relationships taking place. Until nurses and

other health professionals question their practice, care will remain static within parameters defined by the institutional culture they inhabit. (Martin 1997)

The concept of culture lies at the heart of any group activity, including nursing. Williams (1976 p.80) defines culture as a 'particular way of life, whether of a people, a period or a group'. Change must come about within this structure. Williams (1961) calls the process of change 'the long revolution'. He maintains that people can direct their own lives, by breaking through the pressure and restrictions of older forms of society and by discovering new common institutions. The process is 'long' because of the resistance which limits and opposes the change. Cultures therefore come and go in history, change occurs unevenly and new cultures do not arise in an instant out of the ashes of the old. Within any culture there may be three components still at work:

- A 'residual' culture in which the ways of the past live on. (The doctor knows best, the patients and nurses do as they are told and the hierarchical structure predominates)
- A dominant culture that attempts to see itself as 'settled.' (The doctor as a senior member of a team, limited participation by the nurse whose main role is one of support for doctors and care of patients who are allowed limited involvement in decisions.)
- An 'emergent' culture that represents the views of newer, previously unrepresented, groups of people. (Full participation by the patient, nurses and doctors as equal members of the team with the emphasis on the patient as the senior member). (Bamlett 1996 p.5)

Savage (1983) points out that the whole structure of some nurses occupational life is one of subservience and deference to authority. It may be true that there has been a process of change since this was written but even so there remains a 'residual' culture that serves to put pressure upon the nurse to remain true to the values of the medical agenda. (Hugman 1991 p.33) The dominant culture allows the nurse some questioning of authority but poor staffing, low morale and job insecurity can severely restrict the options available so that patient involvement becomes a low priority. (Kitwood 1988 p.162). The nurses find it easier to hide behind the doctors' frame of reference rather than interact with patients on a human level. Kitwood (1988) feels that this non-involvement amounts to a denial of what is important in death and dying and it could lead to the denial of the fact of death itself.

Old Culture

There are other pressures on the nurse which Goffman (1969) describes. His central thesis was that individuals are actors who adopt roles according to the setting or demand of their audience. He feels that sometimes the traditions of an individual's role will lead that person to display a particular impression without being aware that such an impression is created. He likens the roles adopted to a performance that is acted out. It can be either sincere or cynical but either way, because of the demands of the role, it is **required** behaviour. These notions of sincerity and cynicism are not fixed, the individual may move back and forth between them. The performance can

exert demands upon others to value the role or react in a way that confers status upon the individual involved.

If we consider the situation of nurses we can see that despite their 'ceremonial subordination' to doctors, and a relative low rate of pay, they are held in high esteem by the patients. They are also awarded a high social status by society. To be successful in the role 'front' is necessary. A front can be either a setting, (such as furniture, or decor) or personal front, (revealed in insignia of office, uniform, posture or speech patterns). The nurse in hospital and other settings is expected to adopt a certain role and the role is then reinforced by the front displayed in their work environment and personal presentation.

Goffman (1969) points out that there is usually an established front for all social roles and that these fronts are difficult to change. Added to this is the perception of the role by the audience, who expect a certain pattern of behaviour from the nurse. Any attempt to breakdown that perception could well be prevented by the audience. They will treat the nurse only at an occupational face value, allowing a limited set of role options within their interaction. The audience will of course include not only the patient who is relatively powerless in this situation but also the doctors, nurse managers and other members of the health care team. Goffman (1969) maintains that the team has the character of a secret society with strict rules on covering up mistakes, respect for other members of the team and restricted membership. No member is allowed to join both team and audience. Advocacy is therefore reduced by these, usually unspoken, rules. Group solidarity is used to discourage disloyalty and to

create an image of the audience that tends to dehumanise ('The appendix in bed two'). Within this system the nurse is restricted in the options available for nurse/patient interaction as he/she has difficulty functioning outside the accepted role definition.

The process is, therefore, two way: the audience's expectations of the individual and the power of that individual to create a certain reaction from the audience. In the specific case of the patient this reaction can be controlled by nurses via restrictions they place upon contact. The maintenance of distance provides a way in which, according to Goffman (1968) awe can be generated and sustained in the audience. To talk of 'awe' is perhaps misrepresenting the relationship between the nurse and patient. What such restrictions may create however is a feeling of difference that serves to distance the nurse from the patient and so restrict communication channels. The patient's concept of the appropriate role of a nurse is confirmed and so the boundaries to interpersonal behaviour are set automatically.

What this illustrates is a dominant culture of care within which nurses work that defines how they will act in any given circumstance. Using the ideas of Lukes (1974), it is possible to see that the position of nurses is fixed within a dominant culture of health care, the nurse held firmly within given but, in the main, hidden boundaries (Martin 1996 p.4). Actions are therefore socially structured and culturally patterned by the very practice of the institution. What must be challenged is the view that such cultures are natural and unchangeable. Leary (1995) feels that,

Unless explicitly motivated to do otherwise, people try to protect images of themselves that are consistent with the norms of a particular social setting and with the roles they occupy. (p.67)

If people convey to others that they are weak, dependent, helpless, sick, etc., they may trigger a reaction from the audience of pity, contempt or concern. This may also result in the internalisation of these self presentations. They may begin to see themselves as having a problem and so create a cycle of maladaptive behaviour.

The nurses' response may be to adopt the 'bedside manner'. The patient, doctor and others expect it and the nurse gains self esteem from it. The result is that the team will allow the nurse continued membership. Should the nurse extend his or her role to include advocacy for or empowerment of the patient he/she may be judged to have breached the expected parameters of the role by the team. Even if the patient's best interests are being served, the power of the team to effect the outcome of such breaches will take precedence over any benefits. Such challenges to the role of the nurse can only come about if and when the team see it in their own interests as well as the patient's.

The power of a culture stems from the fact that when people are immersed in it, the framework that it provides seems self-evident. (Kitwood 1995 p.7)

What is important, therefore, is the potential for new cultures to develop which will change the focus of the discourse and enable the nurse to challenge the team in the interests of the patient. The concept applies to most setting in which nurses care for dying patients. The community nurse, for example is in a special position in that he/she is, in effect, a guest in the patient's home. They are, therefore, more able to

discard the old culture, having an environment that is remote from the institutional structures. The Macmillan nursing service has shown the way to this change within the community setting. Jack (1995 p.39) feels that the credibility of the health and welfare professions is currently at a low ebb. Regarding community care, he emphasises that professionals must provide the effective service people want rather than the treatment that professionals think they need.

Malignant Social Psychology Theory

Palliative care has now become a legitimate option in diverse settings, hospital, nursing home, community. Unless and until such an approach is adopted more widely, nursing staff will tend to remain within the old cultural norms. An approach that addresses the broad cultural ideology is needed to bring about a major shift in all environments where dying patients are nursed. With this in mind, it is useful to consider a development that is taking place in dementia care. The Bradford University Dementia Group's work arose from a conference in 1994. The principal advocate is Tom Kitwood who has written a number of influential papers on the subject. He challenges the accepted notion that the cause of dementia is purely neurological impairment and points to the importance of malignant social psychology as a contributing factor. He states,

...human beings are far more deeply affected by the social psychology that surrounds them than is commonly recognised. In particular, the maintenance of

self-esteem is essential for good learning, efficiency and constructive relationships with others. (Kitwood 1990 p.178)

What happens, when malignant social psychology is evident, is a damaging of self-esteem and a diminishing of 'personhood'. Recognition of 'personhood' means being cared for and treated as one who has valid experiences that must be taken into account. Kitwood recognises that good care giving requires a person to 'be there' for the other, which includes a high level of empathy and imagination in the carer. He feels there are two main reasons for the presence of malignant social psychology and lack of empathy: i) They do not feature strongly in the training of many professionals, and ii) The busyness and pressure which many care givers face. While Kitwood is addressing the care of people with dementia, his ideas can be applied to a broader context that has a bearing on the care of dying people. His categories of malignant social psychology have direct relevance to the everyday life experience of dying people. A few examples from Kitwood's work will make this clear:

- Treachery: The use of dishonest representation or deception to obtain compliance.
- Stigmatisation: Turning the dying person into an alien, a diseased object, an outcast.
- Invalidation: The ignoring or discounting of a dying person's subjective state - especially feelings of distress or expressions of pain.
- Banishment: The removal of the dying person from the human milieu, either physically or psychologically.
- Objectification: Treating a person like a lump of dead matter, to be measured, pushed around, drained, filled, polished, dumped, etc. (Kitwood 1993 p.104)

Kitwood's emphasis has been changed to apply the ideas to dying people, but his overall approach still applies. The way we interact with people has a direct consequence on that person's behaviour, well-being and self-esteem. In the case of the person with dementia, self-appraisal is complicated by neurological impairment, but the effect remains the same. 'Normally... a relationship is constituted in the talk and other experiences of those who are involved in it, and cannot exist as something imposed upon them by outsiders'. (Shotter 1993 p.170) The importance of the nurse/patient interactions is highlighted by considerations of what can result in malignant social psychology bearing on the dying patient.

Patients' and Nurses' role

Davis (1981) looks at the question of role from a different perspective. He points out that nurses have a stereotyped perspective of the acceptable role of patients and interact with them accordingly. Any patient who fails to meet that expectation will tend to be 'ignored, forgotten or treated with sarcasm'. Taken to its extreme he gives the example of the patient who is considered not to be legitimately in pain. He found this led to avoidance or worse an angry response, Kitwood's notion of invalidation. The patient is not perceived to be complying with their role parameters. Pain relief is given so the patient should now be quiet and grateful not still complaining. Abraham and Shanley (1992) feel that sanctions on the nurse to live up to expectations of the role can be harsh to the extent that his or her job may be in danger. As already discussed, we are expected to manage our impressions, the way we are perceived, so

that others will continue to categorise us as members of the team. They also give the example of the Milgram experiments (1974) when people were required to give what they thought were electric shocks to others even to the extent of causing apparent distress. The presence of an authority figure taking responsibility for the consequences increased the likelihood of the volunteers continuing to give the shocks. This experiment gives weight to the theory that nurses will remain in role and carry out orders from doctors and others even when it causes patients distress. It is important to note however that greater emphasis on accountability of the nurse and awareness of the need to be critical when making care decisions or carrying out orders may be changing this situation of obedience without question.

New Culture

The maintenance of self esteem and personhood is therefore not the property solely of the individual. It is provided by and dependent upon the presence of others and the empathy that others need to employ in order to understand in what way the dying people themselves make sense of their Actions. As Kitwood and Bredin (1992 p.280) state, 'Persons exist in relations, interdependence is a necessary condition of being human'. The old cultural view of 'them', the patients, and 'us', the staff, can no longer prevail. The idea that patients are ill, demented, dying and we are well, normal, healthy, is not an acceptable position to take. It results in the dying person becoming a kind of 'alien' dependent on the care of 'superiors', to use an analogy from Kitwood. The potential for all of us to become **them** must be acknowledged to breakdown the

unequal concepts. Care needs to be co-operative and reciprocal for it to be empowering.

Kitwood (1994 p.2) has identified a number of tactics which nurses and other professionals can use in day-to-day practice. Assessment, care planning, therapies, care interactions are, he maintains, mere aids and should not be used as 'fixes' to facilitate evasion or buck-passing. Clearly, such activities are useful but when they become the central focus of contact with patients they serve to distance the nurse and reinforce the them/us approach. These structures of the dominant culture, control nurse/patient interaction and deny patients involvement in decisions. Kitwood points to some practical ways in which the nurse can create a new culture. Speaking at the Alzheimer's Disease Society's AGM in 1996, he outlined the stages necessary for cultural change. They included, the recognition of people's needs and how they can be met, but, more than this, he emphasised the need for a person-centred approach to care. This must not be limited in its options but includes consideration of a range of options involving the patient as the central decision maker in the process of care planning. The patient, therefore becomes the team leader, the nurse and other care professionals enablers in the process of care. Nurses, in whatever setting they work, must become aware of the malignant social psychology aspects of their practice and move towards a new relationship that empowers the dying patient. The new culture therefore values the person by ensuring care becomes not only person-centred but is also controlled by the person it most affects, the patient.

Empowerment is about processes which permeate organisations and professional thought, the challenge is to create a culture in which such processes are able to thrive. (Stevenson and Parsloe 1993 p.58)

This tension rooted in the structure of professional power, between the old and new cultures is slow to change, so it is to this process of change and the role of education within this process that this paper now concentrates. To explore these issues empirical work with student has been employed. It is to the methodological approach that the next chapter is addressed.

Chapter 4 Methodology

A New Paradigm approach to the research undertaken here has been employed using the ideas of Reason (1988) who emphasises the need to do research with and for people rather than on people. The notion that research is neutral and value free is rejected by Reason. He feels that we must move away from the idea that there is one truth. The strength of new paradigm research lies in its emphasis on 'personal encounters with experience and encounters with persons' (Reason 1981 p.242). Meyers (1993) states,

Where as the more traditional approach often relied on external researchers acting as consultants in prescribing practice, more modern approaches encourage practitioners to act as researchers by systematic reflection on their everyday practice. (p.1067)

Habermas's critical social science, which rejects objectivity and truth, is central to the approach in that the emphasis is placed on the need for self reflection and interpretation of practice by participants. Habermas (1976) maintains that any serious social analysis must address the question of whether social norms that claim legitimacy are genuinely accepted by those who follow and internalise them or are they merely means of stabilising relations of power (Lukes 1982 p.137). In attempting to address this dilemma the research has involved the individuals at the centre of the power relationships in an attempt to draw out results that begin to challenge such relationships. By an examination of the culture of care in which they practice, the

students may begin to understand the ways in which social events, behaviours and processes can be causally attributed.

The methodology of Geertz (1993), which is sometimes called 'thick description' has been employed to analyse the data. In this method descriptive narrative accounts are made with the purpose of discovering within them the cultural contexts in which power is experienced. In Geertz's view (1973: p.405-6 cited Rice 1980: p.218) 'thick description' of excerpts from social life that are often thought to be insignificant, reveal symbolic structures which can be used to define the cultural context in which interactions occur. In contrast with structuralist anthropology, these symbolic structures are not describable in terms of logical relationships or 'intrinsic affinity' between the cultural artefacts or states of consciousness they appear to connect (Rice 1980 p.218). Instead they are seen as active forces within narratives of everyday life, such as Geertz's description of a Balinese cock-fight, which bring about, sustain and give meaning to an ongoing pattern of life. Hence we are looking primarily at accounts of nursing practice for symbolic structures that play a role in creating, sustaining and completing the action of the narrative. Geertz identifies such structures in the way in which three main narrative components in anthropological accounts are defined and made understandable within the narrative. These components are the symbolic structures that are used to explain and differentiate :

- the persons within the narrative,
- the character of time within the narrative, and
- the order and organisation of interpersonal behaviour.

It is argued that through the 'flow of behaviour', or social action, cultural forms find articulation. (Geertz 1993)

The substantive research for this study was conducted with 30 students on the ENB931 (Death and Dying) module and 15 students on the ENB934 (Care of people with AIDS and HIV) module. A shorter initial study was conducted with 9 students on an earlier Death and Dying module and the methodology, while similar, contained some differences that are outlined in the next chapter. All students involved in the main research project were registered nurses with varying degrees of experience. None were less than one year post registration and many had been working as registered nurses for up to 20 years. All worked in areas that involved a high proportion of dying patients (See table 2)

Number of students in each care setting

Acute Hospital	17
Hospice	3
Care of Older People (NHS)	4
Care of Older People (Private)	10
Community	11

Table 2

The nurses in the study have a great deal of experience of caring for dying patients in the different settings identified above. This archive of experience is a rich source of information and insight from which to construct a deeper and substantially richer analytical account of the factors which bear on whether dying patients are empowered or disempowered. Central to this process is my own experience and status which

affected the relationship between the nurses and the researcher. This special relationship allowed for a closer identification of mutual understanding to develop, which included, elements of empathy with their practice and allowed my own experience to become part of the interpretative resource of the study. As a result the nurses were, on the one hand, able to talk about their practice more easily and yet, on the other, unable to side-step the real problems associated with the empowering process.

