HOME CARE NURSES' CONTRIBUTION TO THE INTEGRATION OF PALLIATIVE CARE SERVICES

by

Mary Theresa Frances Legault

B.Sc.N., University of Ottawa, Ontario 1975
M.S., D'Youville College, Buffalo, New York 1990

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Department of School of Nursing

The University of British Columbia
Vancouver, Canada

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Abstract

The purpose of this study was to explore and interpret the contribution of nurses in the development and provision of integrated palliative care services for diverse populations. This issue has emerged as a relevant policy challenge. Many researchers and policy makers have recognized barriers to access and gaps in the utilization of services. The specific elements of quality palliative care in the home are not well understood. Ethical issues are challenging for nurses and families. Another major gap was to determine appropriate services to meet the care requirements for marginalized populations. Ethnographic approaches are ideally suited to the study of health services, such as palliative home care, to develop a narrative description and analysis of the experiences of a particular group of people, as well as events, and trends. In total, there were 52 participants including home care clients, their family members, home care and shift care nurses, clinical nurse specialists, nursing administrators, and a hospice physician. Data collection methods included participant observation, fieldnotes, interviews, and documentary review during fieldwork that occurred over a two-year period.

Findings of this study are organized into three major themes that emerged from the data. The first was that home care nurses made valuable contributions to quality of life and quality of palliative care through coordination and integration of services amidst the complexities and challenges of the health care system. The second theme illustrated dramatic differences in quality of life and quality of care for mainstream and marginalized populations as reflected in the client and family experiences, nursing practice, and program models of care. Critical tensions within the health care system
comprised the third theme, which showed that current programs are unable to keep pace with the rising expectations and demands for services.

By examining these findings in the context of the existing empirical and theoretical literature, several issues became evident. The nature of palliative care is dynamic and changing. Within the mainstream context, programs must be responsive to specific needs of extended segments of the population including people with long-term and chronic illness, the elderly, and cultural minorities. For marginalized people, the challenge will be to provide specialized services based on the principles of harm reduction for primary care, crisis care, hospice care, and long term care. The complexity of home care nursing practice is reflected in the multiple dimensions of personal qualities and competencies required for providing quality palliative care and coordinating and integrating services. A vision of integration for community-based palliative care services entails the development of regional networks that address the needs of diverse populations and ensure accountability for resources and quality of care, within the framework of national initiatives for the reform of health care and social policies. Building family and community capacity and strengthening the ability of home care nurses to contribute their knowledge and expertise will ensure future development and integration of quality palliative care services. These challenges are consistent with the need to continually renew and adapt all aspects of the health care system to address the changing nature of society and its evolving health concerns through public participation and active involvement of nurses.
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Dedication

This research is dedicated in memory of my father-in-law

PETER JAMES OSBORNE

who lived his dying with incredible persistence

and in joy of being with family.
Definition of Terms

The terms palliative care, hospice care, and end-of-life care are often used interchangeably in the literature, yet the meanings vary depending on the country of origin and the health care system. In addition, palliative care nurses work with people in a variety of settings including: acute care institutions, in general or specialized palliative care units; homes; intermediate and residential care facilities; and in community hospices. Their roles vary by regional and provincial jurisdictions. The following definitions will clarify the meaning of the terms used in this research.

End-of-life Care

In the literature to date, end-of-life care usually relates to care of people who are imminently dying and as a component of palliative care. Because of the long association of palliative care primarily with cancer, the Canadian Senate committee prefers the term end-of-life care, which extends to all end-of-life situations. They define end-of-life care as including pain and symptom control, appropriate use of life-sustaining treatments, and support for clients and families (Carstairs, 2000).

Home Care Nurse

In Vancouver, community health nurses are employed by the regional Vancouver/Richmond Health Board and work either in prevention (with a focus on health promotion) or home care. They are primarily baccalaureate prepared. Home care nurses provide acute and long-term nursing care to people in their homes. For many nurses, palliative care is a large component of their general nursing practice. In each community health area, there are some home care nurses with advanced palliative care experience who take on the role of hospice resource nurses, which is referred to as an enhanced generalist model.
Home Support Worker
Home support workers are employed by private agencies and contracted through the Home Hospice Program to provide various services such as cooking, laundry, and basic care for specified periods of time. Their experience and training varies considerably.

Hospice Nurse
Hospice nurses are registered nurses who work with individuals and families in a community-based hospice setting.

Integration
Integration of palliative care services can be described as a coordinated, planned community based program of care for people living with a life-threatening illness that is provided by a collaborative, interdisciplinary team to ensure continuity across the continuum of care throughout all care settings. The overall integration of health care services is the responsibility of the regional health authority.

Palliative Care
Palliative care is a combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. The continuum of palliative care may encompass the time from symptom development and diagnosis, throughout the illness experience to dying, death, and bereavement. Palliative care may be combined with therapies aimed at reducing or curing illness, or it may be the total focus of care and is primarily directed towards improving quality of life (Ferris & Cummings, 1995; Hanson, 1995).
Shift Care Nurse

Shift care nurses are registered nurses who provide continuous palliative care to individuals and families in their home throughout the day and night during eight or twelve hour shifts. In other areas, they may be referred to as home hospice nurses. Although their primary responsibility is for end-of-life care, the nurses may also be requested for short-term client assessment and symptom management, or for respite. They are employed by the Vancouver/Richmond Health Board through the Home Hospice Program and requests for services are usually made by the home care nurse or family physician. Nurses experienced in palliative care may also be contracted from private agencies for shift care work.
CHAPTER 1
CONTEXT OF THE RESEARCH

Policy Framework

We don’t have a strong public health care system in this country because of politicians. We have it because the public demands it, and nurses have been the enablers of public opinion.
(Ginette Lemire Rodger, 2000, p.240)

The International Perspective

The World Health Organization (WHO) in the Alma Ata Declaration proclaimed primary health care as the strategy for achieving "Health for All by the Year 2000" (WHO, 1978). The approved definition from the 1978 WHO conference is:

... essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self reliance and self determination... It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work and constitutes the first element of a continuing health care process (WHO, 1978, p.21).

The basis for international reform in health care policy stems from this philosophy of primary health care. In 1985, the World Health Organization (WHO) officially recognized the role of nurses in the implementation of primary health care. The following year, WHO sponsored an international conference on nursing leadership in Health for All. WHO’s member states were encouraged to work closely with the nursing profession in the planning, implementation and evaluation of primary health care (Rodger & Gallagher, 1995).
The Canadian Perspective

The health care system throughout Canada is in transition with the most significant trend being the shift to community based health care. The intent of the current health care reforms is to preserve the existing structure of our publicly financed health care system (Medicare) through more efficient and effective management. All provinces in Canada have fully participated in Medicare since 1971. During this time there was a proliferation of hospitals and medical school admissions. In retrospect, Rachlis and Kushner (1989) advised that "we might have ended up with a more balanced system had we covered community nursing care first, then built the system 'from the ground up'" (p. 17). By the late 1970's, access to health care was threatened with the widespread practice of hospital user fees and physician extra-billing. The federal government's response was to pass the Canada Health Act (1984) which reinforced the five principles upon which Medicare had been founded: comprehensiveness (the provision of medically necessary services inside or outside of hospitals); universality of coverage (services for all people); portability (interprovincial coverage); accessibility (reasonable access of services under uniform terms and conditions); and public administration (provincial accountability) (Rachlis & Kushner, 1994). Each province varies in interpreting these principles, accounting for major differences in health care policies throughout the country. However, adherence to the basic principles remains mandatory in order for the provinces to receive federal transfer payments. It remains to be seen how the provinces will interpret these principles with the signing of a new federal provincial Agreement on Health Services (Canadian Intergovernmental Conference Secretariat, 2000).

Lobbying efforts of the Canadian Nurses Association (CNA) in their 1980 report Putting Health into Health Care were considered in the amendment to the Canada Health Act. Unfortunately the CNA was not successful lobbying for inclusion in the Canada Health Act of coverage for preventative care, community clinics, home care, and the right
for nurse practitioners to bill for service (Rodger, 2000). In the following years, the CNA developed a five-year plan to guide the implementation of Canadian nursing primary health care strategies, and was committed to the co-ordination and support of provincial nursing association primary health care activities (Rodger & Gallagher, 1995). The CNA remains an active contributor in Canadian health and social policy and an ongoing proponent of a national home care program (CNA, 2000).

The British Columbia Response

From 1990 to 1994 the Registered Nurses Association of British Columbia (RNABC) operated its New Directions for Health Care program to influence change in health care policy from a nursing perspective and to advocate for a health care system based on the principles of primary health care (RNABC, 1994a). In fact, the title of this program was adopted by the government.

The principles of the Canada Health Act and primary health care have been upheld in the process of health care reform in B.C. The Closer to Home report in 1991 resulted from an extensive 20-month public review of health care conducted by the Royal Commission on Health Care and Costs. The findings described the health care system as one of the best, but major concerns were expressed over inequalities in health and access to health care throughout the province. Also lacking were an overall plan and system for evaluation (Royal Commission on Health Care and Costs, 1991).

Recommendations from the Closer to Home report included that communities be empowered to: determine their own health care needs; allow decision-making closer to home; allow for people to be cared for in their home; and access health care services at an institution as close to home as possible. The response of the Ministry of Health was a plan for health care reform, titled New Directions for a Healthy British Columbia (British Columbia Ministry of Health & Ministry Responsible for Seniors, 1993). The plan
outlined five strategies for the development of effective and efficient community-based health care delivery: better health, greater public participation, services closer to home, support for formal and informal caregivers, and effective management. Health care services were decentralized with the formation of 11 Regional Health Boards and 34 Community Health Councils. The boards are comprised of public representatives and are responsible for the development of health care priorities and, since 1997, the disbursement of funds in their designated regions.

Nurses comprise the largest number of health care professionals in Canada. Their practice is directly affected by health care reform and restructuring, and although they are in a pivotal position to influence decision-making in health policy, they have traditionally had little voice in the process. Nurses have been upheld as the key to health reform (Rachlis & Kushner, 1994) because they have a long tradition in advocacy for those receiving health care and are committed to quality care. Nurses are skilled in congregate decision making and are well suited to non-hierarchical leadership in the pluralistic sector of the health care system (Warkentin & Butler, 1993). Because health care decision-making has become more collaborative, the expertise of nurses is recognized as a valuable asset to interdisciplinary teams. Because nurses are involved daily with clients and families in varied settings, they facilitate public participation, especially of those in marginalized populations.

Nurses in British Columbia have identified four guiding principles for coordination and integration of health care: multidisciplinary approaches to care; consideration of the social determinants of health; a focus on health promotion and illness prevention; and a focus on the needs of people, families, and communities (Legault, 1994). These principles mirror major health challenges for British Columbia as outlined in the provincial health officer’s report to maintain and improve the health of British Columbians by supporting quality of life and minimizing inequalities in health status (Millar, 1997). Home care nurses work more autonomously than nurses in institutional
settings and often take the lead in coordinating the client's care within an interdisciplinary team. As primary health care workers, the contribution of these nurses is highly respected by families, physicians, and other health care professionals.

**Palliative Care**

Nationally, 75% of all deaths still take place in hospitals and long term care facilities. Only about 5% of Canadians receive integrated and interdisciplinary palliative care. Although one-quarter of total deaths in Canada are related to cancer, people with cancer account for 90% of those receiving palliative care (Carstairs, 2000).

Palliative care has been designated as a core service in British Columbia and continuity of care is a guiding principle, regardless of setting. Health authorities are expected to provide an integrated network of palliative care services to clients and their families across a continuum of care (Carstairs, 2000).

In Vancouver, palliative care service delivery has become a significant concern for health care providers as people and families experience gaps in services in trying to balance their care in hospital and at home. Further development of integrated palliative care services is a priority for hospital and community services due to costs for providing institutional care. To support quality of life for clients and families assuming a greater responsibility for palliative care and wishing to remain at home as long as possible, continuity of care is essential.

To explicate the contribution of home care nurses in this changing health care system, one can examine the development of palliative care services. Care for the dying is increasingly becoming a nursing responsibility. Nurses have the greatest and most prolonged contact with the dying in institutional settings. Support available from community nursing services is key to the choice of place of care for patients and families (Corner, 1993).
With the ongoing trend of hospital bed closures and shorter length of stay resulting in limited access to acute care beds, home care nurses are experiencing the impact of caring for an increasing number of people who die at home. In some Vancouver communities, up to 43% of people receiving palliative care are supported in a home death. The largest number of people requiring palliative care have cancer; the second largest group have AIDS; and the remaining people suffer from chronic illnesses such as congestive heart failure, respiratory disease, amyotrophic lateral sclerosis (ALS), multiple sclerosis, and Alzheimer’s disease.

Demands on palliative care services will continue to increase over the next decade due to an increase in persons living with advanced cancer, especially within the 60-79 year old age group, and increasing prevalence of persons living with HIV/AIDS in Vancouver. As persons with end-stage cardiovascular, respiratory, and chronic illness are generally older, the gradual aging pattern will increase referrals to palliative care services (Vancouver/Richmond Health Board, 2000).

Economic factors continue to drive palliative care programs. Up to 77% of health care dollars are spent in the last six months of life on heroic medical interventions, making palliative care programs a cost-effective alternative (Health & Welfare Canada, 1990). Unfortunately, palliative care programs rely disproportionately on charitable donations and most of the costs and other burdens of home care are assumed by families (Carstairs, 2000).

Theoretical Framework

Health policy refers to courses of action that affect institutions, organizations, services, and funding arrangements that we call the health care system. Although health policy has distinctive features, it also overlaps with social policy and economic policy
Thus, the theoretical framework includes perspectives from nursing theory, social theory, and policy process.

Theoretical underpinnings reflect the researcher's values and beliefs, add strength and clarity to the study when made explicit, and guide the development of the research questions, method, and data analysis. Theoretical assumptions for this study are derived from three theories: Parse's Theory of Human Becoming (1981, 1998); an ecologic framework for community health and empowerment (Eng, Salmon, & Mullan, 1992); and the Advocacy Coalition Framework for policy process (Sabatier & Jenkins-Smith, 1993). These perspectives inform and build upon one another and contribute to the conceptual framework of a partnership model.

**Theory of Human Becoming**

Nursing theories have developed from various perspectives to address relationships among four concepts: person, health, environment, and nursing. Selected major theories have focused on phenomena related to interpersonal relationships (Peplau, 1952); needs (Henderson, 1966); energy fields (Rogers, 1970); self-care (Orem, 1971); systems (Neuman, 1974); adaptation (Roy, 1976); human becoming (Parse, 1981); cultural care (Leininger, 1985); and caring (Watson, 1985). Nursing practice has been defined in terms of a problem-solving process that involves assessment, nursing diagnosis, planning, implementation, and evaluation. The goal is to change or control the person's behaviours or environmental factors, thereby returning the person to a state of well being called health.

Parse's Theory of Human Becoming (1981) recognizes people as knowledgeable about their own health and able to make decisions about their own care. A human science theory of nursing, it describes the person as a freely choosing unitary being who lives according to value priorities, which over time comprise their quality of life. Humans and
the universe are co-created as rhythmical patterns; health is defined subjectively as human becoming. People are the experts of their own lives and give personal meanings to their lived experiences. The nurse is guided by their choices, hopes, and dreams. Nursing practice focuses on quality of life from the person’s and family’s perspectives (Parse, 1981, 1992, 1995, 1998).

Parse defined community as a oneness of human connectedness and an ever-changing process. She affirmed that the individual is community, the family is community, the group is community, and the world is community. All people are health care recipients and community members (Parse, 1999).

The tenets of the theory are congruent with the living-dying process and the philosophy of palliative care which honors person-focused, family-centered care, and the right of people to participate in health care decisions that affect their quality of life (Lee & Pilkington, 1999; Mount Sinai Hospital/Casey Hospice House, 1995). The Theory of Human Becoming offers an identity for nurses and carves out their unique contribution to the health care system.

**Ecological Perspective**

Community-based nurses view health broadly, as including both social and environmental determinants. This link between organisms and their environment provides a framework to enhance health through social change in communities (Eng et al., 1992). Health is recognized as a common social good and a resource for a sustainable society (Kickbusch, 1989).

Within this framework, community health is defined as *community competence*. Social change is effected by community control over the following parameters: definitions of health include a social analysis; strengths are assessed instead of weaknesses; goals are described in terms of community health outcomes; interventions
are organized around human rather than disease categories; and people's motives are elicted (Eng et al., 1992). Community competence operates through collective mediation to enable helping systems such as families, neighbourhoods, and organizations, to manage relations with the larger society and institutions. Levels of change include: perceptions and behaviours of individuals; social support functions and social networks; and services and policies of institutions. Multiple levels of intervention are required for building community competence and improving health.

Several strategies for health care professionals working within this framework are relevant for community health nurses. First, the community must be given serious consideration in relation to people's health. Secondly, health care professionals need to develop a passionate involvement, which reflects a merging of vision, power, and concerns with community members. Third, informal and non-traditional caregivers must be included as part of the health care team. Fourth, education of health care professionals in community work is essential. Finally, institutions can belong to the community by incorporating community members at all levels of decision-making and action (Eng et al., 1992). Congruent with Parse's Theory of Human Becoming, this framework views people as experts in their own lives, but incorporates also a broader community experience.

Advocacy Coalition Framework

Traditional models for policy process were similar to the problem-solving method of the nursing process and included the following stages: problem identification, agenda setting, adoption, implementation, and policy evaluation. Despite the conceptual strengths and broad acceptance of these models, limitations have been identified as to their usefulness as a basis for research. Such linear models did not account for deviations from the sequential stages in practice or consider that policy evolution often involved
multiple cycles. For example, the top-down approach tended to neglect other important players such as the public (Sabatier & Jenkins-Smith, 1993).

