PERCEPTION OF PALLIATIVE CARE PRACTICE
OF HEALTH CARE PROFESSIONALS IN A MENTAL
INSTITUTION: A DESCRIPTIVE STUDY

By

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ABSTRACT

The purpose of this descriptive study is to investigate the perception of practice of health care professionals at a mental institution, as it pertains to their work with dying patients, and also to identify areas of change. The conceptual framework is constructed of six factors important to palliative care that have been identified from the literature. These are personal death anxiety, organizational structure of the hospital system, role expectations of professionals, teamwork, education and training for care of the dying, and conveyance and exchange of diagnostic information. The sample surveyed by a written questionnaire included physicians, psychiatrists, health care workers, social workers and pastoral care workers from the Geriatric Division of Riverview Hospital, Port Coquitlam. The findings indicate that age, sex, marital status and length of working experience at Riverview Hospital had no significant association with personal death anxiety. Informal education such as workshops and in-services had a significant correlation with personal death anxiety, as did perception of being competent and/or confident about working with the dying. The study also raised concerns that not all was being done for the dying patients and their families at this institution. Suggestions such as education and training, support mechanisms, and less stereotyping of professional roles were
offered to improve this situation. As well, findings indicated that there was a need for palliative care service either in the form of a team or separate unit, or simply the practicing of the palliative care philosophy.
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DEDICATION

To those people who have shared with me the gift of life in the midst of death. Their lessons of courage, strength, and dignity will always be remembered. May they be in a kinder, gentler place, and may I never forget that dying is something that does not have to be done alone.

C.
 CHAPTER ONE

 Introduction

 Approximately 70% of Canadians now die in institutions and not at home with their families (Mount, 1978). Deaths occur in acute care hospitals, extended care facilities, or in similar institutions such as mental institutions. About 80% of these people will be over the age of 65, and more often than not, death will result from a prolonged chronic disease rather than from a quickly terminating acute illness (Vernon & Loveless, 1984). Thus, the most common scene for death has shifted from the home to the institution, just as the more common age of death has shifted from the younger to the older age group (Brim et al., 1970). This phenomenon now poses an interesting challenge to our health care system, as it attempts to incorporate appropriate practices and policies to deal with the issue. On a larger note, it poses a problem for the social and cultural context of society as we struggle to bring sensitive humane care to the terminally ill. One might assume that the burgeoning of articles and books on the issue of death and dying signifies that palliative care is a salient issue in current medical practice. However, the critical issue remains one of integrating the knowledge into actual care situations, so that it does not remain outside of mainstream medical practice. "Without the integration of the
knowledge into an approach, there is the danger that the topic and its many ramifications will become like the dying person - often isolated and set apart on the periphery of care" (Barton, 1977, p.3).

In this chapter we will look more closely at the dying situation in our society, especially as it pertains to the elderly, and more specifically the mentally ill elderly in a mental institution. We will examine various reasons as to why we have moved to institutionalize the dying and the ramifications of this move. We will then look at one possible response to this phenomenon, namely palliative care. The concept of palliative care will be defined, as well as its historical roots in Canada and development into a social movement and integration into our health care system. Finally, we will discuss the role that social work can play in palliative care.

a) Underlying Values Towards Death in our Society

Guerra (1984) asserts that attitudes toward death have evolved through five stages in the last millennium. He describes the first stage, "We All Die", as a time where concerns for the individual who was dying as being secondary to the good of the family and of society. This general attitude lasted into the ninth century. The next stage is described as "Death of Self". "Here the focus shifted from
the deathbed to the funeral, with the salvation of the individual and the survival of the immortal soul taken as the greatest concerns" (Guerra, 1984, p.13). This attitude prevailed in the eleventh through the thirteenth centuries. The third stage, "Protracted and Imminent Death", focused on the "savage and untamed power of death" as humanity was horrifyingly scourged. "Thy Death" followed this stage in the eighteenth century. During this period there was a decline in the use of ritual as a way of avoiding death's reality, and an increase in expression of grief, as death was accepted as a great personal loss. The final stage, a twentieth century phenomenon is "Inverted Death", which is characterized by the relegation of death to medical technology. "The dying are to be dealt with and disposed of in as efficient and nontraumatic a manner as possible" (Guerra, 1984, p.13). Indeed, our society has created a "variety of death specialists for dealing with all aspects of dying - hospitals to house the critically ill, morticians to handle the preparation of the body for burial, and funeral directors to deal with the details of burial" (Carter & McGoldrick, 1989, p.457). As a result of the intervention of all these individuals, the family is distanced from the dying individual. It must be noted, however, that the rituals around death and the disposition of death are being changed or eliminated by some of the younger sectors of our society as a reaction to this
distancing. For example, the traditional rituals for funerals and burial are changing.

The society we now live in has been described as being death denying and age defying (Carpenter, 1984). We are uncomfortable and afraid of death even though it is an inevitable and real part of life. Regardless of age, the majority of people deal with death by denying it. For most of us, death is considered to be an invader and not a natural ending to life. Death is usually associated with old age so old age is often denied also (even though the alternative to growing old is to die young). "The fact that most dying is done by the elderly and the elderly tend to live on the periphery of society, means that death itself tends to be more hidden" (Thompson, 1979, p.xvi.). This obscurity of death has contributed to the 'conspiracy of silence' about death in our society. This societal denial has important implications not only for treatment but for the impact of dying on the family. The modern attitude toward death appears to have resulted from family and society attempting to protect themselves from the effects of having to contemplate the death of a loved one. "Perhaps in the attempt to protect itself from the socioemotional disruption occasioned by dying, society tries to bury it" (Carpenter, 1984, p.27). The consequent tendency to hand over responsibility to the hospital, to medicalize the problem, is the inevitable result of treating death as
something threatening and forbidden.

Despite the trend in recent years towards more community health care and prevention programs, and towards deinstitutionalization, society is still for the most part delegating the responsibility of terminal care to the institutional setting. With this development, the responsibility for terminal care has been abrogated to the professionals. In our technological society, families have become more dependent on the health care professional for the care of the elderly and dying. This dependency has had the result of discouraging critical examination of their roles and responsibilities in this field. The responsibilities of the health care professional are to the dying individual, the family, and to the integrity of the profession and institution.

On a more positive note, it might be suggested that we are perhaps entering a sixth stage of attitudes about death and dying in our society. We are beginning to experience a shift away from the strictly scientific view of health care philosophy to a more humane view. This shift in focus has been accompanied by a shift in services available to the seriously and terminally ill. This social movement will be explored in later sections of the Chapter.

b) The Institutionalization of the Dying
"Dying is rapidly becoming an institutionalized process" (Barton, 1977, p.3). The dying process has moved toward the institutional setting because of important changes in our society. The society of today is highly urbanized, industrialized, and mobile. Calvin Goldschneider (1971) points out that in the change from a preindustrial to an industrial society, we have gone from uncontrolled to controlled mortality (cited in Backer et al., 1982). With our control over mortality and our belief that death can be "cured", dying has become institutionalized. More and more hospitals have become designed and organized for the purpose of controlling death.

Modifications in family structure, as well, have had an important influence on the care of the chronically and seriously ill. The extended family structure of the past has given way to new forms of family structures that are smaller and more isolated. These family structures with greater mobility and less stability are less able to provide support and care when one of their members is sick, and must rely on outside support. Naturally, this support is drawn from the wider community such as various social agencies and institutions.

The changing role of women in our society has especially influenced families' reaction to terminal illness and to the treatment of death. Carter and McGoldrick (1989) explain
that, historically, women have cared for the ill and dying members of their family and society. There has been a shift in the social and political context of our society, especially with the feminist movement and the rise in cost of living. Women are having fewer children and are waiting longer to have them, and more and more women are entering the workforce. Yet even with this change of family role, women are still tied closely to the caretaking of the ill. However, it is becoming more difficult as women raise their own children, care for aging parents, and hold down jobs. According to Newsweek Magazine, more than half the women who care for elderly relatives also work outside the home, and nearly 40 percent are still raising children of their own (Beck et al., 1990). As the pressures of the caretaking jobs women take on become too great, reliance on the health care system and its institutions may take place but at great psychological and emotional cost.

Advances in medicine in this century have directly resulted also in the institutionalization of the dying. The advances in technology and diagnostic procedures have all impacted the nature of our health care system and its delivery of services. The setting in which the advanced care can be received is the hospital. Thus, this is where there is a tendency to place all severely ill people. However, the hospital has itself developed into a complex social
The benefits of the technologically sophisticated medical care have been remarkable. Many diseases and disabling conditions have been improved in their potential for cure. Unfortunately, it may be argued that with the pronounced emphasis on cure and mastery over disease, the provision of supportive palliative care for the incurable has suffered. Our ability to prolong life is counterbalanced by the prolongation of the dying process.

As medicine grows more scientific and sophisticated, more knowledge of the causes of death is gained. However, the next logical step is then to find ways to avert the disease, and therefore death. Thus, the 'natural' link between dying and medicine is strengthened. There is a tendency to "biologize" the human being, thus cessation of personhood becomes equated with the biological running-down of the body (Rollin, 1984).

Dying does involve biological factors, there is no denying that, but it is much broader in scope. Death is as much a social construct as it is a physiological event. In effect, hospitals end up denying the social existence of the individual. Dying in a hospital tends to be a restrictive and impersonal experience, as compared to dying at home. A person able to die in his or her own home will be surrounded by familiar objects and loved faces. Thus, the familiarity of home can to some extent narrow the gulf between life and death.
The expanding technology has also led to increased specialization of the professionals. Although the positive outcomes of this development are obvious, specialization can also lead to less continuity of care for the patient, as care can be provided by a large variety of people. Therapeutic, interpersonal relationships between the caregiver and the patient that may have existed with less specialization, appear now to have deteriorated (Barton, 1977). The move toward more technology has resulted in less concern with the psychosocial care and emotional support of the patient.

The current state of the economics of health care also affect the care of the terminally ill. The current thrust in the economics of health care, is of course, cost containment. Health care providers are reimbursed according to fee schedules for specific procedures that are done and not for general types of care or preventive services such as palliative care. Thus, the psychosocial dimensions of patient care and the concern with patient comfort and support of family may become secondary to efficiency and cost-effectiveness because these services do not fall within the fee schedule.

c) Professional Attitudes Towards the Dying, the Elderly, and the Mentally Ill

In our society, the dying, the elderly, and the mentally
ill are often afforded little social value, and the attitudes towards these populations tend to be relatively negative. It may follow that professional attitudes towards these groups will reflect societal attitudes. Indeed, a study by Stockwell (1972) showed that the elderly, the dying and the mentally ill were viewed by nursing staff to be the most unpopular patients and there was a measurable difference in the quality of care they received. Therefore, it might be assumed that if a person is elderly, dying, and also suffering from a mental illness, the attitudes directed at him or her might very well be negative in nature. Professionals, in general, do not seem to like working with elderly populations. Many prefer not to work with elderly clients because they are regarded as unchallenging, boring, and unrewarding. Even if elderly clients are not dying they tend to be treated as if they are. "Like the dying, their problems are popularly seen as incurable, irreversible, and inevitable" (Silverstone, 1984, p.3). Medical staff in a sense "write off" the dying elderly with the tacit sanction of society. Nurses have been timed as responding considerably more slowly to the calls from elderly patients than from younger non-terminal patients (Rollin, 1984). These practices demonstrate that the differing expectations with respect to the course of the illness and the results, are often dependent on the nature and extent of social value afforded to the person being served. The dying
elderly person further serves as a constant reminder of medicine's ultimate failure.

In contrasting the abundance of pediatricians with the lack of specialists in geriatrics, it has been suggested as a probable reason for such disparity, that whatever the doctor does for children they generally recover, whereas whatever is done for the aged all of them eventually succumb (Worcester, 1977, p.3).

This negative view of the elderly is unfortunate because many of the problems they have are reversible, or at the very least can be ameliorated. Elderly people have just as much capacity to change and grow psychologically and spiritually in their remaining years as someone at another developmental stage.

The professionals associated with the various institutions in which people die will be involved in the death of many of the aged. It would be naive to assume that the meaning old age has for these people would not influence how they relate to and treat the older person who is dying. In caring for the dying elderly person, the health care professional will experience the full range of human emotions and attitudes that any normal human will experience. Often then, they will use coping strategies and defensive manoeuvres to allow their work to continue unhindered. Unfortunately, a method often used is to depersonalize the dying individual.
Is the reason for this increasingly mechanical depersonalized approach our own defensiveness? Is this approach our own way to cope with and repress the anxieties that a terminally or critically ill patient evokes in us? Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending death which is so frightening and discomforting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being which would remind us once more of our lack of omnipotence, our own limits and failures, and last but not least perhaps our own mortality?

(Kubler-Ross, 1969, p.9).

As Kubler-Ross notes, constantly facing the death of others also means that one has to contemplate his/her own mortality. As health care professionals, we need to learn to communicate with each other about our own fears of death as well as the difficulties of working with dying individuals.

The situation is further complicated when dealing with the dying elderly person suffering from mental illness in a psychiatric institution. The mental illness itself provides a strong alibi for professionals and families to avoid dealing with the terminal illness in an open manner. Perhaps there is an assumption made that discussion about the illness with
patients will only upset them further because they are not emotionally stable enough to integrate the information, or conversely, that the patients would not understand at all the meaning of death. Can we ethically deny to dying persons information that would provide them with an opportunity to make peace with themselves and their family, and to control the manner in which they would like to die? The nature of the mental illness itself may have important implications for involvement in terminal care.

What are the specific needs of this population as they undergo the dying process? To what extent are they being met, and what more do we need to learn before we can properly and appropriately meet those needs? We need to seriously ask ourselves what it means to be old, mentally ill and dying.

2. WHAT IS PALLIATIVE CARE?

One of the most rapidly growing trends in terminal care is the concept of palliative care. Palliative care or hospice care refers to a philosophy of care. Palliative care comes from the Latin word "pallium", meaning "to alleviate without curing" (Holt, 1989, p.13). Several features characterize palliative care as being distinct from other traditional health care models. The Subgroup on Palliative Care Services
in Hospitals, an affiliation of the federal/provincial Working Group on Special Services in Hospitals, defined palliative care as follows:

'Palliative care' refers to programs or services that provide care to those patients for whom treatment aimed at cure and prolongation of life is no longer appropriate but for whom therapy aimed at improving the quality of the remaining life is the primary objective. Palliative Care offers therapeutic services designed to address the physical, psychosocial and spiritual needs of dying patients and their families (Health and Welfare Canada, 1982, p.1).

Thus, palliative care is active, compassionate care of the terminally ill. Its aim is to improve the quality of life of the terminally ill so that "these people can truly be said to live until they die" (Canadian Medical Association (CMA), 1987, p.34). Palliative care considers both the dying person and the family (as defined by the patient) to be the unit of care and involves them in the decision-making related to that care. The patient and family are assured this way that their beliefs will be respected and that the conduct of the patients care will be in line with those beliefs. Palliative care "attempts to restore to the individual control over his or her life at a time when a series of unresolvable losses occur and individuality is threatened" (CMA, 1987, p.34).
Palliative care needs to be provided by a trained team of professionals and non-professional members (CMA, 1987). The team should at least include physicians, nurses, social workers, spiritual counsellors, and volunteers. It also needs to be available 24 hours a day, 7 days a week. For patients who are able to be at home, continuity should exist between the home setting and inpatient setting. As well, active support needs to be available throughout the bereavement process.

Palliative care is a conscientious approach to meeting the needs of the dying patient and the family, through compassionate involvement. It is the facilitation of resources to the concerns and needs of the individual, family and friends. It is the catalyzing of communication about the uncertainties and anxieties of life and death that so often get lost in the frenzy to save life. It is the connectedness that helps a person live a quality existence until death.

In a society typified by "mastery over the environment", the objective of standard medical therapeutics is mastery over disease and thereby, death (Corless, 1983). When this is no longer feasible, it appears that there is "nothing more to be done". Those concerned with palliative care argue however, that although nothing further can be done about the disease something can be done for the patient. Symptom control and a concern with the physical, psychological, social, financial,
legal, and spiritual aspects of patient and family are appropriate areas of action.

Palliative care programs have many things in common. Their orientation is humanistic in their concern for the well-being of the patient and his or her family. They are holistic in directing attention to the whole patient and drawing upon the whole armamentarium of medical care through the use of a multidisciplinary team. Their focus is upon life and living rather than upon death and dying. They view death as a natural part of life, but as one that, like birth, can be made easier by the provision of some help (Zimmerman, 1986, p.12).

However, it is erroneous and misleading to make the assumption that the concept of palliative/hospice care is being used "to describe a single universe of institutions and programs that share a great similarity in their purpose, organization, and function" (Zimmerman, 1986, p.15). Although palliative care programs share a common purpose, they may differ widely from one another in the way they achieve that purpose. There are numerous models for the delivery of palliative care in existence in North America and Great Britain. They range from free-standing hospices, hospital-based palliative care units, palliative care teams, to community-based care programs (Health and Welfare Canada, 1982). Each program must take an
individualized approach to serving its community based on the size and nature of the population to be served, available resources such as trained caregivers and funding, as well as an interest to support such a service. Each type of program brings with it advantages and disadvantages, but whatever model of delivery is chosen, it is important that the philosophy of palliative care be faithfully applied. Advocates of palliative care stress that there is a limit to what modern medicine can do. Once that point has been reached, curative treatment should cease, and a patient should be able to live out the remaining time as comfortably as possible. The philosophy of palliative care is that it is not a "place", but rather it is a program and it is an attitude. "It is a basic difference in attitudes about the meaning and value of human life, and about the significance of death itself, which we see at work in the place called hospice" (Stoddard, 1978, p.11).

In summary, palliative care is a nontraditional response that encourages the dying person and his or her family to take back and own the experience of death. How present the concept of palliative care is in our medical institutions has important implications for the person. How we die is a reflection of what we are as a community and what we value as a society.
3. THE PALLIATIVE/HOSPICE CARE MOVEMENT

a) The Social Movement

Many authors have referred to the rapid development of palliative/hospice care programs as instituting a social movement (Dubois, 1980; Corless, 1983; Saunders, 1980; Stoddard, 1978; Torrens, 1985). While the concept of hospice and palliative care is not new, its current incarnation dates from the 1960's and has the appearance of "an idea whose time has come" (Dawson, 1990, unpublished). It has been argued that hospice care is not a new development, but rather a return to old values. Clearly it utilizes some techniques that date back many years, however, as we have seen in the previous section, it does represent some new applications of old knowledge. Certainly this approach has immensely enlarged the scope of our capacity to deal with the terminally ill.

The impetus for the hospice movement as an alternate form of care for the terminally ill has clearly arisen as a result of two major influences. First was the unveiling of the taboo of death and dying particularly by Elisabeth Kubler-Ross and by Cecily Saunders, who revived the term 'hospice'. Clearly, both of these women have increased public awareness of the needs of the dying and their families and have contributed much to our understanding of the dying process itself and methods for humane care.

Second, the apparent inability of large medical
institutions and their professional caregivers to provide the humanistic and individualized care required by the terminally ill gave birth to the concern for "doing something" for dying individuals and their families. Interest has been demonstrated by both consumers of care and professionals alike, who have attempted to break through the taboo of death.

With the spread of the hospice concept in our culture, many of us may discover that we are learning from the sick how to be well again, and from the dying how to live (Stoddard, 1978, p.36).

Closely associated with this movement is an increase in concerns about human rights, including the right to die, the right to diagnostic disclosure, and the right to participate in decisions's about one's own medical care (Silverstone, 1984).

Zimmerman (1986) comments that he finds the phrase "hospice movement" both awkward and confusing. He argues that because we have reached the point where hospice programs are a common part of our health care reality, we need not refer to it as a new phenomenon sweeping the nation. His point may contain more validity in the future as there remains much resistance to the concept of palliative care. Until this resistance is almost completely eradicated, the designation of palliative care as a "movement" is still required to keep the momentum going towards complete integration into the health
care delivery system. Zimmerman (1986) further states that perhaps the term "movement" reflects the relatively greater involvement of individuals outside the medical field in the development of hospice programs. This may be accurate in terms of the development in the United States, however, in Canada the palliative care programs are for the most part hospital-based (Health and Welfare Canada, 1982). It may be said that palliative/hospice care programs have not provided all of the answers to the problems of caring for the terminally ill, but it may be providing a new focus.

We have begun to realize, I believe, that the enemy all along was not death, but our own unwillingness to incorporate its reality into our consciousness (Stoddard, 1978, p.6).

b) Palliative Care in Canada

The first palliative care programs in Canada began to develop in the early 1970's. Dr. Balfour Mount is recognized as being the father of palliative care in Canada, although he did not spearhead the first program. A 1973 study at the Royal Victoria Hospital in Montreal revealed that the physical and social needs of dying patients went unrecognized and unmet. Mount found significant problems such as isolation, lack of communication between the staff, patients, and families, and unmet medical needs. Thus, in 1975 after almost
two years of discussion and planning, a Palliative Care Service was opened at the Royal Victoria Hospital. Interestingly, the program was not in a separate freestanding building such as the archetype St. Christopher's Hospice in London; it was integrated into the existing parent hospital. Although a similar unit had been established a short time earlier at St. Boniface Hospital in Winnipeg, the program at Royal Victoria rapidly became a prominent program. Under the leadership of Balfour Mount the program has become a model for palliative care units around the world, and remains Canada's largest comprehensive program. While home care is the main focus of the service, there is also a palliative care ward in the hospital, and a counselling service to acute care beds.

Since the opening of the first two units in Canada at St. Boniface Hospital and Royal Victoria Hospital, a lot of interest in palliative/hospice care has been generated throughout Canada. The development of programs has been virtually all centered around hospitals, as opposed to the development in the United States where the initiative came from groups outside of the medical system. In Canada, it has not been economically feasible to set up new institutions devoted entirely to palliative care. The organizational constraints of integrating into the current health care system has slowed the development of programs but has not halted it.

A survey conducted for the Palliative Care Foundation in
Canada in 1982 revealed that there were 64 hospice programs already operating and a further 18 to be implemented within 12 months of the survey. An additional 25 hospitals stated, "that even though they did not have formal programs of palliative care, they felt that they followed the general philosophy of palliative care in their present program and that they included the usual hospice component services in their regular array of services" (Torrens, 1985, p.52).

This study also found that services or programs varied considerably in size ranging from those in large teaching hospitals with a complete ward of designated beds for hospice patients to those serviced by a single person.

In general, the majority of the formally organized existing programs were located in large teaching hospitals or general hospitals. The majority of the informal palliative care services (ie. programs that offered care that followed the usual models without a formalized policy) were located in small hospitals, especially in the western provinces. Thirty-five percent of the programs had inpatient beds specifically designated for hospice patients, and sixty-five percent used whatever beds were available scattered throughout the hospital. A third of the programs provided home care as well as inpatient services.

Symptom control services and counselling for patients and families before death were included in virtually all the
palliative care programs in Canada. Only 75% of the services, however, included bereavement counselling for the family after the death had occurred. Large percentages of the programs included religious counselling and staff education. Additional services such as music therapy, dietary counselling and clinical pharmacy services were also described by a few respondents.

In summary, palliative care programs in Canada are hospital-based or hospital-sponsored, and there are virtually no freestanding hospices and relatively few community-based programs. The hospital-sponsored palliative care programs in Canada may be rather sizeable operations depending on the location, but they also may be quite small with no actual inpatient beds of their own and virtually no permanent or part-time staff. Details of palliative/hospice care in Canada can only be discussed in general terms until there is a uniform data-collecting system and standardization of terms and procedures.

In British Columbia the first palliative care program began in 1980. In 1983 at a provincial forum, the need for guidelines in development was discussed, and this resulted in the B.C. Hospice/Palliative Care Association (HPCA) being formed a year later (Downing, 1988). This organization has divided the province into eight regions, which hold their own educational and administrative meetings throughout the year.
and an annual general meeting. As well, the BC Medical Association have a Palliative Care Committee.

According to Downing (1988), the palliative/hospice programs in B.C. are divided by the HPCA into four levels based on how many of nine "components of care" a program offers. The nine components of care are administrative, symptom control, home care, hospital services, bereavement services, pastoral care, volunteer involvement, professional training and education, research and evaluation. Thus, a Level 1 program has only one component whereas a Level 4 Program offers six to nine components. As of June 1987 there were eighteen Level 1, twenty-six Level 2, three Level 3 and three Level 4 programs (Downing, 1988). It is obvious from these statistics that the majority of the programs are small and have limited services to offer. The BC HPCA's categories are being used by other provincial associations as a basis for revising their own guidelines.

c) Palliative Care and the Health Care System

It is clear from the previous discussion that in Canada palliative care is associated with the current health care system and probably will continue to be. However, what is not clear is how integral a part of the health care delivery system it is. The rapid growth of palliative care programs has not been accompanied by evaluation. Therefore, although
there is an increasing wealth of information about the actual numbers of palliative/hospice programs that are in existence, there is actually very little detailed information about the intensity of services they provide or even on the impact on the patients. There is virtually no information about the numbers and kinds of patients not being served. With the rapid growth of palliative/hospice programs in Canada, there must necessarily arise questions of responsibility and accountability.

Torrens (1985) argues that the suddenness of development and unplanned growth has had both negative and positive effects. A positive implication of the lack of formalized planning is that it allowed the developers to be unrestrained in their enthusiasm and their thinking by any previous models. If it had been necessary to go through formal planning procedures as other health programs, there would probably be fewer programs in existence and less of a variety. Certainly the hospice movement would not be as strong and as vital as it is.

On the negative side, without the formal planning, a number of programs were developed without adequate resources or clear definition of purpose and objectives, especially in the United States. Probably, a number of programs began without a clear understanding of what was needed or possible in that community. Attempts have not been made to determine
how the program would cooperate with and be integrated into the pre-existing health care system. Understandably, this has had the consequence of alienating and causing resentment in certain parts of the system.

In the future, especially as the competition for scarce health care dollars grows, new programs will have to be appropriately planned and objectively evaluated. This will benefit the health system, the palliative/hospice programs, the hospice movement itself, and the patients they are intended to serve. As it is, there is little back-up funding to establish or enhance existing programs. By and large, it is the Level 3 and 4 programs that have funding support from health care institutions or government.

Palliative care will necessarily have to become an integral part of our health care system. Ours is a society with a rapidly aging population, and diseases like AIDS and cancer are on the rise. More and more, Canadians and their families are facing terminal illness. Indeed, many issues facing health care involve palliation care, such as living wills, euthanasia, death with dignity; home versus hospital care, use of acute beds for the dying, lack of funding, adequate fees for medical care of the dying at home; training, research and quality assurance in palliative care. These issues face the providers, funders, and receivers of hospice care.
Until now, palliative care has largely been a middle-class phenomenon. Most patients are female, white, and have a family in attendance (Torrens, 1985). The problem, unfortunately, is that there are many dying patients who do not fit this description. For example, patients with alcoholism or mental illness, or lack of a permanent home or family, need hospice programs as much as the preferred patient now being served, perhaps even more. "Hospices must care for patients across the social and racial spectrum if they are to fulfill their highest ideals and purposes" (Torrens, 1985, p.70).

The majority of patients in hospice/palliative care are terminally ill from neoplastic disease. Although there has been a moderate amount of experience, not a great deal has been written about terminal care for patients with nonmalignant disease. In actuality most published material describing hospice care for noncancer patients has dealt with a single disease entity or has considered the topic only briefly and peripherally. There has been a natural tendency in much of the literature on hospice to slide back and forth in discussion of terminal illness and cancer as though the two were the same.

Obviously, there are many disorders aside from cancer that are progressive and for which treatment offers, at some point, no reasonable prospect of reversing or materially
slowing the disease. The point at which this occurs varies from one disease to another. Some, such as certain neurological disorders are incurable from the time the diagnosis is first made. Diseases also vary in the speed of their progression once they are incurable. The objectives and principles of care for these patients is still to provide an optimal balance of quantity and quality of life for each patient.