Students on the two modules were asked to consider a critical incident or incidents related to the issue of empowerment and/or advocacy and write short notes or essays interpreting what had happened. They were asked to reflect on the incidents and think about their own practice in the light of the outcomes. Pusey (1995 3rd ed.) discusses reflection in the light of the works of Habermas and comes to the conclusion that,

...reflection is the social process through which irrationally, impaired or broken communication is restored and so 'rationally redeemed'. (p.71)

Use of reflection in the research process can act as a dynamic element that serves to expand the scope of the results. It also acts as an emancipatory force that enables the nurse to understand the reactionary processes at work in his/her day to day practice. The students selected their own subjects and either looked at their own practice or observed other nurses in practice.

The short papers they produced were then used as a basis for group work in the classroom. The students working in small groups were asked to identify common themes and share common experiences which they transferred to flipcharts. The

results were then presented to the whole group for discussion. The participants were encouraged to use the results of the classroom work in their summative written work to address the issue of validity and maintain the process of inquiry throughout the duration of the modules. This group discussion revealed elements of the 'taken-for-granted', tacit professional discourse which revealed element of reflective practice which added to the interpretation of the written work. Reliability was maintained across groups by ensuring that the same criteria was understood by all the participants involved.

However the question of whether the research is replicable is more complex. The **method** is replicable but not in the usual sense of experimental design. It is unlikely that two researchers will produce the same theoretical constructs. According to Turner (1981 p.230) the researcher should ask the participants if the results accurately represent 'what you say to me'. In the case of new paradigm research this is not essential as the results arise directly from the research process and are formulated by the participants themselves. However the interpretation of such results is left to the teacher/researcher and it is this interpretation that may need to be agreed by the participants. The rationale for such an approach is outlined by Meyers (1993 p.1068) who agrees with McNiff (1988) when she argues that making practitioners aware and critical of practice encourages them to develop theories that allow them to give reasoned justification for action. It could be argued that this approach is unscientific (Shapere 1971). However Reason (1994 p.332), quoting Freire, underlines the importance of making connections between subjective and objective experience, the former never being isolated from the latter. The subjective experiences of the nurses

are valued in their own descriptive and analytical accounts. The level of reliability is attempted to be maintained by cross-referencing with each other, leading to a cumulative approximation to objectivity.

What is called data in this context is really the researchers construction of multiple constructions which mediate what the participants and their colleagues say to each other in everyday practice. Research thus becomes a process of interpreting meanings, and drawing out explanatory conclusions, based on such interpretations. While it could be argued that such a process leaves the cultural analysis incomplete, it does make available accounts given by participants exploring their own practice, thus adding to the cumulative record of what 'man [sic] has said' (Geertz 1993 p.30).

Chapter 5 Ritual Action, a barrier to empowerment ?

Rituals within nursing are central to the concept of advocacy and empowerment. In this initial study several themes emerge relating primarily to the role of the nurse as advocate, that emphasise the affect of the ritualistic behaviour of the nurse in day-to-day actions. Walsh and Ford (1989) offer the following definition,

Ritual action implies carrying out a task without thinking it through in a problem-solving, logical way. (p.ix)

This is the starting point from which the hypothesis arises that such ritual action will inevitably affect nurse/patient interaction and the ability of the nurse to act as advocate. Rituals arise in practice for a number of reasons. Consideration of two theories based on the works of Mary Douglas give some clues as to how they may occur.

Douglas (1969) links modern notions of hygiene around the home, municipal sanitation and, by implication, the hospital, with earlier symbolic rites of primitive religions. Our ideas of dirt have become dominated by knowledge of pathogenic organisms and as a result, a whole set of rituals have developed around the danger dirt appears to pose. In hospital, for example, different mops are designated to different areas of the ward (kitchen, toilet, bedside etc.). Different coloured bags are assigned to different types of waste material and different categories of soiled linen; all for reasons that have been identified as 'safe practice'. All are inevitably bound up

in ritual, which, for domestic staff and nurses, become part of the daily routine structure of their work.

Such rituals, Douglas tells us, can be found in primitive religions where 'uncleanness' was seen as 'bad'. She found that contact with corpses, blood or spittle may be held to transmit danger. This belief has obvious parallels in hospitals today. The emphasis on infection control and the fear of contact with body fluids, with accompanying ritualistic behaviour, could well be seen in the same light as those of Douglas's primitive rituals. Such fluids are still classed as 'unclean' holding such dangers as HIV, hepatitis or septicaemia. A recent survey of nurses found that 37% felt it acceptable to refuse to care for HIV patients. It also found that a larger proportion felt they should know patient's HIV status (Akinsanya and Rouse 1992 p.400). Their fear of the imagined dangers overruled their duty to care.

Ritual inevitably becomes a part of the ward routine. The rituals of maintaining hygiene standards and of ensuring infection control are incorporated into the routine of the day. The 'danger' posed by blood and other body fluids become focused, not on the agent of the danger, but on the owner of the body fluid, the patient. The fact that it is the nurse who poses the greatest danger because he/she is the one who can transfer the infection from one place to another, very often despite the rituals involved, tends to be a secondary consideration. It is the patient who is seen to present the danger with the possible result of avoidance or distancing by the nurse.

A second example of how these rituals arise stems from Douglas's (1970) ideas of the links she identified between ritual and speech forms. Using the theories of Bernstein (1964) she illustrated how such speech forms were generated in social relations. Their selection and emphasis exercise a constraining effect on social behaviour so that every meal, bathing, bedtime etc. is structured to support the social order controlled by the nurse. Douglas likens ritual language to Bernstein's restricted code which, if used by nurses, could shorten the range of interpersonal communication by condensing it into predetermined forms. The result is a common set of assumptions that never need to be made explicit but inevitably become a system of control. The language of the nurse is full of jargon and abbreviations which are impossible for those outside the profession to understand. Holland (1993) states,

Ritual as communication, therefore, has a property of language that can only be understood within a specific cultural context and only by those who can "decode" its meaning. (p.1463)

The process may not be as overt as the rituals surrounding the disposal of body fluids, however, it amounts to the same thing when applied to the unspoken fear of, for example, death and dying.

If we take this at face value, ritual can only serve to bring about an uncaring approach. Douglas's discussion of speech codes may also have a link to the notion of an acting out of emotion. Whilst maintaining an appearance of care, behaviour is structured to enable the nurse to show some degree of distancing. This is functional in that the nurse can play a part in the routine of the ward without becoming too involved with the patient. Rituals that are set within this routine serve to control the

options open to both nurse and patient. As a result this restricts avenues that would have allowed the patient some power over their environment. The ritual becomes a rule or set of rules that allow no other course of action. The nurse is a part of that ritual in that he/she plays out the role within both the routine of infection control and restricted language options.

By an understanding of ritual behaviour, linked to routines and language, choice is clearly limited and interpersonal relations restricted. Douglas's notion of hygiene may affect interaction with the patient creating a 'them and us' mentality which serves to label the patient as 'dangerous', to be handled with care. Inevitably the patient becomes an object within the structured routine of care and any control he/she may have is limited by the narrow framework of their sick role.

Methodology

The initial study was conducted with nine students on the Death and Dying module. All were registered nurses with varying degrees of experience, none less than two years post registration. All worked in areas that involved a high percentage of dying patients. (See table 3)

Number of students in each care setting

Acute Hospital Ward	2
Rehabilitation Ward	2
Elderly Care Ward	2
Nursing Home	2
Community	1

Table 3

The students were asked to look at advocacy as a means of empowering dying patients. As in the main study they worked in groups to consider critical incidents from practice which they had written-up as part of the formative process of the module. Brief notes were kept, during groupwork, on feedback sheets and these were then shared with the whole class. All feedback sheets and tutor's notes were then retained for data analysis.

The study took a two-stage approach:

- Responses from a classroom-based exercise.
- Short written reports from practice.

The Glaser and Strauss grounded theory approach (1967) was used to facilitate the analysis and it was found that two main themes emerged:

1. The effect of the ritualised nurse/doctor relationship on the ability of the nurse to act as advocate.
2. Other ritual action which affected nurse advocacy.

Results

For ease of analysis the two sets of results will be addressed separately with discussion at the end.

Classroom Work

The influence of the doctor was identified by several students. Two issues emerged related to the ability of the nurse to advocate. One student described how she was able to change practice on pain control by standing up to the doctor. She stated,

'I would scream and shout until I got what I wanted. There's no way I'd let it [poor pain control] happen.'

The overemphasis in the language illustrated her frustration and the depth of feeling she had on the issue. Because of the continual pressure, the routine policy was changed to the satisfaction of the nurses involved. This concession by the doctor was clearly not easily won. She said that before this it was a process of *'negotiation, frustration and anger'*. Her role as advocate was frustrated by the power the doctor alone held to increase pain control.

The second issue that arose was related to the routine of information-giving. Of a situation where it was unclear whether the doctor wished the patient to have full information, the student said,

'I would not say about a stent [to relieve pain in pancreatic cancer] to the patient because the doctor may disagree.'

If the patient should ask about any further treatment the nurse stated that she would *'get the consultant to tell the patient'*. The student felt that 'treatment' was the doctor's

area of concern, even if he/she was not altogether honest with the patient. However she did state that, *'I wouldn't lie to the patient'*. Three nurses were involved in this discussion and all agreed with this approach even if conflict with the doctor arose. The way conflict was avoided was by omitting to give information to the patient, avoiding patients' questions or passing the patient onto the doctor. This situation clearly limited her role as advocate and served to distance her from the patient by the restrictions on the information she could give.

Written work

The theme of domination by the doctor also emerged in the written work. One student stated,

'I asked the doctor, who said that people who said they wanted to know their [prognosis] did not always want to know everything. The doctor used David's denial as a way of opting out of the big question' [Am I dying?]

The nurse never challenged this position and she concluded,

'I felt that David had never really had a choice in his care and that we were not really fulfilling his needs'

To illustrate how the nurses avoided the disclosure of diagnosis, she gave the following example, *'Nurses tended to explain a skin itch as an irritation caused by dry skin/sheets'* [rather than the cancer]. This process of avoidance of the truth by the nurse may well have led to physical avoidance of the patient and therefore an inability by the nurse to act as advocate. If the nurse is unable to be honest with the patient he/she will be fearful that difficult questions will be asked which the nurse is

not allowed to answer truthfully, an example of Glaser and Strauss's closed awareness context.

The second theme identified emerges more clearly in the written work. The students addressed other barriers to advocacy and the affect this had on patients. One student stated,

'...initially given guidance to choose he [the patient] would have managed at least some of his last weeks in his own home'

The nurse did not give this guidance mainly based on her assessment of the patient's ability to understand the choices available. Avoidance of the issue resulted *'because of cerebral palsy and slight speech impediment'*. The nurse identified this as leading to *'a low expectation of his understanding'*. The student justified not giving information based on poor cognition while acknowledging that the patient could have managed at home. She quotes the patient, David as saying, *'I always thought I would die in my house'*. This example underlines the earlier examples of avoidance and therefore poor advocacy skills.

The picture is not straightforward, however. In many instances, nurses are able to act as advocates despite the restrictions placed upon them. Another student gives the example of a patient who was informed by the nurse that he did not need to have the bronchoscopy that the doctor wanted him to have. As it was for diagnostic purposes only and other tests had already confirmed his diagnosis, she advised against it. In fact it was possible for the patient to go home, which he chose to do. The student stated,

'The nurse could see no reason for the further tests, and gave him information to make his own choice.'

Another student explained how acting as advocate was possible for her. She explained,

'I believe if I hadn't been there, knowing the patient as I did, that a decision to N.G. feed would have gone ahead, prolonging the life of a lady who didn't want any further intervention and knew all about her illness.'

These two examples give some indication of the power nurses have in some situations to advocate on behalf of their patients, but the examples are few and the culture that the nurse works in tends to limit such interventions by the nurse. Barriers to advocacy were identified based around the ward rituals and routine. The next quotation gives an example of how this works.

'Often terminally ill patients are washed by the night staff and the [named] nurse in charge of care does not see the need to go in until necessary (i.e. Sometimes 2 or 3 hours later)'

She observed that nurses do not like to become involved and 'distance' themselves; *'i.e. I'm the nurse, I have the knowledge - so therefore do as I say.'* She gave the example of a patient who was expected to have a slow death. The nurse had distanced herself by attending only to the routine tasks. The patient had been left unattended for some time and, when another nurse walked past, she noticed that the patient had died. *'She was alone, unattended by nursing staff or visitors/relatives'.*

A similar breakdown in care occurred with a patient diagnosed as 'Alzheimer' but who still had some understanding. The nurse felt that, once labelled, he was no longer consulted and his wishes were ignored. All further communication was with his wife who was told *'there is nothing we can do'*. She describes how,

The patient was diagnosed/labelled dementia - but wasn't as "demented" as had been suggested. He did have some understanding.'

The culture of care which dictated that people with dementia were unable to participate in care decisions served to disempower the nurse and led to a lack of consultation with the patient.

An examination of the written work showed evidence of several instances where not enough information was given. Although a community nurse emphasised the importance of *'allowing her [the patient] to talk about how she felt and answer any queries honestly and openly'*, it is clear from the data that the students found such situations stressful. One student summed up her feelings with the following quotation,

'I felt extremely guilty because I just didn't have the time to go and ask him how he was coping.'

Discussion

The two main themes that emerged relate directly to the nurse's ability to act as advocate for the patient. The problems around the power of the doctor are clearly

central to the issue and need further exploration. Issues of information giving and disclosure, which can lead to distancing and conflict, also need to be explored. Ritual action would appear to underpin most of the nurses' responses, so that discussion will centre around this concept.

As discussed, nursing practice contains a range of ritualistic behaviour that affects nurse/patient interaction. As Douglas (1994) points out,

Living in a community means accepting its standards, which means either playing the roles that are approved, or negotiating the acceptability of new ones...

There are pressures on nurses to accept the status quo. Even from this short study we get an idea of the power of the doctor to control the action of the nurse. Chapman (1983 p.19) gives the example of the ritual humiliation of a senior nurse by a consultant during a ward round. The nurse was asked to do four things simultaneously and her inability to do them effectively was met with disapproval from the doctor. The reaction of the nurse was to apologise for being slow. An example of this subservient attitude is illustrated in the research. In David's case, the nurses colluded with the doctor, by avoiding the truth and lying to the patient, rather than confront the doctor or tell the patient his prognosis. The student related that the patient '*could not understand how he was not getting better and he would like to know why...*'. The report ends at this point with three dots as if to suggest the unfinished and perhaps unsatisfactory nature of the situation. As Walsh and Ford (1989) remind us,

The unwritten rule is that nurses must only tell patients the same story that the doctor has given, they must defer to the doctor. (p.102)

Further work by Ford and Walsh (1994 p.29) came to the conclusion that the view of female nurses as naturally suited to provide care while men (doctors) tell them what to do should be anathema to all nurses. It is true to say that this form of hierarchical oppression occurs in other ways not related to nurse/doctor relations. Chapman (1983) calls this 'rites de passage' and links it to ritual initiation into the profession. Chapman states,

Seniority is acclaimed by the wearing of different coloured belts, dresses or different shaped hats... These material symbols are jealously regarded. (p.18)

While some of these symbols are being phased out, there remains a rigid status structure that serves to limit and define the responsibility of individual nurses. The concept of ritual is central to the way in which the nurse works. (See figure 4) The routine and rituals of the ward culture have a direct effect on other nursing practices. The hierarchical structure, dominated by the doctor, disempowers the nurse in many areas of work. The research has highlighted some examples of this in practice and further research, examined later, will give more evidence to show the affect this has on patient disempowerment. The other areas highlighted in figure 4 are worth exploring a little further.