The *Advocacy Coalition Framework* for policy change was proposed by Sabatier and Jenkins-Smith (1993) as an alternative to the traditional policy process. According to this model, policy change over time is a function of three processes. The first process is the interaction of competing advocacy coalitions within a policy subsystem. An advocacy coalition is comprised of people from public and private institutions who share a set of basic beliefs and who seek to influence the government's rules, budgets, and personnel to achieve their goals over time. The British Columbia Hospice & Palliative Care Association and the Canadian Palliative Care Association are advocacy coalitions which strive to promote awareness and funding for palliative care programs in regional, provincial, and federal governments. Since the introduction of block funding for health and social programs, these groups have been competing with other advocacy groups not only in the health care system, but also in the education and social services sectors. The second process in this framework is the identification of changes external to the subsystem including socioeconomic conditions and the influence of other government sectors that provide obstacles or opportunities to the competing coalitions. An example would be the increased awareness for palliative care following *The Special Senate Committee on Euthanasia and Assisted Suicide* (Neiman, 1995). Thirdly, one needs to examine the effects of stable system parameters, such as social structure and constitutional rules, on the constraints and resources of the health care system. This would relate to the principles of the Canada Health Act which are constantly being challenged.
Partnership Model

The following partnership model evolved from the above theories related to nursing, community competence, and the policy process. This model was developed as a conceptual framework to guide this study. The three interconnecting circles depict the nurse, clients and families, and other health care providers. Relationships are found in the intersections between each group. The centre of the circle represents a complex network

Figure 1

Partnership Model for Primary Health Care
of key players in an ideal system of primary health care wherein the nurse, clients and families, and other health care providers are active participants in health care decisions and in accessing available resources. The middle circle denotes the community context, defined as an interactive network of families, neighbourhoods, organizations, and institutions, the health of which is directly related to the health of its members (Eng et al., 1992). The outer circle represents the broad scope and influence of provincial and federal ministries of health.

Theoretical assumptions derived from this partnership model include:

1. Nurses develop therapeutic relationships with people and families and play a major role in the delivery of health care services.
2. Nurses also have a significant role in collaboration with interdisciplinary and intersectoral teams for the development of health care policy.
3. Clients and families have a right to be active participants in health care decisions and to choose care that is appropriate for their condition and considerate of their family's involvement.
4. The community's health is related to the health of individuals and families.
5. The health care system has a responsibility to provide equitable and accessible care for people of all ages, cultures, and economic status.

Strong partnerships are required to achieve an integrated and seamless system of health care within institutions and across the public and private sectors. Palliative care provides an excellent perspective from which to study this broader picture. Palliative care is an important part of the home care nurse's role. The palliative care team is comprised of a wide representation of health care professionals and community members. Provincial and national palliative care organizations are well established. Palliative care professionals are committed to honoring the wishes and changing needs of the person and
family. End-of-life care affects persons of varying ages, cultures, and socioeconomic status.

**Summary**

Nursing leaders have been instrumental in promoting primary health care as the basis for health reform. The implementation of regionalization continues to have an impact on health care in British Columbia. Nurses are active partners with clients and families and other health care professionals to meet provincial health goals. Nurses know the gaps in service and support the principles of health care reform. The nurse works closely and in partnership with clients and families. A partnership model for primary health care based on nursing theory, social theory, and policy process will provide the guiding framework to explore and interpret the contributions of nurses in the provision of quality palliative care and the integration of palliative care services.
CHAPTER 2
HISTORICAL BACKGROUND AND CURRENT STATUS OF PALLIATIVE CARE

A literature review of the current status of palliative care follows and includes: the changing role of community health nurses based on primary health care principles; trends in palliative care; and issues related to the integration of palliative care services, including utilization of services, economic considerations, and continuity of care.

The Role of Community Health Nurses

Community health nurses, with their community care orientation, have been leaders in social and health reform. In a comprehensive review of community health nursing in Canada, Rodger & Gallagher (1995, 2000) reported that, with the domination of health care by acute care institutions during the 1970's and 1980's, nursing practice and education became extensions of the medical model with a curative focus on disease. Community health nursing has since shifted from the medical model to a primary health care model for practice, education, and research, with the hope that community health nurses can reclaim their legacy and enhance nursing practice.

Primary Health Care

Following the leadership of the World Health Organization (1978), the International Council of Nurses (1988), and the Canadian Nurses Association (1988), the RNABC (1994b) embraced the principles of primary health care in planning and future development of health care in British Columbia. Primary health care strives to ensure a continuum of care that reflects active involvement and ownership of the communities in which it is practiced (Eng et al., 1992). The five principles of primary health care are: accessibility to health and health care; participation of individuals and communities;
interdisciplinary and intersectoral collaboration; health promotion and illness prevention; and the appropriate use of technology (RNABC, 1994b). The role of nurses in health care reform in British Columbia will be described in accordance with these principles and within the context of palliative care.

Accessibility

Home care, I believe, will rise as promise achieved or fall as promise deceived depending largely on whether or not it occurs in homes that the world has passed by. (Roy, 1998b, p. 3)

Accessibility to health and health care implies a continuing and organized system of health and social services available to all people with no financial, geographical, or cultural barriers. Inequalities in health status and in access to health care services are serious concerns in British Columbia (Royal Commission on Health Care and Costs, 1991). Significant disparities exist throughout the province, with low income and disempowered groups having a poorer health status. This situation is prevalent in rural communities as well as within the six community health areas of Vancouver. According to a report of the provincial health officer, the regions with the best social and economic status had the best health (Millar, 1997). This finding is reflected in the inequitable distribution of palliative care services. The greatest number of planned home deaths occurs in the most affluent communities, while marginalized populations rely primarily on institutional care (Robens-Paradise, Cardiff, Fryer, & LeMire, 1997).

Marginalization refers to the process through which persons are peripheralized based on their identities, associations, experiences and environments. In this research, marginalized population will refer to individuals living on the margins of society. Margins are defined as the boundary-determining aspects of persons, social networks, and communities (Hall, Stevens, & Meleis, 1994).
Another report by the B.C. Ministry of Health and Ministry Responsible for Seniors (1995) identified groups in society that have poorer health or barriers to required health care. These groups are referred to as designated populations and include children and youth, seniors, women, aboriginal people, members of ethnocultural groups, people with mental disorders, and people with disabilities. Minority cultures and groups often have distinctive beliefs and less powerful social positions leading to the problems these sub-groups and health professionals have in devising mutually satisfactory health care (Waxler-Morrison, Anderson, & Richardson, 1990). From a nursing perspective, the determinants of health in these designated populations must have priority over the increasing demands for health care services.

Most palliative care studies have dealt with individuals who live in homes with family support and who have access to palliative care services. What about the marginalized groups in society? Based on experience with people living with HIV/AIDS, Johnson (1995) challenged us to apply our theories of family care and support to family units that are transient, living in chaos, and often suspicious of health care professionals. He stated that it is insufficient to translate institutional experience with palliative care to the context of community because of divergent points of view on quality of life by health care professionals and by clients and families.

Smith (1994) also expressed concern for the lack of palliative care services for poor people with AIDS, such as street people, sex-trade workers, and drug users. In a Toronto study of 70 people with AIDS from varying backgrounds, Smith showed that the poor were unconnected to family and/or community and relied heavily on professional caregivers, receiving notably fewer hours of care. In contrast, middle class people developed relatively extensive community networks. Smith (1994) commented that "established systems of palliative care frequently count on middle-class support networks to be in place, both in terms of finding a place to die and of actually delivering palliative..."
The Toronto situation is comparable to the lack of palliative care services for marginalized populations in Vancouver’s Downtown Eastside.

Public participation

The goal of greater participation by individuals and communities in the health care system is to "ensure that health needs and services are more closely matched" (B.C. Ministry of Health & Ministry Responsible for Seniors, 1993, p.13). People have the right and the responsibility for the decision-making and care of their individual health and that of their community (RNABC, 1994a). Two Closer to Home initiatives evolved from this principle: the formation of Regional Health Boards and Community Health Councils for the local management of health care services and the provision of more services in people's homes, local communities, and regional areas.

Of concern to nurses in the regionalization process has been the exclusion of health care professionals from membership on the Regional Health Boards and Community Health Councils. Nurses throughout the province were actively involved in the development of the interim structures, but are now limited to advisory roles.

Examples of public participation and community organization in palliative care are the British Columbia Hospice and Palliative Care Association (BCHPCA) and community-based AIDS service organizations. The BCHPCA was incorporated in 1985 as a formal provincial association and is comprised of community volunteers and health care professionals from nine regional hospice groups in BC (BCHPCA, 1994). By contrast, the community-based AIDS service organizations were comprised of volunteers, mostly gay men, with few health care professionals (Johnson, 1995). Services were funded by the government and provided exclusively to members of the gay community. Smith (1994) was concerned that middle class gay people with AIDS could count upon relatively extensive community networks compared to limited community support for
drug users, homeless people, or poor gay men. Once again, marginalized groups are limited in participating in mainstream organizations.

**Interdisciplinary and intersectoral collaboration**

Intersectoral collaboration is a strategy for addressing environmental, economic, and social determinants of health. The control and dominance of health care by physicians has limited the involvement of other health care professionals and those outside the health sector. Another barrier is the public's view of health as the control of disease by medical care. Marmor, Barer, and Evans (1994) noted that, despite nearly two decades of efforts to redirect health policy away from curative medicine to more fundamental interventions, the task remains largely undone.

Interdisciplinary collaboration requires health care professionals to shift from independent to interdependent roles, mutual respect for others, and shared leadership to face changing patterns of health care needs and public expectations (Stewart & Langille, 1995). Home care nurses try to generate and foster collaborative partnerships between hospital and community health care providers. A decrease in health care dollars has heightened the competition for research funding and program initiatives, which can either inhibit collaboration or promote partnerships to share scarce resources.

**Health promotion**

Health promotion, as defined by the Ottawa Charter (Epp, 1986), enables individuals and communities to increase control over and to improve their health. The underlying principles include addressing the broad determinants of health; effective public participation; combining diverse but complimentary approaches; and appropriate utilization of health care professionals (WHO, 1986).
To facilitate empowerment of people toward greater participation in their own care, health care services must be offered in ways that respect autonomy, are culturally sensitive, and reflect understanding of the broader context of the individual and community experience (Labonte, 1993). Health care professionals must switch from a provider to a partnership role with people and communities. A focus on strengths and assets rather than needs and deficiencies is congruent with a partnership model for primary health care (Eng et al., 1992) and developing community capacity, especially in low-income neighbourhoods (McKnight & Kretzmann, 1992). This perspective of health promotion is applicable to palliative care as people and families struggle to maintain control over their lives and their care while relating to health care providers. Conditions which rob people of control in their lives increase distress (Redding, 2000).

Appropriate technology

Technological care consumes a large portion of the health care budget and does not always have a useful outcome (Rachlis & Kushner, 1994). From a holistic perspective, nurses advocate that technological innovations be subordinate to quality of life from the perspective of the person and family. In palliative care settings, nurses can challenge unnecessary technological care and to support people's decisions to refuse treatment that is medically futile.

The British Columbia Ministry of Health (1993) has stipulated that resource allocation be based on quality, appropriateness, effectiveness, equity, and affordability. Increasing spending for treatment-based medical care and research can divert finances away from community-based health care services, such as hospice, and social programs, such as low-income housing.

Based on a survey of activities in which Canadian community health nurses were planning to promote and implement the principles of primary health care, the areas of
greatest emphasis were in accessibility, public participation, health promotion, and interdisciplinary collaboration. Continuing challenges are to increase intersectoral collaboration and to advocate for appropriate use of technology (Rodger & Gallagher, 1995, 2000).

Harm Reduction

Primary health care is reflected in the philosophy and principles of harm reduction which guide the practice of home care nurses working with marginalized populations (McAmmond, 1998). This approach minimizes harm from substance use and endeavours to improve quality of life from the perspective of the person. Appropriate care is creative and flexible to ensure access to the full range of health care and social services. Health promotion is different than in the traditional approach. For example, safer drug use is encouraged to decrease infection and the transmission of AIDS and hepatitis, rather than limiting drug use. In contrast to standard anti-smoking health promotion programs, nurses often provide cigarettes to encourage client participation and promote a less harmful addiction (Griffiths, 1996; Robb, 1995). Public participation and interdisciplinary and intersectoral collaboration are essential to ensure that health care and social services match the needs of the individual. A set of principles combining key harm reduction and palliative care principles has been developed to care for injection drug users living with HIV/AIDS (McAmmond, 1998).
Trends in Palliative Care

Dying with dignity comes through dying without pain, alert, and with your emotional and spiritual needs supported by people who will walk the journey with you. (Ley & van Bommell, 1994, p.68).

History

Palliative care can be traced to the United Kingdom in the 1970s, with expansion of palliative care programs to Europe and North America during the 1970s and 1980s. The original programs were based outside of mainstream health care and focused on adequate patient and family treatment and teaching. The growth of palliative care as a discipline has increased awareness beyond service and teaching to include an emphasis on administration and research (Bruera, 1994).

Today's challenge is to integrate the principles of palliative care throughout the existing health care system. A comprehensive palliative care program includes interdisciplinary care; relaxation of bureaucratic regulations; a focus on the important issues of patients and families; the maintenance of hope; conservative investigations; and the integration of complex therapies in the home (MacDonald, 1991).

Theoretical Models of Care

Early definitions of palliative care were developed by health professionals who were caring for people with cancer and described as "services intended to improve the quality of life for the terminally ill, generally in the last six months of life" (Health & Welfare Canada, 1990, p. 27). Palliative care has now become a major industry due to an aging population with greater incidence of cancer and a growing resistance to life-prolonging medical treatment.

An early theoretical model of palliative care encompassed a defined period of active aggressive treatment after diagnosis, followed by a terminal phase of supportive
and palliative care, death, and bereavement (see Figure 2). A reconceptualization of palliative care was based on the experiences of persons living with HIV/AIDS and addressed the balance between active treatment and supportive care. The divisions fluctuate between curative/aggressive treatment and supportive/palliative care as shown in Figure 3 (Foley, Flannery, Graydon, Flintoft, & Cook, 1995). In these models, death and bereavement were not considered as palliative care.

Figure 2. Palliative Care (Cancer Model)

Figure 3. Palliative Care (AIDS Model)

From these earlier conceptualizations, the Canadian Palliative Care Association developed a comprehensive model incorporating the continuum of palliative care as illustrated in Figure 4 (Ferris & Cummings, 1995).

Figure 4. The Continuum of Palliative Care

Palliative care is now more broadly defined as a philosophy of care, and as the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with life threatening illness. 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. 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 (Ferris & Cummings, 1995).
In accordance with the new definition, the Canadian Palliative Care Association has developed a set of 14 palliative care principles: meet physical, psychological, social, and spiritual expectations and needs; ensure access and equal availability without discrimination; ethics; right to information, choice, and empowerment; client and family as the unit of care; interdisciplinary team; continuity and quality of care; community collaboration; broad based governance and administrative support; program evaluation; and education, information, research, and advocacy for palliative care. These principles serve as a basis for the development of practice and program standards.

Experience from an integrated palliative care unit at St. Paul's Hospital in Vancouver has shown that the parameters of care for people with AIDS apply also to people with cancer. With advances in treatment, some cancers are becoming more like chronic illnesses with episodes of wellness and recurrence. This pattern occurs also for people living with HIV/AIDS, as life expectancy has dramatically increased. The ethical and treatment issues are similar for both groups (Fraser, 1995).

At the same time, there are unique features of palliative care for people with HIV/AIDS. The average person with AIDS in Canada is 30 to 35 years of age, has few financial resources, insufficient preparation for a debilitating aging process, and little social support. The fastest growing groups of persons infected with HIV in the 1990's were heterosexual women and their children. In 1997, 50% of new AIDS cases were attributed to gay men (a decline from 80% in the 1980's) and 20% to injection drug use, (an increase from 5% in 1993) (Health Canada, 1999). Stigmatization of the AIDS population remains a barrier to accessing effective care and treatment. The illness trajectory includes depression and mood disorders; polypharmacy and drug side effects; multisystems disease; chronic infections; dementia; and multiple losses (Foley et al., 1995). In addition, treatments such as blood transfusions, total parenteral nutrition, and intravenous therapies are often given to maintain quality of life. It is difficult to predict
death and the dying process can be lengthy. Most people living with AIDS know more about their disease and its treatments than their care providers and demand involvement in their care. Homelessness, inadequate housing, and the need for long term care for people with disabilities are increasing (Nicholson & Turner, 2000).

Developing creative and flexible models of community-based care has been proposed to meet the challenges of palliative care in the future. Such programs would include enhanced home care, community hospice, day care, and partnerships with community hospitals and agencies.

Ethical Issues

Discussions about ethics are guided by the principles of autonomy, beneficence, and justice. Autonomy refers to self-determination, personal liberty, and freedom of choice. Beneficence ensures that any decision is in the best interests of the person. Justice relates to the overall question of fairness and equitable distribution of scarce resources. In palliative care, the trend is away from an ethic of prolonging life at all costs, and toward an ethic that emphasizes quality of life and dying (Carstairs, 2000).

Roy (1994) distinguished between clinical ethics within palliative care and the ethic within which palliative care operates. Clinical ethics within palliative care relates to decisions required of and for the dying, their families, and the health care professionals who work with them. The ethic within which palliative care operates specifies the vision, values, and mission that are a measure of humanity. Roy (1997) described the philosophy of palliative care as a "heightening of humanism towards the dying" (p. 3).

Literature on clinical ethics relates to care and comfort, consent and communication, and prolongation or termination of life (Wilkinson, 1993). Palliative care research related to the rights of individuals and families within the health care system is uncovering ethical concerns resulting form the medicalization of death and dying.
Gregory and English (1994) challenged the myth that health care professionals must medically control human suffering. They stated that the quest to control suffering transforms a profoundly complex human experience into a physical condition amenable to treatment. The endurance of suffering is possible within the perspective of palliative care, which is to embrace the suffering of others and accompany them on their journey. "Understanding, empathy, and compassion are offered as alternatives to control" (p. 18).

The challenging question remains: "Will increased longevity bring enhanced quality of life, or greater and longer suffering? Enhanced quality of life may not come from new medication or technology but from a new way of sharing and relating to each other" (Foley et al., 1995, p. 22).

Rodney (1994) called for "a shared sense of moral community between ourselves as health care professionals and those whom we serve" (p. 42) in dealing with complex issues associated with life-prolonging treatments in acute care settings. This prolongation of death has led to controversial issues of euthanasia, physician-assisted suicide, and advance directives. The Canadian Nurses Association (1994) policy on advance directives stated that all persons have the right to make decisions regarding their health care and treatment including the right to refuse life-sustaining treatment. All those involved in health care have a duty to uphold the client's right to self-determination. Ley and van Bommell (1994) described euthanasia as "a desperate response to an intolerable situation" and believed that "palliative care is not a response to euthanasia. Palliative care and euthanasia are responses to health care systems that do not meet the needs of people who are dying" (p. 67). In the Canadian Senate report on euthanasia and assisted suicide, Neiman (1995) wrote that the debate with respect to how we die cannot be limited to a discussion regarding assisted suicide and euthanasia alone, as many people are more fearful of the process of dying than of death itself. Other considerations that were explored in detail included: the availability and quality of palliative care, pain control and
sedation practices; withholding and withdrawing life-sustaining treatment; and advance directives.

