# Mind, Body, and Spirit:
# Exploring The Need For A Hospice In Kings County

by

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## Abstract

During the past twenty years, palliative care has emerged as a new and significant component in the continuum of health services in Canada. Palliative care services address the holistic needs of those who are dying, their important ones and their care providers. This thesis applies a needs assessment approach to ascertain the current need for a hospice in Kings County. The objectives of this research were twofold: first, to identify the unmet physical, psychological, social, spiritual, information and financial needs of individuals faced with life-threatening illnesses and the needs of caregivers. Second, to determine the need for a free-standing hospice facility in Kings County.

In 1997, a mail-survey and in-depth personal interviews were conducted for this study. One hundred and fourteen people returned the survey, and ten people were interviewed. The sample population was selected from recommendations by persons on the Palliative Care Advisory Committee who were knowledgeable about potential and existing palliative care clients.

The findings contained in this thesis suggest there is a need for a freestanding hospice facility in Kings County. As well, this research indicates palliative care programs and services in Kings County are not presently addressing the essential and desired needs of the dying, their significant others and their caregivers. A list of recommendations is included in Chapter Six.

## Acknowledgments

Many people were instrumental in the completion of this thesis. I wish to extend thanks to the individuals with life-threatening illnesses, their significant others and the caregivers who participated in this study and so openly shared their personal experiences with death and dying. I am eternally grateful and your experiences will live on in my heart.

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# Chapter One

# Introduction and Literature Review

## Introduction

This thesis evolved from a research project that I was employed to conduct for the Victorian Order of Nurses (VON), Kings Branch. Prior to this experience, I was unaware of the complexity and plight faced by individuals with life-threatening illnesses, their significant others and their caregivers in my own community in their search for comprehensive palliative care. My journey into the realm of caring for those who are dying in Kings County has been life altering. I now recognize that death, like life, can bring both joy and sorrow. I have learned the simple philosophy that death is a natural part of the end of life as we presently know it.

Palliative care is a philosophy of health care developed to address the needs of those with life-threatening illnesses. It focuses on the needs of the patient and significant others when cure for a terminal illness is no longer available. The primary goal of palliative care is to improve the quality of a person's life as death approaches, through the assessment of pain and the control of symptoms. These may range from the physical, psychological, social, or spiritual. Palliative care involves providing information, comfort, and supportive strength to patients, their significant others and their caregivers as they move toward the reality of death. At the same time, all that are associated with the patient such as family, friends and caregivers are provided with a sense of hope and reassurance. Palliative care is not focused on death: rather it is specialized care for the living.

The research conducted for this thesis can be interpreted as participatory action work that seeks to meet the community's needs (Babbie 1995). The following study entails an examination of the unmet physical, psychological, social, spiritual, information and financial needs of individuals faced with life-threatening illnesses and their caregivers. Not only does this thesis deal directly with the perspective of those who are dying and their significant others, it gives formal and informal caregivers an opportunity to offer their views in terms of the needs of the dying. By incorporating these perspectives, a holistic overview of palliative care in Kings County is achieved. Moreover, the current programs and services provided for palliative care clients and their significant others in Kings County are evaluated. Furthermore, this study determines the need for a free-standing hospice facility in the community and it provides all who are involved with palliative care in Kings County input into the creation and composition of a freestanding hospice. For the purpose of this thesis, the term 'palliative' refers to programs for the dying in the hospital, nursing homes and community while the term 'hospice' refers to a grassroots community-based building or home program for the dying and their loved ones.

Despite efforts to include all the informational sources in the community of palliative care, certain limitations do exist. First, it should be understood that this thesis, to some extent, reflects a white, female, Anglo Saxon heterosexual point of view. Second, the interpretation of the data is from a sociological perspective and not a medical model viewpoint. This is my background and social upbringing. I believe it would be an erroneous assumption on my part to believe I could have written this thesis from another perspective. For example, as a white woman, I cannot fully describe the needs of a black gay man dying with AIDS. The limitations of my point of view should not be interpreted as a dismissal of other cultural or ethnic perspectives, but rather as an honest reflection of from where this thesis has come and from the underlying bias contained in the following interpretation of the data.

Chapter One introduces the thesis topic and provides an overview of palliative care. The purpose of the literature review is to expand the reader's understanding of the power and importance of hospice care in Canada. On-line searches of a number of databases were used to identify the literature. The main focus of the searches was on Canadian literature. However, due to the scarcity of literature published on Canadian hospice care, international literature has been used in some instances to provide a more global perspective.

Chapter Two describes the sociological aspects related to health issues in the following ways: to define disease, illness, and sickness from a sociological standpoint; to provide an overview of the social forces that evoked the palliative care movement; to examine modern health care systems and Canadian health care and mortality.

Chapter Three introduces the challenges facing palliative care in the community as generated by the data which are the focus of this study. It provides a statistical profile of population characteristics of Nova Scotia and the County of Kings as well as a summary of cancer and AIDS rates of occurrence in Canada and Nova Scotia. Also included in this chapter is a discussion of the potential populations who could use a hospice in Kings County. For the purpose of this study, the concept of *community* refers to a group of like-minded individuals in the municipal unit of Kings County.

Chapter Four reviews the methods used to study the physical, psychological, social, spiritual, informational and financial needs of individuals faced with life-threatening illnesses, their significant others and their caregivers. Methods used to determine the need for a free-standing hospice facility in Kings County are also reviewed. On the topic of methodology, this chapter will detail the elements of this thesis such as a discussion of participatory action research, the purpose and objectives of the needs assessment, measures used, the sample population and sampling method.

Chapter Five presents the data and analysis. Topics addressed in this section include: background characteristics of the sample population; examination of unmet physical, psychological, social, spiritual and information needs of individuals living with a life-threatening illnesses, their significant others and caregivers; assessment of the community's familiarity with palliative care programs and services in Kings County; critique of programs and services for palliative care clients in Kings County; need for a freestanding hospice in Kings County; the types of programs and services that could be offered in a freestanding hospice setting; and finally discussion of the dissenting views on whether to have a freestanding hospice in Kings County. This information is broken down according to questions presented in the survey *(see Appendix 1).*

The final chapter has a concluding summary of the research findings. Also included are recommendations for palliative care in Kings County and the creation of a hospice care facility.

## Literature Review

> There is an image of dying people that many Canadians have--the person is comatose, hooked up to monitors with intravenous tubing sticking out everywhere. We have too often seen our loved ones like this and we have seen them in pain and suffering.
>
> Hospice care is different. It makes sure that someone is relatively free of pain, is often able to be awake so they can remain an active part of their families until a few hours or days before death, does not use monitors or tubes, and tries to give as much control to the patient and family as they choose to have (Van Bommel 1992:24).

At a moment in history when technology in every discipline is expanding at an alarming rate, it is ironic that we are moving back towards an awareness of our parents' and grandparents' wishes for an experience of death--accepting it with a new understanding as an integral, dignified part of our life process and importantly, bringing the dying back into our homes and communities. The palliative/hospice movement has been a crucial component reflective of this change.

A central theme of palliative/hospice care is the belief that the terminally ill should be relieved of pain and that, whenever possible, the dying should have the dignity and support of a home environment and family or significant others. The palliative care movement has been successful in bringing both of these messages, and the techniques that support them, to millions of individuals over a relatively short period of time. It is perhaps not surprising when we consider how deep a human chord is struck by such basic concepts.

In my opinion, the present generation of Canadians has not learned to cope very well with death. Former generations faced death better because they grew up in a world that recognized dying as part of living. In what seems to have been a simpler time, perhaps they were closer to the natural order of life. For them it was common to lose friends, siblings and loved ones by the age of puberty. Dying and grieving were part of community life--whether in city neighborhoods, small towns, or rural farmlands. Mostly, people died at home where their families closed ranks in mutual support, helping both the dying and themselves to face the unknowable journey of life.

## The Role of Palliative Care in Health Care

The role health care plays in treating and serving the needs of the chronically and terminally ill has been increasingly questioned from all sides. A number of researchers have identified deficiencies in care for those with life-threatening illnesses. There is evidence that the physical, psychological, social, spiritual and information needs of terminally ill patients and their significant others are not met. (Abel,1986; Gilbar & Steiner,1996; Luchins & Hanrahan,1993; Saunders, 1990). The terminally ill and their significant others often experience feelings of isolation and depersonalization instead of receiving compassionate understanding and care specially geared to their needs. The reliance on technology that epitomizes the health care system, combined with medical education that emphasizes diagnosis, treatment, and curing, is thought by some to become irrelevant and even alienating when a cure is no longer a possibility. Death is seen as a failure in an environment that is devoted to fighting to keep people alive. Numerous researchers have documented the psychological needs of the dying patient (Cassileth et al.,1985; Kastenbaum,1995; Ross & MacDonald,1994; and Zimmerman,1981). It is estimated that between 25 and 45 percent of individuals facing a terminal illness experience some form of clinical depression (Hospice Association of America 1996:12). The depersonalizing aspect of high-technology medicine has been said to ignore the needs and strengths of the *whole* person in pursuit of eradicating the disease. The management of health services and the case routine of hospital protocol may be counterproductive in meeting these needs and may even serve to distance the patient from their caregivers, friends, families and significant others. Therefore, patients may experience *social* death before biological death (Kastenbaum 1995:43). Nonetheless, palliative treatment is a form of care, which is often debated and unfortunately, often misunderstood. Assisted suicide and euthanasia debates and practices have made society question the methods of responding to and treating individuals with life-threatening illnesses and chronic disease.

## What Is Palliative/Hospice Care?

Hospice care and palliative care are similar in definition. The term hospice, derived from the Latin term *hospitium*, lends the meaning 'to host'. Hospice originated in medieval Europe. It described a place where travellers, weary from journeys, could seek shelter, nourishment, and rest. Coincidentally, the term palliative implies 'to relieve symptoms of a disease without curing' or 'to provide comfort care'. Throughout the United States, Europe and the United Kingdom, the word hospice is used most often. In Canada, the French translation of the term *hospice* meaning 'dying in the poor house' resulted in the term palliative care being adopted in the mid 1970s (Von Bommel 1992:23). In terms of common usage, the word 'palliative' in Canada often refers to a hospital program while the word 'hospice' often refers to care provided in the community.

Palliative care is based on the belief that every person has the right to participate in informed discussions about their health care options and that patterns of care vary among patients. It evolved from the management of persons living with cancer and the ideology that cancer can be beaten. (Kristjanson 1996:3).

Over the years, there have been many definitions of palliative care. They have similar core elements but contain subtle nuances that have implications for health care planners. The early definitions of palliative care talked about it in terms of 'to cloak' or 'to cover', and 'to ameliorate symptoms of distress' and focused primarily on the end of life after curative efforts had been exhausted (Kristjanson 1996:4).

More recently, the view of palliative care as presented by the Canadian Palliative Care Association and in the 1989 document produced by Health and Welfare Canada, was that we are looking more at a continuum of palliation that might begin at the onset of a an illness or occur in conjunction with active treatment from time to time (Kristjanson 1996:4). Currently, there is no nationally accepted definition of palliative care. The Canadian Palliative Care Association's working definition is:

> Palliative care, as philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illnesses. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs, and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.
>
> Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.
>
> While many service providers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized palliative care program may be required as the degree of distress, discomfort and dysfunction increases.

> Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing
> (CPCA 1995:41).

Health Canada's definition of palliative care is:

> Palliative care is a program of active compassionate care *primarily* directed towards improving the quality of life for the dying.
>
> It is delivered by an interdisciplinary team that provides sensitive and skilled care to meet the physical, psychosocial and spiritual needs of both the patient and the family. The philosophy and principles of palliative care may apply to patient population other than the dying and palliative care programs may have a *secondary* role in addressing the needs of these populations (Health Canada 1989:1).

The principles of palliative care in Canada have been outlined by the Canadian Palliative Care Association. *(see Appendix 2 for a more detailed description of the principles)* They are:

1. Meet the physical, psychological, social and spiritual expectations/needs of the patient and family
2. Access to information and services should be available 24 hours a day, 7 days a week
3. Equal availability of palliative care services without discrimination
4. Ethical principles are integrated into the provision of care and program development
5. Patient, family, caregiver and service provider have a right to information
6. Patient, family, caregiver and service provider have a right to choice/empowerment

7. The unit of care is the patient and family
8. Care is provided by an interdisciplinary team of caregivers and service providers
9. There should always be continuity of care
10. The palliative care needs of the community be met through collaborative efforts of partnerships and mutual support
11. Broad based governance and administration of programs is required to ensure support and accountability
12. Quality of care is to be delivered by all service provider within professionally accepted standards of conduct and practice
13. Program evaluation be conducted to ensure quality palliative care and to maintain standards of conduct and practice
14. Education, information, research and advocacy for the development and maintenance of palliative care standards

(CPCA 1995:43).

Despite the brisk evolution of thinking about whom palliative care should be directed and what it includes, the primary model still in the minds of the public and most health care practitioners is outdated. Kristjanson (1996:20) asserts the following view:

> When all else fails, palliative care might be offered. What is important about the preponderance of this inaccurate definition is that this may discourage people from transferring people to palliative care services and may also discourage inclusion of palliative care services during phases of active treatment.

### Who Is Usually A Recipient of Palliative Care?

According to USA and UK population health statistics, historically, most palliative clients have been older adults suffering from cancer; however, this is changing. In general, palliative care patients are nearly as likely to be male as female, with a small percentage of females being greater than males due to female longevity (Hospice Association of America 1996:9; and St. Christopher's Hospice Information Services 1997:3). As well, the large majority of users are white. Non-whites appear to be under-represented in the use of palliative care because of cultural beliefs of decreased reliance on formal health institution's arrangements of care, accessibility problems and increased family involvement of the dying at home (Hospice Association of America 1996:9). Across studies in North America and UK, the average age of palliative care users appears to be in the mid to upper 60's. It is clear that almost all palliative care patients have had cancer as their primary diagnosis. Malignancies of the lung, colon, breast, and prostate are most common. Other frequent diagnoses upon admission for palliative patients are diseases of the circulatory system with congestive heart failure; diseases of the respiratory system; diseases of the nervous or neuromuscular system and sense organs, including Alzheimer's, Parkinson's, Meningitis, Multiple Sclerosis etc.; and infectious and parasitic diseases, which include Human Immunodeficiency Virus (HIV/AIDS). (Hospice Association of America 1996:9; and St. Christopher's Hospice Information Services 1997:3).

The length of hospice stay is a crucial indicator of the composition of patients admitted, and it often correlates significantly with the intensity of resources required on a daily basis. The length of stay for patients in a hospice strongly relates to their functional status and nursing care needs at the time of admission. The average length of stay in the US and UK hospices is less than 22 days. This suggests that patients closer to death may have more severe conditions which are likely to require inpatient care. In general, the median length of stay appears to be between 30 and 45 days, with an average ranging from 17.7 to 115 (Hospice Association of America 1996:7; St. Christopher's Hospice Information Services 1997:3). However, it should be noted that the length of stay in a hospice program for children with a life-threatening illnesses and individuals with HIV/AIDS are varied because of the unpredictability of the disease trajectory. Some hospice client stays are for the purpose of pain control and symptom management, these clients are sometimes discharged to die at home or return at a later date.

With the advent of HIV/AIDS in Canada, some palliative care programs and services are reorienting their policies to work with younger patients who do not view entering a hospice as a final decision to give up hope or discontinue activities geared toward positive healing. In fact, some AIDS patients experience fluctuations in their health that allow for periods in which they do not require hospice care (Flannery et al., 1997:17). This underscores the importance of flexibility in policies regarding palliative care programs.

## Where Did Hospice Care Originate?

The term *hospice* stems back to medieval times when it was used to describe a place of shelter and rest for the weary and the sick travelers returning from religious pilgrimages, and later a place for wounded Crusaders to rest and receive treatment (Munley 1983:28).

The modern hospice movement generally credits Dr. Cicely Saunders for instituting the founding philosophy of hospice care. She established St. Christopher's Hospice near London in 1967 where her program combined modern pain control techniques with compassionate care for the dying (Munley 1983: 28). However, there were actually a few institutions in existence before St. Christopher's that offered palliative care to the dying. Dr. Saunders learned her techniques for pain control at St. Luke's Hospital in London where she worked as a volunteer after the Second World War and she worked at St. Joseph's Hospice, founded in 1905. St. Luke's was founded in 1893 as a 'Home for the Dying Poor', and there care was provided for those dying of cancer or tuberculosis (Saunders 1990:14). Saunders states "the general attitude of the staff, the standard of nursing, and still more, the control of pain achieved by the regular giving of oral narcotics was impressively better than anything seen in teaching and general medicine" (1990:14). Dr. Saunders, impressed by what she saw at St. Luke's, went on to establish a program at St. Christopher's Hospice in London. With the assistance of Dr. Saunders, the movement spread to North America in 1974 with the opening of the New Haven Hospice in Connecticut (Munley 1983: 28).

Eliabeth Kubler Ross is also credited with pioneering the palliative care and hospice movement when she reached a broader public in 1969 with the message that we can and must relate to the dying as persons. She introduced the examination of the individual and society's perspective of death and dying at a time when death was considered largely as a frightening taboo, only to be whispered about. Kubler-Ross states the following view:

> Death has always been with us and will always be with us. It is an integral part of human existence. And because it is, it has always been of deep concern to all of us. Since the dawn of humankind, the human mind has pondered death, searching for the key that unlocks the door to life (1969:23).

Kubler-Ross proposed that the terminally ill pass through a sequence of five stages: *denial* of the terminal condition; *anger* and *resentment* ('why me'?); *bargaining* with God (or physicians) for more time; *depression* stemming from the impending loss of everything and everyone; and, finally, peaceful *acceptance* of one's fate (Kubler Ross 1969:37).

Although, Elisabeth Kubler-Ross's five stages have since been criticized, thanks to her we have seen palliative care emerge throughout the world, and witnessed a re-examination of the nature and experience of death and dying. Kubler-Ross has travelled throughout North and South America, Europe, Australia and Japan holding seminars on accompanying the dying. The death-education movement is largely due to the early work of Kubler-Ross and has enabled us to deal more openly and humanely with death and grief (Kastenbaum 1995:104).

## Palliative Care in Canada

The early palliative care movement in Canada tended to be institution-based. The first palliative care programs were established in Montreal and Winnipeg hospitals in 1975. The subsequent palliative care programs and services in Canada have historically originated at the community level. These programs and services emerged from unmet needs and wants of the community. This local development of programs and services has led to an inconsistency in the services provided across Canada.

The current palliative and hospice care movement is bringing the dying back into our homes and communities. It is helping society view death as a natural part of the life process rather than as social problem. Palliative care focuses on the relief of symptoms, pain control, and provision of support to patients and their families. Palliative care programs in Canada play an important role in helping the dying and their significant others provide this special care. Programs are committed to educating and expanding the general knowledge of palliative care to health care practitioners and the public, as well as increasing the availability of this special type of care in Canada (CPCA 1995:12).

Although individual programs vary, there are at least six identifiable types of palliative care programs in Canada:

1. ***Home care and community hospices.*** With home care, the patient may choose to remain in the home until death and is treated by visiting doctors, nurses, licenced practical nurses (LPNs), home support workers, social workers, spiritual counselors, volunteers and other caregivers. People receiving care in the home may sometimes go to the hospital or clinic to receive medical treatment for pain and symptom control.

2. ***Free-standing Hospices.*** This facility is separate from any other institution providing only hospice care (i.e., Canuck Place in Vancouver, British Columbia, Maison Michele Sarraizin in Montreal, Quebec, and Casey House in Toronto, Ontario). Patients are often referred by a family physician or specialist. These facilities do not have operating rooms, specialized life-support systems, or any features of a hospital.
3. ***Palliative Care Units in a Hospital.*** A separate unit is located within a hospital which provides palliative care. These units are often designed and decorated to give a more home-like atmosphere than other hospital units.
4. ***Palliative Care Team (consultation team) within a Hospital.*** Rather than having a separate unit within a hospital, many hospitals now have a multi-disciplinary team of nurses, doctors, social workers, pharmacists and other caregivers who provide care to patients regardless of where they are located in the hospital. The team educates the regular caregivers in pain and symptom control and encourages the emotional, spiritual and informational supports that individual patients need.
5. ***Extended Care Services.*** These are programs are in institutions such as nursing homes and long term care facilities. These facilities may have a palliative care team and/or a special unit for patients who are dying.
6. ***Regional Palliative Care Programs.*** Some regions of Canada e.g. Victoria, British Columbia, and Ottawa-Carleton, Ontario have regionalized

their palliative care programs to coordinate the services of hospital-based and community-based hospice programs (Van Bommel 1992:26-27).

Despite the existence of many programs in Canada, few patients receive the benefit of palliative care. Von Bommel (1992:12) estimated that only 5% of individuals who are dying receive palliative care. Although medical therapies are technically available, accessing these therapies remains a problem. Many patients with life-threatening illnesses experience problems with pain and symptom management, notwithstanding the availability of effective medical and alternative therapies.

Current trends involve a broad spectrum of palliative care services ranging from when an individual is first diagnosed with life-threatening illnesses to the final days of care. In a health care system that emphasizes treatment and curing, the use of trained volunteers has ensured that palliative care programs meet the needs for care within already constrained budgets. The present emphasis on evidence-based medicine and cost-benefit analysis or efficiency program evaluations may threaten the validity of palliative care programs that cannot be measured and justified in this way (Singer & Martin 1996:1).