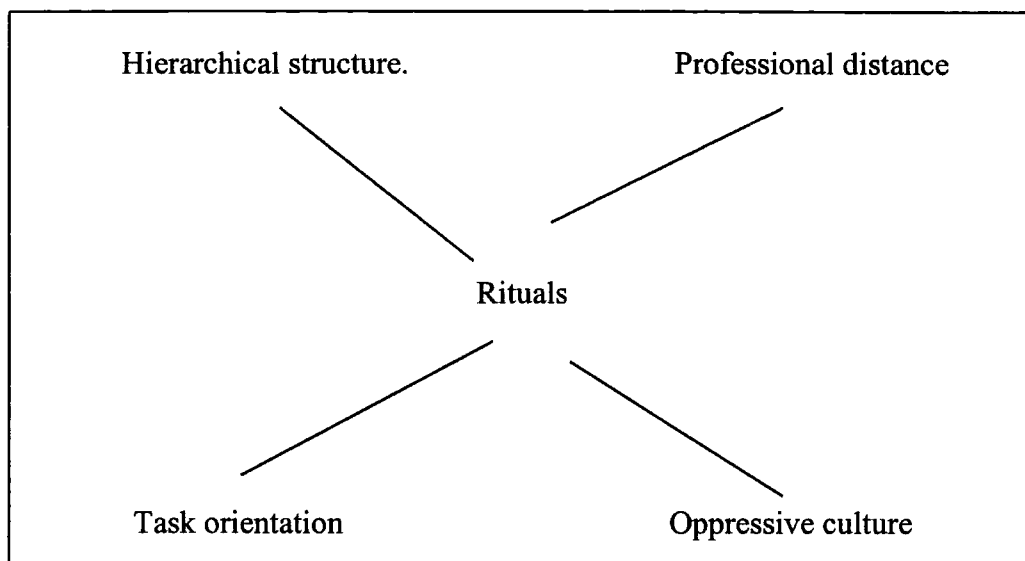


Figure 4

Professional distancing

Kahn and Steeves (1988) identified the dialectic nature of the argument by underlining the ideological context. The belief that caring is part of a professional identity, as well as inherently therapeutic, leads to a major problem when applied to the care of dying patients. On the one hand, the nurse must have compassion, empathy and an individualistic approach while, on the other, he/she may need to maintain professional distance to survive. The rituals that serve to distance the nurse from the patient serve to overcome the anxiety associated with care of the terminally ill. The handover, for example, gives the nurse the opportunity to transfer the burden of care to another nurse whilst away from the ward. At the same time he/she can transfer the anxiety associated with the situation. The community nurse who participated in the initial study related that she found that, since leaving the ward situation, she was taking her work problems home. This may be due to the lack of a

handover that would have transferred the problems to another until she returned to duty.

Task orientation

Walsh and Ford (1989 p.120) observe that nurses are preoccupied with 'getting the work done by lunchtime'. The morning routine is virtually the same for all wards. It starts with handover and report, and are followed by a series of tasks, which last throughout the morning. Breakfast, washes, observations, drugs etc. all have to be accomplished. This set of tasks contributes to the 'busy nurse syndrome' which keeps the nurse active all the time and protects him/her from the need to talk to the patient. Wolf (1988) splits the tasks into 'sacred' and 'profane' activities. The 'sacred' being wound care, hand washing and drug dispensing; the 'profane' include emptying bedpans and vomit bowls. Wolf feels that these tasks are necessary for patient 'well being', tasks that are seen by the nurse as 'doing good and avoiding harm'. What is omitted from this is the situation that arises from such 'busyness'. Nurses are legitimately able to distance themselves from patients. They have no time for nurse/patient interaction and so advocacy cannot occur.

Oppressive Culture

The oppressive culture works against the nurse and the patient. The patient has power taken away from him/her once admitted to hospital (Goffman 1968). This leads to

their exclusion from the decision-making process in ways highlighted by the research. However, the nurse is also disempowered and if the nurse is to empower the patient it is necessary for that nurse to first be empowered. As Ford and Walsh (1994) state,

The issues of oppression and empowerment are central to liberating nursing from ritualistic practice and therefore allowing nurses the chance to grow and express themselves to their full potential. (p.25)

One way they suggest of doing this is by the equitable distribution of power so that nurses participate fully in action and decision making. The other side to this redistribution is the difficulty that nurses have with the realisation of their subordination to others. This lack of understanding, which amounts to a measure of oppression, serves to undermine the process of redistribution of power. (Martin 1996 p.4) However the failure to bring about this cultural change will mean the continuance of a depersonalised, routinised conveyer-belt approach to care. DeLuca (1995) feels that the educators hold the key to this change. If they come to understand the meaning of the rituals they can probably address ways of changing practice. She is aware that it is problematic in that,

...attempts to eradicate rituals are attempts to change powerful attitudes that may have originated from needs nurses themselves might not consciously or rationally be able to acknowledge (p.141)

This initial study highlighted areas which need further exploration. It showed that the methodology required some adjustment for the main study and this was addressed by

employing the concept of 'thick description' from the ideas of Geertz (1973), outlined in the chapter on methodology.

Chapter 6 Empowerment and the dying patient

Empowerment of dying patients by nurses would appear, on the face of it, to be a simple strategy to enhance choice and control. However, when critical incidents from practice are examined more closely, several complex issues arise. First nurses, as we have discussed, are themselves subject to, as well as agents of, complex hierarchical structures. They are situated within the system of the assessment and delivery of care and are victims as well as agents of the institutional culture. The process of empowerment involves the nurse becoming aware, through their critical thinking and reflection, of the power they exercise and which is exercised upon them.

Yet, as Lukes (1974) shows, the exercise of power is often invisible to those upon whom it is exercised as well as to those who exercise it. Discussed earlier are some factors that disable the nurse from self-reflection and critical thinking about the exercise of power on and by them in everyday practice. To understand the ways nurses have of empowering patients it is useful to examine the complexities of the nurse/patient relationship as it is experienced by them as agents.

This examination can be performed by the process of critical reading of nurses' accounts of their practice. Examples of practice will be given based on data collected from the student work, as outlined in chapter four. We can start with a 'thick description' of an account of a critical incident by Student A, in order to show by example, how symbolic structures organise the definition of persons, time and the organisation of interpersonal

behaviour. These structures can be seen in Geertz's terms to play roles that reinforce and perpetuate one another.

'It is 12 noon on a busy surgical ward. Nurses and other members of the team are occupied in various "tasks" and routine ward work. A staff nurse walks past Mrs Smith who is lying on top of her bed. Mrs Smith says to the nurse "I know that you are busy but can I have some painkillers my leg is still hurting me?" Nurse replies to Mrs Smith, "Oh no, I'm sorry its only 2 hours since you've had them when I did the medicine round. You rest on top of the bed and give the tablets chance to work. I'll be back later and see if you've settled. They are quite strong analgesics that you have had. " The nurse is quite defensive and abrupt with her patient. The nurse's tone shows no empathy and doesn't allow for any interaction or advocacy to take place'

In this account narrative, time is characterised as both a limited resource, in which each moment is to be filled by action, and as a lengthy space for inactive endurance. Both characterisations of time are under the control of the nurse's discourse and are clearly related to ways in which the persons of the narrative are defined. For instance the patient's role is symbolically structured as waiting in time. The role involves being forced to bear the various meanings attributed to that role by those in control of the action of the narrative.

Among those meanings of the 'patient' role are passivity (wait and see), self-denial, lack of authority, endurance and accepting the role of being the object of other people's interpretation (in so many professional assessments). In contrast, the nurse's role is to dramatise the 'busyness' which measures the scarcity of her time in an unending series

of routines and short encounters. In older definitions of the word 'patient' both passivity, endurance of pain and the state of being the object of the others interpretative skills can be found. Interestingly they are present here too, with echoes of the 'patience of Job.' Hence, in Geertzian terms, symbolic structures characterising time play a role, together with those which define and differentiate the persons in the story, and order their interactions. The nurse's busyness and shortage of time mirrors her control of the narrative pace and foreclosure. It mirrors her authority over the patient's level of endurance. In all three components of the narrative identified by Geertz (persons, time and interactions) the distribution of busyness and authority in the role of nurse symbolise the precedence over inactivity and subjection that makes this a revelation of the unseen power in the interaction. After all, in this story the 'patient' makes an attempt to renegotiate her role and assert her own right to identify and act on her needs. The nurse uses her characterisation of time to contest the patient's right to interpret her own symptoms and to then assert that the patient colludes with the nurse's view that she be passive within the interaction.

'You rest on the top of the bed and give the tablets chance to work. I'll be back later and see if you've settled.'

The use of the word 'settled' is important here. It is not the pain to which the nurse is referring but the patient. It could be interpreted as 'stop being a nuisance' or 'be uncomplaining'. In other words if the patient would 'settle' then the problem of the patient's pain would not need to be addressed by the nurse. It is a form of control by the nurse as she is indicating that the patient should stop complaining even though there may still be a problem. The patient has in turn acknowledged that the nurse was busy by the way she stated her request. The nurse is able to use this perception of her

role to advantage by dismissing the patient's request and by asking her to try and 'settle'. The term 'settled' completes the narrative and determines the pacific front which shows the 'patient' has accepted and internalised her passive and powerless role in the story.

A deeper symbolic structure is also revealed here between things in the story which 'work' (in the sense of act purposefully and act effectively), like the tablets, and, of course the nurse, and things which do not since their role is to be worked upon (the patient and her stubborn resistance).

It is well documented in the literature that the traditional nurse/patient relationship was based on a formal structure that emphasised the role of the professional (Hugman 1991). Nurses are permitted to display only a certain controlled level of emotion, must retain control over the outcome of interactions and value their own assessment of the timing, duration and pattern of their interventions in order to retain the status of professional. It is clear from much of the research that this formal relationship has changed little over the years. Morrison (1994 p.42) reminds us that still today we perceive 'good' patients as those who do what they are told and don't 'make trouble' for the staff.

The short illustration above underlines the dismissive approach that may be adopted with patients who are perceived to be a 'trouble'. Although the medication was given two hours ago, the patient is told to give it a chance to work. The patient is being asked to stop complaining by use of the tactic 'nurse knows best' i.e. the tablets will work eventually, so wait 'patient'ly. The student goes on to observe that the body language of

the nurse gave out the signal that she was too busy to care. She gave attention to residents who were uncomplaining as part of the routine of the task orientated work.

The student herself appears to have a dual role in the narrative. She both empathises with the 'patient', thus sharing power with her, but also maintains her symbolic connection with the world of the working ward. The first sentence (*It is 12 noon on a busy surgical ward*) can only be understood if a value is given to the word 'busy' which understands the world of work rather than the world of waiting. Does this compromise the student? We can reflect on this when considering the teaching of reflective practice at a later point.

The second example from student 'B' gives a similar picture. Although not strictly a terminally ill patient, it does give a clear picture of the problem under discussion;

Mr. Smith, a wheelchair bound stroke victim expressed his wish to use the telephone to speak to his son. It was 7pm and two care assistants were in the process of giving out the nightly drinks and sandwiches etc. They continued with their task and disregarded his wish, as this was a regular request from Mr. Smith and he did not have a good relationship with his son. The care assistants controlled the situation by carrying out their ritualistic duty of providing residents with the nightly drinks and snacks and completing the task before the next handover of nursing staff, therefore justifying their actions. The care assistants by their body language and non-verbal actions in communication ignored Mr. Smith's request. i.e. The care assistants walked passed Mr. Smith and continued with the nightly routine by catering to the other residents' dietary

needs. At 10.45pm the resident was very unsettled and did not want to go to bed until he had telephoned his son.

At first sight this episode appears to be carefully analysing the deficiencies in the care assistants' approach to their work with Mr. Smith. The writer points out that the agenda set by handover and task related routines are both, in her words, 'ritualistic' and attempts to 'control(...) the situation' by the care assistants. The writer adopts the language of critical reflection to show some of the ways in which Mr. Smith is disempowered. Clearly the writer in this role believes that the voice of Mr. Smith should have been heard. However significantly the care assistants are judged by yet another focus within this narrative. Their work fails to 'settle' Mr. Smith. Indeed silently present in the narrative is the judgement that the care assistants do not adequately 'control' Mr. Smith's behaviours; other-wise he would have gone to bed, at the time required, 'settled'.

In reading this narrative we see the writer taking two stances; that of the promoter of critical reflection on practice and of the practitioner who attests the success of care by the ability to 'settle' patients. This ability is the mark of the professional. What is demanded of the care assistants is not only that they listen more effectively in order to hear Mr. Smith's contribution to maintaining his own well-being but that they can more effectively control and settle him into the 'patient' attitude in a 'professional' manner. We have seen the effect of ritual and routine in this initial study but it is worth considering a number of other tactics which marginalise the patients or residents who are demonstrating behaviour considered to be inappropriate or 'unimportant' by the nurse. In a sense what we have is a conflict about the role of the nurse that is only half

conscious in this account. The nurse becomes a reference point for human communication and a professional whose efficiency will be judged by the ability to make all things fit the routines of her practice, i.e. patients in bed and settled.

We see this conflict again subtly in the following example where the nurse's characterisation of time follows two patterns:

'It was the week before Christmas and a terminally ill man in his 40s required a nightly visit by the district nurses on the evening service. He had chosen not to go to bed as he associated going to bed with dying. We lay on a camp bed in front of the fire ... I went up stairs to wash my hands when I heard a little voice say "who's that?" ..it sounded just like my own son. The seven year old came out of the bedroom and we started to chat. I asked him what Father Christmas was bringing him. He replied, "I just want my daddy to get better" It shook me ... It really brought it home to me just what this family were going through. I don't believe you have to experience a situation to be able to show empathy. However, I could see the situation from the family's perspective much clearer.'

The beginnings of a 'shared humanity' are apparent from this account. The professional control of time within her encounter is measured by achieving a significant settling of the situation of her patient before leaving. Of course, if this were not the case, the nurse too would leave her situation 'unsettled'. Hand washing in this account operates as a symbol that closes the encounter. It is done at the end of her shift. But it also marks professional practice. It is associated with distance and differentiation and notions of ritual and hygiene identified by Douglas (1969). The comment '*It shook me*' could indicate that 'empathetic insight' had occurred leading to a closeness and the situation of

shared humanity described by Taylor (1994). But it also indicates that the symbolic structures in the narrative of time, persons and interactions have been disrupted and unsettled. The '*Who's that?*' may be difficult for the nurse to answer as she is caught between roles - mother/own son and nurse and has no way of foreclosing the incident. We are unaware how she answered the child's question, she merely reflects on her thoughts at the time and her conflict between her role of mother and nurse. Taylor would maintain that it is the aspect of shared humanity or, as she calls it, 'ordinariness' which is important in the nurse/patient interaction, but it could be argued from the student's reflections that 'shared humanity' is not an easy or settling approach for the nurse to adopt. McMahon (1991) seeks to categorise the idea more precisely. He includes concepts such as developing partnership, intimacy and providing comfort in his list. He also includes wider issues such as teaching, complimentary health and physical interventions. He concludes that therapeutic nursing is, 'about achieving beneficial outcomes for people by applying nursing interventions to problems designated as being those of the patient rather than the property of one discipline or another.'(p15)

Ersser (1991 p61) points out that, owing to a high level of stress, nurses control their true feelings. At one level this is another motive for 'settling' patients. It ensures that they have not got the power to disturb the nurse's mask of professional control of a situation. They fear that disclosure may threaten their ability to interact with patients successfully. The 'bedside manner' described as an 'armoury function' allows the nurse to work in a way that is unaffected by excess emotion, and by extension, insecurity. (1991 p.63) Nurses can use this façade of caring to shield themselves from any meaningful interaction with the patient. Taylor (1994 p.20) calls this the ability to avoid 'the

vulnerability inherent in his or her own humanness'. Nurses call on a range of tactics that serve to remove them from meaningful relation with the patient. We can see from the first two examples that the nurses are able to control the situation by use of such tactics. Ritual, special language and busyness are some of the ways in which the nurse shields him/herself from interaction with the patient, leaving no time for interpersonal relationships. May (1990) gives examples of nurse/patient interaction that is task-orientated, superficial and routine. He discovered that physical tasks were seen by nurses as 'work' whereas verbal communication was not. This may account for the fact that less busy periods are not used to talk to patients (Jarrett & Payne 1995 p.73) but given over to routine work such as tidying the office or cupboards. This approach by nurses, according to Macleod-Clarke (1982), leads to patients adopting a passive role, perceiving the nurse as too busy to be worried. The task-orientated approach to care can lead to a 'restricted' language that only values certain types of interaction (Douglas 1970). This narrowing of focus could result in reducing the patient perception of what is acceptable to discuss with the nurse and what is not. One can liken this to a construction of the patient's reality similar to that described by Berger and Luckman (1967).

