

OPENING UP AWARENESS: NURSES' ACCOUNTS OF NURSING THE DYING

DAVID FIELD

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PART I: PRELIMINARIES

"the availability of good care tends to vary inversely with the number of people suffering from a condition. And we all die."

A. Cartwright et al LIFE BEFORE DEATH

1: INTRODUCTION

Most deaths in our society occur in hospitals or other institutions for the care of the sick. The main group of people caring for the dying in these institutions are nurses. This thesis looks at nursing the dying as seen from the perspective of nurses, and mainly focusses upon hospital nurses. The focus is deliberately quite narrow in that the concern is with social and psychological aspects of nursing the dying and not with the 'practical nursing work' which is involved. The present chapter serves to place the research reported in chapters three, four, five, and six in the context of the relevant research and debate on the topic of death and dying. Chapter two addresses methodological and methodic matters. The final chapter discusses the research findings and look at organizational features of hospital work and at aspects of nursing which relate to them.

This chapter begins by looking at the organization of hospitals and the consequences of organizational arrangements for the care of the dying. This is followed by a brief consideration of the organization of nursing. Next comes an overview of attitudes towards death and dying, followed by a look at the attitudes of health care professionals. The chapter closes with a review of material bearing upon the central concern of this study - awareness and disclosure of dying in hospitals.

HOSPITALS AS ORGANIZATIONS

Cartwright et al (1973) estimated that nearly a third of all hospital beds were occupied by patients who were dying, or who would die within the year. In England and Wales in 1984 over 62% of all

deaths occurred in hospitals or other institutions for the care of the sick, and nearly another six percent of all deaths took place in other institutions (OPCS, 1986a). Nearly 5.5% of all hospital admissions in England in 1984 were 'discharged dead' (Govt Statistical Service, 1986). While for dying patients and their relatives their experience is unique and problematic for hospital staff care of the dying is part of their work. The ways in which staff define and perform such work has an important, if not crucial, effect on the experience of dying for patients and their relatives. Such definitions and performance are themselves shaped in various ways by the organizational demands and routines of hospital life. The two groups of hospital staff most directly concerned with such work are doctors and nurses, with the everyday care and close contact with the dying falling to the latter.

Hospitals are organizations characterized by a number of sometimes competing goals and a complex division of labour (Alexander, 1984; Freidson, 1963, 1970; Mauksch, 1966; 1975; Perrow, 1965; Strauss et al, 1985; Tuckett, 1976). The complexity of hospital work is made abundantly evident in the work by Strauss and his colleagues (1985). They note that "hospitals are quite de-centralised in terms of their ward functioning and work" (75), although to some extent such autonomy is limited by the dependence of wards and units on other parts of the hospital for resources and services. Hospitals can thus be seen as comprised of 'multiple work sites' with little central co-ordination or control over these various 'workshops'. Not only are the work sites different from each other in terms of their organization and clinical work, but within each a variety of work tasks must be performed and coordinated with each other. Strauss et al identify and discuss the following types of work done by doctors, nurses, and other staff: machine work, safety work, comfort work, sentimental work, and

articulation work. As they point out modern hospital care involves a plethora of staff, and different staff will be more or less responsible for different types of work - although both doctors and nurses will do all of these - and disputes between staff over work priorities and performance will occur. These will obviously affect patient care.

Another way of looking at the complexity of hospital organization is by a brief specification of the main areas of activity which take place within them (Perrow, 1965; Tuckett, 1976). As a pre-requisite for the clinical work of hospitals the basic 'hotel functions' of catering, cleaning, laundry, and so on must be provided together with the clinically related services of laboratories, radiology and the like. Staff must be hired, assigned to units, and paid. Goods and equipment - both 'durables' such as monitoring machines, and 'consumables' such as drugs and syringes, must be ordered, serviced, and delivered to the appropriate work sites. The provision and co-ordination of this range of goods and services may be quite complicated and difficult to maintain at a satisfactory and predictable level (especially in times of tight financial budgets), yet without them the treatment and care of patients is impossible.

Clinical work is seen as the rationale of hospitals by most people. The clinical treatment of patients with the aim of restoration of normal functioning or maximal rehabilitation, often involving the use of expensive drugs and complicated technology, assumes a central position in hospital life. This area of activity is the main province of medical staff who are supported in their work by nursing staff and a host of other workers. The predominance of chronic disease conditions within modern hospitals makes the goal of complete cure and

recovery difficult to achieve in most circumstances, and may make clinical work very complex and difficult to orchestrate (Strauss et al, 1985). Although chronic illness predominates most doctors, it seems, operate with an 'acute care' philosophy which may mean that incurable and terminally ill patients are seen by them as unrewarding, and so receive less attention from the doctors. Certainly acute services receive proportionally more resources at all levels (not just clinical) than chronic services (DHSS, 1983, DHSS & Welsh Office, 1981; Garner, 1979).

Related to and usually subordinated to clinical therapy is patient care. Indeed the two are only analytically separable in everyday hospital life. 'Care', which refers to the attention paid to the physiological, psychological and social needs of patients, is an essential component in the treatment of all patients and is primarily the province of nursing staff. It is especially important and central for the terminally ill, particularly at that point when interventionist aspects of clinical treatment of disease becomes subordinated to the requirements of 'palliative care' as such patients near the end of their lives. The 'professionalization' of British nursing around the 'care' dimension via the emphasis upon individualised patient care and the introduction of the 'nursing process' has both enhanced the importance of patient care as an aspect of hospital work and served to increase the area of potential dispute between doctors and experienced nursing staff over patient management.

Another important area of activity in most British hospitals is the training of new staff. Hospitals are important sites for the training of a whole range of health care workers, and the presence of large numbers of trainees has a profound effect on patient treatment and

management. Indeed, in some settings trainees - House staff, student and pupil nurses - may provide the main source of labour. A number of consequences flow from both the reliance of hospitals on staff in training to provide a significant part of their work force and the use of patients as 'learning material' for such staff (Atkinson, 1981; Backer et al, 1982; Melia, 1981; Oleson & Whitaker, 1968; Quint, 1967). The constant flow of trainees through the wards and units may present some problems of continuity in ward functioning and to a lesser extent patient management as new staff have to 'learn the ropes' of the work setting. Mistakes inevitably occur, which can lead to patient discomfort and even clinical danger. Also, patient selection and choice of treatment may be affected to some extent by training considerations.

A final area to consider is that of research. With the ever increasing specialization of modern medicine and its dependence upon high level technology, hospitals have become the main sites for the research development of clinical medicine. Not only clinical researchers but a variety of other researchers (even sociologists!) can be found in hospitals. As with teaching activities, the aims and requirements of such research activities are different from and may conflict with the goals of patient treatment and care. As with teaching, research requirements may affect the selection and treatment of patients, and may divert staff and resources from other areas of hospital activity.

These general features of hospitals bear directly and indirectly upon patient treatment and care, and the ways in which patients experience their hospitalization. To coordinate this plethora of diverse activities requires rules and routines whereby staff work can

be coordinated and controlled. For example, the collection, collation and distribution of information about patients - which is central to their treatment and care - cannot be left to chance or purely individual action but requires some systematic control and coordination. The various formal rules and routines provide the framework within which nursing (and other) work takes place, but these are amplified by informal routines and arrangements. Both formal and informal arrangements are continuously negotiated by staff (Strauss et al, 1985; Strauss 1978), and the negotiations between staff as to the meaning and applicability of these rules and arrangements is as important as the formal rules and organizational structures - hospitals are not fixed and immutable organizations, but rather, are 'structures in process' (Glaser and Strauss, 1968). Indeed, given their complexity, continual negotiation and communication between staff both within and between the various work sites of the hospital are essential.

THE ORGANIZATION OF HOSPITALS AND CARE OF THE DYING

There are a number of features of hospital life which bear directly on the consideration of nursing dying patients in hospital which are briefly considered here. More extensive discussion can be found in Glaser and Strauss (1965, 1968), Mauksch (1975), McIntosh (1977), and Sudnow (1967) whose work is drawn upon in various ways.

Hinton's analysis of the costs and benefits to the terminally ill of dying at home, in a hospital, or in a hospice, (1979), clearly demonstrates that different settings may produce differing patterns of cost and benefit for the dying. Thus, where dying takes place is an important variable. Different organizational contexts (wards, units)

are characterized by different rhythms and flows of work, and have different (or no) routines for coping with death and dying. They will also vary in the resources available, staff numbers and training, staff turnover, and management structure, all of which will affect nurse-patient relationships. In general more resources of all kinds are allocated to the 'acute' services (where 75% of all deaths occur), and thus dying patients on 'chronic' services such as geriatrics will have fewer resources, including nursing staff, available for their care.

The care of dying patients on different units depends in part on the characteristics of both 'normal' and dying patients. Death on a coronary care unit is very different for staff than death on an acute surgical ward, or on a general medical ward. In the former death is to a certain extent expectable and staff can psychologically 'offset' such deaths against their many successful recoveries. On the surgical ward, the discovery of a terminal cancer at a routine operation may severely disrupt the 'sentimental order' of the ward, and an unexpected death on the operating table certainly will. On the medical ward death will, as in coronary care, be expected but the process of dying will typically be more extended and involve older patients than in the other two settings. Glaser and Strauss discuss such differences fully in their work emphasizing that the period of time over which death occurs and its predictability are major factors affecting how staff treat the dying patient. Another important characteristic is the age of the patient. In our society it is easier for staff to accept the death of elderly patients. In particular young dying children are psychologically difficult to nurse (Backer et al, 1982; Benoliel, 1983; Epley & McCaghy 1978; Hale et al, 1984; Kalish & Reynolds, 1977; Quint, 1967; Stedeford, 1985).

While the physiological, psychological, and social care - as distinct from the therapeutic cure or treatment - of the patient is primarily the province of the nursing staff, such care is at least nominally under the control of the doctor. Doctors can and do impose restrictions on the care offered by nurses to patients (e.g. Knight & Field, 1981; Quint, 1967). Two features in particular seem crucial to the care of the dying. First, it is the doctor who decides whether 'active' curative treatment aimed at eliminating or controlling the disease process - sometimes at the price of unpleasant 'side effects' - shall be continued as the main focus of attention, or whether it should be replaced by an emphasis on the assessment and control of symptoms in 'palliative' terminal care. While such decisions may be made in discussion with nurses it is the doctor who has the final say, and who legitimates entry to the dying 'career'. Second, the doctor controls the information which nurses are allowed to give to patients and to relatives about diagnosis and prognosis. Nurses may be forbidden to reveal that a patient is dying, even if they consider that such information should be given. It is not being suggested that relations between doctors and nurses are exclusively hierarchical and formal, as there may be much discussion and negotiation between them about patient care, especially when a 'team' has been together for a long time. However, in our hospitals the final decision-making power rests with the doctors, and is acknowledged by nurses to do so.

THE ORGANIZATION OF NURSING

The organization of the nursing profession has a bearing on the nursing care of the dying. Of particular salience are patterns of recruitment, training, nursing turnover, and the organization of

nursing work. The key feature of nursing as an occupation is its definition in relation to the medical profession as a subordinate and ancillary activity. This largely stems from the concentration of nursing work in the hospital, where the parameters of nursing activity are controlled largely by other groups within the hospital hierarchy. This position of nursing stems back at least to the Victorian era and Nightingale's definition of nursing work: "All nursing work flowed from the doctor's orders, and thus nursing became part of doctor's work, a technical trade rather than a 'natural' practice of femininity or a part of the exercise of charitable impulses. Nursing was thus defined as a subordinate part of the technical division of labour surrounding medicine." (Freidson, 1970:61).

Nurses are recruited predominantly from young females (UKCC, 1986) most of whom, it seems, enter nursing with a conception of nursing as a caring occupation - what Schulman called the 'mother surrogate' role (Schulman, 1972; Moloney 1986). This pattern of recruitment has consequences for both nursing turnover and doctor-nurse relations. Turnover, which is high, is partly explicable by the pattern of nurses leaving work to have and raise families (Hockey, 1976), and partly by low pay - a characteristic of predominantly female occupations (Dept. Employment 1985; Redfern, 1981; Webb, 1982). The importance of further training as a means to career advancement is another factor leading to high rates of turnover of nurses on hospital wards (Melia, 1981). This pattern of recruitment and high rates of turnover means that most nurses will have had little, if any, direct experience of death and dying, especially during the early years of their nursing career. For example, Simpson (1975) in his study of student nurses in London found that only 12% had experienced a death in their family, and that 35% had never witnessed death, not even during their training. This lack

of general and death-related experience creates difficulties for the nurses in their work with the dying (Charles-Edwards, 1983). It must also, one presumes, have profound effects upon their care, and upon the experience of dying for the terminally ill and their relatives.

Game and Pringle (1983) claim that the subject of death "was carefully avoided in training" until recently. The results of a 1984 survey of UK nursing schools (Field, 1986) suggests that this is no longer the case, and that it is a topic receiving serious attention in these schools. Studies from the USA report more favourable, less fearful, and less avoiding attitudes towards death and dying as a result of death education (Bugen, 1980; Leviton, 1977, 1978-9; Miles, 1980; Murray, 1974; Watts, 1977). However, in Britain a survey by Birch (1983) presents a generally unsatisfactory picture of teaching about death and bereavement in our nursing schools, and many of Field's respondents expressed reservations about the efficacy of their teaching even though there was a generally positive view of the impact of their teaching upon trainees. The main reservations expressed related to the lack of correspondence between the school situation and the trainees' experiences on the wards. It does seem that training for the nursing of dying patients is still inadequate, especially with reference to psychological factors. Yet the care of the dying in hospitals often devolves to nursing auxiliaries, pupil and student nurses who are unskilled, unprepared and often unsupported by their more experienced colleagues (Knight & Field, 1981; Quint, 1967). Melia's apt description of the trainee nurse as 'nursing in the dark' seems to have particular weight where nursing the dying is concerned.

Another aspect to consider here is the relationship between doctors and nurses. The doctor-nurse relationship of superordination/

subordination reflects traditional male-female relationships within western society, as Quint points out (1967), and is not based simply on functionally differentiated roles and tasks within health care work. The fact that most nurses are female appears to contribute significantly to the continuation of the subordinate position of the nurse in the hospital hierarchy despite general changes towards greater equality (Game & Pringle, 1983; Rosenthal et al, 1980), and may contribute to the reluctance of nurses to go against 'doctor's orders' to withhold terminal prognosis from patients (McIntosh, 1977; Simpson, 1975).

The organization of nurse training contributes to the inability of nurses fully to control their work partly by its effect on the organization of nursing work on the wards, and partly by the psychological effects it has on students and pupils. This has been well described by Melia (1981, 1984) who points up the contradictions between the training school and ward experiences of the trainees. The discrepancy between the school-based 'professional' and the ward-based 'traditional' strands in nursing is marked (Habenstein & Christ, 1953), and the view of nursing found in the two locations is very different. Nursing schools are likely to emphasize the professional role of the nurse and to see social and emotional problems as part of the legitimate area of nursing concern, and to transmit a view of individualized or 'whole person care' as embodied in the use of the 'nursing process' (Henderson, 1969; Crow & Kratz, 1977). Senior hospital nurses are more likely to emphasize a management, 'task oriented' approach to nursing (Melia, 1981; Pembrey, 1980; Redfern, 1981; Runciman, 1983), and on most wards trainees are seen as essentially another pair of hands (Clarke, 1978), and are given the routine day-to-day work which has to be done. They are not, it seems,

systematically trained to assume responsibility, to take decisions about the care of individual patients, or to talk to patients. The messages given in training school are not usually reinforced and supported on the wards (Bendall, 1976; Melia, 1981; Simpson, 1980).

The paradox is that the attempt to 'professionalize' nursing by rooting it in an esoteric body of knowledge and practice exclusive to nursing, as embodied in the nursing process, represents a fusion of the 'traditional' and 'professional' aspects of nursing around the (idealized) traditional nurturant and caring role of the nurse. Despite this, the nursing process is often viewed with suspicion and hostility in the wards, and is not implemented wholeheartedly (Melia, 1981). It will be interesting to see what effect the proposed changes in the organization of nurse training (Royal College of Nursing, 1985; UKCC, 1986) has upon nursing practice and upon the strained relationship between 'professionalizers' and 'traditionalizers' within British nursing (Moloney, 1986: 45-47). The research on which this thesis is based suggests that where the nursing process is taken seriously it is an important element leading to the provision of good nursing care of the dying.

ATTITUDES TOWARDS DEATH AND DYING

There is now a considerable literature bearing on the attitudes held towards death and dying in modern Western society which will not be more than briefly reviewed here. More extensive surveys can be found in Benoliel (1983), Kastenbaum (1977), Riley (1983) and Schneidman, (1980). At the outset it should be noted that much of the literature is speculative and not firmly grounded in empirical research evidence. Research evidence on the attitudes of the general

population is sparse, and mainly limited to the USA as is the research into the attitudes of health workers. Many of the research studies are flawed by methodological shortcomings (Benoliel, 1983; Rodabough, 1981; Simpson, 1980).

In his influential book Gorer (1965) suggested that death had become a 'taboo' topic in the twentieth century, replacing sex as the area which it was forbidden to discuss or mention. However, since that time death and dying have become if not popular subjects at least the subject of debate, discussion, and research. In 1979 Simpson reported there were more than 750 books on the general topic, and by the mid 1980's the number of publications in english alone must run well into four figures. The subject of death and dying is certainly not restricted to a limited group of practitioners and researchers isolated from the rest of society, as Lofland amply demonstrates in her Foreword (Lofland, 1978:10-13). The respectability of these topics as an area for legitimate scholarly inquiry and academic research has been validated by the attention paid to it by those eminences grises Philippe Aries (1974, 1981, 1985) and Norbert Elias (1985).

In his paradigmatic discussion of 'Death and social structure' Blauner (1966) argued that death is less pervasive and central in modern societies than in non-modern societies, and linked this firmly to changes in demographic structure consequent upon changing patterns of mortality. Mainly as a result of low rates of mortality in the early years of life modern societies such as Britain have a significant proportion of their population beyond working age. In 1984 15% of the UK population was over the age of 65, and 6.4% over the age of 75 (OPCS, 1986b, Table 1.1). Death in our society now

mainly occurs among these age groups with the result that "as death ... becomes increasingly a phenomenon of the old, who are usually retired from work and finished with their parental responsibilities, mortality in modern society rarely interrupts the business of life" (Blauner, 1966: 379). Such societies have also, according to Blauner, 'Bureaucratized death' by making hospitals, funeral organizations and the like primarily responsible for its management. Thus it can be largely ignored by the general population, although the lack of funeral and mourning rites may make it harder for the bereaved to cope with their loss.

Blauner's thesis has been generally accepted, with many writers suggesting that members of modern western societies are less accepting of death than were people in previous eras because they have less exposure individually to death and dying. As Elias expresses it, these changes mean that psychologically people can keep death at a distance because "it is easier in the normal course of life to forget death" (1985:8). Following well established sociological reasoning (e.g Durkheim, 1960), he argues that modern western societies are characterized by a high degree of individualization, and so their members experience themselves as unique and separate beings. Further, death and dying are no longer surrounded by the rituals of departure of earlier eras, but have to be constructed anew by those involved. These factors of infrequency of death, individuation, and absence of shared meanings and rituals about death and dying, combine to make them unfamiliar and feared conditions.

More contentiously some writers have taken the above argument a step further and argued that these societies are 'death denying' and 'death avoiding'. For example, Aries asserts that "The old attitudes

in which death was both familiar and near, evoking no great fear or awe, offers too marked a contrast to ours, where death is so frightful that we dare not utter its name" (1974:13). There is no consensus about the validity of this view (Kellehear, 1984), and it seems hard to sustain. For example, a national US survey "found that most people at all ages held non-threatening images of death" (Riley, 1983).

The study by Williams (1986) of the views of older Aberdonians about death and dying seems to offer a more satisfactory representation of attitudes towards death and dying in our society. He reports that four coherent patterns could be discerned which his sample drew upon in their reasoning about death. The two most common patterns were what he calls 'ritual death' and 'disregarded death'. 'Ritual death' included the belief that the dying person should be prepared for their death, have had the opportunity to make farewells to relatives and friends, and be aware of their terminality. This is very similar to the pattern which Aries and Elias suggest existed earlier in European history. This pattern was strongly evident in the sample, but the modal view was that of 'disregarded death'. In this pattern the elements included a preference for quick and unaware dying - although this was often seen as difficult for the bereaved to cope with.

An important feature of Williams' study is the complexity of attitudes and reasoning about death and dying which were found. Williams suggests that different 'strata' of attitudes are evident, with an emerging pattern of 'controlled dying' focussing around the core ideas of an aware terminally ill person who might wish to have the option of euthanasia. Attitudes were not necessarily clear cut, and people often held what they recognised were conflicting attitudes,

e.g. that a quick death was desirable and that death should occur after 'reunion' with family. Generally speaking the Aberdeen study supports the view that people do not wish to know about their impending death, but does not necessarily support the view that death is highly feared.

ATTITUDES OF HEALTH CARE PROFESSIONALS

There is good reason to believe that there is a relationship between professional attitudes towards death and dying and the psycho-social experiences and well being of the dying. Doctors and nurses have more frequent and sustained contact with death and dying than do most other members of our society, and the nature of such contact can be intense and highly stressful. The difficulties met by terminally ill people may be exacerbated by the failure of doctors and nurses to deal adequately with their own reactions to death and dying. The 'closed awareness' to the nature of their condition and the 'social death' of many terminally ill patients (Glaser & Strauss, 1965; Sudnow, 1969) are likely to be, at least in part, a product of the difficulties which hospital staff have in discussing and dealing with death and dying (Backer et al, 1982, Charles-Edwards, 1983; Lowenberg, 1976; Munn, 1983; Quint, 1967; Redding, 1980).

Normally whether or not to disclose 'bad news', especially a terminal prognosis, is controlled by doctors. Until recently doctors and other hospital staff did not normally inform dying patients that they were dying. It seems that between 70 and 90% of physicians preferred not to inform patients of their impending death (Cartwright et al 1973, Duff & Hollingshead 1968, Fitts & Radvin 1953, Gilbertsen and Wangenstein 1961, McIntosh 1977, Oken 1961, Ward 1974). Nurses

have been reported to show a similar reluctance to disclose such information (Bond, 1983; Charles-Edwards, 1983; McIntosh, 1977; Simpson, 1975).

Failure to inform dying patients that they are dying persists for a number of reasons. There may be genuine uncertainty with regard to both outcome and/or the time of death. Doctors and nurses claim that 'not telling' protects the patient from depression and anxiety. Not telling protects hospital staff from becoming too closely implicated in the patients' dying and so they can maintain the pretence of 'everything as normal' and not get involved in the handling of death. In a similar way it may be thought to 'protect' or 'make things easier' for the family. Finally, the work routine of the ward may become disrupted by disclosure of impending death and the resulting necessity for staff to spend time coping with the psychological problems of the dying. Whatever the reasons it seems that there was, and in many British hospitals still is, a general 'decision rule' (Scheff 1963) to conceal the fact of their impending death from dying patients.

An influential body of opinion (Saunders 1959, 1978; Hinton 1967; Kubler-Ross 1970, 1975) holds that patients should be informed of their condition for both moral and 'practical management' reasons, and there is a growing body of evidence to suggest that there has been a move within medicine and nursing towards greater openness with dying patients than existed a decade or so ago (Bowling & Cartwright, 1982; Carey & Posavic, 1978-9; Field, 1984; Greenwald & Nevitt, 1982; Novack & Plumer, 1979; Rea et al, 1975).

There are a number of reasons adduced in favour of a policy of

disclosure of terminal prognosis to the dying. It is argued that disclosure resolves the problems of 'forced pretence' and patient suspicion by allowing open talk between patient, staff, and families. It thus obviates the problem of patient mistrust in the face of a conspiracy of silence, and reduces the loneliness and isolation of the patient which would otherwise result from the denials of others that anything is wrong coupled with their withdrawal from the dying patient. It is also claimed that non-disclosure of terminal prognosis to the suspicious far from diminishing anxiety actually increases it, whereas disclosure of prognosis decreases anxiety and ultimately depression. Openness, by alleviating anxiety, also seems to have a positive effect on the management of distressing physical symptoms, especially pain. Further, patients who are aware of their impending death may put their practical affairs in order and 'finish their lives' symbolically. Finally, it is argued that as many dying patients do become aware that they are dying (Carey & Posavic, 1978-9; Cartwright et al, 1973; Glaser & Strauss, 1965, 1968; Hinton, 1972, Kubler-Ross, 1970; Witzel, 1975), and as it is consistently reported that a substantial majority of people asked, would want to know if they were dying (Kelly & Friesen 1950, Aitken-Swan & Easson 1959, Cappon 1959, Gilbertsen & Wangensteen 1961) there seems to be no good reason to withhold such information. Particularly as those who do not wish to know of their impending death seem 'not to hear' such news (Kubler-Ross 1970).

To close this brief discussion of attitudes towards death and dying, it is generally agreed that death, and particularly dying, is feared; that such fears are not uniform; and that pain and loss are important elements in the fear of death and dying. Disclosure of their impending death to those who are dying is generally avoided.

Doctors and nurses, as members of our society subject to similar experiences and societal beliefs as the rest of society, could be expected to hold broadly similar attitudes and beliefs to the general population. Research with medical students at the University of Leicester suggests this is the case (Howells & Field, 1982; Howells, Gould & Field, 1986), and does not support the view of Fiefel et al, (1967) that medical workers have higher levels of fear. The 'conventional wisdom' which seems to be developing within medicine and nursing is that openness and honesty are important aids to assisting the terminally ill with their dying, and that contrary to previous beliefs such frank disclosure diminishes rather than increases anxiety and depression in the terminally ill. When and how to disclose the bad news remain problematic.

AWARENESS AND DISCLOSURE OF DYING IN HOSPITALS

The preceding sections have reviewed the complexity of hospital organization and how in general terms this affects the care of the dying, and current views about attitudes towards death and dying. This final introductory section brings together these two elements in a discussion of the management of awareness and disclosure of death in hospitals (the situation of dying at home will be discussed in chapter six). The work of Anselm Strauss and his colleagues is central to our understanding of such management, and forms the starting point for this thesis.

In Awareness of Dying (1965) Glaser and Strauss distinguish between 'quick' and 'slow' dying trajectories, and note the different organizational features of such trajectories. Generally deaths which occur over a short span are easier for hospital staff to cope with

than slow deaths (but not for the family or friends of the deceased), unless they are unexpected. For example, an unexpected death on an operating table can cause major problems for the smooth functioning of a surgical team. Quick deaths most commonly occur in emergency and intensive care situations where outcomes quickly become apparent. Most deaths in hospitals are not of this nature, and slow dying is more common and more problematic for doctors and nurses. It is this type of dying trajectory in particular which generates the various problems associated with awareness and disclosure of dying. In slow dying the patient is on a lingering downward trajectory, with symptoms often becoming worse and harder to manage. Not only may there be technical aspects of care which are difficult to coordinate and manage, e.g. balancing various drug regimes, but these often have a 'moral overlay' also. How long, for instance, should life be prolonged by the use of uncomfortable invasive treatment when it is known that recovery is impossible?

One critical dimension to the care of the dying is knowledge of the fact and duration of dying. Do staff know? Does the patient know? This is not necessarily straightforward. for the clarity and certainty of time of death have become blurred with the predominance of chronic disease and the capacity of modern medicine to intervene in disease processes to avert and retard the dying process (Culvert & Gert, 1982; Veatch, 1976). Sudnow in his discussion of the 'problematic notion' of dying makes a useful distinction between 'clinical death' - the appearance of 'death signs' upon physical examination (e.g. cessation of heart function, flat ECG); 'biological death' - the cessation of cellular activity; and 'social death' - which is "that point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for

treating him, and when he is, essentially, regarded as already dead" (1967:74). He provides a number of graphic examples of terminally ill patients being treated as socially dead, e.g pre-wrapping and binding of patients' feet ready for delivery to the morgue. It seems reasonable to suggest that there may be a process of 'social dying' for the terminally ill as others withdraw from social interaction with them, a view supported by Glaser and Strauss's work. What is clear is that certainty of death may develop slowly over a long period of time, that even when the fact of death is certain its timing may remain in doubt, and that 'social death' may often precede 'biological death' (Glaser & Strauss, 1965, 1968; Sudnow, 1967).

Glaser and Strauss identify several types of staff/patient 'awareness contexts': closed awareness, suspicion awareness, mutual pretence, and open awareness. Closed awareness refers to the situation where staff (and possibly relatives) know that the patient is terminally ill but the patient does not. The difficulty with this type of awareness context is that of maintaining the context with non-comatose patients, and it is in this type of situation that 'social death' is most likely to occur. Most patients are not sufficiently experienced to recognise the signs of impending death, and their families often concur with or request the with-holding of the terminal prognosis from the patient. Further, as Glaser and Strauss point out

"hospitals are admirably arranged both by accident and by design, to hide medical information from patients. Records are kept out of reach. Staff are skilled at withholding information. Medical talk about patients generally occurs in far-removed places, and if it occurs nearby, it is couched in medical jargon. Staff members are trained to discuss with patients only the surface aspects of their illness and ... they are accustomed to acting collusively around patients so as not to disclose medical secrets. The power of the hospital personnel over the patients is vast, since the patients are at their professional mercy for recovery and for such personal everyday requisites as feeding, washing, and even being turned in their beds." (1965:31)

Despite all the above, it seems that most terminally ill patients will eventually move from a closed awareness context to one of the other types of awareness of dying. For example, Hinton (1980) found that 66% of his sample of dying patients indicated to him that they knew they were dying - although they had not necessarily revealed this knowledge to hospital staff or to their relatives.

There are several factors which may lead the dying to a growing awareness of their impending death. Patients may become suspicious about their condition due to bodily changes and/or their physical deterioration. In particular certain physical signs, such as lumps or sores which fail to heal, may be believed to be signs of cancer, and hence indicative of possible terminality. Changes in treatment regimes are another 'cue' for patients. Changes in behaviour by staff and relatives towards the patient, especially non verbal signs of stress and general avoidance of talk about 'the future' provide another important set of cues. In the study of the surgical ward reported in chapter three we found that the most important cues for dying patients related to treatment and the lack of clear diagnosis.

Closed awareness most frequently breaks down into suspicion, which may be very destructive for staff/patient and patient/relative relationships. It is in this awareness context that patients may engage in a variety of behaviours aimed at 'trapping' staff and relatives into revealing that their suspicions that they are dying are correct. Patients in this state may also be very alert to the various cues which indicate that all is not well. In the mutual pretence context all parties 'deny' the fact of impending death, and references to the future may be dropped and talk restricted to 'safe topics'. This may solve the interactional problems of the closed and suspicion

contexts. It may not, however, allow what Kubler-Ross (1970, 1975) refers to as the final 'stage' of dying - acceptance of one's own death - since the patient will be unable to discuss it with others. Of course, it is possible that different types of awareness context will exist between the same patient and those with whom s/he is in contact, as Hinton's research confirms (Hinton, 1980).

In the preceding section it was indicated that there appears to be a move towards open awareness as the preferred type of relationship between the dying and hospital staff. Here the fact of death is known by all parties, and also as far as possible the likely time of death. In this context patients may become involved in decisions about the management of their care (although not all will choose to do so), and can make practical arrangements for their impending death (e.g. making a will, settling business affairs). The problem which this thesis addresses is 'what are the features of nursing work which best facilitate an open awareness context'?