A landmark study in the United States involved over 9,000 adults in hospital with life-threatening illnesses (Greipp, 1996). The purposes were to improve end-of-life decision-making and reduce the frequency of painful and prolonged treatment patterns prior to death. The intervention was an education program by specialized nurses to assist patients, families, physicians, and hospital staff to elicit client preferences, improve understanding of outcomes and pain control, and facilitate advanced care planning through client-physician communication. Unfortunately, there was little or no improvement in the study outcomes. The findings suggest that people at the end-of-life are given few choices and when they are, their decisions are often ignored. Greipp (1996) called for support and utilization of hospice care and for more aggressive and creative means of dealing with the unethical practices in care of the dying.

With respect to the ethics of palliative care, Roy (1995a) cautioned that with fiscal restraints, health care resources might be triaged so that those who are dying receive last priority for care. He reminded us that an economy is for a society, not vice-versa, and that the health care system exists for the sick and the dying. Rodney (1994) also cautioned that patient best interest, rather than economic costs, must drive decisions to withhold or withdraw life-prolonging treatment.

Research Priorities

The majority of nursing research in palliative care during the 1970's and 1980's has focused on: 1) the attitudes and experiences of nurses caring for the dying; and 2) communication with patients, families, and other health care professionals. Most of the
research took place in institutional settings and was related to people with cancer (Wilson-Barnett & Richardson, 1993).

A report of the directions for palliative care nursing in Canada demonstrated a shift in research priorities (Kristjanson & Balneaves, 1995). Nurses are adopting the standard principles of practice developed by the Canadian Palliative Care Association (Ferris & Cummings, 1995). Although there have been tremendous advances in issues such as pain and symptom management, research is moving toward exploring the concepts of total pain and suffering. Coordination of palliative care services is becoming prioritized during this time of health care reform. The context of care has shifted from the hospital to the home setting. Research with vulnerable groups is a priority for the provision of equitable and accessible palliative care services (Kristjanson & Balneaves, 1995).

Most research on death at home focuses on people with cancer. Other studies have related to place of death, retrospective patterns of usage of home palliative care services, and demographic characteristics of clients receiving home care. Perceptions of home care providers and the needs of home hospice families have been studied extensively. Qualitative research is required to gain the perspectives of clients and families, especially those in socially marginalized groups. In addition, studies that evaluate the outcomes of palliative care at home would provide direction for service provision. The social context of death at home warrants research to better understand the renewed interest in home death, changing family structures, and the influence of assisted suicide (Stajduhar & Davies, 1998).

The Canadian Senate has recently proposed research priorities for end-of-life care, including measures of appropriate and cost-effective health care services and analysis of demographic, geographic and cultural variables. Recommendations include that the Canadian Institutes of Health Research be encouraged to establish an institute that focuses on end-of-life care; the Canadian Institute for Health Information develop
indicators for quality end-of-life care; and the federal Minister of Health coordinate and implement a multi-dimensional agenda for end-of-life research that involves relevant departments, agencies, and other levels of government (Carstairs, 2000).

**Palliative Care Education**

The palliative care education literature reveals recent strides in the awareness for and development of programs for nurses, physicians, and allied health professionals. Integration of current programs, multi-institutional collaborative projects, and interdisciplinary programs are being developed. Few initiatives have been reported in relation to education for family caregivers and the general public.

In the past, palliative care education has emphasized death and dying rather than the broader perspective of quality of life (Corner, 1993). A survey of physicians and nurses in four hospitals was conducted by the Greater Victoria Hospital Society Palliative Care Committee to assess palliative care educational needs (Samaroo, 1996). The nurses' priorities were emotional support and family care; symptom control; staff education and communication; and ethical decision making related to resuscitation and euthanasia. Pain and symptom control were the physicians' priorities. Findings of this study highlight the concern of nurses with the broader scope of palliative care.

Inadequate basic and continuing education in palliative care have been cited as obstacles to family physician involvement in care of the dying at home. Consequently, there is a need to educate family physicians in the standards of modern palliative care (Brenneis & Bruera, 1998). In Ontario, the Ministry of Health has allocated funds to support creative, collaborative interdisciplinary palliative care educational programs. Education for family physicians, especially from rural and remote areas was one priority (Hall, Hospé, & Scott, 1998). At the Ottawa Institute of Palliative Care, the coordinators for family physician education, and nurses and allied health education have merged their
educational mandates to develop three 30-hour interdisciplinary advanced education programs (Bouvette & Weaver, 1999). There has also been a fellowship in palliative medicine since 1990 (Viola, Chater, Seely, & Scott, 1999).

More globally, physicians in Australia have developed a competency-based program for general practitioners to become palliative care physician specialists and consultants to their colleagues (Yuen, Barrington, Headford, McNulty, & Smith, 1998). A collaborative program for physician education has been established between the University of Arizona and community hospices (Bishop, Gores, Stempel, Torrington, Tynan, Jaskar, & Garewal, 2000).

Better palliative care education for physicians is expected to lead to a reduction in the utilization of expensive investigational procedures that do not procure any changes in treatment or in the natural process of the disease; reduction in the utilization of expensive, ineffective, and sometimes harmful treatments; and improvement in the support given to clients and caregivers (Shvartzman, & Singer, 1998).

In the United States, nurse researchers at the City of Hope National Medical Center are involved in a study to strengthen nursing education to improve end-of-life care. In reviewing nursing textbooks, it was found that only 2% of overall content related to end-of-life care. Other strategies are to improve end-of-life content in the nursing licensing exams and support nursing organizations to improve end-of-life education for nurses (Ferrell & Virani, 2000).

In Edmonton, a multi-institutional collaborative project is developing and assessing web-based palliative care programs including an online multimedia information bank for educators, an educational support network for rurally-based physicians and nurses, and an online interdisciplinary course (Peden, 1999).

Palliative care courses are offered in nursing programs at some colleges in Vancouver and in the baccalaureate nursing programs at the University of British Columbia and the University of Victoria. The Department of Family Practice at the
University of British Columbia has established an interdisciplinary Division of Palliative Care to further practice, education, and research in palliative care. The Vancouver Palliative Care Coordinating Group provides ongoing educational opportunities for the general public and for health care professionals. Such events have included regular public forums and celebrations of life, an educational campaign targeted at family physicians and oncologists to promote referrals to community-based services, and palliative care research dinner presentations. Members of the Vancouver Home Hospice Program provide regular interdisciplinary basic and advanced educational programs in palliative care.

Integration of Palliative Care Services

Organizational models of palliative care throughout the world are relatively new (post 1980) and increasingly complex (Ford, 1993). The trend in Canada is to develop a comprehensive network of services between institutional and community settings, including partners such as hospital palliative care units, home care, intermediate and extended care facilities, private hospice facilities, volunteer hospice organizations, and social services.

The first palliative care programs in Canada emerged in the late 1970’s. In 1982, the Vancouver Home Hospice Program and the Vancouver General Hospital Palliative Care Unit were created as a joint initiative, one of the first provincially-funded programs. The Vancouver Palliative Care Coordinating Group was formed in 1988 to provide an advisory forum for the planning, coordinating, and development of palliative care services (V/RHB, 2000). Service enhancements to the Home Hospice Program were created in 1995 through Closer to Home funds. The goals of the program are to:

1. provide people with a terminal illness the choice of receiving care at home up to and possibly including the time of death
2. offer support to families during the person's illness and during their bereavement
3. promote the appropriate use of acute care hospital resources (Robens-Paradise et al., 1997).

Integration of palliative care services can be explored by examining issues related to utilization of services, economic considerations, and continuity of care.

**Utilization of services**

Utilization analysis of the Vancouver Home Hospice Program indicated that for individuals whose location at time of death was an acute care hospital, length of stay has been steadily declining since 1990. There was an increase in the number of people who died within 48 hours of admission. These observations could be due to bed closures and high occupancy rates, but could also mean that people stay home as long as possible with home care support or that they have had no support at all, as in the case of marginalized populations. The utilization-related goals of the Home Hospice Program are outlined in Figure 5. In this evaluation, most people and families viewed the home as the preferred place to die as long as pain was controlled and required support was available. The program encourages palliative care at home for as long as possible, but seeks to give people the opportunity to die in their location of choice. On average, only 20% of deaths occur at home. At times, the needs of palliative care clients are greater than can be provided at home. If a hospice bed is not available, the only option is admission to hospital, and hopefully in a palliative care unit. In contrast, people living in the Downtown Eastside of Vancouver, the poorest neighbourhood, have longer-than-average hospital stays before death with a trend for increasing length of stay over the past few years (Robens-Paradise, et al., 1997).

A retrospective analysis of administrative data of all the deaths in Vancouver from 1990 to 1993 in adults over 16 years of age with cancer or AIDS, the purposes of a
Figure 1. Continuum of Care for the Terminally-Ill

Legend
- Main careflow targeted by program
- General careflow
- Rare careflow

second utilization study were to: a) determine the proportion of terminally ill patients who accessed palliative care services prior to death; b) document trends in the location of death; and c) determine if a relationship existed between access to palliative care services and location of death (Cardiff, Hsu, & Kuhl, 1998). By 1993, approximately 77% of Vancouver residents who died of cancer or AIDS had had some contact with palliative care services. Unfortunately, this study was unable to quantify the length of contact with the palliative care service, the timing of the contact in relation to the date of death, or the qualitative aspects of the services, all key considerations.

Thirty to fifty percent of patients admitted to hospital for palliative care were not connected to the Home Hospice Program. By 1993, about 30% of deaths were at home. There was a higher probability of home death for clients with cancer who were referred to the Home Hospice Program, but not for people with AIDS, suggesting different patterns of dying and health care and social factors. Although 50% of people who received palliative care services died from diseases other than cancer and AIDS, 90% of patients in palliative care units had cancer or AIDS. Further research must determine if the palliative care requirements of people with life-threatening illnesses other than cancer and AIDS are being met.

**Economic Considerations**

In an international study of palliative care services, Ford (1993) reported that lack of sufficient resources and facilities was the greatest difficulty, especially where funding was available only for parts of a program. In Canada, it appears that the greatest handicaps to palliative care at home are limited home support and health care funding.
Funding for 24-hour home care for prolonged periods of time may be the only way to assure a home death. Despite the need, economic constraints make this option inaccessible in many communities (Fainsinger, Demoissac, Cole, Mead-Wood, & Lee, 2000). An effective and efficient integrated palliative home care program can reduce the cost of care of the dying in the short term and reduce the need for hospital beds in the long term (Morch, Timka, & Granerus, 1999). Unfortunately, monetary rather than rational medical and ethical principles are dictating the agenda for health care reform (Dossetor & MacDonald, 1994).

A review of literature on costs of palliative care revealed the following: a) costs of end-of-life care can be considerable, depending on the model of care; b) costs of care increase with distance from home; c) family expenses are substantial and not considered in most cost-analysis studies; d) families with higher incomes can afford more services to support a home death; and f) some treatments given to dying people are costly and are medically futile. The current state of palliative care in Canada is far from optimal as only a minority of Canadians have access to comprehensive palliative care services (Chochinov & Kristjanson, 1998).

Findings of the Vancouver evaluation suggest that, in economic terms, location of death is not as important as the length of stay of terminal hospitalization. Providing community-based services to clients until the time of death is less costly than providing a combination of home care and acute care services. To be cost neutral, the average length of hospital stay should be six days. The report concluded that "the potential for cost savings would only be realized if there is a concurrent shift in the resources from the acute hospital sector to the community sector" (Robens-Paradise, et al., 1997).
Continuity of care

The goal of an integrated palliative care program is not only to provide quality

care at the end of life but to ensure that there is ongoing communication among all

members of the health care team and the person and family throughout the continuum of
care which encompasses treatment, palliative care, and bereavement. This is an ongoing
challenge for the home care nurse as the respective roles of family physicians and
specialists are unclear. Often a person is discharged from hospital when "nothing more
can be done" and no referral is made to home care or the family physician is not prepared
to assume the responsibility for care at home. In the Vancouver study, two-thirds of
referrals to the Home Hospice Program came from hospital-based home care liaison
nurses and many of the physician referrals came too late. MacDonald (1993) has insisted
that cancer centres must prioritize palliative care and ensure effective links with
specialized palliative care programs. Another problem is that family physicians tend to
refer people first to the hospital rather than the palliative home care program (Robens-
Paradise, et al., 1997).

Issues related to utilization of services, economic factors, and continuity of care
raise the question of "the place in the system" for palliative care. To gain recognition for
palliative care in the health care system, many health care professionals have advocated
that it become a specialty practice. By doing so, it is hoped that resources for practice,
education, and research can be secured. This would lead to the development of standards
of practice and accreditation of programs which will have direct bearing on quality of
care (Ford, 1993). Some community-based programs prefer to remain autonomous,
affiliated with, but outside of the acute care system.
Gaps

Recurring themes in the literature and current issues in palliative care point to three gaps in knowledge and practice: caring for marginalized populations, responding to ethical issues, and developing flexible, comprehensive organizational models of care.

The most evident problem is how to provide palliative care services that are accessible and appropriate for marginalized populations. This has been identified by community health nurses (Johnson, 1995; Smith, 1994), policy makers (Millar, 1997), and in program evaluations (Robens-Paradise, et al., 1997). Lack of access to palliative care services has led to the emergence of the term "disadvantaged dying" (Corner, 1993). Home care nurses work extensively with people on the fringe of society, but the shortage of low-income housing, community-based health care, and hospice facilities leaves only the option palliative care in acute care settings. Nurses in the community are often the entry to the formal health care system for marginalized populations. This places community nurses in a prime position to be involved in the development of health care policies for this population.

The second gap in understanding ethical issues related to palliative care. Nurses develop close relationships with families at the end of life and observe how people integrate their experience of suffering. They are also involved in helping families with their mourning rituals and expression of grief in the loss of a loved one. For these reasons, nurses are often asked for ethical advice regarding withdrawal or refusal of treatment. In most instances patients are comforted with open communication, adequate palliative care, and symptom control.

A third consideration is how to support people’s choices in palliative care. Flexible organizational models for comprehensive, integrated palliative care services need to be developed so that resources are available in the home and in the acute care setting for treatment, respite, supportive, and end-of-life care. Home care nurses work
from a primary health care model and provide care in difficult circumstances. This knowledge and experience may help in further development of an integrated palliative care program.

Statement of the Problem

With changes in our health care system and an aging population, there is an increasing demand for home care nurses to provide palliative care. The actual and potential contributions of nurses need further exploration to address the gaps related to appropriate models of care for marginalized populations, ethical issues at the end of life, and the integration of palliative care services across the continuum of care.

Purpose

The purpose of this study is to explore and interpret the contribution of nurses in the development and provision of integrated palliative care services for diverse populations.

Research Questions

The following research questions will be addressed from the perspective of the participants.

1. What barriers do nurses and families identify to the access of palliative care services?
2. What gaps do nurses and families recognize in palliative care services in the hospital and community?
3. What are the attributes of quality palliative care?
4. How do nurses contribute to the quality of palliative care?
5. What ethical issues do nurses experience and how do they deal with them?
6. How do nurses contribute to the integration of palliative care services for people and families at home?

7. What more needs to be accomplished to develop an integrated system of palliative care?
CHAPTER 3
METHODOLOGY

Questions about health policy can be addressed at three levels of analysis or emphasis: micro, meso, and macro (Palmer & Short, 1989). At the micro-level the researcher attempts to explain how decisions are made or how particular organizations operate. At the meso-level, the focus is on ways in which the health care system converts demands into policy. At the macro-level, the existing health care system is critiqued and interpreted within its economic, sociopolitical, and cultural context. Using this approach, health policy analysis includes the study of the inputs to policy, the policy-making process, and the outcomes of policy. Utilization of this framework is supported in the analysis of the politics of nursing (Hewison, 1994). The research questions for this study are related to the micro-level of analysis, assuming that what occurs at the micro-level (in practice) will reflect the macro forces (within the health care system).

Ethnographic research is well suited to answering questions related to health policy. The scope of research can range from micro-ethnography to macro-ethnography (Spradley, 1980). This continuum corresponds with the micro, meso, and macro levels of policy analysis. A micro-ethnography might focus on a single social situation whereas a macro-ethnography would involve the study of a complex society consisting of numerous communities. Macro-ethnographies occur over many years and often involve numerous ethnographers. This study will focus on a single institution (the health care system) in a single community (Vancouver).
Ethnography

Ethnography has its roots in anthropology and was originally defined as the disciplined study and work of describing a culture, the aim of which was to understand the world from the participants' point of view. Ethnography is not studying about people, but rather learning from people. At the core of ethnography is concern for both the explicit and tacit meanings of actions and events to the people we seek to understand (Spradley, 1980; Wolcott, 1985).

Post-structuralist ethnography can be defined as an interpretive science in search of meaning. It differs radically from traditional ethnography (ethnoscience) that was not unlike experimental science in search of laws and causal explanations. Culture is described as a context and the task of ethnography goes beyond observation to a thick description of the meanings of human action (Geertz, 1983). Other substantial features of interpretive ethnography include an emphasis on exploring the nature of particular phenomena and a tendency to work with unstructured data (Atkinson & Hammersley, 1994).

Germain (1986) described ethnography as both a product and a process. As a product, ethnography is a narrative description and analysis of a particular group of people. As a process, the research method involves an extensive period of fieldwork consisting primarily of participant observation and intensive interviewing.

The research method of ethnography has seldom been made more explicit than by Spradley (1980). He described the steps in ethnographic research as a cyclic pattern rather than the traditional linear research process. The diagram in Figure 6 illustrates this ethnographic research cycle. The cycle begins with selection of a research project and determination of the scope of the investigation along the continuum of micro-ethnography to macro-ethnography. Broad descriptive questions are
Figure 6. The Ethnographic Research Cycle


asked at this point which will inform broad descriptive observations. Fieldnotes are recorded, and after analyzing the initial data, the research is narrowed by more focused questions and observations. Further analysis then leads to very selective research questions and observations. The research cycle is thus comprised of participant observation and recording fieldnotes, concurrent data analysis which leads to finding new ethnographic questions, more data collection, more fieldnotes, and more analysis. The final major task is writing the ethnographic account, which can still lead the researcher to
asking new questions and further data collection. For this reason, it is advisable to include the writing early in the research cycle.