Julia Neuberger (1986 p.22) gave the outline for the development of the emotional approach when she claimed that patients do not want caring staff who do not care. She pointed out that giving support does not always mean being strong, cool and calm. Smith (1992) develops this idea by employing the theories of Hochschild's (1989) and applying them to nursing. Hochschild's study looked at air-hostesses and identified what she called 'emotional labour'. It can be defined as,

The induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial safe environment (Smith 1992 p.7)

The process may be a functional one, required as part of the job, allowing the employer to exercise a degree of control over employees' emotional activity (1992 p.147). Jobs that require a high component of emotional labour are more likely to be undertaken by women, and so gender stereotypes and patriarchal expectations are factors to take into account. Smith agrees that Hochschild's approach is also relevant to the role of nurses. Taylor (1994 p.20) asks whether nurses, who are unwilling to be authentic in their self-disclosure, are in fact blocking the patients' chances for self-disclosure and authenticity? For the nurse/patient relationship to be successful it appears from the evidence that there has to be a more genuine relationship of empathy and honesty with the patient. Morse et. al. (1992 p.816) write about the 'emotional empathy' which, by way of a process they call empathetic insight (a reflexive sensation aroused by observation of the patient's distress), the nurse can 'experience' the patient's suffering and so give verbal comfort. The question remains as to whether this emotional response is a genuine one or whether it is a response based on expectations of women's roles. Student 'C' gives a further illustration of how this can work in practice. She states,

'A patient asked me if I would be annoyed if she gave me a present. She said while she was still alive she wanted me to take the present ... I was overcome with emotion and accepted the present. I said every time I wear it I will remember you. ... I feel that the patient wanted to be remembered so very much, and by saying that I will remember her when I wear the present was exactly

what she wanted to hear and why she had given it to me. She said I made her feel secure and that she had faith in me to help her to get through the difficult times, that I knew what to do to help her when she was not feeling well, when she had pain and discomfort and that she could talk to me and I would understand.'

This description illustrates a situation where the patient is more at ease when this particular nurse is present. The nurse has used the gift relationship in order to enable the giver to negotiate a position of relatively greater power. The empathy shown by the nurse is also a negotiation with known and shared ideas of what constitutes professional distance, particularly around the giving of gifts, which allows the patient to feel able to talk freely with that nurse. The result would, hopefully, lead to a more open and therefore honest relationship in which the patient's wishes are valued and empowerment enhanced.

There is a similarity here to the role of the air-hostess; the nurse can, and in this case does, show empathy to encourage a feeling of security in the patient. However the nurse must be able to care for all patients equally. The question of whether this is a 'genuine' or an acted out response here may not, in the context of this study, be the central dilemma. He/She may employ an 'acting out of emotion' to ensure the culture of care is an empathetic one. If the end result is the same then, it could be argued, that the nurse/patient relationship is not damaged. The student stated in her writing that she was '*overcome with emotion*' when she received the gift. Clearly she had genuine feelings at the time but her ability to maintain such an emotional level with every patient is debatable, and so these feelings would need to include some acting out in order to

maintain her role. Ersser (1991 p.60) acknowledges that the technique is present in nursing. He agrees that the emotional work of women is used to affirm, enhance and celebrate the well-being and status of others.

Hochschild's view that air-hostesses were exploited by such patriarchal expectations holds true for nurses but in their work, merely acting out a role of caring may not always be possible. In the examples above the nurse has clearly developed a close relationship with the patient over time. It is difficult to imagine an air-hostess being able to accomplish such a relationship, given the relatively short time spans involved in their working relationships. The nurse may, therefore, be more likely to develop a relationship that involves genuine emotion than the air-hostess.

Ersser argues that nursing must become pro-active in care decisions to be effective. An example from a community nurse illustrates what is meant by this. Student 'D' states,

'On discharge he (the patient) was referred by the discharging ward to the care of a named GP and the district nurse for assessment of needs. ... It was felt that a referral to the Macmillan Nursing Service would be appropriate. My colleague approached the named GP who was reluctant to refer Mr. G as his perception of the Macmillan Nursing Service was that she only saw the patients in the "terminal" phase of their disease. A visit was arranged for review of Mr. G's medication and need for oxygen therapy. Mr. G was subsequently referred to the Macmillan Nurse when the GP realised his condition. ... Mr. G required the nurse to act on his behalf to ensure that he received the necessary advice and

support at this stage of his illness. By advocating with the GP the Macmillan Nursing service became available to the patient'

The nurse was pro-active in the face of GP opposition. It is not altogether clear but it would appear that she used the excuse of medication review to get the GP to call and see for himself Mr. G's condition, while at the same time advocating on behalf of the patient. This aspect of the nurses' role will be addressed more fully in the next chapter to demonstrate that nurses can use a range of such tactics to get the doctors' compliance.

Ersser (1991 p.68) emphasises 'presence' as an important factor in the process. Maintaining contact allows the patient the opportunity to develop trust in the nurse as a basis for forming a relationship. This then avoids the problem of the nurse being always 'busy' and therefore unapproachable by the patient. For dying patients in particular the fear of death is often experienced as the fear of being alone. The value of 'presence' can help to bring relief in this situation. Student 'E' demonstrates this,

'The lady needed an awful lot of time. She knew she was dying and knew her condition was deteriorating rapidly, therefore she wanted to say so much regarding herself, friends, family and would sometimes become disorientated and appear confused, but she was really giving vent to her anger. By sitting with her, calming the situation and listening she would become more relaxed and able to actually say what she wanted to say. ... by allowing plenty of time to discuss what we were going to do and what she wanted we were able to build up a good relationship with her and for the most part she felt in control over her life.'

This is one example of a therapeutic dimension that could result in a closer relationship between nurse and patient and so lead to 'therapeutic empathy'. The problem with this theory lies in the use of the word 'therapeutic'. It moves us away from identification with the role of carer, to that of treatment (therapy). If the job of the nurse is reduced to treatment, then the nurse/patient relationship may suffer the same fate as the doctor/patient relationship, valuing only activities that bring about a perceivable therapeutic outcome. In this passage we can see this tension in the identification of the patient's anger in accordance with a stages theory of dying, such as that of Kubler-Ross (1970). The nurse's role is to calm the situation and value is given to this process in the extract. However it is possible to see parallels with the earlier discussion of 'settling the patient' and the importance given to the nurse's role in this process of 'moving on' the patient from the stage of anger to that of settling the patient. Anger is viewed as inappropriate and the need for anger by the patient is seen as an unwanted response that stops meaningful communication. Seen from the nurses point of view, it is clear that value is given to the calmer communication that subsequently resulted rather than the communication which arose with the anger. At this level the power to define what is meaningful remains with the nurses.

It may be possible to see a change of emphasis when it comes to the care of the dying patient. The position of the nurse may be different in many ways. First the striving for treatment and cure is not so urgent or may be absent altogether. Copp (1986) states,

When cure is no longer a reality, the teaching team literally and figuratively abandon the patient, leaving him [sic] to whom? Those who remain constant may be members of the clergy, the nursing staff and the family. (p.255)

In this situation, many tensions between the nurse and the doctor have become defused. The nurse has greater potential for an active role in decision making and disclosure of information. However, the situation is not resolved. The doctors retain legal responsibility for the patient and many constraints on nurses remain. Depending on setting (Hospital, Hospice or Community) the degree of autonomy will be different. As Bailey (1990 p.19) points out in relation to the hospice, their role is to share power and help the patient and the family help themselves. The potential for the nurse to become empathetic is increased because of the changed direction of care from treatment to a palliative approach. It is important to emphasize the word potential, because several factors must be taken into account before change can take place. The following example from a hospice nurse gives weight to this statement;

'Inexperienced or nurses new to the hospice often identify nursing with 'doing' rather than being. I have experienced, on occasion, when the unit has been quiet on a weekend, a nurse saying "there is nothing to do". The doing being the bathing, bedmaking, medicines etc. It is at these times when all the doing has been done that nurses can take the opportunity to sit and hold the patient's hand or talk to patients who wish to do so. Being is much more important than doing.'

Penn (1994 p.41) points to studies that arrive at the conclusion that nurses display avoidance behaviour when caring for people with a poor prognosis. She deduces from this evidence that the nurse as patient advocate, even in palliative care, may be an

unrealistic notion. The example above and the exploration of ritual behaviour in the previous chapter, may hold clues to why this occurs. The student relating the example gives priority to the tasks to be done (bathing, bedmaking medicines etc.) and gives secondary importance to interpersonal skills: such as holding the patient's hand or talking. Only when the doing has been done can empathetic presence take place.

The hospice movement has begun to bring about a change but whether this has been reflected in other areas is debatable. The following example graphically illustrates the problem of distancing in a nursing home setting from student 'F';

'On observing nurses caring for Mrs X I felt they were afraid of the situation they were in. She [the resident] was much younger than most of the other residents we care for. They coped by constantly tidying up the room etc., and though they carried out their duties very well they seemed to have to be doing something all the time and were unable to just sit with her and chat or even just hold her hand.'

This case was difficult as the lady was constantly asking questions and wanting staff opinions not only regarding her medical problems but to do with the complex family situation. I felt that most members of the staff felt inadequate at times and diverted the conversations at first.'

While there are many problems with the concept of empathy, it may remain the only viable approach, particularly when considering dying patients. Given the growing atmosphere of openness and honesty, displaying empathy without any loss of professionalism, is increasingly possible for nurses. Of course factors such as

distancing, power differences and levels of emotional involvement must be considered. However, if the context is right, the nurse is more able to act for the patient.

One further factor that must be considered is the need to provide education that will facilitate a change in nursing practice. The change will not happen automatically, since, as we have seen from the research, nurses may continue to avoid the dying patient. The care of the dying must become central to nurse training, so that nurses can practice skills that serve to improve the patients' quality of life, self-esteem and well-being. It is only then that a true partnership will arise and empowerment begins to become a reality.

Chapter 7 Advocacy as a route to empowerment

The document **Guidelines for professional practice** (UKCC 1996) has clarified the position regarding the role of the nurse as advocate. It states,

Advocacy is concerned with promoting and protecting the interests of patients or clients, many of whom may be vulnerable and incapable of protecting their own interests and who may be without the support of family or friends.(p.13)

Exploring the extent to which nurses can act as advocates, given the many factors that affect the role, is therefore important. This focus by the UKCC on issues of advocacy and autonomy brings to light many problems faced daily by nurses in their practice. The UKCC (1996) states that, 'If possible, the patients and clients should be able to make a choice about his or her care, even if this means that they may refuse care.' Read with the section on consent, it is possible that conflict could arise around the role of the nurse as advocate.

It is important to be clear about the different forms and definitions of advocacy. For the sake of clarity, The United Kingdom Advocacy Network (1994) has evolved the following definitions:

- legal advocacy - representation by legally qualified advocates, usually solicitors.
- citizen advocacy - a long term, one-to-one partnership, between user and advocate, usually as part of a co-ordination scheme, with a paid co-ordinator and volunteer 'partners'. This kind of advocacy tends to be more common in the learning

disabilities field, but may have some role to play, particularly for people with mental health or organic difficulties.

- formal advocacy - this is a comparatively new term in this country, and usually refers to schemes run by voluntary groups that are not user-led. These schemes sometimes refer to themselves as professional advocates. Co-ordinators are salaried and advocates are often paid. They sometimes adopt an 'expert' model of advocacy that involves them in giving advice, prioritising options, counselling and medication. These activities do not encourage empowerment through advocacy. They often act for both carers and service users. Often they are managed by major voluntary service providers.
- peer advocacy - support from advocates who themselves use or have used the services eg. mental health. Peer advocates may also be citizen advocates, they maybe part of a user-run advocacy group, or a project providing an independent advocacy service in health units and/or in the community.
- self-advocacy - people speaking out for themselves, which is the expressed goal of many citizen and peer advocacy projects. Survivors Speak Out is a self-advocacy group for individuals labelled as having mental health problems, while People First is a successful learning disabilities group.

We can see from the above list that the professional does not fit easily into any of the categories, the closest being 'formal advocacy'. The nurse, it is argued, as representative of the health authority, cannot truly advocate for the patient (Gates 1994). However, the UKCC includes the role in their guidelines and Gates does emphasise the importance of the role. He feels that nurses can and should act as

advocate. It is therefore to this issue that this chapter is addressed. Can the nurse advocate for patients and if so, what form does it take? Can it become a pathway to the empowerment of the patient?

It is true to say that nurses are encouraged to involve patients and carers at all stages of the nursing process. However, this may amount to little more than the nurse stating the usual options and the patient agreeing to them. Waterworth and Luker (1990 p.974) carried out a study that called into question collaboration with the patient. They found that patients will accept a collaborative role, just to please the nurse while not really wishing it. Although the sample (n=12) was small, it suggests that lip service may be given to collaboration merely to meet the demands of the Code of Conduct. Advocacy is central to the effective working of the nursing process. Even in the situation described by Waterworth and Luker the nurse has a duty to ensure that patient autonomy is maintained.

The problem remains of how we ensure that the nurse has the means to function in this role. Gates (1994) states;

Establishment of collaborative nursing advocacy schemes... built upon partnership between patients, clients and practitioners ... is an element of total care that is at present absent from much of nursing practice.
(p.100)

Although nurse advocacy has been under discussion for some years (Abrams 1978, Curtin 1979, Castledine 1981) little real progress seems to have been made. According to Dalrymple and Burke (1995 p.68) advocacy is about a partnership

approach and they identify several points of relevance to the process which are important to the role of the nurse. They are;

- Advocates need to retain the flexibility to adapt the process to the wishes of the individual involved.
- The user should feel in control of the process and needs to trust the advocate only to take action which has been agreed.
- Advocacy is about empowerment.
- Advocacy is about supporting people to speak for themselves or presenting their views for them.
- Advocacy ensures that people make informed and free choices.
- Advocacy is about advising, assisting and supporting. It is not about pressurising or persuading, which would then disempower.

The fact that patients need advocates, therefore, is not in question. It would appear that the nurse is best placed to carry out this role for patients. Brandon (1995 p.11) asks, who else is going to speak out on a daily basis for the powerless except the service people? So, if the role is necessary, the nurse is there to do it, and the UKCC urges it, why is it not happening? What are the problems? There are several papers published recently which explore this dilemma. (Allmark & Klarzynski 1992, Kendrick 1994, McNally 1995, Mallik & McHale 1995) Summarising some conclusions they draw in order to understand the problem is useful at this point. Discussion of the nurses reflections, focused around the main concepts discussed in the above papers, will help to apply the ideas to practice.