In order for palliative care to occupy a larger role in our health care system, it needs to be extended beyond our hospitals. Long-term care facilities, mental institutions and community mental health centres all need to look at implementing programs and policy. Historically, palliative care efforts have been afforded to patients perceived to have a "difficult death". Gradually, the emphasis has moved more broadly to all dying patients, regardless of whether their death seemed to be difficult or not. To continue this approach, palliative care programs must make their way into all arenas and institutions where death may occur. If this is not accomplished,

history will judge the hospice movement a social movement that occurred in industrialized nations in the latter part of the 20th century and that was committed to improving the lives and death of a largely middle-class clientele" (Corless, 1983, p.350).
The hospice movement cannot be dependent on only a few enthusiastic lay persons and health professionals if it wants to be more closely integrated into the existing health care system. Government support as well as societal support is also needed. Fortunately there has been considerable direct and indirect government support in Canada. In 1982 the Policy, Planning and Information Branch of the Department of National Health and Welfare evaluated costs of palliative care. In particular, the researchers looked at two Canadian studies and two American studies and concluded that there was a basis for believing that palliative care services could reduce aggregate health care expenditures in Canada.

Indeed, according to rough estimates based on the scant evidence available, the increases in hospital costs could be reduced by as much as $700 million per year if an integrated, national palliative care program were introduced (Health and Welfare Canada, 1982, p.9).

Obviously, government support of such a program is closely linked to economics. The nature and degree of that support will fluctuate depending on the outcome of carefully detailed economic assessments of this alternate form of care. Likewise, societal acceptance of such a program is dependent on the type and degree of government involvement in the financing of such a program. In 1981, the Department of
National Health and Welfare published guidelines for the establishment of palliative care services in hospitals, thereby implying that it was encouraging the development of such services.

In summary, palliative care as an alternate type of care occupies an important place in our health care system, however, that role needs to be expanded. This expansion within the system should be based not on instinct, enthusiasm, and humane values alone, but on careful needs assessment, resource allocation studies, and cost-effectiveness studies. In the next section, the particular situation faced by Riverview Hospital as it focuses on the palliative care question will be discussed.

4. PROBLEM DEFINITION: PALLIATIVE CARE AND RIVERVIEW HOSPITAL

Riverview Hospital is the provincial mental institution for British Columbia. "It has been the treatment, rehabilitation and asylum centre for adult and elderly people with the most serious and disabling mental illnesses" (Province of B.C., 1987, p.1). In the 1980's government, health professional bodies and lay groups called for guidelines and policies on resuscitation efforts and palliative care in long-term care institutions, such as
Riverview Hospital. There is currently no formal palliative care program in place at Riverview Hospital, although Bhopal writes that the institution has been "providing palliative care for many years to particular patients" (1989, p.1). This indicates that perhaps an unacknowledged informal palliative care program does exist. The 1989 Accreditation Survey Report recommends the creation of formal written guidelines and policy:

It is noted that there is no policy for "Do Not Resuscitate" orders nor guidelines for providing palliative care to the terminally ill patient. It is recommended that a clear policy and guidelines on these issues be developed to guide the medical and nursing staff in their work (p.17).

The lack of formal policy is perhaps due to a lack of clear understanding of what specific needs a mentally ill person has when dying. Despite the prevalence of chronic mental illness, there is a sobering lack of information about how these people experience the dying process. Less is known about whether or not their needs are being met. There is little known, therefore, about the palliative care needs of the mentally ill and the most appropriate means to meet them. The most appropriate model of palliative care service delivery will need to be decided upon, taking into account the hospital's mandate, environment, and internal resistances.
Of concern to Riverview Hospital is how to apply palliative care principles to patients who are suffering from peripheral and central nervous system disorders. These people may well benefit from hospice care, but experience with this application has been limited. Dementia of various types, particularly of the Alzheimer's variety, comes immediately to mind, particularly in view of the immense strain that this condition places on family members. Persistent vegetative state possibly presents another interesting application for hospice principles at Riverview Hospital. Here, of course, the benefits would be derived almost exclusively by the family.

Over the last two years special committees have been striving to create written guidelines at Riverview Hospital. Two separate and consecutive special committees of the Medical Advisory Committee have been involved in this project. The first committee on Palliative Care was large and multidisciplinary in composition. It investigated palliative care issues relevant to Riverview Hospital, and produced two documents - a draft policy and guidelines (Bhopal, 1989). The second committee on Palliative Care is a small one. It has been appointed to further investigate and act on finalizing a policy and guidelines. Riverview Hospital is the first mental institution in North America to be concerned with creating a palliative care policy. The importance of this is brought
sharply into focus when we consider that as the population in our country ages, the population of long-term psychiatrically ill patients is also aging and a good number of these patients will likely die in institutions.

Riverview Hospital can be commended for its attention to the issue of palliative care and its efforts to integrate it into the institutional delivery of services. However, it seems somewhat premature to introduce a policy without investigating the nature of the environment and community into which it is being introduced. Thus, in keeping with Torrens' (1985) recommendation for objective assessment and planning procedures, this study was conducted to assess the need for a formalized palliative care program. This study is an investigation into the perception of practice by health care providers as it pertains to their work with dying psychiatrically ill elderly patients in the Geriatric Division of Riverview Hospital. To what extent is palliative care believed to be already practised, and what areas of practice can be changed and improved upon? To what extent is there a need for a formalized palliative care program? As well, it is my intention to use the findings to assess what factors could hinder or facilitate the successful introduction of palliative care guidelines and policy. In the next section, factors related to therapeutic care of the dying will be outlined. These factors are important to understand as they may serve as
the foundation for resistance or enthusiasm on the part of the organization in implementing a program.

5. KEY FACTORS RELATED TO THERAPEUTIC CARE OF THE DYING

Because of the non-traditional nature of palliative care, a unique situation arises when you try to implement the concept in a field setting such as Riverview Hospital. In the literature, we can find several beginning explanations for the difficulties that may arise during implementation over and above those factors discussed in Section One. A number of key variables related to appropriate care of the dying individual and their families have been identified. To the degree that these factors exist or do not exist, they will have an impact on the therapeutic care of the dying individual and their families. This study explores the current situation at Riverview Hospital concerning palliative care practice in reference to these factors.

Therefore, the conceptual framework of this thesis is constructed from six variables that have been extracted from the literature on palliative care and dying in institutions. These factors are:

i) death anxiety

ii) organizational context of the hospital

iii) expectations of professional role

iv) education and training in caring for dying persons
and their families

v) teamwork

vi) communication and exchange of diagnostic information

These realistic issues are not mutually exclusive but are very much intertwined and will influence each other. They will be further explained and discussed in Chapter Two.

6. ETHICAL ISSUES ARISING IN PALLIATIVE CARE

Palliative/hospice programs are beginning to serve a larger and larger proportion of those people who die in our country. As this specialized service becomes more generally available in our health care system, the various institutions and agencies will have to make very important decisions regarding policy and delivery of services. In undertaking the policy-making process, it becomes clear that there are a number of value dilemmas that arise. These ethical issues confront caregivers and policy-makers alike, and cannot be avoided when dealing with the sensitive issue of death and dying. These issues are difficult to resolve and the impasses reached in trying to do so can often lead to resistances on the part of the health care personnel, as often the apparent solutions conflict with their professional credo.

Lynn and Osterweis (1985) explain that our health care is
essentially guided by three moral principles:

a) patients should be primary decision makers;

b) informed consent is an essential element of ethically correct decisions, and

c) society is obliged to distribute health care in an equitable fashion (in Torrens, 1985, p.200).

Depending on the setting and the application of these values, the potential for value conflicts arise. Riverview Hospital, for example, will have difficulty in formulating policy that does not create conflict, because oftentimes the first two moral principles cannot be followed. Knowing how to resolve the ethical dilemmas that arise has important implication for providing optimal patient care.

The first ethical issue is how to define terminal illness or, in other words, the passage from living to "dying". There is an arbitrary line that moves a person from one phase to the other. That transition has important implications on the patient's psychological, social, and emotional outlook, as well as on the type of treatment they will receive. When and by what criteria do we decide to move from curative to 'care' treatment only? Some palliative care programs will not accept patients unless all of the available active treatment options have been tried. Therefore, this begs the question, how many options with what likelihood of success must a patient have tried and found to be unsuccessful before he or she is
permitted to choose hospice care? We need clearly written policies regarding high-risk procedures and unexpected outcomes to care that both may cause iatrogenic suffering or even death.

Another issue regarding treatment options is: when does treatment aimed at symptom control border on murder? For example, a side effect of morphine is to reduce respiratory capability. As a person’s physical pain increases and the dosage of morphine likewise increases to compensate, that person is being put in a position of risking pneumonia or respiratory insufficiency. This may result in the person dying before he/she would have if left untreated. A similar situation arises for those whose cause of death is malnutrition or dehydration. Providing food and water is obligatory in most situations. However, not all patients benefit from the provision of food and water. Lynn and Osterweis (1985) explain that patients who are close to death seem to die more comfortably if somewhat dehydrated and in negative nitrogen balance. When is this choice not to intervene acceptable and not malice?

An important ethical dilemma, and one that especially affects Riverview Hospital involves competency and informed consent.

In order for patients to make fully binding decisions regarding health care, they must
be acting voluntarily and without undue external influence, they must be adequately informed about their situation and the likely effects of various choices, and they must be competent to deliberate and choose in a way that is both reasonable and responsive to each patient's own values and concerns (Lynn & Osterweis, 1985, p. 205).

Ascertaining that patients are informed and that they really understand their treatment choices is difficult in the best of circumstances. However, in this emotionally charged situation of life and death, it becomes even more difficult. Finally, what rights do mentally ill patients who are deemed incompetent have in regard to their own treatment? Many who have been institutionalized for long periods of time have not had the opportunity to make choices for themselves. Being presented suddenly with the possibility of being involved in deciding their own treatment and care issues may, in fact, be more anxiety-provoking.

Palliative care recognizes that not only is the patient the unit of care but also the family, and facilitates the values of self-determination and promotion of well-being. However, a dilemma arises when the dying patient is deemed incompetent to make decisions for themselves and the family becomes the patient's spokesperson. How can the values of self-determination and promotion of well-being be respected
and guide decisions when someone else acts on behalf of the incompetent patient? How does one resolve the dilemma that arises when the best care for the incompetent patient conflicts with the wishes of the family. It is too easy to follow the wishes of the family when the patient is voiceless and powerless, leaving himself/herself with no real advocate.

As we have seen, these value dilemmas raise more questions than answers. However, it is in discussing these questions that progress is made. As medical technology advances and the underlying societal values toward death begin to change, more questions will confront the health care professional and those working with dying people. The fact that people die will never change. However, the approach we take to help them through that process can change. One health care profession that can assist with this movement is social work. The role that social work can play in palliative care will be discussed in the next section.

7. PALLIATIVE CARE AND SOCIAL WORK

Palliative care and the social work profession have had a long association. Millett (1989) states that indeed social workers have been an integral part of the hospice movement. In fact, Dame Cecily Saunders, the founder of the modern hospice movement was herself a social worker before she became
a physician. Unfortunately, however, in a 1988 survey conducted by Rodway and Blythe (1989) it was found that half the palliative care facilities in Canada do not employ social workers. There is considerable work to do in ensuring and enhancing the social work role in this very important area.

In most of the literature one finds agreement that palliative/hospice care is best delivered by the collaboration of an interdisciplinary team. Each discipline has a special contribution to make in carrying out the caring philosophy of palliative care. Often the various roles become blurred, however, and it is important to delineate what each profession can potentially provide. What then, can the profession of social work bring to palliative care?

Essentially, the tasks of the social worker in providing palliative care are the same as those which pervade all of social work. Pilsecker (1979) provides a summary of social work tasks appropriate to helping the terminally ill and their families:

1) helping patients and families to get in touch with their feelings and understand their behavioural options;
2) assisting patients and families to develop and/or maintain meaningful communication with one another;
3) aiding patients and families to locate and utilize other resources;
4) helping health professionals involved with the patient/family to acknowledge their own feelings, to understand the feelings and needs of the patient/family, and to learn effective and sensitive ways of meeting those needs.

In accomplishing these tasks, the social worker may find himself/herself functioning in a variety of roles (Millett, 1989; Rodway & Blythe, 1989; Stark & Johnson, 1983; Rusnack et al., 1988). These roles include:

1) Counsellor - providing psychosocial intervention to patients and families during dying process and grief process;

2) Enabler - helping patient and family to talk about death and dying, and reaching out to others involved to talk about impending death;

3) Educator - providing instruction in coping skills to patient and family; providing instruction to staff regarding dynamics of people coping with terminal illness;

4) Advocate - representing the interests of the patient when communication breaks down between the patient and staff and/or family (Rusnack et al., 1988), and helping them navigate the health care system;

5) Mediator - serves as an intermediary in conflictual situations;
6) Participant - participating with patient in defining the problem, assessing support systems, and identifying options;
7) Collaborator - participating within the interdisciplinary team in defining, assessing, carrying out, and evaluating plans of action;
8) Maintainer - helping maintain daily interstaff communication;
9) Sustainer - contributing to the emotional support of staff;
10) Consultant - discussing with a member of another discipline the most effective way they might help in a particular situation.

The philosophy of palliative care is very much in keeping with social work tradition of being not only concerned with the welfare, comfort, and safety of the individual but also with the functioning of the family system and the social service network, and ultimately the interaction between these spheres (Stark & Johnson, 1983). Social workers are uniquely qualified in taking this holistic perspective. In this respect, social work serves an ecological function (Rusnack et al., 1988). "It seeks to integrate care within hospice by bringing together the self-care of patients with the caring functions of family, other hospice disciplines and the social service network" (Rusnack et al., 1988, p.5).
The majority of social work time is probably spent in direct service to patients and families. The moving away from active curative treatment to supportive palliative care represents a very difficult time. This transition requires a change in focus and that important decisions be made. It is a highly emotional time of life where all concerned struggle between the desire to maintain hope and acceptance of the inevitable death. There is an increased focus on relief of symptoms. Of course symptoms go well beyond the physical to the psychosocial, emotional, and spiritual. It is in these realms that the social work role is enhanced, as social workers are educated and trained specifically in psychosocial matters. It is understood that reducing the psychosocial pain of an individual will substantially reduce the physical pain, and thus the need for medication. In this respect, Rusnack et al. (1988) suggest that palliative care can be "curative for the patient as the objective of such care is to provide a sense of well-being, ease and restoration" (p.4). This is a hopeful way of reframing an unfortunate situation in order to help the patient, staff, and family in their struggle. Rusnack et al. (1988) further adds that palliative care can be a preventive process for the family by enabling them to constructively cope with physical and emotional aspects of caring, grief, loss, and bereavement. Thus, social workers seek to prevent problems which may arise after the loss of a
Helping patients die is difficult. In few other areas of social work practice is the worker faced with issues such as suffering, stress, depression, hopelessness, despair, dependency, and fear. Therefore, it is crucial for the social worker to undergo a critical self-assessment before engaging in this work. In order to feel comfortable with, and thus effectively reach out to the dying, one must come to terms with one's own feelings about death. As well, Pilsecker (1979) suggests that we also need to look at our ability to tolerate uncertainty and ambiguity which abound in terminal care. We must be flexible enough to go with the uncertainty of the dying trajectory, and learn to "discard our neat conceptualizations" (Pilsecker, 1979, p.371). There is considerable stress associated with this uncertainty. One can never be sure of the course of the illness. "Every remission brings the hope of life, and every exacerbation the fear of death" (Brown, 1989, p.470). If as professionals we can learn to tolerate this uncertainty, we will be in a better position to help the dying person and family deal with it by maintaining an open environment where it can be discussed.

Beyond direct service to patients and their families, there is a vital role that social work can play in such areas as education, research, consultation, and program and policy development. These roles might best be fulfilled in
collaboration with the health care team. However, the author feels that we need to assert the unique contribution we can make as a profession. We need to work beyond the confusion and self-doubt that characterizes our profession, especially in the secondary setting of the hospital.

8. SUMMARY AND ORGANIZATION OF THE RESEARCH REPORT

Chapter One has been an introduction to the report. The most common scene for death is in the institution, and this has created an interesting challenge to our health care system. This is especially true as our society ages. We live in a society that is uncomfortable with death, aging, and mental illness. It has been argued that the increasing institutionalization and scientization of death has resulted in the depersonalization of death. In response to this development there has in recent years been a movement towards providing more humane care to the dying in the form of palliative care. Palliative care is a return to old values and aims to improve the quality of life of the terminally ill through compassionate attention to physical, psychosocial and spiritual needs of the patient and family. In Canada, palliative care has been for the most part hospital-based. It has been evaluated as being economically cost-effective to the health care system, yet is still met with resistance because
of professional, organizational and ethical concerns. The problem is then one of how to expand the availability of palliative care to other institutions such as a mental institution. Finally, the role that social work can play in advocating for palliative care was discussed.

Chapter One has been an introduction to the report. Chapter Two outlines in more detail, using previous studies and anecdotes, the conceptual framework for the study. Factors that effect the therapeutic care of the dying will be explored in detail as to how they may affect the provision of services to the dying and their families. Chapter Three will explicate the research design, ethical issues and problems encountered in carrying out the research project. Chapter Four will outline the major findings of the thesis research. Chapter Five will include a discussion of those findings, as well as explore some implications of the findings for practice, program and policy development at Riverview Hospital. A conclusion, including thoughts on the future of the palliative/hospice movement as it pertains to the larger health care system and to Riverview Hospital, will end the report.
1. INTRODUCTION

The literature review has been developed to place the problem studied in theoretical context. In this chapter, we will begin by asking the question: do mentally ill people experience death in the same way that "normal" people do? Studies that can help to answer this question will be outlined. Next we will examine six factors that may be critical for an organization to examine if considering practice and policy issues around dying and death. Literature relevant to each factor will be presented in order to gain a better understanding of why it might be difficult to implement knowledge of treatment of the dying into practice.

The palliative care movement has generated a burgeoning of books and articles written about the dying individual and the dying process. These, however, have mostly been general reviews with little or no research or have not included subjects with mental illness. Two prominent studies have created increased interest in death and dying. The first series of studies by Eissler (1955) was landmark research charting the feelings of the dying person, coping mechanisms used, and relationships to the doctors. The drawback of these
studies, however, is that they dealt only with a select population of terminally ill individuals, the young, intelligent, mature, and emotionally responsive.

As well, the work of Kubler-Ross contained in her book *On Death and Dying*, which appeared in 1969 sampled mature, middle-class, hard-working, verbal people who were dying. Like the cases in Eissler's book these cases are not suitable as models for the treatment of the dying patient in the general population because they do not reflect the significant limitations in relatedness, emotional stability, intelligence and accomplishment that are found in the general population (Levinson, 1975, p.28).

Individuals characterized by higher psychopathology have yet to benefit from the increased interest in the management of the dying patient.

"People with chronic mental illness face death in different ways: some exhibit the same reactions "normal" people do, whereas others react in ways that are unique to the mentally ill" (Lanza, 1988, p.167). Despite the prevalence of chronic mental illness, little has been written about the ways these individuals experience the grieving process and the implications of their experience for health care providers (Lanza, 1988).

Many authors have attempted to describe the grief process
of a normal dying person (Hinton, 1967; Kubler-Ross, 1969). However, few studies have dealt specifically with the issue of how chronically ill psychiatric patients face death. Feifel (1955, 1956, 1963, 1973) is perhaps one of the only authors to focus on this area of interest. He conducted a series of studies regarding meaning of death in 'normal' and mentally ill populations. In 1955, he surveyed 85 psychiatrically ill patients representing a cross-section of diagnostic categories residing in a Veterans Administration Hospital. The results showed that most patients viewed death as the inevitable final process of life, and as a time of rest and peace from the turmoil of life. Interestingly, he also found that a prominent theme was death by a traumatic event and this was interpreted as reflecting inner aggression towards others and self. This finding may indicate a difference in the way psychiatric patients view death.

When asked hypothetically what they would do if they could only do one thing before dying, patients' most common response was that they would like to do something to benefit others. These responses were found to be in contrast to normal groups who put self-interest and self-gratification before religious or social activities. Feifel concludes that because of strong guilt feelings and a desire for peace of mind, mentally ill people may have a greater need than others to make amends to others before dying.
In a later study, Feifel and Herman (1973) investigated the hypothesis that mentally ill persons manifest greater fear of death than normal persons, at least at unconscious levels. The corollary proposition was that the greater degree of emotional disturbance, the more widespread the fear of death would be. Their hypotheses were based on the observation that ideas of death recur in numerous neurotic patients and in the hallucinations of many psychotic patients. Therefore, their study examined the idea that psychiatric illness may be a path followed by emotionally disturbed patients to deny concern about death. The subjects were 90 mentally ill patients, while the control group were 95 healthy individuals. The subjects were asked to respond to items dealing with conscious, fantasy, and below-the-level-of-awareness reactions to their own death, frequency of death thoughts, and perception of life-after-death. The authors found that no significant differences were found on any of the three levels examined. Remarkably, what was most apparent was the similarity of response in the two groups. The pattern in both groups was disavowal of fear of death at the conscious level, ambivalence at the fantasy level, and apprehension and negativity at the level below awareness. There was also no significant difference between the groups on either frequency of death thoughts or view of personal fate after death. Both indicated they thought about death "occasionally".
Feifel and Herman (1973) concluded that their study did not support either of the predictions. There was no significant difference between mentally ill and normal subjects in their reactions to death and that the degree of mental illness was not a major factor relating to fear of death. They suggested that the dominance of cultural imprinting with regard to the outlook on death appears to be such that it overrides any difference in emotional health.

In a pilot study by Christ (1965) to determine how a group of geriatric psychiatric patients felt about the topic of death, one hundred acute psychiatric geriatric patients admitted to San Francisco General Hospital were examined. He found that sixty-two could give relevant answers to most of the questions on their attitudes toward death. Furthermore, the patients were fearful of death but were willing to discuss it, even relieved to do so. Even those with terminal illness were able to discuss it. His findings seem to be in accordance with Feifel's work in this area.

Templer (1976) concludes from a review of studies that there are two general determinants of degree of death anxiety: one is general psychological health, the other is life experiences concerning the topic of death (Lonetto & Templer, 1986). In regard to psychological health, the results of scores of studies almost invariably show death anxiety to be associated with pathology. In the studies Templer reviews,
psychiatric patients do score higher than normal individuals. This is in contradiction to Feifel and Herman's studies, as well as Christ's. Therefore, this apparent contradiction supports the notion that not much is really known about how psychiatric patients experience the meaning of death.

Based on these limited number of studies it may be said that there are variations in the way the mentally ill face death, especially in the need to make amends, and that this is also true among those who have not suffered from mental illness. Moreover, it appears that there are more similarities than differences in the ways that the mentally ill and those who are not mentally ill approach death. It would be fair to say that more research is necessary to identify and distinguish just what the differences are to enhance direct practice.

Levinson (1975) also believes that the progress that has been made in the knowledge of theory and practice have not reached those patients with a higher degree of psychopathology. His challenge is to bring the treatment of the dying patient to all individuals regardless of psychopathology, socioeconomic status, race or religion.

2. CONCEPTUAL FRAMEWORK AND ASSUMPTION

In order to address the challenge that Levinson (1975) has set forth, obstacles in the treatment of these dying
patients must be carefully delineated and confronted. Because of the non-traditional nature of palliative care, a unique situation arises when you try to implement the concept in a field setting. "The medical care of the dying patients has expanded beyond pure medical technology into the realm of psychosocial consideration" (Gerber, 1988, p.13). Although the need for psychological help during the dying process is well appreciated in concept by physicians, nurses, and other professional staff, the actual implementation of emotional care in these circumstances is all too often wanting or inadequate (Klagsbrun, 1988).

In this thesis, we will discuss six major and realistic issues that influence the transition from knowledge and theory to practice in care of the dying. These variables will form the conceptual framework for the research project. By examining each of these factors in this study we can determine which play a role in the way the dying patient and their family are being cared for at Riverview Hospital. They have been chosen because they appear in the literature frequently, and form a framework that seems to cover most of the major issues that may face practitioners as they work with dying patients and their families. They are:

(1) personal and professional death anxiety

(2) the organization of the hospital system and its inherent pressures
(3) role expectations placed upon the health care professional
(4) education and training in caring for dying persons and their families
(5) issues of teamwork amongst health care professionals
(6) the conveyance and exchange of diagnostic information.

By no means do these issues account for all the factors that may confront practitioners. As well, these factors must be regarded as not being mutually exclusive but as overlapping and intertwined. Although these factors have been extracted from the medical, sociological, and psychological literature regarding dying in medical institutions, an assumption is being made by the author that they will be equally valid for a mental institution, as these institutions also operate under a medical model and are organized in a similar fashion.

3. FACTOR ONE: Death Anxiety

In the literature, we can find several beginning explanations as to why it is difficult to work with dying patients and their families, and why their needs may not be adequately addressed. The first is to consider the fear of death that health care professionals may have as individuals outside of their professional role. As we have discussed in
Chapter One, the personal anxieties of health care professionals are largely dependent on the attitudes prevalent in society at large. Fear of death is a fairly universal phenomenon. The fact that death is not as visible as when individuals died in their own home is cited as a likely cause of our reliance on defense mechanisms when confronted with death and the anxiety it provokes. The defense mechanisms of avoidance, denial, projection, rumination, and isolation are quite commonly employed by people in the face of death, either their own or someone else's.

The philosopher Jacques Choron has delineated three components to the fear of dying: the fear of dying, the fear of what happens after death, and the fear of ceasing to be (McCarthy, 1980). He suggests that the fear of dying and ceasing to be involve a myriad of factors extending from a fear of pain and suffering, helplessness, dependency, and loss of control of one's physical and mental abilities at one end of the continuum, to fear of abandonment and of being separated from loved ones and loss of one's love for others at the other end.

Templer (1986) also has suggested that death anxiety can be composed of three to five independent components and that the most consistently reported are:

1. Concern about both the cognitive and emotional impact of dying and death
2. Anticipation and fear of the physical alteration brought about by dying and death
3. Awareness of the finite time between birth and death and of the rapidity of its passage
4. Concern about the stress and pain accompanying illness, disease, and dying

(Lonetto & Templer, 1986, p.4).

Lonetto and Templer (1986) assert that, based on studies, these descriptive components represent sources rather than surface dimensions of death anxiety. Death anxiety is clearly a fundamental human anxiety, while its components have joined together in such a way as to make it a distinctive form of anxiety. McCarthy (1980) suggests that the expression of the self in the defense against death anxiety corresponds to the individual's attitudes towards life roles.

What the above discussion suggests is that the variable of death anxiety is a very unstable one. There seems to be no agreement in the literature as to exactly what death anxiety is, although according to Marshall (1982) in the area of death and dying there is an "inordinate emphasis on measuring the fear of death" (p.303). Is death anxiety a multidimensional construct or a single construct? Does death anxiety differ from separation anxiety or general anxiety, or is it simply a part of these anxieties? Are feelings of death anxiety significantly different if they are founded on different
component combinations, or are these feelings similar regardless of which components combine?

There is a need to design better methods to tap into this information. According to Schulz (1978) many of the inconsistencies in the death anxiety data will probably be clarified once researchers begin paying close attention to the components of death anxiety instead of treating it as a unitary concept (in Lonetto and Templer, 1986). Furthermore, research has been inhibited because neither theoretical or empirical evidence has indicated what level of fear is "normal" or "pathological" (Marshall, 1982). More studies are needed, especially those using older subjects as well as subjects from various social and ethnic backgrounds. There has been a general problem in validating research done on death anxiety because there are only a few measures against which cross-validation can be attempted. Having said that, various findings regarding professional behaviour with death anxiety, and various correlates of death anxiety will be discussed.