The Canadian Palliative Care Association was established in 1991 in an effort to standardize palliative care in Canada. According to the *1997 Canadian Directory of Services: Palliative Care and HIV/AIDS,* there are 594 palliative care programs in Canada. Located in both urban and rural settings throughout ten provinces and two territories, these programs seek to fulfill the holistic needs of each community with respect to dealing with life-threatening illnesses. Table 1 shows the number of programs in each province.

**Table 1: Number of Palliative Care Programs by Province and Territory, 1997**

| Province or Territory | Number of Programs |
|---|---|
| British Columbia/Yukon | 75 |
| Alberta | 31 |
| Saskatchewan | 32 |
| Manitoba | 35 |
| Ontario | 303 |
| Quebec | 38 |
| New Brunswick | 11 |
| Nova Scotia | 48 |
| Prince Edward Island/ Newfoundland | 21 |
| **TOTAL** | **594** |

It should be noted that the directory information (CDSPC&HIV/AIDS) is collected by a self-reporting questionnaire. The number of programs in Canada may not truly represent all existing palliative care program services and accessibility. Some programs in an urban setting offer a wide variety of services while others in a rural setting may only provide one service. This could lead to the misconception there are numerous accessible programs widely dispersed throughout Canada.

All provinces and territories are working to integrate palliative care services as part of the expanding range of community-based health care services. There is also an effort being made to ensure that these services are an essential part of an increasingly regionalised health care delivery system. For instance, Quebec has integrated palliative care into the network of services offered by the Centre locale des services communautaires, or CLSCs. Saskatchewan has developed guidelines for developing an integrated palliative care service in regional districts governed by district health boards (Canadian Palliative Care Association 1996:7).

There are some indications that palliative care programs are benefiting from increases in provincial funding allocated for community-based health care. For instance, in some provinces, such as Ontario and British Columbia, palliative care services have benefited from special provincial funding program specifically directed toward innovations, demonstrations, or collaborative initiatives in community care (Canadian Palliative Care Association 1996:7).

The importance of providing education and training in palliative care is increasingly recognized. Several provinces have developed educational initiatives that draw upon expertise available in urban centers to provide training that reaches all regions. Manitoba has implemented the Terminal Care Education Project in which multidisciplinary teams from various regions receive training at the Winnipeg Palliative Care Unit, after which they return home to train other service providers. There are examples as well of educational outreach initiatives in Newfoundland, British Columbia, Nova Scotia, and Ontario (Canadian Palliative Care Association 1996:7).

Palliative care education is striving to respond to the unique geographical and cultural needs of diverse, as well as remote communities. In Newfoundland, remote communities are served through teleconferences, phone-in consultations using a 1-800 number and through in-service training during site visits by a palliative care consultant. In contrast, the Northwest Territories have developed culturally-sensitive training programs which take into account traditional native views about dying, and First Nations staff receive training without having to leave the communities they live in and work (Canadian Palliative Care Association 1996:8).

In spite of the positive signs, it is also evident that community-based palliative care faces the same challenges across the country as other health orientated home care programs. The extent to which palliative care services are available through home care programs varies from one province or territory to the next. Even within one province or territory, the availability of community-based palliative care can vary greatly from one health region to another for a variety of reasons. Eligibility criteria for palliative care services, the range of services available and the extent of public coverage for services also vary across the country (Canadian Palliative Care Association 1996:8). These issues go beyond palliative care to become part of the larger challenge to improve our national health care system. However, the right of all Canadians, to be assured of the best possible care when they face death, is a compelling reason to resolve the existing and long-standing disparities in end of life care, regardless of place of residence or illness.

# Chapter Two

## Sociological Aspects of Disease, Illness and Sickness

Disease is an objective fact of life that is socially defined. The number and kinds of disease recognized by any society is dependent on the state of knowledge in that society and the nature of the culture. Equally, the conditions under which people feel ill or become defined as sick is socially, culturally, and historically constrained. So long as people normally prefer life to death and health over disease, health care services and allopathic medical intervention is unavoidable. This chapter will describe the sociological aspects related to health issues in the following ways: explain the definitions of disease, illness, and sickness from a sociological standpoint; give an overview of the social forces that evoked the palliative care movement; and examine the modern health care systems and health in Canada.

### Disease, Illness, and Sickness

In everyday language, disease, illness, and sickness are interchangeable terms. However, sociologists generally distinguish between *disease, illness,* and *sickness.* *Disease* refers to "the biological dimension of being frequently unhealthy in which there is some change of bodily functions that results in a reduction of capabilities or a shortening of the normal life span" (Twaddle &

Hessler 1977:97). These events are, to varying degrees, objectively measurable and can be said to exist whether or not they are recognized by anybody. Although an individual may first notice changes in her/his body, a physician most often determines the identification and labeling of disease. "By definition, the concept of disease is most consistent with the positivist philosophical tradition, and it is the dimension of non-health that is most central to medical practice" (Kurtz & Chalfant 1991:29).

*Illness* by contrast, is "the personal experience of the person who acknowledges that he or she does not feel well" (Twaddle & Hessler 1977:97). People frequently define themselves as unhealthy based on subjective feelings, and reporting these feelings can result in others defining them as unhealthy. Experiences such as pain, weakness, dizziness, nausea, and anxiety are examples of this subjective definition. "By definition, the more subjective state of illness is more consistent with the philosophical tradition of idealism than is the case with disease, and it is the dimension of non-health most frequently recognized by the sick person themselves" (Kurtz & Chalfant 199:29). Illness is usually assumed to be caused by disease, and it is frequently the trigger that initiates the seeking of medical care. It is not, the same as disease, however, since feelings of illness can take place in the absence disease and disease can take place, at least at some stages, in the absence of illness (Twaddle & Hessler 1977:97).

*Sickness* involves "the social actions taken by the person as a result of illness or disease, such as taking medication, visiting the doctor, resting in bed, or staying away from work" (Twaddle & Hessler 1977:97). When people are defined by others as being unhealthy, or they describe themselves as unhealthy publicly, a shift in social identity takes place. The people in question carry a new label, such as 'sick', 'ill', 'diseased', or 'sickly' (Twaddle & Hessler 1977:97). Under these conditions, they are treated in a manner that differentiates them from people defined as healthy. Cockerham (1982:89) states:

> whereas disease is a socio-biological status and illness is a socio-psychological status, sickness is a social status. The events that lead to the definition of sickness may be either disease or illness or functioning in a social order. Furthermore, whereas the investigation of disease is the province of biology and medicine and that of illness is the province of psychology, sickness is the unique province of sociology.

In addition, it must be said that while sickness is usually presumed to reflect disease or illness, it can occur independently of both (Twaddle & Hessler 1977: 97).

Illness, sickness, and disease are integrally related because they are all socially constructed experiences. People do not experience or talk about their illness in a social or cultural vacuum. Everything that people feel, say, think, and do in regards to their illness is culturally and socially mediated

## Social Forces That Evoked The Palliative Care Movement

Social movements emerge when some form of structural change or transformation in society affects numerous people's lives (Garner 1972). A person loses their job, a relationship breaks up, or someone dies, and these circumstances reflect the personal troubles of the parties involved. However, when unemployment rates soars, divorce rates drastically climb, or death takes place through disease or famine, we have the makings of a public issue that can fuel collective action. Social movement analysis assumes a link between grievances of a collectivity of individuals and actions to address those grievances (Paradis 1988:58). The palliative care and hospice movement represents one such instance.

Goldberg describes social movements in this way, "a social movement is a formally organized group that acts consciously and with some continuity to promote or resist change through collective action" (1991:2). This description of rational, purposeful and social action by groups is a rather recent phenomenon. Early social movement theorists used collective behavior models to explain unconventional group action (e.g., riots, hysteria, revolution), more contemporary analysis includes models that explain more moderate forms of change including reform oriented movements (e.g., the women's movement, the consumer movement, etc) (Paradis 1988:58). The palliative care movement can be characterized as a reform movement with a specific goal: the establishment of palliative care programs and hospice facilities as a significant part of the continuum of health services.

Sociologists have long been involved in the area of death and dying and are credited with influencing the work of early palliative care and hospice organizers. Cofounders of the first hospice facility established in United States in 1974, Florence Wald and Ed Dobihal were much impressed by the work of Fulton

(1965), Glaser and Strauss (1967), and Sudnow (1967) and were inspired in their early efforts to provide better care for the dying (Paradis 1988:57). Ironically, while the subject of death has held the interest of many sociologists, palliative care has been shown much less attention. Few articles on palliative care and hospice facilities have been published by any of the major sociological journals and even fewer books on the subject have been written. However, the palliative care movement is considered by many sociologists and non-sociologists alike, to be a major health care reform movement; one which has been largely responsible for the public discussions and increased media attention to issues of death and dying (Kastenbaum 1995:112).

The demands of meeting the economic and social needs of an growing older population and increases in the incidence of chronic diseases and illnesses, has placed serious strain on social institutions and raised important questions on their ability to adapt. Pressure to reorganize the delivery of medical care and social services to the terminally ill, has become particularly important because of the rising costs, and perceived insensitivity to the patient, their family and significant other's needs. Palliative care, therefore, provides a useful force for studying the context and processes of a changing health care system in response to the growing desire for a 'good death' (Paradis 1988:58).

The palliative care movement was founded on strong philosophical principles and a unity of purpose and community that is often hard 'to replicate in less cohesive settings' (Saunders & Baines 1983:12). Health care professionals working in the field of palliative care developed and share a system of values that is built upon the principles of palliative care *(See Appendix 2).* Aiming to provide person-centered holistic care, health professionals care for the dying person's physical, psychological, social, spiritual and information needs. The palliative care model of medicine, challenges mainstream medical model by offering an alternative, often referred to as a 'better way to die' (Palgi & Abramovitch 1984:388). James and Field (1992:1364) assert the palliative care movement is "unashamedly reformist and the ideological base of this distinctive approach is usually contrasted with that of acute and curative medicine". Palgi and Abramovitch (1984) note that the modern hospice movement revolves around the concept of a good death. "The concept of good death is conceptualized as a series of social events that involve the dying person as well as the other interactants who may include family, friends and health professionals" (Palgi & Abramovitch 1984:404). Taylor (1993a) states the following view of the concept of a good death:

> If a patient is to have a *good death* they should: ideally be involved; provide effective symptom control so that the patient may complete their living and die pain free; and work toward providing an environment where the patient my die peacefully and with dignity.

The hospice movement draws its momentum from the demographic transition and technological change that followed the close of the nineteenth century (Bolaria & Dickinson 1995:18). In 1900's, most deaths occurred from infectious disease with pneumonia. By the last quarter of the twentieth century, however, the epidemiological profile had changed. As a result of public health measures, improved nutrition, institution of occupational health standards, and pharmacological advances of the twenties and thirties, infectious diseases yielded to heart disease, cancer and other chronic disorders as the major cause of death (Bolaria & Dickinson 1995:18). This demographic transition created a new set of societal problems affecting the terminally ill, their families and significant others and the network of interlocking institutions that comprise the health care system. Collective response to the personal and institutional stress of contemporary dying led to the emergence of the palliative care movement and pressure to alter existing provisions of terminal care (Paradis 1988:59).

Change in patterns of mortality and morbidity during the first quarter of the twentieth century altered the existing temporal phasing of life course by expanding the period in which the average person dies. In contrast to the swift and often sudden death characteristics of infectious disease, chronic disorders often involved a lingering trajectory that may be further prolonged through medical science (Glaser & Strauss 1965). Early detection programs and improved diagnostic techniques also can lengthen the dying period by informing people of the fatal illness long before the symptoms are subjectively felt. Following the disclosure of a life-threatening illnesses, the individual is thrust into a new phase of living based upon an altered biological and social status that may last for months or even years.

There are negative properties associated with the social role of dying. As a fatal illness progresses, pain and symptoms of the illness can force the individual to withdraw from the work force, a primary source of personal identity in our society. Normal family roles may need to be relinquished at the very time when the person is struggling to counter a diminished social self. Meanwhile, family and friends may shun the dying out of discomfort with that individual's altered state of health or to avoid the burden of caregiving. The challenge for a person with a terminal illness, their family and significant others is to find ways to live out what can be a lengthy period of the life course of dying in a manner that is personally satisfying and which preserves a positive self-image for all.

Palliative care and the hospice movement emerged out of personal experiences of family members and significant others and in partial response to the needs of health care professionals to have individuals die more comfortably and to have some relief from the burdens of care. Concerned family members and health care professionals joined efforts for the formation of the palliative care movement, due to the fact that those who are dying typically lack the biological time or physical strength needed to forge or maintain a movement on their own behalf (Abel 1986:71).

In this regard, what has been described so far is a series of societal stresses, brought about by demographic changes in mortality and morbidity, which led to a generalized perception of family members, significant others and health care professionals of individuals with life-threatening illnesses that *something ought to be done.* This needs assessment for a hospice facility in Kings County ensues similar studies of social movement theory that suggest societal strain is necessary element for collective action. This element is an ideology that can unite people together in joint purpose and provides a direction for advocates to follow through with a specified action. The need to investigate the establishment of a hospice facility in Kings County was a collective action of professional and non-professional caregivers of palliative care clients who had identified gaps and problems with the exiting programs. This collective action of persons sought to resolve the problematic issues surrounding care of the dying in their community by inciting the first stage of creating a hospice facility, a needs assessment.

## Modern Health Care Systems

At a high level of generalization, the health systems of capitalist nations at similar levels of economic development are much alike. Coburn et al. maintain that in response to similar forces and by diffusion, such nations have adopted fundamentally similar institutions for providing health care:

> A hierarchy of healing occupations and professions under a dominant biomedical profession; hospitals as key institutions; public health, industrial health and environmental legislation; specialized organizations for the training and socialization of health workers, and so on (1987:7).

With some variations, these societies have also developed methods for making increasingly costly health care available to most segments of the population; often health-insurance schemes have been instituted involving provincial financing and/or control (Coburn et al. 1987:6).

There is now a fair degree of uniformity in the health values, beliefs, and expectations held by the lay public in different societies. For the most part, Coburn et al. (1987: 8) believe there "is an acceptance of modern medical science as the basis for valid knowledge in health; a high valuation placed on personal health; a less fatalistic acceptance of disease, illness, and injury; a desire for active intervention in illness episodes; and high expectations for good health care".

Advancements in health care systems have led to improved health status for most individuals. Bolaria and Dickinson (1994:18) state "a convergency theory view would infer that most advanced industrial societies have followed a broadly similar path in the increased longevity and lowering morbidity of the population, as well as an evolution of the health systems".

## Canadian Health Care and Mortality

Since the Second World War, Canada has developed a state-financed system of health care insurance. Under this system, known as *Medicare*, every citizen of Canada is eligible to receive 'free' necessary medical and hospital services. Constitutionally, health care is a provincial responsibility. Therefore, the specifics of health care insurance are slightly different for each province. In the past, the federal government has attempted to ensure a degree of uniformity between provinces through a number of cost-sharing arrangements. These arrangements make the receipt of federal funds contingent upon the provinces' meeting certain minimum standards of comprehensive coverage, universality, portability of benefits, accessibility and public administration on a non-profit basis (Bolaria & Dickinson 1994:26).

Health, illness, and death are not randomly distributed in Canadian society. Rather their incidence and prevalence are inextricably linked to the social organization of the society. One aspect of this social organization is the extent of inequality in social structure which causes different life changes and unequal access to social resources such as food, recreation, satisfying work and adequate shelter (Mahowald 1993:153). "Because of that unequal access, people who differ in age, sex, income, class, occupation, ethnicity, marital status, rural or urban background, and religiosity differ in their rates of sickness and death" (Mahowald 1993: 153). Table 2 provides an overview of moralities by province and year.

**Table 2: Moralities by Province and Year, 1992-1997**

| | **1992-1993** | **1993-1994** | **1994-1995** | **1995-1996** | **1996-1997** |
|---|---|---|---|---|---|
| | **Number of deaths** | | | | |
| **Canada** | **201,808** | **206,465** | **209,435** | **212,233** | **216,491** |
| Newfoundland | 3,815 | 3,977 | 4,111 | 3,933 | 3,947 |
| Prince Edward Island | 1,122 | 1,120 | 1,143 | 1,189 | 1,221 |
| Nova Scotia | 7,560 | 7,544 | 8,072 | 7,720 | 7,833 |
| New Brunswick | 5,802 | 5,873 | 5,894 | 5,918 | 5,984 |
| Quebec | 50,648 | 51,581 | 51,849 | 53,103 | 53,520 |
| Ontario | 74,638 | 77,302 | 78,166 | 78,951 | 80,848 |
| Manitoba | 9,247 | 9,184 | 9,243 | 9,602 | 9,791 |
| Saskatchewan | 8,013 | 8,273 | 8,244 | 8,217 | 8,214 |
| Alberta | 14,938 | 15,757 | 15,632 | 16,199 | 16,727 |
| British Columbia | 25,629 | 25,476 | 26,716 | 27,031 | 28,050 |
| Yukon | 125 | 128 | 124 | 142 | 127 |
| Northwest Territories | 271 | 250 | 241 | 228 | 229 |
| From July 1 of one year to June 30 of the next year. | | | | | |

(Statistics Canada, CANSIM 1997: Matrix 5773)

Mortality is one of the many summary indicators of disease burden. The leading causes of death in Canada today are cancer, heart disease, cerebrovascular diseases, chronic obstructive pulmonary diseases & allied conditions and accidents. Table 3 represents a breakdown of selected leading causes of death by gender.

**Table 3: Selected Leading Causes of Death by Gender, 1995**

| | Number | % | Total | Males | Females |
|---|---|---|---|---|---|
| | | | Rate [1] | | |
| All Causes | 210,733 | 100.0 | 666.9 | 857.8 | 522.5 |
| Cancers | 57,810 | 27.4 | 184.9 | 234.7 | 150.3 |
| Diseases of the heart | 57,461 | 27.3 | 179.9 | 238.7 | 134.8 |
| Cerebrovascular diseases | 15,537 | 7.4 | 48.1 | 53.5 | 44.0 |
| Chronic obstructive pulmonary diseases and allied conditions | 9,185 | 4.4 | 28.8 | 44.7 | 19.3 |
| Accidents and adverse affects | 8,823 | 4.2 | 29.0 | 39.9 | 18.5 |
| Pneumonia and influenza | 7,382 | 3.5 | 22.7 | 29.6 | 18.5 |
| Diabetes mellitus | 5,496 | 2.6 | 17.4 | 20.9 | 14.6 |
| Disease of arteries, arterioles and capillaries | 4,858 | 2.3 | 15.1 | 20.6 | 11.2 |
| Hereditary and degenerative disease of the central nervous system | 4,762 | 2.3 | 14.8 | 16.4 | 13.6 |
| Suicide | 3,963 | 1.9 | 13.3 | 21.5 | 5.3 |
| Psychoses | 3,780 | 1.8 | 11.5 | 11.0 | 11.4 |
| Nephritis, nephrotic syndrome and nephrosis | 2,598 | 1.2 | 8.1 | 10.9 | 6.3 |
| Chronic liver disease and cirrhosis | 2,235 | 1.1 | 7.2 | 10.6 | 4.4 |
| HIV infection | 1,764 | 0.8 | 5.8 | 10.7 | 0.9 |
| Neurotic disorders, personality disorders and other nonpsychotic mental disorders | 1,265 | 0.6 | 4.0 | 5.3 | 2.8 |

[1] Age-standardized mortality rate per 100,000 population

(Statistics Canada 1997:Catalogue no. 84210XPB)

Statistics Canada reports the proportion of deaths from heart disease have been decreasing over the past twenty years or so, especially for women. On the other hand, the proportion of deaths due to cancer has been increasing. "Heart diseases, cancers, and accidents are called the diseases of civilization, the diseases of affluence, or what Omran (1974) has called 'man-made' diseases" (Bolaria & Dickinson 1994:67). Their causes are different from those of the diseases of the developing world. Inadequate nutrition, and lack of clean water and birth control are no longer problems for most of the developed world. Rather a combination of lifestyle, environmental, work-related, and other factors are important in explaining today's mortality rate.

# Chapter Three

## The Challenge Facing Community

During the past twenty years, palliative care has emerged as a new and significant component in the continuum of health care services in Canada. The first hospital palliative care programs were introduced in Montreal and Winnipeg in 1975 and the first community-based free-standing hospice was founded in Toronto, Ontario, under the leadership of June Callwood in 1983. Since then, the number of palliative care programs has risen dramatically. According to the *1997 Canadian Directory of Services: Palliative Care and HIV/AIDS*, there are 594 palliative care programs now in existence in Canada. These programs are located in both urban and rural settings throughout ten provinces and two territories. These hospitals and community-based programs seek to fulfill the total holistic care of each community in dealing with terminal and life-threatening illnesses.

Every community is, and will be, confronted with the challenge of caring for individuals with terminal and life-threatening illnesses as life expectancy and the incidence of chronic disease increases. In Canada, the aging of the population is expected to result in the increase of deaths from cancer, cardiac, respiratory and other chronic illnesses. In 1989, 2.9 million Canadians were over the age of 65 years. By the year 2011, this number is expected to reach 5 million. In 1995, deaths from cancer were approximately 61,500. However, the number of cancer deaths is expected to increase to over 105,500 by the year 2010 (Stein 1997: 39).