Parentalism

Nurses may be likely to make care decisions based on their own assessment of need without considering the patients' wishes. This is not to be dismissive of the patient but based on the idea that the patient's best interests are decided beforehand. In other words, the patients' best interests are universal and therefore beyond dispute. One student gives the following example from her practice,

'When attending to the residents some nurses took control by suggesting what would be best for her regarding clothes, diet, whether to get up or not so that the job was completed as quickly as possible.'

The nurse may be using knowledge of past similar situations but it results in the patient being disempowered, advocacy being ignored and alternative solutions to care being marginalised (Porter 1988, Everett 1993). The word 'attending' in the above quotation gives a clue to the approach adopted and, when linked to the notion of control, a one way relationship, which neglects the role of the resident results.

Foucault (1976) identified the power of the medical profession by reference to the medical 'gaze', that is able to define what intervention is required. He stated that it was the gaze of the doctor, supported and justified by an institution, that gave the doctor the power of decision and intervention. The ability to decide who is in need of attention in the example above is therefore only within the power of the nurse. The patient is a passive receiver of attention in contrast to the nurses' need to control the situation and get the job done as quickly as possible. It is also possible to interpret the

term 'attending' as giving attention to or listening to, the opposite of what is implied in the extract. The emphasis would appear to have shifted in the nurses' discourse from a patient-centred approach to that of a task-centred approach. The whole emphasis of the extract is, therefore, framed by the task in hand and the work to be done by the nurses. The role of the patient is ignored in this situation and advocacy cannot then be addressed.

A further aspect related to parentalism is the institutional paternalism of the employer. Nurses, although commissioned to act on behalf of the patient, do not have legal protection to carry out this role. The existence of a contract of employment ensures that the nurses' loyalties must remain with the employer. Disclosure of information may be regarded as 'whistle blowing' or, at least, disloyalty. At worst it could result in disciplinary action. Advocacy is therefore severely limited by this situation, if the nurse is unable to be completely open and honest with the patient. (Castledine 1993) The hospital rules are sometimes used to bring about compliance by the patient, as this next example shows.

'The nurse says "There are certain rules by which one must comply. This is the way it is done here..." At this point the patient is placed in a -no choice- position. He[sic] is pushed to comply with rules/routine or else...'

The nurse can remain within his/her contract of employment by excusing certain procedures as out of his/her control. Goffman's (1969) work on asylums highlights this approach graphically, when he describes admission procedures. These include, according to him, a series of dehumanising tasks such as listing property, assigning numbers and even carrying out intimate procedures such as rectal examinations. Many

of these procedures or rules remain in place almost thirty years later and would fall into the category of '*this is the way it is done here*'. The student has highlighted the obvious link between rules and routines to which the patient must comply. Overweighed by ideas of 'busyness' and professionalism, the advocacy role is not perceived by the nurse as an available option in this situation. It is dismissed because of the legislation, hospital policy, rules of the residential home and so on. Thus calling on a higher authority gives the nurse someone else to blame for the situation that results.

It has been shown to be difficult to get support from colleagues following 'whistle blowing'. (Castledine 1993) The situation can lead to 'cultural suicide' (Brookfield 1993) and loss of jobs. Internalised cultural identity not only leads to isolation of the outspoken advocate but serves to reduce the likelihood of the situation arising if the advocate cannot see beyond the constraints of the institutional reality (Martin 1996, Anon. 1995)

Dependency

The institutional system, it is argued, creates an environment of dependency. The patient is too ill to be involved in decisions or, because of the expectation of the sick role, unable to be involved. As a result they should remain passively dependent on the nurse who will make decisions for them. It could be argued that this is an ideal situation for the nurse to become the patient's advocate. However, roles are defined by

the nurse and the patient is expected to display the appropriate behaviour or be viewed as 'deviant' (Cameron & Gregor 1987, Porter 1988, Haigh 1993). If the role expected is that of passive acceptance then problems can occur if the patient, for whatever reason, is not prepared to or not able to comply with such expectations. An example of this, from a student working in a nursing home demonstrates the process. She has written the report in note form but the implications are clear,

'Care assistants taking residents into dining room. Confused resident, whingeing and crying and rather restless. Care assistants continued with taking other residents out and busying themselves in a brisk manner. They continued to and fro, ignoring resident crying and whingeing as she does this a lot'

This resident is not complying with the expected sick role. He/she is making noises of distress, which happen on a regular basis, and so can be legitimately ignored. This begs the question as to why unexpected distress is more noteworthy than distress shown by people on a regular basis. The patient is also destroying the atmosphere of brisk busyness and thus the only acceptable response, from the care assistants' position, is that of denial of the problem, given their knowledge of the particular patient.

If viewed from the patient's perspective, it may be that she too is joining in the busyness of the scene. The patient is seen negatively, as 'rather restless', and yet the restlessness of the staff is acceptable as they '*continue to and fro*'. One could imagine the feelings of the demented patient in this situation as all this activity erupts about her. Kitwood (1990) describes the patient's present reality as, 'everything falling apart', 'nothing gets completed', 'nothing makes sense'. He uses the term 'unattended

dementia' to describe the situation when others are insensitive, uncaring or neglectful. In the situation described above, the patient is expected to remain quietly dependent. She must wait to be taken to the dining table as part of the routine work, dictated by the institutional setting. The patient's perspective of what is happening around her is missing. The word 'whingeing' is particularly relevant as it denotes a meaningless noise of complaint. If the patient's attempts to communicate can be dismissed as whingeing, then the patient's feelings of distress can also be dismissed. As a result advocacy is withheld, because the patient's demands appear to be unreasonable or unimportant by the nurse.

Language

It is the nurse and the doctor who have control of knowledge. Unless they explain alternatives to the patient, avoiding 'special' language (jargon, medical terminology, abbreviation) the patient will not have enough understanding of the situation to make an informed choice (Hammond 1993). Information giving is an important way in which patients are able to take control of their care. Cowley (1993) came to the conclusion in her study that while people were generally happy with the care they received they remained unaware of how to reach the network of services. Patients who do not know what is available are unable to make informed choices about treatment or services on offer. She found that many people assumed that nothing was available (1993 p.55). Avoidance language is one way of restricting information which contributes to this situation, for example terms such as 'a real chance', 'not

infrequently', 'commonly', 'a small chance' are often too vague to have any real meaning. There were many examples of this in the data received, just two serve to make the point.

'I have witnessed on many occasions, staff, both doctors and nurses using technical medical terms to explain procedures etc. Patients are often bewildered or too embarrassed to ask for an explanation'

'The nurse ... uses jargon and the patient appears not to understand his care. The patient looks around and puts his shoulders up as if to say "I don't know".'

What is the way forward, if we are committed to empowerment as a liberating concept in patient care? Other factors clearly have a bearing on the problem and issues of power between nurse and doctor cannot be ignored if the overall picture is to be understood. Doctors clearly see the patients as their responsibility and, as a result, the nurse is expected to carry out doctor's orders without question. In the main, nurses agree with this (Hugman 1991 p.115). There is little evidence that nurses question the doctors' decisions, having either internalised their role in the hierarchy of health care or being too afraid to 'rock the boat'. An example of nurses 'doing nothing' shows how this can work in subtle ways, which avoid conflict with the doctor while maintaining the role of carer;

'Mr. X [The consultant] "Lets see now" With his back to the family he said "one choice would be a femoral by-pass, but looking at this [X-ray] that's a none starter." Turning towards John and approaching him in order to look at his feet.



"Oh there's a big change here, normally a femoral by-pass or it will have to come off."

John. "What the toe?"

Mr. X "The leg" ... How soon can you get in, can you stay now?"

John "I would like to go home for the weekend to see the dog"

Mr. X "Fine - Ward 28 - I'll get the nurse to come and dress the foot"

Mr. X left the room leaving the family in a state of disbelief and upset. Two nurses returned after a short while to find both daughters crying quietly.

Although they were sympathetic they were more concerned about dealing with the dressing.

Nurse 1 "What do you think we should put on "

Nurse 2 "I'm not sure what do you think"

At this time neither nurse questioned the consultant nor allowed the family to express their fears. They failed to act as advocates, by merely attending to the task of dressing the foot, a routine they felt comfortable with. The special language and vague terminology highlighted gives no information to the patient and allows the doctor to avoid the real issue related to the likelihood of an amputation. In a similar way the doctor has used a distancing and closure technique, *'I'll get the nurse to dress the foot'* by way of ending the conversation. *'Dress the foot'* indicates that it is to be covered by the nurse, a symbolic act of completion. By use of this professional language, the doctor has signalled to the patient that his task is over and that the patient is now the nurses' responsibility. It is unclear what the role of the observing nurse was in this situation. Her report of the way in which the two nurses managed the

situation emphasises the importance of the practical aspects of their role and the unimportance of the empathy and communication aspects.

The medical model tends to dominate the health care system even today (Roberts & Krouse 1990). Within palliative care a process of medicalisation is undermining the potential for a nurse-led service (Field 1994). Inroads into control of decision making by health workers, including nurses such as macmillan nurses and hospice nurses, would easily be lost once palliative medicine becomes established as a legitimate area in which senior doctors specialise. This would have the effect of transferring the hospital structures to the hospices. Such a power imbalance can only lead to erosion of the nurse's ability to advocate for the patient (Gates 1994) and must be challenged if patient autonomy is to be preserved.

The above examination of the difficulty nurses have when expected to advocate on behalf of patients leads us to consideration of the routes and tactics available to nurses when advocacy is considered appropriate. Despite the problems highlighted, many nurses are able to represent their patients effectively, so consideration of the communication process best able to accomplish this is necessary at this point. Many of the examples given above have shown what can happen when communications break-down. Consideration must therefore be given to a positive approach to the communication process taking into account the areas of concern highlighted.

The Ideal Speech Situation; a model for change

Taken from the ideas of Habermas (1976), the ideal speech situation may serve as a model for the nurse to advocate on behalf of patients. The important aspect of this concept is to identify if, and when, such a situation can be achieved within nurse/patient communication. The hypothesis is that, once such a situation is in place then the potential for empowerment of the patient is at its optimum. Bernstein (1995 p.50) defines the ideal speech situation as one in which all the participants have an effective equality of chances to take part in the dialogue. Three central criteria must be present to ensure the ideal speech situation is in place:

- Equal rights of discourse.
- Absence of role privileges.
- Freedom from coercion and constraint.

These will be considered in turn.

Equal rights of discourse

All participants must have the right and the opportunity to initiate and perpetuate discourse on any issue. The nurse therefore has a duty to ensure that patients are able to voice their views on all aspects of care and that those views to be valued. This must include the right of the patient to question or defend any functional or normative claim. The nurses' ability to override patients wishes by recourse to claims of superior knowledge, based on routine or custom and practice, must not be allowed to prevail. All conscious or unconscious inhibitions to discourse must also be overcome and nurses should be aware of their distancing and controlling tactics. There are a number

of ways that this process can occur and language is an important consideration. As already discussed, some terms can be too imprecise to hold any meaning and sometimes nurses recourse to 'common sense' solutions to problems of communication avoids real interaction. The concept of 'mumsyness' which serves to jolly along the nurses discourse, without any real interaction, only undermines the patient ability to self determination. One nurse in the study described how she built a relationship with her patients as though they were members of her family. This approach, on the face of it, would appear to be a positive one. When examined closely it was clear that she adopted the role of the mother figure on the male ward where she worked. She used many of the tactics used with her husband, or children, to gain compliance from the patients. It may be that the role of the nurse has parallels with that of the mother but, when taken too literally, this 'mumsy' approach may lead to parentalism of the worst sort. Both nurse and patient, in an ideal speech situation, should be motivated by the desire to reach consensus, not compliance based on the 'nurse knows best' approach.

Absence of role privileges

The second factor that must be in place is perhaps more difficult to achieve. Habermas emphasises that participants to the dialogue must neither possess role privileges nor be subject to one-sided binding norms. The hegemony of the professional environment may serve to undermine true equality in the communication process. In an ideal situation, there would be a rejection of the status of the professional and all that it implies. Uniforms, language, and rituals associated with such role privileges would need to be abandoned, if an ideal speech situation is to become a possibility.

All special knowledge would need to be shared as part of the process of communication in such a situation.

Freedom from coercion and constraint.

Finally, it is seen as important that there is freedom from all forms of coercion and constraint that might, in any way, engender less than full discursive reciprocity. (1995 p.51) All ideas of 'the nurse knows best' are alien to the process of communication and attempts, however subtle, to bring about a predetermined result must be abandoned.

Bernstein points to the significance of Habermas's imagining of the effects on the individual of 'distorted communication'. A false consensus can, he maintains, lead to a distortion of a person's relations with themselves and promote a disfiguring of self-understanding and self-interpretation. (1995 p.52) This situation will inevitably lead to the breakdown of the empowerment process and an undermining of the patients' ability to participate fully in decision-making. Unless the ideal speech situation is in place, patients will be unable to attain a true understanding of themselves, their needs, wants and interests. The analogy of the 'happy slave' is used by Habermas to illustrate this problem. He argues that a person in such a position is unable to discover, form a clear idea of, or know what it is they need and want.

Radwin (1996), while not referring to Habermas, explores the concept through the notion of 'knowing the patient'. That is the process of understanding and treating the patient as a unique individual. He concludes that knowing the patient may be a factor

that facilitates or results in the achievement of positive patient outcomes. This would appear to be one step forward in the move towards ideal speech situation but this still requires the nurse to abandon his/her status before communication can become empowering.

Two final examples may help to illustrate the achievement of positive patient outcomes by the nurse demonstrating empathy and advocacy skills. In both cases conflict arises with relatives but it can be seen that the nurse is able to work effectively towards the outcome the patient wants. The first student describes a problem related to sexuality. She states,

'I discovered Kate didn't want to go home because her husband was making [sexual] demands on her. He would become angry when she didn't respond to him. She asked me to speak to him about the subject as she was afraid to do so. I didn't look forward to this but agreed as I had an obligation as her named nurse and therefore advocate. I had consulted the doctor with the problem and she too agreed to be present to speak to him. After explaining Kath's concerns his reaction was upsetting to say the least. He did not want to listen or talk. We were accused of interfering in their personal life, of turning Kate into an old woman and told to keep out of their business or we would be reported. I felt this example of advocacy unsuccessful because in speaking for my patient a communication breakdown was created.'

While it is true that the end result was unsatisfactory, the nurse had acted as advocate in a difficult situation. The patient had been on the ward for many weeks, following her stroke, and a close relationship had built up between the nurse and patient. As a

result the nurse felt it important to advocate on the patient's behalf in a situation where many would have been reluctant. The nurse was able to develop a close relationship in the situation described which may be more difficult in a transient situation on an acute ward. Communications may have been closer to the ideal speech situation model because of the environment of care. The relationship would have contained fewer inequalities, since both nurse and patient were of similar age and background. The working practices on the ward in question encouraged few symbols of rank. Although the nurses wore white dresses or shirts, they did not display other insignia. Differences of status were therefore reduced to a minimum. The pace of work was slower and communication was not discouraged. There was no strict routine in place, it was possible to spread work throughout the day. Choice and involvement by the patient were also encouraged.

This is not to say that the environment of care was equal to the ideal speech situation but that the potential for this to occur was maximised. In the situation described by the student it is possible to assume that a good relationship had developed between the two women that enabled the patient to approach the nurse with the problem. The nurses used the backing of the doctor, also a woman, in a way that gave her strength to proceed with the role as well as giving her support when it failed to succeed. It is interesting to note, however, that the student used the word 'obliged' rather than a word to denote willingness, when she describes what happened. It could have been the difficult subject matter that led to this obligation or it could have been her difficulty with the concept of advocacy. It is more likely to have been the knowledge gained

from the educational process that would not allow her to ignore this aspect of her role, even in a problematic area such as the one described.