This fundamental human anxiety about death and dying prevalent in our society becomes couched in professional terms in the selective way different populations of patients who are critically ill get treated. For example, according to Weisman (1972), cancer patients are viewed differently from cardiac patients with the same limited life expectancy. Although
cancer patients are viewed to be hopelessly ill, cardiac patients are viewed to be seriously ill with having good chances of recovery. Other patient populations also fill professionals with anxiety: the mentally ill and the frail elderly are cases in point (Stockwell, 1969). Stereotypes about the aging person may impede needed professional intervention. Since it is considered "natural" for an old person to die, the consequent stereotyped expectation may be that the dying older person needs minimal, if any, comfort or support. The disoriented, or the mentally ill, dying person may be denied appropriate care because they are already 'out of it'. Therefore, the juxtaposition of these two labels - to be old and mentally ill - with dying must have tremendous impact on the treatment they receive.

In particular, the literature pertaining to physicians' handling of the dying patient reveals a disturbing pattern. The most typical behaviour of the physician is to emotionally and physically withdraw from the terminally ill patient (Glaser and Strauss, 1968). In the case of the mentally ill dying patient, it may be believed that the person has already suffered a "psychic death" before the cessation of the biological functioning (Feifel, 1955). Glaser and Strauss (1968) report that depending on the physician's estimate of how long the patient will live, almost complete physical and emotional withdrawal from the patient will occur. As the
impending death draws nearer, the physician will remove himself or herself from the situation and only have minimal necessary contact. The consequent behaviours we demonstrate in response to this personal uneasiness have been shown to negatively impact the therapeutic care of the dying patient and their families (Hamric, 1977). The moving away from the dying patient has been observed to produce unnecessary discomfort for the patient at a time when such contact and comfort are most needed. As Feifel (1963) suggests, some patients have more pain from sudden emotional isolation and rejection than from the illness itself (Gerber, 1988). Withdrawal does not necessarily reduce the anxiety the health care professional has about death (Gerber, 1988). It is necessary that the caregiver manage those feelings within himself or herself. Otherwise those feelings might result in avoiding the dying patient or distancing from them. These behaviours further result in poor communication, fragmentation of effort, or lack of teamwork in caring for the dying patient. Interestingly, Feifel’s work suggests that physicians as a group have above average or excessive fears of death, and that they may choose a career in medicine as a way of dealing with these fears (Weiner, 1970).

Lippincott (1972) even goes so far as calling this withdrawal a "conspiracy of silence" between physician and patient, each having needs to deny the inevitable. However,
studies show that the "potential effects for physicians who
inform patients are less personal anxiety, more confidence
when a case is discussed with colleagues and increased
emotional strength to communicate with the dying patient"
(Gerber, 1988, p.16). Informed patients will feel less
isolated, will have more confidence in their care providers
and will have the opportunity to share personal feelings and
work towards a meaningful and dignified death (Gerber, 1988).

Templer has conducted a variety of studies in order to
determine correlates of death anxiety. The instrument he used
was his own Templer Death Anxiety Scale (DAS) which he tested
and developed in 1969. In order to test the validity of the
DAS he administered the scale embedded in the MMPI. He
employed the MMPI because this test contained three well-known
anxiety scales, the Manifest Anxiety Scale, the Welsh Anxiety
Scale, and the Welsh Anxiety Index. "If the DAS correlated as
highly with these scales as they correlate with one another,
then it could be argued that the DAS measures anxiety in
general rather than death anxiety in particular" (Lonetto &
Templer, 1986, p.125). It was found that death anxiety
correlated positively with general anxiety, although not as
highly as the intercorrelations among scales of the general
anxiety themselves. Therefore, DAS is not just another
measure of general anxiety. This is an important point to
clarify before looking at the studies.
In one of the earlier studies in 1971, Templer et al. evaluated the degree of death anxiety as a function of age and sex in diverse populations. They sampled a variety of people from across the age range including upper-middle class (n=283), low-income aides in a Neuropsychiatric Institute (n=125), heterogeneous psychiatric patients (n=137), and highschool students (n=743). Templer et al. (1971) found that there was no significant relationship between DAS scores and age for any group being studied. They observed that this is perhaps inconsistent with a "commonsense" view that the closer a person approaches the end of life, the more fearful of death he or she becomes. They do suggest, however, that this finding is consistent with clinical reports (ie. Kubler-Ross, 1969; Weisman, 1972) that defense mechanisms of denial and repression are used extensively as a means of coping with death anxiety across a large age range. Lonetto and Templer (1986) have suggested after a review of various studies that an inverse relationship is more likely when elderly subjects are included.

For all the groups studied females exhibited higher DAS scores than males. Although the explanation for this result was unclear, Lonetto and Templer (1986) speculated that the greater degree of expressed death anxiety in females may be a product of a culture in which males have traditionally been expected to be brave, and not express emotion. Templer offers
a list of studies that also have repeatedly reported this finding. "In fact, gender may be one of the variables that most consistently relates to death anxiety, not only in North America but cross-culturally as well" (Lonetto & Templer, 1986, p.11). Interestingly, Gilliland (1982) found higher female DAS scores for a general population but very similar means for the sexes in a psychiatric population.

Lonetto and Templer (1986) also report that several studies have indicated death anxiety to be inversely related to income and educational level.

It would appear that there is a slight tendency for the more advantaged members of society to score lower on the DAS. Being white, male, highly educated, from an intact family, with a good income and a higher IQ tends to be associated with lower death anxiety (Lonetto & Templer, 1986, p.13).

In regards to occupation, Lonetto and Templer report that death anxiety does not appear to vary greatly. An interesting finding of Mulholland (1980, 1982) was that the death anxiety of nephrology social workers and social workers providing services in a non-death-and-dying population did not significantly differ. Furthermore, with the nephrology social worker group, there was no relationship between DAS score and number of years worked with these dying patients. It is also reported by Whittenberg (1980) that medical, surgical,
medical/surgical, and ICU nurses did not significantly differ, nor did death anxiety differ as a function of number of terminal patients cared for in previous months or whether or not a death had been witnessed (Lonetto & Templer, 1986). Some differences as a function of occupation or field of study have been found; however, the association could be mediated by certain personality factors.

"For example, Thorson (1977), using the Edwards Personal Preference Schedule, demonstrated that death anxiety is positively associated with succorance, majoring in social work, and being female; it is negatively associated with endurance, aggression, exhibitionism, being male, and majoring in business" (Lonetto & Templer, 1986, pp.31-32). Lonetto and Templer (1986) further conclude that the highly death-anxious person seems to be characterized by greater emotional sensitivity. Perhaps it could be suggested that emotionally sensitive people experience "anxiety" more frequently in relation to any topic, because they are more sensitive to their emotional state.

The number of years of work experience may also be a factor to consider. Denton and Wisenbaker (1977) found that nurses with a number of years of work experience had lower death anxiety than student nurses. McCarthy (1985) found that ICU nurses had significantly higher death anxiety than ward nurses and that there was a negative correlation between death
anxiety and the number of years of nursing. Whittenberg (1980) added to this relationship by reporting that nurses with five or more years of experience had lower death anxiety than those with less than five years. Kane and Hogan (1985) found that younger and less experienced physicians had more death anxiety than those who were older and more experienced.

The relationship between death anxiety and experiencing the loss of significant others is not very clear. There appears to be contradictory results as reported by Lonetto and Templer (1986) in their review of the literature. One study (Cole, 1978-1979) found that those persons who had lost a significant other within the past year had lower death anxiety; while another (Gibbs & Achterberg-Lawlis, 1979) reports that lower death anxiety among terminal cancer patients to be associated with previous experience with a dying person with whom one had a close relationship. Another study (Litman, 1979) showed a rise in death anxiety throughout the course of the year following the loss of an immediate family member; while another (Smith, 1977) reported no relationship between death anxiety and loss of a loved one within the past year. Still another study (Ochs, 1979) reports the death of a close friend or relative within the last two years had increased death anxiety.
4. FACTOR TWO: The Organizational Context of the Hospital System

A major issue outlined by Hamric (1977) in caring for the dying patient is the organization of the hospital system itself. The difficulty is that hospitals are not set up to deal with the dying. More and more hospitals have come to be places designed and organized for the purpose of controlling death. It appears that the organizational context of the hospital is diametrically opposed to the needs of the dying patient (Health and Welfare Canada, 1982). The major goals of our medical institutions is to treat, cure, and rehabilitate. A death is experienced as a failure and personal affront by the health care team. In sociological terms, the dying person is a "deviant in the medical subculture", and serves as a constant reminder of medicine’s ultimate failure (Rollin, 1984, p.99). In terms of Riverview Hospital, the goals are the same as stated above, however, the death of a patient will perhaps not be perceived as being such a personal and team failure. Many of the patients at Riverview Hospital in the Geriatric Division are chronic care as opposed to acute care. Institutions that primarily deal with chronic care cases are perhaps less death-denying than acute care institutions.

In order that organizational objectives can be met, the nature of the activities and behaviours within the hospital need to be predictable. The presence of a dying person in a
cure-oriented organization disrupts the smooth carrying out of the objectives. "Dying patients demand that regulations and routines be changed to meet their need" (Castles and Murray, 1979, p.52). The dying patient often requires far more complicated nursing care than the average patient (Hamric, 1977). The psychological demands of these patients may be greater than the physical demands but often do not receive as much attention. The hospital system rewards personnel for "getting work done" and keeping the organization running smoothly. Thus, psychological care is not consistently reflected in practice due to time pressures and hospital milieu (Hamric, 1977). This can also sometimes be true of mental institution.

The patient is socialized in the organizational context of the hospital institution to be a "good patient" by not complaining, and by surrendering all control to the hospital and its staff. "They are made to feel very small and lost in these institutions with the massive technology, special language, unique style of communication, and complex hierarchy" (Rollin, 1984, p.98). Patients can be depersonalized, treated as cases rather than individuals, and deprived of honest communication about their condition. Doctors and nurses can inhibit interaction because oftentimes the communication they employ is indirect and utilizes jargon. Further, medical staff in a sense "write off" the dying
elderly, with tacit sanction of society. Nurses have been timed as responding considerably more slowly to the calls from elderly patients than from younger, non-terminal patients (Rollin, 1984). Sudnow (1967) even explains how the handling and disposition of the dead body denies that death has occurred. He found in his study that bodies are removed at times when wards might be empty such as mealtimes; the preparation of the body might begin even before death has occurred; and other patients are not told about the death.

A major issue facing the hospice movement is resistance on part of the physicians (Corless, 1983). Physician resistance may result from a "wait and see" attitude about innovation. In other situations, there may be the feeling that holistic care is being given already, and therefore why all the fuss about palliative care? Physicians wishing not to "abandon" their patients often subject them to heroic, expensive surgical and medical procedures whose net result is iatrogenic suffering and miserable quality of life. The physician may do this in the belief that it may help the patient, and if not that person, others in the future.

They are faced with the dilemma of how to practice medicine with a credo that demands faithfulness to the preservation of human life. The question of when to recommend that treatment be directed to cure be stopped is a very difficult
one and demands the mind of the scientist and the heart of the artist (Corless, 1983, p.341).

Doctors who no longer 'hope' for cure are frequently concerned that the referral to palliative care will take away the patients' hope. The ensuing discrepancy in the physicians' behaviour of promoting cure while non-verbally indicating that it is not likely connotes helplessness and hopelessness to the patient. Entering into palliative care actually resolves this for the patient and family (Corless, 1983). This idea is underestimated by some physicians. Depending on how resistant a physician is to palliative care, the timing of the referral will vary. It has been observed that longer involvement in the palliative care system enhances the probability of a more peaceful death by providing an opportunity for the resolution of the problems of living and dying (Corless, 1983).

5. FACTOR THREE: Expectations of Professional Roles

The third major factor is role expectations placed upon the health care professionals. Within a team, members maintain a variety of roles in order to accomplish its tasks or goals. These roles are, in turn, influenced by internal and external role expectations. Internal role expectations involve a person's professional identity, which "is the conceptualized image a person has of [him or herself] as a professional, the knowledge and skills acquired from advanced
professional education, and the understanding of how theses skills can best be applied" (Lowe & Herranen, 1978, p.325). Thus, the internal expectations that each individual has will influence how she or he and others on the team should behave and respond to achieve the collective goals.

Role and function are also influenced by the expectations we perceive others have of us, such as from the members of the various groups that we belong to. For example, we are influenced by the role expectations of our professional group, the organizational group, team sub-groups, and familial associations. Awareness of these expectations placed on us from outside ourselves will influence our behaviour in the group. Within a hospital system external role expectations are a major influence. "Hospitals are among the most complex organizations in modern society, characterized by extremely fine divisions of labour and an exquisite repertory of technical skills" (Castles and Murray, 1979, p.52). Therefore, strict role division and role expectations are necessary to keep the organization running smoothly and efficiently. A common consequence is that health care professionals develop rigid perceptions of each other's roles. It has been shown that in fact, there is little congruence between the way a profession defines its own roles and the way others define them (Lowé & Herranen, 1978). Lowe and Herranen (1978) suggest that this is especially true when professionals
who consider themselves to be of higher status, ie. physicians, are delineating the role of a lower status profession, ie. social workers.

Both internal and external role expectations can lead to role ambiguity where expectations are not clearly defined or communicated. All health care professionals are products of role-oriented training, which is necessary for the development of the professional self. Unfortunately, this may lead to the development of circumscribed and stereotyped attitudes about other professional roles, and to behaviour that can lead to "staking out of one’s territory" (Hamric, 1977). Stereotyped attitudes about role definition can present real problems for those attempting to give care to patients. For example, perceptions of nurses’ role as ward manager, physician’s servant, and technician conflict with the internal expectation that they also provide psychosocial care. In other words, the stereotype held by others of what nurses do does not include psychosocial care, which the nurses themselves consider to be an important part of their role.

Social workers are not exempt from the dilemma created by role conflict. Externally, social workers role may be regarded as arrangers of services and resources with no responsibility for input into patient care. These external expectations are incompatible with our internal expectations, which suggest that we also have roles in providing
counselling, education, consultation, advocacy, etc., resulting in role conflict. Conflict with our internal expectations may also exist in working with the terminally ill. Social workers may be the most optimistic and future-oriented of the human service professions (Ginsberg, 1988). Social workers seem to believe that improvement is possible no matter how pervasive a problem might be. Also, the notion that certain problems have always existed and will continue to exist is not acceptable. For social workers all social problems are, by definition, phenomena to be battled and reduced. Death, as a social problem, is final, non-preventable, universal and irreversible. Death does not fit the models for treating social problems most widely accepted in social work theory and practice today (Ginsberg, 1977). Death creates a professional dilemma, thus we may avoid it or minimize it.

There is also the issue of "professional behaviour", which is associated with lack of expression or emotion. Social workers are as apt as anyone else to be influenced by culture-bound attitudes toward expression of grief and expressing grief themselves. Social workers who are in frequent contact with dying individuals and their families need to recognize the strength of the taboo and their own feelings about grief. The danger is that without accomplishing this task, social workers trying to offer
comfort to dying patients and their families may be, in truth, agents of a conspiracy to contain grief. As social workers we must create an atmosphere in which permission to feel, cry, rage and grieve can be conveyed and acted upon. The task is difficult at best, and impossible for a social worker who is uncomfortable about sharing grief experiences, or fearful of personal feelings about grief and death. A social worker cannot effectively ask others to risk violation of the taboo if he or she has not already taken the risk and come to terms with it. Fear about expressing grief may hold social workers, and other professionals for that matter, to an ineffective, superficial level of practice.

6. FACTOR FOUR: Teamwork

A fourth issue to consider in giving coordinated therapeutic care to the dying patient is teamwork amongst health professionals. Because of the increasing complexities in the health care system, in general, and particularly in medical institutions, teamwork has become the method for the delivery of health care. Increased specialization has ensured that no one individual can possess all of the necessary expertise for the care of patients and families (Lowe & Herranen, 1981). Teamwork can thus provide an organizing and unifying framework for the work of health care professionals.

A team is defined as: "a functioning unit composed of
individuals with varied and specialized training who coordinate their activities to provide services to a client or a group of clients" (Lowe & Herranen, 1981, p.1). There are basically two models of teamwork - an interdisciplinary (integrative) approach, and a multidisciplinary (coordinate) approach. A multidisciplinary model can best be applied when addressing short-term care with specific acute health problems. There is a hierarchial structure with this model, usually with a physician at the top directing team functioning. There is less emphasis on involving the patient in the decision-making process. Multidisciplinary teams are very task oriented. However, the integrative model is functional for ongoing teams who care for patients with chronic problems (Lowe & Herranen, 1981), such as in palliative care. The integrative approach is less of a territorial model of care. With an interdisciplinary team, members can take on the leadership role when their own particular skills are especially needed to solve a problem. All members of the team have equal status, including the patient and family. There is more of an emphasis on the mutual support function in an interdisciplinary team.

Teamwork is a popular concept and its advantages are universally recognized. However, as Lowe and Herranen (1981) suggest, considerable 'confusion surrounds the concept of teamwork, and thus the term has been used rather loosely.
Teamwork can be defined in any number of ways and can evoke a variety of responses. For example, to some, teamwork means collaboration, while for others, it could mean any group action. As health care professionals attempt to practice a concept they are unsure about, expectations are raised and frustrations are heightened (Lowe & Herranen, 1981). Professionals from various disciplines have generally not been trained in working together as a coordinated group. Hamric (1977) asserts that teamwork in reality is infrequently being practised in the modern hospital.

Lowe and Herranen (1978) suggest that there are six characteristics that influence team functioning: (a) goals or tasks of the team; (b) role expectations; (c) communication patterns; (d) decision-making process; (e) leadership; and (f) norms.

The purpose of the team defines the goals or tasks the team wishes to accomplish. In the group process regarding goals, important questions must be raised such as how goals are defined, who sets them, and how much commitment to them is there. The resolution of these questions can have the potential of breaking down the structure of the team if there is disagreement, or can lead to a strengthened structure. In reality, however, organizational constraints, service mandates, and staffing patterns determine how teams are constructed and utilized. The multiplicity of health care
providers and multiple consulting services further complicate the problem. Considerable stress is created by the organizational reality of heavy workloads, shortages of staff, and high turnover rates. The stress is bound to affect the quality of care given to some degree.

As we discussed in the previous section, role expectations play a vital role in group functioning. "Both internal and external role expectations can lead to role ambiguity (expectations not clearly defined and communicated), role conflict (incompatible and conflictual expectations), and role overload (inability to meet multiple expectations)" (Lowe & Herranen, 1978, p.325). In order to function within a team, it is necessary for each member to maintain an equilibrium between internal values and ideas and the external expectations (Lowe & Herranen, 1978), thus reducing the above negative consequences. Of course, this equilibrium is easier to maintain when one is a member of a well-functioning developed team for over a long period of time. In reality, however, this situation is somewhat difficult to achieve. In a large organization the possibilities of transfers and turnovers are real, which disrupt team functioning and development. The more undeveloped and loosely associated a team is, the higher the probability of disequilibrium in role expectations and strict role delineation (Lowe & Herranen, 1978). Unfortunately, when there is a lack of explicit
understanding of other team member's roles and functions, a sense of territoriality, resistance to sharing information, strained working relationships, and unnecessary duplication of work can develop. Fragmentation of the team will also lead to poor communication. Independent and parallel functioning can result from fear of loss of status and place on the team. The obvious outcome is confusion not only for the staff but for the patients as well. Patients may well react to team dysfunction by manifesting feelings of helplessness, which increases their dependency on staff (Lowe & Herranen, 1978). If staff members are not communicating with each other, they may give patients conflicting messages, thus increasing patients' anxiety. "Further, the patients' lack of confidence in the team's ability to provide them with care may manifest itself in increasing symptomatology" (Lowe & Herranen, 1978, p.329). It is especially important in palliative care that the team function as a unit with clear, communicated messages. These messages are based upon the internal and external role expectations of health care professionals. These expectations must be balanced to promote good team functioning.

The way a team arrives at its decisions will also influence functioning. A decision can be reached by default, majority vote, unilaterally, consensus, or unanimity (Lowe & Herranen, 1978). How involved in the decision-making process, and how open someone can feel in expressing their opinion will
impact team functioning.

Depending on the philosophy of the team, the leadership will differ. For instance, if there is an emphasis on pathology and disease rather than an humanistic holistic emphasis, the leadership will be heavily weighted on the medical personnel rather than being a shared venture. Reliance on the medical model and its inherent hierarchial structure has traditionally placed the physician at the head of the team. Therefore, as Hamric (1977) suggests "the orientation of the individual physician has a great deal to do whether a team approach is realized" (p.194). However, an integrative approach argues that shared leadership is preferable.

The final characteristic of team functioning presented by Lowe & Herranen (1978) is its norms. Norms are the unwritten rules that people follow to guide their behaviour and are developed by the team to ensure that there are boundaries between what is acceptable and what is not. Norms then also govern communication patterns, leadership, decision making, conflict resolution, etc. Norms can counteract team development by being too restrictive and narrow, and conversely, by being too general and vague.

A team, like any other group, goes through an evolutionary process with identifiable developmental stages. "The Lowe-Herranen model traces the development of a group of
people working together from the period of formation, through conflict and crises, to resolution, to team maintenance" (Lowe & Herranen, 1981, p.2).

The first stage is "Becoming Acquainted". During this stage the structure of the group tends to be hierarchial with the higher status professionals assuming the position of leader. The patterns of interaction tend to be polite and superficial, with little emotion emerging. It is during this stage that each member struggles to find his/her place on the team, thus conflict is kept to a minimum. Group productivity is low while individual productivity is higher.

Stage two, identified as "Trial and Error", evolves when there is an awareness of the need to work together towards a common goal for patient care. During this stage, the members begin to test the boundaries of the group, form alliances and distance the members perceived to be incompatible. Each member may exhibit these behaviours in order to demonstrate to the rest of the group that his/her contribution is unique. Turfism and minimal communication or collaboration are prominent. Group productivity is still low while individual professionals continue to achieve stated goals.

The third stage, "Collective Indecision", occurs as the team tries to avoid direct conflict and maintain its equilibrium. Boundaries for the group are beginning to develop, although there is no norm of accountability in
operation and so little is accomplished. There does exist the norm of pressure for individuals to conform, and this leads to pseudo-consensus and scapegoating. "This is a period of little or weak leadership and leads to enormous discontent and helplessness on the part of all team members" (Lowe & Herranen, 1978, p.328). The authors also suggest that both team and individual productivity are low as there exists the feeling that no one is listening to the other or being heard.

When an internal or external crisis occurs and forces the team to face the issue of "collective-indecision", the fourth stage is reached. Thus, in the "Crisis" stage, norms are established with more rigidity, roles and responsibilities are further delineated. The team also begins to look more deeply into its own internal processes, thus team productivity is low. This stage is characterized by open expression of emotion and recognition of conflict.

Stage five, "Resolution", is the first level of tangible teamwork. The group has emerged from the crisis and has made a commitment to working together as a team. There exists open communication, shared leadership, decision-making and responsibility. However, this is still a fragile stage where much evaluation is needed so that they can work towards the final stage of team maintenance. In this stage there is high individual and group productivity.

In the final stage of "Team Maintenance", there is a
shared acknowledgement of team tasks with goals being both client- and task-centred and the focus being on the achievement of the stated goals rather than on who does what. There is open communication, resolution of conflicts, compromise, and negotiation as each member recognizes the skills and contribution of the other disciplines on their team. Leadership shifts to the person best qualified for carrying out the client’s care plan. Decisions are supported, accountability to the group exists, and there is a willingness to share information.

The ideal model of palliative care is to use an interdisciplinary (integrative) approach as outlined above. It is important in palliative care, as in all health care, that the patient not be made to feel objectified, depersonalized, or isolated from the decision-making process. An interdisciplinary approach really works to prevent these situations from happening as the patient and family are an equal part of the team and not separate from it.

As we have discussed in Section Four, the hospital is a highly bureaucratized system with emphasis on division of labour, and on hierarchial patterns of communication, decision-making, leadership and rewards (Lowe & Herranen, 1981). In contrast, teams are structured so as to emphasize the sharing of knowledge and communication across disciplines. In order to work, teamwork must be sanctioned and supported by
the environment in which it is trying to operate (Lowe & Herranen, 1981). Therefore, if the institutional organization espouses the concept of teamwork, it must support that concept with commitment. This can be accomplished by shifting the rewards from hierarchial components to explicit recognition of the team delivery model (Lowe & Herranen, 1981). "Impediments to patient care will result for those who attempt to engage in teamwork sanctioned only on paper and not in practice" (Lowe & Herranen, 1981, p.6). The task for the hospital system is to deal with the conflict between the bureaucracy and the team by developing an alternative organizational pattern.

7. FACTOR FIVE: Education and Training in Caring for the Dying

A fifth factor is amount and quality of death education and training in caring for dying persons and their families. The discontinuity between education and service is consistently reported in the literature. The uncertainty and confusion in the minds of health care professionals regarding their role in terminal care and care of the bereaved can, at least in part, be directly attributed to this problem. Corless (1983) suggests that the problems of resistance to palliative care and education are not one and the same but there is indeed some overlap.

As early as 1968 Glaser and Strauss recommended that
"training for terminal care should be greatly amplified and deepened in schools of medicine and nursing" (1968, p.253). They noticed at that time that the emphasis was on learning necessary techniques. The fact of dying and its psychological, social and organizational aspects were either secondary or absent in the education of health professionals. The consequence of this restricted curriculum in education is that the behaviour of the professional towards the dying patient was no different than the average layman's, except that the professionals' technical knowledge of death and dying legitimizes their role with dying people. Thus, Glaser and Strauss (1968) recommended that curriculum be changed, not simply humanized, but drastically changed to address and attack the deep-seated professional values with which they were operating.

With the growing attention on issues of death and dying over the last two decades, academic institutions and professional schools have begun to include courses and lectures on the topic. However, little is known about how to organize and present such material, therefore, perhaps these opportunities have not been utilized to their full potential. Hamric (1977) notes that "while the basic theoretical notions about dying and death are probably dealt with in most undergraduate schools of nursing, there undoubtedly remains a wider variability in the amount and quality of direct clinical
experience students receive" (1977, p.191). In other words, she suggests that students may receive lectures on dying and death, but those thrust into the crucial role of caring for the dying have had little preparation in sharpening interpersonal skills in the terminal care situation through structured, supported, actual experiences with dying patients. Wagner (1972) reports that only token attempts have been made to prepare the nursing student to deal effectively with the physical aspects of terminal care or the feelings of patients, families, and nurses. Dickinson (1981, 1985) shows that only 14 American medical schools offered full-term courses in death education (in Gerber, 1988). However, a full 82% of American medical schools integrate short courses and lectures into the curriculum. Gerber declares that "[physicians] have received a death education of sorts, 'on the street corner', and often find that feelings of incapacity and unpreparedness leave them full of anger, emptiness, and a sense of failure" (1988, p.10).

A study devoted to examining the relevance of palliative care to the Canadian health care system by Health and Welfare Canada (1982) explored possible ways to improve the present situation. One problem identified centres upon education and training in palliative care. Faculties of medicine and schools of nursing were contacted in all provinces, and it was found that only two schools of nursing were giving an elective
course on the topic. However, in all institutions the subject was covered, especially in the medical ethics course. Workshops and elective seminars were also held. In Newfoundland, general practitioners who specialize in palliative care receive a one-month course. The Universite du Quebec offers an elective course in thanatology leading to a certificate.

It would also be interesting to have information regarding palliative care education in schools of rehabilitation, social work, and theology. I can only mention that from my experience at the U.B.C. School of Social Work that no course is offered. The subject is dealt with summarily in isolated lectures or in student seminar presentations. It would be fair to conclude from the above discussion that education and training in caring for dying individuals and their families has not been successfully integrated into the university and college systems.

It would be misleading to suggest that simply because someone has taken a course on the subject of death and dying that that person is prepared and qualified for effectively working with dying patients and their families. Of course, offering such courses is an excellent beginning step in addressing institutional denial. However, an effective educational program needs to include particular critical components. Also, it is important to note that if our society
is death-denying, this means that teachers and learners in death education programs are engaged in "countercultural education" (Morgan, 1988). An effective educational program, therefore, must in part attempt to correct imbalances in our individual and social perceptions of death. "Education about death and dying in the best sense is properly education about life and living, it really assists people to recapture and implement perspectives on life that for many have somehow gone slightly out of focus" (Corr, 1988, p.509).