In writing an ethnography, Geertz (1988) challenged ethnographers to convince the reader that they have not merely been there but that had we been there, we would have seen what they saw, felt what they felt, and concluded what they concluded. He described being here as the intellectual work of reflecting on the field, and the process of analysis and writing of the account. The ethnographic text is built upon concepts from the field and from theories and goes beyond description to the formulation of a theoretical explanation. The value of ethnography in nursing includes the pragmatic outcomes for both theory and practice (Boyle, 1994).

This study is a health science ethnography and can also be described as a focused ethnography, a time-limited exploratory study within a discrete community or organization (Boyle, 1994; Muecke, 1994). The process is guided by Spradley’s (1980) research method, and the product relates to the post-structuralist view with emphasis on the interpretation of cultural meaning. The culture in this study is that of home care nurses, clients, and families in relationships with one other and with the health care system in their experience of providing or receiving palliative care within community.

**Setting**

The Vancouver/Richmond Health Board was established in 1996. Boundaries divide the city of Vancouver into six geographic areas, each with a community health centre. The city of Richmond is the seventh area. This research was conducted throughout all six areas of Vancouver. Vancouver is very multicultural and includes one-third of the province's immigrants and refugees. There is great socio-economic diversity with the highest incomes in the west side and the lowest in the north and east sides of the city.
The primary setting for this research was in the homes of individuals and families affiliated with the Home Hospice Program of the Vancouver/Richmond Health Board. The Home Hospice Program is comprised of an interdisciplinary team of consultants who work primarily with home care nurses and family physicians. Members of the team include palliative care physicians, a clinical nurse specialist, a social worker, and a volunteer coordinator, supported by a program assistant. The team provides consultation, education, and standards for palliative care practice in the community. Additionally, the Home Hospice Program coordinates a shift care nursing program with palliative care nurses who provide 24-hour respite and end-of-life care at home and in residential care facilities. There is also a roster of palliative care physicians who are on-call 24 hours a day, seven days a week after hours when the regular Home Hospice Program physician is not available to provide support (Vancouver/Richmond Health Board, 2000).

Other research settings included two community hospices and a residence for people with HIV/AIDS. Focus groups and interviews with nurses were held at the community health centres and meetings of the Vancouver /Richmond Palliative Care Coordinating Group were attended at various hospitals and agencies throughout the region.

Participants

The first step in recruitment was to engage interested home care nurses. I visited individual health unit offices, spoke with the nursing administrators and staff about my study, and arranged for information sheets to be placed in the nurses’ mail slots. Upon advice from the nursing administrator, I followed up with a visit to various health units at the end of the afternoon when the home care nurses were available, invited them individually to participate, and I also asked if they were caring for clients and families who would be interested in talking to me. The nurses made arrangements to meet with me
at a time and place convenient for them and agreed to ask clients to participate in the interim. Once my research became known, it was easier to recruit more nurses, as there were often many nurses involved in the care of one family.

Individual and family participants at home were recruited upon recommendation from their home care nurses based on their ability and willingness to participate. In a few situations, it was apparent that the client was not able be involved in a study at this time in their life, either because they were too ill or they were not prepared to discuss palliative care. Participants from the residence and the hospice were referred in consultation with the nursing coordinators. In total, ten clients / residents and sixteen family members / friends agreed to be involved. They were visited by the researcher over a period from February 1998 to December 1999.

There were six female and four male client participants, ranging from 35 to 88 years old. Half were under 60 years of age and half were greater than 70 years. Seven people were living with cancer and the three youngest clients were living with AIDS. Six people died at home, one in residence, and one in hospice. The remaining two clients moved from the hospice to supported independent living because their health had stabilized. The man who had AIDS and was a drug addict has subsequently died in the palliative care unit. The clients lived throughout four of the six community health areas. They were all English speaking and of varied cultural heritage. Specific details are represented in Table 1 and summarized in Table 2.
Table 1. Profile of Client and Family Participants

<table>
<thead>
<tr>
<th>Client</th>
<th>Gender</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Family &amp; Friends</th>
<th>Place of Death</th>
<th>Home Visits</th>
<th>Duration (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>female</td>
<td>88</td>
<td>lung cancer</td>
<td>1</td>
<td>Home</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>male</td>
<td>59</td>
<td>prostate cancer, multifocal glioblastoma</td>
<td>3</td>
<td>Home</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>3</td>
<td>female</td>
<td>84</td>
<td>breast cancer, bone metastases</td>
<td>2</td>
<td>Home</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>female</td>
<td>79</td>
<td>lung cancer, stroke</td>
<td>1</td>
<td>Home</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>female</td>
<td>57</td>
<td>breast cancer, lymphoma, bone metastases</td>
<td>3</td>
<td>Home</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>female</td>
<td>77</td>
<td>lung cancer, brain metastases</td>
<td>4</td>
<td>Home</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>male</td>
<td>35</td>
<td>AIDS, MAC, PCP, IVDU</td>
<td>2</td>
<td>Residential care</td>
<td>1</td>
<td>.5</td>
</tr>
<tr>
<td>8</td>
<td>female</td>
<td>72</td>
<td>lung cancer, lymphoma</td>
<td></td>
<td>Hospice</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td>male</td>
<td>46</td>
<td>AIDS, dementia</td>
<td></td>
<td>* Living in residential care</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>male</td>
<td>51</td>
<td>AIDS, IVDU, hepatitis B&amp;C</td>
<td></td>
<td>PCU</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 2. Summary of Client and Family Participants

<table>
<thead>
<tr>
<th>Clients</th>
<th>Gender</th>
<th>Age Range</th>
<th>Diagnosis</th>
<th>Family &amp; Friends</th>
<th>Place of Death</th>
<th>Home Visits</th>
<th>Duration (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>6 female</td>
<td>35 - 88</td>
<td>7 cancer 3 AIDS</td>
<td>16</td>
<td>6: home, 1: residential care, 1: hospice, 1: PCU 1: still living</td>
<td>1 – 9 range</td>
<td>.5 – 9 range</td>
</tr>
<tr>
<td></td>
<td>4 male</td>
<td></td>
<td></td>
<td></td>
<td>4: mean 44: total</td>
<td>5: mean</td>
<td>24: total</td>
</tr>
</tbody>
</table>
Table 3. Profile of Nursing and Physician Participants

<table>
<thead>
<tr>
<th>Professional Title</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care nurse</td>
<td>14</td>
</tr>
<tr>
<td>Shift care nurse</td>
<td>5</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>3</td>
</tr>
<tr>
<td>Nursing Administrator</td>
<td>3</td>
</tr>
<tr>
<td>Hospice Physician</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 4. Summary of All Participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Number</th>
<th>Interviews</th>
<th>Focus Groups</th>
<th>Participant Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client &amp; Family</td>
<td>26</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>25</td>
<td>16</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>Hospice Physician</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>52</td>
<td>38</td>
<td>2</td>
<td>12</td>
</tr>
</tbody>
</table>

The nurse participants included fourteen home care nurses, five shift care nurses, three clinical nurse specialists, and three nursing administrators from the residence and hospice. Collectively, their practice was based throughout all six community health areas of Vancouver. All but one of the nurses had several years’ experience in palliative care. A hospice physician with the Home Hospice Program also participated (see Table 3). Members of the Vancouver Palliative Care Coordinating Group participated in an advisory role, in addition to some who agreed to be interviewed. Letters of support are in Appendix D. In summary, there were 52 participants: 26 client and family members, 25 nurses, and one hospice physician (see Table 4).
Data Collection

Paradoxical patterns of relationship with participants arose in reference to my roles as insider/outsider, nurse/researcher, and participant/observer. A paradox is seeming opposites that coexist as one rhythm, and although one dimension is usually more prominent, both sides of the rhythm emerge in relationship with others (Mitchell, 1993; Parse, 1981). Throughout this study, agency administrators, as well as the nurse and physician participants knew me as a former home care nurse, and therefore an insider in the health department. This was helpful in gaining entry as I was known and trusted by the key players. At the same time, as a researcher, I was viewed as an outsider. The purpose of my research was made explicit in information letters and consent forms and all involved knew that I had ethical approval for access to nurses, families, and information. Family participants also viewed me as a nurse, and again I emphasized that my role with them was foremost as a researcher and an observer, but that did not prevent me from participating in a nursing role at times as requested by the home care nurse or family.

Ethnographic methods included participant observation, fieldnotes, interviews, and documentary review during fieldwork that occurred over two years. The primary methods were participant observation and unstructured interviews to generate in-depth data with a select number of participants. There were a total of 38 interviews with all participants in addition to the two focus groups. I arranged 12 participant observational experiences with home care nurses and 44 independent home visits with clients and families.

In retrospect, there were actually three overlapping phases of data collection related to purposive sampling strategies, accessibility of participants, and concurrent analysis. Phase one involved participant observation and interviews with home care nurses and families in home settings. This was the most time-consuming period as I
visited families over several months until after the death and the bereavement interview. I
did not engage with more than two families at once due to time commitments and to
allow intervals for ongoing data transcription and analysis. To explore the experience of
palliative care for marginalized populations, I then proceeded to work with home care
nurses in the Downtown Eastside and visit the hospices and the Dr. Peter Centre (phase
two). Realizing that access to such a transient population would be difficult, I was
fortunate to engage participants living at a hospice and at the Dr. Peter Centre. These
were safe places to visit and I also recruited the nursing administrators as participants.
The third phase of data collection happened unexpectedly when I was invited to attend
two focus groups, one with hospice resource nurses and the hospice physician, and one
with shift care nurses. It was an excellent opportunity to learn about their issues, and to
ask focused research questions that had been generated from the analysis up to that point.

**Participant Observation**

The first distinct activity of the researcher, participant observation, involves
participating in the daily routines of the setting, developing ongoing relationships with
the people in it, and observing all the while what is going on (Emerson, Fretz, & Shaw,
1995). Participant observation is a mode of being-in-the-world characteristic of
ethnographic researchers (Atkinson & Hammersley, 1994).

The majority of the fieldwork in this study involved participant observation. This
method for research was appropriate for clients and families during a very emotional and
often chaotic time in their lives. On the first family visit, I was accompanied by the
primary home care nurse, with the intent of being introduced and observing the
interactions between the nurse and client. If clients and families were willing to
participate, I then followed up with visits on my own and communicated regularly with
the nurse by phone to inquire about the client and inform her of my observations. I found it natural and less disruptive to meet with clients and family members on more than one occasion before tape recording an interview. Establishing a trusting relationship ensured that the client and family understood my role and felt comfortable sharing their experiences with me. Primarily I observed the clients in their homes and their interactions with the family but I also obliged the participant’s request for information or care procedures. On two occasions, I took an active role to ensure that the family’s plans were met during times of crisis. In one situation, when the family was having serious concerns, I recommended that the home care nurse be replaced by a nurse with more palliative care experience. In the second situation, I supported the family’s plan for a home death when the home care nurse initially disagreed and supported her to arrange the appropriate resources.

When accompanying nurses during their home visits, I was very comfortable observing them and participating, if asked, to assist in the client’s care. We sometimes visited a number of clients and I traveled with the nurses in their car to maximize my time with them.

In addition, I collected data as a participant observer from September 1996 to June 2000 at monthly meetings of the regional interdisciplinary Vancouver/Richmond Palliative Care Coordinating Group which were held at various hospitals and community agencies in Vancouver.

Fieldnotes

The production of written accounts is the second distinct activity in ethnography. Fieldnotes describe experiences and observations the researcher has made during
participant observation (Emerson et al., 1995). Sanjek (1990) described these written accounts as headnotes (evolving analytic notes and memos); scratch notes (the first step); fieldnotes proper (chronological fieldwork notes); and fieldnote records (information organized separately in sets). In addition, the ethnographer's journal is a record of personal experience, reactions, and assessments of life and work in the field.

As most of the fieldwork in this study was comprised of participant observation, I recorded extensive fieldnotes, whenever possible, either during visits or immediately after. If pressed for time, I would audiotape record my observations and comments and expand on them later. Time was planned for daily processing of scratch notes to field notes and for the writing of headnotes and journal entries. I also kept a detailed calendar to track all research activities and contact information.

Interviews

Ethnographic interviewing focuses on the participant’s perspective in a firsthand encounter, thus eliciting the participant’s meanings for events and behaviours (Marshall & Rossman, 1995). Ethnographic interviews are ideally unstructured in that they are based on a clear plan in the researcher’s mind but are also characterized by a minimum of control over the participant's responses (Bernard, 1994). Informal semistructured interviews were arranged with clients and family members at their convenience and depending on the home situation at the time. I invited all family members who I knew and were involved in a home death to participate in a bereavement interview when they felt able. To my surprise, they all agreed and these were the most in-depth and informative interviews. They spoke freely about the entire home care experience for their
parent and for themselves. They shared detailed descriptions of the death at home and offered praise for what went well and expressed disappointment in the difficulties that were encountered.

Home care nurses were interviewed informally at times, such as in their cars while driving to and from visits, and then formally, either at the office at the end of their day or at their homes on a day off, if that was preferred. The nursing administrators and clinical nurse specialist were able to schedule an interview at their place of work. Focus group interviews were arranged with two groups, hospice resource nurses and shift care nurses, during their regularly scheduled meetings. I had not planned for focus groups, but took advantage of the opportunity when invited to participate by the clinical nurse specialists. All interviews were audiotape recorded and transcribed by a transcriptionist.

**Documentary Review**

Gathering documents in the course of everyday events is an unobtrusive research method to develop an understanding of the participants and setting (Marshall & Rossman, 1995). Historical and on-going government documents, agency policies and newsletters, evaluation reports, and media briefs that were relevant to health policy in general and palliative care in particular provided the context for the research and were also examined in relation to the issues raised by the nurses and families. Key portions of text were recorded to utilize as a reference point for interpretation of the observational and interview data. There were three major regional reports on palliative care services during the time of data collection.
Other significant data were obtained from the minutes of the Vancouver/Richmond Palliative Care Coordinating Group. Over the four years that I attended the meetings, there were major developments, most notably the planning and opening of a second hospice, and recently, the completion of the regional plan proposal. In addition, I had access to client records and charts that were reviewed for demographic data and I incorporated comments from letters that I received from family participants.

**Data Management**

In ethnographic research, an ongoing challenge is to keep the volume of data intact, complete, organized, and accessible. The data consisted of headnotes, fieldnotes, interview transcripts, documents, and the fieldwork journal and calendar. Additional family data included letters, photographs, and charts that were organized in separate folders by family number. Agency newsletters, media reports, and promotional material were also filed in folders by agency name. Written data records were filed in chronological order. A word processor was utilized for data storage, searching, and retrieval. Audiotapes and fieldnotes were transcribed by a transcriptionist after each interview and then stored on audiotape, floppy disc, hard drive, and in hard copy. As each interview transcript was coded, a summary of the main themes and significant quotations was compiled. A printed summary was attached to the front of the hard copy of each transcript that was then filed by participant number for accessibility throughout the analysis process. A detailed data file was established in the word processor and coded by participant number and date of entry. All original files were maintained intact, while each revision was dated to track the analysis process. As with other aspects of ethnographic research, recording, storing, and retrieving data are part of the reflexive process as decision making is monitored (Hammersley & Atkinson, 1995).
Data Analysis

Qualitative data analysis is the process of bringing order, structure, and meaning to the mass of collected data. Each phase of data analysis entails data reduction as the volume of data becomes manageable, and interpretation as the researcher brings meaning and insight to the experiences of the participants (Marshall & Rossman, 1995). In ethnography, analysis is an iterative process that permits descriptions and explanations to be developed from data which in turn guide subsequent data collection (Hammersley & Atkinson, 1995). This is congruent with Spradley’s (1980) research method and the development of thick description of ordinary events as described by Geertz (1983).

Analysis of fieldnotes, as well as interview and documentary transcripts, involved processing strategies of an inductive nature and constant comparative analysis (Lincoln & Guba, 1985). This approach is consistent with the meta-theoretical perspective of this study and involves inductive coding of units and categories with a simultaneous comparison of observations. Transcription and analysis of interviews and observations began during the first weeks of fieldwork. Preliminary data analysis occurred simultaneously with data collection and involved a cyclical process that directed the researcher to conduct more focused observations and interviews all the while noting theoretical observations and questions to project next steps in the constantly emerging design.

The interview and fieldnote transcripts were analyzed by coding segments of the text into units and the main ideas were then assigned to specific categories. As analysis proceeded, the reorganization of the data into categories provided an important infrastructure for later searching and retrieval. This was an ongoing circular process involving reading and rereading of the interview transcripts and fieldnotes concurrent with multiple layers of coding to develop themes, issues, and patterns and determining relationships between the findings. The identification of salient themes and patterns that
link people and settings together is the most intellectually challenging phase of data analysis and one that can integrate the entire endeavour (Marshall & Rossman, 1995).

The data were organized into a family data set and a nursing/physician/agency data set. For example, all the interviews, fieldnotes, and documents related to a particular client and family were analyzed and summarized. The data from the summaries of all families were merged while comparing and contrasting the themes, issues, and patterns. The same process was followed for the second data set. These themes were verified with participants in two focus groups in the final phase of data collection. Summaries of the themes from both data sets were compiled and organized for a final intensive interpretive analysis and synthesis that provided the basis for writing the ethnographic account. The data were developed into an analytic structure and further refined into meaningful descriptions having significance to related theory and concepts as well as the research questions. Conclusions became explicit through increasing analysis grounded in and verified by the data. The data analysis process was discussed, on an ongoing basis, with dissertation committee members and consultants who are experts in palliative care.

**Ethical Considerations**

There were generic and situation-specific ethical considerations (Marshall & Rossman, 1995). Generic ethical approval was granted from the University of British Columbia and the Vancouver Health Board research departments. Recruitment of voluntary health care professional participants was initiated by the researcher. Participants were provided with a letter explaining the nature, method, and purpose of the study and asked to sign a consent form (see Appendix B). They were free to withdraw from the study at any time. Confidentiality of names was maintained in written materials and in presentations. A written summary report of the research will be offered to all participants.
People in palliative care are highly vulnerable. Their rights of informed consent, freedom to withdraw, and voluntary participation require particular attention and ongoing monitoring. In addition, caregiver and researcher roles should be separate in order to eliminate pressures to participate. In this study, I was clearly identified as the researcher and I referred any client and family concerns to the primary nurse. In palliative care, the ethical quality of research lies in the relationship between the researcher and the participant rather than in the expected results (Kristjanson, Hanson, & Balneaves, 1994).