Beyond Canada, the World Health Organization (WHO) projects that by the year 2015, 15 million people will develop cancer. This is in contrast to the 9 million people in 1985. The WHO also estimates that by the year 2000 there could be as many as 110 million people infected with the AIDS virus (Stein 1997: 39). The United States Center for Disease Control reports that as of November 1995 there were 501,310 cases of AIDS and 311,381 deaths caused by the virus. In addition, AIDS is the leading cause of death among Americans ages 25-44 (U.S. Center for Disease Control 1997:www.etwcin/nffar/stat.htm). Similarly, with the increase in cancer cases and with continuing spread of viruses such as HIV/AIDS we need to have more health care resources secured for the future.

Federal and Provincial governments are struggling to reduce debt loads and annual deficits that are totalling in the billions of dollars. As a result, hospitals, health care organizations, health workers, and others are challenged to be more creative in the programs they offer to provide more cost-effective services to the people in their community. In this decade, Canadians have already witnessed a twenty percent downsizing in hospital budgets (Statistics Canada 1997: Catalogue no. 82-221-XDE). The impact is greater in Nova Scotia. Table 4 shows the number of hospital beds decreases in each province from 1986 to1995 and the percentage of change.

**Table 4: Bed Counts: Number of Hospital Bed Decreases, 1986-1995**

| Province | 1986-87 | 1994-95 | Percentage change |
|---|---|---|---|
| Newfoundland | 3,401 | 2,753 | -19.1 |
| Prince Edward Island | 755 | 513 | -32.1 |
| Nova Scotia | 5,705 | 3,722 | -34.8 |
| New Brunswick | 5,151 | 3,397 | -34.1 |
| Quebec | 54,741 | 38,849 | -29.0 |
| Ontario | 51,181 | 37,303 | -27.1 |
| Manitoba | 6,369 | 5,527 | -13.2 |
| Saskatchewan | 7,272 | 4,675 | -35.7 |
| Alberta | 17,990 | 8,372 | -53.5 |
| British Columbia | 19,466 | 15,527 | -20.2 |
| **CANADA*** | **172,425** | **120,774** | **-30.0** |
| **Includes Northwest Territories and Yukon* | | | |

(Statistics Canada:1997 Catalogue no. 82-221-XDE)

There has been an increased emphasis on caring for people in their homes as expensive hospital stays are reduced and Provincial home care services and home hospital services are introduced. Hospitals and other health institutions will no longer be the only primary health care providers. Many more people with terminal and life-threatening illnesses will remain in their homes and receive medical and emotional support from both professional and lay volunteer personnel. In addition, family and other caregivers are assuming more responsibilities and duties in providing palliative care and emotional support for their loved ones. Increasingly, it is important to have a supportive circle of family and significant others provide physical and emotional care for those who are dying as health care resources are limited. Furthermore, for those who must remain in hospital, there will be fewer professional staff to attend to their physical and emotional requirements. Our own lifestyles could be dramatically altered at the times when we become involved as caregivers, with family, close friends or associates diagnosed with a life-threatening illness. If sufficient resources are not available the burden of care will be considerable. The recipients of health care, their families and significant others need to be trained to provide the support that is necessary as they struggle with the illness and an uncertain future. How well will caregivers cope and adjust? Moreover, whom can we turn to for support, information, and understanding during this time? Finally, we must ask ourselves what we should do after the death of a spouse/partner, family member, friend, or associate. Family members and significant others need support to maintain and build relationships after the death. As well, those in the workplace who are affected by a life-threatening illness or death of a family member, significant other, or an associate, need the support of trained professionals and volunteers to help them through the crisis so they can continue to be productive members of their community.

It is the responsibility of every community to review its resources and prepare for an increase in the number of individuals faced with life threatening diseases and illness. Without such preparation: hospitals will become overcrowded; home health and palliative care programs will be inappropriately financed and utilized; and long term care facilities will remain inaccessible because of lack of beds. Most importantly, who will care for those without the support of family and significant others?

## Population Characteristics of Nova Scotia

Nova Scotia covers 52,840 square kilometers with a population of 909,282 persons living in the province. The vital statistics for Nova Scotia as of July 1996 were 10,488 live births and 7,750 deaths (Nova Scotia Statistical Review 1997:10). The 1996 Census confirmed that the population in the province is aging. There has been an increase in the population of those 35 years and over (+10.1% since 1991) and a decrease in the under 35 year age group (-7% since 1991). The senior population, aged 65 years and over has grown from 72,470 in 1971 representing 9.2% of total population to 119,115 seniors in 1996 representing 13.1% of the population. Historically, this is the highest proportion of seniors in Atlantic Canada and the third highest in Canada (Nova Scotia Statistical Review 1997:9).

## Population Characteristics of Kings County

The Kings County region of Nova Scotia is famous for its fertile soil and fruit orchards and the North and South mountain ranges separated by a wide valley floor. Kings County is characterized mainly as a rural farming area, which entertains a strong and viable business district. The land area of Kings County covers 2,182. 24 square kilometers. The population of Kings County, including its villages and towns represents 59,193 persons (Nova Scotia Statistical Review 1997:5). The vital statistics for this area indicate there were 737 live births and 439 deaths in 1995. The 1996 Census data shows that Kings County exhibited the strongest county population growth in the province with a 5.1% increase since 1991 (Nova Scotia Statistical Review 1997:4).

## Palliative Care Services and Programs in Kings County

There are various services, programs, supplies and equipment required for the care of palliative clients, their families and significant others. Appendix 3 represents an inventory of such assistance which is provided in part by the service agencies, associations, and businesses listed in Appendix 4. *(Care provided by physicians is not indicated here).*

## Cancer Rates in Canada and Nova Scotia

The National Cancer Institute of Canada maintains that cancer is primarily a disease of the elderly. Estimates for 1997 indicate that 59,600 (45%) of new cases and 34,500 (56%) of cancer deaths occur in Canadians aged 70 years and older. An additional 34,300 new cases (26%) and 14,700 deaths (24%) occur in older adults 60-69 years. By contrast, only 1% of new cases and 0.3% of deaths occur before the age of 20 years (National Cancer Institute of Canada 1997:41).

Table 5 depicts an individual's lifetime probability of developing and dying from different types of cancer.

### Table 5: Lifetime Probability of Developing and Dying From Cancer by Gender, 1997

| | Lifetime probability of: | |
|---|---|---|
| | developing | dying |
| | % | |
| **Male** | | |
| All cancers | 40.9 | 26.9 |
| Prostate | 12.3 | 3.8 |
| Lung | 9.1 | 8.2 |
| Colorectal | 6.3 | 2.9 |
| Bladder | 2.7 | 0.9 |
| Lymphoma | 2.5 | 1.5 |
| Oral | 1.6 | 0.6 |
| Stomach | 1.5 | 1.1 |
| Kidney | 1.5 | 0.6 |
| Leukemia | 1.3 | 0.9 |
| Pancreas | 1.1 | 1.2 |
| Melanoma | 0.9 | 0.3 |
| **Female** | | |
| All cancers | 35.0 | 22.4 |
| Breast | 10.8 | 4.0 |
| Colorectal | 5.6 | 2.7 |
| Lung | 4.7 | 4.2 |
| Lymphoma | 2.2 | 1.3 |
| Body of uterus | 2.2 | 0.6 |
| Ovary | 1.5 | 1.1 |
| Pancreas | 1.1 | 1.2 |
| Leukemia | 1.0 | 0.7 |
| Kidney | 0.9 | 0.4 |
| Stomach | 0.9 | 0.7 |
| Bladder | 0.9 | 0.4 |
| Cervix | 0.8 | 0.3 |
| Melanoma | 0.8 | 0.2 |

(National Cancer Institute of Canada: 1998).

In the province of Nova Scotia, it is estimated that there will be 5,200 new cases of cancer and 2,400 deaths related to cancer in the year 1997 (National Cancer Institute of Canada 1997:20). The tables below represent the incidence of diagnosed cancer *(see table 6)* and mortality *(see table 7)* due to cancer in

Kings County. The table further breaks down the age distribution and cancer sites in Kings County for the years 1991 through 1995.

**Table 6: Incidence of Cancer in Kings County by Age, 1991-1995**

| Cancer Site | Total | 69 yrs and under | 70 yrs and up |
|---|---|---|---|
| Stomach | 25 | 7 | 18 |
| Colon, Rectum | 178 | 80 | 98 |
| Lung, Pleura | 203 | 113 | 90 |
| Breast | 155 | 92 | 63 |
| Melanoma of Skin | 38 | 25 | 13 |
| Cervix Uteri | 17 | 12 | 5 |
| Corpus Uteri | 19 | 10 | 9 |
| Ovary | 25 | 18 | 7 |
| Prostate | 214 | 79 | 135 |
| Kidney, Ureter | 52 | 32 | 20 |
| Bladder | 74 | 32 | 42 |
| Hematopoietic | 30 | 14 | 16 |
| Lymph Nodes | 81 | 49 | 32 |
| All other Cancers | 211 | 115 | 96 |
| Total | 1322 | 678 | 644 |

**Table 7: Mortality Due To Cancer In Kings County by Age, 1991-1995**

| Cancer Site | Total | 69 yrs and under | 70 yrs and up |
|---|---|---|---|
| Stomach | 25 | 5 | 20 |
| Colon, Rectum | 43 | 16 | 27 |
| Lung, Pleura | 148 | 64 | 84 |
| Breast | 43 | 18 | 25 |
| Melanoma of Skin | 1 | 0 | 1 |
| Cervix Uteri | 6 | 3 | 3 |
| Corpus Uteri | 1 | 1 | 0 |
| Ovary | 12 | 6 | 6 |
| Prostate | 55 | 7 | 48 |
| Kidney, Ureter | 12 | 6 | 6 |
| Bladder | 13 | 2 | 11 |
| All Other Cancers | 321 | 135 | 186 |
| Total | 680 | 263 | 417 |

(Nova Scotia Cancer Registry 1997).

## AIDS Occurrences in Canada and Nova Scotia

In Canada, there are no statistics that accurately depict the incidence and mortality of Human Immundeficiency Virus/Acquired Immune Deficiency Syndrome. The issue of confidentiality and the 'social stigma' affiliated with this virus accounts for the under reporting of cases. The statistics provided in this section are only *reported* cases of HIV/AIDS in Canada and so it is imperative to remember that of the total 14,836 reported cases, this may represent only a small portion of those Canadians affected by AIDS. (Health Canada, May 1997:25). This is representative of statistics since the early 1980's. The number of deaths due to AIDS reported since the beginning of the outbreak is 10,837. The number of total cases reported in the Atlantic Region (including NS, NB, PE, NF) is:

| | |
|---|---|
| Males | 385 |
| Female | 41 |
| TOTAL | 426 |

(Health Canada, May 1997: 25)

The Nova Scotia Department of Health states that the total number of AIDS cases reported since the illness was first diagnosed (1983-1995) by gender in Nova Scotia is:

| | |
|---|---|
| Male | 196 |
| Female | 17 |
| TOTAL | 213 |

These total statistics illustrate that for the Atlantic Region 50% of the reported cases are in Nova Scotia.

The only statistics that could be obtained by region in Nova Scotia are reported cases of HIV (1983-1995). There is no indication in this report of how this data was collected or how accurate a reflection it is of the true number of cases. This report maintains that in the Western region of Nova Scotia are:

| | |
|---|---|
| Male | 36 |
| Female | 5 |
| TOTAL | 41 |

(Nova Scotia Department of Health 1995:12).

The reported cases of HIV for the Western Region make up 19.2% of the total reported cases in Nova Scotia. In consideration of the likely increase in AIDS and life-threatening illnesses in the Western Region it is important to prepare and organize health resources for the future care needs of our community.

## Who Could Use A Hospice Facility?

Caregivers, families and significant others working directly with and for individuals with life-threatening illnesses informally identified a gap in palliative care services in Kings County. Consequently, a group of enthusiastic caregivers, family members and significant others initiated a community response to investigate and conduct a needs assessment in Kings County for a hospice facility. In addition, recognizing the existing need of terminally ill patients, the likely increase of chronic diseases and life-threatening illnesses, as well the potential for greater demand of health care services given the aging of the County population, the need for a community hospice facility is an essential segment in the continuum of health services

The services that exist in Kings County for palliative care clients, their family and significant others that address the home care needs are: Victorian Order of Nurses and related programs (Home Support Workers, PEP and Supportive Care Volunteers); private nursing agencies (CareForce Nursing Services, Evangeline Home Care Nursing); the Palliative Care Nurse and Discharge Planning Nurses at the Valley Regional Hospital; HomeCare Nova Scotia Palliative Care Program; the Canadian Cancer Society; the Canadian Red Cross; Kings County Mental Health Services, private counselors and support groups (Living with Cancer, Mid-Valley Palliative Care, Valley AIDS Concern Group, and Care For the Caregiver Support Group); Life Line Oxygen & Medical Supplies; and local pharmacies and churches. As well, when care is no longer feasible at home the Valley Regional Hospital provides palliative care in hospital.

In order to provide a perspective on how many people in Kings County could utilize a hospice program, the provision of statistics based on rates of clients using existing palliative care services has been compiled. However, it should be noted that not all of these clients would use an inpatient program. As well, there may be duplication of statistics, as clients were not cross-referenced. Not withstanding, during the month of June 1997, the Valley Regional Hospital's palliative care nurse, reported there were 32 inpatient and 29 outpatient follow-up cases of clients in a palliative state of care. Meanwhile, the VON Supportive Care Volunteer Program Coordinator indicated during the same month there were 38 individuals in Kings County drawing from these services. At the same time, VON Nursing Staff indicated there were 21 clients in a palliative state of care. Finally, HomeCare Nova Scotia's reported that there were approximately 14 individuals whose home services were termed palliative care in June 1997.

# Chapter Four

## Methodological Approach

### Participatory Action Research

> Research isn't magic. Research findings are meant to be applied. No matter how persuasive a piece of research is, it can't change anything unless it's acted on and used. We can use the insights we gain in many aspects of our work--from developing service to doing advocacy (Barnsley and Ellis,1992:9).

The methodology used throughout this thesis is participatory action research. It is an approach to research that brings interested people together to confront a common concern of interest for the betterment of the community. Participatory action work combines research, learning, and advocacy. The roots of participatory action research are in the developing countries--in the fields of adult education and agricultural research although it is now becoming more widely used in North America. In particular, feminist community activists implement participatory action research as a means to bridge the gap between theory and research in academia and applied action in the community. The development of participatory action research was based on the understanding that traditional research methods sometimes alienate individuals and on the belief that people are capable of learning, changing and transforming their own world (LeComte, Millroy and Preissle, 1992:497).

## Definition of Participatory Action Research

Barnsley and Ellis (1992:9) define participatory action research as "the systematic collection and analysis of information for the purpose of taking action and making change". The process of taking action and making change affects all members involved the research. Reinharz (1992:180) suggests "that learning occurs for the researcher on three levels in any research project: the level of the person, problem, and method". By this, Reinharz (1992:180) proposes that "the researcher would learn about herself, about the subject matter under study, and about how to conduct research." The researcher is not the only person who benefits. Carr and Kemmis (1986:62) state "participatory action research is a form of self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of these practices, and the situations in which the practices are carried out".

## Participatory Action Research As Method

Action or participatory action research as it is most often called today, has a number of unique features that differentiate it from other approaches and give strength in community-based practice (Barnsley & Ellis 1992:9). It requires the active participation of whoever may be influenced by the research: professionals, non-professionals, and consumers themselves. An important feature is that the research is conducted by the group. The researcher plays an equal but different role; facilitating the research process and possibly providing technical assistance, resources and education required (Whyte 1990:11).

The research question originates in the community and arises from the queries and concerns of the participants. Research design and methods are chosen to suit the objectives of the study. Participatory action research methods must be understandable to the participants and at the same time be rigorous enough to maintain standards of validity (Barnsley & Ellis 1992:10). Surveys, interviews, oral histories, and focus groups are commonly used methods of data collection, with participants sometimes involved in the analysis of the data. Intended outcomes of participatory action research projects include practical knowledge, action, and the empowerment of disadvantaged groups (Barnsley & Ellis 1992:10).

## Issues of Participatory Action Research

The issues surrounding participatory action research include the nature of scientific knowledge, vulnerable groups as participants, and researchers as participants (LeComte, Millroy & Preissle 1992: 22). There is wide debate on the type of knowledge produced through participatory action research. Because the researcher has less control over the process, some people have concerns about validity and reliability. Specific questions focus on the value of data obtained through less controlled methods, including whether the research findings are usable beyond the immediate context (LeComte, Millroy & Preissle 1992:22). Nevertheless, there are techniques for enhancing validity that can be used in the research, including triangulation of data, bracketing, inter-rater reliability testing, interview replication tests, repeated validation of themes and reflexivity questions (LeCompte, Millroy & Preissle 1992:23). It should be also noted that new strategies are often developed throughout the research process to ensure validity and to cope with unanticipated research problems such as confidentiality, while not alienating the participants.

Another area of concern is that participants may lack energy, resources and confidence to commit to a project and this may result in attrition over the course of the research (Whyte 1990:7). It may be difficult for people in vulnerable groups to trust others. However, Barnsley and Ellis (1992:11) assert that "when community members have ownership of the research process, there is a better chance the research will be relevant to them. If it is relevant to them, they will likely be more willing and able to act on it". More significantly, it is still difficult for researchers to see the stakeholders as equal participants in determining their needs--let alone as partners in research and its outcome (Whyte 1990:13). It is only recently that social science researchers and other professionals are recognizing participants as full and equal actors.

For the researcher, the struggle lies in maintaining the delicate balance of sharing expertise without taking over. Differences in understanding the research process and in the interpretation of qualitative data sometimes arise. It is important for the researcher to acknowledge these differences and work with participants to resolve any conflicts (LeComte, Millroy & Preissle 1992:27).

The support of participants in this type of research ranges from minimal, wherein the researcher shares the findings with participants, too maximal, wherein the group controls the entire process (Reinharz 1992:182). This process becomes easier with increased experience, knowledge and self-awareness of both the researcher and the participants (Reinharz 1992:182).

The members of the *Palliative Care Advisory Committee* to this study were comprised of family and significant others of dying individuals, formal and informal caregivers to them and an academic based researcher *(see Appendix 5 for list of committee members).* The committee held meetings which served as an opportunity for participants to share their concerns, as well as a chance to question procedures and practices that have caused conflict in the past. However, while not every question put forth by the committee was resolved by the researcher, it was an occasion that all persons involved had a chance to talk and exchange viewpoints. The involvement of the committee was a vital and important part of the research process. Although, they did not actively collect data for the needs assessment, they were consulted regarding direction and guidance at various stages of the research.

## Historical Overview of the Project

The need for a hospice was identified when concerns were expressed by individuals volunteering and working with palliative care clients in Kings County. It was evident that certain people in the community did not have the support necessary to enable them to die at home in comfort. Home Care Nova Scotia's

(HCNS) mandate does not provide for 24 hour home care. Thus, persons in Kings County who choose to die at home need to have secured financial resources for medical services, supplies and equipment, family or significant others who are able to care for them, and who can be supported and/or relieved by the formal caregivers provided through HCNS. The alternative for those with minimal financial resources, home support and care is hospitalization. Hospitalization has been the choice of many; however, it is at great expense, and for some, hospitalization would not be the preferred choice should other options be available.

An informal review of the clients serviced by VON, Kings Branch from January 1996 to September 1996 indicated that up to six clients per month would have chosen to use the services of a hospice in the long term (six weeks or more) and another six clients per month would have used the hospice to provide respite care for up to a week at a time if a hospice had been available.

A focus group was held two years ago at the Eastern Kings Memorial Health Centre Clinic in Wolfville, with a variety of interested health care providers and concerned community members to discuss the need for a hospice. A total of 17 individuals participated in the focus group. Present at the meeting mentioned above were representatives from the VON (two nurses, the coordinator of palliative care volunteers and the coordinator of volunteer services), the health promotion nurse at Eastern Kings Memorial Health Care Clinic, the Director of the Kings County Home Support Agency, four palliative care volunteers, the coordinator of the Valley AIDS Concern Group, four

HomeCare Nova Scotia care coordinators, the palliative care nurse and two researchers from Acadia University.

Other uses for the proposed hospice facility identified by the caregivers who participated in the focus group, included short term respite care; pain and symptom control management; the opportunity for younger people to die in a hospice facility as opposed to a hospital or their own homes as they did not want to cause their young children or their partner additional stress. In addition, a hospice facility could be a place to provide caregiver (professional and others) counseling; and resources such as a setting in which day care could be provided for dying persons who have small children and whose partners need respite. It was pointed out by many present that continuity of care would be an extremely valuable asset of the hospice experience, and the hospice would be able to apply for more flexible funding to pursue programs and services not presently supplied by government agencies.

All present at the focus group unanimously agreed that each of the services represented had sufficient clientele who could benefit from a hospice, thus warranting the need for further research. As well, those in attendance were supportive of and excited about exploring the need for a community based hospice. All agreed to participate in further discussions of this project and to assist with conducting a needs assessment. Furthermore, the participants of the focus group established the following purpose and objectives of this needs assessment:

1. To identify the unmet needs of individuals faced with a life-threatening illnesses, their significant others, formal/informal care providers; and
2. To determine the need for a free-standing hospice facility in Kings County.