Morgan (1988) suggests that education about death, dying and bereavement is best when it takes place in an atmosphere in which the whole person is involved, i.e. by addressing cognition, affect, and behaviour. Death education should involve a process of sharing information, an attempt to identify the underlying values that impact feelings and actions, and an effort to develop behaviours to cope with the ways in which death impinges on life (Corr, 1988). Death education is best accomplished when it is interdisciplinary in nature.

I would encourage an approach in which both emotional and intellectual, individual and socially oriented, experiential and scholarly facets of the educational process are welcomed. A course in death education can make its most significant contribution if it helps us to integrate our total selves, rather than lead to
either 'emotional trips' on the one hand or aloof intellectual analysis on the other. There is no better area in which to bring our thoughts, skills and feelings together (Kastenbaum, 1977, p.11 cited in Morgan, 1988, p.526).

"Just as death is a natural part of life, opportunities for education about death arise in the midst of living" (Corr, 1988, p.509). There are essentially four common types of opportunities for death education (Corr, 1988). The first two models fall within the formal educational system, whereas the last two do not. The first model that likely comes to mind is a formal course on death and dying, as we have already discussed in this section. These courses can be taught by a single instructor or from the standpoint of a particular profession or academic discipline.

A second opportunity within standard academic settings has manifested itself in the form of units or aspects of courses offered within traditional disciplines or subject areas. According to Corr (1988), the integration of death education in these ways into the broader curriculum does not necessarily dilute or fragment its integrity. "Rather, it follows the principle that topics related to death are to be found throughout the spectrum of living" (p.510). Further, brief exposure may be less threatening, and may prepare the way for fuller and more explicit treatment at a later level.
Education is not confined to the limited time frames of the classroom; and events in life that impinge on the community, home, family, etc., can have power and potential far exceeding traditional forms of teaching. Such events can inspire at least two additional forms of death education. Therefore, the third model of death education has been called the "teachable moment" - an opportunity created by an event that stimulates cognitive inquiry in a relatively non-threatening way (Corr, 1988). Corr (1988) describes a fourth form of death education as "a nurturing moment". By this, he is referring to occasions when normal people are upset in such a way that they need an opportunity to vent and share feelings and to gain support from familiar people around them. For example, death of a friend, neighbour, or relative can excite strong emotions. If we learn to use death as an opportunity for growth, it can be a very important occasion for learning how to deal constructively with the problems of life.

It is important to note that no one ever comes to terms with death within this life in such a final way that there is nothing left to do. Living always offers some potential for advancing and deepening one's appreciation of the significance of death. What is essential in death education is initiating a process of reflection and self-discovery, not finishing it.

Although education and training in caring for the dying individuals and their families has not successfully been
integrated into the university and college system, informal in-service training is on the rise, especially in long-term care institutions. The necessity of this enterprise is paramount when we consider that the actual dying process is varied. Staff must deal with long-term dying, short-term dying, unexpected death, and emergency transfers. How well staff members cope with this reality depends very much on each member's perception and preparation. Historically, health care professionals have received a reductionist approach to the issue of death and dying, rather than a holistic approach. In other words, they have focused on the disease and how it affects the functioning of the body, rather than considering all of the bio-psycho-socio concerns of the individual. Thus, it is understandable that when faced with having to meet the needs of both the patient and his/her family in palliative care, this may encourage resistance. Education and training should prepare individuals to function as effectively and comfortably as possible in their roles. By training and education efforts, we are establishing a value system for care of the dying.

8. FACTOR SIX  Conveyance and Exchange of Information

The final factor is the issue of diagnostic information and the manner in which it is communicated (Hamric, 1977). In the literature, little attention is paid to the unique
communication problems which exist in conveying the prognosis of death. The implication of more people dying in hospitals is that news about dying and death largely will be given in an institutionalized setting. How, to whom, and what news is given then become important issues. For example, whether or not the patient is aware of the diagnosis is of crucial importance to his or her treatment and care, especially for nursing personnel who spend a large amount of time in day-to-day interaction with patients. Glaser and Strauss (1965) have given detailed descriptions of the effect of "who, in the dying situation, knows what about the probabilities of death" (p.ix) on staff-patient interaction and patient care. "Awareness context" was the term Glaser and Strauss used to represent this component of the environment, and they found that four contexts were particularly important in the dying situations they studied. They also found that the patterns of interaction within each context occur predictably.

The first, which they labelled "closed awareness context" was one in which staff know the patient’s diagnosis but the patient did not, a situation with which most nurses are familiar. Patients must be led to believe that their illnesses are not fatal and that things will turn out ‘all right’. Patients who remain in a closed awareness context until they die have little chance to say good-bye to their lives, their friends, their families. They do not have a
chance to put their business and personal affairs in order and may make future plans that have to be undone after they die. Family members cannot share their grief with their dying loved one. On the other hand, hospital staff may prefer the closed awareness context in that they do not have to talk about death. Patients who are unaware of their dying may die without much emotional turmoil and the routine of the ward will thus be less disturbed.

The second was a suspicion context, in which the dying person suspects what others know and tries to confirm or negate that suspicion. Patients in this awareness context seem always to be on the offensive in trying to get realistic information from a defensive staff. This is very uncomfortable and unstable state for patients, as there is no consensual validation of their perceptions with staff, and vagueness and insecurity persist.

The mutual pretence context exists when all people involved know that the patient is dying but all in some way tacitly agree to act as if this is not so. There are various rules to follow in playing the mutual pretence game. Dangerous topics are avoided, while safe topics are permissible for discussion as they signify that life is proceeding as usual. One of the consequences of the mutual pretence context is that patients may have some privacy and dignity in their dying. However, as in the other awareness
contexts, isolation and loneliness can occur. Hospital ward organization and mood may be less tense than in suspected awareness. Staff may feel more comfortable in that they do not have to work "psychologically" with a dying patient.

The context of open awareness exists when all people involved acknowledge openly their knowledge that the patient is dying. Staff and patients may have different expectations of each other in terms of the dying process, but one of the positive aspects of open awareness is that these discrepancies can be discussed. Awareness of impending death gives patients a chance to close their lives with some control. They can plan for their family, finish projects, say farewell to friends. They can play a part in managing their own death.

On the other hand, some patients may have a great difficulty in accepting knowledge of their impending death. With these people, open awareness may bring much fear and unresolved despair. This concern may be especially important for the mentally ill who tend to have less skills in coping with stress.

Pine (1975), wrote a paper describing and discussing some of the unique aspects of the institutionalized communication of messages about dying and death. In his paper, he develops two communication models which describe the channels for messages about dying and death. Institutional messages about dying are described separately from institutional messages
about death. "Namely, messages about dying are future-oriented prognostications: while messages about death are of a past event, that is, a completed occurrence" (Pine, 1975, p.2). News about dying was shown to be different than news about death in the way they are communicated.

Most physicians feel that the giving of the diagnosis is their responsibility. However, Mount (1978) discovered that most physicians are not in favour of telling the patient of impending death but would want to be told themselves. This demonstrates a divergence of attitudes towards news about death. Part of the communication problem may be related to their personal anxiety about death, and partly to their medical training which lacks in instruction on how to communicate bad news. "Two of the guidelines given to medical students regarding communication about death are, 'do not tell the patient anything which might induce psychopathology...and hope must never die too far ahead of the patient'" (Pine, 1975, p.3). Of course, this fear would be intensified if one was dealing with a dying person who was already suffering from psychopathology.

Pine (1975) describes how when the physician, who is the gatekeeper to institutional care, has decided that a patient has gone from "having a chance to recover" to "dying" he either implicitly or explicitly communicates the information to the nursing staff. When the doctor has given the
"official" message, both the physician and nursing staff alter their handling of the patient. Very often, the hospitalized patient who is dying is not told directly, and "often becomes and remains an atomized individual in the series of interconnected networks of institutionalized communicating interactors" (Pine, 1975, p.3). Who will talk to whom about the dying patient was found by Pine to be an intricate series of networks of communication. The flow of the message of dying can be conceived of as starting with the physician and spreading in multiple steps "from doctor to nurse, doctor and/or nurse to family, to other hospital staff, to other patients, and to others in an institutionally structured manner" (Pine, 1975, p.5). News usually spreads rapidly and fairly completely soon after the doctor reaches their decision to disseminate the message of dying.

Pine (1975) suggests that there are two gaps in messages about dying. The first is the awareness gap between the knowledgeable personnel and the dying patient and the family. Being aware of a person's impending death implicitly forces the physicians to decide whether or not, to whom, and how they should communicate such information. There are primarily four channels available to attempt to bridge the awareness gap. First, there is the institutional channel of hospital procedures such as the critical list and intensive care units. Second is the channel of roundabout explanations through
others, by encouraging nurses and other staff to be truthful, at least to the dying patients family. The patient is seldom sent news deliberately through this channel. Third is the channel of progressively worsening statements by tracing the history of the illness and giving less encouraging news with each step. Pine says that most often the full truth about dying does not emerge directly but is implicit in general behavioural patterns. Finally, there is the channel of frank explanations. However, even then the eventual course of the illness is often omitted.

The second gap in messages is what Pine refers to as an "importance gap". "This occurs primarily because of the vast difference between the relationship of doctor to patient and of family to patient" (Pine, 1975, p.5). Physicians do not stand to suffer as greatly from the potential loss of a patient life as does the family of that patient. This gap is usually bridged through the channel of progressively worsening statements. The message is made more easily acceptable by establishing an historical progression leading to eventual death.

The manner of announcement of a death also generally follows a well-established pattern. The announcement is usually preceded with some "medically relevant causal antecedent" (Sudnow, 1967, p.137) and is told in a factual straightforward manner. The news about death also spreads in
a patterned institutional manner. "Those who are entitled to a direct communication about death, can be conceived of as forming a series of concentric rings around the dead person, with each ring being differentiated from the others by kinship, age groups, and friendship distinctions and with the occupants of each ring differentially expecting to be informed of the death" (Pine, 1975, p.6). Therefore, the flow of the message starts with hospital staff, spreads to the doctor, who then tells the immediate family, who spread the news on outward (Pine, 1975).

In discussing the gaps in messages, it appears that there is not an awareness gap as a death is communicated directly and explicitly. However, there is a notable importance gap. The importance of the news that death has occurred is very different for the doctor than for the family of the dead person. The gap is bridged by disseminating news by "proper" institutional means such as obscuring visibility of death to eventual announcement by the "proper" person, namely, the physician. News about death, then, are transmitted largely by institutional channels of communication.

Therefore, in general both messages are distasteful. The news are in opposition to the attitude that life ought to be prolonged and that every effort should be aimed at preventing illness leading to death. Also, the institutional senders of the message usually have a relatively small emotional
investment in the situation, whereas the recipients most often have a large one. Both messages are permanent, and place the concept of dying into delimited temporal perspective. Finally, there is the underlying factor that both messages are difficult and embarrassing to communicate. However, since news about dying is somehow received by the dying patient’s family and at times by the patient themselves, this suggests that there must be channels of communication over which such information may flow. These channels largely are institutionalized and they flow by following culturally-induced patterns of behaviour.

9. SUMMARY

In this chapter an analysis of studies relating to the mentally ill and the meaning of death was given. These few studies have raised more questions than answers such as, do the mentally ill experience death and dying in the same way as "normal" people do? From Feifel’s series of studies it can be suggested that the mentally ill view death as a time of peace, and that they have a great need to make amends. It was also thought that death would occur by a traumatic event. This is an area that more research will have to be conducted.

It was also suggested that appropriate practices in caring for the dying had not reached people with a higher degree of psychopathology. In order to address this
suggestion a discussion of six factors that might influence the transition from theory into practice in care for the dying in a mental institution followed. These factors were personal and professional death anxiety, the organization of the hospital system and its inherent pressures, role expectations placed upon the health care professional, education and training in caring for dying persons and their families, teamwork, and conveying and exchanging diagnostic information. The deficiencies that exist in the care of the terminally ill cannot be related to just one factor. All of the above factors must be taken into consideration. These are by no means all of the factors either. These have been identified because they are the most prevalent and also because other factors can be contained within the larger issue. How well these factors are dealt with will determine the appropriateness of care given to the dying individual and their families, whether mentally ill or not.

The issue of death anxiety is an interesting one. As a variable it is a very unstable one, yet the literature suggests that if it is present it can lead to negative behaviour such as distancing and withdrawing from the dying individual. Death has also been correlated with such variables as sex, age, marital status, death of a significant other, and length of occupational experience, with interesting results. This will be duplicated in this study. The
remaining factors were included and discussed to help explain the situation that might exist at Riverview Hospital. How organizations such as hospitals accommodate dying patients, especially dying elderly, was discussed, and possible reasons for resistance to palliative care. Expectations of professional roles can also be important, especially if they are stereotyped and circumscribed. These expectations were shown to have important implications as to how staff members will behave in a given situation. Team functioning will also affect communication and coordination of care. Characteristics necessary for team functioning and the developmental stages of teamwork were outlined. The extent and quality of education and training in caring for the dying will also affect therapeutic care given to the dying person. The final descriptive factor was conveying and exchanging diagnostic information. The studies outlined suggest that the more open the communication, the less isolating death will be. In the next chapter the methodology used to study these factors at Riverview Hospital will be outlined.
CHAPTER THREE

Research Design

1. LEVEL OF DESIGN

The purpose of this descriptive study was to investigate the perceptions of health care professionals regarding practice with dying patients in the Geriatric Division of Riverview Hospital. The analysis of the perceptions of current practice by the various professionals was accomplished in reference to six factors identified as having an effect on the therapeutic care of the dying person. These factors are:

1. Personal and Professional death anxiety
2. Organization of the hospital system
3. Expectations of professional roles
4. Teamwork
5. Education and training in caring for the dying and their families
6. Conveyance and Exchange of diagnostic information.

The goal of the study was to determine if any of these factors played a role in the way the dying patient and their families were being cared for, and to see how these areas of practice were being done, and which staff felt change was needed. To what extent is palliative care believed to be already practised, and what areas of practice can be changed and
improved upon? To what extent is there a need for a formalized palliative care program? The conceptual framework helped to order the data and generated descriptions and explanations that contributed to an understanding of the problem studied and to further plan intervention and development of research.

The variable of death anxiety was measured using the Death Anxiety Scale (DAS), developed and tested by D.I. Templer (1969). The DAS scores were correlated with various personal variables such as sex, age, marital status, length of work experience, experience of death of a significant other. It was predicted that:

1) Death anxiety will be greater for females than for males.
2) Death anxiety will decrease as age increases.
3) Death anxiety will be greater for married people than for single people.
4) Death anxiety will vary inversely with length of experience working at Riverview Hospital.
5) Death will vary inversely with personal experience for death of a significant other.

As well, DAS scores were correlated with various areas of professionalism, such as the work and educational experience of the respondent. It was predicted that:
6) Death anxiety will vary inversely with past work experience with the dying as a student.
7) Death anxiety will vary inversely with past work experience with the dying as a professional.
8) Death anxiety will increase if currently working with the dying and their families.
9) Death anxiety will vary inversely with formal educational experience and training in working with the dying and their families.
10) Death anxiety will vary inversely with informal educational experience and training in working with the dying and their families.
11) Death anxiety will vary inversely with feeling of competence and/or confidence in working with dying people and their families.

These predictions are based on the previous studies on correlates of death anxiety that have been discussed in the Literature Review.

The remaining five variables provided descriptive information specific to Riverview Hospital and the practices and policies regarding work with the dying mentally ill elderly in the Geriatric Division.

To repeat, the factors which comprise the conceptual framework have all been identified and extracted from literature describing the situation in medical institutions.
where people may die. An assumption is being made that these factors will be equally valid in a mental institution such as Riverview Hospital. This assumption is based on the fact that mental institutions are often categorized together with medical institutions as being similar in organizational structure and mandate. In actuality, the philosophy, and milieu that exist in the mental hospital may significantly differ, and thus change the nature of these factors. The conclusions made in this study represent only a beginning analysis, and therefore, must be cautiously generalized to other mental institutions.

2. CHOICE OF METHODOLOGICAL ORIENTATION

This research is essentially quantitative in nature, although there are qualitative aspects woven through the design. The two approaches are compatible as different levels of information are being sought. First, the quantitative aspects of the design are included to determine the distribution and frequency of the responses to the various questions, as well as to test levels of association between DAS and the variables listed above. The quantitative aspects of the paper do not test for cause-effect hypotheses, only correlations. For example, do the scores from the standardized measure, the Death Anxiety Scale, correlate with
work and educational experience, sex, age, marital status, or length of career in a particular work setting? Hypotheses can be created about the social reality that the quantitative approaches address. These associations were tested to see whether or not certain personal or professional characteristics vary with death anxiety. It is thought that the presence of death anxiety in a person will affect the therapeutic care given to a dying individual and their families.

In addition, qualitative methods are utilized in the design, especially in the section of the survey questionnaire that measures staff perceptions of institutional practices and policies around death in the Geriatric Division. Grinnell explains that "qualitative research methods assume that subjective dimensions of human experience are continuously changing and cannot be studied using principles of quantitative research methodologies" (1988, p.186). Therefore, the intention of the qualitative methods was to evaluate the subjective understanding of what the professionals believe should be accomplished and done to change this area of practice. Of course, the qualitative analysis can only be valid at the point and time of the research study. The section of the survey questionnaire measuring staff perception is designed in a way that can be closed-ended or open-ended. For example, question 33 asks "Do
you work as a member of a team when you are working with the dying and their families?". If the respondents answer "yes" or "no" the question is essentially closed-ended. However, if they choose to answer "depends", then they are required to write in the space provided the rationale as to why they responded that way. This allows the question to be open-ended as well. Respondents have the opportunity to share their points of view about the palliative care situation. Of course, there is always the danger that there may be some inconsistency between the response and actual behaviour. The qualitative nature of the design is less intrusive, which has important implications when considering the sensitive nature of the topic under consideration.

3. SAMPLING DESIGN

This study uses nonprobability sampling, precisely, availability sampling. A multigroup design was utilized. From a list of all staff in the Geriatric Division, potential respondents from five professional groups were contacted. A total of 58 potential respondents were finally surveyed. The professional groups surveyed and the number of respondents in each category were: general physicians (10), psychiatrists (10), health care workers (25), pastoral care workers, (5), and social workers (8). The size of the sample for each group
was determined in reference to the number of staff in each of the departments. For example, there is a large number of health care workers working in the Geriatric Division, as opposed to social workers of which there are only eight. Therefore, the sample size for the health care workers is larger in relation to the other professional groups surveyed in order to increase the representativeness of opinions. The original proposal required that occupational therapists, physiotherapists, recreational therapists, dieticians, psychiatric nurses, and psychologists would also be sampled. This first sampling design would have ensured that all members of the 'team' would have been surveyed to create a more complete picture of perceptions of palliative care practice at Riverview Hospital. However, the nature of the final sample was determined by the Scientific Review Board of Riverview Hospital. The rationale used to determine the final sampling procedure was to include only five professions who were assumed to have the greatest contact with a dying patient and his or her family. Psychiatric nurses were excluded due to the fact that, at the time the proposal was being processed by the Scientific Review Board of Riverview Hospital, their professional union was in arbitration and a strike was in effect. The operational definitions for each profession are taken from the British Columbia Mental Health Society job description forms and can be found in Appendix A.
4. DATA COLLECTION

a) Procedure for Data Collection

The data was collected by means of circulating 58 written questionnaires (see Appendix D) to general physicians (10), psychiatrists (10), health care workers (25), social workers (8), and pastoral care workers (5). The cross-sectional survey was completed by a broad mix of people from different age groups, educational experience, work experience, and years of experience at Riverview Hospital. Thus, a description of the social reality as experienced by the respondents was generated from the data collected. The survey was distributed at no cost through the intrahospital mailing system and by hand. A period of two weeks was given in order to respond, after which a follow-up letter (see Appendix E) was sent to department managers and individuals to remind those who had not responded to do so. As the respondents were not asked to identify themselves, it was impossible to know which individuals had not responded, thus follow-up letters were sent to all involved. The completed questionnaires were returned to the Geriatric Division Social Work office where a separate mailbox had been created for the researcher. No access was available to other people in order that strict confidentiality of the results be maintained.
b) Advantages and Disadvantages of Written Questionnaire Survey

The written questionnaire survey method was elected as method of choice for several reasons. First, it is the least time-consuming for the respondent, and it is most convenient to administer. The group to be surveyed was too large to conduct face-to-face interviews in the time available to the researcher. As well, the topic under consideration was very personal and was addressing a politically-sensitive issue. It was hoped that more candid results might be obtained if the respondents are able to answer the questionnaire in private at the time of their choice. Understandably, a written questionnaire concerning issues of palliative care and death and dying is viewed as being less intrusive than a face-to-face interview.

Disadvantages of using a written questionnaire method are that it takes longer to receive a response, and that the response rate might be lower than if personal interviews were used. In order to control the effects of these two factors, the time limit of two weeks and the follow-up letter are applied. Pre-testing the instrument in a pilot project also helped reduce and eliminate offensive questions that otherwise would have slowed or impeded response. This pilot project is outlined in Appendix B, including findings, discussion, and modifications made to the questionnaire.
5. THE MEASURE

a) Construction of the Measure

The instrument itself was divided into four sections, and for the most part involves closed-ended questions with nominal level responses. The entire instrument takes no more than twenty minutes to complete, and is anonymous. Identification numbers are only put on the questionnaire after they have been returned.

**Section One: Death Anxiety**

The first section of the questionnaire was a 15-item instrument that was designed to measure the respondent's anxiety about death, and thus addresses the first factor of the conceptual framework identified in Chapter Two. The Death Anxiety Scale (DAS) was developed and tested by D.I. Templer (1969). It includes a broad range of equally weighted questions addressing death, thoughts of death, disease and time perspective (Marshall, 1982). One advantage of the DAS is that it has been studied and used extensively with a variety of populations including males, females, adolescents and adults, psychiatric patients, and a number of occupational groups (Corcoran and Fischer, 1987). The norms that are reported vary from 4.5 to 7.0 with DAS scores being higher for females and psychiatric patients. In terms of sensitivity to age differences, total score tends to decrease as the age of
the respondent increases, meaning anxiety decreases. In terms of reliability, the Death Anxiety Scale is reported to have fairly good internal consistency with a Kuder-Richardson formula coefficient of .76 (Corcoran and Fischer, 1987). "The DAS also has good stability with a three week test-retest correlation of .83" (Corcoran and Fischer, 1987, p.141). The DAS has been reported to have good concurrent validity, correlating .74 with the Fear of Death Scale (Corcoran and Fischer, 1987, p.141). "It has also demonstrated good known-groups validity, distinguishing significantly between a group of psychiatric patients who verbalized high death anxiety and a control group" (Corcoran and Fischer, 1987, p.141). Marshall (1982) reports that construct validity has been provided in the DAS by the finding of no correlation between the DAS and several measures of religious affiliation, belief, and activity in a sample of college students for whom religion was believed unimportant. Religious subjects had lower DAS scores, suggesting that religion provides a source of support against death anxiety (Marshall, 1982). In terms of convergent validity, the DAS correlated .74 with the Boyer FODS in a sample of 77 undergraduates. Discriminant validity "means that a construct can be empirically differentiated from other constructs" (Grinnell, 1988, p.118). Templer (1970) suggests that death anxiety differs from general anxiety because of moderate correlations of the DAS with the Welsh
Anxiety Scale (.36), the Anxiety Index (no significance at p<.05), the Manifest Anxiety Scale (.39) and an "emotional words" test (.25) (Templer, 1970). Finally, Templer demonstrated that there is not excessive inter-item redundancy in terms of face validity (Marshall, 1982).

**Section Two: Life, Work, and Educational Experience**

The second section of the instrument was geared to elicit information from the respondents on their life, work and educational experience with dying patients and their families, and on the type of training received (ie. formal or informal). It does not measure the depth of experience but simply the possibility of experience. Also, the questions contained in this section were correlated with DAS. For example, the respondents are asked if they have ever experienced the death of someone close to them, ie. a friend or relative. Past and present professional work experience with dying patients, and formal and informal educational experience related to death were investigated. These are included to directly address the factor concerning education and training identified in the literature review. The final issue addressed in this section is competence and/or confidence in dealing with the dying to provide a subjective measure of where the respondent believes he or she are at that point in time in terms of working therapeutically with dying patients.
Section Three: Perceptions of Practice

The third section of the questionnaire addressed staff perceptions of professional and institutional practices and policies related to dying in the Geriatric Division. The questions were derived from the operational definition of palliative care, and covered such practices as meeting physical, emotional, and spiritual needs of the dying individual; needs of the family; and support of the caregiving staff. Also, questions directed at institutional practices such as meeting the pressures of the organizational context, teamwork, role expectations, and exchange and communication of diagnostic information were contained in this section. As well, respondents could indicate the areas of practice where need for change was recommended. Finally, the respondents were asked to comment in an open-ended fashion, their general opinion about whether or not all that can be done for dying patients is being done, and the need for a special palliative care unit or team.

Section Four: Demographics

The final section was a demographic section to provide background information about the respondents. This section asked for such information as sex, age, marital status, length of work experience at Riverview Hospital, specific location where currently work, and professional status. This data was
used for correlations with DAS to study the effect of the variable of death anxiety on practice, and to organize respondents into various categories.

b) Reliability and Validity

It is necessary in any research study to discuss the validity and reliability of the instrument being used. The reliability and validity of the Death Anxiety Scale (DAS) has previously been discussed (see pp.112-114). Reliability and validity for sections 2, 3, and 4 of the measure were not determined.

6. DATA ANALYSIS

In the analysis of data collected both descriptive and inferential statistical measurement were used. Descriptive statistics provide a means by which the sample data can be organized, summarized and interpreted. Inferential procedures allowed the researcher to make generalizations from the sample to the population from which the sample was drawn. The data was analyzed using the Statistical Package for the Social Sciences (SPSS:X). Responses were coded by number and entered into the computer.

The data first underwent a univariate analysis. The data for each question were represented in frequency tables
that included both percentages and proportions. Percentages are necessary for comparing the distribution of the variables with the different occupational groups, particularly since the groups were of a different size. The central tendencies of the various categories of data can be reported. In particular the DAS was scored by assigning a score of one to each item correctly answered (1=T, 2=F, 3=F, 4=T, 5=F, 6=F, 7=F, 8-14=T, 15=F) and then totalling across items (Corcoran and Fisher, 1987). Therefore, the resulting index varies from 0 through 15.

Bivariate analysis was used to measure levels of association. Measures of association describe the degree of correlation between variables. The purpose of cross-tabulating was to determine if there was a potential relationship between variables, and thus, to test hypotheses. The statistical test used for nominal data was chi square ($\chi^2$). This statistical calculation is the determination of the difference between the observed frequencies and the expected frequencies.

7. ETHICAL ISSUES IN THE RESEARCH

All U.B.C. research proposals need approval from the Ethics Review Board of U.B.C. and the research site in accordance to ethical standards and procedures. As this
research only involved the survey of professionals in an institution rather than clients and their families, the number of ethical issues were significantly reduced. Other issues to consider were confidentiality and anonymity, voluntary and informed consent, regard for privacy, use and accessibility to data, and loss of professional status.

To ensure complete confidentiality and anonymity, the respondents were asked in the covering letter (see Appendix D) not to write their names anywhere on the questionnaire. As well, the respondents were informed that all potentially identifying information would be coded into numbers. The covering letter also included a statement that the respondents could withdraw from the study at any time and they would not be penalized for doing so. A promise was made to the respondents that no deprivation in professional status would occur as a result of their responses.

Informed consent is implied if the questionnaire is returned. The phone number and address of the researcher was provided in case there were any questions or concerns. There was no coercion involved in obtaining respondents.