The second example was more successful but conflict still occurred;

'It took him a long time to say what he had to say. I asked him to repeat it. He said again "Has Susan been - does she know I'm dying?". I gently told him no - Susan hadn't been but didn't he remember they had all fallen out two years ago. He then spoke again - it was barely audible but both myself and another nurse heard him say "I want to make my peace with Susan and I want to see her baby before I go". These words took many minutes for him to say. I reassured him that I would do my best to contact his daughter.

I knew the hostility his family felt towards Susan but as David's advocate I knew I had no choice. I contacted the family GP and explained my dilemma. He said he would support me in all I did. I then decided I would call his wife. She became very angry and verbally abusive to me. Telling me to stay out of family affairs and not to interfere in private matters that didn't concern me. I told her I knew he was very sure of what he was saying. She then threatened me saying she would sue me if I contacted Susan against her wishes. I tried to explain I was David's advocate and that despite her threats I must act and do my best to carry out his wishes. I decided I had no choice but to telephone Susan. Susan answered the phone and she said she would come as soon as possible. At 5pm Susan arrived on the ward with her baby. She was very emotional and we had coffee together to discuss David's condition and his wishes to make peace with her. Susan stayed with her father about half an hour then left because she didn't want to meet her mother

and sisters. I went to see David when she left. He was trying to communicate something. I had to kneel beside his bed to hear him slowly and laboriously say "Thank you, you've made me a very happy man, I can go now." He died during the early hours of the morning. On reflection I know I did the right thing. When I meet his wife and daughters in the street they ignore me. If this is the price to pay for being David's advocate I will pay it.'

It is clear from this shortened account that the nurse found the situation emotional. She could have avoided the conflict and kept to the routine tasks of care. She could have kept a distance, in order not to become emotionally involved. However she had built up a relationship with the patient over time, and was prepared to advocate on his behalf, even though it resulted in conflict between her and the family. In both these examples the nurse has sought and received the doctor's support and perhaps this has helped them to face the conflict that arose. The emotional empathy demonstrated by the second example, highlights the value this 'strategy' can have when issues of advocacy arise and bring about a positive patient outcome. In both cases the patient was disempowered by their illness rather than the culture of care. The role of the nurse, by communicating at a human level and attempting to employ the three factors necessary for an ideal speech situation, lead to an empowering process taking place. Even though in the first situation the result was not successful, the nurse was prepared to advocate and face the conflict that came from the patient's husband.

We need to be aware of the various factors that effect the process of true communication between nurse and patient. These can be explained by use of a diagram. (See figure 5) Within any nurse/patient relationship there is an area of shared

knowledge usually related to day to day tasks. It may also include some knowledge about the disease and disease process. At this level of knowledge relationships may go deeper than that normally expected from nurses. The personal self of the patient is exposed and the nurse acts on this information to effect the outcome the patient wishes. The nurses personal self is also exposed a little, in the second example above, as she has to deal with her relationship to the family involved, not only at work but also *'in the street'*.

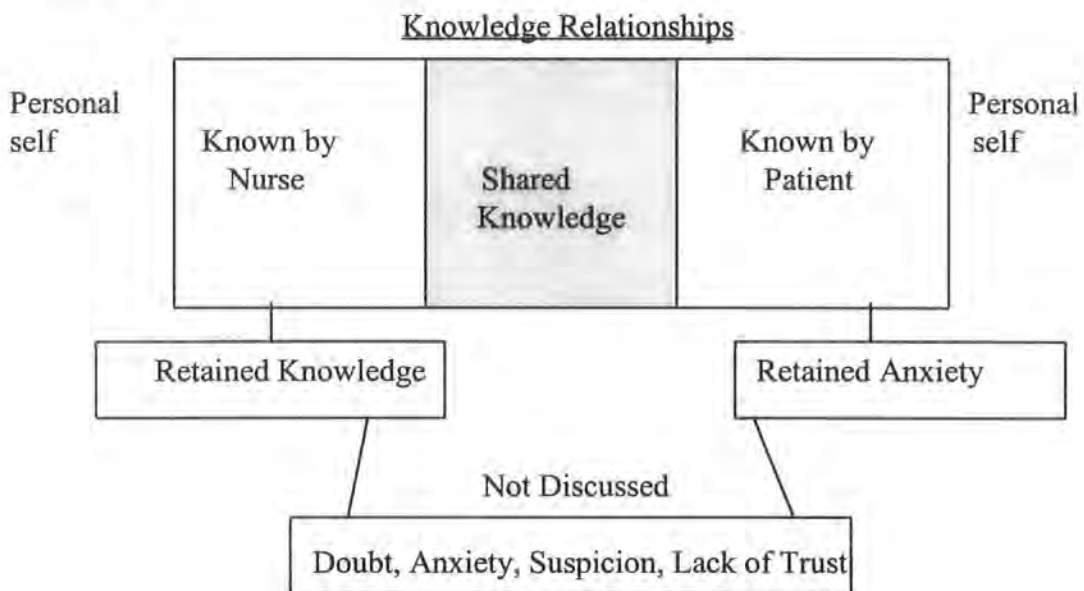


Figure 5

However, there is information/knowledge which only one party owns. This knowledge can be called retained information and it takes a different form for nurse and patient. In the case of the nurse, it may be related to prognosis, treatment, after care etc. and is retained by the nurse for reasons that he/she may justify as being in the patient's good. To discuss with the patient all the likely outcomes of their illness, good or bad, it could be argued, may confuse or worry the patient unduly. The patient has a similar store of retained information, 'worries', for instance, that he/she has not

discussed and which are causing anxiety. The patient knows that the nurse has further knowledge and the nurse is aware of this fact, but chooses not to address it or disclose it to the patient. The result is an area of conversation that is avoided and can lead to suspicion and lack of trust on the part of the patient. It is therefore only through shared knowledge that communication can take place. Because the nurse is the gatekeeper for the release of such knowledge, he/she has control over the communication process and so has the power to change it. In an ideal speech situation, this would be opened up to allow the patient access to the nurses' retained knowledge, but in a way that was controlled by the patient. The communication process between nurse and patient can be seen as a scale that ranges from 'banter' at one end to 'information giving' at the other. With this range of options in place, a discourse is possible that could hold the potential for an ideal speech situation to develop. Unless nurses address the issue of what is to be discussed with patients, and how the patient can take control of such discussion, the move to an empowering environment will be slow to develop. The communication process will remain at the functional level of either 'banter' or mere information giving. The nurse would continue to have control of the scope of such information, as well as the ability to initiate and set boundaries on the nature of the nurse/patient relationship itself. Had the issue, raised in the examples, not been discussed, a high level of anxiety and lack of trust could well have resulted. The ideal speech situation may be just an ideal but clearly there is the potential for nurses working in a supported cultural environment to come very close to such a goal.

Chapter 8 Educating for Empowerment

As a result of examining the various concepts that could enhance empowerment of dying patients, it has become clear that a number of pathways are available. The nurse is able to intervene and enable the patient to take control by a variety of methods. Awareness of the role of the nurse as advocate is one major approach that has been explored. The importance of the culture of care is also highlighted and the relevance of the ideal speech situation identified. Many barriers to empowerment have emerged, particularly the constraints that ritual and routine impose on the nurse's ability to see beyond the confines of the purely task-orientated approach. These barriers serves to stifle attempts to see the value of a new culture to the caring process. The power of the doctor to undermine the nurse's ability to advocate has also been discussed. Underpinning all these concepts is the role of the educator, who attempts to steer the nurse through the maze of his or her practice and, depending on the approach adopted, enables the nurse to see the potential for change which the new culture demands.

Training cannot be effective if the student is faced with the stress of day-to-day practice, which limits and undermines any incentive for reflection and change. Many factors can come together to undermine the progressive nurse, but in areas where dying patients are cared for, it is useful to consider factors related centrally to the ways that people react to crises such as death and dying.

Janis and Mann (1977 p.7) identified common reactions to such situations. They relate to individual decision-making and can be applied to the situation of the nurse as well as that of the patient. The situation that causes most stress and difficulty for the nurse to advocate on behalf of patients effectively is 'defensive avoidance'. This occurs when both the new and the old course of any action or decision related to patient care carries serious risks and no alternative solutions can be found. Janis and Mann feel that this results in:

- Procrastination - putting off the decision.
- Buck-passing - shifting the decision to someone else.
- Bolstering - persuading yourself you're making the right decision although there are serious doubts.

These tactics can only lead to a lack of action on the part of the nurse. Decision making becomes a complex process and the ways in which both nurses and patients react can differ widely, leading to loss of control by both. It is also important to note that the action taken by each may affect the other to the extent that both nurse and patient become disempowered. The problem, already discussed, of distancing may then occur. The example given in chapter four serves to underline this;

'Often terminally ill patients are washed by the night staff and the [named] nurse in charge of care does not see the need to go in until necessary (i.e. Sometimes 2 or 3 hours later)'

The student goes on to describe the care of a patient who was expected to have a slow death. The patient had been left for sometime unattended and, when another nurse walked past, she noticed that the patient had died. *'She was alone, unattended by nursing staff...'* The nurse, in this situation may have distanced him/herself from the

patient to avoid the difficult situation. The patient then loses faith in the nurse who no longer appears to be approachable.

Uncertainties are more difficult to deal with and decision-making becomes a major source of stress. Unless nurses are prepared to acknowledge uncertainties in their own practice and appreciate uncertainties faced by the patient, relationships between them will not change. The fear nurses hold of not having the answers, and as a result distancing themselves from patients, must be addressed. An examination of Janis and Mann's theory shows where the problem lies. If nurses and patients were to work together at the point of 'defensive avoidance' tactics such as procrastination, buck-passing and bolstering could be avoided. If both are suffering from stress, from not working in partnership and not sharing difficulties around decision making, neither will have the resources to take control of their environment. In fact, by the nurse not working with the patient, levels of stress will be increased, the patient will have little information on which to make decisions, and no-one will be available with the expertise to give such information to the patient. In other words, they will have no one to act as advocate. The nurse who is feeling 'boxed-in' will see the role of advocate as threatening to his/her professionalism; falling into the trap of bolstering to justify poorly thought out decisions, or buck-passing by referring back to the, more powerful, doctor

Bursztajn et.al.(1990 p.7) urged an acceptance of uncertainty as a positive step towards a more equal relationship, enhancing rather than threatening trust. For dying patients, uncertainty is one of the main worries (Buckman 1988). Consultation and

advocacy can come together at this stage to move the patient through the emotions and dilemmas faced. This may then enable a partnership to develop between nurse and patient that could produce the situation of advocacy and autonomy recommended by the UKCC. If stress is present when making decisions, the nurse will find it compounded if unable to be completely honest with the patient. Training must, therefore, take account of such factors that serve to reduce the nurse's ability to advocate effectively.

Critical Reflection

To enable the nurse to understand how their practice can limit patient autonomy, students' reflection on critical incidents can be incorporated into the curriculum programme, and it is to this approach that this chapter is addressed. The substantive research in this study relies on such reflection on incidents from practice. In view of this, it is useful to examine the value of such reflection and the problems that can arise from it. Schon(1987 p.10) notes that research is separate from professional practice and has been increasingly captured by its own agenda, divergent from the needs and interests of professional practitioners. To address this problem, as we have seen, the professionals directly involved in the area under examination are also centrally involved in the research process. Schon (1987 p.162) also reminds us that a 'designer-like' practice cannot be conveyed to students wholly or mainly by classroom teaching. The important concept is being able to get in touch with the actual doing, the actual

behaviour, in order to discover what you're really doing. Schon identifies a three stage model for this process;

- The first stage is to discover what you are doing. To make changes before this is accomplished may only lead to further problems such as changing things which are going well.
- The second stage is the reflection-in-action. An immediate response taken as situations arise.
- The third stage requires you to put into words what it is you do when you reflect -in-action. It is at this stage that this paper focuses its teaching strategies.

In the literature there is some debate around a definition of critical reflection (Martin 1996). Brookfield (1987) states that being critical entails a continual questioning of assumptions and Burnard (1989) highlights the need to see other possibilities, intelligently discriminate between them and to identify new ideas. Taking these factors into consideration we can broadly agree that the central premise must include aspects of questioning and analysing (Pless and Clayton 1993). Jones and Brown (1991) identify two main **essential** components of critical thinking, namely reflective scepticism, and exploring and imagining alternatives. They feel that the teacher needs to have a clear understanding of what is required if application is to be successful. The central theoretical dilemma remains however, why do nurses have difficulty with critical reflection?

Most literature on the subject gives the impression that the fault lies mainly with the educational process (Gross et.al. 1987, Meleis and Price 1988, Smith and Russell 1991).

Whilst this is a major factor, there is also a need to look behind this assumption to understand the situation of nurses in relationship to their ability to question and analyse care. Brechel et al(1993) came to the conclusion in their study that there was no correlation between years of education and years of nursing experience with either critical thinking or clinical judgement. Other studies have contradicted this (Gross et.al. 1987, Sullivan 1987). However it is still necessary to understand what brings about barriers to critical thought that even education and experience may not always overcome.

Brookfield (1993) acknowledges the problem. He feels we must wrench ourselves out of habitual ways of interpreting practice, the problem being that nurses believe they will never "get" critical reflection, that it is "beyond them". What must be addressed therefore, is the question of why these reactions occur in the first place. If we look at Brookfield again he points to another problem that may hold a clue. The problem he calls 'cultural suicide':

Nurses who expect their efforts to ignite a fire of enthusiasm for critical reflection...may be sorely disappointed when they find themselves, regarded as uncooperative subversives.(p.198)

This is perhaps the starting point for further exploration of the issue. How does this word subversive arise? Do the critical thinkers, who are being ostracised by their colleagues, then present as 'deviant' figures within the cultural norms of the nursing profession?

Hugman (1991) point out a contributing factor to the process of defining norms. He writes about the power doctors have over nurses and the fact that both professions will always act on the basis of expectation, established through training and previous negotiation. Keddy et. al. (1986) give weight to this in their study of the nurse-doctor relationship. However, according to Hugman, the nurse's role is not only defined by the power of the doctor but also by accepted expectations, within their culture, of how they will act in any given situation. Applying this analysis to the power theories of Lukes(1974) we can see that the position of the nurse is situated within that of 'non-decision'. Lukes emphasises that power is not merely sustained by a series of individually chosen acts but, more importantly, by the socially structured and culturally patterned behaviours of groups and practices of institutions, which may be manifested by individual inaction. Taken to its logical conclusion, Lukes points to the power which can shape an individual's very wants so that,

they accept their role in the existing order of things, either because they can see or imagine no alternative to it, or because they see it as natural and unchangeable.(Lukes 1974 p.24)

The nurses, who regard their critical thinking colleagues as subversives, have therefore internalised their role to the extent that they can see no reason to change and when asked to, feel it to be 'beyond them'.

Wilson-Thomas(1995) reminds us that, in the past, nursing knowledge had been focused on describing, explaining, predicting and controlling, from a reductionist perspective, thus emphasising the gap that now exists between nursing philosophy and theory. This gap creates conflict around practice decision-making, leading to stagnation, where

'custom and practice' solutions are applied to care problems. Consideration of the emancipatory learning described by Habermas (1972) brings some writers to the conclusion that it will make nurses aware of their plight and so take action to change it (Apps 1985). The problem highlighted by this study is that, in the main, this does not appear to be happening. Action remains on a superficial level and change is, as a result, fragmented and resisted by the system, in the ways that Brookfield has outlined.