Situation-specific ethical issues can be described within an ecological framework (Flinders, 1992). The standards of informed consent, avoidance of harm, and confidentiality take on a broader scope in ecological ethics that emphasizes the interdependent nature of relationships, striving to situate moral decisions within their broadest possible context. Informed consent goes beyond collaboration to include cultural awareness. Avoidance of harm, wrong, or imposition is expanded to include avoidance of self-interest and the recognition of the participant as part of a larger system. The third consideration of confidentiality includes responsive communication in making public what has been learned about the lives of the participants. I felt a strong moral obligation to represent the views of the participants, especially the nine people who have died. This ecological viewpoint is in accordance with Bruera's (1994) insistence that palliative care research must provide meaningful answers to relevant questions for a vulnerable population.

Awareness of reciprocity issues is also an ethical responsibility for qualitative researchers (Marshall & Rossman, 1995). Especially in palliative care research, client and family participants generously share their privacy and time to be observed and interviewed during a difficult time in their life. In recognition of this, I helped out with basic care, answered questions, and contacted other health care providers as requested. Acting on behalf of participants while collecting data can give the ethnographer firsthand knowledge of their day-to-day experiences (Lipson, 1994). I attended two memorial
services upon invitation from family members. I graciously accepted tea and small gifts to respect cultural traditions. Thoughtful gestures such as bringing flowers from my garden during visits were greatly appreciated by clients and families. This giving back was also helpful in building trust and maintaining access.

**Adequacy of the Inquiry**

A number of methods and criteria have been proposed for establishing the trustworthiness or soundness of qualitative research. Furthermore, the researcher must demonstrate the usefulness of the research in relation to the conceptual framework and the research questions (Angen, 2000; Marshall & Rossman, 1995). Qualities of interpretive researchers ideally include excellent interpersonal skills, resilience, patience, and persistence in the face of ambiguity and slow progress, and versatility, flexibility, and meticulousness in carrying out the details of the project. A passionate involvement in the topic of study, moral integrity, and being a creative and persuasive writer will all enable the researcher to create a valid interpretation. To be consistent with the research design and the analysis process, the trustworthiness of this research will be discussed in terms of Mueke’s (1994) evaluation for health science ethnographies and the four constructs: credibility, transferability, dependability, and confirmability as proposed by Lincoln & Guba (1985).

*Credibility* refers to the synchronicity between the constructed realities of participants and the reconstructions attributed to them by the researcher. Techniques for increasing credibility include prolonged engagement and persistent observation. Because of the unpredictable nature of palliative care, I engaged with participants over several months to obtain a comprehensive account of their experience as well as follow through
my commitment as a researcher. Mueke (1994) recommended that there is a sufficient period of time allotted for fieldwork to ensure the development of trust between the researcher and participants and that the researcher has sufficient personal involvement to experience the insight and competence for data analysis and interpretation.

**Transferability** relates to the application of the study findings to other contexts. This can be accomplished through thick description, which means providing as complete a database as is possible, and through theoretical sampling. Multiple sources of data were collected including participant observations, interviews, focus groups, as well as chart review and documentary review to elicit divergent accounts of the palliative care experience. Diversity of client and family participants was planned in collaboration with the home care nurses to represent a broad perspective related to illness, socioeconomic situation, family experiences, and place of death. What is most important is that the participants are studied in their natural environment. Throughout this research, the fieldwork occurred in the participants’ place of work or residence. The value of the study is greater with the researcher’s exposure to a variety of situations (Mueke, 1994).

**Dependability** refers to the tracking of changes and shifts in the ongoing interpretation of the data and depends upon careful documentation of the analysis process. The research design evolved with increasingly refined understanding of the setting. Accounting for these changing conditions was accomplished through keeping a detailed, comprehensive, reflexive journal and recording analytical and procedural notes simultaneously throughout the process of analysis.

**Confirmability** assures that the data, interpretations, and findings are rooted in contexts and persons apart from the researcher. Confirmability is accomplished by
tracking the data to their sources and making explicit the logic underlying the interpretations throughout the writing of the ethnographic account. Preselection of research questions must not compromise the inductive nature of health science ethnographies (Mueke, 1994). Although the semi-structured interviews in this study were based on the research questions, the process was open and participants were encouraged to share whatever was on their mind at that point in time. In addition, the initial process of analysis was an inductive approach of contrast and comparison, and identification of patterns in the narrative. Ethnography has a reflexive character in that the researcher is inherently part of and affected by the field of study. All description, understanding, and explanation are based upon the knowledge of the participants and the knowledge of the researcher. Thus ethnography is produced from the reflexivity of the ethnographic experience and depends on the intersubjective creation of meaning and understanding (Angen, 2000).

In summary, this study is a focused ethnography guided by Spradley’s (1980) research method to explore the contribution of home care nurses to the integration of palliative care services. Settings were within diverse communities in Vancouver and participants included home care nurses, clients, families, and a hospice physician. Participant observation was the primary data collection method, in addition to interviews and documentary review. The data were organized and developed inductively into an analytic structure through constant comparative analysis and further refined into meaningful descriptions having significance to related theory and concepts as well as the research questions. Generic and situation-specific ethical considerations were considered in relation to palliative care research. Trustworthiness was established based on
evaluation for health science ethnographies (Muecke, 1994) and criteria for soundness in qualitative research developed by Lincoln and Guba (1985).
CHAPTER 4
PRESENTATION OF FINDINGS

This study examined the network of professional relationships in the practice of palliative care between nurses, client and families, and other health care providers to address the following research questions: What barriers do nurses and families identify to the access of palliative care services? What gaps do nurses and families recognize in palliative care services in the hospital and community? What are the attributes of quality palliative care? How do nurses contribute to the quality of palliative care? What ethical issues do nurses experience and how do they deal with them? How do nurses contribute to the integration of palliative care services for people and families at home? What more needs to be accomplished to develop an integrated system of palliative care? The data gathered provide compelling support for professional partnerships in characteristics of palliative care and in issues related to service delivery. Even though the context of community and the health care system is challenging and constantly changing, opportunities exist for examining program models of care. In this chapter, findings will be presented concerning the context within which relationships are found and function, actual experiences of clients, families, nurses, and hospice physicians, specific issues related to marginalized populations, and tensions within the health care system.

Home care nurses develop trusting professional relationships with diverse individuals and families throughout their lives in their homes and neighbourhoods. Care during a life-threatening illness and at the end-of-life takes on special significance. With sometimes limited health care resources, nurses provide skilled and compassionate palliative care to comfort and support people who wish to remain in their homes as long
as possible. Home care nurses are key to ensuring coordination and continuity of care throughout illness, dying, death, and bereavement. They are also part of a health care system that they constantly challenge to ensure quality care.

When living with a life-threatening illness, individuals and families endure personal struggles in their relationships with the health care system. They often gain new strengths and insights through the months or years of caring for themselves or others. People usually experience episodes of acute illness requiring short-term hospitalization intermingled with periods of relative comfort. Over time, many health care professionals may become involved yet continuity of care is not a given.

The Home Hospice Program model is challenged when meeting the needs of marginalized populations. Nurse participants explained that socioeconomic determinants of health varied considerably between the city's diverse neighbourhoods and accounted in part for major differences in palliative care nursing practice. There are serious gaps in accessible and appropriate palliative care services, especially for persons living with AIDS and drug addictions. Care for marginalized populations profoundly lacking in integration of services. Nurses are challenged daily to meet clients' basic needs for food, shelter, comfort, respect, and support.

The current Home Hospice Program model of palliative care services cannot meet these challenges without major changes. Increasing tensions within the health care system to balance rising expectations of clients and families with limited resources are ongoing concerns. This complex network of relationships between clients and families, nurses, and other health care professionals provides the focus for addressing research questions related to principles of primary health care across the continuum of palliative care.
The major themes were developed from the analysis of all data sources, including observations and interviews with clients, families, and health care professionals, as well as from extensive field notes and documentary analysis of ongoing changes in the Home Hospice Program. The participants’ words and the researcher’s field notes illustrate these themes. The research findings are organized into three sections: the current context and practice of home care nurses; quality of life and quality of palliative care as experienced by clients and families in the mainstream context and in marginalized populations; and increasing tensions within the health care system.

4.1. The Current Context and Practice of Home Care Nurses in Palliative Care

Palliative home care nursing practice is contextualized within the mutual experiences and relationships of home care nurses with clients, families, other caregivers, and family physicians. Both a formal and informal network of care providers and resources, as well as broader system support sustains this team. The V/RHB Home Hospice Program is structured on a model of client and family-centred care as depicted in Figure 7. The inner triangle represents the primary care team, including the home care nurse, family physician, and others who provide direct care and support to clients and families. The secondary care team encircles the primary care team and is comprised of both a formal and informal network of community and institutional care providers and resources, which may include the interdisciplinary Hospice Consultation Team, Home Support Services, shift care nurses, hospital palliative care units, and residential care. Utilization of these services is based on the client and family care requirements which are determined in collaboration with the primary care team.
Figure 7. Vancouver / Richmond Health Board Home Hospice Program Model

POLICIES
PROCEDURES

Home Support Workers  Nutritionist  Volunteers

Physiotherapist

Other Caregivers

Occupational Therapist

Social Worker

Pastoral Care

Residential Care

Shift Care Nurse

Specialist Physicians

Home Care Nurse

Home Hospice Consultation Team

Family Physician

Clinical Nurse Specialist

RESEARCH
EDUCATION

1. Primary Care Team (triangle)
2. Secondary Care Team (circle)
3. System Support (square)

The system level of support is depicted by the square and encompasses policies, procedures, documentation, communication, research, education, and administration. Within this program model, clients who require palliative care are considered a priority and are to be seen by a home care nurse within 24 hours. Ideally there are no wait lists. A client is considered for admission to the Home Hospice Program when the majority of care requirements are palliative, such as support and symptom management, and life expectancy is months, not years. It is not necessary for the clients to agree that they are dying. Care is provided in the home whenever possible and specialists are consulted only as necessary.

Throughout the fieldwork experience with nurses as they visited with clients and families or met for individual interviews, they demonstrated a passion for palliative care nursing as well as strength and determination in meeting the ongoing challenges to providing care at home. This section is based primarily on the perspectives shared by the nurse and hospice physician participants and addresses the research questions related to barriers and gaps, ethical issues, and nurses' contribution to quality palliative care and integration of services. The current practice of home care nurses is portrayed through: establishing meaningful nurse / client relationships; recognizing individual and family strengths and struggles; ensuring continuity of care; honoring clients and families in ethical considerations; fostering nurse / physician relationships; and advancing palliative care as a specialty nursing practice.
Establishing Meaningful Nurse / Client Relationships

Establishing meaningful nurse / client relationships was a major theme reported by many nurse participants in this study. This process was essential to building trust and, at the outset, involved explaining the nursing role, describing the resources of the Home Hospice Program, and learning as much as possible about the client and family.

In most palliative care situations, the home care nurse was able to establish a long-term relationship with the client and family. Although there was a model of primary nursing, typically, several nurses were involved in providing care and communicated with one another about the current situation. They came to know the families well through regular telephone contact and home visits.

To offer anticipatory guidance for end-of-life care, the nurses balanced sensitivity to the client and family’s readiness for information while ensuring sufficient time for them to work through the process. The client and family trusted the home care nurse to respect and support their plan of care. They expected and appreciated the nurses’ basic honesty. Overall, nurses recognized the client and family as the experts in their own lives and respected their desire for control over making decisions and choices.

In two family situations, the home care nurses, who were not the primary nurses, disagreed with the client and family’s plans for a home death. In the first situation, the home care nurse lacked experience in palliative care and described the client as “demanding with home support workers” as her physical condition declined. She supported a plan to consider long term care arrangements without consulting the client’s sons. This was not in the client’s best interests as she was dying and the family was very upset. Fortunately, at the request of one of the sons, the inexperienced nurse was replaced.
with a home care nurse who was very experienced in palliative care. She quickly and expertly assessed the client’s condition, met with family members, involved the family physician and hospice physician, and arranged for 24-hour shift care nursing. The home care nurse described how she supported the sons as their mother was nearing death:

I just said to the son, ‘You know this has been a very long time for you, hasn’t it been?’ And he just sobbed. And he sobbed and he sobbed and he sobbed. My heart was breaking for him, so I went and gave him a big hug. And then I went and sat back down again and we talked about it. And he cried for a good half-hour.

When the other son and his wife came in too, we informed them. I said, ‘You know she was on a different level now and we could have some changes’ and that basic honesty. You have to mix that empathy and compassion with it. But it was interesting, because when I went in the following week one day when the younger son was there with his wife, she said, ‘Well you know I want to thank you for being so compassionate and for letting us know’. Because it was at that time they needed to know. She was dying.

Developing a trusting relationship with clients and families was key to preparing for the coming events. The woman died the following week in the comfort of her home with experienced nursing care and with her family present.

In the second situation, a man who was being cared for by his daughter and wife had suddenly became comatose. With assistance of the primary home care nurse, the family arranged for a hospital bed and equipment necessary to manage his care at home, and the daughter took leave from her work. The family requested that I visit and, during this time, another home care nurse arrived and told the daughter that her father should be admitted to hospital. Although very experienced, she demonstrated an abrupt manner of telling people what to do, and had not established a positive relationship with this client and family. Although distraught, the daughter finally convinced the nurse that she wanted
to keep her father at home. Subsequently, additional home support and shift care nursing were arranged. The client died at home two days later with his wife and daughter.

As illustrated, some home care nurses had difficulty assessing and accommodating the palliative care requirements and wishes of clients and families. Reasons included lack of knowledge, lack of experience, lack of interpersonal skills, and taking charge of the situation without consultation with the family. Furthermore, when several nurses were involved with care, or when they visited clients when family members were not present, it was more difficult for nurses and families to establish meaningful relationships.

For all of the other nurse participants, their relationships with clients and families were based on mutual respect and trust. They highlighted the importance of interpersonal skills combined with clinical judgement, in understanding the complexities of the client and family situation. The following section explores how nurses identified and acknowledged the strengths and struggles of clients and families.

Recognizing Individual and Family Strengths and Struggles

Nurses often reported a remarkable strength of families throughout the long and intense palliative care experience. The nurses assisted clients to seek as much support as possible, while continuously monitoring the abilities of family caregivers under changing circumstances. Even the strongest families could become fragile at the end of life.

Although one family member was usually designated as the primary caregiver, the children and spouses supported each other as much as possible, even from a distance. The main family caregiver was often very knowledgeable and competent with caring for the
client under the guidance and supervision of the home care nurse. In this study, neighbours, friends, and even church groups provided support to the family as needed. Many families managed well on their own with minimal support from the home care nurse, until the client’s condition declined. Others had large extended families who shared in the caregiving responsibilities. Some families found strength in their cultural traditions, and religious or spiritual beliefs and practices.

Complex family dynamics were common given the intensity and duration of the care giving responsibilities. Early recognition of family difficulties by the nurse was crucial to preventing major crises. Honoring and supporting the client’s wish to die at home was possible only if advanced planning had been initiated and resources arranged within a reasonable amount of time. One daughter vividly described her anxiety as her father’s condition quickly deteriorated:

I started to speed. I felt like things were spinning out of control because I didn’t really know how to take care of him in the next stage and I didn’t know about the equipment I needed or the people I needed to have on hand. And 20 loads of laundry in 4 days!

I just knew that I couldn’t cope with the sheer quantity of work that needed to be done to take care of him. And I knew too that we had talked about him going to the hospice and I had put him on the waiting list the year prior, because his condition was so severe at that time. And we were told that it might come to that, but when it really came to the time where he might need that, it just didn’t seem appropriate to part with him. Like it just didn’t really seem an option anymore.

He was really happy here and it was his home. And you know we were celebrating Christmas and the tree was up and the music was on, and it just didn’t seem like the right time to sort of take him somewhere else. To this foreign place, and start trying to rebuild in a time where the time seemed really limited and it seemed like a lot of disruption for what it would really bring him.

I was sort of in disbelief, because I guess I wasn’t up to the same speed as the nurse. I mean although people were saying he could die within the next day, I hadn’t lost hope. I didn’t know that he wouldn’t eat or drink again; at least I wasn’t sure, because there had been so many times when we’d been brought to
the brink of disaster and have him brought back to full quality living. And then brought back to the edge of this precipice and you don’t know which edge or which precipice is really the edge of the precipice when you’re going through this, and I think that’s sort of a roller coaster.

Even the most competent and committed family members felt very stressed towards the end of life. They often failed to recognize impending death if not informed and guided by the nurse.

Supporting a person to stay at home depended greatly on the family members’ capabilities. The nurses recognized the families’ stress as a response to crisis and addressed their many questions and anxieties. As one shift care nurse explained, her goal was “to prepare families for death so that they could be as present as possible in the last moments”. The nurses were ever mindful of the struggles of the individuals and families throughout these difficult times. They cared for the client and family as a unit in the home. Needs of the caregivers were considered as important as those of the client. Nurses emphasized the importance of remembering that the family members were the primary caregivers and, along with the client, the decision-makers. The home care nurses were skilled in assessing the family strengths, as well as their limitations. At times, the client was well cared for, but the family caregivers were exhausted. The nurse had to know when to arrange for respite services and supports, and when the care requirements were beyond what the family could provide. The nurse needed to identify and capitalize on the family’s strengths, support them during stress and crisis, and be prepared for the inevitable challenges of working within complex family dynamics throughout the continuum of palliative care.
Ensuring Continuity of Care

Establishing professional nurse / client relationships and learning about the uniqueness of each family situation provided the groundwork for continuity of care across the continuum of palliative care. Nurses explained that the key considerations in planning and supervising care among a number of health care providers required that they be flexible, and have exceptional critical thinking, assessment, and communication skills.

From the initial referral of a client to the hospice program until their death, the home care nurse provided ongoing assessment and continuity of care. Additionally, the home care liaison nurse was instrumental in arranging home care services prior to the person’s discharge from hospital. If the hospital team anticipated complex care requirements and difficult family dynamics, the home care nurse was invited to attend a family discharge planning conference at the hospital, usually on the palliative care unit. To plan for transition home, the home care nurse met the client and family, as well as the family physician. In this way, a seamless continuum of care was ensured, thus minimizing possible crises and probable hospital readmission. Due to other work commitments, home care nurses were unable to participate as often as they would have liked, but they could always call the hospital nurses or physicians for further information.