As a result of the stated concerns of clients, staff and volunteers, VON Kings Branch sought funding to explore ways of providing individuals with the option of dying in a 'home-like' atmosphere. VON Kings branch hired me as the principal researcher for this exploration. I selected the research design for the needs assessment which was conducted between March and October of 1997 in Kings County, Nova Scotia. Under the direction of a 20 member *Palliative Care Advisory Committee*, data were collected from palliative care clients, their families and significant others, along with personnel involved in the existing programs and services in Kings County

## Research Design and Methodology

The research design used to gather information for this needs assessment includes two types of research methods: a mail survey and a series of semi-structured personal interviews. Both the questionnaire and the interview guide posed the same questions. A cover letter explaining the needs assessment was included with the survey as well as an invitation to participate by questionnaire or in an interview *(see Appendix 6 and 7)*. The survey consisted of eighteen questions divided in three sections *(see Appendix 1)*. The first section dealt with different types of needs (i.e., physical, psychological, social, spiritual, information and financial) that persons living with a life-threatening illness and those who care for them could encounter. The physical, psychological and social needs questions included suggestions or prompts, housed in brackets, in order to achieve clarity in the respondent's thought processes with respect to the nature of the complexity of these needs'. Following the different types of needs questions was a definition of palliative care. The definition was used to ensure that the participants understood the meaning of palliative care. Furthermore, this section posed questions with respect to the respondent's knowledge and criticisms of services and programs for palliative clients in Kings County.

Section two provided the definition of a hospice facility according to the mandate of the VON, Kings Branch. This definition was incorporated due to the possibility of the participant's unfamiliarity with the concept of a free-standing, inpatient hospice care facility, as opposed to inpatient care provided in a hospital or long term care facility in Nova Scotia. It also provided additional clarity for the respondents to answer the question whether or not they felt the need to establish such a facility. Additionally, this section included a check list of the types of services they would like to see offered in a hospice setting.

Finally, the third set of questions were demographic in nature, inquiring about gender, age, education and the exact role they played with dying individuals.

A draft of the survey questions was reviewed and pre-tested to 10 members of the Palliative Care Advisory Committee. I reviewed the pre-tested questionnaire and subsequent revisions were made. The questionnaire was administered from May 5 to July 27, 1997. Interviews were conducted between June 20 and July 25, 1997.

## Sample Population and Sampling Method

In total, 374 individuals were approached to participate in the needs assessment. One hundred and fourteen (114) returned the questionnaire with 10 people interviewed, for a total of 124 participants. The response rate for this study was 33%. The sample population was selected from groups of persons who were knowledgeable about palliative care. Participation in the study was voluntary for all groups in the population. The sample population consisted of the following groups:

1. Individuals with a life-threatening illnesses, their families and significant others;
2. Formal care providers: VON nurses, Licensed practical nurses (LPNs), care coordinators and home support workers, physicians, clergy and alternative health practitioners; and
3. Informal care providers: VON/PEP Palliative and Supportive Volunteers, Friends of Bereavement Support Group, Living With Cancer Support Group and Valley AIDS Concern Group.

In this section, I have provided the administrated number of surveys for each group.

### ***Individuals With A Life-threatening illnesses, Their Families and Significant Others.***

The sample list of participants for the dying, their families and significant others was a *purposive* sample compiled by the VON nursing staff, the Valley Regional Hospital's palliative care nurse and discharge planning nurse, as well as the VON Volunteer Supportive Care Coordinator. Potential participants from the VON caseload (N=41) were sent a letter and consent form inviting them to join the study by the VON, Kings Branch Executive Director *(see Appendix 6 and 7).* The letter gave the respondents the choice of having a personal interview or receiving a questionnaire by mail. Potential respondents from the Valley Regional Hospital caseload (N=20) and clients of the VON/Volunteer Supportive Care Program (N=19) were contacted by telephone and asked if they would like to participate in the needs assessment.

If the individual agreed to participate, a home visit interview was scheduled, or if they desired a questionnaire was sent out by mail. Twelve individuals agreed to be interviewed, while two declined to include their information upon completion of their session. The remaining ten interviews averaged two to four hours duration, allowing time for emotional support to follow.

### *Formal Care Providers*

The sample of formal care providers included in this study were: VON nurses, LPNs and Home Support Workers; HomeCare Nova Scotia Care (HCNS) Coordinators, Physicians, Clergy and Alternative Therapists.

The VON staff and HCNS staff (N=90) surveys were administered during regularly scheduled meetings. The respondents had the opportunity to either submit the questionnaire by mail or deposit it in the questionnaire box at the VON office.

Questionnaires for Physicians (N=56) were placed in their mail boxes at the Valley Regional Hospital, Eastern Kings Memorial Health Centre and Western Kings Memorial Health Centre. The option was to leave the survey in the box or return it by mail.

Administration of the questionnaires to members of clergy population (N=20) was handled in a similar fashion to the physicians. The surveys were placed in the Chaplain's Room at the Valley Regional with the same options of return.

The final group in this category, namely the Alternative Health Practitioners (N=25) were contacted by mail. This method did not prove to be successful for reasons unknown to the researcher.

### *Informal Care Providers*

Informal Care Providers such as volunteers and local support group members (N=93) were contacted at monthly meetings and by telephone through the coordinator and were asked if they would like to participate in the study. Those who agreed were given a questionnaire and provided with the same return options.

In addition, an advertisement was placed in the local newspaper and on the local cable television network announcing the needs assessment and inviting the community to participate. This was successful in attracting only one individual to participate.

## Methodological Issues

Various methodological issues need to be addressed. The sample population was drawn from caseloads of VON Kings Branch and Valley Regional Hospital. Given that the participants in the study included those in receipt of health care, directly or indirectly, they were considered to be a vulnerable and captive group of individuals. Lasagna (1981) contends that ethical issues should be considered when conducting research with vulnerable and captive populations whether or not the subject or society receives any potential benefits from the study. The societal benefits of the needs assessment are numerous, however, the tangible benefits for the participants may not be as obvious. Yet, a typical response from the participants in this study is summarized in the words of a 74 year old widower:

> *I'm happy to do it [participate in this study] because I don't often get a chance to help people much anymore. They're always helping me, you know. So it is nice to be able to do this. If taking part in this could help someone in the future, I am glad.*

It is important to acknowledge those who are in this study as well as those missing from this needs assessment. The reader will recall that only 33% of the sample population voluntarily returned the questionnaire and/or participated in the interview schedule. There are many reasons why people do not respond to a request for participation in research: time constraints; lower levels of literacy; and avoidance of the topic of death. Furthermore, it has now been amply demonstrated that people who respond to research requests are different from those who do not. Non-responders tend to be more dysfunctional in a variety of ways than do responders; that is, responders tend to be a biased sample of all service recipients and who often are highly motivated or opinionated (e.g., Bass 1982; Hayslip, Hoffman & Weatherly, 1990-91). The findings suggests the participants in this study, may be from among the more functional families or caregivers, with greater socioeconomic resources as well as caregivers whose patient relationships were less impaired or whose illnesses demanded less strenuous care. An anecdotal reason for the low response rate might be that for some, the experience of caring for a loved one is over, death has occurred and therefore, a form of emotional closure has been achieved. Reliving an experience that might have been less than ideal could be extremely painful. Whether or not a more representative sample would have yielded different findings or more conclusive findings remains to be seen. This experience does suggest that if sound and productive palliative care research on unfavorable outcomes of service is to be done, greater efforts will be required to obtain representative samples.

## Rationale of Methodology

Choosing a method of analysis best suited to gathering information with the intent of successfully and competently completing a study can be complex. This having been said, it is often true that the research objective dictates the method best suited for the project at hand. The objectives of this research were twofold; first, to identify the unmet needs of individuals faced with a life-threatening illnesses and their caregivers. And second, to determine the need for a free-standing hospice facility in Kings County. It is for this reason, as indicated earlier, both a mail-survey and face to face interviews were adopted as methods for conducting this needs assessment.

The survey questionnaire as a quantitative methodology held appeal due to the ease of contacting individuals of various ages and backgrounds living in the demographic area. It was also thought that a survey would provide an inexpensive means of collecting a large number of perspectives, which in turn increases the reliability of results. In addition, the survey method can be accomplished with minimal staff, cost and resources. Given that the needs assessment was staffed essentially by myself, it provided an attractive method for collecting data. Furthermore, the mail questionnaire gave the respondents more opportunity and time to give thoughtful answers and to consult with others on their perception of care. Finally, this style of data collection provides greater anonymity. The assurance of anonymity with mail questionnaires is especially helpful when the survey deals with the sensitive subjects of death and dying which are not easy for most individuals to discuss openly. The disadvantages associated with mail-survey research include low response rates and no opportunity for further discussion or exploration of a topic.

Interviews were chosen as a method to complement the data collected by questionnaire. The interviews were seen as an integral part of this needs assessment because they provided a needed opportunity for the 'voices' of the people in the community themselves to be heard. The interviews were semi-structured, using an interview guide containing the questions from the survey as a focus for investigation. The interviews enabled me to illuminate and uncover areas that were not clearly defined in the questionnaire results. As well, the interview style allowed for the collection of supplementary information about the participants and their home environment. For instance, on more than one occasion, participants gave me a tour of their home and the rooms in which they cared or had cared for their loved ones. In addition, it illustrated to me how they had their house set up so that the person for whom they cared for could still be a part of everyday living. The potential weaknesses of the interview approach provide for investigator or respondent biases and restrictions in sample size due to economic and time constraints.

Despite the deficiencies inherent in the two research methods selected, the mixing of the two methods was complemented by allowing the weaknesses of one to be supported by the strengths of the other. It is believed that through the use of both qualitative and quantitative research methods, a more complete picture of the experiences and needs of palliative care clients and caregivers in Kings County has been attained.

## Handling of Data

Analysis of the data collected from the needs assessment was performed solely by the researcher. Nominal data from the questionnaire were coded numerically and entered into *Excel* spreadsheet program. Percentages were obtained from coded responses. All percentages have been rounded to the nearest decimal point. The qualitative data collected from the open-end questions and the personal interviews were coded using a simple category system of key words and concepts. Recurrent themes and patterns emerged from key words and concepts and were then sorted for similarities and differences in responses. An italicized font and indent represent direct quotes or the 'voices' of the participants in the study.

# Chapter Five

## Presentation of Data and Analysis

As explained earlier, data collection was in the form of a survey and interviews. To simplify data presentation, the compilation of answers obtained from the questionnaire and interviews will appear in the same order as it did in the questionnaire. An italicized font and indent represent direct quotes or the 'voices' of the participants in the study.

### Background Characteristics of Sample Population

Of the one hundred and twenty four participants included in the study, ninety-one were female, twenty-nine were male, and four did not indicate their gender. The mean age group of the respondents was between fifty and fifty-nine years.

A sizable proportion (40%) of respondents identified themselves as having received a graduate level of education. Nine percent of respondents had attended undergraduate university education, seven percent had community college education, twenty-two percent had a high school level, ten percent represented trade school education, one percent had an elementary school education, while seven percent indicated ‘other’. Four percent did not provide this information.

When respondents were asked what their relationship or role was to palliative care clients in Kings County, a majority (37%) reported that they were the family, friend, or significant other of someone who had *died*; thirty-five percent reported they were *formal caregivers*; ten percent reported they were the an *informal caregiver*; seven percent reported they were an *individual* with a life-threatening illnesses; seven percent reported they were family, friend or significant other of someone who was *dying*; two percent reported their relationship was *other* and two percent did not provide any data. Many people in the study held multiple roles, so some categories were overlapped (i.e., a formal caregiver could be caring for a loved one at home). In addition, most people did not indicate their role as a formal caregiver.

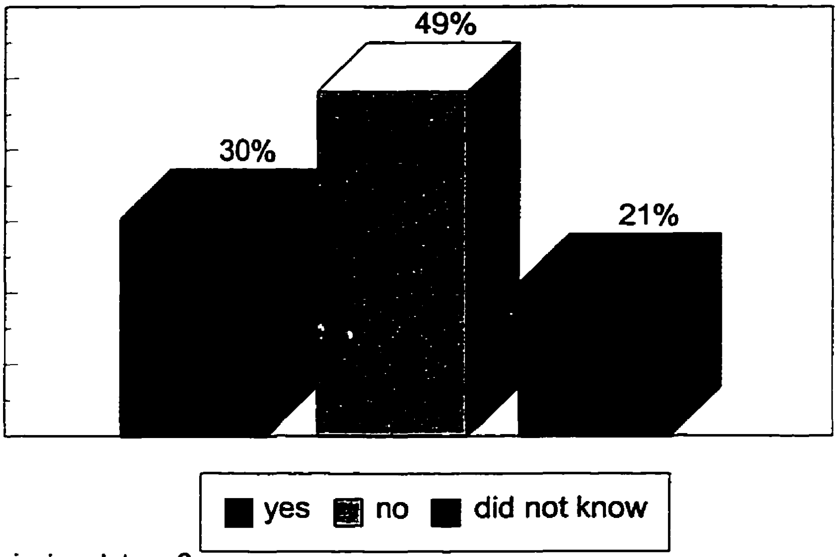
## Physical Needs

### *Do you feel the physical needs (i.e., symptom and pain control, personal care) of the dying are adequately met in Kings County?*

Nearly half the sample (49%) felt the physical needs of the dying were not adequately met, thirty percent felt the needs were adequately met and twenty-one percent did not know *(see chart 1).*

**Chart 1**

Physical Needs



missing data = 2 cases

Pain control, symptom management and physical care of the dying is a major worry for significant others and caregivers. Pain management and the control of other physical symptoms are crucial to the principles of palliative care. Specific physical symptoms besides pain that are commonly dealt with by palliative care clients, their family and caregivers are: decreased appetite, nausea, vomiting, constipation, diarrhea, incontinence, night sweats, fever, chills, breathing problems, fatigue or weakness, seizures, thrush or sores (mouth or throat), bed sores and skin problems. If someone's physical suffering is not dealt with first, there is little chance much can be done to alleviate non-physical symptoms. Many patients with life-threatening illnesses in Kings County experience problems with pain and symptom control management despite the availability of effective medical therapies. Although medical therapies are technically available, accessing these therapies remains a problem. A number of barriers preventing effective pain and symptom management for the dying were identified. Foremost, accessibility and availability of medication are clearly a problem for those caring for the dying. The inaccessibility of certain drugs and therapies is due to professional caregivers lack of education, understanding, and experience with pain and symptom control management. In addition, often there is poor communication between the dying and their professional caregivers. The successful management of pain requires constant monitoring and updating of changes in the threshold of pain with medication. An excessive period of waiting for a physician's order to increase or change a medication or treatment has resulted in unnecessary suffering of the patient and the family members. Another reason for the inaccessibility of medication is because local pharmacies do not keep certain drugs in stock because of lack of demand or the drug prescribed is relatively new and they have had no prior demand for the drug to keep it in stock. Many of these issues surrounding pain and symptom control management are echoed in the words of the following participants:

One nurse who had cared for numerous home patients commented,

> *Not all physicians are comfortable in appropriate pain management of dying patients. Doctors are still reluctant, on the whole, to order adequate pain medication. Some families and some physicians still are reluctant to allow appropriate levels of analgesia.*

A daughter whose father died stated,

> *Pain control is a difficult problem, the pain pump is not available in all areas and not all drug stores can fill them. Doctors are not up to date in pain management [i.e. clients are home out of sight, out of mind].*

Another nurse agreed,

> *Formalities often frighten and overwhelm the family by the amount of care required for a terminally ill patient and are often afraid to administer medication. I have experienced people dying at home and have not been able to have the doctor involved, return calls or visit when requested therefore unable to meet the needs of my clients.*

One formal health care provider said,

> *There are problems with obtaining orders for medication, payment and transport to the client are sometimes a problem. Even then we are limited and cannot always control pain and nausea.*

A female friend who assisted with the care of a person who had died stated,

> *I was main support for a terminal cancer patient. There were times when we waited for over an hour for someone to come with pain relief medicine.*

An LPN asserted,

> *The person I took care of experienced great difficulty when she began taking morphine because of inadequate doses - but this was due to limitations of her physicians expertise.*

A niece of a person who died stated,

> *From my experience there appears to be a need for greater communication between professionals involved and the patient and family. Better communication would certainly help eliminate the confusion and frustration of meeting the physical needs of the dying.*

The experience of those in this study reveals that palliative care home care services require longer and more frequent visits, more intensive service and more night visits. Palliative care clients have extremely limited physical capabilities. Therefore, even if only the physical needs of the dying are met, a higher caregiver/patient ratio is required. In Kings County, 24 hour care is not available in the home through HCNS (HomeCare Nova Scotia) program, as a result additional supportive care is required from family members and friends of the dying. For families, partners and significant others of persons who are dying, obtaining enough care and help from persons trained to care for palliative clients is a problem.

A daughter whose mother had died stated,

> *I wanted to bring Mum home from the hospital. She could have stayed with me but all I could get from home care is 4 hours a week. She needed to have someone stay with her while I was at work. I couldn't get anyone to come in during the daytime. Four hours is not adequate and I couldn't afford to keep someone with her. Why did they make such a big fuss about home care if they couldn't provide it?*

A daughter who cared for her mother at home before she died declared,

> *I had no time for anything but care for Mom. Home support program was limited. A couple of hours a week was not enough. Sure it gave me time to get the groceries but not much else. Taking a walk for pleasure was out of the question. My brothers and sisters had jobs, kids and other responsibilities. Also, they lived too far away to come and relieve me.*

A nurse said,

> *As a patient or client comes closes to death, I feel that his/her needs increase, but the amount of help available to them (especially trained sensitive help) does not increase.*

A former nurse and volunteer who works with the dying stated,

> *For some it is, [physical needs are met], for others, it isn't, and they are largely dependent on families educational, financial and social status. Sometimes they are dependent on the physician's knowledge and comfort dealing with the dying person.*

A father of a person who died added,

> *Usually the patient only has 'professional' care for a few hours a day, then it is left up to family members to cope with the care of the dying when they are under stress and pressure and have full time jobs of their own.*

It is important to note that a small proportion of participants in the study were satisfied with the physical care they received. Pain control, symptom management, and physical care were adequately met and no problems were detected.

A spouse of a partner who died asserted,

> *We were very lucky. My husband did not experience any uncontrollable pain. He had patches that seemed to control his pain really well. Only on the day he died did he seem uncomfortable and I called his doctor and he came by to the house and gave him an injection that eased it.*

A daughter whose mother had died stated,

> *I could call him (family physician) at anytime of the day. I even had his home telephone number. When he was away, he made sure I could get a hold of someone, usually the VON.*

A husband whose wife had died commented,

> *I can't speak for others. But in my case with my wife, I felt the care was excellent. A very adequate combination of home care and in-home doctor visits.*

A daughter whose mother had died agreed,

> *Only with the help of the VON, did I manage to get through the rough months of looking after my mother. The VON came in every day and towards the end twice a day.*

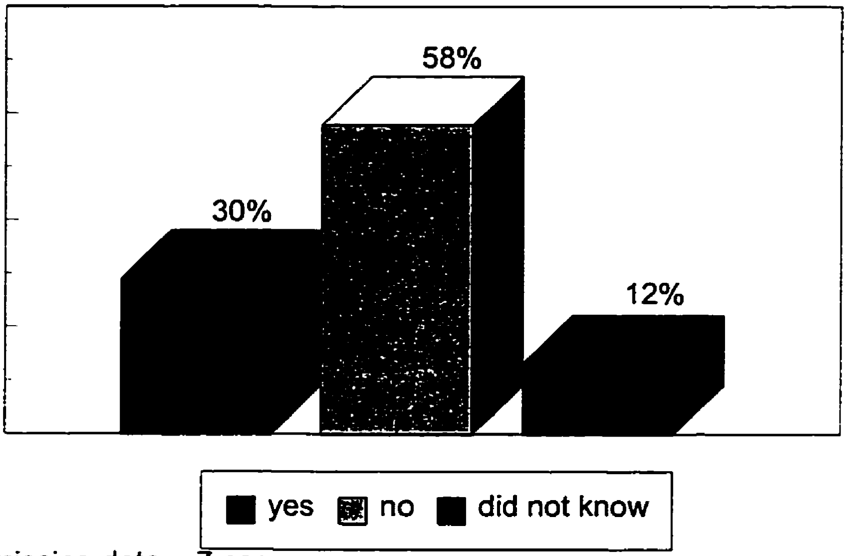
**Psychological Needs**

### *Do you feel that the psychological needs (i.e., emotional, mental well being) of the dying and those who care for them are adequately met in Kings County?*

A large proportion (58%) of the sample do not believe that the psychological needs of the dying, and those who care for them, are adequately met in Kings County. Thirty percent felt that the needs of the dying and those who care for them are met while twelve percent did not know *(see chart 2).*

**Chart 2**

Psychological Needs



missing data = 7 cases

It is important to recognize that palliative care is intimately connected with loss, dying and death. And, with death comes a wide variety of emotional and psychological responses. It must be acknowledged that grief is a normal and expected response to loss. Death can be peaceful, yet it can also be a struggle. To care for someone who is dying is to recognize that palliative care is for the living as well the dying. Caregivers, family members and the dying expressed a number of common emotional responses to the psychological care of palliative care clients in Kings County. For instance, many participants felt that living with and/or caring for someone with a life-threatening illnesses profoundly changes one's life perspective and their relationships. As well, for some of those living with a terminal diagnosis, life plans and thoughts of the future are abruptly halted. Moreover, for many caregivers the experience of having clients, family members and people they love suffer pain or discomfort, as well as the death itself is emotionally draining. Feelings of fear, anxiety, guilt, denial, anger and sadness are often evoked because of the intimate relationship of care and the various losses that are experienced by the person who is dying, their family and caregivers. In particular, it was observed that confusion, depression, memory loss or forgetfulness and lack of self-esteem of the dying caused just as much suffering for the family and caregivers as did the physical complaints of poor health.