2: METHODIC ACCOUNTING

This chapter presents an account of the research procedures used in this study together with a discussion of the problems associated with their use. It starts with a general discussion of methodological issues and the use of language, and then considers the more directly practical questions of what was done and how.

METHODOLOGICAL ISSUES

The methods used to investigate a research problem are conditioned both by the practical issues surrounding access, choice of method, etc, and by the theoretical presuppositions and prejudices of the researcher. Indeed, the latter also influences the choice of the research problem itself. The present study rests firmly - despite some reservations (Field, 1974) - on what is widely known within the discipline of sociology as the symbolic interactionist perspective (Blumer, 1969a; Goffman, 1959; Manis & Meltzer, 1967; Mead, 1934; Meltzer, Petras & Reynolds, 1975; Mills, 1940; Natanson, 1956; Reck, 1964; Rock, 1979; Stone, 1970; Stone & Farberman, 1970; Strauss, 1946, 1959; Turner, 1962). In particular, as can be seen in the previous chapter, it has been heavily influenced by interactionist analyses of hospital life, especially those by Anselm Strauss and his colleagues (Davis, 1963; Fagerhaugh & Strauss, 1977; Freidson, 1963; Glaser & Strauss, 1965, 1968; Goffman, 1961; Lorber, 1981; Mauksch, 1975; Quint, 1967; Roth, 1963; Strauss et al, 1963, 1964; Strauss et al 1985).

The central tenet of symbolic interactionism is easily stated: we

are human because we talk. Language allows humans to 'stand outside' and 'apart from' the immediate world of activity in ways which are impossible for other animals lacking humanity's symbolic capacity. Unlike other animals, humans interact with each other and with their physical environment in a symbolic rather than a 'signal' manner (Mead, 1934, 1964; Bruner, 1964; Flavell, 1968; Bernstein 1972). There is no intrinsic meaning to objects in the world, rather their meaning is constructed, transmitted, and negotiated by humans, mainly through the linguistic medium (Blumer, 1969b, 1977). Language provides a 'pool' of shared meanings about the world which serves to coordinate human actions and provides the primary mechanism for the development of self-awareness and self-objectification which are pre-requisite for human social interaction (Flavell, 1968; Mead 1934).

THE USE OF SPEECH AS DATA

This study is primarily based on interviews with nurses. Many writers have pointed to the difficulties associated with the use of linguistic behaviour in a seemingly endless series of debates stretching back, at least in social science terms, to the debates over linguistic relativity (Sapir, 1949; Whorf, 1956; Hymes, 1966; Slobin, 1971) and more recently the ethnomethodological critique of sociological practices (Attewell, 1974; Benson & Hughes, 1983; Cicourel, 1973; Douglas, 1971; Garfinkel, 1967; Turner, 1974; Wooton, 1975). It is therefore necessary to justify the use of interview conversations as valid bases for making statements about nurses' experiences of and attitudes towards nursing the terminally ill and, more problematically, for making statements about their other behaviour.

Language production and 'meaning imputation' do not occur in a vacuum independently of the empirical characteristics of the social contexts within which individuals act. 'Structural Constraints' upon behaviour exist no matter what ethnomethodologists and phenomenologists may assert¹. There are factors 'external and constraining' to any one individual - for example, legal rules governing permissible nursing work - which, as Durkheim (1950) so aptly put it, assume the nature of 'social facts'. Such 'social facts' may, indeed must, be interpreted and negotiated by individuals (Blumer, 1977; Mead, 1934; Strauss, 1978) but there are limits constraining such interpretation. In this work the concern is to specify the nature, shape, and influence of 'structural features' of nursing work as they impinge upon nursing the dying, and to attempt the specification of their influence upon nurses' experiences and interpretations of such nursing work. We shall also consider the resources which nurses themselves bring into such work. How do nurses make sense of their encounters with the dying? What are their experiences of nursing dying people and dealing with their relatives? What resources - personal and 'structural' - can they draw upon to help them in their work? What practical features of the organization of their work constrain, facilitate, and shape their interactions with the dying, and, hence, influence their experiences with and attitudes towards them?

Despite the difficulties involved nurses' verbal behaviour is taken as a valid basis for such an attempt, for language use is intimately connected with the social situations which it refers to and makes sense of (Mills, 1940). As Burke (1941) puts it "'social structures' give rise to 'type' situations. Subtle sub-divisions of relationships involved in competitive and co-operative acts - the names for typical

recurrent social situations are not developed out of 'disinterested curiosity', but the names imply a command (what to expect, what to look for)". (Quoted in Duncan, 1961). The use of speech as data is, then, not based on any ignorance of the many problems associated with inference and proof in such usage. Rather, such problems potentially apply to any and all language use whether it be in scientific research or everyday life (Cicourel, 1964; Schwartz & Jacobs, 1979). These problems are discussed on pages 38 - 44.

Before leaving the question of language use, two short comments on the use of language in this work are in order. The terms 'dying' and 'terminally ill' are used interchangeably with no attempt to specify the precise shading of meaning between them. Thus the interviews were mainly couched in terms of 'nursing the dying' with no attempt to be more precise than that in the interview conversations. It was felt that it would not be appropriate to start an open-ended interview with a precise and technical definition of what was meant by 'dying'. Rather, the term has sufficiently shared consensual meaning for it to act as a suitable starting point and stimulus for nurses to discuss their feelings and experiences, and, if they so desired, to offer their own definitions of 'dying'. Ambiguity is, after all, an ever-present characteristic of human social life (Stone, 1970) and in our society ambiguity is increasingly an important characteristic of death (Sudnow, 1969: 61-75; Culver & Gert, 1982).

It has been attempted to avoid the sexist use of language, but where to do so would have been unduly clumsy the following conventions have been used. Nurses are generically referred to as female since this reflects the preponderance of females in the occupation and amongst those whose accounts provide the main basis for the study.

Doctors are generically referred to as male because that is how the nurses referred to them.

THE SAMPLE

The medical and surgical wards and the coronary care unit (CCU) referred to in this study were all part of a medium sized (900 bed) general hospital located in a Midlands city in England. The hospital is referred to as 'Midland General' and the city simply as 'City'. Other devices to preserve confidentiality include the changing of details incidental to the study focus, such as altering ward numbers and simplifying ward plans. Access to the medical wards and the CCU was obtained through the nursing officer in charge of the unit containing them. There was no compulsion to be interviewed placed upon nurses by him or by the Sisters.

As can be seen from Table 2.1 the nurses interviewed were drawn from three different settings. The entire day staff (18 nurses) of a general medical ward were interviewed over a nine week period in 1982. All but two of them were female, and their nursing experience ranged from trainees on their first ward to one nurse with twenty years experience. In addition seven nurses from an adjacent medical ward were interviewed, but when the taped interviews with five of them were stolen it proved impossible to continue with the planned comparison of the two wards. Most of the nurses working in the general medical setting (12) were between the ages of 20-25. Interviews were very variable in duration, lasting from 15 to over 50 minutes. The interviews with trainees were typically shorter than those with the qualified nurses, while the interview with the Sister lasted over an hour. Nine of the ten trainee nurses interviewed for the study were

TABLE 2.1 SOME CHARACTERISTICS OF NURSES INTERVIEWED AT TIME OF INTERVIEW

NURSE	TIME IN GRADE	AGE	INTERVIEW GROUP	OTHER NURSING EXPERIENCE
PB	6m	20	Ward 6	
PC	1y 3m	21	Ward 6	
PF	1y 9m	39	Ward 6	
PJ	6m	20	Ward 6	
PM	1y 9m	20	Ward 6	
SA	4m	20	Ward 6	
SD	9m	25	Ward 6	Qualified Psychiatric Nurse
SG*	1y 9m	26	Ward 6	Qualified Psychiatric Nurse
SH	3y	20	Ward 6	
SU*	3y	22	CCU	
ER	1y 6m	22	Ward 6	'heart wards'
EW	6y	54	Ward 6	A: Medical wards (14y)
EY*	7m	21	Ward 6	
EA	10y 3m	30	CCU	Geriatric in small hospital
EC	1y 9m	21	CCU	
ED*	4y 9m	24	CCU	Intensive Therapy Unit
EK	2y 7m	23	CCU	Geriatric ward
EO	5y	30	CCU	Geriatric in small hospital
EP*	2y 4m	22	CCU	A: Geriatric in small hospital
ES	2y 3m	23	CCU	
ET	3y	26	CCU	Geriatric ward
EZ	2y 2m	22	CCU	Young Disabled Unit
RE	2y 3m	23	Ward 6	
RI	2y 3m	23	Ward 6	
RL	2y 10m	28	Ward 6	
RP	9m	27	Ward 6	Geriatric ward
RF*	3y 6m	28	CCU	Medical ward
RJ	2y	24	CCU	Geriatric ward
RM*	2y 2m	28	CCU	Medical ward
RN*	2y 11m	28	CCU	
RQ	5y 10m	29	CCU	Small District hospital
RB	2y 5m	23	Community	Medical ward
RH	1y 8m	23	Community	Medical ward
RS	4y 11m	31	Community	Community night nurse
RV	11y 5m	34	Community	Medical ward
RW	7y 3m	28	Community	DN Assistant
RZ	2y 1m	23	Community	Oncology ward
CK	8y	43	Ward 6	Paediatric, Renal, Other Medical
CR*	(6y)	34	CCU	Medical ward
CY*	3y 6m	28	CCU	Other CCU, Paediatric
CG	1y 6m	26	CCU	Other CCU, Intensive Therapy
CV	6y 4m	32	CCU	Other CCU, Cardiac Surgery
CO*	3y 7m	30	Community	Oncology ward
CQ*	3y 4m	25	Community	
CE	(10y)	37	Community	Community night nurse
CI	(4y)	28	Community	Intensive Therapy Unit
CL	(15y)	43	Community	Family Planning Clinic
CN	14y 5m	35	Community	Community night nursing
CT	5y 4m	29	Community	Community night nursing
CU	(13y)	40	Community	Community night nursing, Marie Curie nurse, Paediatric

Nurse status is explained in the text. A indicates nursing auxiliary

* Indicates male nurse

() approximate duration

working on ward 6.

Nineteen of the twenty nurses working on the coronary care unit were interviewed over an eight week period in 1983. One of these was a final year student nurse and the remainder were all qualified nurses. Eight of the nurses were male. Interviews usually lasted between 20 to 30 minutes, although some were longer and the interview with the senior Sister took well over an hour partly because it also covered the general history of the unit and a comparison with other CCU's.

The third group of nurses interviewed were qualified nurses taking the District Nurse Certificate course at City's nursing school. Access to this group arose from DF's position as a lecturer on the course. All of this group had previous nursing experience. Over half of the 22 person intake had been working as community nurses for some time and were seconded to the course by their employing authority in order to gain the newly introduced certificate, possession of which had become mandatory for employment as a community nurse. The majority of these nurses had worked as community night nurses and so could be expected to have had a great deal of experience of nursing terminally ill people at home. At the start of one of DF's classes the group was asked to fill out a questionnaire about their experience of nursing the terminally ill in the community (Appendix). Subsequently the 14 nurses who had indicated their consent were interviewed towards the end of their course and after lectures had finished during a six week period in 1984. By this time all of them had experienced at least two deaths of patients they had been nursing in the community. This 'community nurse' group had the oldest mean age of the three interview groups (Table 2.2). All of the 'community' nurses

TABLE 2.2 SELECTED CHARACTERISTICS OF TRAINEE AND TRAINED NURSES
INTERVIEWED

	SEX		AGE		STATUS*		C
	FEMALE	MALE	MEAN	RANGE	SEN	SRN	
<u>Trained Staff</u>							
Ward 6 (n = 8)	7	1	30.1	21-54	3	4	1
CCU (n = 18)	11	7	26.3	21-34	9	5	4
DN course (n = 14)	12	2	30.6	23-43	-	6	8
Trainees (n = 10)	8	2	23.3	20-39	5	5	-
All Groups (n = 50)	38	12	28.1	20-54	18	21	13

* Nurse status is explained in the text. For trainees status refers to intended qualification.

interviewed (8) were in the Sister/Charge nurse grade with the exception of two staff nurses who had been 'assisting on the district'. The remainder of the interviewees from the course were ex-hospital nurses.

In all, 49 successfully transcribed interviews were collected over a two year period lasting from April 1982 to March 1984. Tables 2.1 and 2.2 present in summary form some characteristics of the nurses interviewed. The intention of selecting the three different groups of CCU, 'community nurse' and medical ward nurses was to sample three different settings within which nursing of dying patients occurred, and to examine the possible effects of these different settings on such nursing work. However, the possibility that three sub-groups within the occupation have also been sampled cannot be discounted. That is, there may be an affinity between the type of nursing work entered and personal characteristics of nurses working within these

settings. Unfortunately, the only 'hard' data bearing on differences between the groups is that of age, so this possibility cannot be investigated.

CHOICE OF METHOD

The preferred method of data collection was participant observation, and chapter three is based on a participant observer study supervised by DF. However, this method was not available to DF for three main reasons. First, he could not be absent from his work at the University where he was employed for the continuous periods of time (i.e. nursing shifts) such a method required. Second, the only possible role available - that of nursing auxiliary - would inhibit movement through a range of settings and could be restrictive in terms of eliciting views and information. Third, he was well known to many of the hospital staff, and this would have led to questions about what he was doing working as a nursing auxiliary in the hospital. 'Pure observation' as the main research method would have been very difficult, and would in any case have involved time resources which were not available. However, observation was used as an adjunct to the interviews.

Before discussing the interview method it seems desirable to indicate why participant observation was the method of first choice as this will help to explain the type of interview format chosen and the way in which the data generated by the interviews have been analysed and presented. Participant observation is one of the methods of research associated with what is rather loosely termed 'qualitative sociology'. Such research is concerned with the discovery and generation of 'existing knowledge'. As Schwartz and Jacobs put it,

"qualitative methods, which use natural language, are best at gaining access to the life-world of other individuals in a short time ... quantitative methods are best for ... the clear, rigorous, and reliable collection of data and permit the testing of empirical hypotheses in a logically consistent manner" (Jacobs and Schwartz, 1979:5).

Quantitative methods such as the sample survey are based to a large extent on prior knowledge and information about what is to be studied (although not necessarily in a detailed way). When little is known about the research area participant observation may be a better method of gaining an understanding of people's attitudes and beliefs, and how these influence and are influenced by their experiences and behaviour. The participant observer 'suspends belief' in the normal and taken for granted assumptions about the social world and its organization, and instead attempts to discover how people order their behaviour and interpret their world (Hammersley & Atkinson, 1983). Such a setting aside of one's day to day knowledge of the world is easier in an alien society where there are quite evident differences in language, belief, and activities, than in one's own society. It is however an essential and important feature of the method, and of qualitative research generally.

This feature of participant observation clearly reflects its anthropological heritage, and also suggests why the method is so closely associated with the symbolic interactionist perspective within sociology with its emphasis on the 'social construction of reality' and its concern with how individual actors collectively create the social worlds they inhabit (Blumer, 1969; Rock, 1979). These concerns form the theoretical bases for the present study.

It could be argued that the method of participant observation most fully allows the researcher to act upon the belief that "communication as symbolic interaction between two (or more) human beings is the basic condition" (Duncan, 1961: 94) for it potentially allows access to a wider range of behaviour and symbolic meanings than can be tapped by other research methods (Becker & Geer, 1970). Indeed it incorporates such methods as interviewing within it. In the course of participating in the life of the group being studied the researcher will inevitably ask questions, seek clarification, and talk with members of the group in more or less directive and systematic ways. 'Key informants' may be used, and life histories collected as an important part of the research activity. Such activities are essentially similar to the unstructured interview, which is the main method of data collection used in this study.

Both participant observation and the unstructured interview attempt to be non-directive and responsive to new and unexpected information, although the latter inevitably has a narrower focus of concern, and cannot draw on direct experience of the researcher as participant in the group's activities. In both the researcher learns by asking questions to test 'leads' and 'hunches' derived from previous research contacts. Finally, both attempt to gather detailed descriptive material of the ways in which individuals make sense of their lives without imposing the researcher's concepts or categories upon such descriptions.

INTERVIEWING

Informal audio-taped interviews were conducted with each nurse.

For hospital based nurses the interviews took place in a room away from the main nursing area while for the community nurse group they occurred either at the university or at DF's home. The interviews were unstructured and conversational in style. There was no interview schedule, and no pre-specified set of questions which had to be asked. Although there was an 'agenda' of topics which it was hoped to cover (see pp. 46 - 47), the emphasis was on allowing the nurse to talk freely and to provide as much detail as possible. After the interview DF transcribed the conversation, which was then typed. A copy of the typed transcript was sent to the nurse once all the interviews with the group had been completed so that she could see what had been said and to allow for any censoring of the transcript, although in fact no one did so.

A portable tape recorder was used to tape the interviews, and its use caused some problems. The reason for taping the interviews was that tape recording greatly reduces the element of selective interpretation by the researcher of what the respondent is saying during the data collection stage (Hammersley & Atkinson 1983). Discussion with colleagues who had used this method of data recording extensively and reports of published research based on taped interviews (e.g. Lofland, 1971; Quint, 1967; Rubin, 1976) indicated no serious deficiencies to its use. Certainly it would not have been possible to record the nurses' accounts fully without the tape recorder, and in any case it was felt that taping would be less intrusive than the researcher frantically scribbling down as much detail as possible.

In general the above considerations were confirmed, and many nurses did seem to forget that the tape recorder was there or to be

unaffected by it. Some, however, did say that they were aware of it throughout, and on several occasions further elaboration of nurses' views were forthcoming after the tape had been switched off. There were also the occasional technical hitches, e.g. forgetting to restart the tape immediately after an interruption. At one point a ward clerk switched off the tape recorder at the wall socket between interviews but fortunately this was discovered before the next interview had proceeded very far and the nurse was willing to repeat the interview at another time. On balance, the use of audio-taping and the laborious task of verbatim transcription seems justified by the wealth of transcript material generated and by the capacity to review easily sections of interviews to check against biased interpretation or faulty recall.

At the start of the interview and before the tape recorder was switched on DF would explain who he was and what he was doing. A typical explanation might be as follows:

2:1 DF Basically what I'm doing is talking with nurses about their experiences of nursing dying patients. How I got into this is through my teaching at (...) where I lecture about death and dying. I thought I ought to find out how nurses viewed nursing dying people by talking to them about their experiences. What I'd like to do is ask you some general questions and let you talk as much as you want. I probably won't say very much, just let you talk. I'm using a tape recorder because that is the best way to get down exactly what you've said. After the interview I will transcribe the tape, get it typed up, and send you a copy. That way you can see what you said and can change anything or let me know if you've changed your mind and don't want me to use anything that you've said. You can be as frank as you like because you can always tell me if there is something you don't want me to use. Is that o.k?

At this point the tape recorder would be switched on, DF would say who he was talking to, and commence the interview. At the end of the interview the nurse was asked not to say anything about the questions asked to other nurses. It should be noted that on the three occasions

when nurses indicated their comments were 'off the record', that section of the transcript was obliterated.

In the early part of the interview information was obtained about the nurse's career and her experience with dying patients. With the nurses from the medical wards DF then asked if the nurse would tell him about "anyone (dying patient) in particular you remember", and from that point the interview proceeded in conversational style covering the 'agenda' of topics in no fixed order. Other starting points were used on CCU and with the community nurse group which related to their particular type of nursing experience. Many of the topics were introduced spontaneously by the nurse without DF asking about them, and most nurses talked freely with a minimum of prompting. The initial agenda of topics was derived in part from previous research literature (especially Glaser & Strauss, 1965, 1967), in part from previous research on an acute surgical ward (see chapter 3), and in part from ongoing research with medical students (Howells & Field, 1982, Field & Howells, 1986). During the course of the research new topics were added to the agenda as a result of what nurses were saying while other items were dropped for reasons explained below.

There are a number of problems with the interview method of data collection which have been extensively reviewed (e.g. Becker & Geer, 1970, Cicourel, 1964; Denzin, 1970; Hammersley & Atkinson, 1983; Hyman, 1954; Schwartz & Jacobs, 1979). Cicourel perhaps overstates the case with his remark that "... interviewing is complex and difficult because it necessitates presenting, establishing, and maintaining appropriate and possibly conflicting roles" (1964:76). Nevertheless, his critical reworking of Hyman's seminal work and his list of "unavoidable problems ... basic to the interview and routine

exchanges in everyday life" (99) aptly identifies and discusses the problems encountered in the present study. His analysis therefore provides the guidelines for the following account.

Cicourel's first set of 'unavoidable problems' is that "The nature of responses generally depends on trust developed early in the relationship, status differences, differential perception and interpretation placed on questions and responses, the control exercised by the interviewer, and so forth" (99). Generally it seemed that trust was not a problem. The nurses seemed to place a high level of trust in the researcher as exemplified in their willingness to talk openly about 'bad behaviour', and to criticise other staff at all levels. They were clearly not always giving 'safe' and 'acceptable' views.

'Status' was more problematic. The status of interviewer and interviewee seemed unproblematic; in our society these are well known (e.g. through knowledge of media interviews) even by people who have not been interviewed before (Schwartz & Jacobs, 1979). However, other status attributes intruded problematically into some interviews. Some nurses, especially trainee and enrolled nurses seemed to regard DF as of superior social status to them, possibly as a result of his 'latent identity' (Hammersley & Atkins, 1983) of university lecturer, and this may have had an inhibiting effect on their responses. Certainly some interviews did not flow smoothly. In these cases it seemed that it was the status attributes of the nurses rather than of the interviewer which were most relevant (although of course the two interact); namely, lack of experience (trainees) or/and their social class (enrolled). The language habits and general assumptions of the latter group (Bernstein, 1972; Schatzman & Strauss, 1955; Ashton & Field,

1976) could explain some of the difficulties encountered. As the interview was dependent upon a relatively 'elaborated' mode of discourse, and was attempting to elucidate the underlying bases of the nurse's attitudes, it is scarcely surprising that nurses who habitually used 'restricted' modes of discourse could have difficulty. Although, as Labov has forcefully pointed out (1972), this does not mean that such individuals are unaware or unable to express themselves clearly. Still, some interviews were a struggle. The following extracts exemplify this type of difficulty in its most extreme form.

2:2 DF Do you talk to them a lot about these sorts of things?
EA Yes I do

2:3 DF Did you spend a lot of time with your patients in geriatrics?
EA Oh I tried to.
DF Did you get a lot of deaths when you were there?
EA In the winter time! I'm afraid so, yes.

Later on the interview 'flows' more easily and with greater elaboration.

2:4 DF Of the two settings which you've nursed on, which do you prefer?
EA Well, I enjoyed doing the geriatric nursing but I was ready for a change, and I enjoy what I'm doing now.
DF Have there been many deaths on the unit since you've been there?
EA Not many. Not as many as at the geriatric ward, but most of the ones on here have been rather sudden.
DF Does that make it easier, the fact that they're sudden?
EA No it makes it worse.
DF Why?
EA I don't know. It's just somebody sitting up feeling quite well one minute and the next minute they're just taken in and they just die. I think that it's a shock.

It should be emphasized that most interviews were not like this.

'Differential perception and interpretation' was not a problem as far as this can be known. Indeed, the open-ended unstructured interview format was chosen precisely to allow the expression of a range of perceptions and interpretations, for although he had some

general ideas DF did not know exactly what nurses would say. As Garfinkel has observed and documented (1967: 77-94), people presume meaning and intent within task oriented (and other) interactions such as the interview, and their responses reveal the meaning which they intuit. On a number of occasions nurses would interpret a question, comment, or even a gesture, in a way not originally intended and many of these 'misinterpretations' proved to be useful in opening up new areas which had not been previously considered, or in amplifying existing categories. For example, DF had assumed that dying patients were different from other types of patients and initially couched questions in terms of that assumption. A nurse's 'misinterpretation' revealed that this was not necessarily a valid assumption to make, and led to the exploration of ways in which the terminally ill were similar to and different from other types of patients. 'Misinterpretation' and 'naivety' by DF were also used as ways of getting nurses to amplify, clarify, or expand on a topic in a non-directive manner, or to cross-check information. (Naivety as a tactic is discussed by Hammersley & Atkinson, 1983; Denzin, 1970; and with explicit linkage to interactionist methodology, Rock, 1979).

Control of the interview seemed largely unproblematic. Interviews were generally relaxed and friendly even though, given the topic, they were sometimes characterized by a high level of emotional affect as well. The move from one agenda topic to the next was generally smooth and part of the 'natural flow' of conversation. As all hospital based interviews and most district nurse interviews occurred during work time there was an interviewer perceived time constraint. To a certain extent this restricted the scope of the interviews, although such restriction may well have been a useful focussing constraint. The main consequence was to limit the amount of cross-checking and

'validating' of responses within (but not between) interviews. In any case as Cicourel writes, "Checking out responses for consistency and depth may lead to uneasiness and avoidance patterns on the part of the respondent ..." (99).

"Both the respondent and the interviewer will invariably hold meanings in reserve; much remains unstated even though the interviewer may pursue a point explicitly". (Cicourel, 1964: 99-100). For example:

2:5 DF What's the problem (causing friction on the unit) now?

CV What happens is each year you get this cycle. We have a quiet patch and people start niggling, and then they want a unit meeting ... When I originally started I was all for democracy and I thought unit meetings would be marvellous, and at the time they were necessary. Now I think they are a waste of time. Despite all the back chat and complaining going on people won't say anything at the meetings. People don't want democracy as long as they're vaguely told or given a choice between A and B (...)

DF was unable to discover what the current point of contention was in the interview, and learnt only that:

2:6 CV When we are busy we are busyee and people don't get off on time or get any breaks (...) and you've got patients all over the place; in and out; sick; dying; and it is very hairy. So when we get a patch like this you see because we are used to being fairly active this is what happens - you can see it coming.

Not only did nurses 'reserve meanings', but DF also concealed his views on matters of direct research interest (e.g. the nursing process) or which might prove to be contentious (e.g. the value of hospices).

Conversations are situationally located and so both transient situationally specific features as well as more durable 'universal' aspects were elicited by the unstructured interview. The most

dramatic example of this was the interview which was interrupted by a cardiac arrest.

2:7 (Beginning of second interview with RQ)

DF Of course its difficult to start again. You said you weren't attending last time because you were expecting something to happen.

RQ Yes. You know you get that feeling; sort of tightness in the stomach, and then everything happen doesn't it?

DF When we were talking I heard (SrG) shout to (CR) and I wondered if something was happening but you didn't seem to be doing anything so I thought 'well I'll just go along with it' as it were.

RQ Well, I didn't want to panic unduly. Well, not panic, but rush out there unduly. But as soon as I heard the arrest call I knew it was for us.

In this case both parties were distracted by what was occuring in the immediate vicinity to the detriment of the interview. This extract also highlights a second situationally-related problem. Interviews conducted in the hospital were subject to interruption, with negative consequences for continuity and 'mood'. One interview was in fact terminated (after 25 minutes) because two interruptions made it too difficult to continue.

Another problem relating to the 'situated' nature of the interview is that commonly shared meanings and background conditions may be so well known, 'obvious', and taken for granted by the participants that they are not conveyed to the interviewer. DF never became fully conversant with the technical jargon used by nurses. More importantly, although he was concerned with and enquired about the structure and organization of nursing work he could not assess all the changes in working conditions which might affect nurses' responses. For example, on a follow-up visit to CCU to discuss the first draft of Chapter 5 an important amplification about the general context of CCU work during the interview period was obtained. It became apparent that preceding and during the study period the nurses were concerned

about the high level of 'unsuitable' admissions to the Unit which had been steadily increasing. DF became aware of their concern over 'unsuitable patients' but without fully relating it to the more general underlying structural problem of how to control admissions to CCU in such a way as to restrict such admissions.

A final set of problems related to the performance of the interviewer role. Mental alertness varied with each interview, as did DF's 'emotional tone'. These would certainly have had some consequences for the interviews and affected the 'structural problems' of interviewer performance: "The interviewer cannot possibly check his own responses in detail and follow the testing of an hypothesis during an interview; he is forced to make snap judgements, extend inferences, reveal his views, overlook material, and the like ... The interviewer cannot escape from the difficulties of everyday life interpretations and actions" (Cicourel, 1964:100, and see also Hyman's exhaustive discussion, 1954).

Despite the problems discussed above, most of which were known prior to starting the research, it seems that the interviews were largely successful in eliciting relevant and valid information, although the interviewers' belief that the interviews are 'satisfactory' and fruitful measures of 'reality' does not guarantee that they are (Hyman, 1954). The interviews have face validity, and are characterized by internal consistency and consistency between interviews. The use of observation and questionnaires provides some sort of 'triangulation' (Denzin, 1970) and supports the general picture presented by the interview material. The extensive use of transcript material should enable readers to form their own opinion about this matter.

ANALYSIS OF INTERVIEW MATERIAL

Each self contained meaningful statement was coded into as many categories as were applicable. Such categories are difficult to define precisely and formally which is unsurprising since even in syntactic analysis there is difficulty in defining analytic categories larger than the word (Coulthard, 1977). There are not, it seems, any agreed rules for the identification and reliable distinction of 'meaningful utterances' in either sociolinguistics or ethnomethodology (Coulthard, 1977; Goffman, 1981). For DF's purposes a 'self contained meaningful statement' was simply any portion of speech which conveyed at least one intended meaning. These could be single words, e.g. "yes" or "no", or sentences or clauses, e.g. "It's much easier to nurse someone who is dying if they know they are dying".

Large file cards were used to order the categories and to facilitate comparison and cross-referencing of statements. Every statement relating to a category was listed on the appropriate file card and indexed by nurse initials and transcript page number, together with a brief indication of content. An example is shown below.

2:8 Specimen file card

Emotional Involvement (Ward 6)

SA 1 - Shouldn't get involved; can't help it.

PM 1 - her first death: Man with cancer, crippled.

4 & 5 - trying to retain distance but can't with nursing process and patient allocation. Not an advantage to get involved.

PF 4 - gets involved, but no problems tho' affects/upsets her for a day.

SG 5 - never been emotionally involved.

... And so on.

Each group of nurses were listed separately to allow easy comparison within and between groups.

In the process of reading and categorizing the transcripts, and in comparing items within the same category, new agenda topics and categories were generated. As this process continued certain regularities within categories became evident and a category might be judged to be 'theoretically saturated' (Glaser & Strauss, 1967), i.e., no new information was being found. When this happened only a count of the category instance was recorded. Some categories were dropped from the interview agenda and others modified to elicit more precise and useful data as a result of this categorization process.

The initial interview agenda comprised the following: nurses' experiences of dying patients; effects of patient age, expectedness of death, duration of terminal stage, and awareness context; communication with patients, and with relatives; emotional involvement; nurses' personal experiences and attitudes towards death and dying. During the interviews the following agenda items were generated: death as a 'blessing' or 'release'; 'bad deaths'; laying out; the ward as 'family'; death 'in absentia'; keeping in touch with relatives after a death. Not all of these were subsequently found to generate enough analytic content to pursue further.

The following topics emerged from the analysis of the first group of interviews and were systematically examined with the two subsequent groups: the nursing process and care of the dying (theoretically the most significant emergent); how dying patients differ; achieving open awareness. To 'make room' for these new topics the following categories were omitted from the agenda for these groups, although this did not prevent nurses from spontaneously introducing them: Age (general consensus of opinion that young dying patients were harder to

nurse); personal experiences/attitudes (no consistent effect discernible); 'laying out' (not relevant); death 'in absentia' (tangential); 'bad deaths' (arises spontaneously, otherwise tangential). Other categories, e.g. the ward as 'family' were reformulated in the light of different work situations and experiences. For further discussion of this type of procedure see Glaser & Strauss (1967), Hammersley & Atkinson (1983) and, with reference to her research on student nurses, Melia (1981, 1982).