Concern for the privacy and dignity of the respondents is more difficult to address as the questionnaire contains very personal and sensitive material. Again, if the respondents felt the need to debrief from the experience of completing the questionnaire they could do so by contacting the researcher.
The respondents were told in the covering letter and in the introduction to the questionnaire that they were not required to answer any questions that they felt uncomfortable with. A certain amount of invasion of privacy is unavoidable when one is dealing with such a sensitive and personal issue as death.

Data were accessible only to the researcher and her supervisor, and only for educational purposes. The raw data was destroyed after the completion of the research project.

8. PROBLEMS ENCOUNTERED IN THE RESEARCH

There is no research project that is without its share of problems and this was no exception. There is a particular dilemma in designing research related to issues of death and dying in the organizational context of a hospital institution. Obviously, when one is proposing research in the area of death and dying, one has to be sensitive to and cognizant of various personal and professional beliefs, values, expectations, and decision-making processes regarding this area. One also has to be aware of ethical concerns when involving the family and most importantly the dying individuals. It was with this consideration that the author chose to proceed with a less interfering design and only survey the professional staff. This design would not threaten the well-being of the client in any way. As well, this design better suited the purpose of
the study, which also included providing education and increasing awareness for the concern of the welfare of the dying individual and his/her family.

Before granting approval to do the research, the Scientific Review Board of Riverview Hospital had to carefully assess the professional and political implications of such a study, and determine whether or not it was in the vested interest of the Hospital to have the research conducted. This consideration took five months to complete, partly out of respect for the contentious history of palliative care at this institution.

The second major problem encountered during the research was a strike by the psychiatric nurses at Riverview Hospital. Because of this development, the Review Board drastically altered the sampling design to exclude nurses and six other professional groups and to include health care workers. In effect, this resulted in reducing the power of the study because it would be impossible to get a complete picture of the current situation regarding practice with dying individuals. Also, it made the data collection procedure more difficult to accomplish, as health care workers are supervised by the nursing administration. Once these issues were resolved the project proceeded without further problems being encountered.
9. SUMMARY

In this chapter the research design of this project was outlined. Specifically, the level of design, choice of methodological orientation, sampling procedure, data collection methods, description of the measure, and ethical issues were discussed. As well, the rationale for choosing the design was discussed for each area, including the strengths and weaknesses. Chapter Four will report on the findings of the research project.
CHAPTER FOUR

Results

1. INTRODUCTION

Overall, the results indicate that this study has been a useful exercise to come to some understanding of the perceptions of palliative care practice by health care professionals at Riverview Hospital. It has identified key areas of practice that are done well, and others that need to be changed or improved upon. It has provided valuable information that the administration at Riverview Hospital can use as it contemplates the best approach to take in caring for its dying patients in the Geriatric Division. Therefore, in the following chapter the results of the correlations of the variable of death anxiety with the various personal and professional variables will be presented. As well, a description of staff perceptions specific to practices and policies regarding the dying will be explained.

2. DEMOGRAPHIC DESCRIPTION OF RESPONDENTS

The results of the study showed that 23 out of 58 questionnaires were completed, for a return rate of 40%. This is considered to be a fairly reasonable response rate in
research circles. The final sample consisted of social workers \((n=8)\) [SW], health care workers \((n=10)\) [HCW], general physicians \((n=2)\) [GP], psychiatrists \((n=2)\) [Psych.], and pastoral care workers \((n=1)\) [PCW]. The percentage of returns according to discipline was social workers \((100\%)\), health care workers \((40\%)\), physicians \((20\%)\), psychiatrists \((20\%)\), and pastoral care workers \((20\%)\). Because of the small sample size, particularly for each of the individual professions, the findings discussed in this chapter must be interpreted with caution. The percentages presented in this chapter will also be valid percentages, meaning percentages not including missing cases. In other words, the valid percentage is the percentage given for all who answered the question.

The demographic breakdown was 16 \((70\%)\) of the respondents were female, and 7 \((30\%)\) were male. In terms of age, half of the sample was below the age of 40, and the other half was 40 or older. About two-thirds of the sample were married, and the rest were single, separated or divorced. Of the respondents, five \((23\%)\) had worked less than two years at Riverview Hospital, eight or 35\% had worked between two and five years, two \((9.0\%)\) had worked between ten and fifteen years, and seven \((32\%)\) had worked over fifteen years. The median for length of work at Riverview Hospital was greater than two years and less than five. The shortest someone had worked was three months and the longest was twenty years. Of
the general physicians, psychiatrists and pastoral care worker, all had worked at Riverview for less than five years. In contrast, the social workers and health care workers in the sample had more experience at Riverview Hospital.

3. SECTION ONE: DEATH ANXIETY SCALE (DAS)

This section is included in the questionnaire to address the first variable of the conceptual framework, namely, personal anxiety of death. As well, the possible correlates of death anxiety will be discussed in terms of the findings achieved.

a) Overall DAS Scores

The overall mean of the Death Anxiety Scale, the arithmetic average, is 6.35 with a standard deviation of 3.17. The mean falls within the norm that Templer (1969) established for the scale, which is 4.5 to 7.0. Kurtosis is .246 which means that the distribution is skewed to the right or toward larger numbers. The distribution is fairly normal, and the fluctuation about zero could have been resulted from sampling variation. Therefore, on the average, Riverview staff in this study was found to have expected or normal levels of death anxiety.
b) DAS by Profession

For this sample the professions can be categorized from least anxious to most anxious in this order:

<table>
<thead>
<tr>
<th>Profession</th>
<th>X</th>
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</thead>
<tbody>
<tr>
<td>1) general physicians</td>
<td>3.0</td>
</tr>
<tr>
<td>2) social workers</td>
<td>5.5</td>
</tr>
<tr>
<td>3) health care workers</td>
<td>6.8</td>
</tr>
<tr>
<td>4) psychiatrists</td>
<td>8.5</td>
</tr>
<tr>
<td>5) pastoral care worker</td>
<td></td>
</tr>
</tbody>
</table>

Again it must be noted, that due to the small sample this finding must be interpreted with caution. Of interest, the social work group have the widest range of scores going from 1 to 14, with a mean of 5.5. As a group they were all within or below the norm except for one respondent. The score for the pastoral care worker has been withheld to maintain confidentiality.

c) DAS by Gender

It was predicted that death anxiety will be associated with respondent’s gender. Results indicated, however, no significant correlation between the variables. Overall the mean for the female respondents (6.44) is slightly higher than for the male respondents (6.14). Two of the seven males were above the norm as opposed to 6 of the 16 female respondents. The range for the male respondents was also narrower than for
the females. Specifically for the social work sample, the female respondents have a higher mean at 5.8 than the male respondents at 5.0.

d) DAS by Age

The DAS scores can also be reported in terms of the ages of the various professionals. The hypothesis is that death anxiety will decrease as age increases. Overall the results showed that DAS scores were not significantly correlated with age for this sample. Interestingly though, those who scored above the norm and were 40 or older were all female.

e) DAS by Marital Status

The prediction made concerning DAS and marital status was that death anxiety will be higher for married people than for single people. However, although a statistically significant correlation was not found (r=.33 p=.07), the trend for the DAS scores showed that the single respondents tended to have higher scores than those who were married. The two respondents who were separated and divorced scored even lower. Within the social work sample the mean for single respondents was 6.0, married 5.5, and divorced 5.0.

f) DAS by Length of Work Experience

The final correlate for the DAS scores is length of work
experience at Riverview Hospital. It was predicted that death anxiety will inversely vary with length of experience working at Riverview Hospital. The respondents who worked under two years and over fifteen years have the highest means at 7.4 and 7.6 respectively, which are both over the established norm. Otherwise the trend (Kendall's Tau is \(-0.321, p=0.034\)) is that DAS increases with length of experience. The group of respondents who had worked for two to five years at Riverview Hospital had the lowest mean equal to the minimum value of the norm (4.5).

4. SECTION TWO: LIFE, WORK, and EDUCATIONAL EXPERIENCE

In this section, the correlates of DAS, namely experience of death of a significant other, past and present work experience with the dying and their families, education and training, and feelings of competence and/or confidence when working with the dying, are addressed. The questions concerning education and training also provide descriptive information to address the education and training factor of the conceptual framework.

a) Death of Someone Close

It was predicted that death anxiety will vary inversely with personal experience of death of a significant other.
Death of a significant other, ie., a relative or friend, was reported by a majority (96%) of the respondents. Those who responded that they had experienced a death scored on the DAS across the range of possible scores. Therefore, no trends in terms of experiencing the death of someone close and score on death anxiety were found. We cannot know with any certainty what effect death may have had on the personal anxiety of the respondent.

b) Work With Dying Patients as a Student

Student experience with dying patients was reported by about two-thirds of the respondents (60.9%). The mean for the respondents who had worked with dying patients as a student (5.86), was lower than for those who had not (6.6), which is a marginal difference. The prediction that work as a student would decrease DAS was, therefore, not statistically supported. Interestingly, however, the social workers who responded affirmatively had a mean of 4.0 as opposed to 7.0.

c) Work With Dying Patients as a Professional

The majority of respondents (87%) reported that they had worked with dying patients and their families as professionals. It was predicted that DAS would vary inversely with experience of working with the dying and their families as a professional. Those who had worked professionally had a
DAS mean of 6.3. Those who had not scored a mean of 7.0. The number of respondents who have not worked with dying patients is too low to suggest a true prediction.

d) Currently Working With Dying Patients

It was predicted that those who were currently working with dying patients and their families would have higher death anxiety than those who were not. The overall DAS mean for those working with dying patients (6.1) was lower than those who were not (6.6) but the difference is not significant. At the time of completion of the questionnaire, only ten (45.5%) respondents were working with dying patients. Another nine (40.9%) were not, two (9.1%) were unsure, and one (4.5%) answered that it was not applicable. Of interest, the mean for the social workers who were working with dying patients was 2.0 compared to 8.0 for those who were not.

e) Formal Education Experience

In terms of educational experience, half (52%) of the respondents had some form of formal education or instruction on the subject of death and dying. It was predicted that death anxiety will vary inversely with educational experience and training in working with the dying and their families. No significant correlation was found.
f) Informal Education Experience

The next issue addresses the issue of informal education on the subject of death and dying, such as in-services, training workshops, or conferences. Only 9 of the 23 (39%) respondents had attended such events. Over half of the total sample had not, and one respondent thought it not applicable. Interest in attending these informal education events tended to be highest with the social work sample and the pastoral care worker. Over 62% of the social workers had attended, and the pastoral care worker also responded positively. The general physicians were divided in their answers, and both psychiatrists had not attended any training programs. As well, only 20% of the health care workers had attended, 70% had not, and 10% thought it not applicable.

It was predicted that death anxiety will vary inversely with informal education and training in working with the dying and their families. Interestingly, for the total sample of those who had attended informal training the mean DAS was very low, in fact, below the norm. The respondents who had not attended actually had a mean DAS above the norm at 7.46, and also the respondent who felt it was not applicable had a higher score. Therefore, the prediction is supported ($X^2 = 38$, df=18 $p > .001$). This trend is continued when we look at the DAS means correlated with the responses to this question for each individual profession.
g) Competence and/or Confidence in Work With Dying Patients

Half of the respondents felt competent and/or confident in working with dying people and their families. Another 17% responded negatively to this issue, and another 30% were "unsure". The groups that were positive about their competence and/or confidence were the general physicians and pastoral care worker. The psychiatrists were less sure with one responding negatively, and the other unsure. Five health care workers felt positively, one did not, and four were unsure. Similarly, half of the social work sample felt confident and/or competent, 2 were not, and another 2 were unsure.

It was predicted that death anxiety will vary inversely with feeling of competence and/or confidence in working with dying people and their families. Related to the DAS, those respondents who felt positive about this question had a mean of 5.58, those who were not had a mean of 6.5, and those unsure scored 7.57. Therefore, there is a trend that supports the prediction, although it is marginally significant. This trend was not consistent when the analysis was done for individual professional groups.
In this section the respondents were asked questions pertaining to their perception of palliative care practice and policies of the Geriatric Division. The questions were derived from the operational definition of the concept of palliative care and can be categorized according to the remaining factors of the conceptual framework described in Chapter Two. The factors addressed in this section included the organizational issues of the hospital, professional role expectations, issues of teamwork, and communication of diagnostic information. The questions contained in this section can thus be grouped according to these four variables outlined that can affect the therapeutic care of the dying and their families. The findings will be presented as they pertain to these variables.

a) Organizational Structure of the Hospital System

The issue of the organization of the hospital system and its inherent pressures was broken down into distinct questions to measure whether or not the organization was able to meet the identified needs of the dying patient, family, and caregivers, and where need for change is indicated. In terms of physical needs of the dying patient being met (i.e., pain control and symptom relief), 17 or 81% of the respondents
answered that this need was being met. The remaining 4 or 19% of respondents felt that it depended, especially on the doctor involved. When asked if there was a need for change 4 (31%) respondents felt there was, 6 or (46%) answered "no", and 3 (23%) were unsure.

When asked if the emotional needs of the dying patient were being met 6 (30%) answered "yes", 7 (35%) answered "no", and another 7 (35%) answered "depends". Emotional needs were described as need to express grief and loss, and understanding meaning of their life and death. Those who responded that it "depends" commented that it was dependent on the staff involved and how comfortable they feel with the issue, as well as on the "mental ability" of the patient. There was a clear message for need for change as 10 of the 14 who answered responded with a "yes". The general physicians, psychiatrist, and social workers who responded thought change in meeting this need was necessary.

Spiritual needs are those that deal with the person's relationship with God, however defined by the individual. Over half of those who answered agreed that this need was being met. Four (23.5%) did not think spiritual needs were being met, and another four (23.5%) thought it depended. The latter respondents commented that it depended on whether the dying person made a request for spiritual comfort, and on pastoral care services. Regardless of the number of
respondents who thought spiritual needs were being met, 41.7% still thought there was a need for change.

The next organizational concern related to the needs of the care-giving professionals. Can the caregivers meet their need to express their own grief and loss from the death of a patient, and can they get relief from their burden? Over half (58%) of the respondents stated that this need was not being met. One social worker commented, "I don’t think we look after one another in the way we should. It’s one of those "weaknesses" among mental health professionals". In fact, 6 out of 8 social work respondents did not feel this need was being met, as well as one psychiatrist and 4 health care workers. Indeed, 62.5% of the respondents agreed that there was a need for change in this area.

Palliative care must also necessarily meet the needs of the family of the dying patient, i.e., providing emotional support and help within the bureaucratic hospital environment, as they are included in the unit of care. In terms of the Riverview Hospital organization meeting the needs of the family, 47% thought the needs of the families were being met, 35% did not think so, and 18% thought it depended. One social worker offered that meeting these needs depended on the staff involved and how sensitive particular members of the staff are to this situation. As well, another social worker commented that it depended on the actual availability of the family. An
overwhelming 69% of the respondents felt that there was a need for change in this practice.

Another issue is the availability of support for the care-giving professionals and others working with dying patients, such as counselling services within the organizational structure. Approximately three-quarter (72%) of the respondents did not think that this type of support was available, or if it was available did not know of its existence. Only 11% thought that support was available, to some extent through pastoral care services. When asked if there was a need for change in this area, 92% thought "yes".

The last question that pertains to issues of the organizational structure of the hospital concerned the ability to work "psychologically" with the dying patient considering the work routine of the respondent. One third (32%) of the respondents felt that their work routine did allow them to work "psychologically" with the dying patient, 42% did not, and 26% thought that it depended. A general physician felt that this work could only be done "within the limits of the mental state of the patient". A health care worker suggested that their ability to do this depended on "which type of ward" they were working on at the time. A social worker made the observation that "sometimes numbers are more important than "quality" time". Both general physicians and the pastoral care worker agreed that they could accomplish "psychological"
care of the dying patient within their work routine. The health care workers and psychiatrists felt that their work routine would not allow for it. Social workers were divided on the issue.

b) Role Expectations of Professionals

The second issue addressed in this section is the role expectations of the professionals. A majority of respondents (60%), agreed that their role was stereotyped by others. Health care workers, especially, felt that their role was stereotyped by others. Yet there was not an overwhelming perception for the need for change in this area. Only 46% of the respondents thought there was a need for change, and this group was only made up of social workers and health care workers. The rest of the professions did not really think there was a need for change.

The other question pertaining to role asked the respondents if their professional role limited the provision of therapeutic care to the dying patient. Again, social workers and health care workers comprised the 33% of the respondents who answered positively. The general physician, psychiatrist, and pastoral care worker did not think that their role limited their ability. Interestingly, the social work respondents said that there was a need for change while the health care workers did not. The general physicians did
not think there was a need for change in this area, and all other answered that it depended.

c) Teamwork Amongst Professionals

A team approach to therapeutic treatment of patients is said to be taken at Riverview Hospital. The findings from this study also suggest that there is teamwork amongst the various professional staff. A majority (81%) of the respondents agreed that there was teamwork. Only one respondent did not agree, and that person was a social worker. Another social worker and health care worker thought that it depended, and qualified that by indicating that they were operating under a medical model which restricts team functioning. The majority of the respondents did not feel that there was a need for change in this area. Only two social workers stated that change was necessary.

A different picture appears, however, when the respondents were asked whether or not they personally worked as a member of a team when working with the dying. This time 70% said they worked as a member of a team, and 30% said they did not. It would appear from these results that the professionals recognized the presence of teams but did not work as a team with dying patients. Perhaps, also, this result indicates that there is no shared model of how a team would collaborate when it comes to death issues. Again,
social workers and health care workers stated that there was a need for change.

d) Exchange and Communication of Diagnostic Information

The final issue explored in this study was the issue of conveying and exchanging diagnostic information. Four questions contained in the survey addressed this issue. The first asked if, in most cases, the patient was made aware that she/he were dying. Only 22% of the respondents said that the patient was made aware. Forty-four percent did not agree that the patient was told about impending death. Five out of eight health care workers responded this way. Another 33% thought that the patient was told only under certain conditions, depending on factors such as their level of understanding or mental and emotional stability. Interestingly, no one respondent stated that this situation should be changed. Half of the respondents, including a general physician and a psychiatrist, thought that it should not be changed. The other half answered that change should depend on the situation. One respondent commented that the dying patients should usually be told but with discretion allowed not to tell some.

Some interesting findings appear when the respondents are asked whether or not they believe that most patients understand they are dying when they are told about impending
death. The results are split evenly across the response categories. Thirty-five percent (35%) believe that the patients do understand, 35% believe that they do not, and 30% are unsure or suggest it depends. Those who agree that patients understand when told they are dying include the physicians, psychiatrist, and some social workers. One physician even goes so far as to suggest that the patients "understand before they are told". Most health care workers take the opposite view. Those health care workers who concede that the patients might possibly understand suggest that it really depends on their capability of understanding their situation. Not one respondent felt that there was a need for change in this area. In fact, half of the respondents were opposed to change, and the other half thought change was possible but only under certain conditions.

Next, we must consider the family of the dying patient and whether or not efforts are made to inform them of the impending death. Almost all (90%) of respondents did indeed believe that as a rule, efforts are made to inform the family that their relative is dying. Only one respondent did not think that this was done, and that person was a social worker. Although the response to this question was overwhelmingly positive, 31% still thought there was a need for change. This group only included social workers and health care workers. The general physicians and psychiatrist thought change
unnecessary.

The final indicator for the issue of communication about the subject of death and dying concerned hospital personnel participating in discussion related to death and dying. Three-quarter (76%) of the respondents did not think that discussion of this nature was avoided, yet 19% thought that there was avoidance. These last respondents were social workers and health care workers again. The majority (71%) of the respondents stated that there was no need for change in this area.

e) Qualitative Analysis for Open-Ended Questions

The final questions in Section Three were open-ended questions regarding the respondents' opinion on the state of affairs at Riverview Hospital regarding dying people, and what they would recommend take place to address this issue. A qualitative analysis was done on these questions.

The first question asked whether the respondents agreed that all that can be done for the dying patient at Riverview Hospital was being done. The number of respondents that commented on this question was 17 out of 23. The general consensus on the question indicated that there is not enough being done. Approximately 59% of the respondents stated that not enough was being done, whereas the remaining 41% thought
that enough was being done. However, of this latter group three of the responses were qualified. Many of the comments were directed at outlining the various areas of practice that could be improved to enhance the situation for the dying patients, families, and the caregivers.

A first area of concern is associated with the counselling and emotional support that the dying patient is receiving. Approximately 29% of the respondents articulated this concern. In particular, an observation was made that because the institution is operating according to a medical/curative model, there is little provision for emotional, spiritual, and psychological needs of the patient. Although there is some agreement that physical and medical needs are being met, improvement is needed in terms of helping the dying patients to deal with their unfinished issues. It was explained that in some instances patients meet their needs by having developed supportive relationships with staff, but that for these staff members it was considered above-and-beyond their normal duties to maintain this involvement. Therefore, social support is not provided for consistently across units.

Similarly, there was a recognition by some respondents (24%) that support for the families was lacking. Families as well need psychological and emotional support in coming to terms with this transition between life and death of one of their members.
The social worker respondents (18%), in particular, commented on the emotional well-being of the staff caregivers. It was noted that the stress that the caregivers experience directly affects the care that they give. It was suggested that staff needs may be met through more education and training, and support groups. The Human Resources department and the Chaplain could take a more active role in providing training and education for the staff who are directly involved in caring for the dying patient and family. As well, respondents wished that administration would take a more active role in providing death and grief workshops for staff. One social worker also suggested that it is important to look at cross-cultural issues about death and dying. This same respondent named physicians as being the group that needed the most training in dealing with families and patients, in order that they stop delegating some of the unpleasant tasks to others.

In dealing with the question of whether or not all that can be done for the dying patient is being done, some other concerns were raised. One issue that was noted was the practice of transferring patients off the ward to an acute medical environment (North Lawn) as their medical needs increase. It was recognized that sometimes these patients have been on the same ward for years and then are sent to die in strange surroundings with staff who do not know them.
Another ethical issue raised by a health care worker was the aggressive use of codes. To explain, codes are designations given to patients regarding who will receive extraordinary life-saving measures and who will not. This respondent was disturbed by the effect on the patient of medical practices geared to save life at all costs. This seemed to prevent some patients from dying in a dignified and peaceful way. The health care worker notes, "There is supposed to be peace and acceptance in death. With a policy such as this, and with the age of the patient involved - how can they die peacefully?".

Although most of the respondents agreed that not all was being done and that there were areas of service that could be improved, there were some respondents who felt the situation to be satisfactory. In fact, 6 out of 10 health care workers thought that all that could be done was being done. Says one health care worker, "I believe that the dying patient at Riverview Hospital has the best possible care administered to she/he (sic) and that she/he (sic) are allowed to die with dignity". In particular it was believed that everything was being done for the extended care type geriatric patient. One psychiatrist also agreed, but called for practice to be formalized by a palliative care unit or team.

The second open-ended question concerned the need for a special program to be implemented (ie. palliative care unit, palliative care team) to address the needs of the dying
patient and their families. A total of 17 out of the 23 respondents answered this question. Only two of these seventeen respondents did not think that a "special program" should be implemented. A number of other respondents agreed on the need for a palliative care program but wanted to add some qualifications and restrictions on the nature of this "program". One social worker and five health care workers had no comment to make.

It would appear from those who are in agreement about implementing a special program that a palliative care team (29%) is somewhat preferable to a palliative care unit (18%). There is some concern about segregating dying patients and taking them out of their home environment. A palliative care team could provide the additional care needs on the home ward so that the dying patient could remain in familiar surrounding amongst people they know. A palliative care team could also make provisions for increased emphasis on counselling to deal with the emotional issues, stress, and 'adjustment' on the part of the dying patients and their family.

Those who agree that a palliative care unit is necessary (18%) suggest that patient and family needs can only be met by staff working in a special area. If a unit was available, suggests a health care worker, people would be in a better position to support one another. As well, a special area within the hospital would provide the environment for patients
to come to peace with themselves and their death, and for families to better deal with the impending loss. It is recognized that families are often struggling with guilt feelings about having a relative in a mental hospital. The pastoral care worker comments on the family: "Families need to know that 'working through' grief and death is very healthy. [Families also need to come to terms with] their lack of understanding of illnesses that deprived a loved one of a 'normal life'". A palliative care unit would provide such a safe environment to confront these issues.

It is also suggested by some respondents in response to this question on a special program, that a palliative care policy and philosophy is more important than either a palliative care unit or team at this stage. Further, if policy procedures were implemented on the wards, a special program would not be necessary. It is recommended that the Hospital administrators should provide a clear, straightforward policy and procedural guidelines on death and dying issues.

"The fact that someone is committed under the Mental Health Act should not be a limit to a person's right to have a dignified, pain free, comfortable death" (social worker).

In constructing such guidelines, it is suggested that the hospital administrators consult patients, families, and the
various disciplines for input into this matter. In particular, one social worker requested that there be a policy and procedures for staff to follow in providing support and guidance to the relatives of the patient who has died. In other words, there should be policy regarding bereavement follow-up procedures.

The two general physicians were the most reticent on this question. One physician simply responded by saying, "It would be interesting to study such a proposal". The other was adamant that there was no need for a "policy", and if a program were to be implemented it would be one involving few people, "no rules, no procedural redtape, and consultation only". In contrast, both psychiatrists were in agreement that a palliative care team should be in place, and that indeed all facilities should have such a team.

6. SUMMARY AND CONCLUSIONS

In this chapter the findings from the thesis research project were presented. A quantitative and qualitative analysis were conducted. The quantitative analysis included univariate, bivariate, and multivariate analysis using SPSS:X. More specifically, the quantitative results suggest that overall personal anxiety of death of these professionals falls within the norm. However, for general physicians they scored
below the norm, and the psychiatrists and pastoral care worker are above the norm. When the DAS scores were correlated with sex and age there was no significance, and only a marginal association was found with marital status and length of work experience at Riverview Hospital. Furthermore, DAS scores did not correlate significantly with having worked with dying individuals as a student, professionally, or currently. In terms of education, formal education had no real impact on DAS scores. However, having experienced some form of informal education such as attending an in-service or workshop had considerable significance. In fact, those who had informal education scored DAS scores below the norm as opposed to those who had not who scored well above the norm. Those professionals who perceived themselves to be competent and/or confident in working with dying individuals and their families also scored lower in terms of personal death anxiety.

With respect to organizational issues there was agreement that physical needs of the dying individual were being met. Emotional needs of the dying individual and needs of the caregivers (ie. staff) were said to be not met. Also, there was agreement that there was a need for change in terms of how the family needs were being met, as well as spiritual needs. Generally, work routine was thought to interfere with working "psychologically" with the dying, especially for health care workers, psychiatrists, and social workers.
The majority of the health care professionals perceived their role to be stereotyped, although only the social workers and health care workers thought that this area needed to be changed. In fact, these two groups perceived that the stereotyping of their role limited their ability to provide therapeutic care for the dying.

There was strong agreement that teamwork existed; however, when asked whether or not they worked as part of a team when working with the dying, social workers and health care workers answered that they did not.

With respect to the issue of conveying and exchanging diagnostic information, the results suggested that patients were generally not told that they were dying, and that there was no need for change in this area. The respondents were even unsure as to whether or not patients even understood this information. Conversely, families of the dying patients were told as a rule. The health care professionals also evaluated that the staff does not generally avoid discussing the issue of death and dying.

Overall, the consensus was that not enough is being done for the dying patient, especially in provision of emotional and psychological support. As well, there was recognition that there needed to be increased support given to the families. The social workers were the strongest advocates for increased consideration into the emotional well-being of the
staff itself, through education and training and support mechanisms. There was less consensus as to what form care of the dying individual and the families should take. The presence of a palliative care team seemed preferable to a separate palliative care unit, followed by a philosophical approach that involves no imposed structure or regulations. The results then indicate that further research into the nature of palliative care at Riverview Hospital must be carried out. In the next chapter, the discussion resulting from these findings and final conclusions will be presented.
1. INTRODUCTION

This research project has been entitled "Perceptions of Palliative Care Practice of Health Care Professionals in a Mental Institution". Therefore, not to sound redundant, it is a study of perceptions of practice and not actual practice. It would be impossible to study actual practice by means of the methodology chosen. It is a survey of particular professionals at a point in time on what they believe to be the practice with dying geriatric individuals. Vander Zanden (1984) defines perception as "the process by which we gather and interpret information" (p.33) and which serves as the mediating link between individuals and their environment. Therefore, perception permits us to sense the world around us and assign meaning to this sensory input. We do not respond directly to events, objects, and people, but to the meaning we attribute to them.