A wife whose husband had died said,

> *This has been a totally new experience for me, and it was difficult for me to accept and adjust to the sudden and terrifying changes that occurred before during and after my husband's death. One day he was so confused that he thought the pills I was giving him were to going to harm him. He referred to the pills as 'rat poison'. This was extremely upsetting for me.*

Another wife whose husband died added,

> *My husband was not very nice to be around. He was in pain and was embarrassed about what had become of him. He did not deal with being sick very well and did not want help for it either. He was depressed and wanted me by his side 24 hours a day. He had people doing things for him that he never imagined, like changing his underwear and helping him do simple things like eating. How could I complain about how he*

> *was treating me when he was the one that had to face the fact he was dying.*

A home support worker stated,

> *Because of the work load there is lack of time to listen to information that the client is verbalizing. Many times the patient was alone because I had to work and even though she said she didn't mind, her biggest fear of dying was dying alone.*

Nearly all the participants agreed that the psychological care needs of the dying, their family members and significant others is totally lacking or ignored by most health care professionals. Moreover, it was noted by participants that either they were unaware of, or had to search for the psychological services that existed and many felt that what was offered by these services was not enough. Others expressed a need for more services, education, information, and awareness of the psychological needs of the dying, their families, and those who care for them. The following responses highlight the psychological concerns of the dying and their caregivers in Kings County:

A husband of a wife who died remarked,

> *Most families don't know where to go or turn for this type of advice except their clergy. Doctors don't counsel well or meet the needs in this field. In my case, I would have liked to have had a better support network setup to help myself and children to they deal with the stress involved while my wife was ill.*

A minister said,

> *Doctors give a diagnosis and then the person is left on their own! Not everyone has the ability to search for the help they need.*

A family member of someone who has died stated,

> *I am not aware of any on-going palliative care offered in this area. The dying need someone to talk to consistently with one worker or someone in the community they trust.*

A volunteer stated,

> *The approach to psychological needs seems so cut and dry. In hospitals, they are so understaffed and time seems to be an issue. Mental and emotional counseling requires time they don't have to offer. Few are educated and understanding of the process of dying.*

A nurse added,

> *We need more staff and funding to provide good palliative care to people in the community. Currently, staff are doing more with less resources that they have available. Plainly more resources are needed to address the psychological issues.*

A daughter whose mother had died said,

> *During my mother's five months of illness, support came from VRH palliative care nurse, a few close family members, friends, and me. We'd discussed a counselor but this wasn't provided. Again, health care professionals could be working together more closely as a team.*

A nurse stated,

> *A more effective base of support could be used. Being able to access resources from one point is presently not available for clients in the county. Public awareness is also a big issue that needs to be expanded. It is a scary time for most people. They need trained caring people to care for them. They shouldn't have to search for resources.*

Some participants felt that the psychological needs of the dying and family were often dealt with on an individual basis by family and friends. For instance, whatever emotional support system was in place before the individual was diagnosed with a terminal illness is what sustained them once their health failed. Furthermore, some felt that resources are available to meet the psychological needs of the dying and those who care for them but it is up to the individual to access these resources.

A nurse stated,

> *Depends entirely on individuals, whether needs are recognized and appropriate help sought, help is there. So, education and encouragement to seek help are essential.*

An informal caregiver stated,

> *One tends to be at the mercy of whatever support system they have in place which is almost always not adequate to meet needs.*

A care coordinator said,

> *For some their needs are more than adequately met with supportive friends and family, while for other people they do not have the necessary support of someone to confide this personal issue.*

As one formal care provider stated,

> *I feel that this support is available and adequate (even above average) if the patient and family seek them out.*

An individual with a support group contended,

> *This tends to vary from family to family in my experience depending on the resources available in each family. Single parents, singles, or those with AIDS may not have good support systems in place.*

Some respondents were of the opinion that the psychological needs of the dying are being sufficiently met and/or they have had only good experiences.

A nurse asserted,

> *All of the clients I have seen had accepted the fact that they were dying. Both their emotional and mental well being were surprisingly good. Family counseling has been fair, perhaps a little more time spent with family members would be more adequate.*

A woman whose sister died added,

> *This was my second involvement with death, and I needed explanations as to what to look for emotionally and physically as Mum got worse. Thanks to the VON for keeping me informed everyday.*

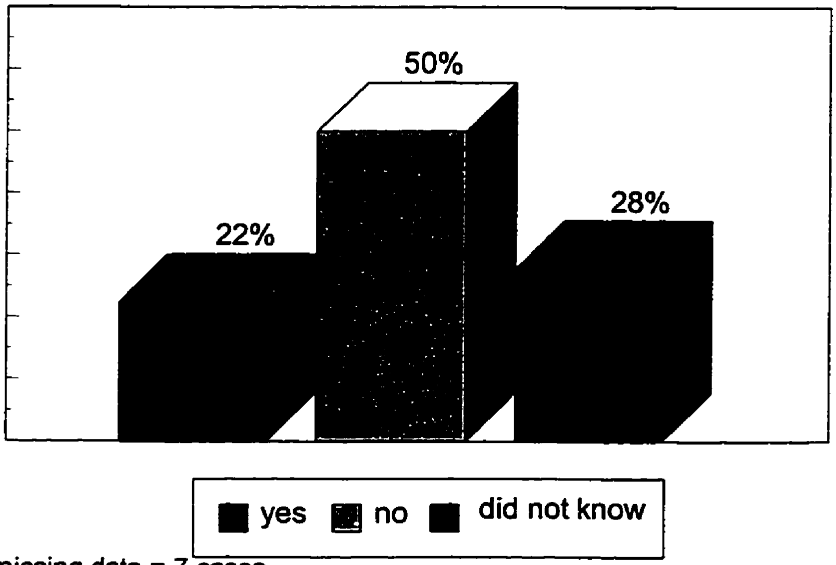
## Social Needs

***Do you feel that the social needs (i.e., recreation, contact with others, support groups) of the dying and those who care for them are adequately met in Kings County?***

Half (50%) of the respondents did not feel the social needs of the dying and those who care for them are adequately met. Meanwhile, twenty-two percent thought that the social needs of the dying and those who care for them are adequately met and twenty-eight percent did not know *(see chart 3).*

**Chart 3**

Social Needs



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The findings of this thesis reveal that palliative care is not confined to the bedside or to the home. It is connected to the larger social and cultural network of which the dying person is a part. The dying and those who care for them do not experience or talk about their illness in a social or cultural vacuum. Everything people feel, say, think, and do about their illness is culturally and socially mediated.

There is a general lack of understanding of the need for social support for the dying, their family and caregivers in Kings County. Despite the fact that many participants cited there is a *stigma* associated with a terminal diagnosis that creates feelings of isolation and alienation for the sick and their caregivers. On the whole, participants felt health care providers are not educated enough about the social needs of dying and those who care for them. However, omitting the social aspect of palliative care means neglecting to care for the person as a whole.

A formal caregiver commented,

> *The view and understanding of social support is minimal. In general, I think we are definitely lacking in education of the social needs for palliative care patients and their caregivers.*

A daughter whose mother died added,

> *During her illness, the only contact Mom had with other cancer patients was during chemotherapy. It perhaps would have helped to meet others out side the hospital setting. I don't think her doctors saw the need for social care.*

A significant other of someone who had died said,

> *People seem hesitant to call for help/support. There is very little planned 'recreation'. There needs to be more contact with families in like situations i.e. support groups especially after death.*

Although palliative care should always be centred around the person who is dying, it is important to consider the needs of those who are close to the dying person. Family members, friends and significant others who participated in this research expressed that those who were close to the dying person were not only losing someone they love, they were losing that individual's connection to the rest of the world: family, friends, work and community. As a woman whose husband had died explains,

> *What social life? It disappeared when I started caring for my husband at home. Both of us were active in the community, but after he was diagnosed things changed. He never wanted to go out of house for fear someone might notice he was dying. We had mutual*

> *friends but many of our friends were his friends from work and they stopped coming to the house because he was rude to them. I don't blame them. All I could do was make excuses for him. But it would have been nice if they had made contact with me after he died.*

Despite the social context of palliative care, some respondents commented that death and dying are dealt with on an individual basis. People die as they have lived. Therefore, if they did not have a strong social network before they got ill, it was not likely they had one when they were dying. Yet, participants overall observed that people avoid individuals who are dying and those who care for them. Moreover, participants revealed that the social needs of the dying were often left up to the family and significant others and social contact was related to those who came to visit.

One volunteer stated,

> *There can always be improvement in this area. Many older people have lived here for awhile and have good support, but some never did have many friends so why would they have any more if they were dying.*

A formal caregiver added,

> *No, it's not, but I think it depends on the individual as to whether it's necessary or not. Some sick people might just want close family and friends around because other sick people might make them sad.*

A home support work affirmed,

> *I feel the dying are usually put in a room at home and forgotten about because family members are present, so they feel nobody from the community needs to enter the room.*

A daughter whose mother had died stated,

> *Immediately after the death of my mother, I had a lot of support but it stopped not long after the first year. I think my family and friends don't realize how hard it can be to take care of someone who is dying. Sure you know it (death) is going to happen and some days you wish it would to take away the pain and discomfort, but once it does your role is over. You are no longer caring for mother. You are alone with no one to take care of; that can be worse.*

The social support groups for palliative care clients and their caregivers in Kings County consist of: Living With Cancer Support Group, Valley AIDS Concern Group, Care For The Caregiver and special topic workshops by the Cancer Society. Yet, respondents indicated there is little or no social support for the dying, their family members and significant others in Kings County. For many participants maintaining social activities was a chore either because they were physically unwell or unable to find proper respite for those whom they provide care. As well, many participants find there is not enough respite care available to attend support groups or the support groups are not at convenient times.

A woman who is caring for her dying sister stated,

> *Once confined to home most of the time due to weakened condition, social contact is dependent upon those who come to the home. Caregivers often are not free to attend meetings and the present one per month for cancer patients families is not adequate.*

A nurse stated,

> *I do not feel there are enough support groups or at least information about them given to those who care for the dying.*

A friend of a person who had died added,

> *If the emotional needs are not met, how can the social needs be met. I do not know of any support groups for the dying and those who care for them.*

A son who is caring for his dying father affirmed,

> *There are good support groups, but they are not always available at a convenient time for caregivers.*

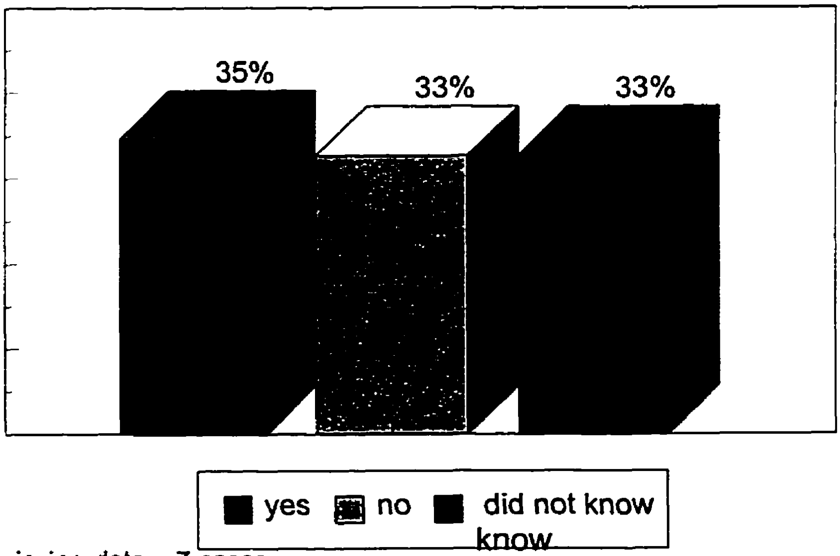
## Spiritual Needs

***Do you feel that the spiritual needs of the dying and those who care for them are adequately met in Kings County?***

Thirty-three percent of the sample population believed that the spiritual needs of the dying and those who care for them are not being adequately met in Kings County. Thirty-five percent believed that the spiritual needs of the dying, and those who care for them, are being met and thirty-three percent did not know. *(See chart 4)*

**Chart 4**

Spiritual Needs



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The quantitative section of this question brought about nearly equal percentages of answers for all nominal category responses. Clearly, this question was not a comfortable one to answer for participants as the data reveals. There is a split in opinion about spiritual care in Kings County for the dying. However, the qualitative findings do suggest that spirituality is a personal issue that is dealt with on an individual or family level. If they were active members in a church, they had good support for end of life care. Yet, if they were not active members in a church, they tended not to feel the same sense of spirituality and support it was capable of offering. Thus, some believed there was adequate support from clergy in Kings County for the dying and those who care for them, while others felt that support was not adequate. Likewise, some participants felt that there is not adequate support for people outside the Christian faith and that spiritual counseling from a non denominational faith is desired by many. Some participants stated the following about the spiritual needs of the dying and those who care for them:

A member of the clergy stated,

> *I guess those visibly connected with churches have their needs met. Others who are not affiliated with a church fall through cracks.*

A volunteer said,

> *This is a very difficult question. I feel 'spiritual needs' are something very personal and profound, and it would be inadequate for me to assume that because we have pastoral counseling that this results in spiritual fulfillment for all.*

A nurse stated,

> *Often on an individual basis, it is addressed through the family's own minister or priest etc., but I feel some would enjoy the benefits if something was available on a ' non - denominational level'.*

A volunteer said,

> *For recognized religion and those who seek chaplain or minister (Christian) help, yes their needs are met. But for other religions - Hindu, Buddhist, Jewish, Muslim and others, I don't think so. Some might prefer nondenominational spiritual counseling.*

A member of the clergy asserted,

> *There are not always people available to help and listen. Some people can find peace before they die and their friends and family can find closure after they die from helping themselves.*

A nurse said,

> *Those in hospital have access to a wonderful chaplain. In the community those who belong to a church probably have support, however there are many (those not affiliated with a particular church) that have no one to confide in.*

Additionally, participants remarked the Clergy have to visit many people and time restraints are an issue. For the most part, home visits are desired on a more frequent basis and as the need increases. In as much as, there is no one person designated for the sole purpose of pastoral care for the dying in their home it is not surprising that many respondents felt neglected by their local clergy.

A friend of someone who had died stated,

> *Although the minister visited periodically, it was no where enough. Lay people helped with poetry, but I*

> *would have liked more from the church than a visit three times in eight months.*

A support group worker with said,

> *I don't feel in many cases the ministers or lay members of the church are involved enough especially prior to death. Maybe that is a problem in our general society. They may feel they would be interfering.*

A daughter whose father had died added,

> *Even our own minister didn't visit regularly. We saw him once in hospital and once at my home. He really ticked me off!!*

A formal caregiver said,

> *It is virtually impossible with staff shortage in hospitals to adequately look after the spiritual needs of the dying. In fact, one chaplain cannot do the work.*

Nevertheless, in general participants reported that death often brings spiritual exploration and affirmation. Many people who are dying and those who care for them come to a deeper religious faith, while others will see life in a new way. Life threatening experiences provoke a re-examination of values and priorities. Some participants remarked that there was a reconciliation of relationships, new insights, and better appreciation of all parts of life. Death and dying also brings to ground a questioning of traditional spiritual practices and beliefs.

A volunteer stated,

> *To me, spirituality is a personal (not religious) thing. Spiritual needs have to be met by one's own definitions and not organized religions.*

A daughter whose mother had died stated,

> *Mom and I had our differences in the past but when she got really sick I think we both realized that I was really losing a part of myself. Mom was not very private about dying. She and I talked openly about death. She wasn't afraid to die. She shared some feelings with me that profoundly changed my outlook on life and dying. I am still really proud of her and what we did together during her last year of life. We prayed together, many times at her request and this brought us closer together.*

A nurse said,

> *Most of us are ill prepared to accept a developmental biological approach to living and dying phases us with a mysterious process.*

A daughter whose mother had died remarked,

> *When my mother first got ill, I thought praying would help out but as she got worse, I lost faith in it. Many people told me of the comfort I would get from it, but it only made me angry at what was happening to my mother. I said bullshit to it. Then one day when my mother was having 'a good day', she told me she was sad that I never prayed with her anymore and that believing in God did not only include the good things in life but also the bad. She wanted me to believe in my faith again and to have hope again. She told me that I could have it again. Her just saying this to me helped me a lot.*

A volunteer stated,

> *If person or family are not connected to an established church they don't always have their needs met. Even in churches, death is not always dealt with in a life giving manner.*

On a positive note about the spiritual needs of the dying and those who care for them, participants remarked that the Chaplain at the Valley Regional

Hospital was greatly appreciated spiritual resource during their stay at the hospital.

A family member of someone who had died commented,

> *In general, it seems pastors are quick to respond to visit where there is a need. The chaplain in hospital is a wonderful new asset. She is very caring and supportive of the patient and the family as well.*

A family member of someone who had died stated,

> *The minister at the hospital was the only individual who visited us regularly. She was very compassionate to our situation.*

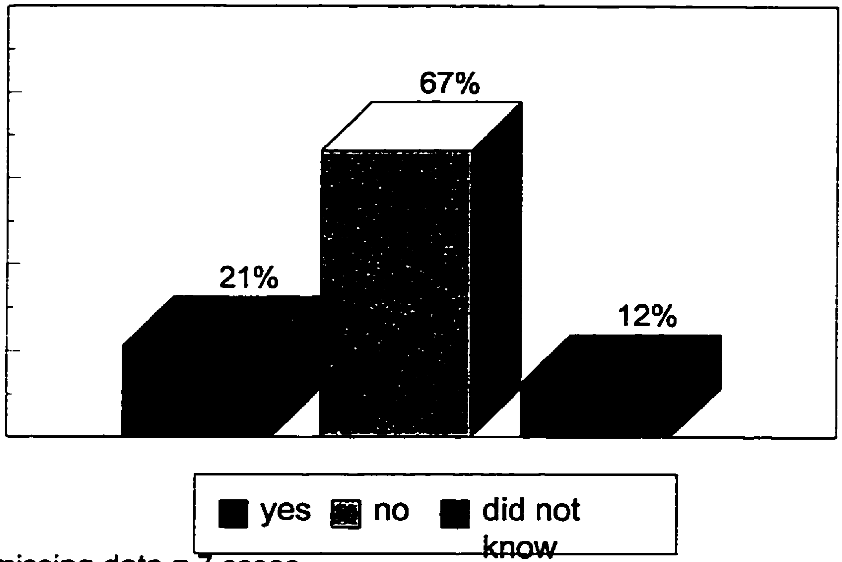
### Information Needs

***Do you feel that the information needs (i.e., understandable information about palliative care, life threatening or terminal illness, loss, grief, death planning and bereavement) of the dying and those who care for them are adequately met in Kings County?***

A large proportion (67%) of the respondents did *not* believe the information needs of the dying and those who care for them are adequately met in Kings County. Twenty-one percent believed that the information needs of the dying and those who care for them are adequately met and twelve percent did not know *(see chart 5).*

**Chart 5**

Information Needs



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The findings of this thesis indicate that people have different levels of information needs. Some participants desire only the basic information such as a simple diagnosis or when medical appointments are scheduled, while others desire a more sophisticated and complex interpretation of their terminal illness and palliative care options. It is important that whatever information an individual requires is attainable and easy to understand. The data suggests information is not easy to obtain and there is a lack of consistent and understandable information between health professionals and the dying, their family and significant others about diagnosis, prognosis, treatment, and care. Many participants reported a fragmentation of service and program information, as well as poor communication among specialists, doctors, discharge planning nurses at the Valley Regional Hospital, VON nurses, HCNS care coordinators, home care workers, patient and family. The deficient intercommunication of information evoked feelings of helplessness and distrust of professionals by the dying and their loved ones

Also identified by respondents was the poor public awareness of where to get information. Physicians and other health care providers do not know where to tell patients to get information. Therefore, obtaining information is left up to the dying, their families or significant others. The problem of obtaining information is directly related to palliative care medical and non-medical services and programs not being coordinated and integrated to serve the dying. There is not one central point of registry for all information of services and programs for the dying. Again, this lack of information has led palliative care patients, their families, their significant others and their caregivers feeling helpless and alone at times to deal with the problems associated with care in the home. The following comments of respondents emphasize the issues surrounding the information needs of the dying and those who care for them:

A daughter whose mother had died stated,

> *It was a rat race. I hated having to repeat our story to so many people. I wish I had just made a handout to pass out to these so called professionals. It wasn't just the Specialists in Halifax either. It was our family doctor; it was Home Care and their different home care and case workers; it was VON, it was the Red Cross, and the Cancer Society.*

A son whose mother had died added,

> *It can be very frustrating not knowing or understanding the stages of palliative care. For someone going through it, information is an asset and sometimes it is not available or family don't know where to get it.*

A nurse stated,

> *Getting information on palliative care is 'helter skelter'.*

A formal health care provider maintained,

> *If it is available, where is the information? Why isn't it circulated to any and all health care practitioners.*

A family member of a person who had died commented,

> *Too much palliative care information is beyond educational levels of patient and family. We had difficulty with the terminology. All we wanted was the basics. Not only that but the fact that we got different information from different sources.*

A family member of a person who had died stated,

> *No information needs are not met, because there aren't always people there to tell you what your going to do, or what's going to happen and it gets confusing for everyone. We had to go to different agencies to get information and all of them had a different story.*

An LPN said,

> *I don't feel that family members are notified of what is available for them and if families don't ask how will they know.*

Notwithstanding, much of the comments of participants on the information needs of the dying and those who care for them have been negative, the VON and related programs were cited as a good resource for information, as well as Valley Regional Hospital's palliative care nurse.