While retaining the words which nurses use the transcript material is presented in a slightly 'idealized' form through the use of 'regularization' and 'standardization'. Slips of the tongue, repetition, self-editing, and most hesitation have been ignored (regularization). Different pronunciations and colloquial forms of the 'same word' have been rendered into 'standard english' (standardization). Although the context within the interviews is relevant for the production of the extracts used these are for the most part at least partly decontextualized and treated as self-contained, isolated units expressing 'universally relevant' meanings (Lyons, 1968, as presented by Coulthard, 1977).

Extracts from the transcribed interviews are numbered sequentially by chapter in order of appearance. Some extracts are slightly edited, and this is indicated thus: (...). To preserve confidentiality nurses are indicated by an arbitrarily assigned letter which is prefixed by an indication of their status: C = charge nurse or sister; E = enrolled nurse; P = pupil nurse; R = registered nurse; S = student nurse. The researcher is referred to as DF. The qualitative nature of data generation precludes the use of statistical analysis. However, where information was collected from virtually all the nurses in a group some numerical

counts are provided.

OBSERVATION

The interviews with the nurses on CCU were preceded by several visits to the unit to observe what was happening. This was felt to be necessary because DF knew very little about the functioning of coronary care units. Time was also spent in observation (mainly at the nursing station) during the interviewing period. Periods of observation lasted between 2 - 5 hours with the earliest starting time 8 a.m. and the latest stopping time 8.30 p.m. In addition to providing a better sense of the functioning of the unit such observation served to introduce DF to the nurses and other unit staff. It also served to supplement interview material and to provide a way of checking nurses' interview accounts with their behaviour - both non-verbal and verbal - in their work environment. Each period of observation was written up as soon as possible after it had ended, with notes on particularly striking events or observations being jotted down on small file cards almost immediately. Extensive notes were not made on the unit, and the full 'write up' often took place late at night due to the demands of DF's other work and commitments. Incorporated into the observational account were comments about DF's own problems and feelings.

Observation was not without its problems, largely of a subjective nature. DF felt very conspicuous sitting beside the nursing station on the open plan unit (see diagram 5.1) apparently doing nothing except perhaps talking to the nurses and doctors. Given the physical layout of the unit it was difficult to 'blend' with the background. Initially some of the nurses and the Senior House Officer found his

presence disquieting, although it appeared that this was soon accepted as 'normal'.

As a result of the observations a much greater range of unit life was revealed than could be conveyed in the interviews and a wide spectrum of people were met and talked with. In addition to the doctors, ward clerk, staff from other parts of the hospital and patients in bed one (next to the station), DF had two long conversations with a terminally ill patient. The first of these was initiated by the patient on the morning that he learnt that he was dying. Despite the occasional psychological discomfort, the observation method proved to be a very useful adjunct to the interviews, and allowed a clearer view of the unit to be gained than would have been possible without it. Extracts from a seven page memo recording a day's visit are reproduced below to illustrate these points.

2:9 Weds 23/CCU/11 - 5

The busiest day so far of any of the times I've visited the CCU. When I arrived at 11 a round was in progress - just started it seems as bed 1 was curtained off with people inside the curtains. 7 beds were occupied with only No.7 empty. When I left at 5 there were again 7 full beds, with 2 new admissions (...)

Apart from lunch break RJ spent almost all her time with a newly admitted patient who was hooked up to various drips which didn't seem to be working too well. Before lunch CG spent a fair amount of time helping her. There was a 'mini- crisis' with CG, ED, and RM all at the bed too for 10-15 minutes. RM had just been telling me that "you can't rely on the monitors too much" when suddenly both he and CG picked up something from RJ's patient. Actually quite impressive how they a) noticed and reacted so quickly, and b) with so little fuss and drama (...)

Just before the new shift appeared a man was admitted to bed 7 (...) (who) was to be paced (...) Dr B asked if I wanted to watch and I'd said "no" before I could think about it. In retrospect personally a chance missed, although possibly the right research decision. Possibly not.

I did get to talk a little with ET whom I'd not met before, and I also got to talk with a terminally ill patient (...)
CV was talking to Dr C about him - "He knows now. He said this

morning 'I'm not going to make it am I?' and I told him 'No. There is a chance you'll never leave here. You could get better, but there is a greater likelihood that you won't'. She said it better than that(...)

It was an interesting day not just because of the high level of nursing work but also for a number of conversations which occurred. Death is mentioned quite frequently and both jokingly and very matter-of-factly. It is, it seems omnipresent. Now they are used to me (ED said "You're part of the woodwork now") it comes out more frequently in terms of "you remember so-and-so who died?" or recounting a gory or particular type of death which had occurred (...)

ED had a couple of (to me) interesting encounters. 1) in the pm. he explained very clearly the pacing wire/box to his patient and his wife in terms of what it did and - if they thought further - he also indicated that the heart was severely damaged(...)

It's midnight. There's a lot happened today which I haven't got down properly. For example, how administrative work just seemed to get swamped out by the immediate demands of patient care after 2.15 (...) The feel of the day was of almost controlled nursing work. There was clearly intermittent pressure on the nurses and at times there didn't seem enough of them.

CONCLUDING REMARKS

This chapter has discussed the methods of data collection and the assumptions underlying their use. The next section of this work examines the experiences, attitudes, and problems of nurses caring for the terminally ill primarily through the device of allowing the nurses to 'speak for themselves'. Of course, every nurse had a different biography, a different set of experiences, and a different story to tell. Some were more articulate than others, or more dramatic in their recounting, and this has had an influence on the selection of quotes. However, care has been taken to quote from as many nurses as possible, and not to quote extensively from only a few nurses. It will be realized that it has not been possible simply to let the nurses 'tell it as it is'. 'It' is many things. The reality of death, as with any other reality, is characterized by multiple, equally true if sometimes contradictory aspects, only some of which

are responded to by nurses and other participants. In order to bring some shape, consistency, and pattern to nurses' accounts the author has had to apply his own sense of what is 'being said' by selecting what seems most apt, relevant, and even 'true'. This chapter has attempted to provide the reader with some idea of the bases for such editorial work. At a minimum this work attempts to render an analysis of nurses' accounts which is 'adequate at the level of meaning' (Weber, 1947:88-100) and which is recognizable to them as an acceptable and accurate depiction of their experiences. Nurses who have seen various drafts have accepted them as recognizable, 'true' renditions. This work also attempts to explicate some of the influences upon nurses' experiences of nursing the dying. This provides the focus for the final chapters.

NOTE

1. Despite the ethnomethodologists' castigation of other sociologists for not taking adequate account of their reliance on commonsense meanings to make sense of their sociological analyses, ethnomethodologists themselves have largely ignored the practical problems of such inevitable reliance. Further, with some exceptions (e.g. Garfinkel, 1967) they have largely ignored the problem of meaning and its bases, and concentrated instead on formal characteristics of rule use and production, especially linguistic forms (e.g. Benson & Hughes, 1983: 154-91; Coulthard, 1979: 52-92; Sudnow, 1972; Turner, 1974; Wooton, 1975). That is, the ethnomethodological enterprise has become diverted from a concern with content in the search for a formal, empiricist, discipline. Thus it has little relevance for the concerns of the present study which is concerned with meanings in use.

PART II: NURSING THE DYING

"We had a patient who was here over a year - and we were all very close to 'C'. I saw him from when he came in, to getting really better, then going down again. It was awful because there was nothing I could do - I just had to sit and hold his hand. At that time we were all taking it in turns to sit with him as long as we could 'cos we just didn't want him to die on his own. Nobody wanted just to go in and find him dead. Which I think goes for most of the patients that you know are on their last legs. You don't want to leave them on their own ... I remember very clearly a patient on geriatrics. I had nursed him on nights, and I went back on to days - he was a double-sided CVA. He was very incoherent. By some miracle could just whisper words. And at night he couldn't sleep because he was so uncomfortable so I used to spend a lot of my nights sitting and talking to him and holding his hand. When I went back on to days I went behind the curtains - and he was really on his last legs. So I just sat with him and held his hand. And I remember the staff nurse coming in and asking me if I had nothing better to do. So I said 'No. Not at this moment, no'. So she said 'would you mind going and finding something to do?' I remember it so clearly. I really hated her; because this man was dying, I'd been with him all this time, and why should he die alone? All she was content with was giving him BPO's and he still had an enema the day he did die. Well he died that afternoon. I felt awful - this poor little man - and just as I went behind the curtains he just said - he grabbed hold of my arms (he got very little movement in that hand), and he just put his hand on mine and whispered 'I love you'. And then he died in the afternoon. I thought 'well it's all worthwhile' because at least he realised that somebody cared."

RE

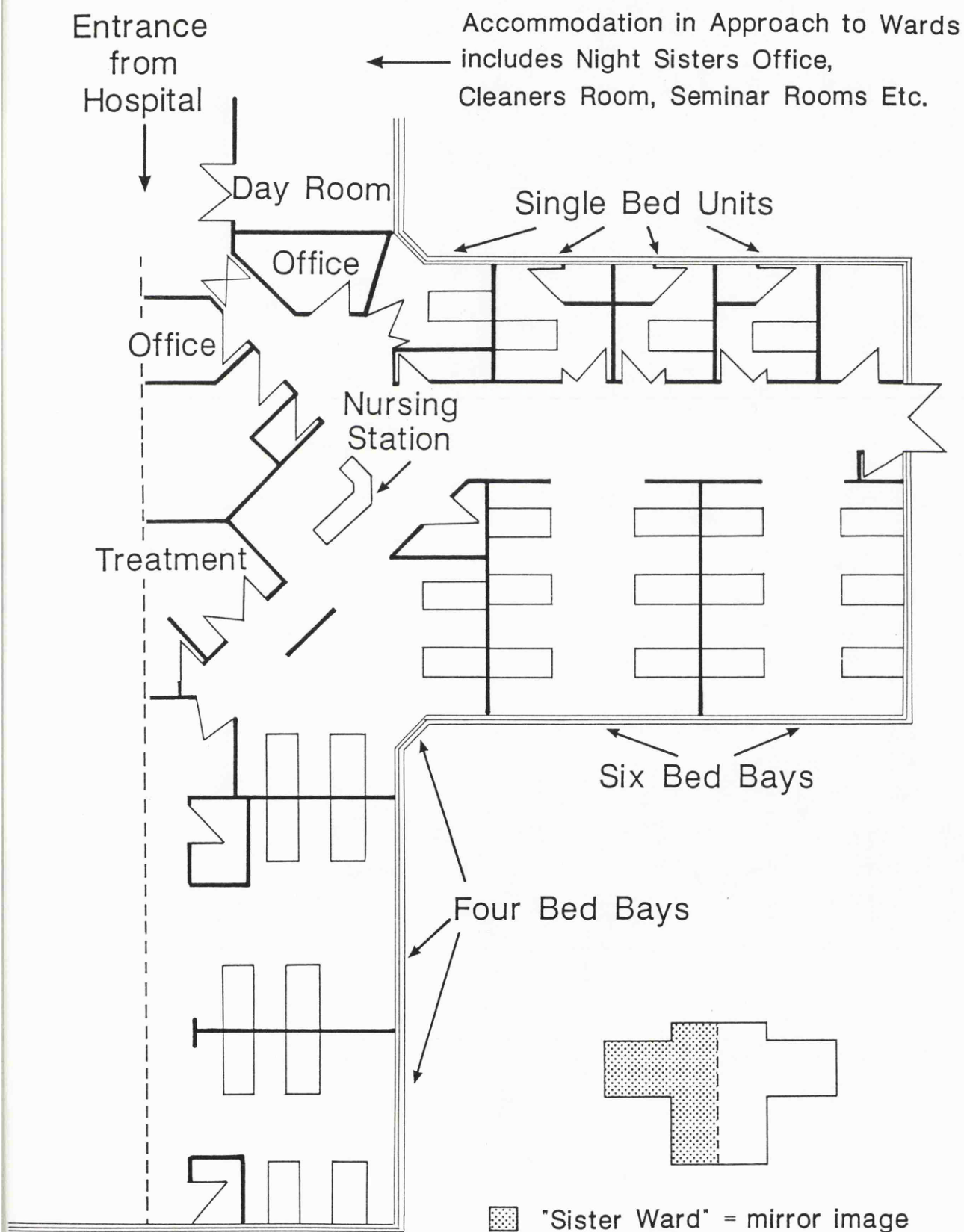
CHAPTER 3: A SILENT CONSPIRACY: NURSING TERMINALLY ILL CANCER PATIENTS ON AN ACUTE SURGICAL WARD*

The purpose of this chapter is to open the discussion of problems associated with nursing dying patients¹ by briefly presenting what might be termed a 'typical' example of such work. It also introduces the two central themes of the study: the problems surrounding terminally ill patients' awareness that they are dying and communication with them, and how the organization of nursing work affects such awareness and communication.

This chapter reports on a participant-observation study of the care of terminally ill cancer patients in an acute surgical ward at Midland General Hospital. The data was collected by Mary Knight who worked as a nursing auxiliary on the ward during the summer of 1979 and whom DF supervised. Using this method meant that we did not have to disclose that we were undertaking a study of the ward and therefore communication and general behaviour were natural and 'normal'. She was able to experience the role of the nurse in interaction with cancer patients, the inherent problems of such a job, and to analyse colleagues' attitudes towards the terminally ill. Furthermore, since we had access to the patients' notes we were aware of their medical diagnosis and prognosis. The disadvantages of such an arrangement were that only a limited view of the general functioning of the ward could be obtained, and that a systematic examination of nurses' attitudes was precluded. Nevertheless, this chapter serves well as a contrast to the findings presented in subsequent chapters and illustrates what may be termed the "traditional" way of coping with

*This chapter is based on M. Knight & D. Field (1981)

Figure 3.1
A Typical Harness-Style Ward Layout



the terminally ill in hospitals.

THE WARD SETTING

Ward 7 was a typical acute surgical ward containing 27 beds catering for male and female patients. The ward was a 'Harness style' ward comprising five bays each containing four or six beds (see diagram 3.1). Sexes were not mixed in four of these bays although the fifth 'acute bay' on occasions contained both sexes. Patients in this bay were often comatosed or heavily sedated. In addition, there were three single rooms which were often used for dying patients, who invariably were heavily sedated or comatose.

The turnover of patients on ward 7 was high (in one week 64 patients spent a period on the ward), and this rapid turnover was a major factor contributing to the strict adherence to routine by the nursing staff in order to cope with the numerous daily admissions, the three days a week which were theatre days, the days when the ward was accepting emergency admissions, as well as the day-to-day nursing needs of the patients. Doctor-nurse relationships were very formal and hierarchical, with consultants and other surgical staff talking only to the sister or charge nurse. This hierarchy was mirrored by a similarly formal ranking of the nursing staff.

The ward was short of fully trained nursing staff. Many of the nursing staff were undergoing their training, and of the regular ward staff three were nursing auxiliaries. Thus unqualified and trainee nurses made up the majority of the nursing staff on the ward. The nursing work on the ward was generally undertaken by these junior nurses on the basis of 'task allocation'. That is, nurses were given

tasks such as taking temperatures or giving bed baths which covered the whole ward, rather than being allocated to look after all the needs of a few specific patients. The ward administration was conducted by the Sister or in her absence the most senior member of staff. Ward 7 was not a terminal ward, and so there was little consideration by the patients that they might die, and amongst the staff there were problems of acceptance when a patient returned from surgery where a fatal malignancy had been discovered. Nurses were forbidden by the consultants to disclose a terminal prognosis to dying patients.

THE PATIENT SAMPLE

From the forty terminally ill patients admitted to the ward during the study period we studied the 13 with whom MK had the greatest contact during her work. This group consisted of eight males and five females whose cancers had been considered 'inoperable' and terminal by the surgeons. Six of these patients died on the ward and the other seven were either sent home or to a place of residential care to die. Twelve of the patients were admitted without a doctor's awareness that they had cancer and without their own awareness of their condition. The majority of them were optimistic on arrival that their condition would be investigated and put right. After a period of time these patients, both those who had had surgery and those who had not, began to question why they were not getting better and in some cases why they deteriorated daily. One patient was aware of her illness and its implications, for her cancer had been detected 18 months previously, and she had returned to hospital because her family had been unable to cope with her care at home.

RECOGNIZING IMPENDING DEATH

Twenty per cent of all patients entering ward 7 were admitted for investigation without a diagnosis having been made, and the majority of admissions which later proved to have terminal cancer came from this group. A small proportion of cancer patients were out-patients whose condition had been mis-diagnosed and who were found to have cancer either after tests had been conducted on the ward, or during surgery.

An important feature of any diagnosis, whether correctly established or not, is that it involves questions of definition. Anyone may read the medical signs and draw their own conclusions, the terminal patient included. However, in British hospitals the attending doctor is the only one who can legitimately define the patient's condition. Ordinarily, only s/he may tell patients that they are dying. (Under extraordinary conditions nurses may tell patients or relatives directly, but this did not occur on ward 7 during the period of study). Nevertheless, the nurses on ward 7 had to assess whether a patient was dying and when s/he would die, and making such assessments was often no easy matter. In reaching their conclusion that a patient was dying nurses might draw on their own reading of cues - how the patient looked and acted, what the charts reported - as well as relying on information and cues given, perhaps unwittingly or obliquely, by doctors. Typically, they tended to trust this latter source more than their own individual or collective reading of cues. Doctors varied considerably in giving nurses a clear basis for death expectations. On ward 7 there was a particularly poor communications network between medical and nursing staff which heightened the relevance for nurses of their own reading of the various cues in

assessing the patient's condition. Thus, although the most legitimate source for forming and expressing death expectations were the doctors, the nurses also observed their own cues constantly (Glaser and Strauss (1965) give a good account of this type of activity).

Nurses definitions of patients' illness status affected their behaviour toward them and therefore when these definitions changed was significant. Glaser & Strauss (1968) discuss this period when a cancer is discovered in terms of a decrease in alertness by the nurses. This was to some extent true of Ward 7, but the greater change in behaviour towards a dying patient concerned the personal attention the patient received. In the majority of cases this increased considerably. In one case, after a patient returned from surgery where a malignancy had been discovered, the nurses' attitudes towards her changed so dramatically that she became suspicious of her diagnosis. Prior to her operation she had received minimal attention and an attitude close to contempt from the majority of nurses since they felt she exaggerated her symptoms. Once the nurses became aware of the nature of her illness they increased their attention, apparently to compensate for their feelings of guilt about their previous attitude.

The most obvious influence on the existence, maintenance or alteration of a patient's awareness about their terminal condition is the doctor's policy of informing the patient of the nature of their condition. Where the practice is to inform patients, they are likely to manifest an 'open awareness' perspective; where patients are not told (as on ward 7) a greater proportion of them will possess a 'closed awareness' or 'suspicion awareness' perspective. In every case observed (i.e. not merely those patients in the sample) the surgical staff on ward 7 did not inform the patients that they had cancer. The

doctors always told the relatives of the incurable patient of the terminal prognosis. However, there was occasionally a breakdown in communication between relatives and medical staff. For example, although a carcinoma was discussed fully between medical staff and nursing staff, when the subject was discussed with relatives, the doctor used the euphemism 'tumour' or 'malignancy'. Although he might have hoped that the relative would presume he meant 'cancer' this did not always follow. Consequently, the doctors frequently felt that they had enlightened the relatives when in fact they were no better informed than before, and in some cases were even more confused. Families typically did not tell their relatives that they were dying, nor did they wish them to be told by hospital staff (a commonly reported phenomenon).

On ward 7 none of the patients we observed (including those outside our core group of 13) had any 'allies' who revealed to them or helped them to discover their impending death. Not only staff and families, but other patients who knew or guessed that a patient was dying colluded in the conspiracy of silence. It seemed that when patients wanted less distressing information or support they could readily find allies among the other patients; when they were dying the others followed ordinary rules of tact keeping their knowledge to themselves or at least away from the dying patients. It seemed that the patients, as the doctors, were reluctant to disclose bad news - what Rosen and Tesser (1970) describe as the 'MUM effect'. Yet despite this 'closed awareness' context which was encouraged on ward 7, only five of the 13 patients we studied were completely unaware of their condition.

There were numerous cues, as Glaser and Strauss (1965) and McIntosh

(1977) have pointed out, which could lead patients to become suspicious that their condition was not what it was purported to be, and which could lead them to suspect they had cancer. A patient might be alerted by their symptoms, or they might compare their condition with that of a relative or friend who had had cancer. A swift admission associated with 'cancer treatment', particularly referral for radiotherapy, was another important cue. Finally, their own physical deterioration was an important cue that something was seriously wrong.

In addition to these 'patient-centred' cues there were verbal and behavioural cues from staff which patients could observe and attempt to elicit. Following Kelly and Friesen (1950) we identified three main strategies of information-seeking by our patients. First, they could pay special attention to the conversation around them, especially during ward rounds. Next, they could directly query staff and although this would not lead directly to answers this could uncover validating clues. Third, they could use indirect questions to 'set traps' for the staff. If staff were successfully to maintain the conspiracy of silence about the dying patient's condition they had to remain on guard against accidentally revealing by their speech or actions that all was not well. Cues that all was not well were particularly likely to be disclosed when staff were unaware that patients were suspicious of their diagnosis and/or prognosis. Thus it was essential that staff discussed patient's conditions and whether they were showing signs of suspicion. However, as communication between the different levels of staff was poor, this did not happen and the lack of such communication increased the likelihood of patients learning about their illness by mistake. While staff persisted in presenting a hopeful picture to the patient (even to the

extent of continuing treatment unduly) inconsistencies and verbal slips often undermined this picture.

The most important cues from medical staff for our patients related to treatment and lack of clear diagnosis. Where the doctor did not give an explicit recognizable label to the patient's condition when the patient had assumed an unthreatening diagnosis would be given, this was likely to be interpreted as something 'more sinister'. Some forms of treatment were known by some patients to be associated with the treatment of cancer, and treatment received served as an important set of cues. Not only the type of treatment received, but also the time taken by the medical staff to reach a decision regarding the appropriate form of treatment, the type of operation, and whether 'major' or 'minor'. A second operation often led the patient to adopt a gloomy outlook. In the same vein supplementary treatment was considered a bad sign. Tests undergone after an operation were also feared and taken as an indication that the doctors wanted to know whether the disease had spread. Cues from nurses came primarily from inconsistencies in their accounts to patients and from sudden changes in their attitude towards them. Junior nurses in particular were likely to reveal such inconsistencies and to be 'trapped' by patients into doing so.

RELATIONSHIPS ON THE WARD

The relationships on the ward, not only between hospital personnel and patients, but also between medical and nursing staff, played a significant part in the awareness of patients, and the ways in which nurses related to them. The strict adherence to routine and the system of task allocation had two main consequences. It made it hard

for the nursing staff to become familiar with the (up to 27) patients on the ward, and for long-term patients, obviously including the terminal patients, it created problems of disorientation. Their 'friends' in the beds near to their own were forever changing and, since ward 7 was a mixed ward and divided into bays of patients of the same sex, invariably the longer stay patients suffered themselves by being moved from one bay to another.

There was a clear division of nursing labour on ward 7. The qualified senior nurses were mainly occupied with the administration and management of the ward and took little direct part in patient care. Third-year student nurses were mainly concerned with acute care patients who were often undergoing very sophisticated treatment. The care of the dying fell to junior nurses largely as a result of the division of nursing labour. These nurses were not allowed into the Sister's office for refuge from working pressures, which reinforced their estrangement from the other nurses, and was an element in the close relationships they developed with patients. The Sister was seen as a 'battleaxe' by both patients and junior nurses and they gave and received sympathy from each other after unpleasant encounters with her. This bond between patients and junior nurses meant that where patients were anxious about their condition they were more likely to question these nurses, whom they considered to be their friends, than other staff.

The medical staff on ward 7 had very little communication with any of the nurses except for the Sister. They maintained an aloofness which was not helpful to junior nurses in situations where they felt that a senior doctor ought to know about a patient's anxieties. This meant that some information of this kind was not related to surgical

staff. Ward rounds on ward 7 were conducted by a consultant and the ward Sister or her deputy. He would go to all the beds in the ward, including those of his colleague. At these beds he would spend slightly less time than at his own beds and patients not only accepted but expected this. It was evident to the nursing staff that he spent longer at beds where the patient had been operated on recently. However, it was also evident that where surgery had been unsuccessful medical staff spent less time with patients (Roth, 1963, reported similar behaviour in his study of TB hospitals). Once patients with inoperable cancer returned to the ward from theatre and their drugs had been prescribed, the doctors rarely asked any more than "Are you in pain?". The question of going home was avoided, as was any discussion with the patient about the operation. In the climate of ward 7, which was geared to repair and recovery, the dying cancer patient was a medical 'failure'. Such patients became anxious when their conversation with the consultant was brief, and invariably once the doctors had left the ward they would question the nursing staff about their condition, asking why the doctors had shown less interest in them than in other patients.

The care of the dying on the ward thus fell, largely by default, to first year student nurses, pupil nurses, and nursing auxiliaries. These junior nurses had the greatest contact with, and greatest trust placed in them, by the patients. It was natural and not uncommon for these nurses to form close bonds with long stay patients, even with the 'awkward characters' because they spent so much time with them, and several patients used the junior nurses as confidants. This was mainly due to the patients' awareness that their fellow patients might have grave problems related to their illness. They therefore preferred to discuss their own illness with nurses whom they presumed to have

knowledge and understanding of it and even of their social problems. These relationships were often very demanding for the young trainee nurses, many of whom would not have resolved their own attitudes to death and dying (Cf. Charles-Edwards, 1983; Simpson, 1975). Although there were many factors which worked to conceal their condition from the dying patients, there were pressures on the junior nurses as a result of their close relationships and frequent contact with dying patients to be truthful with them. This was especially difficult to cope with when a patient was overtly anxious and in need of reassurance.

COMMUNICATION ON THE WARD

The general principle underlying staff-patient interactions was that staff were superior by virtue of their greater knowledge and status. Once this was established, usually unproblematically, communication between staff and patient became routinized and mainly restricted to 'technical' matters. Such routinization contributed to the management of communication in three main ways. First, it ensured consistency in the sort of information which a patient or patients with similar conditions received from any member of staff. Secondly, doctors were absolved from having to take decisions in individual cases - their responses to questions appeared to be generally routinized irrespective of the character of the patient. Thirdly, it ensured that members of staff did not come into conflict over what patients should be told. In particular it was understood by all staff that patients should not be given unfavourable information about their condition. However, despite all this there were sometimes severe problems in interaction with the dying cancer patients, especially for junior nurses who were often explicitly asked by them if they had

cancer.

The pressures of working with the dying were very demanding not only in terms of the amount of nursing care required but also because the nurses felt that they could not allow themselves to become over-involved personally with any one patient. Further, they received no education about the psychological needs of the dying person nor how to come to terms with impending death. As Quint (1967) points out, although young nurses are taught how to care for patients physically and sometimes 'psychologically' they are rarely, if ever, taught how to cope with conversations about death and dying.

The problems of coping with and accepting imminent death provided two basic problems for the junior nursing staff on ward 7. First, it was very difficult for them to talk frankly about death with the dying. No matter how many similar situations they may have witnessed it was hard to reassure the dying patient when they had not come to terms with their own death. Most nurses had not thought of their own death seriously, and for some of them nursing the terminally ill raised questions about this which remained largely unresolved (Simpson (1975) reports similar findings, and DF also found this to be the case for some of the younger nurses he interviewed). This problem occurred even with the patient who was fully aware and resigned to her impending death. Also, the problem was accentuated by the emphasis upon maintaining the 'closed awareness' context, for in this situation the nurse had to come to terms with assuring patients who were confused and anxious about their physical deterioration that they would recover when they would not. The nurses found such lying to the patients distressing, especially when they had built up a relationship with a patient. However, the decision had been made for them by the

surgical staff who decreed that patients must not be told of their terminal prognosis.

There were two commonly used strategies whereby junior nurses could evade patients' questions while maintaining their friendly relationships with them. The organization of work on the ward along the lines of 'task allocation' made it possible for them to be doing work elsewhere and thus physically to avoid contact with the patient and/or suggest that they were too busy to talk. Secondly, they could legitimately plead ignorance of the patient's case by virtue of their low status in the ward hierarchy and refer the patient to more senior staff, usually a doctor, a strategy which Sudnow (1967) and Quint (1965) found to be the most common way of dealing with questions from dying patients in their studies. Communication patterns on the ward reinforced and supported such evasion.

A major factor inhibiting communication between dying patients and surgical staff was the great respect and deference in which these were held by patients. (Cartwright, 1967, reports the same phenomena in her general survey of hospital care). Junior nursing staff often suggested to patients who expressed confusion about their condition that they should "ask the consultant about it", but the patients were afraid to do so because "he's a very busy man". One woman said that he (the consultant) would think her stupid if she asked him to explain her condition to her because he had already done so and she had not understood him. In fact, the consultant had not explained her condition (she had terminal cancer) but had evaded the issue by talking about 'complications' thus confusing her more.

These barriers were also harmful from the doctor's point of view:

patients usually dressed up and 'cheered up' for the consultants and rarely discussed their anxieties with them. These were more often relayed to junior nurses who had little communication to medical staff. These nurses felt that they could not tell consultants of patient anxieties because it was hard for the consultant to accept that a patient who was courteous and relaxed in his presence was to the nursing staff a deeply depressed and anxious character².

These problems tended to alienate further the junior nursing staff from the medical staff and formed a barrier to their communications. Although after a period of time nurses knew whether a patient had cancer because of their access to the patient's notes and their recognition of certain forms of treatment, they did not know how much the patient had been told about their condition. Thus when patients would say "I know I've got cancer" the nurse did not know whether the patient was 'trying her out' and waiting for her reaction, or whether they genuinely knew because they had been told by relatives. In such situations evasion and avoidance of patients were tempting solutions to the nurses' difficulties.

DISCUSSION

The main purpose of this chapter has been to introduce some of the themes which run throughout the rest of this work. The central theme concerns the problems surrounding disclosure of terminality, patient's awareness that they are dying, and communication with them. A closely related theme is the investigation of the structural organization of nursing work which hinders or facilitates such disclosure, awareness, and communication. The example of ward 7 shows that with-holding the disclosure of terminal prognosis from patients does not guarantee that

they will not become aware or suspect that they are dying, a finding which has been well documented (Glaser & Strauss, 1965; Quint, 1965; Hinton 1980), and is well known by hospital staff. It is also clear that such a policy creates problems for communication between nurses and the terminally ill. These problems were largely the product of the organization of nursing work on ward 7. More specific issues raised in this chapter such as close contact with the dying generating involvement by the nurse, and whether entry to the 'terminal status' alters nurses behaviour towards them, will be addressed in subsequent chapters also.

As indicated in the introduction to this chapter a second intention of it has been to open the discussion about the problems associated with the disclosure of terminal prognosis. The denial of such information to patients seems to be based partly on mistaken assumptions about the 'smooth running' of hospital wards. Yet Aitken-Swan and Easson (1959) have shown that the treatment of cancer patients can be controlled smoothly when patients are aware of their condition. Other studies of hospital patients have shown that withholding information from patients may in fact delay recovery (Egbert et. al. 1964; Janis, 1971). While pressures may be alleviated for the doctors by the withholding of unpleasant information from patients as they will then be able to avoid coping with the psychological needs of such overtly aware patients, to a large extent such pressures are merely transferred to nursing and paramedical staff. It is these who have to cope with the constant pretence that 'everything is fine'. In the case of ward 7 this resulted in a breakdown of communications between medical staff, senior nurses, and junior nurses, with the latter bearing the brunt of such dissimulation.