Critical thinking and exceptional assessment skills were required to ensure adequate pain and symptom management, medication administration, and management of concerns of the client and family caregivers. For example, one nurse described her skill in this way:

You get to know them really well. You can tell easily very subtle changes in the dynamics in the person, in the way they’re feeling. They may not even say it. You can just sort of pick up on it. I can feel impending death.
Many experienced nurses felt they had considerable expertise in detecting subtle changes in the client’s condition due to their knowledge of that particular client as well as the general patterns in the progression of end-stage illness.

Flexibility was essential for responding quickly to the client’s and family’s changing care requirements. When these were greater than what the family could provide and what the home care nurse could accomplish during daily visits, several options were considered to ensure continuity of care in the home. Home support workers were often contracted through private agencies to provide respite, basic care, and household duties under the supervision of the home care nurse. This arrangement worked well when the client’s condition was stable, nursing assessment was not required, and the home support worker was experienced in palliative care.

Unfortunately, in many instances, the home support worker lacked experience, as this nurse described:

When I got there the next morning the home support worker was just sitting there. She hadn’t moved. She hadn’t done anything all night because she was frightened. I can understand, because they really don’t have the knowledge and expertise.

The home care nurse monitored the care provided by home support workers and taught and approved extension-to-care guidelines when required. If there were problems, the home support supervisor was contacted and a replacement worker was arranged as soon as possible. These situations placed tremendous responsibility on home care nurses as home support workers have been increasingly hired when neither shift care nurses nor palliative care beds are available. The home care nurse must be able to closely supervise care and make appropriate decisions quickly when problems arise.
Place of death was an important issue for families and their decisions often changed as the client required more care. If nursing judgement were required, then shift care nurses would be arranged for 24-hour care to work closely with the primary home care nurse and family physician or hospice physician to ensure continuity of care. These nurses were usually able to support the client and family in a home death. If shift care nursing was not available, or the family requested that the client go to hospital, then the nurse collaborated with the family physician to arrange for the client’s admission, preferably directly to a palliative care unit. Unfortunately, the client sometimes waited in the emergency department until a bed became available, not necessarily in the palliative care unit. These decisions were guided by the client and family’s plans, but often the factors limiting home deaths were the availability of resources and the ability of the home care nurse to work the system.

Nurses also needed to be sensitive to cultural practices that prohibit people to die at home. One common belief in Asian cultures is that the dead person’s spirit remains at the location where they die. Consequently, families support the dying person at home as long as possible but ask that the death occur in hospital. Nurses obliged this request but explained that it is becoming increasingly difficult to ensure that a hospital bed will be available at the right time.

Caring for the physical needs of one’s spouse was a societal value that also influenced decisions around place of death. One nurse described the following circumstances:

For one family, it wasn’t necessarily just the cultural belief. It was the husband’s belief that the wife shouldn’t be burdened with the care giving because it wasn’t in her background. They were from a high social level and she had never been exposed to things like vomit and bodily functions. So he wasn’t comfortable with
her being available for care giving. And even when we did bring in shift care he
was still very self-conscious and he felt that he was offending his wife somehow.
She would try to say, ‘Well I will do it’, but then to me she would say, ‘Oh am I
okay doing this? Is this what I’m supposed to be doing?’ So it was a fragile
situation and she was very emotional. He didn’t want her remembering him that
way. He had a bit of a disfigurement anyway, and he didn’t want her to have to
live with that kind of a memory. And that’s perfectly reasonable.

In this situation, the man was transferred to hospital, which greatly relieved his
discomfort and that of his wife. Without the stress of caregiving, they could be present
for one other in the way in which they were accustomed. Caring for the physical needs of
a parent was also difficult as their health and abilities declined. In this study, all of the
clients (mothers and fathers) who died at home were cared for by their children
(daughters and sons), with support from nurses or home support workers for basic
physical requirements, such as bathing, bowel and bladder function, and wound care.

The number of health care providers in any given family situation could be
considerable. Of the six clients in this study who died at home, many required extensive
services from home support workers, on average for two months. These accounts
demonstrated wide variability in home support requirements, based primarily
on the capability and availability of family members over the long term. Supervising and
coordinating home support workers was a significant part of the home care nurses’ role.
As needed, the nurses also arranged for client assessment by health care professionals on
the secondary care team, including the social worker, physiotherapist, occupational
therapist, or speech-language therapist. An overview of the services utilized is presented
in Table 5.
Table 5. Summary of Health Care Providers Involved in Home Deaths

<table>
<thead>
<tr>
<th>Client</th>
<th>Number of HCNs</th>
<th>Shift Care Nursing</th>
<th>Home Support Workers</th>
<th>Family Physician</th>
<th>Hospice Physician</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>No</td>
<td>10hrs/night, 3 nights/week for 2 1/2 months private HSW 3 days/week</td>
<td>Involved</td>
<td>No</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>Yes 3 nights</td>
<td>4hrs/day, 3 nights/week 1 month</td>
<td>Involved</td>
<td>No</td>
<td>Occupational Therapist, Social Worker, Speech Language Therapist, Paramedics</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>No</td>
<td>4hrs/weekends, private HSW 4hrs/day, Mon-Fri, x 2 months, all day x 2 weeks</td>
<td>Involved</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>Yes 1 night for assessment</td>
<td>24 hrs/day x 5 weeks HSW at time of death</td>
<td>Limited Involvement</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>Yes 2 nights</td>
<td>1 night before SCN was available (not appropriate)</td>
<td>Limited Involvement, Relied on Specialist MDs &amp; HCN</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>Yes 24hrs x 1 week</td>
<td>2hrs/3days week, 20hrs/day Mon-Fri, x 1 year</td>
<td>Involved, away at time of death</td>
<td>Yes, consulted with locum</td>
<td></td>
</tr>
</tbody>
</table>
The nurses provided many accounts illustrating the unpredictability in securing resources required for death at home and the ease with which the best plans could fall apart in the final days. In this study, the nurses were able, in cases, to address emerging problems and readjust plans to support the clients and families. The most difficult problems arose when the family physicians were not available or involved in the client’s care, at which time the nurses consulted with the on-call hospice physicians. The home care nurses developed tremendous skills in quickly accessing, planning, and coordinating care among a wide range of health care providers in order to avert potential crises in the home. In five situations, the clients died with family present and the support of either a shift care nurse or a home support worker who had been involved on a long-term basis. An example of an unforeseen crisis occurred when one woman died peacefully, but unexpectedly, during the night while her daughter was asleep. The daughter was very distressed when she found her mother dead in the morning. She panicked and called the paramedics who subsequently contacted the family physician to visit and pronounce death.

Overall, clients and families spoke highly of their home care nurses. They were very impressed that their primary nurse knew them well and communicated with other nurses to provide continuity of care. They were given phone numbers to call on a 24-hour basis for home care. An evening nurse was available to visit if required and a nurse was scheduled for on-call every night. A current registry of clients receiving palliative care was available to the on-call nurses. The primary care nurse was responsible for updating this book as required, and ensuring, whenever possible, that other home care nurses
involved with the client and family were experienced in palliative care and well informed of the client’s condition.

Prior to impending death, many nurses considered it part of their role to ensure that the family had planned for funeral and legal arrangements. As this nurse explained, assistance was sometimes required:

This man was a judge and his friends were all lawyers and judges and he didn’t have a will and he didn’t have funeral arrangements. He had nothing. So I was phoning this judge friend and saying, you know, please, you need to phone the funeral home and make all these arrangements and make sure everything’s in order. You know, I was so surprised!

Although the nurses provided anticipatory guidance to the client and family as death approached, they did not estimate the time of death, other than in very general terms. When nurses engaged in this type of advanced planning, family members sometimes felt relieved once their loved one’s suffering had ended. If a shift care nurse was present at the time of death, and the family physician concurred, she conducted the pronouncement. Otherwise, it was the obligation of the family physician to visit the home and pronounce death.

Once a client died, services came to an abrupt end following this period of intensive support and care. The home care nurse visited the family following the death to pick up supplies, to offer bereavement support, and to refer the family to their family physician or other community bereavement services. One home care nurse shared this perspective:

Well, we make visits you know here and there, but bereavement is ongoing of course. There’s no end to grief. So some form of a program of contact is needed for a longer period. There are support groups but some people don’t want groups. They want to be on their own and they want to be able to talk to the people who were there at the time. I’ve had families call me back three and four months later
to say, you know, this is how I'm feeling. And that's okay. You know I don't mind doing that. But there's nothing formally.

It was usually up to the family to call the home care nurse for follow-up. A volunteer bereavement support team, part of the Home Hospice Program, would also call on a regular basis to offer support.

Both nurses and families acknowledged a considerable gap in bereavement care, leaving them feeling unfinished in this process of life to death. Families in this study emphasized the importance of bereavement care from a person who was closely involved with them during the course of illness and home death. This was typically the home care nurse or, at times, the family physician. The response from nurses varied in terms of how they offered bereavement care. Some attended funeral or memorial services, at the request of families, to bring closure to the experience, but only in special circumstances when they had been involved with a family over a lengthy period of time and had developed a positive professional working relationship. In situations where there had been family conflicts, nurses preferred not to continue their involvement. Concerns about the family would be referred to the family physician or social worker as appropriate. Other home care nurses would call or visit the family over several months to provide support. Shift care nurses felt strongly that bereavement care was not part of their role as they were contracted solely for respite or end-of-life care. Most often the family was expected to seek out their own resources based on their needs, as many people sought solace within their own families and community. These accounts illustrate the need for a better-organized, formal program of bereavement care with a flexible, family-centred approach.
Honoring Clients and Families: Ethical Considerations

Another important theme identified by nurse participants as they reflected upon their practice was their role in honoring the clients and families. This was expressed in a number of different ways such as demonstrating respect, dignity, honesty, integrity, and sensitivity as well as being non-judgemental. Many of the nurses described that it was a privilege to care for people at the end of life, and expressed the view that honoring is basic and fundamental to palliative care.

Ethical issues provided an important context in which nurse sought to honor their clients and families. Within the actual organization of nurses' work, dealing with ethical dilemmas is often complicated and difficult. Because home care nurses are often the most intimately and consistently involved health care professionals, they are the ones who are likely to be consulted by families about ethical decision-making. Working effectively within the context of ethical challenges is a critical element of the palliative care nurse's role.

Many nurses identified the first step in addressing ethical issues as knowing the client and family context. After a detailed health assessment, it was important to know if the client or another family member was responsible for making decisions, or if there was to be family consensus on a particular issue. The next step was to assist the client and family in clearly expressing their views with one another. Whenever possible, the client and family perspective on quality of life guided the nurse in decision-making. For example, decisions to die at home, stop active treatment, and have pain relief were often expressed in the final stages of illness.
The nurse supported the client and family decisions in a non-judgemental manner. One nurse explained: “I let the client and family lead the way. I do not impose my own views”. If the client was unable to make decisions, and no family members were involved, the nurse advocated on behalf of the client to provide care within the client’s best interest, based on previous knowledge of the person and available resources.

Some nurses, who were very experienced in palliative care, shared that they had learned to deal effectively with ethical dilemmas over the years. One home care nurse shared this perspective:

I feel comfortable partnering with the client for the care that they tell me they want to have. It happens less often than in hospital because you’re given the opportunity for people to direct you and so I think the ethical things often are when you’re trying to impose what you believe in, that kind of paternalistic medical model of ‘This is what’s best for you. This is what you need to do’. And if you don’t do it then, where does everybody sit with that. Am I comfortable with you not choosing? Am I not fulfilling my obligation to you because you didn’t choose the best treatment in my opinion? So I don’t run into many difficult ethical issues. And I think the program allows for that.

To support nurses who were inexperienced in complex ethical issues and palliative care, the Home Hospice Program developed an ethical decision-making framework that was in the process of being implemented. Developed as a collaborative model, the framework involved the client, family, significant others, and health care professionals. Ideally, the client and family directed the process. In complicated situations, a member of the primary care team was appointed to facilitate options or solutions.

The following sections address common ethical experiences of nurse participants. Nurses described their sensitivity in recognizing tensions and conflict among family members that could lead to disagreements in the plan of care. Decisions regarding declining or prolonging treatment and “no resuscitation” orders were also frequent
considerations. Planned suicide was described by nurses as one of the most distressing events in palliative care practice. In all ethical situations, the nurses’ main role was to support the integrity and dignity of the client and family in decision-making process and its outcomes.

Client and family disagreements

Ethical conflicts arose when family members held different values and beliefs, and one person was more involved in the client’s care than another. One nurse shared her experience with a family, in which the daughter, as primary caregiver, agreed to palliative surgery for her elderly mother, with ovarian cancer and a bowel obstruction. The son, visiting from Holland, requested euthanasia, which was legal in his country. The daughter had only assumed responsibility of her mother’s, but also had to deal with conflicting demands from her brother. Adding to her burden, she was in the process of divorce. The nurse described the final days as follows:

Following surgery, the mother went home with her daughter. In the end, there was no shift care nursing available. I was visiting three or four times a day and the evening nurse was also involved. The mother decided that she was no longer going to eat and said that she wanted to die. She would only take water and she wanted to sleep. We kept her comfortable with analgesics as required. She died very quickly within a week and a half.

This situation exemplifies the tremendous conflict and stress that can arise within families leading to ethical dilemmas amid the untimely nature of death.

Nurses faced ethical challenges when they could not speak openly to a dying person about the nature of their illness. For some families, their cultural tradition was to not inform the parent of their diagnosis and impending death. One family member, usually the eldest, would be delegated as the spokesperson. The nurse was sometimes
limited in assisting the parent to prepare for death. With lack of preparation and planning, care could evolve into crisis management, which would be compounded if there was a language barrier. One nurse shared the following experience:

There are cultural issues as far as whether or not the parents are told that they have a terminal illness. That happens a lot, but people know what’s happening to them. And they want to talk to somebody and the nurse has been very strongly instructed by the family not to say anything. And one daughter called up a nurse to complain that she had discussed palliative care with her father. The nurse explained carefully that her father had brought up the issues. So that’s an ongoing struggle when you’re doing multicultural nursing. You try to abide by families’ wishes and support the client but you feel that tug of war sometimes.

The nurses attempted to speak privately with the parent whenever possible and often found that he or she was actually very knowledgeable about the reality of the situation.

Another difficult ethical situation occurred when the family members and the client disagreed on the place of death. At times, the client’s expressed wishes were to die at home, but in the end, the family was exhausted and unable to continue as caregivers. A nurse shared this experience:

I had a situation recently where the husband just couldn’t do it anymore. His wife deteriorated really quickly and then he couldn’t deal with her at home. He wanted his wife to go to the hospital and she did actually want to stay at home. He had looked after her for a long time. She was a young woman too. We couldn’t get shift care then either. I felt pretty badly about sending her off in the ambulance in the condition she was in because she was barely responding.

This decision was stressful for all involved, but because there were no other options for home support, the nurse followed through with hospital admission.

Disagreements between clients and families and among family members led to ethical conflicts that often involved mediation by the home care nurse. Decisions related to how much to tell a parent, euthanasia, and place of death had to be resolved as quickly as possible to avoid end-of-life crises.
Declining or prolonging treatment

Declining treatment was not usually a problem for clients at home. The nurses and physicians were willing to support the client and family’s wishes to stop active treatment, such as radiation, blood transfusions, and chemotherapy. A common issue was when the client or family withheld pain medication due to fears of addiction from prolonged narcotic administration or reluctance to tolerate side-effects. The nurse would work individually with each client and consult with the family physician or hospice physician to determine the most effective medication regime for enhancing pain control and quality of life. One nurse described how she resolved a situation in which the family declined pain medication for their mother who was suffering:

I find that it is an ethical issue when the family are trying to over-ride what the client might want. And then they do not want you to ask her or to discuss too much. I had a recent situation where the family didn’t want this Fentanyl patch, for whatever reasons, and they made that choice even though it was explained. And then I was in there one day and the mother was in so much pain. I didn’t even look at them. I just asked her directly, ‘Would you like to try this patch?’ She was so distressed she couldn’t even talk and finally she just said a very emphatic “Yes!” And I thought, “Well that’s good. It’s between the two of us”. And to me that was very clear. And they loved her dearly. So they all finally did accept that, but it actually delayed her comfort for about four or five days.

To remain at home and be comfortable enough to address existential end-of-life issues, pain control and symptom management were paramount for the client and family.

At times, nurses, clients, and families had to determine if ongoing treatment was sustaining quality of life or prolonging suffering, especially in the care of children. The most frequent concerns related to feeding and hydration. Many family members viewed feeding and fluid administration as comfort measures, even as death was approaching. As one nurse explained:
That's the one thing people can provide in terms of support is food. And it's tangible. You know, if they don't feel that they can provide what's needed emotionally and spiritually, at least they have this physical thing that they can present. And it becomes a symbol of care giving. We always encourage but do not push. Fluids are important but not necessarily food.

At the end of life, the nurses often considered administering foods and fluids orally to present risks for aspiration. They would sensitively explain to the family that the client's inability to swallow and eat was part of the dying process, and suggest other comfort measures. In many instances, the client refused to eat or drink because they were unable to do so and were ready to die. On request of the family, nurses would administer fluids subcutaneously by hypodermoclysis as a comfort measure.

Knowledge and understanding of the specific family circumstances enabled the nurse to be an effective facilitator in these ethical situations. The nurse engaged openly with the client and family in discussions related to declining or prolonging treatment and to consulted with family and hospice physicians as required. These deliberations inevitably led to further dialogue about resuscitation.

Obtaining orders for DNAR (Do Not Attempt Resuscitation)

Nurses reported that they usually took the lead in discussing the legality and practicality of a no-resuscitation order with the client and family. Obtaining an order for no resuscitation in the home was often very time-consuming for the nurse, depending on availability of the family physician and the family situation. It sometimes took weeks or months to obtain signatures of the family and physician on the official document.

Distinguishing between acute episodes of illness and dying was difficult. Without a DNAR order in the home, several problems arose prior to and at the time of death. The
nurse had advised the family that the policy was to call the family physician and not to call 911 in the event of a planned home death. At times, family members did not agree to a DNAR order and would not sign the form, but understood it was the inappropriate to call the paramedics. However, if a home support worker was in attendance and did not have a DNAR order, then calling 911 was mandatory. If paramedics were called when a person was dying and there was no DNAR order, they were obliged to transfer the person to hospital. Nurses prepared families as much as possible for decision-making, but the family had the right to arrange for a hospital admission at any time.