A husband whose wife had died stated,

> *My late wife was terminally ill for three months and no assistance was forthcoming other than from the palliative nurse at the Valley Regional Hospital.*

A family member of someone who had died stated,

> *We did receive good information but not through the standard channels, the nurse at the Valley Regional helped us, so I don't know if others in similar circumstances would have had access to it.*

A volunteer stated,

> *Good information is available if you have the energy and know how to go after it, but basically, readily accessible information is not available.*

A volunteer stated,

> *I know the VON talk to the dying and caregivers about the above information and I have seen written literature in their homes.*

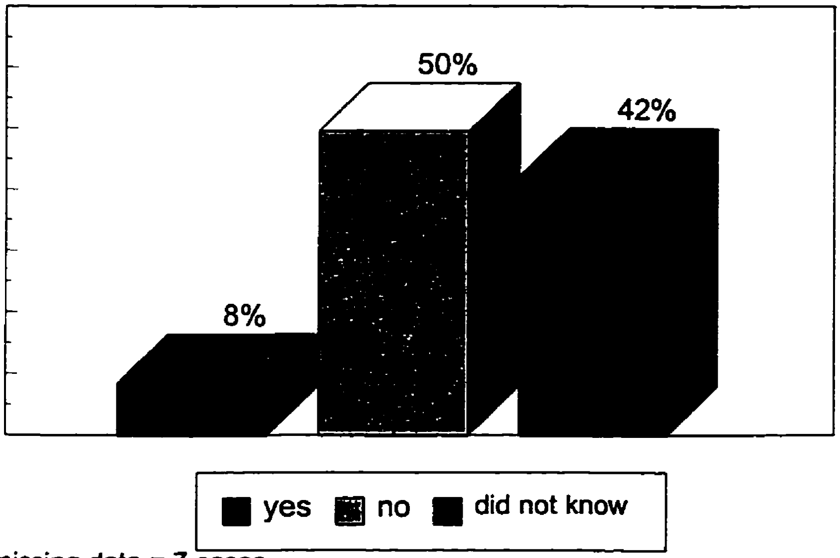
## Financial Needs

### *Do you feel the financial needs of the dying and those who care for them are adequately met in Kings County?*

Half of the sample (50%) did not feel that the financial needs of the dying and those who care for them are adequately met. Conversely, forty two percent did not know if the financial needs of the dying and those who care for them are met and eight percent felt that they were adequately met.

**Chart 6**

Financial Needs



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The experience of many participants in this study illustrates costs of daily living: shelter, food, electricity, telephone, laundry, and other miscellaneous expenses do not disappear when someone receives a life-threatening diagnosis. Existing debts such as mortgages, car payments, or credit cards compound the need for increased financial resources when work is limited or ceased because of an illness. The findings indicate that palliative care is expensive; in particular respondents reported that medical supplies and equipment, medication, chemotherapy, travel expenses to medical appointments, additional home support or nursing care creates financial hardships for many who care for the dying at home. Only the very affluent can afford the help needed to assist a terminal patient living alone who wishes to die in his/her own home. Overall, obtaining the financial resources to support someone with a terminal illness is a serious burden for family members and significant others because federal and provincial health insurance programs do not provide coverage for all medications, supplies, equipment rentals, therapies, and services that a person living with a life-threatening illness requires. As several respondents disclosed not everyone who is in a palliative state of care has private medical insurance coverage to fill in the gaps of *Medicare* and even then, a lengthy ailment can drain allowable coverage for claims under private life and supplementary health insurance plans. Often individuals are required to use personal savings or retirement income funds to help pay for care expenses. Especially vulnerable are individuals with AIDS and younger adults who have not had a chance to develop pension funds and investment resources to draw on for their personal care. As well, some participants remarked that persons living in lower economic circumstances fall through the *cracks* and do not receive the care they need. The following comments highlight the financial difficulties that many participants in the study have encountered:

A nurse stated,

> *Many patients who I have who are under 65 often have to dip into personal, spousal, family savings to pay expensive costs for prescriptions, renovations and care, especially pain medications which should be covered under MSI and Medicare.*

A volunteer said,

> *Sometimes people who need expensive medication cannot afford them, leaving the person in pain until arrangements are made through Social Services for money to help pay for them.*

A form care provider added,

> *I do know that the patch (pain medication) is expensive, and a couple of clients under 65 found this*

> *expensive. One patient I had had to wait for word back for financial assistance. I believe he died either a day after or before the patches were available to him.*

A daughter whose mother had died said,

> *I do not know how I would have paid for heat and food, if I had not cashed in the RRSP's. Nothing was given to help me defer the cost to help me pay for the trips to Halifax for chemotherapy.*

A support group worker stated,

> *Single people and AIDS patients who do not have family or 'other' support structures struggle. They are young and don't have savings or retirement packages to tap into.*

A person living with a life-threatening illness asserted,

> *Our age makes some drugs available through MSI, such as the cost of ambulance transport. Even so, dying is costly in many ways. For example, travel expenses to Vancouver for the only available medical bronchoscoloy are not covered. The limits of reasonable care are not clearly defined.*

A daughter whose mother had died said,

> *There were times Mom suffered from malnutrition because of her chemotherapy, but also because there wasn't enough income for her to get the food she really needed.*

A family member of someone who had died added,

> *Cost of morphine for pain control is obscene! Patients who are not covered by pharmacare must virtually declare bankruptcy or meet the cost alone.*

It was also discovered that many palliative care clients, their families and significant others were not aware of financial assistance programs through various organizations and agencies such as, Provincial and Municipal Social

Services, Cancer Society, Valley AIDS Concern Group, local Churches, and private donations. Again, few of these agencies advertise their assistance programs because of already overburdened budgets of care. Furthermore, those participants who were aware of financial resources available to them commented that the process of obtaining financial assistance tends to be an unnecessary *paper chase.*

In addition, numerous participants felt that palliative care is not seen as a worthwhile medical care expense. Few provisions are made by the community and government in general to meet the needs of the palliative care clients, their families and significant others so that care for the dying does not create economic hardship. The following quotes illustrate this view:

A volunteer stated,

> *There's money for lots of things but when it comes to dying, it is forgotten about. We can't afford to have people die in comfort in Kings County.*

A nurse added,

> *As a society we would never question the importance nor the finances that it takes to establish an obstetrics unit in a hospital but when it comes to palliative care there is always a question can we afford it.*

An LPN said,

> *Government health care cutbacks of palliative care prohibit adequate home care in many cases.*

A volunteer stated,

> *Medication is very expensive and a lot of people can not afford it. Some medications are covered by local organizations, but usually the spouse or caregiver ends up doing without to cover the bills.*

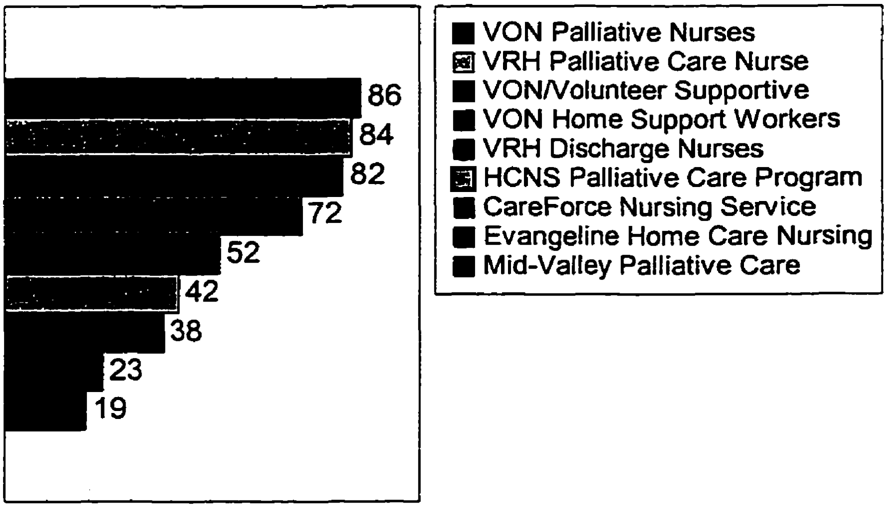
## Palliative Care Programs and Services in Kings County

### *Are you familiar with the following Palliative Care programs and services in Kings County?*

A large majority (86%) of the total sample population indicated that they were familiar with the VON palliative care nurses. Meanwhile, eighty-four percent were familiar with the palliative care nurse at the Valley Regional Hospital; eighty-two percent were familiar with the VON/Volunteer Supportive Care program; seventy-two percent were familiar with VON home support workers; fifty-two percent reported familiarity with discharge planning nurses at Valley Regional Hospital; thirty-eight percent were familiar with CareForce Nursing Services (private nursing service); twenty-three percent were familiar with Evangeline Home Care Nursing (private nursing service); and nineteen percent were familiar with the Mid-Valley Palliative Care Group. *(see chart 7).*

**Chart 7**

Palliative care programs and services in Kings County



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percentage of respondents who answered 'yes'

Furthermore, respondents were asked if there were *other* programs that they felt served palliative care clients in Kings County. They reported such programs and services as, the Canadian Red Cross, Canadian Cancer Society, Living With Cancer Support Group, Being With Dying Support Program, Life Line Oxygen & Medical Supplies, local pharmacies and Churches.

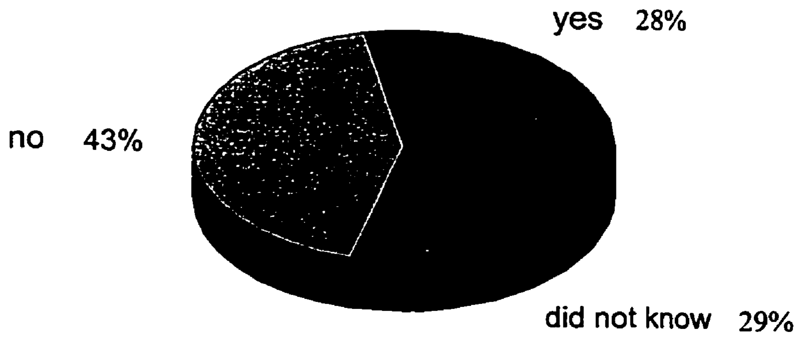
## Critique of Kings County Services and Programs for Palliative Care Clients

***Considering the programs and services that are presently available for the dying, and those who care for them, in Kings County, do you feel that all the needs are adequately met?***

Forty-three percent of the participants did not feel that the existing palliative care programs and services adequately met *all* of the needs of the dying and those who care for them. However, twenty-eight percent felt that they did and twenty-nine percent did not know. *(see chart 8).*

**Chart 8**

Do you feel the needs are adequately met?



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Forty-three percent of the total sample reported that all the needs of the dying were adequately met through the existing programs and services, however, the qualitative responses depict a population who are generally not satisfied with the present care resources for the dying. This question in the survey aroused a gamut of concerns for participants about existing palliative care programs and services offered in Kings County. A concern that was highlighted numerous times by respondents was there is inadequate training of health professionals in palliative care. There is a general lack of understanding among health care providers of the process of death and dying, as well as the principles of palliative care such as, quality of life, treatment of the 'whole person', care provided 24 hours a day seven days a week, the patient and family as the unit of care, personal autonomy of the patient and family, continuity of care, interdisciplinary team work and the patient and the family are entitled to support and respect at all times. In addition, the approach to care is not holistic. Emphasis is on meeting physical needs and ignores the psychological, social, spiritual, information and financial needs that an individual desires. Although the present programs and services emphasis appears to be adapted to the physical needs of the dying, it was suggested by many there is inadequate education on pain and symptom control management for physicians. This inadequate training results in unnecessary suffering of the patient and those who are close to them.

Another valid complaint of the palliative care resources in Kings County was there is no assistance available to families or significance others with the transition phase of bringing the patient from the hospital to the home. Basic practical hands-on nursing care skills are required to care for a terminal patient at home. Simple 'how to' lessons are needed by informal caregivers on the administration of medication, infection control, personal hygiene, treatment of certain symptoms (breathing problems, nausea, vomiting, constipation, or diarrhea), non-verbal observation techniques, lifting or transferring a person, making a bed with someone in it and toileting methods. Families and significant others feel they are thrust into the role of caregiver with little or no direction from health care providers. As well, it was felt that some medical equipment, supplies, and prescription drugs are difficult to obtain. Another concern that was raised was there is no follow up post-care available for families or significant others after a lengthy illness of a loved one.

Many participants commented on the fragmentation of care in their community. There is no central registry point for all information of services and programs for the dying. Considering services and programs are not coordinated and integrated, poor communication between local health care providers exists. Family members and significant others of the dying generally experience difficulty in contacting all health care providers, especially physicians. This poor communication results in palliative care clients and those who care for them searching for appropriate care resources and care for the dying becomes crisis oriented and not preventive. Moreover, this fragmentation of care causes the absence of continuity of care and results in many different health care providers entering the home. Some participants reported up to nine different home support workers alone. Programs and services offered are not flexible to individual situations.

Added to the poor communication of health care providers is insufficient public relations and promotion of the palliative care services and programs that are available. Health care providers and community in general are not aware of existing programs and services for palliative care clients. The programs and services for palliative care clients do not openly advertise their services because they report having enough difficulty meeting the existing demand for services and promotion would cause an increase requisition for services that they would not be able to fulfil. As it stands, there is a general understanding by participants that there is not enough funding provided to existing programs and services for palliative care to expand the present resources.

Some participants identified that 24-hour care, seven days a week is not provided under the HCNS program and the care that is provided is not sufficient. For the most part, participants maintained that not enough respite care is available in the home and hospitalization is the only option when support and finances are insufficient to meet the demands of end of life care. By and large, it was affirmed that the hospital is not an appropriate place for care, because the focus is on acute not palliative care. However, no financial compensation is available for families or significant others who end or limit employment to care for a loved one in the home.

The suggestions and/or modifications that participants in this study identified as possible improvements for existing palliative care programs and services available in Kings County included: first, integrate and coordinate programs and services. Use the 'team' approach to provide care. Create one central access point for palliative care clients. Clearly defined linkages are fundamental to the consistent, cost-effective and competent care of palliative care clients. Second, limit the number of caregivers entering the home to three or four persons per client. Third, increase the number of hours of respite care and home care services in the home. Fourth, educate all health care providers about the principles of palliative care. Likewise, educate all physicians about pain and symptom control management. Increase public awareness of palliative care through the media, pamphlets, radio, etc. Finally, build a hospice and have all services and programs for palliative clients originate from one designated facility

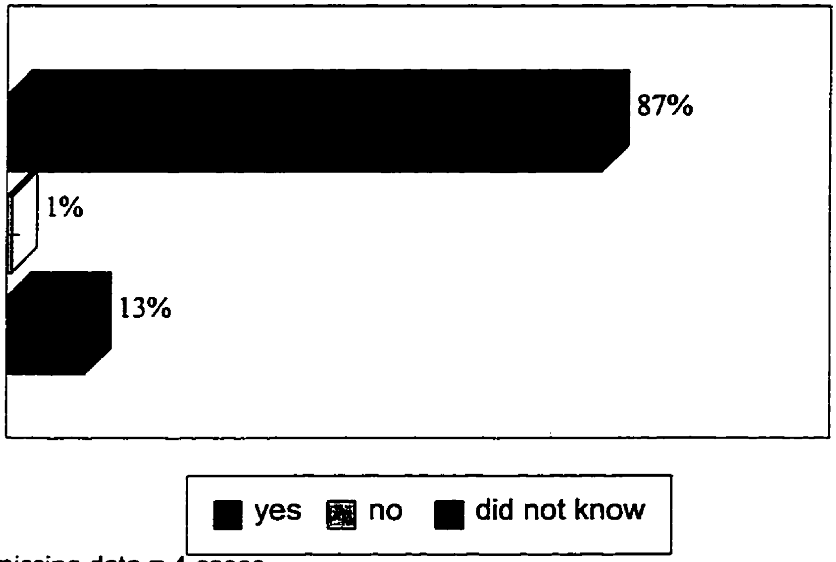
### Perceptions of Need for a Freestanding Hospice Facility in Kings County

#### ***Do you feel that there is a need for a free-standing hospice facility in Kings County?***

An overwhelming proportion of the sample (87%) felt that there was a need for a free-standing hospice facility in Kings County. Only one percent felt that there is not a need for a hospice and twelve percent did not know *(see chart 9).*

**Chart 9**

Do you feel there is a need for a hospice?



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A needs assessment is a way to determine the nature of a problem and what might be done about it. A community needs assessment implies having people most effected by a problem or an issue identify how they see a problem and what they think might be done about it. Although professionals may assume they know the needs and desires of a particular community, members of the community may identify different problem areas and priorities (Barnsley & Ellis (1992).

When the visionary idea of a hospice facility first originated and discussion arose among several health care professionals and palliative care volunteers concerned about the care of people with life-threatening illnesses whose need were not being met, it became clear that there was a need to document the needs and concerns of individuals and families so that any effort would be appropriate for people living in a rural community like Kings County.

Essentially, the participants in this study determine the creation of a hospice facility as addressing the need for the population who 'fell through the cracks' of palliative care services and programs, as well as 'filling the gaps' of the existing palliative care resources in Kings County. The population that they perceive as 'falling through the cracks' of the system are terminally ill individuals who are single and/or have neither familial nor significant others to care for them or the financial resources to sustain private care. Also included in this population are: persons with AIDS, individuals whose family members or significant others are unable to emotionally and/or physically cope with care of a dying person; individuals whose family members and significant others are unable to provide palliative care in the home because of work and other time constraints; and those whose family have chose not too become involved in the care. A hospice facility provides an alternative end of life care option for the dying besides going without the care they need, hospitalization and nursing home care. Furthermore, a hospice provides respite care for the dying and therefore, give the caregiver and the individual with a life-threatening illnesses with a care break. The need for a hospice facility is echoed by the comments of the following participants.

A nurse stated,

> *I believe that there are still persons in this area who are 'falling through the cracks' and either don't have the monetary or family resources as well as external supports to deal with a terminal illness as it is often a long process.*

A volunteer asserted,

> *We need more help for those alone (with no spouse). As it stands now they go without proper care. We need a place that is like home, but has adequate*

> *facilities for pain control. It should a place where the family and even pets can come to visit on a regular basis.*

A support group worker agreed,

> *Single people and people with AIDS have nowhere to go to receive holistic care. They even have trouble now just dealing with basic physical care issues and the hours of care they receive through NSHC. The hospital is too busy and not adequate for this special type of care. Also, home care workers are not always understanding workers.*

A informal care provider stated,

> *For some persons, home is the only alternative for them near the end of their lives. Another choice for persons and families where critical medical needs can be met would be a comfort for many families.*

A home support worker stated,

> *Some families are unable to cope with caring for a family member dying in the home. The care is very intimate body work and some people just can't cope with it. Others have dysfunctional relationships with their children and putting them in this type of care situation is a recipe for disaster.*

A formal health care provider said,

> *Some people do not want to go to the hospital, but they or their caregivers are afraid to be at home. There are a lot of changes a person goes through both physically and mentally when they are dying and sometimes family doesn't want to deal with the care.*

A daughter whose mother had died stated,

> *As many people become more stressed emotionally as well as financially, this feels like a good idea. This would also provide care for those who live apart from family or are unable to receive the overall support they need.*

A family member of someone who had died stated,

> *In a situation where the person who is dying wants to remains at home with the family and not in the hospital but the family and caregivers have become exhausted because of the extent of the physical care and/or they do want the family member to die at home there is no other place to go. This would give the dying a place to go and provide the family with respite care.*

A formal caregiver stated,

> *There are some whose families are unable to care for them at home, but do not wish to be in hospital. With long term illness, respite care offered in a hospice center would be a very nice alternative for both client and family.*

A daughter whose mother had died maintained,

> *There is a need for a place to live until death that frees family to be family. The way it is now I had to spend all my time either providing physical care for Mom or I was taking care of my kids. There was not a lot of time to just visit and talk with Mom. Respite care was not an option because where would she go besides the hospital.*

A wife whose husband had died asserted,

> *Dying in a home-like atmosphere would be so much more comfortable than the Intensive Care Unit.*

The development of a hospice facility to 'fill the gaps' of existing palliative care resources in Kings County addresses needs and wants of the dying and those who care for them that are not adequately met. In this light, a hospice facility is perceived and understood as a 'better' care option, more apt to meet the physical, psychological, social, spiritual and information needs of the dying, their family, their significant others and those who care for them. Similarly, a hospice facility is perceived as a more 'home-like' option of care that provides a loving and compassionate care environment for the dying, their family and significant others.