This brings us full circle. We can see the importance of critical reflection in this process of change but we come up against the 'wall' of cultural suicide, bounded and protected by institutional power structures. The radical nurse has to face the intransigence of the status quo and, unless the emphasis can be shifted, this status quo will remain firmly in place. Only through debate and questioning of the system will we see the emergence of a dynamic model that can begin to change and so emancipate the professional nurse. Freire identifies the central problem faced. He asks,

How can the oppressed as divided, unauthentic beings, participate in developing the pedagogy of their liberation? (Freire 1972 p.25)

This dilemma can be applied to the situation of the nurse as the 'oppressed'; powerless in isolation to bring about the radical change necessary. In order to do this, Freire maintains they must,

perceive the reality of oppression, not as a closed world from which there is no exit, but as a limiting situation which they can transform (p.25)

Once this has been achieved, no mean task in itself, it should result in a reversal of the situation we now face and bring about the cultural suicide of the status quo. It is in

identifying where change may be possible that the research described in this study is addressed.

Schon (1983) identifies the problem faced when he states;

Many practitioners, locked into a view of themselves as technical experts, find nothing in the world of practice to occasion reflection. They have become too skilful at techniques of selective inattention, junk categories and situational control, techniques which they use to preserve the constancy of their knowledge-in-practice. For them uncertainty is a threat, its admission is a sign of weakness. (p.69)

Nurses may allow this to happen in their own practice. Their 'technical expertise' overcomes their ability to reflect and they value the efficiency of 'snap decisions' which avoid the feelings of uncertainty in the way that Schon describes. Martin (1996 p.6) quotes one nurse, in his study, arguing that an over reflective orientation could lead to an inability to act quickly when the occasion demands. The nurse values the ability to act quickly when required, over and above the ability to reflect before making decisions. Janis and Mann (1977) point out the stress that accompanies uncertainty that becomes a pitfall for nurses and a possible sign of inefficiency. What needs to be put in the place of such uncertainty is an awareness that reflection-in-action can be a productive approach which, through examination of critical incidents, can become a dynamic process rather than a static and sterile one. The problem remains, however, that nurses do feel undermined by the process of reflection. Hence it is important for the educator to ensure that their self-esteem is left intact. As Brookfield (1990) states, 'It is no good encouraging people to recognise and analyse their assumptions if their self-esteem is

destroyed in the process' (p.179). It is for this reason that the process of critical reflection in the classroom is owned and controlled by the nurse. If the nurse is able to select his or her own critical incidents for reflection, either in the classroom or in their written work, then the nurse can maintain control over what is addressed and how it is addressed.

Learning from experience

Experience can be defined in a number of ways and in relationship to a number of things;

- exposure to an event, situation, emotion or information.
- knowledge gained over time.
- time spent in nursing. (Watson 1991)

Experience in nursing terms is, therefore, gained by exposure to continuing care of the dying patient over time and in the in-practice knowledge which the nurse accrues from such encounters. However it is important to note that experience and learning are not necessarily the same thing and that one does not automatically follow on from the other. It may be said that learning only occurs if new understanding or change results. Salmon (1985 p.27) points out that twenty five years experience may be no more than one year repeated twenty five times. The 'experienced' ward sister may look down on the student nurse but, unless that sister has learnt from her experience, she may have little to offer the student. The accumulation of experience that the ward sister holds may be dysfunctional in its practice and so inhibit the development of the student nurse. Ritual

approaches, based on custom and practice, without the element of reflection can only lead to a static approach to care. It becomes a process of endlessly renewing mistakes rather than using experience to test out what has been learned and breaking the cycle of reindoctrination. (Cell 1984 p.177)

What then do we mean by reflection and how can it be developed in nurses? Boud et.al. (1985 p.19) call it an intellectual activity, exploring experience in order to lead to new understandings and appreciation. They identify three components;

- returning to experience.
- attending to feelings.
- re-evaluating experience.

To return to experience implies a reconstruction of events, thoughts and feelings. When related to critical incidents, the nurse is asked to recall the salient events and describe the feelings evoked by the experience and any judgements and interpretations made at the time. Examination of Kolb's learning cycle (1984) leads us to the same conclusion (see figure 6). The concrete experience occurs and the nurse then reflects upon that experience. At stage three the learning takes place, when the nurse thinks more deeply about the experience and adds the learning to prior knowledge or, as Kolb puts it, undertakes a process of 'abstract conceptualisation'. This new learning is then applied by way of 'active experimentation' to a new experience to see if it is feasible. Kolb feels that learning from experience is not sufficient, students must be encouraged to apply what is learned to new situations through the process of reflection.

Kolb's learning cycle

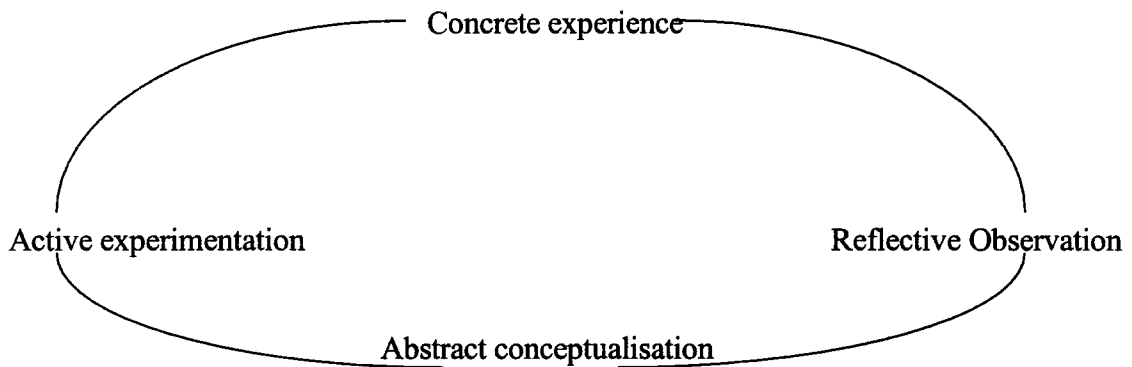


Figure 6

The following example from the research demonstrates the beginnings of this process;

'...she stipulated that she was not to be given any diamorphine (of any sort), and made the sister and myself promise no matter what, she was not to be given any diamorphine, even in the latter stages of death. As Margaret was due to go up to the x-ray department for multiple organ ultra sound scans and multiple x-ray I did not want her to have the (i.v.) Diamorphine as prescribed. I also felt that she needed some form of regular pain relief prescribing. Therefore, I explained this to the doctor over the telephone. The doctor said he would come and review Margaret's pain relief straight away but on his arrival to Coronary Care went straight to Margaret and began loudly saying that she could not refuse to go for the tests. I immediately went over to them and informed the doctor that Margaret had at no point refused to go for the tests, that I had said that I did not want to give her the Diamorphine as prescribed and why, and that Margaret could refuse to go for the tests as that was her right.... On reflection the problem could probably have been handled more professionally than a doctor and nurse having

a heated discussion at the patient's bedside. I felt that the doctor was looking at his textbook rather than looking at the patient...'

The nurse here is recalling the event and describing her feelings, and interpretations of the actions taken. She shows evidence of reflection-in-action and gives a clear example of the three areas identified above by Boud et.al. It is not clear whether the Kolb's cycle model is in place. The nurse would need to show evidence of further reflection, perhaps in the form of reflection of the critical incident, for it to move from mere reflection to a state of learning. The process can be broken down to three stages, similar to those identified by Boud et.al., but related directly to written reflections. They are;

- reflection in practice.
- reflection in writing.
- reflection on writing.

The nurse in the example above has clearly worked through the first two stages but still needs to undertake stage three, perhaps in a classroom setting, to ensure that learning takes place. According to Jarvis (1992 p.85), learning is intimately bound up with action; a potential learning situation arises only when action cannot be performed unthinkingly. The nurse's feelings, expressed in the above extract, about the needs of the patient are clearly demonstrated but it is not clear that learning has taken place which would be applied to a new situation should it arise. When attending to feelings, Mezirow (1981) uses the term 'perspective transformation'. As one becomes critically aware of ritual ways of thinking and acting which limit practice and relationships, a sudden insight into the whole structure or a growing awareness may take place. The change of

thinking can be disturbing and this factor should not be underestimated for the individual concerned. The question arises as to whether the teacher should take responsibility for the results of changes and the problems that may arise for the nurse. Rich and Parker (1995 p.1056) remind us that lecturers will not be there when nurses attempt to use the reflective process in practice. 'Exploring feelings alone can be difficult and may leave the student vulnerable'. This is a dilemma that needs to be addressed in a way that allows the nurse to take control of the process, using it only in situations that he/she feels not to be disturbing. An example from the research demonstrates how a district nurse may feel vulnerable and uncertainty arise;

'G.P. did not approve of the nurse's actions and this would be remembered if a similar situation arose in the future. -i.e. the nurse would perhaps be reluctant to become an advocate for a patient to prevent a confrontation with the G.P. occurring'

The nurse is aware that confrontation with the G.P. will undermine her ability to practice effectively as a community nurse and lead to high levels of stress. The teacher will need to encourage that nurse to address the critical incident and allow, through reflection, some compromise to arise. One nurse involved in the research stated that she would not be prepared to advocate for the patient if it would lead to disciplinary action or dismissal. However many nurses felt able to confront the doctors on matters where they felt that their judgement was in the patient's interests.

The nurse who reflects on a critical incident is likely to begin the process of re-evaluating that experience by a process of validation, that is a rehearsal of the ideas by

thinking through the steps that would have to be taken for change (Schon 1983). Schon describes some of the different modes of reflection as follows:

- reflection on any tactic or taken-for-granted norms and appreciations underlying judgements.
- reflection on strategies and theories implicit in a pattern of behaviour.
- reflection on feelings in a situation which suggest a particular course of action.
- reflection on the way the problem is framed.
- reflection on the role constructed by the helper for him or herself within the larger institution.

If the student is able to focus his/her reflection in line with, and taking account of, these various modes, then the process of critical reflection should be accomplished. To work effectively the process needs to be a personal one, in which we learn something about ourselves as well as our practice. The outcome of 'the self' in relation to reflection should ideally be a changed conceptual perspective. (Boyd and Fales 1983 p.101) It is this fundamental process that is the key to change in action. It is, however, dependent on the capacity of the nurse to explore his or her experiences. According to Boud et al (1985), the success of adopting this approach is affected by the context in which the individual is learning and the level of support, encouragement and facilitative intervention he/she receives.

It is impossible to proceed without taking into account Schon's notion of 'technical rationality' (1983). It relies on the assumption that empirical science is the only source of objective knowledge about the world and that any problem in practice can be solved by strictly scientific research and methodology. Schon's argument is that there is a growing awareness that practice situations are characterised by complexity, uncertainty, instability and value conflicts. Actions cannot then be accounted for by recourse to specialised knowledge alone which ignores, what he calls, the 'swampy lowland' of practice; i.e. the day-to-day problems and interactions for which there are no recognised research-based theory. When professionals fail to recognise or respond to value conflicts, when they violate their own ethical standards, fall short of self-created expectations for expert performance or seem blind to public problems they have helped to create, they are increasingly subject to expressions of disapproval and dissatisfaction (Schon 1987 p.7). It is this that the nurses are asked to consider when reflecting on critical incident. A further example demonstrates this;

'When the doctor came onto the ward I produced Emily's medication sheet, pain chart and nursing records. He looked and said she was on maximum dosage without oversedating. I told him what she wanted and explained her fears. I asked him to listen to her cries and look around at the distress it was causing [others]. If there was no cure for Emily, then surely to keep her pain free at all times was paramount, and if this meant sedation then why not?'

This is one way that professionals, according to Schon, can display their artistry in practice situations. Some professionals are thought to know more than they say, this Schon calls 'knowing-in-action'. It is the ability to carry out actions and make

judgements spontaneously, unaware of how that skill was learnt. This 'professional artistry' stems from a cumulative body of personal knowledge that may include a range of strategies that the nurse can adopt appropriately should the need arise. Such professional knowledge, according to Schon, needs to be tapped to provide a body of knowledge that is directly relevant to the realities of practice. In this way the problems related to value conflicts can be addressed. Nurses who are able to effectively reflect through consideration of critical incidents are also able to challenge such value conflicts and move towards some measure of empowerment of the patients in their care.

The situation is, however, further complicated by the fact that nurses work at two levels of theory, espoused theory and theory-in-use (Argyris and Schon 1974). Espoused theory is what the nurse would say he/she would do in a given situation and theory-in-use is what the nurse, when observed in practice, actually does. The latter results from the need to conform, be approved of and accepted by peers and managers. (Cell 1984) So, although reflection-in-action occurs as the action unfolds, they are restricted in the actions they take by the theories-in-use that allow them to merely conform to a limited set of options. Potential learners can reject the opportunity to learn if they regard learning, or the possibility of change, not to be in their interests (Jarvis 1992 p.85). The process that serves to break the cycle is that of reflection on reflections-in-action so that nurses can consolidate their understanding of a problem or develop a better solution (Schon 1987 p.31).

The mechanisms by which reflection promotes learning remain unclear. The ideas from Kolb attempt to address this dilemma but, even here, it is assumed that reflection will lead to change. What remains unclear is how this happens (Day 1993). Indeed the conceptual clarity of Schon's work has been criticised (Munby and Russell 1989, Greenwood 1993, Day 1993). The conclusion may therefore be drawn that reflection is an adjunct to learning by other means. It is therefore the notion of critical reflection within a broader educational framework that needs to be understood. Burnard (1989 p.271) reminds us that 'education suggests an evolving critical process which enables the learner to make decisions for herself [sic] through the exercise of rational thought.' The approach that uses critical incidents allows the nurse to not only reflect on the event but also become critical of practice in a safe environment. There have been several studies that have shown positive results when this strategy is employed in nurse education (Durgahee 1996 Martin 1996). Clearly there is a wide variation in the implementation and translation of critical incidents into a teaching and learning situation (Minghella and Benson 1995). However there is a growing interest in the role of writing as learning where students use writing as a tool to foster reflection on specific experiences, thus developing new skills, knowledge and attitudes (Parker et. al. 1995). The process requires the student to learn through writing the critical incident for analysis as demonstrated in the examples above. It is felt that reflection, if used correctly and sensitively, can bring about emancipation and empowerment not only for the nurse but also influence the practice of others, in terms of nurse/patient interaction, clinical decision making and ethical debate. (Rich and Parker 1995 p.1051)

Clinical Supervision

So far discussion has been around reflection as part of the educational process. To ensure that reflection becomes part of practice it is useful to examine one method by which this may be possible. King's Fund Centre (1994) define clinical supervision as, reflecting on practice in order to learn from experience and improve competence. They go on to say that an important part of the supervisor's role is to facilitate reflection and the learning process. They see the process, therefore, as one which compliments and extends the learning process. There is also the feeling in the literature that clinical supervision should enhance nurses' and patients' autonomy (Hill 1989). To achieve this Minot and Adamski (1989 p.24) have identified three processes which need to take place;

1. The supervisee expands his (sic) knowledge, acquires new concepts and develops skills in applying familiar abstractions to clinical practice.
2. The practitioner uses supervision to bolster his sense of security, essentially as a support system.
3. The supervisee's grows in awareness and knowledge.

They feel that preparation, at masters level, is essential for the supervisor because of the theoretical expertise and broader perspectives required. This latter, however, may be too much to ask of the nursing profession, at this time, given the relatively low numbers of first degrees held by nurses in practice.

Faugier (1994) feels that much, of what is called, clinical supervision is not as yet reflected in practice. In fact he paints the bleak picture of the nurse practitioner reflecting alone or with peer groups often without adequate guidance or formal structures. The three main structures of clinical supervision cannot be achieved in this way. The formative or educational structure, the normative or quality control structure and the restorative or supportive structure will not be achieved if an informal system is all that exists.