It is important to note that a DNAR order refers only to care at the time of death. In the interim, families had many questions and conflicts with regard to advanced directives. The following situation illustrates one family’s struggle:

There was one client who had signed his DNAR order and his wife was supportive, but the son continued to send him to hospital for intervention. The man had cancer of the prostate with bone metastases. When he went into renal failure, his son sent him to hospital and he came home with bilateral nephrostomy tubes. He lived one month after that, but had repetitive infections. You could see his wife struggling, knowing that he didn’t want any more intervention. So we’d be sitting down having these discussions until finally we were able to say, I think he doesn’t want to do this anymore. His wishes have been expressed. And he did have a very peaceful death at home. It turned out to be a very comfortable position for them. For some families, it just takes more time for them to accept the inevitable.

Through ongoing supportive discussions with the nurse, the son was finally able to come to terms with his father’s dying and accept the natural course of events. Although the nurse facilitated this process, she respected the son’s perspective and waited for him to reach a decision on his own accord.

Cultural considerations were also important when discussing a DNAR order. One nurse shared this experience:
We did get a DNAR for a Cambodian lady, but it took it took three admissions to the PCU over six months until the family would agree to sign. But it was actually to the point of discomfort. They had to work with a translator. And to the family, if you talk about death, it brings it. So you know it is a thing that you have to be culturally sensitive with.

This situation exemplifies the complexity of end-of-life decision-making and the nurse’s in honoring the family’s choices.

Nurse were extremely important in obtaining no resuscitation orders in a timely fashion to avoid prolonging treatment or inappropriate interventions at the end of life. Clear explanations to the family were given so they understood the reasons for a DNAR order and that it did not mean that appropriate treatment was stopped for acute episodes of illness. The nurses understood that each family situation was unique and that sensitivity to the timing and readiness for discussion was critical.

Planned suicide

Of all ethical issues described by nurses, none seemed more troubling than when clients took their own lives in planned suicide. Nurses were hesitant to speak about suicide and were reluctant to share these experiences with their colleagues. They vividly described past events with a sense of intensity and emotion. They explained how their practice in palliative care focused on quality of life and their role was to support clients and families to die a peaceful and dignified death. Suicide didn’t fit in this picture.

Planned suicide occurred more often in persons living with AIDS and/or drug addiction. For people living with AIDS, there was usually a well-conceived plan with friends to assist at the right time. The nurse would simply be advised not to visit again. One clinical nurse specialist explained why suicide had become more prevalent:
Because people living with AIDS had cared for so many people that had died, we started to see a lot of talk about planned suicide. And we heard them say, ‘I’ve got my supply of medications, so that when the time comes, I’ll know what to do’. And then this created a problem for home care nurses. That probably was in the early nineties.

So then we had to really look at how to support the nurses in these situations. It was made really clear if any of the clients started to say, ‘Now I have something that I want to tell you but I don’t want you to tell anybody’ to have the nurses answer, ‘You know I am part of a team that looks after you together with your physicians and your care team. And I can’t make secret arrangements with you about anything’.

Often a nurse would come in at the end of a day and say, ‘Now I just have to talk because the client was planning to have their closest friends in and take their medication and have some wine, and reminisce and let go’. So the nurse would be advised to contact the family doctor and sometimes the physician said ‘Yes, I know. They’ve spoken to me too’. So if it was a rational decision that they were making, that of course was their right.

Home care nurses who were experienced in AIDS care learned to expect these situations, although it was still difficult for them to accept that someone chose to end their life. They knew their legal position in that they could not participate in any way, but expressed feelings of guilt that they might have done something differently to avoid such a tragedy.

When a client decided it was time to end his or her life, nursing care ended abruptly and nurses were left with many lingering emotions leading to accumulated grief and loss.

Suicide was also common among drug addicts when they learned they had HIV or when they grew weary of the ravages of AIDS and were no longer able to adhere to the oppressive drug regime. One participant, who was a drug addict, explained how many of his colleagues who lived on the streets and had AIDS planned their suicides by administering drug overdoses or having someone do it for them. He shared this story:

I lost seven hundred friends this year that I know of. I don’t know exactly how many but lots. Like when I come downtown and it’s everyday people die from ODs but all related to the illness [AIDS], right. And I don’t know but half of them
are probably planned suicide. Probably registered as a heart failure rather than an OD. Right.

These deaths were simply recorded as overdoses. Few people knew that they were planned suicides. The nurses were told simply that the person had died, unless they learned more later on from other clients or from the hotel attendants. The nurses explained that they found it difficult to face such harsh realities every day. They were angry at a society that failed to deal with the hopelessness and desperation of street people.

Suicide also occurred among people dying from cancer or end-stage chronic illnesses. The nurses described these events as unexpected, where even family members had no idea of what was happening. One example was a man who died in his garage with his car running. His wife found him dead when she returned home from work and required a great deal of support from the nurse to help her through this crisis. Another recounted a very stressful situation in which the planned suicide was unsuccessful and she cared for the person at home until death. It was extremely difficult for the nurse to comfort family members under these circumstances. Attempted or enacted suicide was distressing for the palliative home care nurses, who believed in preparing and supporting clients and families for a natural end to life, thus sometimes interpreting suicide as a personal failure.

In summary, nurses described ethical issues as inherent to providing palliative care at home. Honoring clients and families in these difficult situations required tremendous interpersonal skills and knowledge on the part of the nurse. Decisions to decline or prolong treatment involved careful consideration and open discussion with the client and family caregivers. Obtaining a no-resuscitation order required patience,
instruction, and gentle guidance. Dealing with planned suicide, especially when unexpected, overwhelmed and challenged the nurses’ personal and professional values and beliefs. Dealing naturally and professionally with ethical issues within the context of the client and family was a hallmark of an experienced palliative home care nurse, but was often difficult to accomplish.

Challenging Nurse / Physician Relationships

In interviews and discussions with nurses about their practice in palliative care, there were many references to difficulties encountered in their professional relationships with family physicians. The nurses described themselves as key members of the primary health care team who coordinated and integrated palliative care services. The hospice physician concurred. Although the primary care team model of practice included active involvement and responsibility for medical care by the family physician, in this study, it was usually the home care nurse who established a working relationship with the family physician, when possible, and consulted with the hospice physician as required. The nurses reported that they often received more support from the hospice physicians than from the family physicians. Although some family physicians were described as excellent, many were not interested or experienced in palliative care. In these situations, the home care nurses spent considerable time consulting with the hospice physician first and then getting necessary orders from the family physicians, often teaching them in the process.

When family physicians were unavailable, timely, flexible decision-making in response to changing care requirements of the client and family was difficult. This
impacted negatively on the overall quality of palliative care. Fortunately, the hospice physicians were usually able to provide primary medical care for families and support for the nurses in these situations. One nurse described her frustration as follows:

We’re still running into problems sometimes with the family physician’s lack of knowledge and not being willing to consult hospice physicians, so it would be a great help if they were willing to do that or to even acknowledge our expertise as well. There are times that you work with some physicians that are fantastic and then others that are really difficult. You know what you want, but to get what you need you have to figure out how to ask for it without offending them. It’s very difficult and it’s very frustrating. It’s such a huge problem. And what a colossal waste of professional time and energy!

Barriers to family physicians in assuming primary responsibility for palliative care at home included the inability to accept new referrals, the time commitment for home visits, disincentive based on the current fee schedule, and decreasing numbers of family physicians. Furthermore, family physicians without hospital privileges needed support to manage complex care in the community and to be assured that the clients could access hospital care when necessary. Because there are too few hospice physicians in the Home Hospice Program to provide primary care, the program model is designed primarily for consultative care.

To ensure quality palliative care for clients and families, the roles of physicians and nurses are interdependent. Unfortunately, nurses reported spending considerable time developing and fostering partnerships with family physicians. In some situations, positive working relationships were established. When this was not possible, home care nurses explained that they took primary responsibility for palliative care at home with support from the hospice physicians.
The Specialist versus Generalist Debate

One particularly prominent aspect of the nurses' reflection on their practice that helped me understand the challenges they had in fulfilling their role in palliative care was that some considered themselves generalists and others considered themselves to be specialists. Because they were aware of these differing views, they articulated this difference of opinion as a current debate within their discipline. Nurses who found palliative care overwhelming preferred to have the variety and balance of being a generalist. Other nurses who preferred to work exclusively in palliative care felt that being a generalist role would inhibit their ability to expand their knowledge and practice as a specialist.

Traditionally, home care nurses have been generalists by virtue of their community-based practice, providing care to clients and families throughout all neighbourhoods under a variety of circumstances. Palliative care is seen as one component of their practice. The number of clients receiving palliative care at home varies greatly throughout the region. From 20% to 80% of the clients assigned to nurses in this study were designated as palliative, depending on the neighbourhood and also on the competencies and experience of the nurse. Nurses with fewer clients receiving palliative care viewed themselves as generalists, enjoying the variety of nursing experiences. Nurses who had a higher percentage of clients receiving palliative care developed advanced expertise, thus regarding themselves as specialized practitioners. Some of these nurses wished to work exclusively in palliative care. Learning about palliative care was especially challenging for novice home care nurses because, as one
nurse explained: “You’re out there on your own”. Another nurse expressed her concern for new staff:

We really need to help new nurses. If they are going to be the guides or the midwives at the end of life, they need to know as much about that as the training that midwives get at the start of life. I really do believe that.

The participating nurses also recognized that not all of their colleagues were experienced or even interested in palliative care. Consequently, they believed that specialist practice for end-of-life care would be more appropriate for clients and families.

Nurse participants described their specialized knowledge in palliative care as excellent interpersonal and organizational skills, and expertise in complex pain and symptom management. One nurse talked about how she provided holistic care to an elderly woman dying at home.

It really wasn’t until we talked about those other things around if she was ready to die and had she done everything she wanted to do, that we could talk about taking the morphine. She was having increasing pain when she moved. And what was nice with her is that she did stay so lucid right to the end, so that you could have those conversations with her, and let her feel comfortable that you were doing things that she was in agreement with. Even when I found an appropriate dose of narcotic, I really didn’t want to push her into that over-medicated state when she’d been so careful not to go there herself.

The nurses worked from a client-centred model of care, supporting and enabling clients and families to do as much for themselves as possible and to make their own decisions.

Another home care nurse summarized her palliative care practice with the following comments:

The hospice part of our practice is really the most interesting because it’s such a wide scope of skills and challenges, and the rewards are greater. I guess it’s the involvement with not only the client and family that you have with other clients too, but it’s such a critical time in their lives and you become part of it. It just pulls together all of the skills that you might have. You really do end up using a lot more resources. So it’s this whole team effort that comes together and when it all works, it’s always quite challenging, but rewarding, and really very interesting.
Usually we are the main support for the client & family. I think we have a very important job!

Another experienced palliative care nurse concurred:

I think that palliative care and the community hospice care is just absolutely invaluable. I think it is a field that is natural. It's bringing back the natural process of life and death back to families. I mean it really allows nurses to give the kind of care that nurses are educated for. That compassionate, art and science mix. It's an excellent way to nurse.

Many nurses enjoyed resolving the challenges of end-of-life care. One nurse commented: “We make a huge difference and we can turn the situation around very quickly”. They examined personal beliefs and values about life and death on a daily basis. One nurse described this challenge with the following insight:

I think that palliative care can touch a part of you that many people actually never really have to look at or examine. I think it does put you in touch with your own mortality and many people go through an entire lifetime without ever having to do that. And I think that’s a really hard part that often isn’t acknowledged. There is always a little bit of that knocking on the door. I get so much back in return as well and I’m doing a lot of that growth, every time.

Although providing palliative care was overwhelming at the best of times, most nurses reported that they were proud to assist people to die in the comfort of their own home and were gratified by the recognition that they received from families. This experiential learning helped nurses to care for other families in similar circumstances. Several home care nurses and shift care nurses spoke of being honored and privileged to care for people who were dying and that, in facing death, they had developed increased reverence and respect for life. Overall, the nurses recognized their expertise in palliative care, appreciated the holistic, comprehensive approach to care for people and their families at the end of life, and described their practice as challenging and rewarding.
One clinical nurse specialist explained that there were strengths and limitations in either the generalist or specialist view of nursing practice in palliative care. Nurses supporting the traditional generalist home care model promoted the following: accessibility of palliative care to clients without a palliative designation, especially people living with chronic illness; continuity of care by the same nurses throughout the illness experience; and flexibility and diversity in work assignments. Nurses with a specialist perspective acknowledged limitations of this model, including difficulty in developing advanced competence in palliative care; costs of educating all nurses in basic and advanced palliative care competencies; and unrealistic expectations that all nurses would be capable of providing complex palliative care.

Developing palliative care as a specialty nursing practice was supported by nurses wishing to provide care only for palliative care clients in order to: advance their skills; become more knowledgeable of community palliative care services; and have fewer assigned clients and families. Nurses with advanced competencies were better able to support family physicians and required less consultation support from hospice physicians. There were administrative concerns expressed that an advanced practice model of nursing would be more costly in human resources and less flexible in allocating nurses for specialized assignments. Continuity of care could be disrupted if a client was transferred from the primary home care nurse to a palliative care nurse. Home care nurses would have fewer opportunities to apply the principles and skills of palliative care to other populations, such as people living with chronic illness.

In response to the generalist-specialist debate, the clinical nurse specialist proposed an enhanced generalist model of nursing practice wherein all nurses receive
basic hospice orientation with a broad focus on population groups with chronic illness and are assigned to clients with uncomplicated palliative care requirements. Nurses interested in developing specialized knowledge and skill in palliative care could become hospice resource nurses through mentorship and advanced educational preparation. In a focus group session, these nurses articulated their role as: caring for clients and families requiring complex palliative care, along with their general population assignment; providing consultation to colleagues in their neighbourhood team; and participating in program development. They would have preferred to work only in palliative care so that there would be more time for program and community development. Realistically, a limited number of nurses would be able to take advantage of this program because of the home care mandate to provide general health care services to clients and families.

Summary

In the current context and practice of home care, nurses confirm that they have major responsibility for coordinating palliative care for clients and families in the home setting. By establishing meaningful and trusting professional relationships, the nurses addressed the inevitable challenges of working within stressful family situations throughout the continuum of palliative care. Recognizing client and family strengths as well as struggles was key to planning appropriate and flexible care. The nurse-client relationship and the capabilities of the client and family were the underpinnings for enhancing the quality of the palliative care experience.

The nurses relied on expert knowledge, critical thinking, and exceptional interpersonal skills to coordinate 24-hour home care for the client and family until the
time of death. Pain and symptom management were priorities as well as planning for the place of death. In addition, the home care nurses' work extended beyond the home as they consulted with family physicians, hospice physicians, specialists, and allied health care professionals to ensure continuity of care and integration of services. Both family and nurse participants acknowledged a gap in bereavement care and the need for a more formal program to address the immediate concerns of family members. Nurses varied in their abilities to provide ongoing bereavement care, and whereas families wanted to continue their relationship with someone who had been closely involved in palliative care at home.

Complex ethical issues were common in home-based palliative care. The nurses engaged in open and professional discussions with clients and their families to support them through the decision-making process. Ethical issues stemmed from family disagreements in relation to care. Difficult decisions had to be made either to decline or prolong treatment or to sign a no-resuscitation order. Many nurses reported that planned suicide was one of the most difficult ethical situations.

Although home care nurses were autonomous in their practice, they were dependent on a responsive, accessible support system to provide quality care and to honor the client and family's plans for living and dying. Unfortunately, the nurses did not always have the needed resources and information to make informed decisions, so with experience, they learned from one another to develop creative solutions to ongoing problems. Nurses reported that they spent considerable time developing and fostering partnerships with family physicians. They found this ongoing struggle difficult and
appreciated situations in which family physicians were actively involved with and responsive to the client and family, and respected the nurses' judgement.

In conclusion, the work of the home care nurse in palliative care is intense and challenging, both in practice and in health care coordination. Because of this complexity, some nurses believe that palliative care requires specialty status and support, whereas others believe that effective nursing practice is more achievable within the generalist tradition.
4.2. Quality of Life and Quality of Care

While there was a diversity of experiences among client and family participants, there was what I am calling a *mainstream context* reflecting the traditional practice model of palliative care at home and hospice. In this study, there were six participants who died at home and one participant who died in hospice to whom I will refer as mainstream. Members from five of the seven families were also involved in the research. The client and family perspectives relate to the research questions on the attributes of palliative care as well as to the identification of gaps and barriers in services.

I will contrast these findings with a very different population that is *marginalized*, particularly people living with AIDS and/or drug addictions. The perspectives of clients and nurses in this setting highlight dramatic differences in quality of life, quality of care, gaps and barriers in services, and the role of nurses from the mainstream group.

**The Client and Family Experience in the Mainstream Context**

The client and family participants in this study clearly expressed the profound and intense nature of preparing for death and dying. Although there were differences between home and hospice death experiences, all of the mainstream participants embraced their remaining days in a manner that I came to think of as *living their dying*. Quality of life entailed living value priorities such as the simple pleasures of being with friends and families and the freedom to do as one pleased. Being labeled *palliative* and having limits set on one’s life was distressing. The participants spoke about living in hope while creating personal and shared meanings and accomplishing the existential work to be done at the end of life.
For many of these individuals, processes of transcendence and transformation that I have termed “moving beyond” accompanied the palliative care experience. Those who were dying reached a place of peace with freedom from pain and fears. Many families expressed fulfillment in caring for their loved ones and spoke of profound spiritual experiences. Clients, families, and care providers came to terms with recognizing death as part of life and were affected, each in their own way, by grief and loss.

Living One’s Dying

Whether the participants were at home or in hospice, they emphasized that they were very much alive and living life to the fullest, acknowledging their limitations. Many did not speak of dying until death was imminent. Their lives continued to have quality as they focused on what was most important to them in their remaining days.

Quality of life

Although their lives had all changed profoundly, there was clear evidence that each participant valued living, and articulated quality of life in ways that reflected their different personalities and priorities. At the same time there were common themes, the most important of which was being with cherished family and friends as part of their usual everyday world. All of the clients were adamant about not going to hospital unless absolutely necessary and for short term care only. A son explained why he and his brother were committed to caring for their mother at home:

Here she is part of the world still. She follows what’s happening in the news. She’s good company. She’s always been fun, and she still is. It’s her wish to stay here forever. The purpose of mom being here is so that she can have as good a
day as she can get. Even though she can’t get up, she can look out the window from her bed and see the weather and the neighbours walking by.