Therefore, the respondents' task in this research project was to describe their environment by abstracting, generalizing, and idealizing the context. They were in turn asked to describe their perceptions within the conceptualized categories given to them. Concepts were used to organize and
make sense of their practice experiences.

It follows from this, that the author as well, is using her own perceptions of the findings to make interpretations. The possibility for error in interpretation becomes greater as we get further removed from the source. Therefore, this type of study has a serious weakness and due caution must be taken in generalizing from the results. This needs to be further emphasized due to the small sample size. As well, it is important to note that those who filled out the questionnaires may have been less anxious to begin with. Nevertheless, response from each of the professional groups was appreciated.

2. SECTION ONE: Death Anxiety Scale (DAS)

A number of comments have been made in the literature regarding the death anxiety level of many of the health professionals, especially physicians. Although the findings of this study did not support many of those predictions on this subject, the findings are nevertheless predictable in many ways. For example, the two general physician respondents both scored very low, and this is contrary to Feifel’s (1955) hypothesis that physicians have higher death anxiety. Although these findings do not support his hypothesis, that doesn’t necessarily mean that it is any less plausible. It does suggest that we consider some factors that might have
lead us to these particular results. Areas to consider might be the setting and practice situation that the physicians are working in. Most of the patients that these physicians are involved with in the Geriatric Division of Riverview Hospital are either considered chronically ill or are admitted for assessment and short-term treatment. Neither of these two situations are perhaps as anxiety-provoking as the acute care situation where there would be a preponderance of life and death decisions to be made. As well, the general attitudes about the elderly, and mentally ill elderly in particular, that suggests that their death is more predictable and acceptable may prevail. Thus, for the physician, this environment and attitudes that persist may allow the physician to remain detached and use other defense mechanisms to control personal anxiety. It also cannot be ruled out that these two physicians have had positive personal experiences with death and so their anxiety around death may be lower.

Furthermore, if the situation with a terminally ill patient becomes too intense for the physician, that physician can create a socio-emotional distance by referring the patient to pastoral care. Indeed there was a sense that this practice was happening at Riverview Hospital in the qualitative analysis. A number of respondents suggested that the burden for providing education and support should fall on pastoral care services, as if it was the most appropriate department to
deal with death issues. Misconceptions exist about the role of pastoral services in care for the dying. However, clergy vary as much in ability to deal with problems of death and bereavement as do other health care professionals. This was shown in this study where the pastoral care worker had the highest death anxiety score as a representative of that professional group. It is impossible to know whether or not this particular respondent had more death anxiety because of intense exposure to the realities of Riverview Hospital due to the role. Pastoral care workers are normally brought in to handle such cases, so there would be little opportunity to avoid the situation if it arose. Although pastoral care workers are a vital dimension of the palliative care team, it must be remembered that terminal patients have needs aside from religious formalities. We need to appropriately utilize pastoral care services and not simply use them to deal with a situation we might find uncomfortable for ourselves.

Again it is not surprising that psychiatrists also scored above the norm. Traditionally, psychiatrists have not been involved in working with dying individuals, although there is a place for their service. This is very interesting because many of the realities that dying patients experience such as depression, separation, isolation, objectification, and invalidism belong within the province of psychiatry. Weisman (1978) believes that one reason why psychiatrists do not treat
the dying is found in the viewpoint of psychiatric training itself. He suggests that the orientation of psychiatrists is to assume that psychiatric patients are physically healthy, and that the "cause" of the mental disorder is not likely to be the same as that which produces organic diseases from which people die. Consequently, psychiatrists are diffident about treating patients who are "really sick". Most psychiatrists are trained to provide psychotherapy in an office practice or for hospital management of institutionalized patients. They are strikingly unsophisticated about emotional problems of physically ill or terminally ill patients.

In terms of the Death Anxiety Scores found with the social work sample, the results are not that surprising. It might be predicted that as a group mean scores would fall within the norm. The variability of individual scores across the range demonstrates that individually social workers are as susceptible as any other health care professional to experience death anxiety. However, professionally the group scored low and this may speak for the type of training that social workers receive, historical role in palliative care, and general interest in the subject of palliative care. Social work training is offered within a holistic viewpoint and largely focuses on all types of grief and loss issues, and self-determination. Therefore, the relationship between the principles of palliative care and of social work as a
profession complement each other. The predictions that were made before the study regarding personal variables were that DAS scores would be greater for females than for males; would decrease as age increases; and would inversely vary with length of experience working at Riverview Hospital. These predictions were not supported as the level of association was not significant. This lack of significance simply may be due to the small sample.

However, it may also be due to the instrument itself. The scale was developed in 1969 and therefore, is perhaps outdated to some extent. For example, one would be hard-pressed in this fast-paced world to find many people who are not "often distressed by the way time flies so very rapidly", or who would not agree with "I often think about how short life really is". Also, in this rather unstable time politically, economically and socially, most would not disagree with "I feel that the future holds nothing for me to fear". Certainly people are afraid for their jobs, income security, or family well-being. Also, the statement "I shudder when I hear people talking about a World War III" is perhaps not as relevant as it may have been in the 1960's and 70's. Therefore, the results for this scale may have been very different if it was modified for the 1990's.
3. SECTION TWO: LIFE, WORK, and EDUCATIONAL EXPERIENCE

As was discussed in earlier chapters, the life, work and educational experience of a person help shape personal and professional attitudes toward death and thus, subsequent behaviour with dying people. Thus, it was with some confidence that the following predictions had been made:

i. DAS will vary inversely with personal experience of death of a significant other

ii. DAS will vary inversely with past work experience with the dying as a student

iii. DAS will vary inversely with past work experience with the dying as a professional

iv. DAS will increase if currently working with the dying

v. DAS will vary inversely with formal educational experience and training in working with the dying and their families

vi. DAS will vary inversely with informal educational experience and training in working with the dying and their families.

iv. DAS will vary inversely with the feeling of competence and/or confidence in working with dying people and their families.

In regards to the first prediction, there was no apparent difference in scores for those who had experienced a death of
someone close and the respondent who had not. This is not entirely surprising since the respondents were not asked about the recency of the death or the degree of significance of the person who died to the respondent. In the literature review, it was noted that DAS tended to increase if the death of a significant other occurred in the last two years.

Having worked with dying patients as a student had some relationship to DAS scores, especially for social workers, physicians, and health care workers. The mean score for social workers who had worked as students was substantially lower than those who had not. It is interesting to note that health care workers were unsure or thought it not applicable about working with dying patients as a student. Working with dying patients as professionals did not reveal anything significant other than there was a large majority who had done so. Those who had not were health care workers. Currently working with dying patients did not seem to cause a variation in DAS scores. This result was surprising as common sense would tell us that closer proximity to death should increase our death anxiety.

The most surprising results of this section were found regarding the two questions on education. Formal education did not seem to have an impact on DAS scores as compared to informal education where significance was very high. Possible explanations may have to do with the quality of education
and/or the motivation for attending. Those who actually received formal education may be no different than those who had not if the quality of instruction was poor, or if the students were not emotionally ready to learn about this topic. Those who attended informal service would do so on their own volition, and would probably attend because they were less anxious and not the opposite.

Although significance was not great, those who felt confident and/or competent scored lower better on DAS compared to those who were not or were unsure. Therefore, there seems to be an association between the perception of being confident and/or competent and the level of death anxiety one will experience. Intuitively it makes sense that, if you feel confident and/or competent, your anxiety about a situation should be lower. These findings demonstrate that. Those who were unsure scored higher than those who responded that they did not feel confident and/or competent. People who admit their vulnerabilities may be less anxious than people who have not yet faced them directly.

One way that Riverview Hospital might approach the issue of competency in working with dying patients would be to offer some form of educational program or orientation to those already working with dying people and to those who will be. This was suggested by a number of respondents. The focus of a program could be narrow such as pain control or counselling
the bereaved, or could be broad in focus. It has been said that it is the responsibility for anyone working with dying people to be prepared for doing so (Corr, 1988). Preparation entails: 1) initiating reflections on one's own thoughts and feelings about death, and 2) a study of relevant content in the field of death, dying, and bereavement (Corr, 1988). Helpers should be cautious about undertaking interaction with the dying until they have first come to terms with their own concepts, attitudes, limits, motivation and needs in this area. To believe otherwise is to neglect omnipresent concerns for one's own mortality. Of course, this process of reflection and self-discovery can never be finished.

New staff members could be oriented to the basic knowledge about palliative/hospice care. There needs to be a theoretical component to this orientation, as well as practical and experiential training that focuses on the dying situation in a holistic way. A number of methods could be used. First, the presence of positive staff role models who can teach and provide support for new staff members is crucial. The use of a "buddy system", whereby an experienced staff member provides support and help to the new staff member on a one-to-one basis, or the use of a well-organized team approach can be very valuable in introducing new staff members to the most effective ways of dealing with the practical problems and stresses inherent in caring for the terminally
ill. "Orientation should include education on matters relating to death and dying, palliative care, hospice concepts, pharmacology, concepts of pain and symptom control, local policy, nursing procedures, and other matters particular to the area that the staff member is entering" (Zimmerman & Roche, 1986, p.116). Education should also include techniques in stress reduction, skills needed for working in a team, and role expectations.

The need for continued educational programs for more experienced staff must also be acknowledged. "Hospice care is not a "once trained, always trained proposition" (Zimmerman and Roche, 1986, p.117). Opportunities to attend and participate in workshops or in-services are effective methods for providing staff members with the intellectual input necessary for maintaining a high level of patient care. Also, as this study has shown, attending such informal educational programming can also have an effect on personal death anxiety. Moreover, such programs can help alleviate stress by providing a break in routine. Finally, Corr (1988) suggests that an effective educational program must, in part, attempt to correct inbalances in individual and social perceptions of death.
4. SECTION THREE: PERCEPTIONS OF PRACTICE

a) Organizational Context of the Hospital

The next variable addressed was whether or not the organization was able to meet needs of patients, families, and caregivers. The majority of respondents indicated that physical needs were being met. It is not surprising that the majority would feel that physical needs were being met considering that Riverview is a hospital and that most personnel are medically oriented.

Emotional needs and spiritual needs were perceived to not be met as well as the physical needs. This is perhaps true for all the patients and not just those who are dying. Commonly, the quality of life of the long-term geriatric patients at Riverview Hospital has disintegrated at the physical, emotional, social and spiritual levels. They often lack a zest for life; they merely exist in an apathetic state without joy, hope, love, or relatedness to others. The physical structure of the wards, especially in Valleyview where the patients are mostly in extended care, presents an unstimulating environment. Patients rarely interact with each other; the only communication they engage in is with the staff. There is more interaction with the higher-functioning residents of the free-standing units in the Geriatric Division. It does not appear from the results that the situation was much improved for the dying individual and there
was a perceived need for change. Emotional needs of patients with low mental capacity are difficult to meet. There may be an assumption by staff members that because the person is suffering from dementia or some other progressive neurological disorder that she/he does not have the capacity to express emotional needs that are real and that can be attended to. Another possibility is that these needs are expressed but are not recognized because they are masked within hallucinations or confusing chatter. It takes a tremendous amount of patience and energy to interpret and translate between what is a true emotional need and what is not.

Spiritual needs must be differentiated from psychosocial and emotional needs and thus they were included in the study. A spiritual need has been defined as the lack of a dynamic personal relationship with a higher spiritual being (Piles, 1990). A spiritual need can include: 1) a person’s need for love for and from oneself, others, and God; 2) a person’s need to find meaning in one’s life and for purpose and hope in one’s future; and 3) a person’s need for forgiveness from and for oneself, others, and God (Piles, 1990). Thus, a need is emotional or psychological when it is between the individual and others, and a need is spiritual when it is between the individual and his or her God. (Piles, 1990). "While psychology can help people understand their environment and interpersonal relationships within that environment,
spirituality can help people understand the meaning of their lives" (Brooke, 1987, p.194).

While it is easier and perhaps more comfortable to recognize physical, social, and psychological needs and seek ways to meet them, it is less so for spiritual needs. In most situations, everything possible physically is done for the dying patient. However, spiritual needs are an often overlooked area of concern because they get confused with religious concerns. Health professionals can get caught up in offering only medicine rather than being open to spiritual concerns. Many mental health professionals will deliberately avoid discussion of spiritual concerns because of their fear that reference to God or religion may enhance neurosis in psychiatric clients (Piles, 1990). Piles (1990) also reports on spiritual needs not being met because of lack of time, fear that the topic is socially unacceptable for discussion, or because staff themselves may be seeking answers to spiritual questions. However, it is important for the health care professional to be willing to address the inner spiritual experiences of their patients, especially those that may be dying. Need for change might indicate that more education is needed to provide integrated knowledge that puts spirituality in the context of total care rather than setting it apart as the responsibility of pastoral care.

Effective spiritual intervention can be accomplished in
a number of ways including one-on-one interaction and group approaches. Carson (1980) suggests that the therapeutic use of self will help another person move to a higher level of functioning. She defines this as a form of love that is expressed as an act of will and not as emotion, such as by purposeful listening, empathy, commitment, and by sharing personal strengths and talents. The spiritual dimension transcends and unifies the biological, psychological, and cultural dimensions, and gives the person a sense of wholeness that is threatened by illness, loss, and continuous changes associated with aging (Brooke, 1987). Hester (1984) suggests that if we foster the following four values we will be in readiness to promote spirituality. The first is a healthy sense of self. This can be done by becoming aware of one’s gifts, acknowledging one’s limits, caring for one’s health, and developing a life style that involves relaxation, recreation, and quiet reflection. This will help balance the demanding life of working in a hospital setting. The second value is a desire to be in one’s job. "Periodic assessment of job satisfaction and sense of mission can provide a precious source of strength and energy in the difficult times" (Hester, 1984, p.44). The third value is a sense of interdependence in ministry. This can be assessed by appreciation of co-workers, by identifying and acknowledging other’s gifts and talents, by fostering sharing for the good of the community and to add to
the creative energy of the organization. The fourth value is a concern for quality of life. In the midst of the medical technology and medicines, can we offer personal presence and compassion. Hester (1984) asserts that if we have reflected on these values and acted on them we can be open to address the spiritual needs of others.

Carson (1980) also promotes the use of regular group prayer to meet the spiritual needs of chronic psychiatric patients. By this method, the patient learns to verbalize needs and feelings, and moreover, praying in a group allows all the participants to share in each other’s needs, joys, and sorrows, and to be supportive and loving to one another. She suggests that praying also enhances hopefulness by reducing the sense of being alone and abandoned. It also raises awareness of the obligation of health professionals to meet the spiritual needs of patients.

Further, the results of the study indicate that the needs of the caregivers are not being met. In particular the results suggest the need for an institutional mechanism to support the caregivers. Most respondents did not feel that there was anyplace for them to go for support, and if there was, they did not know about it. The institution needs to either put a support mechanism in place, or inform its staff of what is available. There could be a supportive component to ward rounds, kardex rounds, etc., or information on support
available may be added to the orientation of new employees. This would demonstrate to staff members that the organization they worked for is concerned about the personal well-being of its employees, would increase morale, productivity and motivation for the job. Most particularly some debriefing process needs to be implemented after a death has occurred, especially after sudden or unexpected death.

Working with psychiatric elderly patients is, in itself, a very stressful job; working with psychiatric elderly who are dying is even more stressful. It needs to be remembered that health care professionals who work with dying people are first and foremost people who have needs, motivations, and stress. All too often in our attempts to improve the care of the terminally ill we have negated or neglected the difficulties experienced by staff working with these people.

"The metamessage is: It's the patients who are sick and need help. We, the staff, are healthy and well-integrated and can cope cheerfully, with our daily exposure to disease, disfigurement and death. In fact, our very choice of a profession shows how healthy and competent we are" (Vachon, 1978, p.113).

Many enter their profession to work with dying patients with hidden agendas and unmet needs. Many people deal with the stress by ignoring and denying it. Sharing the stress with
others would bring it to the forefront. Others may feel that they just have to accept the stress as part of the job. However, if stress is not maintained at positive levels it can lead to personal and professional negative behaviour. It is therefore important for staff members to provide support to each other.

According to current stress theory, individuals have a finite amount of energy for adapting to stressful situations and, unless this energy is replenished regularly, the supply becomes exhausted (Vachon, 1983). Throughout the medical care system, there are many sources of stress and stressful situations. Those who work with the dying are particularly at risk of depleting the energy they have to give, because of the tremendous emotional investment such work entails.

There are a number of factors in hospice itself that foster development of unfavourable stress reactions. The health care professional working with dying patients day-in and day-out is constantly confronted with his or her own mortality. These unresolved issues can bring on a number of stress reactions. As well, it might be said that many health care professionals who work with dying people may adopt an unrealistic view of what can be accomplished for the terminally ill, and when these expectations are not in accordance with reality, frustration, disappointment and distress can develop. The nature of hospice care itself does
not allow staff to use the usual defense mechanisms in dealing with death and dying. "[The work] is characterized by a high degree of personal attention and emotional involvement, lack of strict role definitions for team members, and an emphasis upon flexible and innovative responses to situations" (Zimmerman, 1986, p.120). These aspects combined with the usual stress-provoking aspects of medical care and care of the mentally ill make hospice personnel vulnerable to staff stress.

Stress can be manifested in a number of ways. For the individual member it can be manifested in symptoms of anxiety, depression, sleeplessness, alcohol and drug abuse, loss of appetite, or difficulty with interpersonal relationships. Once staff stress occurs, it tends to be invasive and contagious. Staff stress may be expressed in terms of staff conflict, particularly in hostility or scapegoating towards other members of the team. It may also be manifested in unexpressed conflict, which may lead to deterioration in team functioning and thus, level of patient care. Therefore, we need to seriously question the assumption that health care professionals are immune from pain and stress by virtue of their profession, not only for personal health reasons as well as for the sake of professional identity.

Staff stress can be dealt with in a number of ways, and of course, the best way is to take steps to prevent its
serious effects from developing. Foremost, staff members must have well-integrated social support systems both within and without the patient care setting to offset the emotionally draining nature of hospice work. Another effective way to decrease staff stress is through the use of a well-organized interdisciplinary team approach to the care of patients. Communication between staff members is enhanced, responsibility is more effectively shared, and no one feels totally alone in caring for the patient. It needs to be emphasized to each member of the team that he or she does not individually need to provide all aspects of care to each patient.

It is important that each hospice program develop its own mechanisms for recognizing and reacting to stress that can develop within the team. This response will have to be individualized but could take the form of informal or formal counselling, modifications in assignment, routine, or schedule, to developing special programs such as experiential workshops for staff support. Staff support groups can be developed within units or across units.

In terms of family needs, less than half of the respondents indicated that they were being met and over two-thirds felt that there was a need for change in this practice. The issue of meeting family needs is problematic for a number of reasons. The situation at Riverview Hospital is unlike the
situation in an acute care facility in respect to the availability of the family. In a large number of cases, it is not known whether the patient has any family. Often family members live in other provinces or other countries. Mental illness in the family is very disruptive to the functioning of that unit. In some situations, the families were torn apart because of the mental illness while the children were very young. Many of these family members feel guilt, anger, and even hostility towards the spouse or parent who could not provide for them. Sometimes these family members will make an attempt to reconnect but they may be confronted by the fact that their loved one does not recognize them. Also, it is difficult for family members to enter the bleak living environment of their relative. When the cost of visiting a relative in the institution becomes greater than the benefit, the family reassesses its priorities and oftentimes decides to limit the frequency and duration of its visits or contacts.

Some situations arise when it is impossible to know who the family may be. For example, on the men’s ward there are a number of men who were admitted from the 'street' because of severe alcohol-related dementia. Sometimes the long and short-term memory of these patients has been impaired to the point that they cannot remember anything about their lives, not even their names.

One social worker suggested that the meeting of the
family needs really depended on the involvement of sensitive staff members. In all fairness, it is difficult to meet the needs of the family. Staff members are aware that family is not involved, and they may come to resent the fact that the patients’ entire emotional and social support must come from them. In a sense, the staff members often become the surrogate family for the patient. In this respect, their role is very different than in an acute hospital where family availability is greater. For many families, the experience of coming to an institution like Riverview Hospital is so anxiety-provoking that it may lead them to react by criticizing the care that their loved one is receiving. Physically, Riverview’s buildings are old and not attractive, the locked doors are intimidating, and the condition of some of the residents can be quite disturbing. People’s visions become blinded by the cosmetic issues and do not perceive the quality of care provided. It takes some exposure to this situation to understand the quality of care given. Therefore, perhaps a response by the staff may be to not involve family because their job can be more efficiently done without family interference and criticism. It is a difficult balance for the staff to keep, i.e. needing family involvement for the emotional and social good of the patient but also needing to efficiently carry out a demanding job that is only rewarded by the work that gets done. The social work department has
implemented a new policy where all family members listed are to be notified to keep some of these connections alive.

The results for whether or not work routine would allow staff members time to work "psychologically" with the dying patient indicated that very few staff felt that it was possible. Staff members do not feel that they have the time or the know-how to work with dying patients, especially with the more difficult cases. There was some recognition that efficiency is rewarded, but not quality time with the dying patient. Health care workers and psychiatrists did not feel their routine allowed sufficient time for palliative care. Health care workers are kept very busy on the extended care wards: they are responsible for the activities of daily living such as bathing, dressing, grooming, feeding, and toileting.

It may be surprising to note that the psychiatrists do not feel that they have the time to provide "psychological" care, since many would suggest that is indeed their job. However, at Riverview Hospital there is a drastic shortage of these professionals. One psychiatrist may have to cover several wards. This has limited their role to being consultants to the team in providing expert knowledge on medication, side-effects, and interpreting the clients' behaviour. The role of the psychiatrist at Riverview Hospital has become somewhat limited and circumscribed.
Social workers as another professional group cannot provide all the "psychological" care. Some of this care can be integrated into their area of practice. For instance, the social worker is required to do a social history assessment and this could involve working "psychologically" with clients as they gather information. However, as is often the case, clients are poor historians because of their condition, so the social worker will rely on old medical charts, family, etc. A large part of the social work routine then becomes filling out forms, making reports, and liaising with family and community services. The recipient of social work services is more often than not the family rather than the patient. Over half (54%) of those that answered stated that there was a need for change in relation to psychological care. However, the only professional group that responded with interest to the prospect of change were social workers, as the majority of respondents who indicated that change in this area was needed were social workers.

b) Role Expectations

As has been discussed, the expectations that professionals have of themselves and others will affect team functioning and thus, quality of patient care. The assumption underlying the question regarding role stereotypes is that these stereotypes interfere with communication, role
expectations, etc. Over half of the respondents did actually perceive that their role was being stereotyped. However, only social workers and health care workers thought that there was a need for change. This might suggest that to some, being stereotyped is not necessarily a negative thing, and that it could even be a positive thing. For example, physicians and psychiatrists may find stereotyping advantageous because it could include decision-making power, expert knowledge, status, etc. Health care workers and social workers are not usually stereotyped as favourably by others. It would appear, then, that professionals with lower status view stereotyping as negative, while more privileged professionals are more positive or at least neutral about the issue. Stereotyping for pastoral care workers may be more acceptable because their role is to some degree very specialized. In regard to carrying out the religious nature of their role, there is no conflict with other professions. In contrast, nurses and psychologists think they can competently perform social work duties. Social workers and health care workers probably perceive that stereotyping diminishes rather than enhances their role. "In working with others, it is easiest to respond to professional stereotypes rather than to learn what other professionals actually do" (Lowe & Herranen, 1982, p.7). The challenge then, according to Lowe & Herranen (1982), is to understand each professional's frame of reference so that
roles and functions can remain flexible.

The results to the question regarding role stereotypes complement the results on the provision of psychological care to the dying patient. In both instances, the professionals who thought their roles were limiting were the health care workers and social workers. Perhaps these professionals felt limited by their lack of power in that they would have to operate within circumscribed roles.

In traditional health care, professional and nonprofessional roles are well defined, and each discipline understands the limits of its own boundaries. Economics, education, and professional specialization have ensured that no one health care professional can treat the total person. Health care professionals treat only that portion of the person as envisioned or described by their limited professional scope of practice.

However, a major characteristic of hospice/palliative care is role blurring (Corr and Corr, 1983). In order to ensure that quality care is not fragmented, the roles of those providing hospice care tend to overlap, especially with home care. For example, a nurse may find himself or herself in a situation where family concerns are raised and may have to deal with it without bringing in the social worker. Conversely, a social worker may be requested to do some form of physical care. All staff members not only must know
everything that is happening with a patient, but must be prepared for and flexible enough to provide almost any care that is ethically permissible. It cannot be a matter of "This is my role and you stick to yours". It is a matter of cooperation in delivery of skills and abilities. If true cooperation between health professionals is to exist, then they must work together, share responsibilities, and know when it is important to relinquish their roles in the true spirit of giving their best to people. The preservation of the integrity of a persons' life may be dependent on professionals looking beyond the periphery of their "professional blinkers" and examine what services are necessary to ensure quality of life.

The results of this study do not demonstrate how flexible the staff of the Geriatric Division of Riverview Hospital are in terms of their role in working with the dying, only that in general, roles are perceived to be stereotyped. Therefore, it is impossible to calculate how much change would be neccessary to accommodate for role blurring at Riverview Hospital.

In order to prepare health professionals to assume these new roles, innovative educational and training programs must be developed. As we develop these new educational programs, caution must be exercised to prevent the limitations and narrowness of the concept of 'specialization' from creeping in.
c) Teamwork

The findings showed that the majority (81%) of those who responded felt that there was teamwork at Riverview Hospital. However, this finding really does not tell us what respondents thought teamwork was. It also does not tell us how cohesive and high-functioning or at what stage of development the "team" might be at.

Perhaps more importantly, when asked whether or not they personally worked as a member of a team when working with the dying, fewer staff members responded positively (70%). So while most people recognized that a team approach was in place, fewer respondents actually felt part of a team when working with dying patients. This may suggest that people are working independently when caring for the dying, or that some members of a team are not recognized as contributing players. For example, health care workers are theoretically a part of the "team" but are often left out of the planning process. If they do go to a ward round, it is to maintain a limited profile. Added evidence of this last hypothesis is the fact that it is the professionals with lower status who do not feel that they work as part of a team.

Health care professionals who work with dying people at Riverview Hospital need to understand and develop a strong commitment to the concept of teamwork. Care of the dying elderly at Riverview Hospital must be a team concern. These
patients may be identified as difficult to manage or may present unique problems, medically, ethically, or psychologically. If the situation arises where each staff member is dealing with the dying individual differently, it may result in unclear expectations for both the patient and staff. Bringing this to the attention of a larger team helps to develop a consistent and jointly formulated approach. However, teamwork takes time, effort, evaluation, and commitment. As was discussed in Chapter Two, teamwork is a developmental process. It is imperative that the team spend time explicitly examining how it will work, i.e., what is expected of the members, what priorities will be upheld, how decisions will be made, what types of communication will exist, etc. The same steps that the staff at Riverview Hospital has taken to ensure that teamwork exists when working with the general patient population must also be taken to ensure teamwork with the dying. This team functioning and maintenance should begin with strong personal and professional identity and understanding of others' roles, as presented earlier. It is with this foundation that a group of health care professionals with similar objectives can work together to meet and exceed those objectives.

The composition of a team working with dying individuals and their families will vary from program to program, however, usually there are particular professionals who comprise the
team. There should be little in the way of a hierarchial structure for this group. Leadership should be shared so that the person with the best skills to handle a situation can take the lead. This way the staff avoids burn-out, care can remain innovative, and communication will remain at an optimum. Physicians, nurses, nursing assistants, social workers, dieticians, pharmacists, psychiatrists, physical and occupational therapists, chaplains, and volunteers all can fulfill a role. As well, speech therapists, art therapists, music therapists, and recreational therapists can also be helpful. The contact of other members of the hospital staff such as housekeeping and maintenance personnel cannot be overlooked. Finally, the patient and family (as defined by the dying individual) should be treated as being central to the team. Team makeup will depend on institutional circumstances, program objectives, and available resources.