NOTES

1. It should be emphasized that such 'problems' are the analyst's, and are not necessarily viewed as such by nurses and other participants. As Sudnow puts it "By conceiving of these categories as 'problematic' I do not intend at all to suggest that their use is problematic for either professional or lay persons, but rather that, from the sociologist's standpoint, they must be so conceived if the proper analytic attitude toward them is to be maintained." (Sudnow, 1967; 61, note 1). The chapter follows the work of Glaser and Strauss closely in its organization and focus (Glaser and Strauss, 1965, 1968).

2. There was sometimes another reason for patients not questioning medical staff, namely, a fear of knowing the truth (this was also found by McIntosh, 1977). One patient, even though he was curious and anxious, and questioned the junior nurses intensely, said quite frankly that he was too afraid to ask the doctors because he knew that they could reveal the truth. To ask them directly could lead to a direct answer which he did not wish to hear from such a definitive source.

CHAPTER 4: 'WE DIDN'T WANT HIM TO DIE ON HIS OWN': NURSING THE DYING ON A GENERAL MEDICAL WARD

This chapter is based on interviews with all the day staff working on a 28 bed general medical ward at Midland General. The interviewing took place over a seven week period during May - June 1982 in the vacant night Sister's office which was located away from the main work areas of the ward. This greatly reduced the opportunity for observation of general nursing work, although some observation was possible and DF met and talked with a few patients as well as 'socializing' with nurses before and after the interviewing. It was thus possible to gain some partial and non-systematic evaluation of how nurses' verbal accounts compared with their 'coffee time' talk and their relations with patients.

THE WARD

Ward 6 was virtually identical in design with ward 7 (see Diagram 3.1), with female and male patients segregated by sex in the four or six bed bays. During the second week of the study period the mean age of the 33 patients who spent time on the ward was 57, with the youngest patient being 19 and the oldest patient 96. Twenty seven percent of the patients were under the age of 50 and forty two percent over the age of 65. During 1982 there were 63 deaths on the ward, but none during the study period. At the time of the study bed occupancy was running at nearly 90%, and was 87.9% for the year (All information is taken from the Medical Unit report for 1982). Despite the high level of bed occupancy the rhythm of work on the ward appeared to be

*This chapter is taken from and expands upon Field (1984)

generally relaxed, and the attitude that nursing work meant doing something to patients (Clarke, 1978) was noticeably absent. During 'slack times' (when most of DF's visits occurred) nurses could typically be found chatting to patients.

Unlike ward 7 the ward was run along team lines, with authority delegated widely among the trained nursing staff. Charge nurse duty rotated among all qualified staff rather than being based simply on seniority (a SEN was in charge at the time of DF's first visit even though two SRN's were also on duty). Trainee nurses were fully involved with patient care and were not relegated to the status of simply an extra pair of hands to perform routine tasks. The delegative and 'permissive' leadership style of the Sister was very evident, and her role appeared to be in large part devoted to supporting the rest of the nursing team, facilitating their interpersonal relationships with patients (and trying to develop their skills) where necessary, and mediating between nurses and patients and doctors. Her leadership style and strongly expressed attitudes were central to the ethos of patient care enacted on the ward.

Nursing work was organized through a system whereby patients were allocated to teams of nurses responsible for all the patients within their bays, and within these teams to individual nurses. The nursing process had been introduced three years previously and was working smoothly after some initial problems (McKeown, 1980). It was now accepted by all nurses, taken seriously and believed to be a relevant and useful way of organizing nursing work. The operation of this pattern of work and belief was to make nurses individually responsible for their patients within the context of team and ward support.

4:1 RL I tend to rely on Sister - I go to her and she advises. When it gets sticky we tend to refer to her and then she helps.

She sort of goes over the sticky bit then she refers it back to us, because she's very good at that.

DF And do you do the same for junior nurses?

RL Oh yes. If they come to us and we feel we can cope with it, we'll cope with it. If we can't we refer it to Sister - we don't try to get out of our depth in it.

Doctor-nurse relationships on ward 6 were much less formal than on ward 7 with nurses allowed a good deal of autonomy. Cases were discussed between medical and nursing staff, and the nurses reported that a good relationship existed between them.

4:2 DF Do you have reasonably good relations with the doctors on this ward?

ER Most of the time, yes. It's very friendly, all of the doctors and nurses are on first name terms. If you ask them 'Will you do me a favour? Mr. so-and-so wants a chat' - he hasn't asked for the doctor, just got you in a bit of a predicament - and they go off. They are quite good.

Medical staff had less active involvement in the care of the dying than nursing staff, and might withdraw almost entirely once the transition from 'therapeutic cure' to 'relief care' (Saunders, 1978) had been decided upon.

In sharp contrast to ward 7 medical staff were willing to accede to nurses' views about the desirability of 'disclosure' of terminal prognosis to patients. For example, a case was recounted by the Sister where medical staff felt that a patient should not be informed that she was terminally ill whereas the nursing staff felt that she should be told. It was agreed that the Sister would tell the patient who, when told, thanked the Sister and made arrangements to ensure that a planned holiday occurred whilst she was well enough to go. Further, a policy of 'open disclosure' existed on the ward which meant that nurses could inform patients about their diagnosis and prognosis - including that of terminality without first having to seek permission

TABLE 4.1: NURSES' RESPONSES TO VARIOUS TOPICS RELATED TO NURSING DYING PATIENTS

Aspect	Unqualified (n = 11)	Qualified (n = 7)
Self		
Scared or disturbed by thought of own death	6	0
Had someone close to them die	6	5
Aspects of Dying		
Harder to nurse young dying patients	10	4
Elderly assumed to have had 'good life'	7	4
Death sometimes a blessing	8	4
Unexpected death harder to cope with	6	4
Short duration of dying easier to cope with	1	0
No difference between dying and other patients*	1	4
Awareness Preferences		
Open	6	6
Closed	1	1
Emotional Involvement		
Involved with dying patients	9	7
Problems from involvement	4	0
Involvement unavoidable	5	7
Kept in touch with relatives*	1	4
Ward seen as 'family' for long term dying patients*	1	6

*Not all nurses referred to these aspects.

to do so from the relevant consultant should the occasion arise. The nursing staff were encouraged by the Sister and the Nursing Officer to follow the open disclosure policy. Both the Nursing officer and the Sister told DF that they regarded helping the nurses in this area as an important part of their roles.

ASPECTS OF DYING

Table 4.1 shows the main topics covered in the interviews and gives a rough indication of the nurses' responses. As expected they found it easier to accept the death of elderly patients than the death of

children or young people. All of the trainees and four of the qualified nurses expressed such sentiments. Young deaths were seen as 'wasteful' and in addition many of the nurses presumed that old people 'had had a good life'.

4:3 PJ I think it's more difficult to nurse a younger person than it is to nurse an older person.

DF Why?

PJ Because life is so short for the younger person. With the older person, they've had their time and you can't prolong life for too long. For a younger person it's quite sad.

The qualified nurses were slightly more complex in their reasoning than the trainees. For them it was not merely that the elderly had 'had a good life', but also that they were perceived as being more accepting and ready to die. The nurse here had been telling DF about her difficulties when nursing teenage leukemic patients at the time when her children were teenagers. Without prompting she went on:

4:4 EW (...) I feel you can help an elderly person more than you can a teenager - an elderly person is more ready to die, I think. Or accepts it more easily. So they are quite - not happy - but they're ready to take all the comfort you can give them. Whereas a teenager, they're frightened if he thinks, or overhears, or feels that he is going to die. He's very, very, frightened.

Nurses sometimes linked the death of the elderly with the view that death could be a 'blessing' or 'release' for patients, but this was by no means seen as an inevitable link. Death was seen as a release for patients who were suffering from painful or distressing symptoms, often over a long period of time, no matter what their age.

4:5 SA (...) they kept giving her more blood and she kept throwing it back - she had a lovely personality, she was so caring (...) I think the staff felt so sorry for her and felt they wanted her to die because she was having to put up with all this; they didn't want her dead but they wanted her to die so she wouldn't have to suffer.

In their study Glaser and Strauss (1968) found that it was easier

for staff to cope with patients who died quickly and expectedly than those who died over a long period of time. Eight nurses said that they found, or anticipated finding, unexpected deaths harder to cope with than expected deaths. However, only one (trainee) nurse indicated that 'quick death' was easier to cope with. The remainder either said that there was no difference or could not indicate how they thought the duration of the 'dying trajectory' would affect their nursing. Some implied that too rapid a death would in fact be harder to cope with as they would not have had a chance to establish a relationship with the patient nor to provide the patient with 'good nursing care'.

AWARENESS CONTEXTS

As already indicated, a central concern of this study is to examine nurses' views of various 'awareness contexts' (Glaser and Strauss 1965). We have seen in the previous chapter that even in a ward which did not allow disclosure of terminal prognosis to patients, and where conditions favoured the maintenance of 'closed awareness', patients became aware or suspected that they were dying. On ward 6 nurses were not asked directly whether they thought that terminally ill patients knew that they were dying, but eleven of them volunteered views on this during the course of the interview. Nine of them were certain that most dying patients knew that they were dying without being directly told.

4:6 RP I think it's easier if they do know to a certain extent. I think even if they haven't been told towards the end they know deep down inside them, and they usually end up telling me they are going to die, then I don't have to tell them.

DF Has that happened to you? Several times, many times?

RP Yes. It's quite common, or it seems to be.

The nurses often adduced examples from their own or other nurses'

experiences to support the view that patients 'knew' of their impending death.

4:7 PJ I think every dying person has got some sort of insight because you come across some uncanny things (...) (like) a patient dying while all the relatives are at home, and the family had just been on holiday and the son had come back from work abroad, and they were all at home (...) and he died that day (when) they were all back together as a family.

Contrary to the findings of McIntosh (1977) and the widely held view that a situation of 'closed awareness' is preferred by hospital staff, only two of the nurses said that they thought it was easier to nurse dying patients who were unaware of their impending death. The majority of nurses who expressed a preference chose 'open awareness'.

4:8 SG I think with patients who are dying you have to make a specific judgement on each person whether you think they can handle the information, and also take into consideration the relatives' wishes. But, as a general rule, I'd say yes, if a person asks you and you think they are up to it, to tell. I find it easier than to carry on a relationship with a patient to its termination, rather than having this superficial relationship that suddenly one day he's going - Boomp - You're left hanging up in the air.

For the younger trainee nurses such a view was largely anticipatory and they were tentative in their choice. Even for trained staff the preference for 'openness' was not unproblematic as this staff nurse indicates.

4:9 DF So you have no difficulty talking to them?

RL Oh no. Sometimes I find it difficult if they don't know they're dying, and the relatives have expressed a wish that they're not to be told and the doctors haven't told them yet. You know ... the time when they first get to know. I find that a bit difficult still. It's alright when they don't know. It's the in-between bit when they are getting to know and they're asking some difficult questions.

As this shows getting to the situation of open awareness may be hard, especially for the trainee nurse. It was in this phase of their relationship that the qualified staff saw the ward Sister as playing an important role as a 'broker' who negotiated the transition to open

awareness when they could not do so. (Glaser & Strauss (1965) and James (1986) report similar patterns). Both the Sister and the Nursing Officer reported that they saw this as an important part of their work.

Despite the difficulties of achieving open awareness all the qualified nurses indicated that they had developed strategies for 'telling' patients the truth about their terminality. Trainee nurses had also developed or anticipated strategies for coping with terminally ill patients although, as on ward 7, these were largely based on evasion. The following extract taken from the interview with the nurse with 20 years' nursing experience illustrates both categories well.

4:10 EW If the patient asks you outright if they're dying and you know then I think a student nurse or a pupil nurse might sort of hedge 'Of course you're not going to. Ask the doctor'. But it depends, (...) Sister does allow us to use our own judgement, but just the same you've got to be very careful what you say.

DF Can you think of anyone you've actually told?

EW I've never actually said to someone 'Yes, you are dying'.

DF But there are ways of saying 'You're dying'.

EW I remember a lady saying 'Well I'm not going to get better am I?' and then I said 'Well no, I don't think so. But nobody knows for sure' - 'If it's left to our care you will go home'.

DF So you always try to be positive?

EW Yes. You try to be positive as well because nobody can say 'Yes, you are going to die'.

(She returns to this issue without prompting at the end of the interview): I try not to lie or pretend to them. Try not to disguise. I try not to kid them along. I try not to say 'Oh no, you're not going to die', try not to do that. That's wrong. They still need the same sort of - they still need nursing. It's just your approach to them. I think you should be as honest as you can. If you can't then I think you should get somebody else to talk to them who can be.

As these paired extracts show, important elements of the strategies

developed were the need to be positive, and a stress on being honest with the dying patient.

EMOTIONAL INVOLVEMENT

One of the reasons suggested for preferring closed awareness is that in such situations staff can maintain emotional distance from dying patients, although the evidence from ward 7 suggests that this doesn't work for nurses who have close contact with them. Given the strong preference expressed by the nurses on ward 6 for open awareness it is perhaps not surprising that nearly all of them (14) said that they were or had been emotionally involved with dying patients, often to the extent of crying and grieving at their deaths. All of the qualified staff and five of the trainees felt that such involvement was inevitable and unavoidable. For the qualified nurses such involvement was not seen as particularly problematic, and five felt that it was positively beneficial and rewarding for them. Trainees were not as positive, with four expressing problems arising from such involvement.

The following extracts illustrate the nurses' accounts of their emotional involvement with dying patients.

4:12 DF Is that a problem of getting involved too closely perhaps?

SD I don't think it's a problem really. I feel that it's unavoidable. If you're keen on looking after people you'll be involved with them ... If it's about their son or daughter or their home you can't switch off and say 'I don't want to hear about that. I want to know where your pain is'. You are involved with them. You're their only contact ... you're the only person they've got to talk to. They tell you everything. So, so you know them.

4:13 This student nurse had just given a very full account of her experience nursing an 80 year old terminally ill woman with whom she

had become very emotionally involved. The woman had died two weeks prior to the interview and the student had shared the death with the woman's husband. Both of them had cried after the death.

SH Well I shouldn't really have done that. I shouldn't have got involved so much probably, but it's hard to draw the line, particularly with someone like her. She was so kind to everybody. And I thought 'well this isn't a very good example for the younger nurses walking out crying with the husband', but I thought 'well obviously they know it's an upsetting thing even though they weren't involved'. And some of them said afterwards they were glad they weren't involved because it would have made them cry. But I wasn't the only one in tears so I didn't feel so bad. It wasn't as if it was just me who was involved with her.

DF Do you feel it is bad to cry when a patient's died?

SH Not really. Not if the relative's there and - he said to me then 'She wasn't just another lady was she?' 'No' I said, 'None of them are. Everybody's an individual here'.

4:14 DF Do you ever find yourself getting involved emotionally with any of the dying patients?

EY Yes I should think you get involved with all patients. I know when you start your nursing they say to you 'Oh don't get involved with patients', but I think it's difficult to nurse someone if you're not really getting to know them. And when in fact we do the nursing process on here everything's a lot more personal. We're on first name terms with a patient, so you do get to know them as people really, rather than just one who's stuck in that bed there.

Another indicator of the high level of emotional involvement which these nurses seemed to have with their dying patients was the contact which some of them maintained with the relatives of patients who had died and with long-term terminally ill patients who had been discharged. The most dramatic example of such behaviour was provided by the Sister. She told DF that she kept in contact with many relatives even though she didn't always want to do so.

4:15 CK (...) Because often they are a terrific drain. And very often - you want to forget about work and it's forced upon you. I always have this terrible feeling that they expect so much of nurses, that you are representing every nurse. So to be unkind or to be curt, or not to have time would, well have a devastating effect on them. They feel they could be next. And so you're obligated to give them every consideration, and yet I don't always want to (...) and I think that possibly

the only common denominator with all these people is that they want to talk about their deceased. I have known them, probably in quite an intimate way. You can't nurse a dying patient without - well you can, but obviously it isn't desirable to keep them at a distance - and so you do get to know them very well. And this is what they're really after. They want to talk about the person, not the death (...) I can never bring myself to cut them off, and they may not be able to do this with anyone else.

Not all the nurses were asked about this type of behaviour as it was an unexpected and emergent topic. Certainly the Sister was atypical in the extent and duration of her contacts, but four of the qualified staff and one student nurse reported acting in this manner (usually unprompted), although not necessarily over long periods of time. It seems that nursing a dying patient in an involved way meant that the nurse also became involved with the patient's relatives who often needed support after the patient had died.

A final indicator of the high level of involvement with dying patients can be seen in the 'adoption' of some long-stay dying patients into the 'ward family'. At the time of the research there was an elderly lady on the ward who had been 'adopted' in this way. She was, it seemed, the latest in a series of such patients to be treated by the staff 'as family'.

4:16 RI (...) She ('D') is like part of the family now very much like 'C' got to be in the end. (...) Sister's already started arrangements for - I know it might sound morbid - but she's told the administration we want a proper funeral, because 'D's' got the money to pay for it and as many of us want to attend as possible.

DF Is that unusual, do you think, for the ward to get that involved with a patient?

RI Not if they're that long-term. We don't usually get patients that long-term. We had 'C' because he was under 60 and couldn't go to geriatrics. There was no place for him. And we kept 'D' because she was another one that was only expected to last a few weeks, and we all got to love her, and Sister K said it wasn't fair to send her to geriatrics where she wouldn't receive quite so much care. So - I don't think anyone can help getting involved though.

When 'D' finally died the funeral was held as planned, complete with flowers, Sister K playing the organ, and with most of the nurses attending the service.

The involvement of nurses with their patients seems to account for another unexpected finding. Five of the qualified nurses and four of the trainee nurses suggested that there was no essential difference between nursing dying and other patients.

4:17 RP Whether a patient's dying or not if they have an unpleasant smell about them they're harder to nurse.

4:18 ER (...) People who are dying - we don't treat them any different, but I suppose (...) you get more satisfaction from sending some home well; we've healed them, better than sending someone home who is terminal, or have somebody die in hospital. But you wouldn't notice any difference in our attitudes towards them.

On probing it became clear that although the practical nursing care of the dying might be different, and although in certain areas (e.g. diet), routines might be relaxed, there was no real difference as far as the nurse-patient relationship was concerned. One nurse even went so far as to say that she got pleasure from nursing the dying.

4:19 DF You said you got pleasure from nursing the dying patient.

EW Well, well perhaps that's the wrong thing - satisfaction I don't mean pleasure: satisfaction. You can see results from nursing a patient that's a long-term patient or dying. You can see what you're doing for them (...) You can make time to sit and talk with them. And obviously if they're dying the physical condition is going to deteriorate so you've got to be that extra bit careful keeping them clean and comfortable. Bathing and things like that. And to me that's nursing.

As this extract shows, nursing the terminally ill could be satisfying for the nurse because it allowed them to implement fully their ideal of nursing care.

DEALING WITH RELATIVES

While the nurse, especially the qualified nurses, presented a generally positive picture of their dealings with the terminally ill, they reported much greater difficulty in their dealings with the relatives of the terminally ill. Seven of the nine trainees reported or expected difficulty in talking with relatives, with the two exceptions being the two student nurses who already possessed a qualification in psychiatric nursing. Four of the qualified staff reported such difficulties also. Basically the nurses' problems lay in knowing what to say to the relatives.

4:20 DF Anything you find particularly difficult? You said 'knowing what to say to him'.

SH That's right. You sort of say 'Oh I'm very sorry, she's died', but after that you can't just take them away for a cup of tea and say 'Well I'll leave you here for a minute'. You've got to be able to say something to relatives. You can't just walk out and say 'Well she's died. I'm sorry about it. Bye Bye.'

Two main areas of difficulty were reported: difficulty in 'breaking the news', and the relatives' failure to accept the news. Both qualified and trainee nurses reported difficulty in 'breaking the news', although unsurprisingly the latter seemed to have greater difficulty than qualified nurses, or were anticipating that they would find telling relatives about the patient's terminal prognosis difficult.

4:21 SD It's very difficult I would imagine. If you've got a wife who comes in and you are the person that's got to say 'Well, he's very poorly' and they say 'well, how poorly?' You can't say 'He's going to die' but you've got to get through to them that they may not get any better; that they may not come out. You don't want to be brutal, but you don't want to give them false hopes.

Even when relatives had been told they would not always accept that their relative was terminally ill. Such denial could, it was reported,

create difficulties for the nurse in relating to the patient because in such a situation the nurse could not easily lead the patient to recognise and accept their terminality. More commonly nurses reported that while the patient would recognise and accept their terminal condition their relatives would not do so. The following extract illustrates both of these aspects. It develops from the discussion of a patient with whom the nurse had become involved.

4:22 DF Is it upsetting to you because of what it means to her, or is it more than that do you think?

ER It's not really the patients, because they take it, they accept the fact. It's the relatives. They think 'Why is it happening to my wife? Why this family? She's only 30. What about the baby?' Whereas the lady in question, she accepted it very well. It's the relatives that I find difficult to cope with.

DF Do you have a lot to do with relatives?

ER Yes (...) If a patient of mine dies I see the relatives. It's far easier to cope with a patient that's dying and knows that they are dying. They've accepted the fact, you've accepted the fact, and you feel quite happy looking after them. It's the relatives that don't accept it and are difficult. They do accept it eventually but it's very difficult at the time for the patient's relatives to think that actually 'He's gone'. I think that afterwards they do think that he's better off, but at the time - especially wives because I think they don't know what to do, they've nobody to rely on any more - that's difficult.

Central to both types of difficulty was that whereas the nurses felt they could offer the patient something positive they often felt that they could offer nothing to the relative. In particular there was nothing they could do to comfort them. Further, when dealing with the patient nurses were in control of the situation, whereas this was not the case with relatives. There was no way the nurse could avoid telling them the bad news, although with the patient they could say very little. Such views were widely shared and were expressed by both the least and most experienced nurses.

4:23 SA Well I think with that particular patient I could have got away without saying much, but with the daughter I had to say something to comfort her but I couldn't find the right words.

4:24 CK The difficulty with the patients is when they say 'Am I going to die?' It is always easy to say to a patient 'You have a malignant disease, but we have this treatment to offer you'. Or, if we have no treatment to offer them, that they needn't worry because we are going to look after them. We will make sure there is no pain (...) And so I always have something to offer the patient. You have nothing to offer the relatives. You're going to tell them their nearest and dearest are going to die. And then what do you have to offer them? Because it is an inescapable fact. You can let them talk, and you can answer their questions. You can support them as you go along. But you can't take away the inevitability of the fact that the patient is going to die.

The strategies developed by the nurses for coping with relatives depended largely on their confidence that they could cope with such situations and were thus found mainly among the qualified nurses. However, the trainees had, at least prospectively, similar potential strategies which they were waiting to try out. An important common aspect of these strategies was 'listening' to the relatives and allowing them (or nudging them) to raise the topic.

4:25 DF Do you find any difficulty talking to relatives of dying patients?

RL I did at the beginning but I feel a lot easier now.

DF What do you think has changed?

RL Probably because I've spoken to more of them. Sometimes I find it's just best not to talk, just to listen to what they have to say. Sometimes they just don't want to talk. They just want somebody to listen to them - I just tend to let them lead the way and just console them really.

DISCUSSION: THE ORGANIZATION OF WORK AND NURSING THE DYING

What emerges very clearly from the nurses' accounts of their experiences of nursing dying patients and of their attitudes towards such work is a consistent set of predispositions to act in particular ways, namely; to become emotionally involved with the patients they are nursing (and their relatives), especially if they are long-term patients; to disclose rather than to withhold information about dying

when this is sought by the patient; to be honest in their dealings with patients and relatives; to accept individual responsibility for patients while working as part of a team; to help and support each other. In short there is a predisposition to provide 'total nursing care' for the 'whole person'. Whether these attitudes were translated into action it is impossible to say in the absence of systematic observation of their work, although there is reason to believe that they were.

General medical wards differ from other wards in a number of ways with respect to patient flow and rhythms of work, and with respect to the characteristics of their patients. They are generally geared towards less intensive therapeutic intervention than acute surgical wards or coronary care units; their patient turnover is on average lower with a concomitant longer term stay; and their patients are older. Patients are typically mature adults rather than children or teenagers. Further, deaths are usually predictable to nursing staff and relatively infrequent when compared with some other settings. Most patients recover or are discharged in an improved condition. Thus, nurses may have more extended contact with patients and so have a greater chance to get to know them, and are dealing with deaths which are less problematic and less frequent than an acute surgical ward such as ward 7. Still, the contrast between ward 6 and ward 7 could scarcely be sharper.

On ward 7 the care of the dying was left to the untrained auxiliaries and first year trainee nurses; on ward 6 it was shared by all nursing staff. Whereas on ward 7 nurses caring for the dying received little support from other - more senior - nurses, on ward 6 the nurses supported and helped each other and the Sister was always

available to 'step in' and help any nurse who was experiencing problems.

One explanation for these contrasts seems to lie in the differing organization of work on the two wards. The system of patient allocation combined with the use of the nursing process on ward 6 meant that nurses could obtain the satisfaction accruing from seeing the direct effects of their nursing work, something which would be harder to do under the more traditional system of fragmented task allocation which was used on ward 7. In addition to such satisfaction one could speculate that feelings of autonomy and self-esteem were also enhanced, and that the pattern of work inescapably generated involvement with long-term patients, and reinforced caring dispositions which might erode under systems where fragmented nursing tasks order the organization of work (Charles-Edwards, 1983).

With specific reference to the nursing of dying patients the combination of patient allocation with the nursing process meant that the nurse would find it difficult to avoid the patient because they were unambiguously the responsibility of individual nurses, rather than the general responsibility of all nurses. Thus the commonly reported pattern of withdrawal from the dying patient could not easily occur in ward 6. Further, such 'enforced' contacts with the dying could lead to familiarity with death and an appreciation of the rewards which can be derived from terminal nursing care, and thus might lead to a breaking down of nurses' fears of death and dying.

4:26 DF Have you talked to patients who have known they were dying?

ER Yes, they tend to accept. Far more than the relatives. You can talk to them, have a normal conversation with them without worrying (...) It's quite easy - well not to start with obviously - you've got to get used to it. The first time it's quite difficult. I was quite shocked the first time that they'd taken the thought of dying so well (...) 'Oh I want to

go out' he said 'for a few weeks and sort out my house and sort out my will, and get everything sorted out so when it happens I know everything's OK'. Well I was quite surprised because I don't really think about death - what'll I do when I die? (...) yet he was quite set: 'Let's get it down before it happens so everything is left all right'. He was great.

In the next two chapters we will look at nurses working in two very different work settings: Coronary care and community nursing, and see how their experiences and attitudes compare with those expressed by the nurses on ward 6. In chapter seven we will examine the relationship between such attitudes and experiences and the organization of nursing work in order to address further the question of which features facilitate or frustrate the implementation of the caring predispositions identified above.

CHAPTER 5: 'DEATH IS NO FAILURE': NURSING THE TERMINALLY ILL ON A CORONARY CARE UNIT

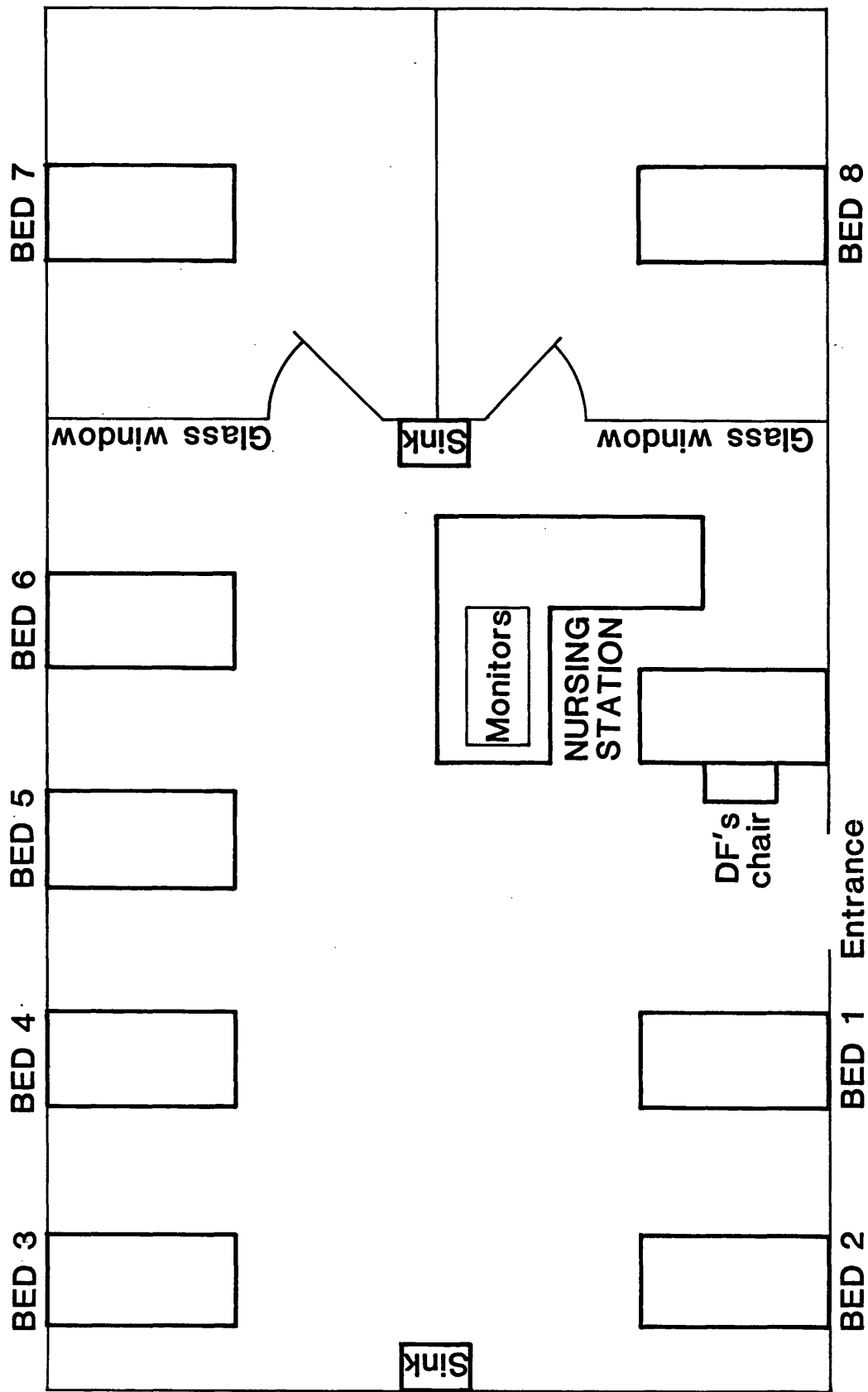
This chapter is based on interviews with seventeen of the eighteen nurses working on the coronary care unit of Midland General Hospital, together with observation on the unit. The main period of study lasted from late October to late December 1983, with the last visit to the unit occurring in early 1984. One nurse is not represented in the transcript extracts as her interview was not recorded due either to tape or operator malfunction, and so only a general account of her interview was available.