Not only did participants see the creation of a hospice facility as addressing those individuals who 'fell through the cracks' and 'filling the gaps' of existing palliative care resources, it was recognized as a chance to improve the overall care for the dying by providing one central entry point of care that coordinates and integrates palliative care programs and services. Moreover, a hospice facility is seen as an information and education resource for the dying and those who care for them in the community. The development of a hospice facility is a place for formal and informal health care providers to receive education in the field of palliative care and pain control and symptom management. The opening of a hospice provides the community with awareness of the holistic approach of palliative care and the concept of a hospice care facility. The following quotes highlight why a hospice facility is needed in Kings County.

A husband whose wife had died stated,

> *I think that peoples' needs would be better served in a hospice when home care is not possible than in hospitals. With so few hospital beds available, I feel there is a need for a place where family can place their loved one and not feel guilty about not taking care of them.*

A volunteer stated,

> *Everyone needs a loving and caring environment where they know they are wanted and will have the help, respect and privacy desired during their last days a hospice would offer this environment.*

A daughter whose father had died stated,

> *All needs can be better met in an atmosphere of love, care and compassion. The active treatment in hospitals is not geared to total care of the person.*

A care coordinator affirmed,

> *Yes, there is a need for a hospice for sick people to get physical, emotional, and spiritual support as well as for their close family and friends to get information on what to expect and how to deal with everything and also get support.*

A daughter whose mother had died stated,

> *A hospice could bring all the palliative care resources together. A place that met all the needs of the dying and their family. We need a hospice where the dying and the support people, family etc. are accepted, nurtured, and made comfortable about what is happening and what will happen as the end draws near.*

An LPN said,

> *There should be a more central place that can draw all these supports closely together and thus, work more closely and efficiently with families and patients to make informed, educated choices and decisions.*

A friend of someone who has died added,

> *At present, the services for palliative care seem so scattered, and if a hospice could localize these services, it would be easier for a caregiver to find the adequate care needed. It would give the family peace of mind in knowing the staff would be trained properly. People are often forced to use less qualified individuals for care either because of unavailability of qualified workers or obviously money or lack of it.*

A nurse commented,

> *Most definitely, it would be a great place to have both for the dying person and the families. It would also be very helpful to acute care facilities in freeing up the*

> *beds now used for terminal care. As a caregiver it would be a great place to receive education on palliative care and advances in pain and symptom control management. Families could use a place that trains them in some basic patient body care skills.*

An informal caregiver stated,

> *We need an open place that people know about and do not have to look for. A hospice would give the community knowledge about end of life care and it's issues.*

A support group worker agreed,

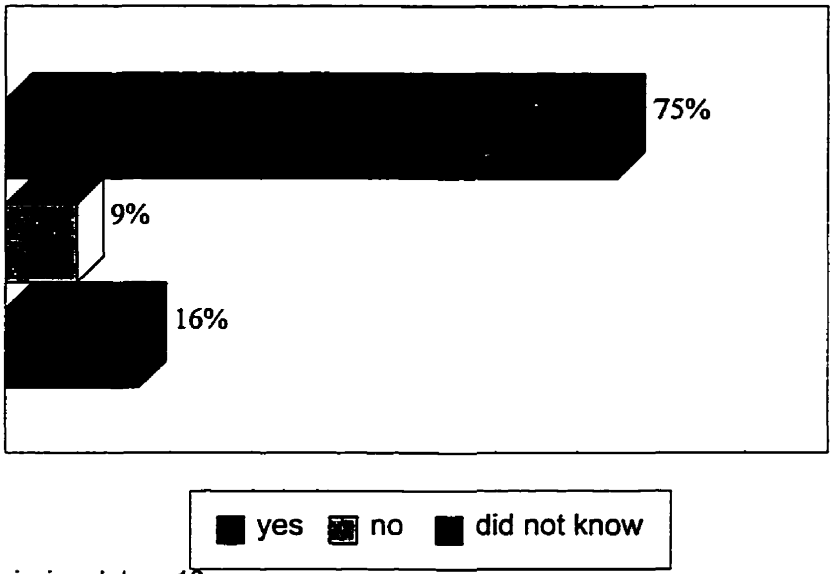
> *The opening of a hospice would help to raise awareness of issues surrounding death and dying and palliative care.*

### *Would having a hospice in Kings County make any difference to you?*

A large portion (75%) of the respondents indicated that having a hospice in Kings County would make a difference to them. In contrast, nine percent reported it would not make any difference to them if there was a hospice and sixteen percent did not know *(see chart 10).*

**Chart 10**

Would having a hospice in Kings County make a difference to you?



missing data = 10 cases

Overall, respondents reported the following reasons why a hospice would make a difference to them. First, the creation of a hospice facility would provide 'peace of mind'. The community would be assured that all individuals who are terminally ill and dying would have the opportunity to receive adequate care and support when they face death, instead of just the affluent. Second, AIDS patients would have a place to receive care. Third, a hospice facility is a care option that a number of individuals could use in the future for their own care or the care of family members, significant others and patients. Moreover, participants stated that a hospice facility would be a valued community asset and that they lived in a compassionate and emphatic community which cared for the dying. As well, their community would be one of the first in Nova Scotia to provide this special type of end of life care through free-standing hospice facility. The words of a formal care provider highlight reasons why a hospice would make a difference to them in their community.

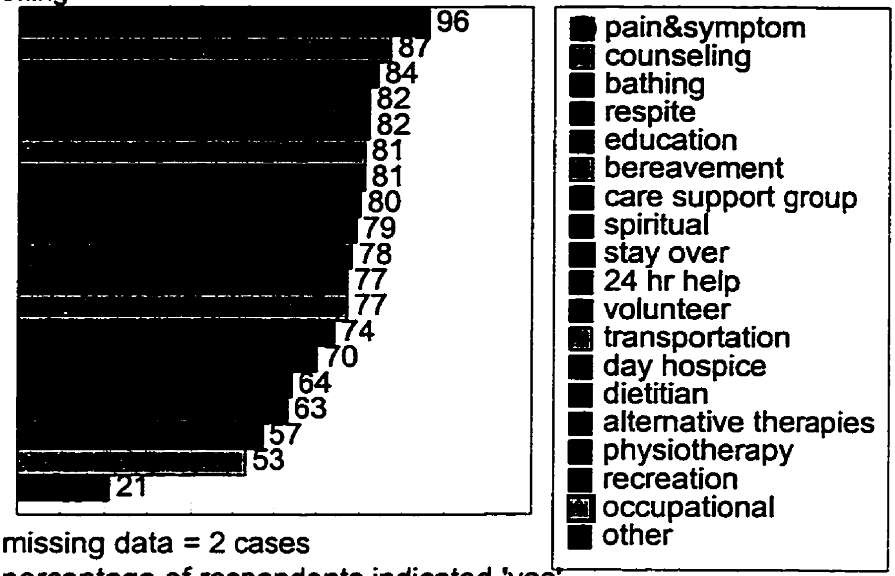
> *We need an institution in Kings County where the body, mind and spirit are treated as a whole entity and not separated. I believe in holistic medicine, and it is practically impossible to care for all the needs of the dying in a hospital. There are individuals who are dying with AIDS and their caregivers in our community who do not know where to turn for help and some are afraid to ask for help so they deal with it alone. A caring and compassionate place needs to be developed so that the community knows that all persons who are dying are cared for without judgement. Also, I want a hospice for my own 'peace of mind'. I want to feel there is a place that I can go if I become sick and need 24 hour a day care. A place that specializes in meeting my needs as a palliative care patient.*

## Types of Services and Programs in a Hospice Setting

The following information was found when participants were asked to check off what services and programs they felt should be offered in a hospice setting. In general, nearly all the participants (96%) believed *pain and symptom control management* should be offered in a hospice setting. While, eighty-seven percent believed *counseling* should be offered, eighty-four percent believed *bathing facilities* should be offered, and eighty-two percent believed *respite care* or *relief care* should be offered. Similar responses were reported by eighty-two percent of participants who felt *educational opportunities (i.e., palliative care, bereavement, treatment options, end of life care, etc.)* should be offered, eighty-one percent who felt *bereavement support and follow up* should be offered, eighty-one percent who felt a *caregivers support group* should be offered and eighty percent who felt *spiritual care* should be offered. A fairly large proportion of respondents (79%) consider that there should be a place for *loved ones to stay over night*, and seventy-eight percent considered the service of a *24 hour help line* should be offered. While seventy-seven percent felt there should be *volunteer services* offered, and similarly seventy-seven percent felt there should be *transportation services* offered. Seventy-four percent felt a *day hospice program* should be offered. In terms of specific professional supports, seventy percent reported the services of a *dietitian* should be offered, sixty-four percent reported that *alternative therapies (i.e., acupuncture, aromatherapy, massage, reflexology etc.)* should be offered, sixty-three percent reported physiotherapy should be offered, fifty-seven percent reported a *recreation program* should be offered, fifty-three percent reported *occupational* therapy should be offered, and twenty-one percent reported there should be *other services* available *(see chart 11).*

**Chart 11**

**Types of services or programs that should be offered in a hospice etting**



missing data = 2 cases
percentage of respondents indicated 'yes'

The additional services or suggestions that were requested by participants in the study for a hospice facility are: pet and music therapy; meditation room; and hair and skin care treatments. Furthermore, special equipment rental and instructions on how to use equipment such as toileting devices, beds, lifts, trapeze bars etc. were suggested and rendering of financial assistance and planning was considered an important service that should be offered. Child care for family and friends while visiting or children's play area was determined a valued asset to be offered in a hospice facility. Participants further suggested some of these services could be offered on a part-time basis or at the request of the client and to avoid duplication of services that could be obtained elsewhere if it was convenient for the client. Moreover, many stated that it would be an ideal place to orient and coordinate all services for palliative care clients in Kings County providing one entry point for all persons.

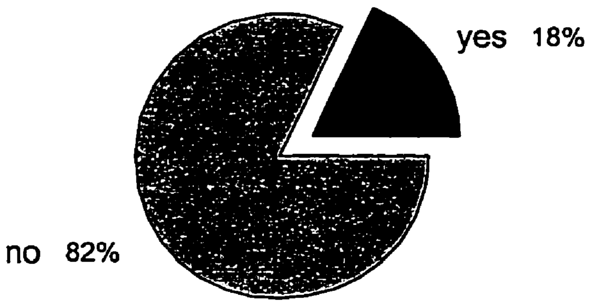
It was also indicated that the hospice provide a 'home-like' environment and to avoid over regulation of the facility and allow for client flexibility of situations. In addition, it was stressed that staff and volunteers not make judgments of the client and/or the families or significant other's lifestyle and to avoid promoting and proselytizing of religion.

**Dissenting Views**

Just eighteen percent of the population reported they would not support the concept of a hospice if one was made available, and eighty-two percent had no reason for not supporting a hospice. *(see chart 12).*

**Chart 12**

Anything that would prevent you from supporting a hospice?



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The specific reasons provided, that would prevent some individuals from supporting a hospice facility in Kings County, can be summarized as follows: the belief that family and friends should take care of the dying in their home; the fear that a hospice would take away funds or emphasis from providing care in the home; there would be too much financial expense of running and setting up a hospice on the Western Region's Health Care Budget; and fear of duplication of palliative care programs and services.

# Chapter Six

## Summary and Recommendations

Palliative care strives to fulfill the total holistic needs of individuals dealing with life-threatening illnesses, as well as family members, friends and significant others who care for them. The physical, psychological, social, spiritual, information, and financial requirements of the dying, and those who care for them, need to be met. The body, mind and spirit of humans are not separate entities that can be divided and cared for separately. This needs assessment has indicated palliative care programs and services in Kings County that are not addressing all the needs of the dying and their care providers. The existing programs and services that provide palliative care need to address concerns around lack of integration and coordination. The information gained through this study process suggests the following pattern of services and new areas for expansion and development.

1. The physical, psychological, social, spiritual, information and financial needs of the dying, their caregivers and significant others in Kings County are not adequately met.
2. There is an array of valuable palliative care services currently being offered in Kings County.

3. Existing services need to strive toward increased coordination and integration.
4. More information is required about existing palliative care services and programs for public consumption.
5. There are clear gaps in the provision of many services. Existing services should be enhanced.
6. The palliative care nursing provided by the VON is crucial in meeting the at home nursing care needs, as well as psychological and information needs.
7. The palliative care nursing position at the Valley Regional Hospital is filling a key role in the provision of information and psychological support.
8. A hospice facility would fill a pressing need in Kings County.
9. A hospice facility must be an option for the continuum of care, but in no way compromise the palliative care offered in the hospital or the home care aspect of palliative care.

## Recommendations

In light of the literature review, focus group meeting, and the 1997 Kings County needs assessment, the following recommendations were derived from this research. These recommendations fall into two interconnected categories: one category specific to the creation of a hospice facility in Kings County, and a general category provides details on the co-ordination of existing services.

Development of a Hospice Care Facility:

There is evidence from this research that supports the development of a separate hospice care facility. The next steps for planning and development of a hospice facility should be explored. The VON, Kings Branch should proceed immediately to conduct a feasibility study into the creation of a free-standing hospice. In conducting this study, it is recommended that the following be considered:

a) The goals and objectives for the hospice;
b) The physical layout and design;
c) Types of services to be offered
d) Staffing (including role of volunteers);
e) How will the hospice fit into the existing continuum of services;
f) The proposed catchment area;
g) To look at funding, financing, legal and regulation issues;
h) Appropriate management structures;
i) Suitable purchase, rental or leasing arrangements of property;
j) Fund-raising strategies; and

k) Public education strategies.

Review of Existing Services and Programs:

The research indicates that palliative care programs and services should be reviewed for their quality of care, appropriateness of service and components that need improvement. The following recommendations are based on the finding of this research:

a) Services and programs for the dying and their caregivers, families, and significant others should be more fully integrated and co-ordinated. A central and easy entry point of access for all programs and services should be established for all palliative care clients while respecting the value of autonomy for some programs and services.

b) Provide more holistic health care with greater emphasis on psychological, social, spiritual, information and financial needs;

c) Provide preventative care not crisis oriented care;

d) Provide 24 hour care, 7 days a week;

e) Increase accessibility to formal caregivers, especially physicians;

f) Increase accessibility to medical equipment, supplies and prescriptions;

g) Provide assistance to families or significant others with the transition phase from hospital and home;

h) Establish additional programs that provide ongoing support for caregivers and increase respite care for individuals who care for the dying in the home.

i) Provide follow up care for families or significant others after a lengthy illness of a loved one;

j) Provide further education programs and information in Kings County for professionals and the general public to raise the level of understanding concerning palliative care services and their underlying philosophy and principals.

k) Increase education and information to caregivers in Kings County on pain and symptom control management; and

l) Increase Nova Scotia Provincial Health Care funding to existing programs and services for palliative care.

This thesis represents a necessary step in responding to the growing need to integrate palliative care as an essential element in the continuum of health care. The aging population, the increasing proportion of deaths due to chronic illnesses, notably cancer, the public debates about the ethical considerations surrounding death -- all these phenomena have contributed to increasing awareness of the importance of quality of care at the end of life. As we shift health care delivery from hospitals and clinics to the community, we must give sufficient place to palliative care in the community. Cost-effectiveness is a relevant, but secondary reason for doing this. More important is the need to give dying people and their significant others the choice of maintaining their quality of life to the very end in the environment where they are most comfortable. It is the right of all Canadians, to be assured adequate care and support when they face death, is compelling reason to resolve the existing and long-standing disparities in end of life care, regardless of place of residence or illness. In conclusion, I leave the reader with the dying person's Bill of Rights.

## The Dying Person's Bill of Rights

*I have the right to be treated as a living human being until I die.*

*I have the right to maintain a sense of hopefulness however changing its focus may be.*

*I have the right to be cared for by those who will maintain a sense of hopefulness, however changing this might be.*

*I have the right to express my feelings and emotions about my approaching death in my own way.*

*I have the right to participate in decisions concerning my care.*

*I have the right to expect continuing medical and nursing attention even though 'cure' goals must be changed to 'comfort' goals.*

*I have the right to be free from pain.*

*I have the right to have my questions answered honestly.*

*I have the right not to be deceived.*

*I have the right to have help from and for my family in accepting my death.*

*I have the right to die in peace and dignity.*

*I have the right to retain my individuality and not to be judged for my decisions, which may be contrary to the beliefs of others.*

*I have the right to discuss and enlarge my religious and/or spiritual experiences whatever these may mean to others.*

*I have the right to expect that the sanctity of the human body will be respected after death.*

*I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death*

(Baddeck, NS Hospice Society of Victoria County 1994:105).

## References

Abel, E.
1986. 'The Hospice Movement: Institutionalizing Innovation'. *International Journal of Health Sciences* 16:1, 71-85.

Auger, J. A. and A. R. Bursey
1997. *The UK Experience and Mind, Body and Soul: Exploring the Need for A Hospice in Kings County.* Wolfville, NS VON, Kings Branch.

Babbie, E.
1995. *The Practice of Social Research, 7th edition.* Toronto:Wadsworth Publishing.

Barnsley, J. and D. Ellis
1992. *Research for Change: Participatory Action Research for Community Groups.* Vancouver: The Women's Research Centre.

Bass, D.M.
1982-83. 'Response Bias in Studying Hospice Clients Needs.' *Omega,* 13, 305-318.

Bolaria, S. B. and H. D. Dickinson.
1994. *Sociology of Health Care in Canada, 2nd ed.* Toronto: Harcourt Brace Jovanovich.

Bruera, E.; Kuehen, N.; Emery, B.; MacMillian, K.; and J. Hanson
1990. 'Social and Demographic Characteristics of Patients Admitted To A Palliative Care Unit'. *Journal of Palliative Care* 6:4, 16-29.

Canadian Palliative Care Association
1995. *Palliative Care: Towards a Consensus in Standardized Principles of Practice.* Ottawa, Ontario: The Association.

Canadian Palliative Care Association
1996. *Annual Report.* Ottawa, Ontario: The Association.

Cassileth, B.R.; Lusk, E. J.; Strouse, T.B.; Miller, D.S.; Brown, L. L.; and P.A. Cross
1985. 'A Psychological Analysis of Cancer Patients and Their Next of Kin'. *Cancer Journal* 55:1, 72-76

Clarke, J.N.
1996. *Health, Illness and Health Care in Canada, $2^{nd}$ ed.* Toronto: Oxford University Press.

Cockerham, W. C.
1982. *Medical Sociology.* New Jersey: Prentice Hall.

Coburn, D., C. D'Arcy, G. Torrance, and P. New
1987. *Health and Canadian Society; Sociological Perspectives, $2^{nd}$* Richmond Hill: Fitzhenry & Whiteside.

DuBois, P.
1980. *The Hospice Way of Death.* New York: Human Sciences Press.

Flannery, F.; Geraci, J.S; Filman, J.; Durkee, L.; and A. Lambert Eds.
1997. *Casey House Hospice: A Hospice for People Living with AIDS, A Model for Collaborative Care.* Toronto: Webcom www.gaytoronto.com/ casey/.

Fulton, R.L.
1965. *Death and Identity.* New York: Wiley and Sons.

Garner, R.A.
1972 *Social Movement in America.* Chicago: Aldine.

Gilbar, O. and M. Steiner
1996. 'When Death Comes: Where Should Patients Die?' *Hospice Journal* 11:1, 31-48.

Glaser, B.G. and A.L. Strauss
1967. *Awareness Of Dying.* Chicago: Aldine.

Goldberg, R. A.
1991. *Grassroots Resistance: Social Movements in Twentieth Century America.* Belmont, CA: Wadsworth Publishing.

Hayslip, B., Hoffman, J., and D. Weatherly
1990-91. 'Response Bias in Hospice Evaluation'. *Omega, 22,* 63-74.

Health Canada.
May 1997. *AIDS in Canada*: Quarterly Surveillance Update. Division of HIV/AIDS Surveillance, Bureau of HIV/AIDS and STD, LCDC, HPB.

Health Canada
1989. *Palliative Care Services: Guidelines.* Ottawa: Health Services and Promotion Brance.

Hospice Association of America
1996. *Hospice Facts and Statistics 1996.* Washington D.C.:Bureau of Policy Development.

Hospice Society of Victoria County
1994. *The Community Hospice Handbook.* Baddeck, Nova Scotia: in cooperation with Health Canada.

James, N. and D. Field
1992. 'The Routinisation of Hospice: Charisma and Bureaucratization'. *Social Science and Medicine.* 34, 1363-75.

Lasagna, L.
1970. 'Special Subjects In Human Experimentation.' 262-275 in P.A. Freund Ed., *Experimentation with Human Subjects.* New York: George Braziller.

LeComte, M. D., W. L. Millroy and J. Preissle
1992. *The Handbook of Qualitative Research in Education.* Toronto: Academic Press.

Luchins, D. and P. Hanrahan
1993. 'What Is Appropriate Health Care For End Stage Dementia'. *Journal of the American Geriatrics Society* 41:1, 25-30.

Kastenbaum, R.
1995. *Death, Society, and Human Experiences, 5th ed.* Columbus: Merrill Publishing.

Kristjanson, L.
1996. 'Generic versus Specific Palliative Care Services'. *Health Systems and Policy Division.* Ottawa:Health Canada.

Kurtz, R. A. and P. H. Chalfant.
1991 *The Sociology of Medicine and Illness, 2nd ed.* Toronto: Allyn and Bacon.

Kubler-Ross, E.
1969. *On Death and Dying.* New York:Macmillan.