Continual evaluation of the effectiveness of teams must be carried out. "Effectiveness" implies that more energy is being focused on accomplishing the team's tasks than on maintaining the group. The team's morale, member satisfaction, and work processes, including communication, decision-making, role expectations, and the supportive aspect of the team should be reviewed. As well, the team should spend time evaluating what personal and professional development needs members have and how the team can help meet
them. Further, each team needs to come to grips with how best to operate within the organizational structure.

d) Exchange and Communication of Diagnostic Information

Only a small minority (30%) of respondents thought that patients were informed of their impending death. Another 35% of the respondents suggested that the patients were only told under certain conditions, such as if the patient's mental stability were such that they could handle being told. More admitted that they may not be told because of the fear of inducing neurotic or psychotic behaviour in the individual, which the informant would feel responsible for.

Not one respondent thought that this situation should be changed. Half of the respondents did not think change was necessary, while the other half of the respondents thought that change should depend on the situation. These results certainly point to the difficult ethical dilemmas inherent in the issue of whether or not mentally ill patients should be or can be told about impending death. These results also contradict the general agreement in the literature that in almost all instances the interests of the patient and family are best served when the patient has some understanding of his or her disease and prognosis. Although a few writers question the therapeutic value of openly discussing death with patients, most authors agree that terminal patients would
prefer to have the opportunity to discuss one of the most important fact of their lives with institutional personnel and loved ones, and want some kind of personalized supportive relationship from them. Terminal patients are likely to fear death, but want information concerning when and how they probably will die. Mount (1978) and others have gathered data indicating that most patients want to know their diagnosis and prognosis; the same data indicate that this is usually not what happens. Hospital staff are described as being unwilling to tell a patient that he or she is dying. Staff then cope with their own fears of death by developing an impersonal attitude, and strategies to force patients and families into behaviours with which the caretaking staff is comfortable.

Part of the reason why patients at Riverview Hospital are not being told about impending death is because there is a generalized belief that the patients do not understand they are dying when they are told. Obviously, if one believes a person is not going to understand, then one may not even attempt to inform that person. The physician and the psychiatrist who believed that patients understood also believed that patients were told about impending death. Many studies have verified that very often the patient senses the outlook long before being told. "Telling" may then not be the accurate way to describe this exchange of information (Zimmerman, 1986). There are obvious differences in
perception of the situation between the professional groups. Most professionals surveyed believed that efforts are made to inform the family about impending death. Still, health care workers and social workers thought there was a need for change. Perhaps the type of change these professionals wanted was to see more family involved in the treatment process or the decision-making. Perhaps by change these two groups were referring to the attitudes that exist regarding the presence of family. As was discussed previously, family involvement can be limited or at a distance, thus, it may be easier and less threatening for staff members to inform the family of a dying patient.

Patient and family understanding of diagnosis and prognosis is an important, complicated, and controversial topic. The issue of what to tell the terminally ill patient about his or her diagnosis and prognosis has received a great deal of attention. Obviously, there can be no uniform policy with respect to telling patients about their disease and prognosis, however, there are some guidelines that can be followed for telling the particular patients at Riverview Hospital who are told. One must begin by listening and continue to listen carefully. Listening is in many ways much more important than telling. It is only by first listening that one can determine what can and should be told. Both listening and telling often need to take place over a period
of time at multiple visits. Patients' needs and capacities for understanding change and evolve so that an ongoing dialogue is essential. As well, understanding is not a consistent progression: a patient may vary immensely from one day to another in what he or she is willing to accept or assimilate. One must individualize on the basis of what is heard. Because of the variability and unpredictability of the dying situation, staff must be knowledgeable in skills necessary for communicating with dying individuals, whether they be withdrawn, hostile, or open to conversation. Absence of such communication is perhaps the greatest barrier to good palliative care. One should be alert, both in listening and in telling, to nonverbal communication. For most patients, the truth presented kindly and at an appropriate time in a suitable setting can open channels for making dying a little more comfortable and a little gentler. Unfortunately, there is no way to be certain that, for a particular patient, one has selected the best of all possible alternatives.

Finally, coordination and sharing of information between members of the health team is vital, especially when we consider that patients vary in their ability and willingness to relate and share with different individuals. Members of the staff will more than likely be the recipients of the institutionalized patient’s confidences. One of the virtues of teamwork is that it provides a number of options to
the patient in this respect. Communication among all members of the health team inhibits deception, avoidance and inappropriate remarks to patients, as well as the frustration that can develop when team members do not understand what is being done and the reasons for it. Patient and family not only must have input in making the decision but a clear-cut understanding of what decision has been made and the reasons for it.

e) Discussion of Qualitative Analysis

The qualitative aspects of the findings regarding the question about whether all that can be done for the dying patient is being done uncovers some concern regarding the care for dying people in the Geriatric Division of Riverview Hospital. Emotional and spiritual needs of the patients and families, it is felt, are not being addressed adequately. The respondents also mentioned a lack of support for the caregivers themselves. There were many valuable suggestions offered to deal with these issues, such as the provision of more education and training, and the creation of support groups.

Aside from the practical issues, the most interesting responses made reference to recognition of very real ethical issues that have to be resolved. A first concern addresses the issue of program implementation and the question of which
type of program would be best for the clients. The current practice consists of moving dying patients from their home-ward to North Lawn when they become too ill or reach end-stage. North Lawn is a unit designated as a medical/surgical area for physically ill patients. There are very valid concerns regarding relocation stress and transfer trauma, and regarding the effects this practice has on the dying process. Relocation stress and transfer trauma are conditions that are thought to result when the elderly are moved from their accustomed environment. "Relocation - that is, mass transfer from an old building to a new one - implies disruption of social networks, as well as confusion generated by new spatial arrangements" (Bennett, 1984, p.231). In the Riverview Hospital situation, disruption of networks occurs because ward mates and staff do not follow the patient from the old building to the new one. It is particularly important for the adjustment of mentally disturbed people to institutional life that routines be familiar and predictable, and that there be continuity in the people surrounding them. As was discussed earlier, the social needs of the patients are for the most part met by staff. When these contacts are severed, and the patient is confronted with new staffing patterns, it can produce negative effects such as debilitating stress and cognitive confusion.

The question is whether this transfer has the effect of
speeding up the process of dying, and if so, whether we can find appropriate means of treating and caring for the dying patients on their home-wards surrounded by familiar staff and staffing routines. Another possibility would be to better prepare a patient for a move to reduce the psychological, emotional, and social stresses attached to the move.

A guiding principle that can be used for practice is the person-in-environment paradigm. The underlying premise is that behaviour is more than a product of intrapsychic functioning or the simple product of the external environment. Rather a synthesis between the individual and the environment works together in shaping and influencing behaviour. Environment should be considered to include both internal and external factors and is both social and physical. Therefore, it can be said that health is a qualitative expression of the interaction among environments. Both physical and social factors need to be appraised to determine in what ways an individual’s health can be enhanced, and the emphasis should be on improving the quality of the internal-external interaction.

Palliative care is still in its early stages of development and not everything has yet been learned about the best manner and method of delivering services. Nothing should be done that might inadvertently foreclose any potentially valuable new options or that might accidentally dampen the
spirit of innovation. A very central policy question that must be addressed by the administration at Riverview Hospital regarding the development of a hospice/palliative program, is which patients should be served by such a program. For example, should a program serve all dying patients or should the program simply serve as a back up program for patients with a particular diagnosis.

If it is agreed that the palliative care program should be a specialized unit, the model that will develop will be very different. Obviously, this unit will be a designated area that is called into play when the standard programs of care are not capable of handling the challenge presented by the dying process. There would most likely exist a specialized team of personnel who would only work on this unit. There would also probably be extensive services available in this specialized unit. The unit could also serve as a centre for research and advanced teaching. The main disadvantage of this model, especially for the context of Riverview Hospital as has been outlined, is the need to relocate long-time residents of home-wards to an unfamiliar and unpredictable surrounding.

If, on the other hand, it is agreed that palliative care should be provided on the home-wards to all dying patients, then a different model of care will develop. In this model, there will be a much greater number of programs, spread more
broadly throughout the hospital. They would be more general in nature and less intensely specialized. The staff members would receive a more general training and would probably not limit their professional activities to hospice patients. They may not even consider themselves specialists in the care of the dying, but rather see themselves as providing good medical or nursing care to a somewhat special population. In these more general programs, less research would most certainly be conducted, and less advanced education and training would probably be carried out.

Further, if the program is broadened to care for patients dying of various conditions, and not a specific one such as for cancer patients, which 90 -95% of hospice programs typically serve, then again a different model will emerge. It will be more diffuse in purpose and will be less clearly visible to the community, including staff members. It will have to develop a broader range of services and capabilities to meet the variety of needs that will arise. The findings suggest that a "philosophy" approach is preferable to a structured program. Rather than having a specific unit, designated beds, or a mobile team, some respondents have suggested to incorporate the philosophy of hospice/palliative care into the existing patient care services. Perhaps this is a preferred approach because it does not require structural change to the system, but simply flexibility on the part of
"Incorporating the concepts of hospice into the existing care services as an alternative approach to hospice care is based on a commitment to the patient and not the disease" (Stark & Johnson, 1983, p.65). The strengths and value of the support system must be considered, especially when a patient and family have been cared for in the system, often for many years. At the time when the patient and family are dealing with the stress of the progression of the disease, familiar people and familiar environment can provide support and nurturing.

Lending credence to this approach is the ecological perspective which suggests that "practice should model itself after life, should utilize natural systems as sources of help and change, and should protect and nurture the sources and opportunities for growth and self-realization that exist in a client's human environment" (Stark & Johnson, 1983, p.65). Not removing the patient and family from the environment in which they have become familiar allows them to continue to feel the support of that environment. Stark & Johnson (1983) suggest also that the patient and family are able to continue in an already-established personal routine rather than having to move to a new environment where they may have difficulty re-establishing that individualized routine.

The disadvantages of introducing this "philosophy"
approach without an accompanying protocol, is that there probably will not exist equal standards of care across working areas. There will be little pressure to seek advanced education and/or training in dealing with dying individuals, as there will always be someone else who can do the job with more interest. It puts no demands on the personnel to change their actual work habits because there is no real reward for doing so. This philosophy would simply become something else routinized into daily professional activity. Programs such as Quality Assurance demonstrate the satisfaction that can be gained when positive changes in work habits are supported and follow a well-established protocol. When staff understands what they are doing, why they are doing it, and are supported for it, they will be satisfied to continue those practices.

Any group proposing to start a hospice program or other form of care for dying patients should move through an organized process of planning that examines the reasons for proposing the program, that tries to determine the need for such a program, and that reviews what is already being done. To some extent this study has addressed the last two factors and has assumed that a program needs to be proposed to better serve the dying patients. This study has determined with some confidence that there is a need for such a program, and perceptions of current practices were assessed. Furthermore, the administration must also consider what type of palliative
care program will best suit its purposes, must review the resources that are available for the program, should identify which patients it feels it can best serve, and must create a phased plan of development for the proposed program.

5. CONCLUSION

Riverview Hospital needs to develop and implement a palliative care program that meets the special needs of the dying and their families, particularly in the Geriatric Division. This policy needs to be studied, practiced, evaluated, and supported within the organizational, economic, and political framework of the Hospital. As a palliative/hospice program develops, it is important that it avoids offering more than it can deliver.

Based on the advantages and disadvantages of the various models and approaches to dealing with dying and death in an institution, it would be preferable that each unit within the Geriatric Division develop a palliative care team, thus allowing each dying individual to stay on the home-unit. The idea of a philosophy approach incorporating the concepts of palliative care without formalizing a program per se is valid as a beginning measure, however, I believe that it would not accomplish the desired outcome. Staff members will not likely alter practice unless there is a mandate to do so and unless
that mandate is supported, understood, and a personal commitment is made. In order for a philosophical approach to work, as I understand it, all of the staff would have to be trained and educated on the basic founding concepts of palliative care. It must be kept in mind that not everyone wants to or feels comfortable working with dying people. These staff members should not then be forced into such a role, as this will only serve to undermine the process.

It is based on this reasoning, and also out of concern regarding relocation, that I propose that each unit develop its own core palliative care team. These would be comprised of staff that would volunteer, would be appropriately screened, trained, and continuously evaluated. They would also need to be supported by other staff and administration. As these teams develop, ideally an environment would be fostered whereby the philosophy approach would spill over to other staff in a less-threatening way. By having designated palliative care teams, the staff members on the team could participate in continuing education, support groups, research, and advocacy.

Unfortunately, a disadvantage to this approach is that many of the professional groups that should be on the team have a small staff within the Geriatric Division itself. For example, occupational therapists, dieticians, pastoral care, physicians and psychiatrists would more than likely have to
overlap their services over several units, and thus would be involved on a number of teams. This may interfere with the cohesiveness of the teams, and may increase workload which would be resented. For example, not only would they have to attend the regular ward rounds but also a separate palliative care round if deemed necessary, and also attend the initial and ongoing educational and support sessions. However, this may not be a large concern because of the numbers of patients that will actually be involved in the program.

The administration may also choose to establish a more centralized, self-contained palliative care unit within the Geriatric Division. If a study of incidence and need determines that such a unit would be feasible and warranted, then a team should be developed that would only work on that unit. Relocation issues would have to be considered and better preparation carried out. Unfortunately, this approach does not encourage staff outside of the unit to understand and commit to concepts of palliative care. Rather than becoming more visible and all-encompassing, palliative care practice may in actual fact become an isolated and pocketed venture within the separated unit.

Therefore, it is proposed that first the network approach should be taken in order to increase visibility of the program, the number of support opportunities, and reduce relocation and transfer trauma. A latent consequence of this
would be a spill-over of philosophy affecting all patient care by all staff. Ultimately then, the hospital might consider a separate unit as well to serve special-needs clients and decisions would have to be made as to who these clients might be.

It will be necessary that the administration consider funding and its availability in determining which approach will be taken. As was discussed in Chapter One, greater funding from government is dependent on the number of components a program has and then, the particular Level it achieves. A Level One program contains one component, and a Level Four program, the highest, contains six to nine components. Thus, it would be appropriate to consider the nine components of care determined by HPCA of BC (administration, symptom control, home, hospital, bereavement, pastoral, volunteer, professional training and education, and research and evaluation) and the feasibility of each being integrated into a program at Riverview Hospital.

Administration, the first program component will also inevitably be the most contentious component at Riverview Hospital. Traditionally administration of palliative care programs have been conducted by physicians. However, because Riverview Hospital is a mental institution and not a general hospital per se, arrangements would have to be made to share administrative power between both the physicians and the
psychiatrists. This will not be an easy task considering the history of mental institutions and psychiatry's place in these institutions.

Questions of how to organize and deliver hospice care frequently prompt controversy concerning its proper place in the existing health care delivery systems. Administration includes everything from the actual organizational structure, financial aspects, and staffing. Financial analysis of hospice care is initiated in the planning process. Hospice program planning must identify hospice care as it relates to the organization providing the service, to those who would receive services, and to political and economic realities. This is a most difficult aspect of the program planning, since the product of such identification often presents the challenge of change to the system. It is essential to organize effectively the resources required to meet the need and demand.

A key feature of hospice/palliative care is that it is directed primarily at symptom control rather than at disease control. In hospice care, symptom control is accomplished with the use of a minimum of diagnostic studies and invasive therapeutic measures. As a result, hospice patients receive relatively little technological care, but a great deal of personal attention to control pain. Emotional turmoil, social problems, and spiritual questions may all contribute to
what Saunders (1980) calls "total pain". Too often we think of pain as a physical biological phenomenon and fail to view pain as suffering, as a human experience involving the whole person. Because pain is complex, its therapy requires an interdisciplinary team. Hospice care must involve a commitment to relieve the emotional and mental distress of patient and family. Some of the suffering of patients can never be eradicated. Even when therapy is successful in relieving the patient's physical agony, there remains a deeper suffering - the weakness and progressive loss of control, the disfigurement and loneliness, the fears and regrets, the guilt and despair. Patients do not expect us to have all the answers. But they long for someone who is willing to listen and in some small way to share in their suffering. The control of pain in terminal disease demands the highest level of scientific knowledge and clinical expertise. The dying person urges us: "Watch with me. Help me to die peacefully without pain, but also help me to live until I die" (Gentles, p.16).

Home care may or may not be an issue for Riverview Hospital, although it is one of the components of a good palliative care program. Many of the patients in the Geriatric Division have been there for years, even decades, and have no other home to go to, or no available family. Provision could be made for the exceptional case, however,
because Riverview Hospital has established Geriatric Outreach Teams that could make it part of their role to follow someone in the community, in the event that she/he is discharged home. There is also a policy that allows patients to take an extended leave without losing their bed at the institution. Thus, conceivably, a dying individual could be moved to home and back under the appropriate conditions.

Hospital care is inherent in this institution although it is a mental institution. There is emphasis placed on physical and medical aspects of care, especially in the Geriatric Division where patients can range from personal care level to extended care level. There is a unit called North Lawn that is a designated medical/surgery area. Certainly, if a palliative care unit were to develop there would have to be expansion of existing resources and necessary equipment. There is an ambulance service available on campus for transfers to a hospital facility.

A bereavement component could be offered at Riverview Hospital but would have to be individualized and flexible. Riverview Hospital is a provincial institution so its patients come from a large geographical area. In some situations, there would be no family or friends involved in supporting the dying individual, except for staff, and, in other situations, there may be family, but at a distance. In this case, possibilities for a bereavement program are limited. For
others, family may be geographically close. However, it must be considered that the bereaved family members may be elderly themselves and have difficulty accessing the institution. For others, any connection to Riverview Hospital would be quickly and deliberately severed when the death occurs. Perhaps the death would come as a relief because it would at least physically eliminate the shame and guilt of having a mentally ill family member.

The purpose of bereavement care is to provide comfort, understanding, support, and information to surviving relatives and friends in an effort to alleviate the distress of bereavement and promote the most favourable outcome possible (Zimmerman, p.92). Obviously, bereavement services to friends and family of Riverview Hospital patients will also have to include the loss and grief issues of mental illness. The bereavement component could include follow-up phone calls, one-to-one follow-up, annual memorial service, and connection to community resources.

Riverview Hospital does have a very active pastoral care services department within the hospital. Unfortunately, the staff is very small, except when it is supplemented with chaplaincy students. The pastoral care staff have an ecumenical understanding and can bring in various religious leaders from the community, if requested. Because of the small staff, it is important that all members participate in
spiritual care outside of the strictly religious formalities.

As well, Riverview Hospital has a very successful volunteer services department. It is understandable that the head of this department has to work very hard at recruiting volunteers. The mentally ill, especially the institutionalized ones, are for the most part regarded as social lepers, and thus, it takes a special person to overcome these prejudices to volunteer in such a place. The task of working with the dying within a psychiatric institution would not attract many volunteers. Riverview Hospital is somewhat inaccessible as well. The volunteer component to a palliative program at Riverview Hospital could include screening, orientation, and ongoing education. The volunteer would work with the patients and families in-hospital and/or at home, as well as be involved in consultation and bereavement follow-up. Although hospice care is labour intensive, much time is contributed by volunteers. Volunteers are essential to successful hospice care; the existence of organized volunteer services in hospitals facilitates recruitment and involvement in the hospice care team. Volunteers can add needed support to a team to defray the burden that full-time staff might feel.

Riverview Hospital has a strong commitment to professional training and education. This is shown by the monthly grand round sessions, as well as ongoing workshops and
educational opportunities provided by the Human Resources Department. There is an excellent library which is connected to a larger library system, including the resources of the University of British Columbia. There is also a good selection of audio and visual equipment. Therefore, there is no doubt that with such a commitment and available resources that Riverview Hospital could develop an in-depth interdisciplinary training and education program for those interested in or already working with dying individuals.

Furthermore, this institution has demonstrated a commitment to research and evaluation of services. Riverview Hospital has prided itself on its reputation for advances in such areas as behavioural and cognitive approaches to treatment, study in organic brain syndromes, medication issues, etc. This institution has the resources to include a research component in its palliative care program. It is only through research that the quality of terminal care can be advanced. Much of what has been documented regarding the advantages of hospice/palliative care over conventional care is anecdotal in nature. At Riverview Hospital, study of how a hospice/palliative program can be integrated into its organizational structure will help the administration make more rational decisions regarding the selection of a model of hospice care that will 'work for that community. Measurement tools also need to be developed to study a number of problems
such as specific needs of the dying mentally ill that are different from a 'normal' population of terminally ill, and other techniques of hospice care that would be beneficial for the mentally ill elderly. Thus, further research at Riverview Hospital would help the administration consider which patients are to be served, how they will be served, and what policies will be developed around that. As more hospice programs develop, and competition for funding sources increases, research will assume even greater significance.

It would appear after a review of the feasibility of the nine components of care that Riverview Hospital has the potential and resources to develop and implement a high level palliative/hospice care program. However, if it is ever to get off the ground, some key administrative issues must be resolved or commitment and support for the program will never be achieved.

The Riverview Hospital administration needs to develop a program that is supported and rewarded by the organization. The working environment of Riverview Hospital can be very stressful for the caregivers, who must perform difficult, tedious, and poorly rewarded tasks in the institutional setting. What the organization will get in the way of involvement from its members is in line with what it gives in the way of rewards. Unfortunately, professional rewards are lacking, especially when working with the dying, since these
are to be found in acute-care curative settings.

Each dying patient is a reminder to hospital staff members of their own potential illness and death, and thus, is energy draining. Health care professionals cannot support the patient and family unless they themselves are supported on the job - by colleagues, supervisors, etc., as they work with the patient and the family and grieve with them over the death of a patient. Eventually, staff can give no longer if they are not emotionally given to. The refilling, the gratification, the rewards come partly from material goods (salary, fringe benefits, working environment) but more from the kindness, patience, approval, support, respect, affection, validation of ideas, encouragement, and even challenge presented by colleagues and supervisors. There needs to be a psychological contract between the organization and the staff member.

Whether people work effectively, whether they generate commitment, loyalty, and enthusiasm for the organization and its goals, and whether they obtain satisfaction from their work depends to a large measure on two conditions. The first is the degree to which their own expectations of what the organization will provide them and what they owe are in line with the organizations expectations. The second factor is the nature of what is actually to be exchanged. The relationship between the individual and the organization is interactive, and ongoing bargaining to establish a workable psychological
contract takes place.

Riverview Hospital is at the forefront of an opportunity to contribute something valuable to the health care system in general, and specifically to the mental health field. Riverview Hospital has the opportunity to raise the level of awareness regarding palliative care beyond what it has traditionally provided. It has a committed staff that is knowledgeable on mental disorders that could be trained and educated to provide palliative care to the people dying within its walls. If properly conducted research is done into palliative care with the mentally ill at this institution, great advances could be made in the hospice field that would open up new avenues so that more people could experience the comfortable death that palliative care provides. We have the capability to be able to provide palliative care to all regardless of condition. Although people with nonmalignant disease constitute a relatively small percentage of patients, it seems prudent to devote some special consideration to their care. By providing humanistic care to the dying mentally ill elderly through a palliative care approach, this institution will be giving the message to society that the mentally ill are people with value and dignity, and deserve to die in such a manner. The mentally ill, the elderly, and the dying have been voiceless, powerless people in our society. There was an increased attention in recent years to the issue of death and
dying, especially issues of euthanasia, right to die, living wills, etc. Riverview Hospital needs to also give attention to this issue. Not only will the hospital benefit (i.e., financially, increased status) from such an endeavour, but the people it is serving, families, and the health care system as a whole.

Patient care in general and care of the terminally ill in particular will be enhanced if hospice becomes an integral part of medical and mental health care, although the relationship between hospice as a part and medicine as a whole is still developing. Although hospice has some features that differentiates it from other aspects of medicine, much is lost whenever hospice is viewed as or becomes a separate entity. To properly fit hospice care into medical and mental health care will take some effort, but that effort should be rewarding.

Hospice/palliative care draws from and contributes to the rest of medical care. Hospice team members come from a variety of fields, bringing their particular expertise to it. Some of the critical elements of hospice care, such as dealing with the patient and family as a unit and the effective use of an interdisciplinary team, can be employed to advantage in many nonhospice situations. In fact, none of the cardinal principles of hospice care described in Chapter One are in any way incompatible with the remainder of medical care. None of
them are even unique to hospice.

Implications of a graceless death of the elderly expand well beyond the individual case. It becomes a broader care issue. The quality of the process of dying is vital in shaping the way in which the bereaved approach the whole subject of death. The terminal illness of a loved one is one of the few contexts in which most people have a prolonged contact with the reality of death. Sadly, families most often are exposed to the graceless death common in modern institutional settings. As a result, attitudes toward death are apt to be negatively influenced.

Such adverse experiences reinforce the cultural message that death is an obscenity which people should avoid at all cost until they must inevitably confront it. Thus, the very discomfort that prevails in our culture surrounding death is bound to be reinforced in all observers because of higher probability that their future encounters with death will be even more disturbing.

In today’s society health care professionals have been challenged to provide humanistic care to the dying. However, the inroads that have been made in providing this care have mainly focused on the middle-class suffering from disease entities such as cancer. Hospice principles clearly have applicability beyond this group. It is time to extend the knowledge that has been gained in palliative care to another
group of dying individuals, namely those suffering from mental disorders that are incurable and often fatal. It is time to afford attention to this voiceless and powerless group in our society, and grant them even in their final days a dignity that may have been absent their entire lives.

The future of the hospice movement remains uncertain. "It is a phenomenon that is challenging the current system, but like any reform, it is facing the complex task of maintaining its basic integrity while remaining elastic enough to accommodate change" (Backer, 1982, p.71). Each project must negotiate the various intricate systems regarding delivery of health care whether they be bureaucratic or governmental. In the face of the overwhelming needs of the terminally ill, change will come too late for many.

Dying is likely to continue to take place in hospitals, for the foreseeable future, as long as we continue to see death as fundamentally and naturally medical. We should mitigate the tragic effects of this distorted vision by de-emphasizing the medical aspects of dying. If the aged must die in hospitals, so be it. But we ought not let the medical shadow obliterate individuality, value and meaning. In caring for the dying and mentally-ill aged, let us recognize death in its total complexity as a problem that transcends the scientific and requires for its proper management the full range of human creativity. What does it mean to be old,
mentally ill, and what does it mean to be old, mentally ill and dying? Our society is in the process of deciding.
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APPENDIX A

Operational Definitions of Professionals
Represented in the Sample

Health Care Worker:

Position Function:
Under supervision of Head Nurse and direction of Nurse 1 or 2, provides nursing assistance by participating in the day-to-day routine nursing care and procedures of patients, participates in the rehabilitative, remotivation and self-care program for individual treatment. May be required to make beds, clean tubs/shower trolleys, mop up spills and wash personal clothing.

Education and Occupational Certification:
Secondary School graduation or equivalent; Completion of related course such as home care of patients is preferred. First Aid, C.P.R. and other training in the Health field are preferred.

Pastoral Care Worker (Chaplain)

Position Function:
Specializes in interfaith, institutional ministry to persons confronted by clearly defined physical, emotional, and spiritual needs. Includes the traditional prophetic,
pastoral, and priestly dimensions of ministry.

Education and Occupational Certification:
Completed a course in Chaplaincy from a recognized School of Theology, including an internship.

**Social Worker I**

Position Function:
Under the supervision of the Psychiatric Social Worker Supervisor, provides direct casework services in response to need, assesses major mental illnesses, chooses and adapts appropriate interventions/treatment options; counsels patients and their families to effect changes in behaviour and attitude; collects data for social history, is accountable to victim, victim's family and victim's system for confidentiality; writes reports and records services that have been performed.