THE UNIT

We begin by considering those aspects of the functioning of the unit which seem especially relevant for the concerns of this thesis. These aspects relate to the organization and experience of nursing work and do not cover other aspects.

The coronary care unit (CCU) at Midland General was one of several units serving the City. It differed from most CCU's in two important ways. First, it had an 'open plan' design, as can be seen from Diagram 5.1, rather than having the more common design where each patient is nursed in a separate room with no view of other patients. Second, it did not admit patients via an accident and emergency unit. Patients arrived either directly as a result of general practitioner referrals or through emergency ambulance admissions. That is, unlike most CCU's there was no 'filtering' or 'vetting' of patients in the hospital to establish their suitability for admission to coronary care prior to their admission to the unit. Over half the admissions to the unit

DIAGRAM 5.1 The Coronary Care Unit



(Not to scale)

proved either not to have heart disease or to have heart disease in association with another condition which made them inappropriate for treatment on the unit. The unit had eight beds, six of them on the open-plan main unit and two in rooms with large glass windows looking on to the main unit. These windows could be screened off with venetian blinds. Long stay and/or more seriously ill patients were more likely to be put into these rooms. Average bed occupancy during 1983 was 6.5 beds per day (81%).

On coronary care, as with ward 6, there was not a great deal of emphasis on 'getting through the work' (Clarke, 1978). The pattern of work on the unit differed from that on the wards in many ways, the most important of which related to the type of nursing work, and the flow of patients through the unit. Nursing work was more technical and 'medically oriented' than on the wards, involving a great deal of expertise about the heart and its (mal-)functioning, monitor patterns, and drug use. The role of the nurse was consequently 'extended' beyond the normal responsibilities found on the wards and nurses were legally covered to administer drugs and to initiate life-saving actions in the absence of a doctor. The work was also more intermittent than on a ward. Some of the differences are neatly encapsulated in the following comparison of CCU work with this nurse's previous experience on a geriatric ward.

5:1 RJ The pace is different. On geriatrics you tend to be busy all the time but the work's different. You're doing a lot of basic things for people that can't do it themselves like washing them and bathing them and taking them to the toilet, and that keeps you going pretty much all the time. You've also got a lot of relatives to deal with and patients tend to stay longer than they do on coronary care. On coronary care the patients are mostly quite fit, apart from the fact that they've had a heart attack so really we just concentrate on one aspect of the heart attack, rather than any other problems, because usually patients that have got a lot of problems aren't admitted to coronary care. The work load is more medically oriented rather than more socially on the ward (...)

It's not sort of ordered or routine but things get done if they need to get done, but if it's not important they might get left. Whereas on another ward things might have to be done by dinner time, it doesn't really matter if it's not done. Things get done that need to be done.

All of the regular nursing staff were qualified, and trainee nurses were not usually attached to the unit although there was a third year student nurse working on the unit during the study period. Apart from the senior Sister who only worked days, the staff rotated through the two day shifts and the night shift. Thus, unlike the wards, there was no separation between 'day' and 'night' staff. 'Charge nurse' responsibility was shared by all nurses who had qualified for 'cover' regardless of whether they were staff or enrolled nurses. All nurses were treated as equal partners within the work team, and each took responsibility for their own patients under the system of patient allocation which operated on the unit. The extra responsibility of the work, the 'extended' role of the nurse and the atmosphere of the unit were all cited by various nurses as attractive aspects of the work. Enrolled nurses in particular seemed to see the first two as important. The senior sister summarized a number of these aspects during her account of the unit.

5:2 CV As far as the SEN's are concerned I think they get treated equally with the staff nurses, and probably more equally than anywhere else. We have this thing called 'cover' so that they are covered to be in charge ... to be safe. Basically to give I.V. drugs without a doctor being there, to initiate treatment etc - and if an SEN is on and they've been covered longer, then they're in charge. And there's no 'yes' or 'no' about it. So they're totally treated as an equal. A lot of them find that they need longer before they'll take their cover, because of the confidence thing - 'My god, can I really be in charge over staff nurses?' I think that's one of the main reasons why SEN's stay longer, because they have far more responsibility here. They just get to do more. They get trusted more. And allowed to think.

A view confirmed by this enrolled nurse.

5:3 DF What do you like about the unit?

ET It's your responsibility as a person. You work your own routine out, whereas it's not set like a ward. You've got

experience in the fact that you're doing things that you wouldn't normally do on a ward, like taking blood, doing ECG's, which is very interesting ... And no two patients are the same, even with the same heart attack no two patients will react the same.

The most obvious characteristic of patient flow through the unit was its great variability. There was apparently a seasonal variation to patient flow, with the greater volume of work during the winter months. However, there was also a large amount of variation from day to day, and hour to hour. Indeed the tempo of work could drastically change in minutes with the admission of new patients. DF witnessed days where only two beds were occupied during his stay and others where seven beds were filled at the start and end of his visit, but with three or four discharges and then new admissions during the day. This unpredictable pattern of patient flow clearly affected nursing work significantly. When the unit was 'empty' there was little to be done, and nurses could get bored. When it was full then they could be very busy, and have no time to take breaks. It was not merely the number of patients on the unit but also their condition which affected nursing work. Very ill patients were much more work than those with a 'simple myocardial infarction'.

Patients admitted to coronary care were typically younger than those admitted to the medical ward, more likely to be male, and, as noted earlier, to be 'fitter'. Most patients stayed on the unit for 24 to 48 hours before being discharged to a ward prior to eventual discharge home. A few stayed longer, and it was this group of terminally ill patients which provides the main focus for this chapter. Few patients actually died on the unit (7.5%), although some would die on the ward or at home after discharge from the CCU.

WORKING ON THE UNIT

All of the nurses had a very positive attitude towards working on the unit. Among the reasons given for why they liked working on the unit were the autonomy and discretion which they were allowed to exercise in the way they did their work, and the responsibility of such work; the appeal of demanding specialist 'medico-technological' work; and the relaxed and informal atmosphere on the unit. In particular the good working relationships and relaxed informal atmosphere were universally agreed to be of central importance.

TABLE 5.1: CCU NURSES' REPORTS ON ASPECTS OF UNIT ORGANIZATION*

Unit seen as a team	12
Good doctor/nurse relationship	15
Responsibility of nurse rewarding	12
Good atmosphere of unit	12

n = 19

* Not all nurses talked about these topics

The 'sentimental order' of the unit (Glaser and Strauss, 1965) was an important feature of its organization, and was something which nurses were both aware of and concerned to maintain. Table 5.1 shows the salient features of this as identified by the nurses in their interviews. They seemed to make the effort to maintain a friendly, open, supportive, 'family' atmosphere which included all members of the unit, i.e. nurses, doctors, patients, cleaner, and ward clerk. A number of the nurses commented on the atmosphere of the unit, usually comparing it favourably with that found elsewhere.

5:4 DF What do you particularly like about working on the unit?

RN I like the more informal atmosphere that seems to exist. I don't know why that should be but specialised units, and certainly coronary care units, seem to have a more relaxed atmosphere than the traditional ward situation, both between staff, and between staff and patients. I think on this unit

that's consciously created to some degree. I think we go out of our way to try and cultivate a sort of ambience because we realise that it must be a frightening experience for the people who come in here. Finding themselves in a place that looks like Apollo mission control, knowing that they wouldn't be there unless their lives were in danger. I think that the more you can take the stress out of that situation the better it is for them. You can keep the lines of communication open.

The maintenance of a relaxed and informal atmosphere and organization of work, where nurses were valued and treated as individuals capable of making decisions sometimes, it seems, clashed with sustaining a high level of professional care at all times. While the nurses were generally satisfied with their standards of nursing care, there were some reservations expressed by a few of them, and some nurses felt that at some times standards suffered.

5:5 RQ (...) we are a relaxed unit but in some cases I think we're too relaxed and little things like reminding them (patients) to take deep breaths and explaining why they shouldn't have their legs crossed in bed, and (so on ...)
The nursing staff should have a laugh and a giggle. It's for our morale as well as the patients but there is a point where you have to draw the line (...)

Within the general ambience of the unit there were changes of mood relating to the pattern, intensity, and nature of the work. Several nurses commented that the 'feel' of the unit depended in part on the patients who were on the unit at any one time, both in terms of their personalities and their disease conditions. On one occasion the unit had filled up with elderly patients who were all simple cases requiring little skilled attention. The nurses seemed to be bored, complained about the 'geriatric cases', and were generally rather 'flat' and lacking in their usual vitality. It was one of those days where:

5:6 ES (...) nobody gets neglected as far as you don't get pressure sores or anything, but I do think care does go downhill sometimes. Especially if you're not busy. If you're busy everything gets done. But like today, it's all bitty and bobby really.

DF Is that the problem, the discontinuity in the pattern of work?

ES I think it is. But there's nothing you can do about it. But I think that must be it. I mean some days you can sit there and drink₁ coffee till ten, then you can't be bothered to do anything.

By contrast to this situation, on the day following a successfully treated cardiac arrest the atmosphere on the unit was noticeably elevated, with nurses smiling and lively, and with a lot of banter between them and the patients. A death, or the recognition that a patient had entered the 'last days' could lead to nurses being quieter and more introspective for a while.

The attention by unit staff to a wide definition of patient care was emphasized by a number of the nurses.

5:7 CY I think there's more emphasis paid on the patient here. If I go back to where I worked or if I go to visit other coronary care units the emphasis is basically on the equipment. The monitor pattern, the ECG's, their enzymes, things like this. And although it would be untrue to say that the patient doesn't have a place it's not the main component. The doctors' diagnosis and everything is centred round the medical aspects, while here the doctors have now come round to a - not a holistic approach - but more psychological, sociological effects of the patient and his family.

An important 'structural facilitator' which worked to maintain the special ambience of the unit and which allowed this emphasis on the importance of personal patient care to be implemented was the high nurse/patient ratio of the unit. Typically the early shift had five nurses on duty and the late and night shifts had three nurses on duty to care for a maximum of eight patients. This high ratio allowed nurses to spend more time with each patient than would be possible in a ward situation, and so to involve the patient in the unit atmosphere. DF observed that many of the nurses as they arrived on duty would go and talk to patients, and would spend a great deal of time during a shift simply talking to patients. Patients leaving the

unit were also seen to make a special point of saying 'goodbye' and 'thankyou' to 'their' nurse.

A final aspect to be considered here is the relationship between the nurses and physicians on the unit. This partly depended on the low level of nursing turnover, especially as compared with the other City CCUs which were reported to have an average length of stay for nursing staff of six months. Before the two new appointments to bring the nursing staff up to full complement which occurred immediately prior to and during the study period, all of the unit's nurses had been working there for over 15 months. Medical staffing was inevitably characterized by a higher rate of change as junior doctors rotated every three to six months. This caused some minor problems for nurses. The two consultants in charge of the unit had both been connected with it since it opened, and had established good working relationships with the nursing staff. Not only were relationships good socially, but nursing staff were consulted about patient care and their opinions were considered seriously.

5:8 ED Because we're such a specialized unit plus quite a few people have been here for quite a long time our views are respected and we are listened to. On night duty when you've got junior medical staff, the nurses really have to inform the houseman, senior houseman what goes on, sometimes the registrars. And the nice thing again is there's a good rapport with the senior medical staff. (...) We have no problem phoning the senior registrar - and they prefer to be called at two, three, four, in the morning or whatever - to say 'we don't think the patient is being cared for how you would like', and they'll have a word with the medical staff and sort out what's what or sometimes just say 'well do what the nurses say' sort of thing.

This mutual respect, trust, and friendliness between doctors and nurses, and indeed all team members, were pivotal to the maintenance of the relaxed and friendly atmosphere so valued by nurses.

TABLE 5.2: CCU NURSES' RESPONSES TO VARIOUS TOPICS RELATED TO NURSING DYING PATIENTS*

Aspects of Dying	
Death often a release (8)	8
Short duration of dying easier to cope with (10)	3
No difference between dying and other patients (10)	3
Patients usually know they are dying (15)	15
Death is not a failure (12)	12 **
Awareness Preferences (13)	
Open preferred	8
Closed preferred	3
Emotional Involvement	
Involved with dying patients (15)	12
Problems from involvement (15)	4
Involvement unavoidable (15)	6
Involvement rewarding (15)	5
Communication	
Open-ness and honesty important (18)	15
Communication with dying patients problematic (10)	2
Communication with relatives problematic (15)	15
n = 18	
* Refers to qualified nurses only. No nurse referred to all topics. The number referring to each topic is indicated parenthetically ().	
**Seven nurses directly expressed this view and a further five implied it in their statements.	

DEATH ON THE UNIT

Having sketched in the parameters within which nursing the terminally ill took place let us briefly consider some aspects of such nursing work on the coronary care unit. Table 5.2 provides a rough indication of the topics covered in the interviews. As indicated in Chapter 2 this was slightly different from that used on ward 6. In particular those areas where a clear consensus was present, such as the effect of patient age or the likelihood of death upon nurses' attitudes, were not addressed in any detail. We shall consider the nurses' accounts under the broad headings of death on the unit; coping

with death; communication with dying patients; emotional involvement; and dealing with relatives.

The first point to make about nursing the terminally ill on a coronary care unit is that death is infrequent. During 1983 there were 59 deaths on the unit and, as far as DF could discern, only four deaths occurred during the study period. A number of patients who are discharged from CCU to a ward or directly home die subsequently, and even though some nurses scanned the obituary columns of the local newspaper and information would filter back to the unit from other sources it was impossible for them to keep track of all their ex-patients and their outcomes.

A second preliminary point is that on CCU the differences between dying and other patients were reported to be much more evident than on ward 6. Not only were deaths relatively infrequent, but the nature and duration of nursing care to be given to dying and other patients differed greatly from other settings.

5:9 RM It's very very different because a non-dying patient is only going to be here 48 hours, and if everything goes according to plan then perhaps will only have a bit of pain for the first few hours. And if you could measure input, that would be very negligible. They spend most of their time eating and sleeping. A dying patient is rarely transferred, a dying patient's going to be here longer than 48 hours. You get to know them a lot better.

While some nurses did say that "they're all treated exactly the same until they die or go" (ET), or suggested that there were no essential differences between nursing the terminally ill and other types of patient, CCU nurses were much more likely to stress the greater amount of nursing time and care involved in nursing the dying, and psychological differences.

5:10 CG There is a difference, but I think your care is the same. You give them the same support. But their outlook is obviously

going to be a lot different. A person who is going to go home is going to need support for when he gets home (...) they're going to lead as near a normal life as we can get them to live. Whereas if a patient is dying, you've got to make sure they get the spiritual support that they need from whatever religion they are. They might want to talk to you or to somebody about who's going to look after the family or something. It's much less a physical thing, somebody who is dying. It's more an emotional, psychological thing.

Two patterns of death (or dying trajectories, Glaser and Strauss, 1965) were characteristic on the unit: 'quick deaths' resulting from cardiac arrest (heart attack), and 'slow deaths' resulting from chronic heart failure. It is this latter category which provides the main focus of discussion in this chapter since it is this type of dying which requires nurses (and doctors) to make choices and decisions over a period of time. Table 5.3 depicts the relation between potential problems and these two types.

TABLE 5.3: NURSING THE TERMINALLY ILL

<u>Potential Problem Area</u>	<u>Cause of Death</u>	
	<u>Heart Attack</u>	<u>Heart Failure</u>
Disclosing Diagnosis	-	+
Communicating with Patient	-	+
Communicating with Other Staff	-	+
Ceasing Active Treatment	-	+
Emotional Involvement with Patient	-	+
Impact on Other Patients	+	-
Key: + More likely to be problematic		
- Less likely to be problematic		

Potentially all patients are candidates for the first category, although this risk diminishes rapidly. CCU's were established precisely to prevent such deaths by speedy, high level, techno-medical intervention. Thus in such situations the nurses' efforts were

focussed on preventing death through the application of their specialized training in a crisis situation. This could be very satisfying and rewarding, especially when they were successful, which was usually the case.

5:11 DF Do you find it difficult being on a unit where you can expect death?

ET No. I find it very exhilarating in fact. You're always on your toes that if anybody does arrest you've got a team. Really it's so exciting in an aspect that we've got to get there and get that person back. I mean nine out of ten we do get back. If they're here in time. If they die in the ambulance and it takes them ten minutes to get here we haven't got a chance, although we do still try.

Problems for the nurses associated with quick deaths from an arrest were concerned with knowing when to stop heroic treatment, deflation and disappointment at failure, and, especially, breaking the news to the relatives.

5:12 RJ That was really sudden. Cardiac arrest. One minute they were on and basically alright. The next minute they've arrested and everybody's jumping on them. It's a lot quicker, and you haven't got time to talk to the relatives or prepare the patient or anything really (...) It's just not dignified dying with a heart attack. OK I know you've got to do everything. That's why they're on the unit. There's no point in having a coronary care unit if you didn't. It's messy. Drips and things. This chap had a drain into his heart that leaked and there was blood everywhere, and blood all over the nurses. I think the worst bit is the moment when they've been trying for about 20 minutes or so and the doctor says 'OK let's call it a day'. That sort of gets to me sometimes 'cos you try and try and all of a sudden you just stop, and the doctors walk out and you're left with this body, with all tubes and drains and things and the bed that's all messed up.

Some nurses expressed the view that such quick 'anonymous' deaths were unsettling because there was no involvement with or knowledge of the patient, although for others coronary care was a good working place precisely because they were unlikely to become involved with the terminally ill.

The terminally ill patient dying from chronic heart failure posed a

different set of problems all relating to their longer stay on the unit. Such patients could stay on the unit for up to two weeks before they either died or, more likely, transferred elsewhere to die. Because they were on the unit longer the nurses got to know them better than other patients, and so might become involved with them with all the costs and benefits this entailed. Their death could therefore prove to be more disturbing than that of a patient who died of a cardiac arrest on admission. However, deaths from chronic heart failure seemed to present less difficulties for the nurses in their contacts with relatives. The senior Sister summed up the comparative situations as follows:

5:13 CV They both have their problems. A quick death is emotionally disturbing because, well it's sad. They're there and suddenly (finger snap) they're gone. It's as quick as that, in a matter of seconds. And a cardiac arrest procedure's pretty horrible even in a slick situation like this (...) (with chronic heart failure) if the decision is that the patient's quality of life is going to be very bad, should we allow them to live? Then that is the decision. And then carrying out the decision. We're so used to acting. To actually sit there is - you find we all start twitching around doing anything in sight.

Deciding whether chronically ill patients had entered the terminal phase, and when to discontinue active treatment were problematic and required discussion with, and sometimes persuasion of medical staff. While the decision to cease active treatment legally rested with the medical staff the nursing staff contributed towards the decision, and as one nurse put it such decisions were 'often prompted by the nursing staff' (CG). The involvement by nurses in this decision making rested on a number of factors: nurses spent more time on the unit than anyone except the senior house officer and had more contact with patients than medical staff; they were more experienced than junior medical staff; and they had developed good relations with the consultants who respected their opinions. The nurses felt that the consultants generally shared their views about the treatment of terminally ill.

5:14 ED There's good rapport between the nursing and medical staff, and medical staff are thinking very much about the patient rather than just curing the disease. Sometimes it goes a little too far but with some patients it's hard not to; you've gone so far it's hard to stop really. Of course there are a few cases like that but most of the time if we feel that the patients are better off left we will do.

5:15 CR The doctors are only here for six months and then they move on, whereas the consultants are stuck with us and likewise we with them, so you develop a fairly close relationship. So you really know when an individual doctor is perhaps getting a little bit out of their depth, and because we're specialists we do know and we should know a lot of what's happening ... We don't have the final say. It's a medical decision ultimately, but we do have some influence on it.

The points at which chronic heart failure become diagnosed as terminal and when the decision to discontinue active restorative treatment were taken did not always coincide. The latter was the area where nurses reported that disagreements with medical staff, especially junior house staff, were most likely to occur, with nurses arguing for 'palliative care' at an earlier stage. Again the senior sister put the positions well.

5:16 DF What about decisions in the life and death situation? Say not continuing to actively treat. Do you participate in that sort of decision?

CV Yes. I don't know how to put it really, junior doctors are inexperienced and a lot of them find it extremely hard to make that sort of decision in the situation where you're resuscitating. They don't know when to stop, and some of them are actually relieved when you turn round and say 'Hey folks I think this is a "no go" area' (...) But often it's a joint decision again (...)

DF What about the 'cooler decision'? Someone who is in chronic heart failure?

CV There we have the problem. Time after time I really want to say 'Now folks, you don't really think that this is a patient that needs to be resuscitated. Have you looked at the quality of life of this patient?' 'Yes, but' 'Yes but what? There is no failure in death'. And sometimes you tend to get a lot of those sort of patients all at once where there's a 'Should we? Shouldn't we?'. and I think that nurses tend to - I don't mean give up - but tend to look at things from that point of view earlier than the medical staff. We see the relatives much more. We see the distress that they are having, and the patient. And it is an extremely difficult problem with advances in medical treatment and it is getting worse.

The rapport with and support from the consultants was important for the resolution of disagreement with junior doctors, since the consultants were reported usually to support the nurses' view. This was described by a number of nurses, all of whom were careful to say that such disagreements were infrequent, and that they could usually be handled tactfully by the nurse. They were also most likely to occur during the early stages of a junior doctor's period of attachment to the unit. In the worst eventuality nurses reported that they could and did telephone the consultant for support, if need be at his home.

Deciding to discontinue treatment was difficult to accept, even when it was obviously the correct choice. While nurses were generally negative about unduly continuing active treatment for the terminally ill and - as DF observed - expressed satisfaction when the decision to cease treatment was made, it seems that some were still uncomfortable with such decisions.

5:17 EK I told you about that chap we got very upset about, and argued about (with the doctor) until the nurses got together and made a decision and went above the doctor (...) I realized he had been such a previously fit man that if we did scrape him through and get him home, then what was he going to be like, and how long was he going to last, and was it really fair? But either way - if you say 'Oh let this one go' or 'We'll go all out to save this one' - either way you're making a decision. But is it really a decision? Is it ever your decision?

One way in which nurses alleviated such anxieties in cases of treatable arrhythmia was to utilize a 'one shock' decision rule. That is, such patients when their heart stopped would be given an electric shock or short series of shocks to re-start the heart, but such attempts would not be persisted with. It must be emphasized that this decision rested with the medical staff, although the nurses could greatly influence this decision.

5:18 RF (...) perhaps sometimes we'll say "Oh we'll give them one shock'. Supposing they are in their seventies and their health isn't too good and obviously the natural process has to happen sometime. Then perhaps you think of a minimum of intervention. Give them a chance of coming round on one shock or something, and say 'Well this person has got to die sometime' (...) It's a funny decision to have to make, but you look at the quality (of life) and realize that well, they've got to go sometime.

If such a patient died then staff could say that they had, after all, done everything possible. However, if the patient did survive this could also cause problems.

5:19 ES Then you think that you're just keeping her alive for your sake when she's so miserable and unhappy. I think she'd be better off if they did let her die next time. But she always comes round. They say 'Oh, perhaps just shock her once', so they do and she survives it. And you feel sorry for her in the end because all she talks about is dying. She just wants to die. And you feel guilty then that you're doing what she doesn't want.

COPING WITH DEATH

Since the purpose of the unit was to prevent death, the possibility of death was to some extent a pervasive and inescapable part of the nurses' work. This being so it might have been expected that when death did occur, or when someone was defined as being in the terminal stages of their illness, this would be regarded by staff as some sort of 'failure'. However, this did not appear to be the case. The infrequency of death, and the nature of death were clearly key features in the nurses' view that death was not a failure as far as they were concerned. The nurses felt that patients died because, quite literally, there was physically nothing more that staff could do for them.

5:20 RN We're dealing with people on a fairly narrow range of medical problems and usually we know whether we can do anything constructive in a situation or whether it's hopeless, and so we're not left with that guilt feeling that I experienced sometimes as a student of not knowing whether there might have been anything more that I could have done, because usually here you say 'Well we did everything that could

possibly have been done in the situation and there was nothing I could have done to avert what happened'. So that's just the way it is.

Nurses seemed to find a patient's death much easier to cope with than junior house staff many of whom - or so it was reported - did see death as a personal failure on their part, and who would try to continue aggressive treatment long after it was warranted. This is not to say that nurses failed to be upset by a death, merely that they seemed to have developed ways of accepting it. The main 'neutralization techniques' (Sykes & Matza, 1957) used were intellectualization, denial, and the rationalizations that there was 'nothing more that could be done', and that death was not only inevitable but also a 'release' for the patient who would have had a very poor quality of life if they had survived.

5:21 DF You said sometimes you get upset when a patient dies. How do you cope with that?

CG Uhm ... Just try to bring oneself round to the fact that there was nothing more that medicine could do for him, and that there was nothing more nursing-wise we could have done anyway. He was comfortable, accepted that he was dying. He didn't die alone and he didn't die afraid. And I just remind myself of the good bits of it. And that he died with dignity. I don't think that you can die with dignity if you are afraid.

Glaser and Strauss (1964) also report this use of 'nothing more to do' reasoning.

Closely associated with the view that death was not a failure, was the view (also expressed on ward 6) that death was often a 'release' for patients.

5:22 EA (...) although most of the times when you do lose them they're better off. You know, not in any physical pain, there's not somebody doing something to them all the time ... when the patient dies you're to some degree a lot more relieved.

Not all deaths were viewed with detachment or equanimity, nor were all

deaths seen as a 'release'. There were clearly some 'failures' - some patients whom a nurse might have felt should not have died - but these seemed to be few and far between.

5:23 RQ Some patients come in absolutely clapped out and the best thing for them is to die peacefully, as peacefully as possible. There's just going to be no way out for them. You can see that. You can feel that. You don't need to know the blood pressure or anything like that, you just know it. Then there is the patient who you've got to know and you feel that he has got a fighting chance, no matter how slim those chances are, and those are the ones that you're fighting for. And you encourage the patient to fight as much as possible as well. And those (pause) - I've not lost many like that, but there have been the one or two.

As this extract shows, cases of 'failure' were closely linked to the idea that nurses are fighting with the patient against the disease. Not all nurses expressed such a view, but there clearly was some tension between the feelings of fighting to 'save' patients and accepting that in some cases death was an inevitable outcome about which nothing could be done.

From this discussion of death and dying on CCU it can be seen that nursing the dying on the unit was different in a number of ways from nursing the dying on acute surgical or general medical wards. The key differences were that death is generally expected (contra ward 7), relatively short term (contra ward 6), and that CCU nurses generally felt that everything which could have been done to prevent the death had been done. In such circumstances death was seen as not only inevitable but sometimes as a release for the terminally ill person. CCU deaths were not only largely unavoidable, they were also to a large extent predictable both in the sense that anyone could die, and in the more precise sense that the nurses could often predict when a patient was likely to die. There were, as one nurse put it 'not many surprises' (RN). Because death was so rarely a genuine surprise for

the nurses this also made it relatively easy to cope with. (There was also apparently a lot of 'mutual leaning' (CR) and support for each other from team members.) Also, it seems that the emphasis on 'caring nursing' which was such an important component of the units' ethos served as a counterbalance to the medico-technical, interventionist, aspect of coronary care nursing work, and made it easier to accept deaths for whom 'everything had been done'.

COMMUNICATION WITH DYING PATIENTS

Most CCU nurses preferred the 'open awareness' context, and said that they found it easier talking with the terminally ill if they were aware that they were dying. However, as on ward 6, there seemed to be some difficulty in achieving the open awareness context. The practical issues of what should be said to the patient, when, how and by whom, had to be resolved for each case. As it is difficult to discuss these problems abstractly, we will begin with an extensive account about one terminally ill patient who was on the unit at the time of the study.

'George' was re-admitted to the unit three days after his discharge from CCU to a ward and stayed on the unit for seven days before being discharged home. He was then readmitted again shortly before the end of the study period and subsequently died. DF noticed that George seemed to occupy more nursing time than most other patients, and his research diary contains several notes of nurses spending long periods of time attending to his physical requirements or simply talking to him. RM's account was verified on a number of points by George himself when he talked with DF.

5:24 DF 'You have enough time for the patient'. In what sense do you mean that?

RM Well initially I think it needs a lot of, not so much time with the patient, but a lot of discussion about the patient away from them and just deciding about how you are going to go about it so each of you is doing the same time. But you need a lot of time just to answer questions, to devote a few hours to be able to do that.

DF Have you spent literally a few hours with a dying patient talking to them about it?

RM Yes. In fact the chap I'm looking after at the moment. You wouldn't call him a dying patient in the fact that he's not going to die in a couple of days, but he's spent the past few days coming to terms with the fact that he's a chronic illness and he is going to die and it could be his last breath. I suppose that the day before yesterday most of the shift I spent with him (...) He's the classic cardiac cripple who goes slowly. He just doesn't have much of a heart left. It's easy with George at the moment because he knows he is going to die, and it's all out in the open. So you don't have to mince words, but you do a little bit because he's not really - well I think it's a rare occasion if someone really comes to terms with their own death. You still have to be very careful, but if it's out in the open it's easy and you know you're not going to upset him. Whereas if you are looking after somebody who is fighting for his life it's difficult to find the right point to - you know, you never give up. Rarely do people give up here. Nobody will take the responsibility to say 'that's it', but you always hope for that one chance. By saying to the chap 'that's it' you might just contribute to their death by giving up themselves.

DF Who told George?

RM CV. Sometimes you don't have any choice, you can't decide who is going to tell them. Suddenly the situation is there and it's no good looking for the nurse that's looking after them or knows them best ... each situation is individual and different from the last one, and you just can't have a set protocol or something. I mean the only protocol can be that as far as possible you tell the truth and a lot of tact and thought and you can't really do harm.

He was very depressed and actually said 'This is it isn't it?', and it was pretty straightforward. She said 'Well I don't think you are going to leave here, do you?' In fact he is. His death isn't really very long away. But we have a bit of a problem with him in that I feel he thinks that somehow he's cheated death, and he's beating it. But really all that's happened is he's changed his state of mind. He's higher than he was; he's just not depressed.

(...) I just gave him the practical duties of getting through the day, and said 'that's what you're concerned with. No matter what, those things have to keep going'. And I suppose you can in a way forget about the future if you concern yourself with a shave, and see what's going to happen after.

DF The other thing you were saying, that everybody involved with the patient was involved in the decision. That means both nurses and physicians?

RM With the time to tell? And how much telling it wants and the rest of it? (Yes) Usually, yes. Well, the ideal situation is that everybody knows what's going on. It has to be because sometimes it's a very subtle build up. You introduce more information slowly and if somebody comes in, and has only got to say a little thing wrong, it messes the whole thing up. So everybody has to know what's going on.

This account exemplifies a number of themes and issues reported by other nurses. Namely, the relative ease of interaction when the patient knew; honesty in communication with the dying; that discussion and communication with other unit staff was essential; that there could be no fixed way to inform patients of their terminal prognosis; the extended period of time over which such disclosure could take place; that disclosure was not a 'once and for all' event; and the belief that in some cases disclosure could lead to patients 'giving up'. There was an impressive amount of consensus about what should be done, but some variety in the nurses' accounts of the mode, ease, and timing of disclosure.

The normative prescription that one should be honest with the dying patient about their condition was perhaps most forcefully expressed by the third year student working on the unit although other nurses were equally explicit.

5:25 DF Did you have much to do in your training with people talking to you about nursing dying patients?

SU Oh yes, you're taught a lot at school how to go about looking after those patients, how to answer the difficult questions patients ask like 'Am I dying?'. That's very difficult for a nurse to tell them that they are. Generally a lot of nurses avoid that question, and don't answer them.