There are a number of models available, of which self-supervision is just one. The more useful are: one-to-one supervision, team supervision and group supervision. It is not important to understand the differences here but merely to be aware that, which ever is in place, the person or people supervising should understand concepts such as empowerment, autonomy and advocacy and ensure that such concepts are central to process of supervision and reflection. The Derby model of supervision quoted by Friedman and Marr (1995 p.24) requires supervisors to ;

- Empower the supervisee
- Support the supervisee
- Develop the supervisee.

With this in place there is the potential for clinical supervision to be instrumental in achieving major attitudinal shifts, vital to the provision of anti-oppressive care and patient empowerment. Woods (1992 p.41) points out that there is almost universal denial that the nurses' actions, feelings and perceptions of the patient are of any importance. He maintains that occupational stress can lead to direct consequences for

the patient and result in reduced contact time, denial of difficulties by the nurse and, more subtly, avoidance of the patient by concentrating on new technologies and techniques. What is necessary is a system which values the personal feelings, experiences and emotions of nurses. A framework is required to enable the recognition of such feelings and a clear understanding of the difficulties that the patient is experiencing. (1992 p.47) Clinical supervision is, therefore, not just a forum for peer group reflection, or a system which reflects on clinical practice within the constraints of clinical nursing processes, it must include aspects of care and care relationships which have been central to this study. It must allow for a consistent and constant reflection of feelings and emotions which would enable the use of self to be valued as central to the nurse/patient relationship.

Chapter 9 Conclusion

...we need nurses who dare to ask us those difficult questions which we only dare to think about. We need nurses who dare to take time to wait for our reaction. We and our relatives need direct emotional support. Nurses and doctors have to stop looking at their jobs as just a profession. (Farrell et al. 1990 p.862)

This quotation, from an interview with a gay man who is HIV positive, sets out the changes which he would like to see and which have, in part, been addressed in this study. He states later in the same interview that,

...generally low morale has created an iron curtain between the health care system and the voluntary organisations. Personally I feel that, generally, the nurses also have this low morale. They have to tear away this iron curtain inside of themselves as well as on-the-job. Starting this change can be frightening for them. (p.863)

Recommendations for change have been given throughout this study and later chapters contain some discussion of pathways to change. The ideal speech situation, and the notion of reflection on writing, are attempts to point a way forward for the process of change. However it would be naive to expect such change to occur easily. As discussed in chapter 3, a change of culture does not happen overnight or arise automatically from the ashes of the old culture. There are powerful forces in place, with vested interests to stop or delay any moves which are perceived to challenge such

power or authority. Ideological factors also have to be taken into account and what is seen as progressive to one person may appear to be regressive to another. The hypothesis of this study is that, unless dying people are given more autonomy over their lives and deaths the oppressive nature of the health care system will continue to impose its will upon this vulnerable group of patients. Any move towards empowerment is to be valued and nurtured, since changes can be of a fragile nature and are soon undermined by the prevailing ideological consensus of the dominant culture. For this reason it is important, in the first part of this conclusion, to consider the ways change can come about and highlight the problems so that they can be addressed.

Orton and Allsopp (1991 p.28) conducted a study of senior nurses who had attended workshops, which involved them in drafting an action plan for change in their place of work. However, when it came to implementing changes, they found constraints arising, particularly around time available to them and inadequate staffing levels. One of the major problems came from their managers, who viewed the plan as an optional extra rather than an important part of the nurses' role, and permission had to be sought despite initial approval. There was little evidence of consultation by managers and feedback was given mainly for poor performance. The resulting low morale can lead to change being abandoned through lack of support and lack of time.

The following key points identified by Reynolds and Dimmock (1992 p.61) may be important factors in any process of change:

- support from managers;

- the right 'climate': receptivity not only to the ideas but to the personality of the person introducing them;
- support for the plans from more than one other person if possible;
- not only the introduction of the change, but also keeping it going, and keeping others enthused;
- not taking on too many changes at once.

Other aspects, which also need to be taken into account, have been identified by Reynolds and Dimmock. They include; a collaborative leadership style, feedback and encouragement, time and regular staff development. One further important factor highlighted by the authors relates to stress of the worker and the ability to express and receive help. Working with dying people can be particularly stressful. Acknowledgement both that this is the case and that there is a need for support networks is crucial to the process of change if stress is not to become a factor leading to burn-out.

The importance of pathways and processes of change are central to achieving empowerment for dying people. Nurses need to have the strength and confidence to facilitate the change agenda and, as we have seen, power structures are only one area of constraint or change. Issues of self-esteem and support must also be considered for the process to be effective. Hopson and Adams (1976 p.13) place self-esteem centrally within the transitions of change. They argue that a cycle of reactions and feelings occur which can be predicted beforehand. This cycle ranges from being overwhelmed by the process, and being unable to act, through various stages, some similar to Kubler-Ross's stages of dying, to a stage of internalisation when the change becomes

part of behaviour. Pearlin (1982) outlines a model with just three main areas important to the process;

- Individual coping mechanisms.
- The availability of support systems.
- Social structural factors such as poverty or racism, emphasising public rather than private troubles.

Both these models can be related to the role of nurses, since both personal and institutional factors have a bearing on their ability to manage and/or facilitate change in their practice.

Miller (1993) feels that the role of the managers is fundamental in the process of limiting or stopping radical change coming about. He gives the example of the apparently democratic and participative manager seeking to bestow autonomy without relinquishing one iota of control. Similarly, top managers may profess to advance radical views, knowing that middle management can be relied upon to take obstructive roles. If the middle managers are not educated to understand the cultural shift central to the success of the change, then little will be accomplished, since the experiment fails to be replicated in other areas. What Miller calls the 'speakers corner' syndrome will prevail where power holders are able to appear radical while, in reality obstructing the threat to their power at the same time as demonstrating their liberality (1993 p.294).

However, advocating the co-option of management into supporting the projects for change is not enough. According to Miller, organisational development cannot be

effective without also being politically active, involving changes in the distribution of power (1993 p.296). The 'personal' aspects of that practical requirement cannot be ignored and, it is clear from Miller's work that, there is evidence that employees may also strive to maintain management at the apex of a dependent hierarchy. Upsetting this structure may make the nurses feel vulnerable to the extent that they opt for the status quo rather than change which exposes them to feelings of fear and loss of professional status.

This process is demonstrated in an account of changes to professional practice in Kirklees and Dewsbury Health Authority (James and Dewhurst 1995). Nurses were incorporated into the changes of a joint-agency unit, with the social services department. Many of the perceived disadvantages were expressed as losses and were painfully articulated. One nurse said she felt stripped naked as she had lost her uniform, ways of working and off-duty time, all at once.

Resistance to change has been addressed by a number of writers. DuBrin (1974) identified ways that resistance can be minimised by the use of several interrelated strategies:

- Selection of positive staff.
- Use of non-confrontational methods of persuasion.
- Minimising disruption to interpersonal relationships at work.
- Introducing change tentatively.
- Sharing decision making.
- Using economic incentives.

These tactics are available mainly to management. It is important, also, however to consider how change may occur when originating from other staff levels. Kotter and Schlesinger (1979) identified six strategies for change which, although still intended for management, could be appropriate for others to consider. They include communication such as giving information, presenting a rationale, and educating employees, as the most important aspect. Other areas include, participation, facilitation and negotiation. In the case of negotiating, for example, a model for change emerges which takes into account a number of factors. (Figure 7)

Factors affecting the process of change

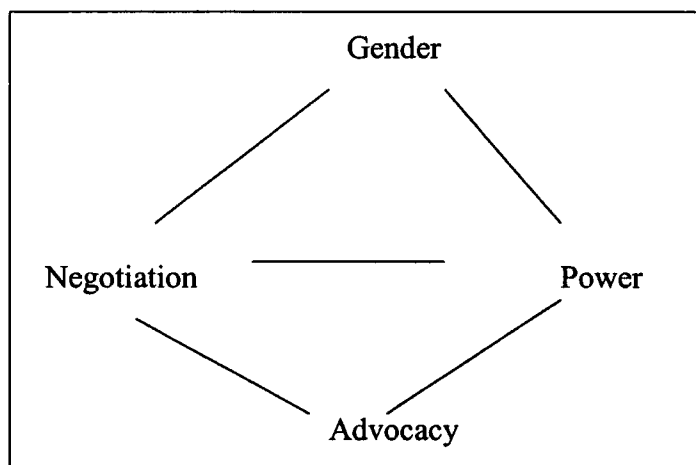


Figure 7

Consideration of the gender of the negotiator may be relevant to the process within the health care system where the majority of general nurses are female and the majority of doctors are male. It is important not to over-emphasise this aspect, but it is clear from recent research that gender can have an effect on the success or failure of the change process and that power is an important aspect of the model. Terhune (1970) found that women tended to avoid destructive competition, made greater concessions and tried to find accommodating solutions. In contrast, Miller (1991)

found that men have greater preference for competitive, unyielding and aggressive strategies. Valentine (1988) found that 'avoidance' was the approach most often used by nurses, and this was confirmed by several studies more recently (Cavanagh 1991, Washington 1990). These findings are not altogether negative as it is clear that women handle negotiations from a view point of personal relationships that are affiliative rather than from the impersonal world (Valentine 1995).

The use of avoidance or compromise (widely used by nurse managers) can, according to Valentine (1995 p.147), lead to stalemate. She recommends that people-orientated, and reconciliation skills should be valued rather than more aggressive models. However, 'avoidance' as a tactic can be problematic when addressing change and needs to be confronted if negotiations are to succeed. Advocacy, which is discussed in chapter 7, may be a way for nurses to confront the problem of change and if built effectively into the model, has the potential for positive outcomes. All four interrelated factors should work together to move the process of change forward once these problem areas have been acknowledged. Discussion so far has led to a gloomy conclusion, given the problems facing the nurse as change agent. However change can and does take place. The need now is for further research, to identify both how the process can best be achieved, and ways of building on the changes which have already taken place within palliative care. These latter changes need to be jealously guarded by nurses if they are to avoid slipping back into old ways of working, even in the hospice environment.

This dissertation has addressed a wide range of factors associated with empowerment. It is important to bring together some of the conclusions, at this stage, and point the way for further research, particularly around pathways to change which will begin to move practice towards the empowering approach advocated by this research. Practice has the potential for major change to take place, as instanced by the hospice movement and the care of people with HIV/AIDS. Now is the time to address similar changes in other areas, particularly areas where dying people receive care.

The main concern of chapter 3 was the culture of care as a macro level concept. Unless culture is examined it will remain oppressive to many people who are vulnerable within the health care system. Heartening work is being carried out in many areas, not least in the area of the care of people with dementia. The work of Tom Kitwood in Bradford and Mary Marshall in Sterling has lead the way, in recent years, to a re-examination of the culture of care that people with dementia face on a day-to-day basis. It is no use exaggerating its current impact, however, given the enormous task faced, as many nurses working with people with dementia are low paid, untrained and demoralised. They have little opportunity to bring about change. Unless problems of funding and, perhaps one could call it, image are considered, the status quo will prevail. Similarly, in the case of dying people, there are real problems of funding and morale in some areas, but it could be argued that there is at least some potential for change given the diverse settings under consideration. Acute medical and surgical services are, no doubt, in need of greater funding but trained staffing levels are higher compared to services for people with dementia. The culture of the palliative care ideology should, potentially, have impact on all areas of care. A new culture of

care is available to the nurse; it is now necessary to adopt the will to bring about this new culture. Perhaps people who are dying cannot be or indeed should not be considered in isolation. All clients or residents of the health care system have the right to self-determination and, therefore, the culture of care should be changing to meet this situation. However it would be naive to expect such changes to occur rapidly and that is why particular areas of concern need to be addressed, such as people with dementia or people who are dying; the most vulnerable and, arguably, the most in need of advocacy or autonomy.

The methodology used in this dissertation has been selected to ensure the nurses views and the nurses perspective has been given and valued when looking at practice. In some instances such accounts have been used to highlight negative aspects of care. This has been done with the co-operation of the nurses involved, who were asked to consider failures of empowerment as well as successes. The use of 'thick description' has emphasised some of the hidden or 'taken for granted' aspect of care. A nurse examining aspects of nursing may be guilty of overlooking areas of practice worthy of note, simply because he/she remains part of the culture from which that practice arose and is unable to easily remove him/herself from its unspoken and very often unquestioned norms. 'Thick description' demands that each concept is closely examined and terminology is questioned rather than taken for granted. In this way all data provided for analysis is used and described in the light of the concepts examined.

The initial study looked at the concept of ritual action and linked this to disempowering practice. Ritual or routine has been identified as central to the way

that nurses work and, unless such rituals are open to question, there is little scope for patients to express their needs and challenge the accepted norms. Rituals demand a set of actions which structure the day for nurses and patients alike, leaving little room for innovation. As a result, the nurses suffer from a stifling culture of task-orientated work which allows for little thought from the nurses and a loss of autonomy for the patients, both trapped within the routines of the day. The need is to challenge these ritual and Walsh and Ford (1989) have clearly begun this process.

Chapter 6 considers empowerment of the dying patient as a central concept. There remain many areas which are problematic and a glance at the research findings can only underline the problem at hand. However the students' reflections towards the end of this chapter leave room of hope. It is clear that in some working environments there is the potential for change. If this chapter is read with the next on advocacy, then this potential is seen more clearly. The final two examples give a clear indication of the way that nurses can speak up for patients. It may only be possible to draw the conclusion that the role of advocacy is easier for the nurse than the process of empowerment, but any move towards the breakdown of disempowerment is to be valued. If the result can be reached through the role of the nurse as advocate then this should be recorded as an effective route towards the empowerment process.

Further limiting aspects arise from examination of the research. The two examples mentioned are from nurses who work in similar areas; they have relatively high staff ratios and the pressure of work is less than in acute areas of practice. This could mean that the ideal speech situation has a greater potential to develop. In any case, the ideal

speech situation could be said to be just that, an ideal in whatever setting. However, if it is seen as a goal then even small steps towards that goal must be valued as improvements in practice develop and change.

The process towards empowerment is clear and, when considered in conjunction with the educational process, has real implication for all areas of practice. All the nurses in the study were attending courses which emphasised the importance of advocacy and empowerment and this was the focus of their reflections. It is necessary to put any findings into context, as these nurses may be said to be more aware of the concepts than nurses who had not attended such courses. Further work is therefore necessary to consider whether there is, in reality, any move toward the implementation of nurse advocacy in practice outside of the educational process. Some nurses stated they had a duty to advocate for their patients. This begs the question of how pressing that duty would have been and to what extent they would have felt bound by that duty if they had not attended an ENB module which emphasised it. Such reservations are necessary and point the way forward for a more extensive examination of practice in this area.

Education is therefore central to the concepts under discussion. Reflection by the students has been used to draw out some of the routes and barriers to advocacy and empowerment. To ensure that the concepts are re-enforced, reflection on writing has been underlined as important to the consolidation of change. However, if change is to be on-going, some form of reflection in practice is necessary and a regular clinical supervision programme is therefore recommended for this to become a possibility.

There is the need to maintain an audit of such a programme for it to succeed. Hence further research is necessary in this area to see if the desired results are being achieved.

This dissertation has highlighted a major concern in nursing practice. The health care system can no longer continue to flaunt the human rights of individuals, by imposing patterns of care and treatment onto people without first giving them the information they need to make informed decisions about their lives. Nurses and related professions must also ensure that people have the right to self determination, and if they are unable to take advantage of that right, then, health care professionals must take seriously their duty to advocate for them in a way which meets the perceived needs of individuals and not the needs of carers or the health service and its workers.

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