Education and Occupational Certification:
Bachelor of Social Work from an accredited University.

**General Physician**

Position Function:
Employees in this position with the Public Service are
generally under the administrative direction of the Deputy Minister, Associate Deputy Minister, or appropriate senior medical officer, and are responsible for the care and treatment of patients as assigned; or performing specialized duties in a public health unit, clinic or facility; may have supervisory or administrative responsibilities; performing other related duties as required.

Education and Occupational Certification:
Graduation from a medical school of recognized standing with a degree of Doctor of Medicine or the equivalent, and registration in the registrar of the College of Physicians and Surgeons of British Columbia.

**Psychiatrist**

Position Function:
A physician specializing in psychiatry, a branch of medicine that deals with the science and practice of treating mental, emotional, or behavioural disorders.

Education and Occupational Certification:
As above
APPENDIX B

Pilot Study Research

1. PURPOSES OF PILOT RESEARCH PROJECT

In March 1990 a pilot test was conducted with the Social Work Department of Riverview Hospital to meet two purposes. The first was to test the measuring instrument in terms of reliability and validity. This test uncovered some difficulties the respondents had in answering the questions, for example, how well the questions were understood, and other ambiguous areas that had gone undetected during the formulation of the instrument.

The second purpose was to obtain information regarding the social work department and the role it plays in this very important area. The written survey of the entire social work department across all three divisions of Riverview Hospital was done as a pilot study because the larger thesis research study was limited to the Geriatric Division only. Therefore, in order to understand the perceptions of all the social workers, and not just the social workers in the Geriatric Division, it was necessary to separate it from the larger study. Approval for the pilot study was given by Mr. John Fox, Manager of Social Work Services.
2. DATA COLLECTION PROCEDURES

The method of data collection was as described in Chapter Three. Thus, 25 social workers were surveyed from across all three divisions of Riverview Hospital by a written questionnaire. Eight (8) questionnaires were sent to the Geriatric Division, which serves adults over the age of 65. Eight (8) were mailed to the social workers in the Acute Care Division. This division is essentially the assessment and short-term treatment area of the hospital for those people below the age of 65. Finally, nine (9) social workers were sampled in the Continuing Care Division, where long-term treatment and rehabilitation is conducted. The purpose of this approach was to measure whether the differences in work setting affected the perceptions and opinions expressed by the social workers. It must be noted, however, that clear distinctions cannot be made as social workers within Riverview Hospital move across divisions during their career at this institution.

3. DATA ANALYSIS

Both descriptive and inferential statistical measurement was used. Descriptive statistics such as frequencies and percentages provided a means by which the sample data could be organized, summarized and interpreted. Inferential procedures
allowed the researcher to make generalizations from the sample to the population from which the sample was drawn. Correlations were made between the scores on the Death Anxiety Scale (DAS) and various personal and professional variables such as age, sex, length of work experience, work and educational experience. The hypotheses that were tested are:

1) Death anxiety will be greater for females than for males.
2) Death anxiety will decrease as age increases.
3) Death anxiety will vary inversely with length of experience working at Riverview Hospital.
4) Death anxiety will vary inversely with work experience with the dying as a student.
5) Death anxiety will vary inversely with work experience with the dying as a professional.
6) Death anxiety will vary inversely with formal educational experience and training in working with dying people and their families.
7) Death anxiety will vary inversely with informal educational experience and training in working with dying people and their families.
4. FINDINGS FROM PILOT STUDY

The results of this study showed that 20 out of the 25 questionnaires distributed in the Social Work Department at Riverview Hospital were completed. There were 7 out of 8 respondents from the Geriatric Division, 5 from the Continuing Care Division, and all 8 questionnaires were completed by the Acute Care social workers. Thus, an excellent response rate of 80% was achieved. However, because of the fairly small sample, reporting of results is done in a cautionary way.

a) Demographic Description of Respondents

Half of the respondents were male and half were female, with one not reporting. In terms of age, over half (55%) of the respondents were age 40 and older, with the remaining respondents below age 40. Three-quarter (73.7%) of the sample was married, while 4 (21.1%) were single, and one or 5.3% was divorced. In terms of length of time working at Riverview Hospital there was quite a range in response. Eight respondents (47.1%) had worked less than 2 years, 3 or 17.6% had worked between 2 and 5 years, one respondent (5.9%) had worked between 5 and 10 years, and another (5.9%) between 10 and 15 years. Remarkably, 4 (23.5%) respondents of those who answered had worked more than 15 years.
b) Section One: Death Anxiety Scale (DAS)

The mean of the Death Anxiety Scale, the arithmetic average, is 6.2 with a standard deviation of 3.35. This falls within the norm that Templer (1969) had established for the scale. Kurtosis is -.742 which means that the distribution is skewed to the left or toward smaller numbers. The distribution is fairly normal, and the fluctuation about zero could have resulted from sampling variation. The range is highly variable with the minimum score at 2 and the maximum score at 13 out of a possible 15. The mean score for each division is as follows: 7.14 for the Geriatric Division social workers, which is marginally above the norm, 5.9 for Acute Care workers, and 5.4 for Continuing Care workers.

In terms of the hypotheses made about sex, age, and length of working experience at Riverview Hospital, a significant association between sex and death anxiety is found (r=.52 p=.01) with women having higher scores than men. Results also showed that DAS scores tended to decrease with age but not significantly, and were generally higher for respondents who were married. There were no significant trends found in terms of length of time working at Riverview Hospital.
c) Section Two: Work and Educational Experience

The majority of social workers (80%) reported no experience in working with dying patients as part of their social work training, whereas most (60%) reported such experience in their work following training. Therefore, while only 3 respondents had worked with dying patients as a student, 12 respondents had as professional social workers, a considerable increase. At the time of the study in March 1990, only 4 respondents or 20% of the sample were working with dying patients.

Over half (55%) of the respondents answered that the subject of death and dying was not part of their professional training curriculum. Informal training such as in-services, workshops, and conferences on the subject of death and dying, however was reported by a majority (60%) of social workers. In fact, 70% of the respondents for the Geriatric Division had done so, which demonstrates high interest in the subject by this group.

In terms of the hypotheses being tested regarding past and present work experience with death anxiety the following results were found. When the issue of working with dying patients as a student was correlated with DAS scores, it was found that the scores were much lower for those respondents who had worked with dying patients as student social workers. In fact, all of the scores for these respondents were below
the mean. Caution is necessary, however, in interpreting this result as it is based on only three respondents. Pearson's R is .42 with p=.03. Similarly, the four respondents who were now working with dying patients all scored below the mean, which was unexpected. Social workers are assigned to units which may or may not house a dying individual. Therefore, perhaps these four respondents scores were lower because working with dying patients on their wards has forced them to come to terms with their own mortality. There were no significant results found when the questions about formal and informal education were crosstabulated with DAS scores, indicating that education on the subject has little affect on DAS scores for this sample.

d) Section Three: Perception of Practice

The results of this section provide information about how the social workers at Riverview Hospital perceive the practices and policies regarding death and dying. The questions were derived from the operational definition of palliative care, and can be categorized according to the four remaining variables of: 1) organizational context of the hospital, 2) role expectations of professionals, 3) teamwork, and 4) exchange and conveyance of diagnostic information. Unfortunately, the results are inconclusive as there were numerous responses of "depends" with no explanation or missing
The issue of the organization of the hospital system and its inherent pressures was broken down into distinct questions to measure whether or not the organization was able to meet the identified needs of the dying patient, family, and caregivers, and where need for change is indicated. In terms of physical needs of the dying patient being met, 30% responded "yes", while another 30% responded "depends". Only one respondent felt that emotional needs were being met, while half answered "depends". The question regarding spiritual needs was not included in this questionnaire so there are no results to report. Again, half responded "depends" to the question of whether or not family needs were being met. Half of the respondents agreed that there was a need for change in this area. In terms of support being available within the organization, only 3 respondents felt that it was, while 2 disagreed, and 8 respondents answered "depends". Over half felt that there was a need for change in terms of making support available to the caregivers. Only 18.2 percent of those who responded felt that their work routine allowed them to work "psychologically" with the dying patient, while 45.5 percent did not.

Two questions contained within Section Three of the questionnaire addressed the issue of role expectations placed upon the professional, in this case social workers. Somewhat
more than half responded that the nature of their role was stereotyped, with 50 percent responding that there was a need for change. Only 27.3 percent felt that their professional role limited them in providing therapeutic care to the dying patient.

In response to questions about the issue of teamwork in the organization, the majority of social workers (81.3%) agreed that there was teamwork. Less than half (45.5%), however, felt that they worked as a member of a team when working with dying patients.

Finally, the issue of exchange and conveyance of diagnostic information was addressed in the written questionnaire. Remarkably, no respondents answered positively that patients were made aware that they were dying, however, 67 percent answered "depends". Interestingly, only one respondent felt that there was a need for change in this area. The reverse is true with respect to families being made aware of impending death of their relative. No one responded negatively, however, half of the respondents felt that change was necessary. The majority (90%) said it "depended" in reference to whether the patient understood that he or she was dying. This result is expected considering that there is a high prevalence of neurological disorders such as dementia in the patients who are dying.

The same open-ended questions found in the thesis study
are also found in the pilot study. In regards to the question concerning whether all that can be done for the dying patient is being done, sixteen social workers responded. Over half of the respondents indicated that there is not enough being done, including all the respondents from the Geriatric Division. The other half simply stated they didn’t know or were unfamiliar, or left the question blank. One respondent from the Acute Care Division responded positively to the question. Some of the negative comment was directed at administration, that because of a lack of policy there was no direction, that there is an avoidance of the issue from the top levels. Others suggested areas for improvement such as support groups for family and staff, expanding the role of the social worker, making resources more available, and increasing training for physicians. One respondent indicated that there was good physical care but that there was limited attention to emotional, spiritual, and "other need". For example, there was little concern for the patients wishes, especially pertaining to prolonging life. There was substantially more agreement regarding the question on implementing a special program to address the needs of the dying patient. Again, sixteen social workers responded to this question. Approximately 70 percent of those who responded to this question agreed with the principle of palliative care. There was a concern expressed about the delicate and controversial
nature of this matter, and that hospital management needed to formally address this issue. One respondent preferred to see an increased level of staffing to allow time for palliative care rather than segregating dying patients on a special unit. The social workers also indicated that the Geriatric Division should be given priority for a program because perhaps there were too few dying patients in the other divisions (except for sudden deaths such as suicide). One respondent answered "definitely, Riverview patients deserve it!".

5. DISCUSSION

An overall impression of the results of this study emphasize the controversial and sensitive nature of the issue of palliative care. The political debate about this issue has been simmering for approximately the last two years. Understanding the emotional history of palliative care at Riverview Hospital can help us to appreciate the hesitancy, and otherwise very neutral stance taken by the social workers in response to the questionnaire. Their response certainly reflects the societal attitude of keeping the issue of death and dying invisible. By not speaking out more forcefully and definitively, the social workers are in effect participating in the 'conspiracy of silence'.

The Death Anxiety Scale measures our personal anxiety
about death. It was expected that the scores for this section of the questionnaire would be considerably higher than they were. However, the ordering of the DAS scores according to Divisions was as expected. It was predicted that the Geriatric Division would have the highest mean of the three divisions. This is because dying people in our society tend to be older and, of course, this division caters to that older group. Working with an older population likely to die may increase one's level of death anxiety because it forces one to take stock of issues of mortality. However, the results also showed that those social workers who were currently working with dying people had a lower death anxiety, perhaps indicating that they had dealt with some of their own death issues.

Thorson (1977) demonstrated that death anxiety is positively correlated with majoring in social work, and being female; and is negatively associated with being male (in Lonetto and Templer, 1986). This study confirms this finding as predicted. The reasons for the higher DAS scores for females is not clear. However, it should be remembered that females have tended to score higher on most self-report measures of anxiety, distress, and maladjustment (Lonetto and Templer, 1986). As well, the greater degree of expressed death anxiety may be the product of socialization.

The results of the question concerning the variable of
education and training were somewhat surprising. The respondents had more formal training on the subject of death and dying than was anticipated. A negative correlation between education and DAS scores was expected, however, this did not appear. Perhaps this result was due to the fact the average age of the social workers was between 40 and 49 years of age, so perhaps formal training was so far in the past it had lost its impact. In the study by Bhopal (1989) at Riverview Hospital, education was listed as a main priority by the larger staff of Riverview. However, the social workers as a group at Riverview Hospital did not seem to lack education and training, as the results have shown.

The next major factor in caring for the dying patient is the organization of the hospital system itself. It is not surprising that the results of this study show that physical needs are being met, as Riverview Hospital is a very medically oriented hospital. Almost half of the respondents answered positively to the question on physical needs, while another 46% answered that it "depends". Also, it is not unexpected that there is inadequate attention to emotional needs, as only 7% of respondents thought emotional needs were being met. There was not a clear response to family needs and caregiver needs being met. Not one respondent answered positively that the needs of the family were being met, while most thought it "depends". The same situation exists in response to the
question regarding needs of the caregivers. However, a greater demand for change in the area of supporting the caregiver was expected, as it is in their best interest to respond positively to this.

In order that organizational needs can be met, it is necessary that the nature of the activities and behaviours within it be predictable. The presence of a dying person in a cure-oriented organization disrupts the smooth carrying out of the objectives. The psychological demands of these patients may be greater than the physical demands, but often do not receive as much attention. This study supports the assertion that psychological care is not consistently reflected in practice due to time pressures and hospital milieu. Almost half of the respondents thought that their work routine did not allow them time to work "psychologically" with the dying patient.

The third factor is role expectations placed upon the health care professional. The literature has suggested that certain expectations and stereotypes present real problems to those professionals attempting to give appropriate care to dying patients. A majority (56%) of social workers agreed that their role is stereotyped and that there was a need for change in this area. One respondent even went so far as to suggest that the staff on the unit he worked on had no idea what he did. The stereotyping of roles is very disruptive to
the cohesion found in staff, as well as communication. The results concerning professional role limiting the provision of care was expected, especially for social workers.

The next major factor identified in the literature is the teamwork amongst health professionals. In general, the response of the social workers (81%) was to suggest that there was good teamwork in the organization. This would suggest that Riverview Hospital is a very unique setting in which morale is very high, as well as the spirit of cooperation. Interestingly, less than half of the respondents did not feel as if they were part of a team when working with dying patients. Perhaps this is a reflection of the status one feels as a social worker and as a non-medical professional in a medically oriented institution.

The last issue is the issue of diagnostic information, and the manner in which it is communicated. It appears that only under certain circumstances are patients told they are dying. In light of the fact that the findings also show that social workers do not usually expect the person to understand that he or she is dying, this is not all that unanticipated. However, this could be a real ethical issue if common practice becomes never to tell the patient that he or she is dying because it is not believed that he or she will understand. Nevertheless, it really points to the need to better understand the meaning of death for the mentally ill and how
we as professionals operate with that understanding. The findings also show that families are told about their relatives impending death. This is at least a positive finding.

Thus, it can be concluded that the six major factors related to therapeutic care of dying individuals are at work at Riverview Hospital and to some degree negatively impact the care given to dying individuals. The factors of education and teamwork do not seem as important to this sample, as do the factors of the organization of the hospital and its inherent pressures, and the conveyance and exchange of diagnostic information. If and when Riverview Hospital has finalized the palliative care guidelines and policy, it would appear that issues such as stereotyping of role and role reduction, and support for the caregivers must be dealt with. Social workers can carve out a role for themselves as facilitators of the fundamental changes to the environment to eliminate or reduce these variables. The usefulness of this study was the identification of the most pressing issues facing successful implementation.

It appears that the social workers are in agreement to having a palliative care unit and/or palliative care team, preferably in the Geriatric Division. As well, it is shown by Buckingham et al. (1972)'s participant observation study that service to dying patients is best achieved using these
modules. The next phase of research in this area would necessarily be directed at exploring what such a program would look like considering the unique and similar needs of the dying mentally ill. This study was limited by the instrument. In the next section, the modifications made to the instrument will be outlined.

Based on this study, it can be concluded with caution that some form of palliative care does exist at Riverview Hospital, as it is claimed. The findings of this study show that the situation is not all bad, but that there are clear areas where improvement is needed. It also appears that the same factors which influence the emergence of palliative care in an acute hospital are equally valid and applicable to a mental institution.

6. MODIFICATIONS TO THE QUESTIONNAIRE

As a result of the pretest of the instrument during this pilot research project, many significant changes were made to the instrument (see Appendix C) in order to increase its internal validity. An attempt was made to eliminate some of the threats to reliability and internal validity such as unclear questions or meaning, complex language, over-judging the knowledge of the respondent, and double-barrelled questions. Of course, certain research conditions cannot be
controlled for in the actual design. For example, history cannot be accounted for in the research design. For instance, some respondents may have completed the questionnaire just after a death had occurred on the unit. The immediacy of this event may result in the respondent answering questions in a way that he or she would not usually have, which may pose a threat to the internal validity of the design.

The first significant change to the questionnaire was to improve Section Three so as to reduce the number of ambiguous responses represented by the "depends" category. This was done in a number of specific ways such as: providing examples for global terms such as 'need'; eliminating certain questions and moving others to Section Two. Added to the instructions was a request that if the respondents chose to answer "depends", they had to qualify that by writing in the space provided why they answered that way. As well, the format was altered so as to give the respondents more room to complete questions 38 and 39, the open-ended questions. These questions were important in that they are change-oriented and thus, it was necessary not to restrict the respondents in the giving of their answers. Section Two was altered in that questions 16, ("Have you ever experienced the death of someone close to you i.e. a friend or relative?") and 22 ("Considering your life, work, and educational experience, do you feel competent and/or confident in working with dying people and
their families?" were both added. Question 46 in Section Four was altered to reflect the changes in the sample demanded by the Scientific Review Board of Riverview Hospital.

7. SUMMARY

In this chapter the findings from the pilot project that preceded the thesis study project were presented. A quantitative and qualitative analysis were conducted. The quantitative analysis included univariate, and bivariate analysis using SPSS:X. A discussion of the findings was included, as well as a description of the modifications to the survey instrument.
Dear Respondent,

I am a Master of Social Work student at the University of British Columbia. I am currently conducting a research project in order to fulfill the thesis requirement. The purpose of the study is to assess what deterrents to therapeutic care of the dying patient exist at Riverview Hospital. Also, to what extent the unique needs of the dying patient of Riverview Hospital are being met by the various professional groups. This study will provide information that will increase understanding of practice in this area in order to ensure quality of life for the dying patient.

The attached questionnaire will take no more than 20 minutes to complete. It is divided into four sections. The first section is the Death Anxiety Scale to measure personal fear of death. The second section addresses your work and educational experience in caring for the dying person and their families. In the third section the questions are directed to the practice at Riverview Hospital, and to identify areas of need for change. The fourth section provides background information about the respondent. You are not required to answer any question that you are uncomfortable with. All the information gathered will be kept strictly confidential and all questionnaires will remain anonymous.

If you agree to participate in this study, please return the completed questionnaire along with this letter by March 23, 1990 to the above address. You have the right to withdraw from the study at any time without penalty. I sincerely appreciate your consideration in participating in this study. If you have any questions or concerns please feel free to contact me at the above address and number. I look forward to hearing from you. Thank you once again.

Sincerely,

Carolyn Tanner

c/CT
Death is one of those ubiquitous topics on which every person is his or her own expert. In the following questionnaire you will be asked questions related to your own personal fear of death, your work and educational experience with death and dying, and your opinion on practice at Riverview Hospital with the dying. It is important that you be as candid and thoughtful as possible; the value of the findings will depend upon your honesty. It should take you no longer than 20 minutes to complete.

SECTION ONE: Death Anxiety

If a statement is true or mostly true as applied to you, circle "T". If a statement is false or mostly false as applied to you, circle "F".

T F 1. I am very much afraid to die.
T F 2. The thought of death seldom enters my mind.
T F 3. It doesn't make me nervous when people talk about death.
T F 4. I dread to think about having to have an operation.
T F 5. I am not at all afraid to die.
T F 6. I am not particularly afraid of getting cancer.
T F 7. The thought of death never bothers me.
T F 8. I am often distressed by the way time flies so very rapidly.
T F 9. I fear dying a painful death.
T F 10. The subject of life after death troubles me greatly.
T F 11. I am really scared of having a heart attack.
T F 12. I often think about how short life really is.
T F 13. I shudder when I hear people talking about a World War III.
T F 14. The sight of a dead body is horrifying to me.
T F 15. I feel that the future holds nothing for me to fear.
SECTION TWO: WORK AND EDUCATIONAL experience

The following section will address your work experience with dying patients, and any education you may have had on caring for the dying and their families.

16. As a student, did you ever work with dying patients?

17. In your work (not as a student), have you ever worked with dying patients?

18. Are you working with dying patients now?

19. Was the subject of death and dying any part of the curriculum in your professional education and/or training?

20. During your career as a professional, have you ever attended an in-service, training workshop, or conference on the subject of death and dying?

SECTION THREE:

The following questions address practice in your work setting at Riverview Hospital. In the "practice" column please check the alternative that best represents your opinion. In the second column, please assess whether there exists a "need for change" relating to the issue and check the appropriate alternative. If the question does not apply to you leave it blank. Feel free to write any comments in the space provided.
<table>
<thead>
<tr>
<th>Question</th>
<th>Practice</th>
<th></th>
<th>Need For Change</th>
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</thead>
<tbody>
<tr>
<td>21. Are the physical needs of the dying patient being met?</td>
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<td></td>
<td></td>
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<tr>
<td>22. Are the emotional needs of the dying patient being met?</td>
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<tr>
<td>23. Do you have the basic knowledge of what the emotional needs of dying people are?</td>
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<tr>
<td>24. Are the needs of the family of the dying patient being met?</td>
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<tr>
<td>25. Are the needs of the care-giving professional being met?</td>
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<tr>
<td>26. Is there support available for people working with dying patients?</td>
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<td>27. In your practice is the patient made aware that he/she is dying?</td>
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<tr>
<td>28. Is the family of the dying patient made aware that he/she is dying?</td>
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<tr>
<td>29. Do you react to a terminally ill patient talking about his/her impending death with relative ease?</td>
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<tr>
<td>Practice</td>
<td>Need For Change</td>
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<td>Yes</td>
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<tr>
<td>Depends</td>
<td>Yes</td>
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<tr>
<td>No</td>
<td>No</td>
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<td></td>
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<tr>
<td>Depends</td>
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</tbody>
</table>

30. Do the hospital personnel around you avoid discussion related to death and dying?  

31. Is there teamwork amongst the various professional staff working on your unit(s)?

32. Do you work as a member of a team when you are working with the dying and their families?

33. Is the nature of your professional role stereotyped by others working in the hospital?

34. Does your work routine allow you the time to work "psychologically" with the dying patient?

35. Does your professional role limit your providing therapeutic care to the dying patient?

36. When told about impending death, does the patient understand that he/she is dying?

37. In general, do you agree that all that can be done for the dying patient at Riverview is being done? Please comment.

38. Should a special program be implemented (i.e. palliative care unit, palliative care team) to address the needs of the dying patient? Please comment.
SECTION FOUR

In order to evaluate this survey it is important to know a few things about the background of each person who responds. Please help by answering these questions.

39. What is your sex?
   __1. male
   __2. female

40. What is your age?
   __1. 20 to 29
   __2. 30 to 39
   __3. 40 to 49
   __4. 50 to 59
   __5. 60+

41. What is your current marital status?
   __1. single
   __2. married
   __3. separated
   __4. divorced
   __5. widowed

42. How long have you worked at Riverview Hospital?
   __months
   __years

43. Which division of Riverview are you currently working at?
   __1. Adult Division
   __2. Continuing Care Division
   __3. Geriatric Division

44. Which unit are you currently working on?

45. What is your profession?
   __1. physician
   __2. psychiatrist
   __3. nurse
   __4. occupational therapist
   __5. physical therapist
   __6. recreational therapist
   __7. social worker
   __8. psychologist
   __9. pastoral care worker
   __10. dietician
   _11. other (specify)__________________________

***Thank you for your time***
SECTION TWO: LIFE, WORK, AND EDUCATIONAL EXPERIENCE

The following section will address your life and work experience with dying people, and any education you may have had on caring for the dying and their families.

16. Have you ever experienced the death of someone close to you, i.e. a friend or relative?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___

17. As a student, did you ever work with dying patients?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___

18. In your work (not as a student), have you ever worked with dying patients?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___

19. Are you working with dying patients now?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___

20. Was the subject of death and dying any part of the curriculum in your professional education and/or training?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___

21. During your career as a professional, have you ever attended an in-service, training workshop, or conference on the subject of death and dying?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___

22. Considering your life, work, and educational experience, do you feel competent and/or confident in working with dying people and their families?
   1. Yes ___ 2. No ___
   3. Unsure ___ 4. Not Applicable ___
The following questions address perceptions of practice in your work setting at Riverview Hospital. In the "practice" column please check the alternative that best represents your opinion. In the second column, please assess whether there exists a "need for change" relating to the issue and check the appropriate alternative. If the question does not apply to you leave it blank. If you chose to answer "depends" please write in the space provided why you have answered in that way.

<table>
<thead>
<tr>
<th>Practice</th>
<th>Need for Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>23. Are the physical needs of the dying patient being met (ie. pain control, symptom relief)?</td>
<td></td>
</tr>
<tr>
<td>24. Are the emotional needs (ie. expression of grief and loss, understanding meaning of death and life) of the dying patient being met?</td>
<td></td>
</tr>
<tr>
<td>25. Are the spiritual needs (ie. those that deal with the person's relationship with God, however defined by the individual) of the dying patient being met?</td>
<td></td>
</tr>
<tr>
<td>26. Are the needs of the care-giving professional (ie. expression of grief and loss, relief from burden) being met?</td>
<td></td>
</tr>
<tr>
<td>27. Are the needs of the family of the dying patient (ie. emotional support, dealing with the hospital) being met?</td>
<td></td>
</tr>
<tr>
<td>28. Is there support (ie. counselling) available for people working with dying patients?</td>
<td></td>
</tr>
<tr>
<td>29. In most cases, is the patient made aware that he/she is dying?</td>
<td></td>
</tr>
<tr>
<td>Practice</td>
<td>Need for Change</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>30. As a rule, are efforts made to inform the family that their relative is dying?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>31. Do the hospital personnel around you avoid discussion related to death and dying?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>32. Is there teamwork amongst the various professional staff working on your unit(s)?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>33. Do you work as a member of a team when you are working with the dying and their families?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>34. Is the nature of your professional role stereotyped by others working in the hospital?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>35. Does your work routine allow you the time to work &quot;psychologically&quot; with the dying patient?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>36. Does your professional role limit your providing therapeutic care to the dying patient?</td>
<td>Yes  No  Depends</td>
</tr>
<tr>
<td>37. When told about impending death, do most patients understand that they are dying?</td>
<td>Yes  No  Depends</td>
</tr>
</tbody>
</table>
38. In general, do you agree that all that can be done for the dying patient at Riverview Hospital is being done? Please comment.

39. Should a special program be implemented (ie. palliative care unit, palliative care team) to address the needs of the dying patient and their families? Please comment.
SECTION FOUR

In order to evaluate this survey it is important to know a few things about the background of each person who responds. Please help by answering these questions.

40. What is your sex?
   ___1. male
   ___2. female

41. What is your age?
   ___1. 20 to 29
   ___2. 30 to 39
   ___3. 40 to 49
   ___4. 50 to 59
   ___5. 60+

42. What is your current marital status?
   ___1. single
   ___2. married
   ___3. separated
   ___4. divorced
   ___5. widowed

43. How long have you worked at Riverview Hospital? (Fill in appropriate numbers)
   ___months
   ___years

44. Which division of Riverview are you currently working at?
   ___1. Acute Care Division
   ___2. Continuing Care Division
   ___3. Geriatric Division

45. Which unit are you currently working on?

46. What is your profession?
   ___1. social worker
   ___2. health care worker
   ___3. general physician
   ___4. psychiatrist
   ___5. pastoral care worker

***Thank you for your time***