DF Do you find that happens in here?

SU No. Absolutely not here. I've been told the patient must know and should be told exactly what was happening, as must the relatives.

There was also agreement that everybody on the team should be kept

informed of the decision to tell the dying person of their prognosis, and that if doctors did not wish such information to be conveyed to the patient they had to tell - and convince - the nursing staff of this fact.

While there was a general consensus that honesty and openness with the dying was the policy which should be followed, there were a range of views about what one actually did. Indeed it was often difficult to elicit anything more than rather general descriptions.

5:26 EK (...) We sit and talk with them, and give them cups of tea, and make sure they understand that there's not a great deal of hope. That sort of thing.

5:27 EC You fear that some patients might ask you if they're going to die but they don't really want you to tell them. They want you to reassure them that they're not.

DF So what do you do?

EC Just answer their questions really as best you can without being too blunt.

One reason for the difficulty in specifying what one did was because, unlike George, there often wasn't a time at which a patient was 'told'. Several nurses stressed that communicating a terminal prognosis was something which occurred over time and as part of the continuing interaction and communication between nurse(s) and patient.

5:28 RN That's difficult to say because actually telling somebody that they've got a terminal prognosis - it never comes out in that sort of way. For a start people usually have a good idea already so it never presents itself in that stark form. People usually make it quite clear to you that they know already, and so you're merely confirming for them something that they've already sussed out. Or they make it quite clear to you that they don't want to talk about it and they won't let you (...) I'm conversing with people all day and the interchange of information is going on all the time. I'm never sitting down and giving them stark facts.

Clearly the high nurse-patient ratio allowed time for such gradual disclosure of prognosis and more nurse-patient contact than on ward 6.

Another difficulty was that there could be genuine clinical uncertainty about prognosis (hence, perhaps, the concern about premature disclosure leading to patients giving up). However, most nurses seemed reluctant to communicate terminal prognosis unambiguously to patients unless they were asked directly. Only three nurses recalled such an occurrence. Nurses felt that the terminally ill usually knew that they were dying whether they were told or not, but that not all of them wanted this fact confirmed (cf. McIntosh, 1970). Further, as we have already noted, several of them felt that in certain cases informing the patient of their terminality could lead to the patient 'giving up', and three nurses gave examples of such an occurrence.

The open plan of the unit, the fact that patients were generally awake and alert, and the ease with which sound carried from behind closed curtains, meant that it was virtually inevitable that other patients would realize that something was seriously wrong when there was a death on the unit. Thus another potential problem for the nurses was the impact of a death upon the other patients in the unit. This became particularly difficult if there were a number of deaths during a short period of time as in such a situation patients would become very anxious.

5:29 EC It's very difficult I think then to cope with the patients who are on the unit and have seen it all because they probably think they are going to be next. They've seen two or three people in the next beds dying, and they just think that everybody on the unit is going to die.

The ways of dealing with such disturbance and anxiety were basically to spend time talking with the patients, and to be honest with them about what had happened. Again some nurses indicated that they would only reveal the death to other patients if directly asked

about it, and some seemed more concerned with distracting the patients. The following nurse indicates some of these tactics.

5:30 RQ As far as possible we try to keep someone who is jolly and bright and happy on the unit and try and keep patients' minds off what is going on, wherever it might be going on. That I think is extremely important. But there again, I think it is also important to go around and discuss with the other patients what has happened and find out - get the 'vibes' if you like - what that patient feels. Patients normally talk when that situation arises. They talk a lot, and you find out more than you probably knew before. And if they don't talk, then they should be talked to. Because they know. But to be told they might see it in a different light.

DF So you don't try and hide it from them?

RQ I don't. no.

There emerges quite clearly from the nurses' accounts of their communication about death and dying with patients in the unit a tension between being open and revealing and the tempering of such behaviour in a number of ways. As we have seen a number of caveats were entered as to why such full and complete disclosure should be softened, modified, or delayed. This tension perhaps reflects the difference between the theory and the practice of nursing the dying on the unit.

EMOTIONAL INVOLVEMENT

One of the reasons which some of the nurses gave for enjoying their work on the unit was that it allowed them greater involvement with patients than was possible in other settings. With the high nurse: patient ratio and the system of patient allocation, the time spent with patients, even over the 24-48 hour length of stay which was typical, was sufficient for these nurses to become more involved with their patients than on a ward.

TABLE 5.4: THE INTER-RELATION AMONG CERTAIN ASPECTS OF NURSING THE DYING

NURSE	INVOLVED WITH DYING PATIENT	PROBLEMS FROM INVOLVEMENT	PREFERRED AWARENESS CONTEXT	APPEARED TO DISSIMULATE OR EVADE	QUICK DEATH EASY	PATIENTS DEATH HARD TO ACCEPT	REWARD FROM NURSING THE DYING
EC	No	Yes	Closed	(No)	No*	Yes	
EZ	No	No			(Yes)		
CY	No	Yes	Closed	Yes	Yes	(No)	
RM	No	No	(Open or Closed)	No	Yes*	(No)	
ET	Yes & No	Yes	Open	No	No	(No)	
EP	(No)	(No)	Open	Yes	Yes*	(No)	Yes
RQ	Yes & No	Yes	(Open)	No	Yes	Yes & No	Yes
EA	Yes	No			No	Yes	
ED	Yes	No	Open	No	No	(No)	Yes
EK	Yes	(No)		Yes			
EO	Yes	(Yes)	Open				
ES	(Yes)	Yes	Closed	Yes	(Yes)	Yes	
RF	Yes	No	Open	No		No	Yes
RJ	Yes	No	Open	No	No	No	
RN	Yes	No	Open	No	No	No	Yes
CR		(No)		(No)	Yes	No	
CG	Yes	No	Open	No	No	No	Yes
CV	Yes	No	Open	No	No	No	

Note: Statements in parentheses () indicate DF's inference based on interview material and observation and conversation on the unit.

5:31 DF What do you enjoy about it (working on a specialized unit)?

CG Involvement. You can get more involved when you have a higher staff/patient ratio as you get in specialized units, which you don't get on the general wards. You've got 30-odd people to look after, that's a lot to remember all the little bits about them, and bits about their family, and just to keep the conversation going. Whereas here it's quite easy really. You get patients you really know pretty much all there is to know - or what they want you to know, anyway.

The question of whether nurses became 'emotionally involved' with dying patients did not seem to affect other aspects of their work with the terminally ill in a consistent manner (Table 5.4). Perhaps one reason for this was the relatively short duration of contact which CCU nurses had with the dying, for even those dying from chronic heart failure were only on the unit for a matter of days or weeks as compared with weeks or months on ward 6. Another reason seems to lie in the nature of such involvement, which in most cases seemed to be contained and restricted to the duration of nursing work with the patient - a characteristic which does not seem peculiar to coronary care as it was also evident on ward 6. It is well stated by the following nurse reflecting on her experience on a geriatric ward prior to coming to the unit.

5:32 RJ ... because it's only short-term involvement. It's not like your mum or dad or somebody that you're going to remember the rest of your life. I mean I've probably got emotionally involved with patients that I couldn't tell you their names now. But while they were alive and I was looking after them I was emotionally involved with them. But now it doesn't bother me, it doesn't matter any more to me that they've died. They were more important to me when they were alive really.

As can be seen from Table 5.4 there was a positive association between becoming emotionally involved and a preference for the 'open awareness' context for nursing the dying, and between emotional involvement and gaining satisfaction or reward from such nursing work. These associations seem based upon the conflation of 'openness' with

acceptance by the patient of their death, at least by most nurses: open awareness and emotional involvement were satisfying because they were linked to the belief that aware patients were likely to accept their deaths and die with dignity.

5:33 RF (...) some deaths are quite pleasant really. You know people who accept that they're going to die and get themselves sorted out and are ready to go. It wasn't so bad. (...) you do talk as you are nursing them because they can do less and less for themselves, so your basic nursing comes in, which is nice because that's what you're trained to do. The actual basic thing, looking after people.

This extract also shows the other main reward from nursing the dying: that it gave the nurse the chance to provide 'basic nursing care' which they saw as an important aspect of their role. In CCU's the majority of nursing work is of a specialized and technical nature. Dying patients provided an opportunity for nurses to exercise other more fundamental nursing skills.

DEALING WITH RELATIVES

Nurses on the unit reported that dealing with the relatives of dying patients was difficult. This was a unanimous view, and most nurses identified the task of telling the relatives of the patient's death or terminal prognosis as one of the hardest, if not the hardest, aspect of nursing the terminally ill. Dealing with the relatives was invariably seen as harder than nursing the dying as the following short extracts show.

5:34 DF What do you find particularly hard about nursing dying patients?

EA Well it's not so much the dying patients really. It's the relatives. Trying to cope with the relatives mainly.

5:35 CY The worst thing is telling the patient. Well even worse than that is telling relatives actually - It is a difficult distressing thing.

5:36 RN It's people's relatives that give me the hardest time emotionally. It's the most devastating blow that anybody can

receive and you've got to inflict it on somebody.

TABLE 5.5: DEALING WITH RELATIVES

<u>Topic</u>	<u>Cause of Death</u>	
	<u>Heart Attack</u>	<u>Heart Failure</u>
Breaking the news	+	-
Relatives' acceptance of death	+	-
Comforting the relative	+	-
Key: + Harder to accomplish - Easier to accomplish		

Both types of death ('quick' and 'slow') posed difficulties for nurses in their dealings with patients. The problems they identified concerned breaking the news to relatives, acceptance by relatives, and comforting and supporting them. As can be seen from table 5.5 all of these were generally felt to be harder where patients had died suddenly from an infarction.

5:37 EP I think it's harder on the relatives when it is a sudden death. A long term thing (...) she can get used to the fact that he's going to die because he's likely to be hospitalized, and she can learn to live without him bit by bit and slowly but surely (...) it's easier for them to handle because they half know, they half expect the patient to die. Whereas with a sudden death it must come as much more of a blow to the relatives and therefore it's not as easy to tell them. It's easier to say to a person 'I'm sorry but he has just died' and they'll probably say 'Yes, I knew he was going to. We all expected it and he knew too', and therefore a lot of pressure is instantly relieved. It's all out in the open. Everybody knows. Whereas with a guy who has just died from fatal arrhythmia, to say to somebody 'I'm sorry he just died'...(trails off).

There was some division of labour between doctors and nurses about telling relatives the bad news, for although this was formally the province of the doctors it was often agreed that because of their greater contact with them, the nurses were more appropriate persons to break the news of terminal prognosis or death to relatives of patients

in chronic heart failure. Conversely, doctors were more likely to inform relatives when a patient died immediately after admission to the unit.

5:38 RQ If the patient's come on like that then I tend to be more involved in the patient and I rarely come in contact with the relatives. You know, always seem to be in the ward rather than discussing with relatives. The doctors have more rapport with relatives then because they want to know what happened; what caused the admission; what precipitated it. And they are the better people to have a talk with the relatives after.

DF Do you see more of the relatives in the long term situation?

RQ Uh huh (agrees). You really build up a relationship with them (...). I think the doctors are involved but they're more the outsiders because they don't know the relatives on a personal basis that we can judge the relatives. Sometimes it is far better for us to tell the relatives about the patient dying than the doctors because the doctors can be too clinical, dramatic, about it. And sometimes they forget that the relative is as much an individual as the patient they've been fighting for.

This division of labour was by no means strictly adhered to. For example, nurses would often have to telephone relatives at home to inform them of the patient's arrest or sudden death - a task they found hard to do. While the rapidity and unexpectedness (for the relative) of death as a result of a heart attack made it difficult to 'break the news' to relatives, when patients were dying from chronic heart failure this task became comparatively easier to do. Whatever the situation, it seemed that dealing with the relatives of the dying was potentially fraught. Patients were either unaware of their impending death (heart attack) or likely to recognize and hopefully come to accept it (heart failure). However, (as on ward 6) relatives were reported as much less likely to accept terminality than were patients. As with the patients, the general policy in dealing with relatives was to be open and honest in communication with them so as to keep them informed and prepared for the worst.

5:39 ED (...) we try to put our emphasis on the relatives. We always make sure that they know as much as the patients (...) it helps make them - patients and relatives - feel at ease, that they all know what's happening and that the nurses aren't keeping

anything from them. It all helps to promote this more relaxed atmosphere and promotes trust in the nurses.

DF Do you ever withhold information?

ED Not really I don't think. Sometimes over the telephone it's a bit hard to explain things, so you probably wait until they come in. You might say 'Well he didn't have a fantastic night' and explain things a bit better when they come in. But if somebody's very seriously ill you certainly say 'His condition's deteriorated quite rapidly' or whatever. You don't hold those sorts of things back.

The main difficulty for the nurses in their dealings with the relatives of the terminally ill was that while the nurses could assure themselves that they had done something to relieve the patient's pain and suffering, and perhaps even help them to a peaceful death. With the relatives such rewards were largely absent, and at the end, there was little or nothing the nurse could offer.

5:40 CR Usually you don't have to say anything, they can see it written on your face. And that's the harrowing bit, when people burst into tears (inaudible) and there's damn all you can do except give them a little bit of comfort.

SUMMARY

Nursing the terminally ill on a coronary care unit initially appears to be stressful and difficult because such a unit has been established in order to prevent death. Thus, one might assume that any death could be viewed as a failure of the unit, and would therefore pose problems for the staff. On the unit studied this certainly was not the case. What problems there were in relation to nursing the dying related primarily to those patients suffering long term chronic heart failure. These problems clustered around disclosure to, awareness of, and communication with the dying and their relatives. In particular they seemed to focus around the dilemma of translating what one should do into what one actually did. Even the most experienced of the nursing staff expressed this dilemma. Opening up awareness, no

matter how desirable the nurses viewed it, poses its own problems of management, just as maintaining a context of closed awareness does.

NOTE

1. Since the time of DF's study there has been a change in the admissions policy and criteria so that GP's now have to justify their admission of elderly patients to the unit rather than, as previously, having the right of automatic referral to the unit.

On 'feeding back' the draft of this chapter to the nurses this section was criticized by them as presenting them in a falsely uncaring light. This was not my intention.

CHAPTER 6: 'I NEVER INTERFERE WITH WHAT THEY WANT': NURSING THE TERMINALLY ILL AT HOME

In England and Wales in 1984 26% of all deaths occurred in the deceased's own home (OPCS, 1986). Most people who die at home will have been admitted to hospital at least once during the last year of their life. For example, 74% of those in the Bowling and Cartwright study spent some time in hospital during their last year of life. Despite this, and despite the fact that most deaths occur in hospital, a large amount of terminal care takes place in the patients own home (Bowling & Cartwright, 1982: 20). The care of the terminally ill in the community is therefore a topic of serious concern, and Wilkes' (1965) comment that "the district nursing service is essential to these patients" remains as valid now as it was in 1965.

This chapter is based on interviews with fourteen nurses attending a course at the local school of nursing in order to obtain the Certificate in District Nursing. Eight of the nurses were already working as community nurses prior to attending the course, most of them as night nurses (6). The remaining nurses had previously worked in hospital settings with the exception of the family planning nurse (details appear in table 2.1). The interview data is supplemented by information obtained from an open-ended questionnaire on 'Nursing the terminally ill at home' which was administered four months prior to the commencement of interviewing (Appendix). Five of the nurses interviewed had not at that time had any such experience and so did not complete the questionnaire, although by the time of interview all nurses had nursed at least two terminally ill patients in the home (in no case was there a contradiction between a nurse's interview and

questionnaire response). Given the disparate and unrepresentative nature of the group no claim is made to portray a valid picture of community nursing of the terminally ill. Rather, the aim of the chapter is to illuminate the nursing of such patients in hospital by drawing out similarities and differences between the two settings.

DIFFERENCES BETWEEN HOSPITAL AND COMMUNITY NURSING

The main differences between community and hospital nursing relate to the nature of place and territoriality in the two settings; the central role of relatives in the home; the isolation of the community nurse from a group of colleagues; the nature of nursing work; and the relationships between nurses, doctors, and clients.

The most obvious and central difference is the setting within which nursing work takes place, since where interaction between health care workers and their clients takes place has implications for the nature and control of such encounters. The 'active practitioner-passive client' relationship identified by Szasz and Hollender (1956) is typical of encounters between nurses and patients and their relatives in hospital settings. It is much less likely to occur in the home where the relationships between nurses and patients and their relatives are likely to be more equal. To use Szasz and Hollender's term, relationships are likely to be, or become, those of 'mutual cooperation', especially between a nurse and the relative(s) she relies upon to maintain patient care programmes.

Quite clearly it is very different for nurses, patients, and their relatives to be nursed at home, with a different pattern of benefits, problems, and costs to be found in the home from those found in

hospitals (Hinton, 1979). In the clinical setting of the hospital patients are dependent on nursing staff for their everyday care as well as for their specialist nursing care. Both patients and relatives are part of a much larger group of patients and visitors with whom the nurses have to deal within the constraints of organizational routines and competing demands. In their own homes patients, and especially their relatives, have much greater control over their lives and are dealing with an individual nurse on a one-to-one basis and on familiar territory.

6:1 RW (At home) they're much more in control of how they run their lives. You have to negotiate with them how they want to do it; in hospital it's the other way around. You could almost set down a procedure for it in hospital whereas in the home you play it by ear.

It is unsurprising, then, that relatives were reported by the nurses to be more relaxed and assertive in their own homes than in hospital settings.

While in both settings the nurse's role is concerned with and constrained by the requirements of the patient and the instructions of the doctor, in the community nurses typically work on their own rather than as a member of a group of nurses working together. Community nurses are both more isolated from their fellow health professionals and have potentially more autonomy and control over their work than hospital nurses. One consequence of this is that it makes them more vulnerable and sensitive to the demands and wishes of patients and relatives, some of which may run counter to their professional beliefs and preferred actions. As one nurse put it:

6:2 CL We have a unique role because we're almost a member of the family (...) It's the uniform and the role that's got you into that so therefore one wouldn't want to abuse that. I'm aware that it's a special position.

The nurse's relationship to the supervising physician, who is

unlikely to see his patients on a daily basis, is also different partly because of their less frequent contact with each other. Nurses usually have more intimate and detailed knowledge of their patients and their relatives and their problems than the physician, although it is the latter who has the authority to control the use of analgesics and other drugs and to disclose or withhold a terminal prognosis. Nurses reported difficulties with G.P.s in both of these areas and indicated that they wished that they had a greater capacity for decision making about these matters.

6:3 CT We're just told what to give and obviously we give that amount. If the doctor is understanding he will say 'use your own discretion' but obviously you can only go so far otherwise you're breaking the law. I think we ought to be able to make more decisions. We have our own patients and we know their needs.

When difficulties are encountered in relation to nursing the terminally ill the community nurses interviewed could not, as was the case with those on Ward 6 or the CCU, rely on the help and support of a like-minded group of colleagues in the immediate work environment. While such support could be forthcoming when the nurse returned to their 'home base' at the health centre it was by no means guaranteed. Nurses indicated that they did not receive much support from the older and more experienced district nurses who would not discuss the topic with them.

6:4 RS Where I've been working at the moment I get quite a lot of support, but it just depends who is on duty. The younger nurses tend to be more aware of the problem whereas the older nurses tend to have the older ideas that you don't discuss it and that the patient or the family doesn't want to discuss it in any event, and isn't it the doctor's job anyway?

In any case, as one nurse remarked, discussing problems associated with the care of the dying with one's colleagues during the short time that they were all together was more likely to depress everyone than anything else: "By the time you've finished everyone goes out with a

long face" (CQ).

Another difference relates to the type of patient being nursed in the community. These are typically elderly people with relatively stable long term chronic conditions, although for community night nurses a substantial proportion of their case loads are terminally ill (two of these nurses reported that they had each nursed well over 300 terminally ill patients during their community nursing career). The community nurses interviewed perceived distinct differences between their nursing of the chronically ill (the bulk of their work) and of the terminally ill. While for the former their aims were directed towards rehabilitation and enhancing the quality of life, for the latter relief of pain and psychological support for the relative were their central concerns.

The rhythm of nursing work in the community is very different to that found in hospitals, being ordered not only by the nature of nursing work but also by the need to travel from one home to the next. This could cause problems for the nursing of dying patients by imposing constraints on the time which nurses could spend with them and their relatives.

6:5 CU I find it harder as a night nurse - we cover a very big area in Market Town, about a 15 mile radius of the town - so we're getting everybody's terminal patients on. Some nights you can have as many as five four- or six-hourly diomorphs or pepedins or whatever. Now I find that more difficult because you know you have to clock watch; that they're all due say between 10 and 12, and if you've got one in Hamlet and one in Riverside (25 miles apart DF) you haven't the time.

Some of Bowling and Cartwright's respondents reported that the nursing care their dying spouse received "was inadequate because it was hurried or infrequent" (p 35).

Community day nurses seemed to have more flexibility in organizing their work than community night staff, probably due to a greater number of 'routine' chronic cases and fewer terminally ill patients on their lists. The following nurse, who came to the course directly from a general medical ward, commented on this and went on to say:

6:6 RH Nurses on the ward never had enough time. There were the ward routines to get through and other types of patients to consider, and if you were seen sitting on a bed that was considered as you were skiving out of your duties ... On the district you are the person who talks to the patient and they respect you talking to them almost as much as doing the general duties for them. They know that they can ask you if they know that you've got the time to talk to them. Some are bothered in case you haven't got the time but they'll always just sit down and try first. You know, start bringing up some conversation and then it'll start to pour out, and they really like you to just sit down and just have a chat.

A final area of difference to comment upon is the way in which the nursing process was used and regarded by community nurses. On Ward 6 and the CCU nursing work was organized through the use of the nursing process, which was valued and generally thought to work. However, acceptance of the nursing process by community nurses was reported to be unenthusiastic, and there were perceived inadequacies in the use of this method of organizing nursing work in the community. The nurses interviewed felt that the nursing process was a superior way of organizing nursing work "if it's used properly" because it was seen to provide a clear plan of action to be followed with regard to each problem - clinical, psychological and social. However, there was general agreement among them that there was resistance to its use by some of the older district nurses who perceived the introduction of the nursing process as a challenge to their professional competence. Further, the process was not used at all by night staff.

6:7 RV It's only we who are doing the course and our practical nurse teachers who are using the process properly and setting out our problems and our goals. The others are just writing it down. They don't understand the true use of it. They think that there's a lot of writing (...) and some of them think it's a waste of time. I don't because I can see the plans working.

It was not merely resistance by conservative nurses to new methods and ideas which accounted for the failure to implement the nursing process. Lack of staff numbers made it difficult to maintain the record keeping, and as the notes were left in the home where patients and relatives could read them nurses felt they had to be very careful in what they wrote. With particular reference to the dying, it was reported that it could be hard to specify in writing what needed to be communicated to other community nurses. These points are illustrated by the following two extracts.

6:8 RZ The nursing process is supposed to be used in the community (but) it's not being used, which leads to disorganization. You go into a house and nobody knows exactly what care to give and what's been given and who's giving it and who's directly responsible, whereas in the hospital situation you've got very clearly defined rules. You all know what everybody else is doing.

DF Do you think that if it was used the nursing process is a better method of nursing?

RV Yes I do. Providing you've got the number of staff then it's a super way of doing it. But it falls down badly when there isn't the staff to implement it because then it becomes a problem to get all your paper work done as well as look after the patients.

6:9 CU I do think it does help but I don't think you can write everything down, and certainly you couldn't write everything down in a house with a terminal patient. You couldn't write down 'Well I think that she needs us to this because of this that and the other'. I think a lot of the things that they actually tell you are the kind of unwritten things, and if you try and write down unwritten things they don't read the same ... you can't make sense of it the way you want it to read, and when it's such a delicate thing as terminal care what they've said to you is very difficult to write down so that somebody can.

The net product of these differences between community and hospital nursing seemed to be that the district nurse group experienced their work as more fragmented and isolated than the hospital nurses interviewed. Consistency of care provided in the community was seen by a number of them to be problematic, and their relationship with other

district nurses and physicians varied much more widely than those of the hospital nurses. Their nursing work also appeared to be characterized, at least along some important dimensions, by higher levels of uncertainty.

TABLE 6.1 NURSES' RESPONSES TO SELECTED ASPECTS OF NURSING THE TERMINALLY ILL AT HOME

Aspects of Dying	
Young terminally ill harder (13)	10
No difference between dying & other patients (14)	3
Patients usually know they are dying (14)	12
Pain control a problem	11
Awareness Preferences	
Open awareness preferred	10
No preference	3
Emotional Involvement	
Involved with dying patients	10
Problems from involvement	5
Involvement rewarding	9
Communication	
Problematic with dying patients	5
Problematic with relatives (13)	4
Disclosure not part of role (13)	11
Support service for nurses needed	8

n = 14

The number referring to each topic is indicated parenthetically () where it is greater than those concurring with the statement.

NURSING THE DYING AT HOME

Having looked at the general differences between community and hospital nursing we shall now focus on nursing the dying at home. Table 6:1 presents the nurses' responses to various features of nursing the terminally ill as reported in the interviews and questionnaires and shows the similarities and differences between this group and the hospital nurses. They are similar to the other two groups studied in their view that younger dying patients present

greater psychological difficulties for them than older dying patients; in their expressed preference for 'open awareness'; and in their propensity to become involved with the dying and to receive satisfaction from nursing them. Like the hospital nurses they also believe that the terminally ill usually know that they are dying even if they have not been made directly aware of their prognosis. However, this opinion is coupled with the belief that it is not part of their role to inform dying patients of their terminality, a task which is seen as falling within the province of the physician. This group of nurses also differs from hospital nurses in their emphasis on the importance of pain control; their consensus that the terminally ill are different from other patients to nurse; and their greater ease in dealing with relatives.

Both experienced community nurses and those entering the course directly from hospital work were agreed as to the differences between nursing the terminally ill at home and nursing them in hospital. We have already noted that they felt that they should not presume upon their special status as visitors to the home, and that they perceived and allowed greater control to relatives of the terminally ill than it was possible for the relatives to exert in the hospital. Nurses were, after all, dependent on the continued help and cooperation of the relatives in their nursing work. They were thus careful not to upset relatives nor to go against their wishes about the care of the dying.

6:10 CE I don't think that nurses who look after the terminally ill at home have any priority or prerogative of care. I think that that should be the relative's decision and I never interfere with what they want. If I go to somebody who is dying who's unconscious, if the relatives don't want me to touch them I never do. For instance, they don't always want you to turn them over and I don't always turn them over. (...)

Another commonly reported difference was that the relatives of the

terminally ill were more comfortable and relaxed at home than at the hospital. This may explain the greater ease which the nurses reported about their dealings with the relatives (of the four nurses reporting that they found relatives hard to cope with two were directly from hospital nursing). Caring for the dying at home, it was felt, allowed relatives to concern themselves only with the impending death without any additional complicating factors.

6:11 OO (...) because people haven't got two sorts of things to come to terms with. They've not got to come into the institution and be 'proper', and then cope with their relatives amongst a lot of others. Those things have gone. They do have to cope with the fact that someone is dying, but they can probably do it much easier in their own environment.

This does not mean that relatives and nurses had no problems. For the nurse recurring problems were that many relatives would not accept the impending death or would not allow the dying person to be told that they were dying. In these situations especially psychological support and counselling were seen to be important aspects of the nurse's role. Indeed, apart from pain control, support of the relative was mentioned most frequently as an important part of their role in relation to nursing the terminally ill.

6:12 DF What do you see as being the role of the District Nurse in the care of the dying?

CI Supportive role mainly. Ensuring that the patient is comfortable and has a dignified death at home. I think being there for patients to be able to talk to and relatives to talk to. To know there's someone professional coming in every day or every other day that they can unburden their minds to if they want.

Another difference which seems to relate to the differences between hospital and community practices was the great emphasis placed by the community nurse group on pain control. This aspect was mentioned relatively infrequently by the hospital nurses, and rarely as being problematic. In the ward and CCU pain control was 'taken as read': it

was something which occurred routinely, automatically, and without difficulty except in exceptional cases. For the community nurse, by contrast, pain control was often a central problem which they often had to argue about with the G.P. in that "often analgesia is not well enough considered or prescribed at home" (RS). Other studies also report pain control as an area of deficit for those dying at home (Bowling & Carwright, 1982; Cartwright et al, 1973; Doyle, 1979; Hinton, 1963, 1979; Lamerton, 1976; Twycross, 1978; Ward, 1974; Wilkes, 1965, 1984).

A final area of difference which seems related to the differing contexts of home and hospital is the nurses' perceptions of the dying. Whereas at least some of the hospital nurses, and particularly those on ward 6, affirmed that there was no essential difference between nursing terminally ill and other types of patients, none of this group of nurses made this claim. The reason for this may be that the contrast between terminally ill patients and chronic patients with relatively stable conditions is much greater than the contrast between the dying and other patients on a general medical ward, or even on a coronary care unit.

6:13 00 The majority of your work apart from the dying is the chronic long term disabled in which case it's really a matter of providing aids and/or nursing care. But they're very static and usually you can put a large input in, decrease it, and then sort of have a maintenance input which can be very minimal ... with the dying person you start off with a reasonably high input and that input becomes greater as time goes on. That input also changes ... with your chronic long term, or even your short ones, you're not looking at the psychological thing so much. You are looking more at physical adaptations for the home, say, or physical things which are easy to obtain and for which the majority of the resources are geared. You've got plenty of resources and help groups and equipment available, and you can have them on and off your books in a relatively short space of time. But with the dying patient very often you're not sure how long the terminal phase is going to last (... and) all that time it requires a much higher input and you've got to sustain that input at level throughout, which is much more difficult.

AWARENESS, COMMUNICATION AND THE NURSE'S ROLE

The community nurses interviewed presented a picture of interactional and communication patterns with the terminally ill in their own homes which was quite different from that reported by the hospital nurses interviewed by DF. In many ways these patterns were similar to those found on ward 6, but with the relatives of the terminally ill (rather than the doctors) acting as the most powerful agents constraining the development of an open awareness context with the dying patient.

The nurses preferred to nurse terminally ill patients who knew that they were dying, (the three nurses who expressed no 'awareness preference' also noted that that it was usually easier to nurse a person who was aware of their terminality). However, by contrast to the two groups of hospital nurses interviewed this preference was hedged around with a greater number of provisos and qualifiers. The ideal situation is expressed by the following two experienced community nurses.

6:14 CU It doesn't really make any difference to me. I think perhaps it (open awareness) is easier because you're there for a longer time they'll talk about things. And the things people have spoken about when you're there for four hours are obviously completely different to what they're going to talk about if you're in for just half an hour.

6:15 DF Is it easier to nurse a patient who knows than one who doesn't?

RW Much easier. Because you don't have to be so guarded in what you're saying all the time. You can make suggestions and talk about things with a purpose rather than hedge all the time because the relatives said they didn't want them to know - you're not exactly sure what they do know and what they don't in those circumstances. Whereas if they're aware they're dying you can find out exactly what they know.

DF You said that the relative may not want the patient to know, do you come across that very often?

RW Initially yes, but as the stage progresses usually the patients become aware that they're not improving and that the condition is deteriorating, and then you usually say to the relatives 'Look, they are aware of what's going on' and things usually come into the open at that stage. Not always right at the beginning.

More typical accounts of what usually occurred are the following statements, both from nurses who did not see it as part of their role to disclose terminality.