Mechanic, D.
1968. *Medical Sociology; A Selective View.* New York: The Free Press.

Munley, A.
1983 *The Hospice Alternative: A New Context for Death and Dying.* New York: Basic Book Publishers

Myfanwy, M., M.I Calnan, and N. Manning.
1985. *Sociological Approaches to Health and Medicine.* Dover, N.H.: Croom Helm.

National Cancer Institute of Canada
1998. *Canadian Cancer Statistics 1998.* Toronto, Canada: The Institute.

National Cancer Institute of Canada
1997. *Canadian Cancer Statistics 1997:10th Anniversary Edition.* Toronto, Canada: The Institute.

Nova Scotia Department of Health.
1995. *Surveillance Report HIV/AIDS and Sexually Transmitted Diseases: 1995 Report.* Halifax, NS.

Palgi, P. and H. Abramovitch
1984. 'Death: A Cross Cultural Perspective'. *Annual Review of Anthropology*, 13:385-417.

Paradis, L. F.
1988. 'An Assessment of Sociology's Contributions to Hospice: Priorities for Future Research'. *Hospice Journal* 4: 57-71.

Reinharz, S.
1992. *Feminist Methods in Social Research.* New York: Oxford University Press.

Ross, M. M. and B. MacDonald
1992. 'Providing Palliative Care to Older Adults: Context and Challenges'. *Journal of Palliative Care* 10:4, 5-10.

St. Christopher's Hospice Information Services
*1997. Directory of Hospices and Palliative Care.* London, England: Information Services.

Saunders, C.
1990. *Hospice and Palliative Care: Interdisciplinary Approach.* London: Edward Arnold.

Saunders, C. and M. Baines
1983. *Living with Dying: The Management of Terminal Disease.* Oxford, England: Oxford University Press.

Senate of Canada
1995. *Of Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide.* Ottawa: Minister of Supply and Services Canada.

Statistics Canada, Health Division
1988. 'A Review of National Health Surveys in Canada, 1978–1987'. In: *Health Reports—Prototype* (Cat 82-003:28–50). Ottawa: Minister of Supply and Services Canada.

Sudnow, D.
1967. *Passing On.* Englewood Cliffs, NJ: Prentice Hall .

Stein, J.
1997. 'Major Causes of Death in Canada, 1993–1995' *Chronic Diseases in Canada Health Protection Branch - Laboratory Centre for Disease Control* 18:2, 39-45.

Taylor, B.
1993. 'Hospice Nurses Tell Their Stories About a Good Death'. *Annual Review of Health Social Science*, 3:97-100.

Turner, B. S.
1987. *Medical Power and Social Knowledge.* London: Sage Publications.

Twaddle, A. C. and R. M. Hessler
1977. *A Sociology of Health.* Saint Louis: The C.V. Mosby Company.

Von Bommel, H.
1992. *Dying for Care: Hospice Care or Euthanasia.* Toronto: NC Press.

Whyte, W. F.
1991. *Social Theory for Action: How Individuals and Organizations Learn To Change.* London: Sage Publications.

Whyte, W. F.
1990. *Participatory Action Research.* London: Sage Publications.

Zimmerman, J.
1981. *Hospice: Complete Care for the Terminally Ill.* Baltimore: Urban & Schwarzenburg.

### *Appendix 1*

## Mind, Body, and Soul: Exploring The Need For A Hospice In Kings County

## QUESTIONNAIRE

**INSTRUCTIONS:**

- **Please respond to the following questions and statements as accurately as possible.**
- **The questionnaire will take approximately 15 minutes to complete.**
- **There are a total of 18 questions in the questionnaire.**
- **Please write on the back of the sheet if the space provided is not adequate.**

### Section A:

1. Do you feel that the *physical* needs i.e. symptom and pain control, personal care of the dying are adequately met in Kings County?

☐ yes
☐ no
☐ do not know

Please explain. ***Please print***

______________________________________________

______________________________________________

______________________________________________

2. Do you feel that the *psychological* needs i.e. emotional, mental well being of the dying and those who care for them are adequately met in Kings County?

☐ yes
☐ no
☐ do not know

Please explain. ***Please print***

______________________________________________

______________________________________________

______________________________________________

3. Do you feel that the *social* needs i.e. recreation, contact with others, support groups of the dying and those who care for them are adequately met in Kings County?

- ☐ yes
- ☐ no
- ☐ do not know

Please explain. ***Please print***

________________________________________

________________________________________

________________________________________

4. Do you feel that the *spiritual* needs of the dying and those who care for them are adequately met in Kings County?

- ☐ yes
- ☐ no
- ☐ do not know

Please explain. ***Please print***

________________________________________

________________________________________

________________________________________

5. Do you feel that the *information* needs understandable information about palliative care, life-threatening or terminal illness, loss, grief, death planning, and bereavement of the dying and those that care for them are adequately met in Kings County?

- ☐ yes
- ☐ no
- ☐ do not know

Please explain. ***Please print***

________________________________________

________________________________________

________________________________________

6. Do you feel that the *financial* needs of the dying and those who care for them are adequately met in Kings County?

☐ yes
☐ no
☒ do not know

Please explain. ***Please print***

______________________________________________

______________________________________________

______________________________________________

For the purpose of this questionnaire, ***Palliative Care*** is defined as the active care of persons at a time when their disease is no longer responsive to curative treatment. It is a holistic approach to care providing physical, emotional, social, spiritual and informational supports to help improve the quality of a person's remaining life, and recognizes the patient and family/friends as the principal decision makers.

7. Are you familiar with the following Palliative Care programs and services in Kings County?

| | | |
|---|---|---|
| Palliative Care Nurse at Valley Regional | ☐ yes | ☐ no |
| Discharge Planning Nurse at Valley Regional | ☐ yes | ☐ no |
| Victorian Order of Nurses Palliative Care Nurses | ☐ yes | ☐ no |
| Palliative Care Home Support Workers | ☐ yes | ☐ no |
| Palliative Care Volunteer Program/PEP | ☐ yes | ☐ no |
| CareForce Nursing Services | ☐ yes | ☐ no |
| Evangeline Home Care Nursing | ☐ yes | ☐ no |
| Mid-Valley Palliative Care | ☐ yes | ☐ no |
| Home Care Nova Scotia Palliative Care Program | ☒ yes | ☐ no |

Other ***please specify***______________________________________

8. Considering the programs and services listed on the previous page that are presently available to the dying and those who care for them in Kings County, do you feel that all their needs are adequately met?

☐ yes
☐ no
☐ do not know

Please explain. ***Please print***

______________________________________________

______________________________________________

______________________________________________

9. What changes or modifications, if any, do you feel should be made to the existing Palliative Care programs and services offered in Kings County? ***Please print***

______________________________________________

______________________________________________

______________________________________________

**Section B:**

For the purpose of this questionnaire, a ***hospice*** is defined as a facility which:

1. Provides palliative care to dying persons
2. Provides respite care for the dying persons
3. Provides information for formal and informal caregivers
4. Coordinates bereavement support groups
5. Trains people to provide care to the dying persons

10. Do you feel there is a need for a hospice in Kings County?

☐ yes
☐ no
☐ do not know

Please explain. ***Please print***

______________________________________________

______________________________________________

______________________________________________

______________________________________________

11. Would having a hospice in Kings County make any difference to you?

☐ yes
☐ no
☐ do not know

Please explain. ***Please print***

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

12. What types of services or programs do you feel should be offered in hospice? ***Check all that apply***

☐ pain control and symptom management
☐ physiotherapy
☐ occupational therapy
☐ alternative therapies acupuncture, aromatherapy, massage, reflexology etc..
☐ dietitian
☐ day hospice care
☐ respite care (relief care)
☐ bathing facilities (special lifts, whirl pool etc.)
☐ counseling
☐ spiritual care
☐ caregivers support group
☐ bereavement support/follow up
☐ recreation program
☐ education palliative care, bereavement, treatment options, end of life care etc..
☐ 24 hour help line
☐ place for loved ones to stay over night
☐ volunteer services
☐ transportation
☐ other
***please specify***____________________________________

13. Is there anything that would prevent you from supporting the concept of a hospice if one was made available in Kings County?

☐ yes
☐ no

Please explain. ***Please print***

____________________________________________

____________________________________________

____________________________________________

14. If there is anything further that you would like to comment on about a hospice in Kings County or this questionnaire, please indicate. ***Please print***

____________________________________________

____________________________________________

____________________________________________

**Section C:**

15. Indicate your gender.

☐ female
☐ male

16. Indicate your age.

☐ less than 19 years old
☐ 20-29 years old
☐ 30-39 years old
☐ 40-49 years old
☐ 50-59 years old
☐ 60-69 years old
☐ 70-79 years old
☐ 80-89 years old
☐ 90-99 years old
☐ more than 100 years old
☐ *wish not to disclose*

17. What was your last completed year of formal education?

- ☐ elementary
- ☐ high school
- ☐ trade school
- ☐ community college
- ☐ university
- ☐ graduate studies
- ☐ other please specify____________________

18. Which category best describes you?

- ☐ individual with life-threatening illnesses

- ☐ family, friend, or significant other of someone who *is* dying
  *please indicate your relation* ____________________

- ☐ family, friend, or significant other of someone who *has* died
  *please indicate your relation* ____________________

- ☐ formal care provider {such as, physician, nurse, LPN, alternative health practitioner, clergy, care coordinator, and home support worker}
  *please indicate* ____________________

- ☐ informal care provider {such as, volunteer, support group participant}
  *please indicate* ____________________

- ☐ other *please indicate* ____________________

**Thank you for your participation.**
**Your effort is greatly appreciated.**

**If you have any questions or concerns,**
**please feel free to contact Alison Bursey at 542-1521**

## *Appendix 2*

## Canadian Palliative Care Association Principles of Palliative Care

### 1. *Meet Physical, Psychological, Social and Spiritual Expectations/Needs*

Care is directed towards meeting the physical, psychological, social, and spiritual expectations/needs of the patient and family with sensitivity to their personal, cultural and religious values, beliefs, and practices.

### 2. *Access*

Patients and families have timely access to information and the services provided by palliative care when they need and are prepared to accept them.

Information and services are provided in a language that they can understand.

Essential palliative care services are available 24 hours a day, 7 days a week.

### 3. *Equal Availability without Discrimination*

Palliative care services are equally available to all regardless of their age, gender, national and ethnic origin, geographical locations, race, color, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, family status.

### 4. *Ethics*

The ethical principles of autonomy, beneficence, non-maleficent, justice, truth telling and confidentiality are integrated into the provision of care and program development.

### 5. *Right to Information*

It is the patient's right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options.

It is the family's, caregiver's and service provider's right to be informed about the disease, potential treatments and outcomes, appropriate resources and options, respecting the patient's right to confidentiality.

### 6. *Right to Choice/Empowerment*

Decisions are made by the patient and family in collaboration with the caregivers and service providers, respecting the level of participation desired by the patient and family.

The patient's and family's choices for care, setting of care and information sharing are respected.

### 7. *Unit of Care*

The unit of care is the patient and family.

### 8. *Interdisciplinary Team*

Care is provided by an interdisciplinary team of caregivers and service providers working collaboratively with the patient and family.

### 9. *Continuity of Care*

A coordinated, continuous plan of care, which minimizes duplication, is maintained across all settings of care from admission of the patient, to bereavement support of the family.

### 10. *Community Collaboration Through Partnerships and Mutual Support*

The palliative care needs of a community can only be met through the collaborative efforts of available services in partnership at patient care and programmatic levels.

### 11. *Governance and Administration*

Governance and administration are essential to support the program and ensure accountability. Broad based governance includes community representatives, caregivers, service providers, patients, and families.

### 12. *Quality of Care*

Care is delivered by all service providers within professionally accepted standards of conduct and practice.

### 13. *Program Evaluation*

Program evaluation is essential to the delivery of quality palliative care and to the maintenance of standards of conduct and practice.

### 14. *Education, Information, Research and Advocacy for Palliative Care*

Education, information, research and advocacy for the development and maintenance of public policy, palliative care standards and resources are essential to improve the delivery of palliative care (CPCA 1995:43).

## *Appendix 3*

## Inventory of Services, Programs, Supplies and Equipment For Palliative Care Clients

1. In patient health care facility
2. Pain and symptom control
3. Emergency care
4. Help line (24 hours a day)
5. Nursing service
6. Dietitian
7. Swallowing disorders therapy
8. Enteral feeding
9. Enterostomal therapy -ostomy teaching, problem solving
10. Physiotherapy
11. Occupational therapy
12. Speech - language therapy
13. Oxygen and respiratory home care
14. Counseling
15. Alternative therapies -acupuncture, massage, aromatherapy, etc.
16. Foot care
17. Blood collection
18. Specimen collection
19. Medical equipment rental
20. Medical equipment loan
21. Supplementary foods
22. Meals
23. Special medical supplies, pads, dressing, etc.

## *Appendix 3 continued*

24. Breast prosthesis
25. Vascular compression garments, extremity pumps and accessories, socks, turbans, etc.
26. Information/educational resources
27. Special Workshops -coping with chemotherapy and radiation side effect, or wound and skin care
28. Home support service -light house keeping, personal care, meal preparation
29. Respite care
30. Support groups -Living With Cancer, Reach For Recovery, Valley AIDS Concern Group
31. Supportive one-on-one visiting--volunteers
32. Bereavement support
33. Transportation -volunteer
34. Financial assistance

## *Appendix 4*

## Service Agencies, Associations and Businesses Providing Support to Palliative Care Clients

1. *Berwick Physiotherapy Clinic*
2. *Canadian Cancer Society*
3. *Canadian Red Cross Society*
4. *CareForce Homecare Services*
5. *Community Services, Wolfville*
6. *Evangeline Nursing Home Care Nursing Services*
7. *Eastern Kings Memorial Health Centre*
8. *Home Care Nova Scotia*
9. *Kings County Social Services*
10. *Kings Physiotherapy Clinic*
11. *Kings Rehabilitation Centre*
12. *Life Line Oxygen & Medical Supplies*
13. *Mid-Valley Palliative Care*
14. *P.E.P Program (VON Volunteer Services)*
15. *Pharmacies across the county*
16. *Royal Canadian Legion*
17. *Senior Citizens Secretariat*
18. *Valley AIDS Concern Group*
19. *Valley Physiotherapy Clinic*
20. *Valley Regional Hospital*
21. *Veterans Independence Program*
22. *VON, Kings Branch*
23. *Western Kings Memorial Health Centre*

## *Appendix 5*

## Palliative Care Advisory Committee Members

Brenda Allen

Dr. Jeanette A. Auger

Alison Bursey

Nancy Chipman

Angela Fraser

Pat Weber Gibson

Gail Gordon

Dr. Roger Hamilton

Dr. Susan Hergett

Jennifer Longley

Mary McMahon

Jane Mc Phee

Fran Nichols

Liz Porter

Valerie Randall

Sue Smiley

Diane Tedford-Litle

Rev Boyd Vincent

Linda Ward

## *Appendix 6*

Dear Past Recipient of VON Care

The VON, Kings Branch is engaged in a study to investigate the need for a hospice in Kings County. We have defined ***hospice*** as a facility which:

- Provides palliative care to dying persons. ***Palliative Care*** is the active care of persons at a time when their disease is no longer responsive to curative treatment. It is a holistic approach to care providing physical, emotional, social, spiritual and informational supports to help improve the quality of a person's remaining life, and recognizes the patient and family/friends as the main decision makers.
- Provides respite care for the dying persons
- Provides information for formal and informal caregivers
- Coordinates bereavement support groups
- Trains people to provide care to the dying persons

We have reviewed our files and have drawn up a list of persons who have recently lost a loved one. Your name was on this list. Would you kindly consider becoming a participant in this study

A set of questions has been designed to gather information about your experiences and opinions of end of life care in Kings County. It is hoped that your responses will provide an overview of the needs of the dying and those who care for them.

Although participation in this study is voluntary and you may decline to participate by ignoring this mailing, we hope you will participate to help create a representative sampling of end of life care issues in Kings County.

If you choose to participate in this needs assessment, any information you provide will be kept strictly confidential. Please fill out the attached consent form and mail or return to the VON office in Wolfville by ***date 1997***. If you have any questions or concerns regarding any part of this research project, feel free to contact Brenda Allen, VON, P.E.P coordinator, or myself at 678-1534.

Thank you for giving this request your serious consideration.

Alison Bursey

## *Appendix 7*

### Consent Form

**Study Title:** *Mind, Body, and Soul: Exploring The Need For A Hospice In Kings County*

I agree to participate in this study. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

I know that my participation in this study is strictly voluntary. I know that I have the right to withdraw at any time and that the care of myself or family/friends and my relationship with the health care team will not be affected.

I understand that identifying the needs of the dying might cause some anxiety and/or fatigue. I realize that the study will take approximately 20 minutes to an hour of my time and will involve either a questionnaire by mail or a personal interview.

**Please check the box to indicate you preference.**

☐ ***questionnaire by mail***
☐ ***personal interview***

____________________________________________________

Date Name please print

____________________________________________________

Address please print

_________________________

Telephone number

* ***Please mail response by July 27, 1997***

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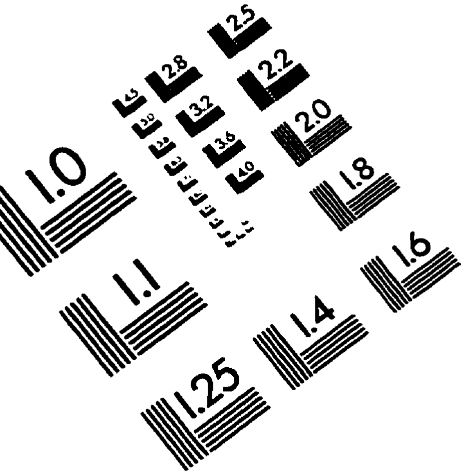

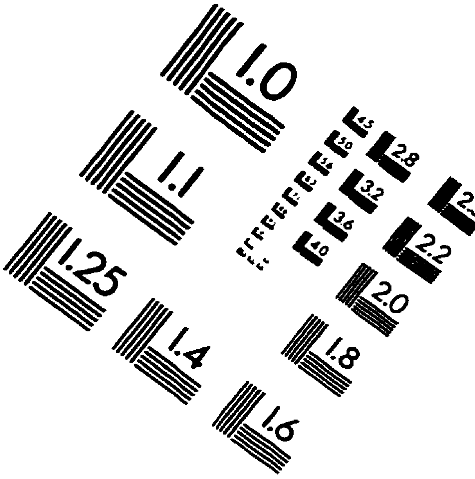

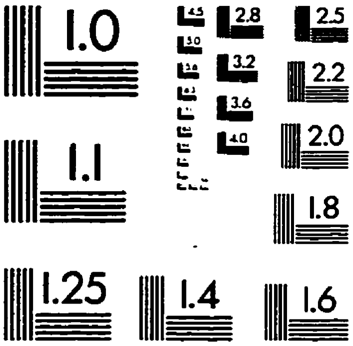

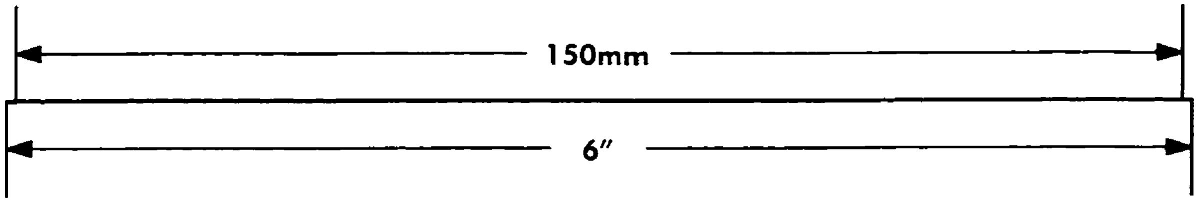

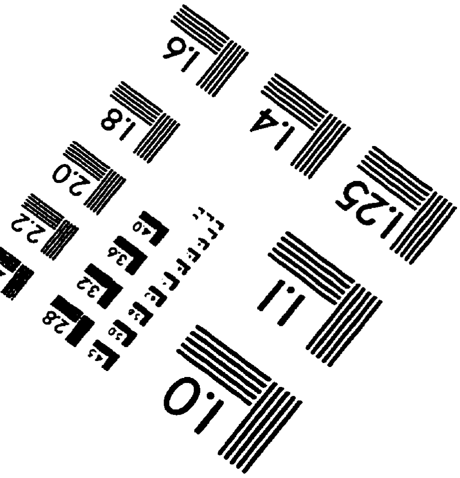

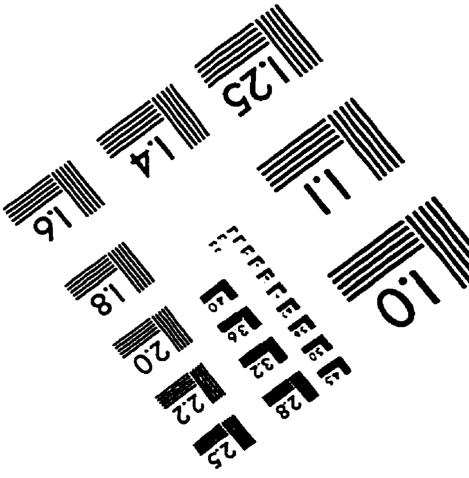

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