6:16 CE Some are told too late. For instance this chap of 40 last year. He was dying for a long time but he went into hospital and they didn't tell him he was dying in hospital. He wasn't getting any better and his G.P. told him, but too late (...) he died very angry. It was dreadful for him and for his family.(...)
That's hard (if they suspect) because they ask questions in a certain way so that you don't give them a truthful answer. They would never say 'Am I dying?'. They always say 'I am going to get better aren't I?'

DF What do you say?

CE I say 'What has the doctor said?' often in that situation, but sometimes I say 'Yes'. I mean people look at you so desperately. They so desperately want you to say yes, and they know that they're dying but they don't want you to tell them. And often relatives don't want you to tell them that their loved ones are dying. They know but they just don't want you to.

6:17 RS I've been dealing with one particular patient for quite a time now and it's really been a horrible situation because she knows full well what's wrong with her and doesn't want - does want - I don't know: for a long time she wouldn't discuss things at all ... you couldn't ask if the lump in her breast hurt her because she'd just say 'Don't talk about it. I know it's there. I don't want to discuss it'. So for a long time it was rather difficult discussing anything; all conversations seemed to be leading down the same road and they'd have to stop. I was rather anxious that I was going to go one step too far one day (...) This particular day she just said that she knew there was no future for her and she was finding it very difficult to cope with. She'd always been in control of her life and it was horrible not to be in control anymore. If there was something she could do she'd be happy to do it. And she said she was continually finding herself involved with happy-go-lucky conversations with people talking about things which didn't matter. She was embarrassed because she felt people must realize she wasn't really bothered. She had one thought going round in her mind and that was all she could think about and she was obsessed with it. And yet she still didn't mention that the thought was that she was dying.

The central element shaping the difficulties which the community nurses had in attaining a situation of open awareness with their dying patients was that they met the relatives of the dying on a one-to-one basis as a visitor to their homes. Several nurses reported that relatives generally did not wish the terminally ill to know that they were dying - a similar situation to that reported by the hospital nurses. Given the generally long duration of such nursing contact and the necessity for the nurse to have the active support of the main carer in the home it would be difficult, and possibly inadvisable, to inform the dying of their prognosis when the relative did not wish them to know.

6:18 DF Did you find relatives were resistant to people getting to know?

CL In my cases yes. Two of them didn't want their wives to know, I think mainly because they couldn't cope with it. It was obvious that their relationship was such that it would be a bit too hard for them.

DF What were your inclinations in those situations?

CL I would accept that. I don't think you should go in and cause great catharsis everywhere (...)

DF So basically your attitude is that you will go with the relatives wishes?

CL Yes I think so. If I'd known the family a long time and I'd been going in for a long time and I suspected - and the G.P. was aware - that may be it would be better to say yes then I would favour it (disclosure).

For the nurse who wished to lead a dying patient to awareness of their condition there was often another important constraint. It was often hard to call upon a doctor to provide high status 'medical legitimation' for such action, particularly as many (but by no means all) G.P.s were reported not to approve of telling such patients their prognosis. Whereas in the two hospital settings reported in chapters 4 and 5 the doctors allowed nurses to exercise their judgement in

disclosing to patients their terminality or in leading them to awareness, in the community many G.P.s not only did not allow this but actively discouraged it. From the nurses accounts it is evident that this caused difficulty for them in their work with the terminally ill. (For reports on the attitudes and problems of G.P.s with respect to community care of the terminally ill see Bowling & Cartwright, 1982; Rosser & Maquire, 1982; Still & Todd, 1984; Wilkes, 1965.)

It was not merely the attitudes of G.P.s but also those of the older, more conservative, district nurses which caused frustration for the younger nurses in their practical placements.

6:20 RB I have mainly watched the District Sister I have been working with. However, my main problem is knowing just how much truth should be told. This has been influenced by my hospital experience, where the ward sister told most patients their prognosis. From what I have seen/heard on the district it seems that the truth is often avoided unless the patient has been told in hospital. (Questionnaire reply).

It seems, on the basis of this very restricted sample, and from limited contact with district nurses in other contexts, that a large proportion of practising community nurses do not see disclosure of their terminality to the dying patient as part of their job. This contrasts markedly with the situation found on CCU and ward 6 where most qualified nurses, especially those with greater nursing experience, saw this as part of their work. Thus, there was little peer support for community nurses who wished to 'open up' the awareness of dying patients forthcoming from their more experienced colleagues.

The nurses' own perceptions of their role were important. While the hospital nurses accepted that, even though they found such a task difficult, disclosure of terminality could be part of their role most community nurses clearly defined this task as outside their area of

responsibility. None of those who reported on this matter who had previously worked in the community said that they would inform a dying patient about their terminal prognosis (6), although one said that he might lead them to an awareness of their dying. This attitude was also found among the district nurses interviewed by Cartwright et al (1973). By contrast only one of those nurses who had come to the course directly from hospital work said that they would not disclose a terminal prognosis to patients, the others (5) saying that they would either disclose prognosis or lead the patient to awareness of it.

Although the reluctance of these community nurses to disclose a terminal prognosis to a patient is indisputable, it must be asked whether such reluctance was entirely a result of the structural constraints arising from the arrangements of their nursing work identified above. There may be an attitudinal component to this reluctance which is age related. Dividing the nurses into two age groups revealed that all of the nurses aged 29 or older (mean age = 34.25) said that telling the dying about their terminality was not their responsibility. Only one of these would do so "if the time was right". By contrast, only one nurse aged 28 or less (Mean age = 24.8) said that she would neither disclose nor lead the dying to awareness of their terminality. This exception was a nurse who had been working 'on the community' before entering the district nurse course.

While the older nurses did not see disclosure as part of their role some of them did express the view that they would like to be able to tell patients of their impending deaths if they thought it would be appropriate. The dilemma of this group is well caught by the 25 year old charge nurse who felt that he could not disclose terminality, but wished that he could do so. He had been talking to DF about two of

his patients who became suspicious because their overt conditions - fractured femur, arthritis of the spine - were not consistent with their increasing deterioration.

6:19 CO (..)So I'm constrained as to what I can talk to him in his medical condition. He knew he was incontinent because he couldn't control his bowels, and he knew he was getting a large pressure sore and he couldn't feel it. He was told it was arthritis and for a while he was happy to oblige with arthritis but as he deteriorated he couldn't see how arthritis could be the sole cause.

DF What did you do?

CO What I did in that situation was get the wife told and support the wife. As concerns the patient himself you go through a chronic dialogue: 'this is a chronic long term disease. It very often gets worse before it gets better. It's going to take months to get better if it does at all, but it's usually a gradual period of degeneration'. So you're sort of spelling a gloomy picture for them without actually telling them the true diagnosis.

DF Are you trying to lead that man to the realization that he's probably dying?

CO Not purposely, but I think he knows.

DF What would you like to do?

CO I would like to tell the patient. I would like to have the authority to be able to say 'Yes, you've got such and such, let's talk about it'. It's not always possible ... I went to the G.P. and I went to the hospital and I went to the wife and the daughter and the son and I couldn't get one of them to tell him, and the G.P. just wouldn't talk.

DF If you'd been in the position where legally you could have told him would you have done that?

CO Yes.

DF Even though all these other people didn't want you to?

CO Yes. I was extremely tempted to anyway. Really I suppose it came back down to when I was on my general training it was accepted that nurses did not, and it was only doctors that told patients. So in the end that was the one factor which over-rid everything else. I'd very much have liked to have done.

The net result of the features discussed in this section was that nurses most usually conceded to the pressures from relatives and G.P.s to attempt to maintain a situation of 'closed awareness', with all the

problems which that entails.

CONCLUDING COMMENTS

This chapter has focussed primarily upon the differences between nursing dying patients in their own homes and nursing dying patients in a hospital setting. As individuals the main differences between the community nurses and the qualified hospital nurses interviewed for this study is that the former are more reluctant to communicate a terminal prognosis to patients. Although this may be partly a function of age related attitudes (they are older than the hospital nurses as can be seen in Table 2.2), it is suggested that other factors are more important in inhibiting the translation of their expressed preference for an open awareness context with the dying into actuality. These factors are the relative isolation of the nurse from a group of peers who would support him or her in their work with the dying; lack of support from G.P.s to disclose terminality; and their dependence on relatives for the success of their work.

Before closing this chapter it should be noted the discussion has been about the placing of emphases and not about absolute statements of factual differences in practice between community and hospital nurses. In their interviews the experienced community nurses would both emphatically deny that they would consider disclosing terminality unless it was cleared by the G.P. or relative and also recount cases where they had led patients to awareness of their dying and/or acted as intermediaries between patients who knew they were dying and relatives who did not wish them to be told that they were. They also reported evasion of questions, and difficult situations stemming from their inability and unwillingness to disclose terminality. It is

perhaps unsurprising that when this group of nurses were asked whether they saw any need for a 'support service' for nurses who nursed the terminally ill they replied more affirmatively than the nurses on the coronary care unit.

PART III: DISCUSSION

"For better or worse the human condition is a condition of imperfect communication, and we solve our problems in society as best we can through recalcitrant and mystifying symbols that cause the problems we must solve if we are to act together at all."

H. D. Duncan, Introduction to K. Burke, PERMANENCE AND CHANGE

7: THE ORGANIZATION OF NURSING WORK AND NURSING THE DYING

This chapter draws together the themes running through the preceding accounts of nursing the dying and attempts to specify the features of nursing work which best facilitate an open awareness context for nursing the dying. In chapter two the main concern of this work was identified as "to specify the nature, shape, and influence of 'structural features' of nursing work as they impinge upon nursing the dying, and to attempt the specification of their influence upon nurses' experiences and interpretations" (p.27). Another question which emerged was "what structural features support and enhance or, alternatively, restrict and constrain such openness?". The main features bearing on the nursing of the dying, at least as they have emerged from the present study, are shown in Diagram 7.1. A subsidiary question which was posed in chapter two was "what were the resources which nurses brought with them which influenced their work with the dying?". Before considering these questions it will be useful to summarize briefly the findings of Part II.

In chapter three the salient findings were that the hierarchical organization of nursing work in the acute surgical ward meant that care of the dying fell largely to young, inexperienced, and untrained nursing staff. These nurses received little support from more senior staff in their care of the dying, and were not allowed to disclose terminal prognosis to their patients. To cope with the problems of nursing the dying these nurses used a variety of strategies to limit or avoid contact with the dying, and were aided in such strategies by the system of task allocation which organized nursing work on the ward. Another consequence of task allocation was that nurses were

less likely to get to know patients well because of their limited contact with them, although this was less likely to apply for dying patients due to their longer length of stay on the ward. Nurses on ward 7 felt that they should not become over-involved with patients. Despite the attempt to maintain a situation of 'closed awareness' many dying patients discovered or suspected that they were dying, partly as a result of the poor communication between staff which meant that they were not receiving the same message about their condition from all staff caring for them.

In chapter four a very different situation was described. Care of the dying, as with other nursing work, was shared by all nurses. The ward functioned with an overt philosophy of individualized patient care, work was organized by allocation of patients to individual nurses, and the 'nursing process' was accepted as the basis for nursing work. Central to the ethos of the ward and to the care of the dying was the ward sister's leadership. When nursing the dying nurses reported that they preferred 'open awareness', but had difficulty in leading patients to such awareness. The ward sister played an important role here in 'opening up' awareness. Nurses also reported that they became emotionally involved with their dying patients, that they regarded this as unavoidable, and that such involvement could be a positive feature for them in nursing the dying. This different approach to, and experience of, nursing the dying seems to be directly connected to the differing organization of nursing work between wards 6 and 7.

The coronary care unit described in chapter five presents yet another situation. It was similar to ward 7 in the 'medico-technical' nature of its work, the short length of time which normal patients

stayed on the unit, and the age of patients. It was similar to ward 6 in its use of the nursing process, the wide definition of nursing care, and the individual allocation of patients to nurses within a context of supportive team work. It differed from both wards in its high nurse:patient ratio, the absence of training and unqualified nursing staff, the greatly extended role of the nursing staff, the absence of any separation between day and night staff, and its very variable pattern of work. Death on the unit was infrequent, and dying patients were regarded as different from other patients in important ways (contra ward 6). Possibly because of the clear cut nature of what could be achieved to avoid death, and their feeling that everything which could be done to save life had been tried, CCU nurses did not regard death as a 'failure' on their part. CCU nurses seemed to become less involved with the terminally ill than nurses on ward 6, and to view such involvement less positively. They did not, however, report the pattern of evasion and avoidance found on ward 7, but preferred openness and honesty in their communication with the dying and their relatives. There was a tension between their expressed preference for openness and its implementation, with a marked reluctance on the part of some nurses to initiate or lead patients to a situation of open awareness.

The final situation to be looked at was the nursing care of the dying in the community. The main difference between this setting and the hospital settings was, of course, that the dying were nursed in their own homes, and so the nurses were dependent upon relatives for help and cooperation in their nursing work. The bulk of their nursing work was with chronically ill people from whom the dying were seen to differ in the nature of the care they required. The nursing process was not in evidence as a tool for nursing care. Community nurses

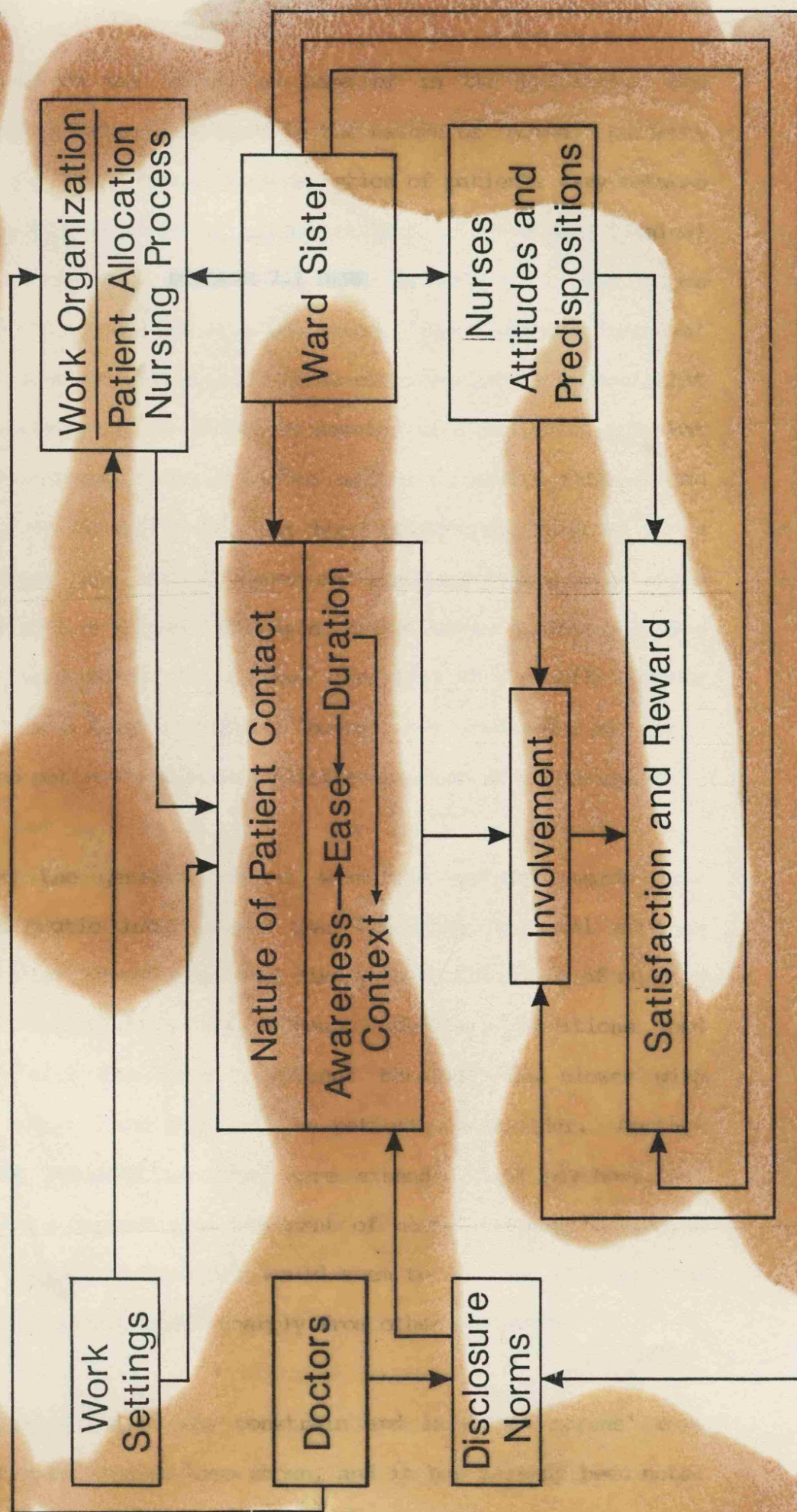
worked largely on their own, and with little support from others to 'open up' the awareness of the dying to their fate. Although they might believe that an open awareness context was preferable for their work with the dying they did not see the initiation of such awareness as part of their role. It seems that the autonomy of the community nurse was limited both by her reliance on relatives and by her difficulties with supervising G.P.s both of whom usually favoured a closed awareness context. There was a difference between older nurses and those entering district nursing work, with the former being more disposed towards disclosure of terminal prognosis and the use of the nursing process than the latter.

WORK SETTINGS

Some of the differences identified above can be simply attributed to differences in the settings within which nursing work took place. To specify precisely the grounds for such attribution can be, as the work of Strauss and his colleagues shows, very complex (Strauss et al, 1963, 1964; Strauss et al, 1985). It is important to do so, however, for many of the difficulties which nurses experience in their nursing care of the dying relate to the structural conditions of their work. What will be attempted in the rest of this chapter is the specification of this and the other elements identified in Diagram 7.1 as affecting the nursing of the dying in hospitals. Community nursing will be referred to in a less systematic manner, primarily by way of comparison and elucidation.

It has already been noted that where dying takes place is an important variable. For example, in chapter 6 it was noted that relationships with relatives of the dying seemed to be influenced by

Figure 7.1 The Organization of Nursing Work and Nursing the Dying



whether the patient was nursed at home or in the hospital. One important variable between settings is the nature of 'normal' patients in each setting. The disease characteristics of patients vary between the three hospital settings described in part II. On the surgical ward and CCU patients were young and acutely ill (sometimes chronically in CCU). Patient stay was short, 'recovery' and 'success' the norm, and turnover was rapid. These characteristics suggest that little involvement would be likely to develop with patients, and that the focus of nursing work would be medico-technical rather than psycho-social. In these settings the dying patient was an anomaly - a possible 'failure' who stayed longer and challenged the normal work routines. In such a context the dying could become problematic for nurses working with them. The chronic care load of generally elderly patients found on a district nurse's 'books' also produced a situation where the dying patient was markedly different from other patients.

By contrast the general medical ward was geared towards less intensive therapeutic intervention than the acute surgical ward or CCU. 'Recovery' or 'cure' were less likely to be the goals of nursing work, rather alleviation of chronic disease conditions and rehabilitation were the norm. Patient turnover was slower with concomitantly longer term stay and the patients were older. Contact with individual patients was thus more extended, and psycho-social aspects were more evidently a component of normal nursing work. In this setting the long term dying would seem to be less of a problem and were less likely to differ sharply from other patients.

Patient characteristics may constrain and influence nurses' role performance as many studies have shown, and it has already been noted that nurses find nursing young dying patients more difficult to cope

with emotionally than nursing elderly dying patients. Thus, the characteristics which are important are not simply those related to a narrow definition of disease, but also relate to social and psychological aspects. For example, whether a patient is alert, confused, or comatose clearly effects the type of communication that the nurse can have with them. Kelly's review clearly demonstrates the importance of patient characteristics such as age and personality which are not related to their disease condition (Kelly, 1982). Dramatic examples of how this may work in relation to the nursing of the dying are provided by Sudnow (1972) and by Strauss (1970).

Another relevant feature of work settings is the nature and level of staffing. The pace and intensity of work for nurses is not simply determined by patient characteristics, but is also greatly influenced by the number and training of nursing staff available to deliver such care. At its simplest this can be viewed in terms of the time which is available for nursing work. All of the settings studied seemed to be fairly well staffed, and so lack of labour was not a noticeable problem for them - a sharp contrast to the 'geriatric' settings upon which a number of interviewees had worked. However, the much higher nurse:patient ratio on CCU meant that these nurses normally had more time to spend with patients, with the consequence that they could pay more attention to psycho-social aspects of care, and did not feel 'swamped out' by more narrowly defined clinical tasks of physical care. On CCU, then, staffing levels clearly enabled more time to be spent communicating with the dying than on the other settings. On both wards around half of the nursing staff were untrained or training nurses whereas on CCU and the community they were virtually all qualified. On the wards there was inevitably a certain division of

labour as a result of these differences in skill levels while in the latter settings all nurses were eligible to perform skilled nursing work (although the division between 'first' and 'second' level nurses (UKCC, 1986) can be crucial). Where there are training nurses some conflict between 'training' and 'service' requirements is likely, and as was seen on ward 7 this may be directly consequential for the care of the dying.

The physical environment of the ward seems to be important also, for "The design or shape of the physical environment in which patients receive nursing care appears to influence both the amount of time and the kind of contact between nurse and patient; ..." (Walker, 1982: 408). Unfortunately the research methods used and, to a lesser extent, the study sites chosen in this work do not allow a direct assessment of this variable. Entry to hospital is a stressful event for patients, and the physical arrangement of wards and units may contribute to such stress (e.g. the reported comparison by a nurse of the CCU to 'Apollo control'). Unfamiliarity and stress may inhibit patients and relatives from seeking information or making demands of nursing staff, and this may become particularly problematic for the terminally ill if they are physically isolated in single rooms or side bays. In such cases their physical separation from the life of the ward or unit may become an important part of a process of 'social dying'.

It is argued below that regular contact with patients over a period of time leads to both greater ease in nurse-patient interaction with the dying and the greater likelihood of disclosure of terminality to them. The characteristics discussed above are important to our consideration of nursing the dying because of their influence upon the

nature of patient contact which is found in different work settings. However, equally important is the way in which nursing work is organized within settings. Two apparently identical work sites may provide very different terminal care as a result of the different ways in which their nursing (and other) work is organized.

WORK ORGANIZATION

The organization of nursing work within each setting is another important influence on nurse-patient contact (Alexander, 1984). The importance of work in this respect is well stated by James: "it is the 'work' of the unit which structures the ideals by which 'care' is practised. On the one hand 'work' consists partly of imposed events, tasks and routines which are to be accomplished, thereby fulfilling organizational needs, and on the other hand (it) is also subject to manipulation by the nurses. Since it is they who implement most of the 'work' - guided by ideals of 'care' - their interpretation of it and ways of carrying it out exercise a constant effect on ill-people through their relations with them." (1983:2).

Nursing work, like any other role behaviour cannot be specified in all its details by others but involves a certain element of 'role making' by the nurses themselves. The extent to which such role making is allowed or constrained by the nature of nursing work and its organization will vary from task to task and from setting to setting. In any setting there will be a number of work tasks which must be performed, e.g. giving injections and administering drugs, but the manner in which such tasks are performed may nevertheless vary quite markedly. Nursing work can be construed as doing things to patients, or as working with patients. Most nursing work in most settings

involves at least the potential for contact with patients on an interpersonal basis rather than simply relating to them as physical objects, hence the latter way of construing their work seems most appropriate, and is behind current definitions of good nursing practice in terms of individualized patient care (UKCC, 1986). It is true that some tasks, e.g. those involved in dealing with a heart attack, will be so demanding that there is little room for role making, and everything stops for their performance. At a less intense level the monitoring of machines may impose similar constraints. However, other tasks may be so routine that they can be 'fitted in' to ongoing nursing work quite easily, and these tasks will make up the bulk of nursing work in many settings.

Apart from the nature of the specific nursing tasks constraints may be placed upon individual role performance by a number of other factors. Two constraints upon nursing work which will be reviewed below are the attitudes and instructions of doctors, and the ways in which ward sisters perform their roles. The skill level of the nurse has already been mentioned as another constraint upon her action. This refers not only to the formal level of nursing skill (SEN, SRN and so on), but also to the nurse's confidence in her ability to perform specific tasks. For example, in part II it has been seen that nurses are not always confident in their ability to 'lead' dying patients to an awareness of their impending death.

The method whereby nursing work is organized is possibly the most important factor influencing the ways in which nurses perform their roles. "There is evidence that appropriate nursing ... is related to individualised rather than non-individualised nursing. A number of studies describe non-individualised nursing linked to the failure to

meet patients' needs." (Pembrey, 1980:9). It was the difference between nursing methods which seemed to contribute most to the differences in the nursing care of the dying between the surgical ward on one hand and the general medical ward and CCU on the other. The individualized system of patient allocation combined with the use of the nursing process on ward 6 and CCU meant that nurses could obtain the satisfaction accruing from seeing the direct effects of their nursing work, something which would be harder to do under the more traditional system of fragmented task allocation which was used on ward 7. In addition to such satisfaction one could speculate that feelings of autonomy and self-esteem were also enhanced, and that the pattern of work inescapably generated involvement with long term patients and reinforced caring dispositions which might erode under systems where fragmented nursing tasks order work organization (Charles-Edwards, 1983). With specific reference to the nursing of dying patients the combination of patient allocation with the nursing process meant that the nurse would find it difficult to avoid the patient because they were unambiguously the responsibility of individual nurses, rather than the general responsibility of all nurses. Thus the commonly reported pattern of withdrawal from the dying patient could not easily occur in ward 6 or CCU. Further, such 'enforced' contacts with the dying could lead to familiarity with death and an appreciation of the rewards which can be derived from terminal care nursing, and thus might lead to a breaking down of nurses' fear of death and dying. This latter consequence was reported by a few of the nurses.

Closely associated with and reinforcing these different methods of organizing individual nursing work were other organizational differences. Ward 7 was very hierarchical, and the care of the dying

was left to the untrained auxiliaries and first year trainee nurses; whereas ward 6 and CCU were 'egalitarian' and the care of the dying was shared by all nursing staff. While on ward 7 nurses caring for the dying received little support from other - more senior - nurses, on ward 6 and CCU the nurses supported and helped each other and the Sister or Senior Sister was always available to 'step in' to help any nurse who was experiencing problems. The importance for nursing the dying of a system of work organization which provides help and support for the nurse in such work has been seen in part II. For example, in chapter 6, community nurses were seen to have little support from colleagues and to report that they felt the need for such support.

A view commonly expressed in discussions about the routinization of hospital work is that such routinization, although largely inevitable, has negative consequences. However, it must not be assumed that routinization of nursing work is necessarily and inevitably undesirable. Work routines can be both restrictive and reassuring for nurses - and also for patients - by providing structure and certainty for them. The discussion in this chapter has been about those elements of work organization which allow role making and autonomy to nurses in their work performance, and has not looked at work routines. By focussing primarily upon the interpersonal 'care' dimension to the neglect of the more precisely defined 'work' dimension the positive functions of task specification and control have been largely ignored in this thesis.

The organization and performance of nursing work is clearly central to the consideration of nursing care of the dying. It is worth repeating the central difference between wards 6 and 7 in this respect: on ward 6 the organization of nursing work meant nurses could

not avoid their dying patients, on ward 6 it meant they could easily do so. James (1983, 1986), in her study of nursing work in a hospice makes the useful distinction between 'work' and 'care'. She notes the tensions created between the demands of work - defined in terms of finite and achievable nursing tasks - and the emphasis on 'patient-centred care' which was infinitely demanding and with no clear boundaries. Such a distinction has not been made in this work, and so these two aspects of nursing activity have been conflated in the analysis and discussion. Their separation seems analytically useful. The demands on the nurses stemming from their interpersonal care of the dying can be both stressful and demanding and therefore the fixed routines of doing physical nursing tasks, and especially comfort work, can be reassuring for nurses because they provide an important sense of visible achievement (Glaser & Strauss, 1965; James, 1986).

DOCTOR-NURSE RELATIONSHIPS

Doctors have not figured as central characters in this discussion of nursing the dying, although it has been quite evident that they were major actors in the dramas and routines which such work entailed. On ward 7 and for the community nurses they figured as inhibitors of the development of open awareness contexts in nursing the dying, whereas for the nurses on ward 6 and CCU they allowed nurses autonomy in the move to such a context for the care of the dying.

The central feature of relationships between doctors and nurses is that doctors control large areas of nursing work. They do this both directly through 'doctors orders' specifying clinically relevant nursing tasks associated with therapeutic intervention into and

management of disease processes, and indirectly through their general instructions about nursing work. Restrictions on the nature of nurses' communication with the dying are most likely to stem from the latter rather than the former type of control. Even where nurses exercise autonomy and responsibility for patient care it is likely to be of a limited nature, and within an ambit of activity embedded within and hedged around by clinical control (Moloney, 1986). Despite their numerically small numbers, senior hospital doctors exercise a great deal of control over nursing work, and nurses must negotiate the 'space' they require for the implementation of their work in the manner in which they wish to do it. Where they have a clearly defined and well established expertise, e.g. as in CCU, they are more likely to be able to shape their work to their own requirements than where their expertise is lower, e.g. as on wards 6 and 7. Continuity of doctor-nurse relationships over time is also likely to lead to the development of greater autonomy for nurses, as can be seen from the accounts of CCU and Ward 6 where nursing turnover was low.

The division of labour between doctors and nurses is clearly crucial to the relationship between them. As has already been indicated in chapter one this in important ways reflects and is reinforced by the general character of gender roles and relationships in our society. Nursing work is largely defined in terms of personal care of patients - working with people, whereas doctor work is largely defined in terms of clinical treatment and management - working on or in people. Nurses' work is, at least in principle, more all encompassing than doctors' work. The terminology of Strauss et al (1985) is useful to describe briefly these differing emphases. While nurses will perform discrete tasks associated with 'machine work' or 'safety work' assigned to them by doctors these tasks are often

embedded within ongoing 'comfort work' and 'sentimental work'. In particular, nurses are more likely to do the important 'articulation work' which relates the different areas of patient centered activity together. An example of such work is the pattern found on both ward 6 and CCU of a nurse 'dropping out' of the continuing ward round in order to explain to her patient what the doctors had said about them. The sentimental tasks are "intertwined with other types of work" and are an important component of the 'sentimental order' or ward climate, and contribute to the sense of satisfaction, worth and identity which nurses develop. The extent to which the nurses are constrained in their performance of such 'care work' (James, 1983, 1986) by doctors is important for their terminal care work.

The attitudes of doctors and nurse to their work and about their respective roles are also important. We have already seen that an important element influencing the community nurses' care of the dying was their belief that disclosure of a terminal diagnosis to their dying patients was not part of their role. Most doctors and nurses accept and believe that doctors should give orders to nurses and control their nursing activity in general. Most nurses are, it seems, still 'traditionalizers' who are willing to accept a passive role in patient care. The 'professionalizers' in nursing schools and the Royal College of Nurses must first convince practising nurses of the need for nurses to exercise greater autonomy and decision making before they can persuade doctors to concede this to them. The high levels of nursing autonomy found on ward 6 and CCU seem at least in part to be related to the very aggressive style of the Nursing Officer running the unit and the firm belief of the ward sister on ward 6 and of senior nursing staff on CCU that there was a legitimate and indisputable basis for them to control their nursing work in the way

which they as nurses thought best.

THE ROLE OF THE WARD SISTER AND WARD CLIMATE

Given the focus of interest of this study the role of the ward sister (or senior sister on CCU) was not targetted directly for investigation, although it became quite apparent that they were central to the nursing care which the dying received on both ward 6 and CCU. According to Mauksch (1966) the nurse performs a key coordinating function in hospitals by virtue of her position at the intersection of so many hospital activities and groups of other workers, and by her continuing contact with patients. The 'coordinator of coordinators' is unarguably the ward sister. It is the ward sister or charge nurse who has greatest contact with doctors in negotiating nursing work in relation to 'doctors orders' and who organizes and allocates work to nurses. S/he plays a key position in establishing and maintaining the 'sentimental order' or 'ward climate', as can be seen from the accounts of ward 6 and CCU, and as can be inferred from the account of ward 7.

Recent research into the role of the ward sister has mainly focussed upon ward learning climates, but there is agreement that 'good' learning climates are equally beneficial to patient care, and that the ward sister is "the person, above all, responsible for the climate of the ward" (Orton, 1981:62). Orton sums up such a climate as "a happy purposeful environment guided and regulated by a confident, considerate ward sister who led her staff and student within a team" (1981:45). Fretwell (1980) also emphasizes the key role of the sister in providing good communication and information, negotiation, and teamwork. From the literature it seems that such

'ideal' sisters or charge nurses and good ward climates are rare. Both ward 6 and CCU approximate these rare situations, and therefore it must be emphasized that the findings reported in this thesis are from unrepresentative settings. The account of ward 7 appears to provide a better approximation of the norm, as was suggested there.

What are the key components of ward climate which the sister or charge nurse so greatly determines? Orton (1981) identifies individual autonomy, the degree of structure imposed, rewards, and consideration, warmth and support, as the key variables and links these to leadership style. On ward 6 an 'employee-oriented' style enhanced individual autonomy within a well focussed and supportive structure. This allowed nurses to gain satisfaction and reward from their nursing work with patients, and to be confident that when they experienced problems, e.g. in nursing a dying patient, then more senior staff would be on hand to help them. The Sister's strong belief in the use of the nursing process was another important element in the ethos of nursing care found on the ward. A similar situation was found on CCU where the structuring of work was to a much larger extent shaped by the medico-technical tasks of patient care. The apparently very high level of nurse morale and satisfaction on these settings seemed to be directly related to these factors. By contrast morale - at least among junior nurses - was poor on ward 7, and this was directly linked to the 'climate' of the ward. Work here was fragmented, nurses were not supported by seniors, and satisfaction and reward seemed scarce.

The nursing care of the dying can be improved by general improvements in nursing standards which seem to be connected to the ways in which ward sisters and charge nurses perform their

coordinative role. The important principles of 'recognition of the patient as an individual' and 'good communication' are often more honoured in principle than in practice. The ward sister plays a key role in the implementation of these principles by her control over information and work organization. For example, Melia (1982) identifies lack of information from senior nurses and the organization of nursing on the wards as the sources of difficulty experienced by student nurses in communicating with patients.

The autonomy of nurses from the doctor is another aspect which is greatly influenced by the ward sister, for if they are deferential and meekly accepting of a medical definition of nursing work then other nurses can hardly act otherwise. Runciman found that the "inability to challenge medically sanctioned routine and policy, and the perception of doctors as more powerful than nurses" was one of the problems which ward sisters reported (1983:34). In her interview study "disagreeing with doctors' instructions" emerged as a problem, "the main areas of conflict concerned the care of the terminally ill ... and the care and (unnecessary) resuscitation of elderly patients" (1983:95). She also found that the sisters had difficulty in speaking out and expressing doubt to medical colleagues. It is significant that on ward 6 and CCU such reluctance to challenge and negotiate the proposed care of the dying were not evident.

DISCLOSURE NORMS

Disclosure norms establish predispositions towards action, and may also impose direct constraints upon nurses' behaviour as we have seen in chapters three and six. They are central to the differences between settings which are reported in this thesis. Indeed, it could

be argued that this factor is the single most important factor influencing how dying patients come to learn about their impending death. Such a view, however, must not obscure our appreciation of the complex interaction between the various elements in the organization of nursing work which affect the care of the dying. As Glaser and Strauss (1965, 1968) have discussed disclosure norms fully in the work upon which this thesis is based it is not necessary to do more than reiterate their importance here, and briefly to specify their nature in the four settings.

On ward 6 and CCU disclosure and open awareness contexts were encouraged, and nurses did not have to consult the medical staff before they could 'tell' patients they were dying. It would be very unlikely, however, that the general situation had not been discussed by nurses and doctors, and a joint decision reached. By contrast on the surgical ward nurses were forbidden to disclose a terminal prognosis to a patient, even where they felt that this was desirable or necessary. In the community there were also very strong norms of non-disclosure. The greater ease of interaction with dying patients on ward 6 and CCU seems to flow directly from the disclosure norms in operation in these two settings. These disclosure rules themselves were firmly embedded in the method of nursing work used and other structural features of the organization of nursing work.

NURSES' ATTITUDES AND PREDISPOSITIONS

Disclosure norms cannot be divorced from the more general attitudes and predispositions of nurses. Attitudes towards death and dying have already been reviewed in chapter one, and will not be referred to again here. How nurses view their work in general, and their nursing

of the dying in particular interact very powerfully with the structural factors which have been discussed above to shape their nursing care of the dying and what they are likely to say to patients about their terminal condition. These personal attributes or characteristics of nurses are the material from which roles are 'made' and shaped to individual requirements.

It is beyond the remit of this thesis to examine the personal characteristics of nurses and their influence upon nursing the dying in any systematic and detailed manner. The characteristics to be considered here are age, communication skills, fear and anxiety, and gender identity. Religious beliefs are also known to be significant (Bakshis, 1974; Hinton, 1972; Intermed, 1976), but these are not amenable to modification through education and the structuring of experience for ethical reasons.

It has been suggested that personal fear of death is related to the anxiety about dealing with dying among health care professionals (Glaser & Strauss, 1965; Howells & Field, 1982; Intermed, 1976; Sundin *et al* 1979). A number of studies indicate that such anxiety can be reduced by a variety of educational strategies (Benoliel, 1983, Field, 1986). Fear and anxiety are, as would be expected, negatively associated with nurses' ability to tolerate an open awareness context in nursing the dying (Glaser & Strauss, 1965), and are also negatively related to self-confidence and satisfaction from nursing the dying (Intermed, 1976). Individual experiences of death, particularly the first experience of nursing a dying patient, are also known to be important (Hoelter & Hoelter, 1980; Quint, 1967), and improving the first experience of nursing a dying patient through better support and advice is an obvious and essential step towards enabling nurses to

cope with the care of the dying.

From the evidence presented in part II it would seem that one way to break down or reduce anxiety is to provide a positive experience of nursing the dying within a supportive work environment, so that these initial apprehensions can be overcome before they become part of a negative feedback sequence of anxiety, avoidance, low satisfaction and reward, and lack of confidence in the nurse's capacity to relate to the dying.

7:1 DF When I was doing the lectures on this topic you were very upset and said you weren't sure you could cope. What's happened in the interim? You're much more positive.

RH I know. It was the contact with the MacMillan nurse, and also just chatting with other people in the group helped me a lot. I think it was just I wasn't aware how other people felt. Nobody had let me know that they felt the same way. That it was a very difficult situation to handle, but it got easier. And never really being in that situation before I was just afraid. I didn't know what to expect. But just over the small experiences I've had I feel happier. I feel as if I could start to handle a situation better now than I would of done before. (Pause) I feel much better about it because it was worrying me a lot. An awful lot.

The literature on ward climate referred to above suggests the type of environment in which this sort of positive learning is likely to occur.

In chapter one the point was made that nursing is predominantly a female occupation, and a number of consequences of this were identified. In the interviews with nurses no discernible difference between the attitudes of female and male nurses towards their work with the dying was discernible (the intermed study found that male nurses coped better 1976:153). The precise consequences of the female basis of nursing for the care of the dying are difficult to establish. James's (1986) analysis suggests that they are connected to the downgrading and 'invisibility' of the 'care' dimension of nursing.

She writes "Informal caring, nurturing and loving roles, which were a substantial part of the lives of the nurses outside the unit were drawn upon ... Caring for the dying embodies all these aspects, although they are usually explained in less elevated, more human terms." (1986:186). Because this type of care is thought to be part of the 'natural' behaviour of women it is felt that it does not need to be taught. It is not closely monitored, and thus it is vulnerable to erosion under the pressure of heavy medical work loads. When nurses are experiencing difficulty in relating to dying patients they may ignore such psycho-social carework and concentrate exclusively upon the highly visible (and essential) bodily comfort work of symptom relief and the like. In this way, to use James's memorable phrase, the 'love' part of the 'work' of caring for the dying is lost.

COMMUNICATION SKILLS

The topic of communication skills is obviously a matter of central importance to this discussion. The open awareness of patients creates communicative problems for nurses of a different kind to those of closed awareness, as staff have to stage their behaviour in such a way as to create trust and confidence in their patients, while managing some of the ambiguities which remain, e.g. about time of death. In the interviews with nurses it was evident that they possessed varying amounts of expertise and confidence in their communicative skills. Statements offered about deficiencies in communicative skills with the dying included "I'm just not very good at all" (EO), "I'm frightened to say the wrong thing" (SA), and "my command of the english language isn't the best so actually putting things over I find quite difficult" (ED). Given the hazards to conversation in both open and closed awareness contexts such deficiencies may be an important

inhibitor of interaction with the dying.

Communication patterns with the dying are, however, part of a more generalized pattern within nursing (and medicine) of restricting and limiting communication with patients. Clarke, in her review, reports that nurses do not spend much time with patients in other than task oriented or superficial conversations (1983). Bond (1983) reports a similar pattern in her study of communication on Cancer wards, and found a similar pattern of routinization of communication to that reported by McIntosh (1977). Quint (1967) suggests that the rules covering conversations with patients are unclear and are not taught but assumed to be part of any nurse's commonsense repertoire. The problem, then, is how to learn the "delicate conversational nuances" which prolonged contact with the dying requires. The research of Quint and others suggests that failing to do this, nurses learn to avoid such talk, and that they need support and help if they are to continue talking to the dying. The examples and strictures of their seniors are largely unsupportive and provide examples of how to avoid and shut off conversations about emotional well-being or psychological reactions rather than how to 'open up', facilitate, and manage them. Deficiencies in communication are embedded within and sustained by traditional methods of nursing work. For example, "Observations showed that individual patients' characteristics were not routinely assessed and they did not appear to play a decisive role in communication. There was no obvious theoretical basis for nurses' communication ..." (Bond, 1983:71).

Both verbal and non verbal communications are important in interactions with patients. With dying patients in particular the non verbal channel may be crucial. Nurses should be able to 'read off'

non verbal signs of distress, willingness to listen, information seeking, and so on, as well as controlling their own signals to the patient. The discrepancy between the verbal and non verbal channels has already been pointed to as a major source of unwitting disclosure to dying patients in closed awareness contexts that all is not well.

The two main ways to rectify the problem of deficient communication skills are through education and guided experience. Although formal didactic teaching may be beneficial, experiential learning is more appropriate (Durlak, 1978; Maguire, 1983; Miles, 1987). At present the learning of basic communication skills, and the support for trainees to use them in their ward learning situations appears to be unsystematic and left to chance in many instances. Good 'role models' are also scarce, although Orton (1981) suggests that most nurses learn good practice from this source.

THE NATURE OF PATIENT CONTACT

The disadvantages of the research methods chosen for this study become apparent when we turn to discuss the nature of the contact between nurses and patients. The reliance on nurses' accounts of their contacts coupled with the absence of systematic observation of such contact compel the exercise of caution in this discussion. Given the strong rhetoric in nursing of providing 'good comfort care' and of attending to the social and psychological needs of patients a 'social desirability' component may be present in these accounts. Also, it is well known that there is a gap between what we say and what we do (Deutscher, 1973). As Wright observed in his study of hospice nursing, "Most nurses state(d) that they do not mind talking with patients about their fears and emotions. Little such talk actually

takes place, however." (1981:140). The attitudes and accounts given by nurses are not, however, without significance. Even if they may be more honoured in the breach than in practice their invocation is nevertheless significant. The language and ideas which people use to describe their occupational activities stabilize and guide their behaviour in their occupational settings, even though such behaviour is also shaped by other contextual features. The 'vocabularies of motive' (Mills, 1940) which are produced by nurses to refer to and make sense of their nursing care of the dying are thus important indicators of their expectations and patterns of behaviour.

The 'reality' of nurse-patient contact is, like any other reality, multi-faceted and varying, even between the same nurse and patient at different times. What we are interested to examine here, then, is not a simple depiction of what actually happens in the contacts between nurses and patients, but what emerges from the nurses' accounts as being influential in shaping such interaction, what they believe should happen in their nursing of the dying, and how to facilitate this desired type of contact. In particular the focus is upon the 'opening up' of awareness which nurses in this study saw as desirable and beneficial for nurse and patient. The relevant factors and their hypothesized relationship are shown in Diagram 7.1. These derive from the nurses' accounts and also from the evidence from other published research referred to throughout this thesis. The relationship between these factors is easily expressed in general terms, and a more precise delineation of each element has been attempted above.

At the most general level considered here the nature of the work site within which nursing work with the dying occurs sets certain parameters to such nursing work. Another set of constraints may arise

from the method whereby nursing work is organized, although there may be facilitative and supportive aspects to this also. Together these two sets of variables provide the skeletal framework of role obligations and expectations within which nurses will interpret and construct their role performance. Key figures within work settings, who serve to shape and control the organization of nursing work, are doctors and ward sisters or charge nurses. The attitudes and predispositions of the various participants will also influence and steer nursing work and behaviour, and in particular attitudes towards death and dying, and towards the disclosure of diagnosis and prognosis to the terminally ill.

Nursing the long term terminally ill is reported by the majority of the nurses interviewed to be easier for them if the dying patient is aware of their prognosis (Glaser & Strauss, 1965, also found that many of their nurses preferred openness). The open awareness context is for them associated with greater ease in interaction with the patient. The time dimension is important in two ways: with long term patients the nurse can get to know the patient better which leads to easier interaction. It is also easier to lead the patient to an awareness of their dying over a period of time. In settings like coronary care the high nurse:patient ratio may allow such developments to occur over a fairly short time span.

Despite their expressed preference for an open awareness context most nurses seemed to rely on more skilled senior colleagues to actually 'break the news' or to lead patients to a realization of their terminal condition. For most nurses intention does not lead to action without external facilitation. Not all nurses held an unequivocal commitment to open awareness, and these nurses seem to be

more typical of the wider profession. For such nurses the nature and organization of their work may be the key determinants of whether or not they nurse the dying in an open awareness context. Whether or not a nurse favours an open awareness context seems to be closely associated with their experiences of the personal costs and rewards which nursing the dying has for them. This is best examined by a consideration of their emotional involvement with patients.

EMOTIONAL INVOLVEMENT

The importance of involvement by nurses with the dying patients they are caring for is described well by James in her study of hospice nursing:

"Being 'involved' meant making an effort to be friendly and approachable and responding promptly when patients asked for attention, so that the kind of care nurses felt able to give depended on personal factors, their own feelings, as well as on how Byresford was organised. ...

'Care' requires time, involvement, and a good atmosphere, but this is part of getting information about an individual patient which may then be remembered for future use, or acted upon by all nurses to improve an ill-person's care. ... The emotional involvement was part of getting to know the patients, ..." (1986:157).

This view is supported by the finding of a large scale unselective US study that uninvolved nurses were more likely to become discouraged and depressed, and were less confident about their provision of technical and psychological care of the terminally ill (Intermed, 1976:152). The study also found that many nurses became personally involved with dying patients and grieved at their death.

One of the arguments of this thesis is that emotional involvement by nurses with dying patients is more likely to be a positive than a negative feature of nursing the dying for both nurse and patient. A system of individualized patient care seems associated with good

nursing care of the dying and also, it seems, inevitably creates a certain amount of involvement. It is, however, clear that high levels of involvement may cause difficulties for nurses, and that many nurses therefore endeavour to limit or avoid it. In this thesis two contrasting attitudes towards involvement of nurses with their dying patients have been reported. At one extreme, as found on ward 7, nurses avoided involvement and felt that they should not get over-involved with patients. The student and pupil nurses interviewed on ward 6 reported that this was what they had been taught in nursing school. By contrast the experienced nurses on ward 6 reported that they did become involved with the dying patients they nursed and saw this as largely unproblematic, inevitable, and rewarding. Nurses on CCU and community nurses fell between these extremes in their attitudes towards involvement with patients.

An example of the difficulties surrounding the control of involvement was provided by one of the nurses on CCU. The first interview with her was interrupted by a cardiac arrest on the unit shortly after she had been describing her problems about becoming over-involved with some of the dying patients she had cared for.

7:2 DF Do you feel really upset when you lose someone like that?

RQ Yeah. Really upset. I mean it affects me at home and (...) I just couldn't accept that I'd lost someone that I feel as if I'm fighting for (...) It's a real kick in the stomach. It's horrible.

DF How did you cope with it?

RQ Cried. Well (pause) it wears, you know. It just becomes part of the past. When you think about it, it's there with you. You become all choked up again.

DF Are you becoming choked up again now?

RQ Yes. But, um, you have to learn to live with it. I mean many times I've thought of handing in my notice because it's not - it is part of the job but (inaudible)

(...)

RQ Usually I try not to (become emotionally involved with patients) because I know what it does to me, and I think as I'm in nursing longer I am becoming harder. I hope I don't become too hard, but I am gradually putting up a barrier between me and the patients which I find is getting thicker (Interruption)

In the management of the cardiac arrest RQ gave the patient cardiac massage and kept talking to her throughout the crisis. In the second interview talk drifted back to the topic of emotional involvement:

7:3 DF When we talked before you were giving me the negative side of the emotional. You said you were trying to give yourself a little bit of distance.

RQ Yeah. Building up that barrier. (...) I felt that I was not looking at the person, not feeling the vibes of the person anymore. But after the other day I don't think I can say that again. I did feel as if I didn't want to know what the patient was feeling or worrying about because I didn't want to, I really didn't want to get as upset again. Not only for my job here but for my marriage (...) my husband doesn't like seeing what it does to me and he doesn't want me to get like that again (...) But after having a success I realize that the barrier is not between me and the patient now.

(...) It's something that I probably would have liked to make myself distant from, but having my eyes opened somewhat I realize you can't. While I am here I will be involved.

The experience of this nurse exemplifies Vachon's view that emotional involvement with the dying is an important source of stress for nurses, and that it may interfere with their personal lives (Vachon, 1983). Other nurses interviewed indicated similar, but less extreme examples. Hockey (1979) identifies conflict between 'professional distance' and personal involvement as one of the central problems for nurses in the care of the terminally ill. If emotional involvement with dying patients is indeed inevitable under an individualized method of patient care then the problems which such involvement may cause nurses must be dealt with. The rewarding and beneficial aspects of emotional involvement which were reported by many of the nurses interviewed may for some nurses be insufficient on

their own to offset the difficulties engendered. Better training and preparation may help, but a good and easily available system of social and psychological support for nurses is an obvious corollary to individualized patient care. Nursing the dying is not, after all, the only type of nursing work which engenders personal coping problems for nurses: 'caring for the carers' is essential. As Charles-Edwards comments "The value to the patient of close, trusting relationships has been demonstrated repeatedly, and it is essential that this should become more widely acknowledged and accepted by nurse managers. Only then will they begin to look at the emotional needs of nurses created by these relationships and seek ways of meeting them." (1983:240).

CONCLUSION

This chapter has discussed two interrelated issues. At the more general level it has examined the relationship between structural aspects of hospital work organization and the action of individuals working within them. While structural features may severely constrain and influence individual behaviour, there is nevertheless scope for individuals materially to shape and influence their work performance. Doctors and ward sisters/charge nurses are identified as two sets of individuals who by virtue of their structural positions have a particular capacity to exert such influence. Organizations consist of people acting with reference to each other, and while the characteristics of organizations affect their participants' actions, the organizations themselves are materially affected by the attitudes, personality and other personal attributes of their members.

The second issue addressed was the elucidation of those features which hindered or facilitated the nursing care of the dying. Again,

both structural and individual aspects are relevant. At the individual level a number of characteristics which militate against ease and openness in caring for the dying were identified. Nursing staff are generally young, and hence likely to have little direct experience of death and dying prior to their entry into nursing. They are likely to share the apparently widespread hesitancy and uncertainty about interacting with the dying found in our society. Hence, better training and support are needed if the nursing care of those dying in our hospitals is to be improved. Young females entering nursing are likely to see their role as doctors' helpers giving personal care to patients, and their lack of autonomy at work will in part be due to their acceptance of medical dominance in the definition of nursing work. Such unquestioned acceptance of 'doctor's orders' may be detrimental to their care of the dying.

A number of structural aspects were also identified which affected the nursing care of the dying, in particular the methods used to organize nursing work. Nursing remains a very hierarchical occupation, and despite the new 'professional' emphasis in nurse education to encourage initiative and decision making it seems that trainee nurses are not normally encouraged to question or discuss treatment with their superiors during their training on the wards. In the wards they are still generally expected to remain silent, accept orders, and respond to commands. Where work is organized on a basis of task allocation their capacity to develop expert knowledge of their patients is diminished, and they are unlikely to be able to exercise autonomy in their care of patients. One can see that in such situations - as exemplified by the surgical ward discussed in this thesis - nurses are unlikely to develop or to be allowed to practise the types of decision-making and communication skills necessary for

the good nursing care of the terminally ill in an 'open awareness' context. By contrast where nurses have a high degree of autonomy and where individualized patient care is the norm, as on the medical ward and CCU, the organization of work seems to encourage - even demand - greater initiative, self-sufficiency and decision-making from the nurses, and serves to support caring attitudes. In such situations the nurse can develop expert knowledge of patients which others will lack, and can therefore contribute meaningfully to the planning and delivery of care. This thesis has also shown that the beliefs and attitudes of nurses towards a positive acceptance of such arrangements of nursing work are a necessary and integral part of the structural facilitation of good nursing care of the dying.

8: OPENING UP AWARENESS

The impetus for the research reported in this thesis came from my teaching of medical and district nursing students, and their concern for how they would cope with their work with the dying. My hope is that this study may in some small way lead to an improvement in the care of the dying. A note of caution must be expressed about the quality of the data. This study is based on nurses' accounts of their behaviour rather than upon observation of their behaviour. Although the latter strategy for gathering data was ruled out for this study it is nevertheless likely to generate valid and useful information which the unstructured interview method is unable to tap. In particular it is well known that there is often a 'gap' between expressed attitudes and actual behaviour. The scope of the study might also have been improved by sampling a wider range of work sites. This would have entailed the use of more structured and focussed data collection techniques, e.g. the use of a semi-structured interview schedule similar to that used by Simms (1984) in her pilot study of nurse training for terminal illness. This would be a logical follow up to the present study.

My belief that a situation of open awareness between the dying, their carers, and those emotionally close to the dying, is beneficial for all concerned may not simply be a product of the detached and scientific interpretation of research evidence and clinical anecdotes. While I have attempted to maintain a 'value neutral' stance in the preceding chapters it is entirely possible that my own values and attitudes have in some way influenced the selection, presentation, and interpretation of the data. The very title of the thesis in itself suggests my bias towards disclosing terminality to the dying, a bias

based upon strong personal beliefs about honesty, integrity and the right of individuals to know what is being done to and for them. In proceeding to make recommendations about how nursing the dying can be improved for nurses, the dying, and relatives of the dying, such bias is hard to set aside. Indeed, it provides the 'value relevance' for this work.

THE MOVE TOWARDS OPEN AWARENESS

In the two decades since Glaser and Strauss published their seminal work Awareness of Dying (1965) there has been a shift in the attitudes of health care professionals towards the care of the dying. The debates generated by the work of Glaser and Strauss, Saunders, Kubler-Ross, and others about whether to disclose a terminal prognosis to a dying patient have been largely superceded by questions about how to disclose such a prognosis. True, the situation described by Duff and Hollingshead in 1968 where "Each member of the group functioned within a framework of ambiguous definitions of what might be done, what should be done, what must be done" (303) has not altered significantly, but the way of responding to such ambiguity has shifted towards openness with patients and away from the evasion which Duff and Hollingshead found. While not all doctors and nurses believe that the dying should be informed of their impending death, 'expert opinion' is certainly to do so. Why has this change occurred?

In large part the change has been consequent upon, or at the very least closely linked with, changes in the practical care of the dying. Doctors and nurses can now offer something positive to the dying which previously they could not. The management of pain and other distressing physical symptoms which the dying experience are now much

better understood and more likely to be successfully achieved. This is not to deny that there are still major deficits, nor that too many people die in unnecessary pain and unrelieved suffering. Still, the possibility exists, and is known to exist, for the relief of physical distress. It is also recognized that the control and relief of such physical symptoms as pain, breathlessness, and the like contribute significantly to the alleviation and reduction of anxiety, depression and psychological distress among the dying. These changes in technology - providing the means for better physical care of the dying - and in knowledge - providing a better understanding of how to manage the dying - are clearly important factors leading to greater openness with the terminally ill. The development and dissemination of such expertise and knowledge have been largely a product of the hospice movement.

Changes in medical and nurse education may also have been consequential. In Britain one of the results of the Todd Report (1968) was the introduction of behavioural science teaching into most British medical schools, and in nursing schools behavioural science teaching has a longer, better established, and more accepted role. Thus, the present generation of doctors and nurses are more firmly grounded in basic human sciences than previous generations were. They are likely to be exposed to teaching about communication skills, the effect of cultural differences on health and illness behaviour, practitioner-client relationships, and other topics which are relevant to the practice and appreciation of 'whole person' care. In particular nurse education incorporates such an approach as being a core feature of nursing practice. They are also likely to receive direct teaching about death, dying and bereavement, and about their roles in caring for the dying and their relatives. Despite the

acknowledged deficiencies, not least the discrepancy between what is taught in the nursing school and what the trainee experiences and observes on the wards, it seems that such changes have led to some change in attitudes among health professionals with probable improvements in the care of the dying as a result.

It seems unlikely that this greater emphasis on inter-personal skills, greater openness, and more accepting attitudes towards death and dying among health care professionals could have appeared independently of more general changes in society. These more general changes - if changes they be - have not been adequately examined. The great volume of literature and mass media coverage of death, dying, and bereavement in recent years is surely indicative that death is not hidden away nor a 'taboo' subject in our society. While changes in demographic and familial patterns have led to less personal exposure to death and dying by ordinary members of our society this does not necessarily mean that death is greatly feared by them. Unfamiliarity and uncertainty about how to act towards the dying should not be confused with fear of death and dying. The conventional academic wisdom that death is feared and avoided seems to be both oversimple and unhelpful in understanding how we deal with the dying.

RECOMMENDATIONS

A number of general and specific recommendations for the improvement of the nursing care of the dying become obvious as a result of the findings of this thesis. They are not claimed to be new, as they have all been suggested by others. They are, however, worth reiterating. General recommendations are:

1. Nurses should be allowed greater autonomy and decision making capacity in their care of patients.
2. Nursing work should be organized through individual patient allocation and the use of the nursing process.
3. Greater nurse stability to allow teamwork to develop. This can only be achieved by the retention of nurses via better pay and conditions, and the freeing of career advancement from the need to move jobs.

Specific recommendations are:

4. Wards and units should adopt a clear policy of disclosure about the diagnosis and prognosis of terminal conditions. This policy should be known to all staff, and cases of non-disclosure should be justified.
5. There should be full communication of information about the terminally ill, joint decision-making about their care, and full cooperation within the health care team, especially between doctors and nurses, in the implementation of such care.
6. Better training and education both in basic communication skills and in death education.
7. The provision of support services for nurses caring for the terminally ill, especially those in particularly stressful settings e.g. ^{Intensive}Intensive Care Units. The experience of Oncology wards and hospices show this is an important feature of good terminal care.

CONCLUSION

The realization of nursing care for the 'whole person' and the derivation of satisfaction and reward from such caring nursing can flow from the types of structural arrangements identified in this thesis. In particular they seem to be closely associated with the individualized methods of patient care which are currently being introduced into nursing. Far from being detrimental to the nurse a certain level of emotional involvement with patients seems to be to the mutual benefit of nurse and patient, and can pertain, as the evidence in chapter four shows, even in such an apparently negative situation as nursing the dying. The predisposition to care is, one suspects, an important characteristic of entrants to the health care professions. Studies of medical students suggest that it may quite quickly be transformed as they lose their 'idealism' (Becker & Greer 1958), develop 'detached concern' (Fox 1975) and in many other ways change their earlier commitment to caring for 'whole people'. A similar process may also affect nurses (Clarke 1978, Melia 1982). Such change is not inevitable, but structurally induced during the course of nurse training and the early ward experiences as a qualified nurse. The proposed changes in nurse education stem from a recognition of these (and other) negative consequences of the current training of nurses. However, the removal of barriers to 'good nursing care' of the dying is not in itself sufficient to guarantee the delivery of such care. Nurses must also be taught how to manage the difficult interpersonal communication skills required to 'open up' awareness of dying, and must be supported when they experience personal problems arising from their close involvement with dying patients.

APPENDIX: DISTRICT NURSE QUESTIONNAIRE*

*It should be noted that the primary purpose of this questionnaire was to recruit nurses who would be willing to be interviewed about nursing dying patients in their own homes.

NURSING THE TERMINALLY ILL AT HOME

Years since Nurse Registration..... Your age..... Your Sex: M/F

1. How long have you been district nursing?

..... Years Months

2. Have you nursed anyone in their own home who was terminally ill?

YES/NO

If YES how many terminally ill patients have you nursed at home in the following age categories?

Age of Dying Patient	Number nursed	Terminal Condition and Cause of Death (if known)
----------------------	---------------	--

0 - 4

5 - 15

16 - 29

30 - 59

60 - 74

OVER 75

3. In your experience, what are the major problems (physical, psychological, social) experienced by terminally ill patients dying at home?

4. In your experience, what are the major problems (physical, psychological, social) experienced by relatives caring for the terminally ill dying at home?

5. What have been your major problems (physical, psychological, social) in nursing the terminally ill in their homes?

6. As a general rule, do you inform the terminally ill of their prognosis?

7. Do you generally inform the relatives caring for them?

8. Do the terminally ill usually know that they are dying? (How do they find out?)

9. What difference does it make in nursing the terminally ill if they are aware that they are dying?

10. Are there any differences between nursing the terminally ill and other patients?

11. Would you be willing to talk with me about your experiences of nursing the terminally ill in the community?

If you are willing to do so please complete the information below.

Name:

Contact address
and/or phone number

Time available (if known)

THANK YOU FOR YOUR CO-OPERATION.

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OPENING UP AWARENESS: NURSES' ACCOUNTS OF NURSING THE DYING

ABSTRACT

This thesis is primarily based upon unstructured interviews with nurses about their experiences of and attitudes towards nursing the dying. The main focus of the thesis is upon nursing the long term dying within a general hospital as seen from the nurse's viewpoint. The research is based upon the work of Glaser and Strauss which identified patterns of communication between health care workers and dying patients as being crucial to the experiences of the dying, and is broadly supportive of their findings. Many of the nurses interviewed expressed a preference for nursing dying patients who were aware of their dying. However, despite this preference for 'openness' most nurses reported difficulty in achieving this situation. Nursing the dying in an open awareness context was associated with emotional involvement with the dying, and with satisfaction from such nursing care. It is argued that open awareness and good nursing care of the terminally ill is more likely to occur under a system of individualized patient care which is coupled with team support of individual nurses. The other features which affect the likelihood of open awareness developing are patient characteristics, doctors' views about disclosure, and individual characteristics of nurses.