This woman had lived over 50 years in the same home, and she had many friends and neighbours who were involved in her care.

In one family, the client was divorced and had been living with a woman who limited his family involvement. The woman had paranoid schizophrenia and her husband had died from a brain tumor. Although she was very dependent on the client, she knew that she would be unable to care for him when his health declined. The client’s daughter explained why it was so important for her father to move into her apartment.

I think the most important thing for me was to have dad here because I felt that he was peaceful and quiet and I knew that he was getting really good nutrition and vitamins and proper rest. And not having people sort of coming and going and being disruptive and, I knew that he was getting quality time. And I think that gave me strength to continue in the situation. I wasn’t really losing faith but I was losing hope that he would have a peaceful death. That was one main thing, having him here. The other thing was knowing that he could have mom’s support. And I know that mom could communicate and understand him and you know he could share things with mom that he couldn’t necessarily share with me. Not because we weren’t close, but there were things that dad wouldn’t tell me that he would tell mom and he would talk to her about being frightened or worried about his illness and he would sometimes not tell me things like that. He’d pretend that everything was fine because he’s my dad.

This man wanted peace and the freedom to come and go as he pleased. He was very content that he could be with his daughter and former wife in the remaining time he had to live.

For many people, the quality of their life was expressed in terms of the simple pleasures of everyday life, such as eating what and when you wanted. Because such freedoms were highly valued as a part of living their dying, the advantages of being at home or hospice, instead of in an institution, were evident.
All six participants who chose to die at home demonstrated a strong will to live. That is why they wanted to be home - to be connected to the living. They had made their wishes very clear to family members, the home care nurses, and the physicians. They continued to live their passions, such as gardening, crocheting, or keeping in touch with world events. The nurses believed that one-to-one care in the home created an environment in which people had a better quality of life than they would if admitted to hospital. Further, they believed that people retained their will to live and therefore lived longer if permitted to remain in their homes throughout their dying experience. A nurse recalled one of her client’s wishes: “He wanted to stay at home because he said ‘I’ll die if I go to hospital. That’ll be the end of me’. He’d be totally knocked out in hospital. And you know he probably got better care at home.”

The client and family certainly experienced more autonomy in their own home. They came and went as they pleased and carried on with the simple routines of life. The family was less disrupted than when the client was in hospital and they could be together 24 hours a day. When it became burdensome to travel outside the home for medical and lab appointments, the clients chose either to be admitted to hospital for a short period of time, or to decline treatment and request that the family physician and lab technicians visit at home. Fortunately, for all six families, the primary care team was able to support them in a planned home death.

The woman who I met at the hospice had to give up her apartment because she could no longer live independently. After a long stay in the palliative care unit, she was transferred to the hospice. Her daughters and friends visited regularly, and she especially enjoyed the company of the other residents, and being cared for by the many staff, the
highlight being afternoon tea. Her life had been abusive and for her, at this time, she had comfort, contentment, and all that she needed in her new home. She amazed everyone by living for another year.

Through everyday experiences amidst family and friends, the client participants embraced living to the fullest extent possible, enjoying the simple pleasures that were important for them.

Living with hope

Another prominent value shared by clients and families was to live with hope for the future, however uncertain it might be. Unfortunately, some participants felt their hope vanish when their doctor told them that they had a specified number of months or years to live. For example, one man with a brain tumour was told by an oncologist that he had three months to live and he lived one year from the time of diagnosis. He said that it had a very negative impact on his family. His daughter described that event:

Without having some hope you can't have a future. And so I asked the doctor not to put any time limits on it. And then the next doctor he saw did. He said he had three months to live. And that really crushed him that day. He was looking forward to something that was six months away at that time. But he just gave up and died.

Although some physicians believe that proposing limits on life help the family prepare financial and other end-of-life arrangements, all of the clients in this study had outlived their predicted life spans.

Several participants described sensitivity to the use of the terms palliative, hospice, and terminal especially in relation to not giving up hope. Many people didn’t
know exactly what these terms meant and if they did, they were more apt to describe themselves as “sick” rather than “dying”. One nurse shared her views as follows:

I work with them whatever way they’re feeling. So what, if they never totally accept that they’re dying. I mean I don’t know if I would either. I don’t push them to talk about it. If they feel like they want to talk to me about it, then I talk to them about it and then if they don’t, you know, I don’t. That’s just the way they cope. But sometimes the opportunity will come up, and you’ll be able to say, well have you dealt with this or what are you doing about that or how do you feel about this? I usually let the people dictate. I don’t say, oh how do you feel about dying?

It’s interesting because even when I say I’ll tell you about the Palliative Care Program, I think to myself, you know, Palliative Care Program? They may not see themselves as palliative, and so sometimes I’ll say, ‘Well I’ll just tell you about the services that are available for you’.

Or, the other thing is the hospice physician. Well they want to know what a hospice physician is. And I say, ‘Well, it’s somebody who comes to your house and helps you with symptom management and works with your family physician so you don’t experience a lot of pain. I don’t say they’re somebody to help you with dying.

Another nurse found it difficult when clients did not accept that they were “palliative”.

She shared this story:

One of the things that is difficult is our expectations of the client and how accepting they are of being defined palliative. We know they are palliative but they are not willing to accept that they are palliative and they continue to treat themselves as someone who is sick. And who’s very far away from being palliative. And do not want to and refuse to accept the fact that they are dying. We sometimes have a hard time accepting that kind of client.

We have a man like that right now who walked out of the Cancer Clinic with chemotherapy running in his IV and went to a meeting and the IV went dry. But he seems to be managing very well doing it his way. And his wife is a psychologist even. He probably will never accept that he’s dying until he just drops dead. And that’s the way it is.

The nurses recognized that most people preferred to talk about living and would talk about dying only when and if they were ready.
Clients had to be identified as "palliative" before they had access to the services they needed to be supported in their home. However, for many people, the "palliative" label created a complication because it was at odds with their desire to retain an attitude of hope. Health care professionals needed to find appropriate ways to convey the reasons for palliative care services without actually forcing clients and families to confront time and mortality before they were ready. The nurses' sensitivity and respect for the person's need for hope were essential, especially in the context of being categorized with a life threatening illness.

Many client participants spoke freely about their hopes and dreams. When their conditions were relatively stable, they dreamed about long term plans, such as travelling to new or special places in the coming months or year. Hoping to walk again, see clearly, and have energy were common desires. Hopes for children and family members were also shared. In time, the clients would speak instead of their day-to-day dreams, and hoping that tomorrow would be a better day. As death approached, they hoped for peace and freedom from suffering and pain. As daily circumstances changed and plans evolved, hope served a purpose in living their dying.

Creating personal and shared meanings

Many participants shared the significance of creating meaning of their experiences and of their life in general. For clients and families facing death, everyday life had new meanings. They found significance in simple pleasures amidst pain and suffering. One man loved gardening and had planted many bulbs in the autumn preceding his death that winter. His daughter was looking forward to the spring when the flowers
would remind her of him. For some people, eating a favorite food was a reminder of their cultural traditions and their past. For families and friends, preparing special foods symbolized caring and nurturing. Family celebrations were of major importance, as everyone knew it was perhaps the last special occasion together.

Many clients explained that being at home had special meaning related to their family history. For one family, saying goodbye to their mother as she died was very significant because they had had no involvement when their father died. The daughter described the family situation:

I think it was really important for me to have been so involved with my mom’s care because I felt so cheated when my dad died. And it took me a long, long time to get over my dad’s death, if you ever do get over it. Because he was taken from the house in the morning by ambulance and none of us thought to say goodbye. Mom never even got to say goodbye. And he died on the operating table. It took me a long time to come to terms with that. So comparing that, mom’s death was a lot softer, well more natural too. I mean you know she was 87. So it’s been a really good healing for me in that sense too.

Another woman’s sister had died peacefully at home and had left her financial support so that she could do the same. She felt that she was honoring her sister by spending her final days at home, although she was concerned about being a burden to her children. In another family, the client’s mother had been very unhappy in a nursing home. Therefore, she and her sons were most reluctant to have her go to an extended care facility. In addition, this woman was profoundly deaf, and had great difficulty communicating outside of her home. In all of these situations, there was not only great comfort, but also significant personal and shared meanings for living their dying at home.

Some participants also overtly explored the ultimate meaning of their lives as they lived their dying. They posed existential questions in wonder or fear of what lay ahead. Several elderly participants questioned why they “lasted so long” and said that they were
“ready to go.” In contrast, others felt that their lives had been too short and wondered why they had to leave the world at this time. Clients, families, and nurses faced many questions about the meaning of life and death, and came to new realizations, each in their own way, as they journeyed together and learned from one other. These everyday meanings of being at home and the more profound existential meanings were necessary for actively participating in preparation for the end of life.

Accomplishing work at the end of life

Another way in which these participants lived their dying was by identifying things remaining to be accomplished in their lives. All of the clients shared the many plans and projects they wished to complete before they died. Family members also had a sense that there was much work to be done in a limited amount of time. Advanced planning for place of death, end-of-life care, funeral and legal arrangements were practical tasks that needed to be considered and accomplished. Adult children caring for their parents at home were committed to following their parent’s wishes and to “giving back” for all the years they had been nurtured and loved.

For many client participants, the work that remained had to do with leaving the relationships they had with loved ones as positive and clear as they could. Life review and sharing memories were ways to acknowledge one another and to mend or strengthen relationships. Many participants spoke freely of their childhood, family relationships, joys and sorrows, accomplishments and regrets. One woman who had had an unhappy marriage was comforted in sharing that she had done her best and had kept the family together. Her son lived in Japan and her husband had traveled extensively for years. She
enjoyed looking back at family holiday photographs, as it was the only time when the entire family was together. Although she said that she had never wanted children, she eventually became very close to her daughter who was her primary caregiver. Although initially quite reserved and stoic, over the months that I visited she enjoyed sharing detailed stories about her life in Hong Kong and in Canada.

Several client participants shared that they wanted to be remembered by their families and friends and engaged in creating special projects for this purpose. One person had been fundraising for a year to build the fireplaces at the new hospice. Now, as a resident, he was consulting and raising more money to create stained glass windows above the main fireplace. A woman who enjoyed crocheting was very busy making a sweater for her daughter and other gifts for her friends and family. Her many crafts around the house were also full of memories. It was a way of giving, but also of being remembered.

Through these experiences and stories, I learned that dying is very much about living. The client participants were focused on quality of life and all demonstrated a strong will to live, up until the end of their lives. They valued being with family and friends and having a sense of autonomy. Talking about death and dying did not preclude talking about and enjoying life as it was for them. They had plans, hopes, and dreams, and lived each day to the fullest, accepting that some days were better than others. It wasn’t easy and the journey at times was much rougher and longer than expected. The focus was now on retaining hope, even when the conditions under which they received care made it clear that they were considered palliative. They found new meanings in the simple pleasures of life as they reviewed their past and questioned their future.
Throughout the illness experience and amidst the suffering and unpredictability of death, each client and family cherished these meaningful life events. All of these themes reflected aspects of active living, not withdrawing from life, and were important contextual aspects to understanding the nature of their palliative care experience.

Moving Beyond

The second major aspect of the client and family experience in the mainstream context of palliative care is described as moving beyond and is a natural progression from living one’s dying. Many of the participants recounted a process of transcending the death experience or of being transformed by it. Life was changed and unfamiliar. They developed an ability to recognize death as part of life and experienced a profound sense of peace. Transcending the early pain of grief and loss was difficult and challenging.

Recognizing death as part of life

One major aspect of moving beyond was the capacity to recognize that death was part of life. For these participants, dying at home or hospice was described as a very natural process. Prior to and immediately following death, the family members continued their vigil. For the majority of family participants, this was their first encounter with a death at home. In all situations, the people died in peace and comfort. Except for one woman who died alone in her sleep at night, family members were present at the moment of death.

Several clients and families talked about “letting go” as death approached. They shared this difficult experience with each other and the nurses. Some families had
difficulty parting with the body and, as friends and neighbours dropped by to visit, they decided to have the wake at home. Throughout this time, the family members described how they taught others not to fear death and how they themselves were amazed at how well they had risen to the occasion. One woman expressed these perceptions:

I felt really at peace with his death. It surprised me that I felt that way, but it also surprised people. A lot of people expect for you to break down and sob uncontrollably and I always thought I would. And it was really interesting because so many of our friends had apprehensions about death. You know people are very afraid of dying. It’s funny because people kept saying; ‘Oh you’re so courageous’. I keep thinking well, no. It’s just that, for a lot of reasons, I’ve been able to come to terms with the fact that death is really just another form of life. And I think that’s the main lesson.

This woman explained that she was very surprised at the peacefulness of her father’s death, especially because she had been extremely anxious at the time and had no idea what to expect.

Being at home also permitted the family to honour religious and cultural traditions. One Chinese woman was Buddhist and her daughter was obliged not to move her mother’s body for eight hours, as it was believed that the soul could take that long to depart. The daughter gave this detailed account of her mother’s death:

I told my aunt, who is usually very stubborn and wants everybody to be Christian, that my mother cannot be moved for eight hours. And it has to be done that way. She needs to hear the Buddhist chanting. I played the tapes right after because I couldn’t say anything. I’m supposed to chant it but I can’t. I was crying. And so I keep it on. So mom died at 7am and the funeral home came at around four o’clock in the afternoon.

The daughter also said that she could not move any of her mother’s belongings in the home for thirty days because it was believed that the spirit would return one more time to visit the home.
Those who died in the hospice had become very aware of death and had had many opportunities to talk about their fears of dying with staff and with others in the same situation. In home and hospice, being with people who were dying became part of life for family, friends, and the nurses. In learning about death, they were learning about life.

Achieving peace

Many participants described ways that they were finally able to achieve a sense of peace and transcend the experience of dying and death. Those who were dying described it as freedom from all pain, worries, and fears. They took great comfort in knowing that they would not die alone, and that they would be in the company of their family or caregivers. There would be time to say goodbye. Many family members also described an overwhelming sense of peace knowing they had done their best. They gave very detailed and vivid descriptions of the death experience. Here is one daughter’s account:

Around one o’clock, I was supposed to go somewhere and I just said to my sister, ‘I don’t feel right. And I’m not going to go’. So we stayed with mom - the three of us. And it was just probably around one o’clock on we just knew. Everything was more labored and the discoloration was starting in her arms. And even the color of her skin was different. And so we just talked, we just talked her through it. And she was taking (sighs) harder breaths. It seemed to be really hard to breathe. But we just told her, let go. We told her we were all here and everybody was here and then my sister said to her, ‘Follow the light mom. Follow the light’. And I said to her ‘Go and be with dad, mom. We’re all here’. And she just let out a few more breaths and then that was it. That’s how she went. And it was very, very, very peaceful. And when she let her last breath go, we were waiting to see if she was going to take another one, right? And she didn’t. And she was gone. It was really peaceful for her. And she just looked like she was sleeping. And we held hands around mom and the three of us said a prayer and when my oldest brother said, ‘I’ve lost my best friend’, that just tore me up you know. He was just always so good to her. And she did want to be at home. She did not want to die in a hospital and it was just really great that we could do that. If we had to lose her, this was the best way.
Even though the death of their mother was painfully emotional, the family members were comforted in being present for her especially under such peaceful and natural circumstances.

Some people described a sense of knowing when the soul had departed from the body and that their parent was finally at rest. A daughter portrayed this account of her father’s death:

It seemed very apparent to me, when I looked at him after he died, that his body was empty. You notice the most bizarre things; he was empty like a shell. Like to see the physical aspect of the person but not to see the humanity and the emotional side of him there anymore. Half an hour later, it wasn’t like he was back, but almost like he sort of smiled physically to let us know that spiritually he was okay. Probably everyone smiles when they die. I don’t know. Mind you, the nurse said they don’t. She said some people look like they’re very pained. He was just like when you lay in the sun and you feel that warmth. And all the strain of the past year just went away, and then he had this look, a smile like he was just as pleased as punch, you know. And it was lovely to see that. And I think of him all the time, with that smile. We were most relieved to see him back to looking his old self, younger, relaxed, and so perfect. It was apparent that his spirit had risen up, and his face settled into a most beautiful smile. We knew that he was fine.

The shift care nurse had created a peaceful milieu with candles burning and soft music playing all night. She woke the family to be present at the time of death in the early morning. The daughter and mother prayed together and explained how they found the strength they needed from their religious beliefs.

A hospice nurse shared this account of a peaceful death:

We had a thirty-five year old lady, with an eighteen-month old child, die of ovarian cancer. She was only here four days. There was so much sadness that this family had. Her mother had died of ovarian cancer four years before. Her husband had no idea she was so close to death. Actually her death was beautiful. She wasn’t native, but the Shaman was in doing her healing ceremony and a massage therapist came. She just slipped away during all this. For me, that was a difficult one because I had to tell her husband how sick she was.
Especially in the hospice setting, clients were assured that they wouldn’t be alone at the time of their death and the staff were very experienced in providing comfort and supporting the family. Many family and nurse participants shared a profound sense of peace in being with the person who was dying and were thus able to move beyond their most recent struggles to a place of comfort within.

Transcending grief

Several family participants explained how they were able to transcend grief in their bereavement. The experience of grief and loss was described as a natural yet painful unfolding of events. The families knew that grieving could be lifelong and facing the reality of the person’s death took time. During bereavement interviews, some family participants explained that they focused on the immediate tasks such as organizing the funeral and memorial services, which served a useful function in the early period of grieving. Legal and financial obligations were arduous and were often delayed as long as possible until the family members had the strength to deal with them.

A few people described perceiving the absence and the presence of their loved one all at once. One daughter expressed this paradox as “the empty chair”. Every time she looked at her father’s favorite chair she could sense his presence, while feeling and knowing the pain of his absence:

I think the strangest thing about it all is that I look at his chair there and it’s empty. I’m really happy and I feel relieved of a lot of my responsibility. I don’t have to be home to cook dinner. I don’t make proper meals anymore. I’m on my diet. I just can’t get over that he won’t be sitting in that chair. I almost feel like he went on a holiday and he’s got to be coming back. And I guess that’s part of the shock and eventually I’ll realize he’s gone. And then I started crying as I was writing an email to my friend. Every time I sort of revisit that, I realize that no, he’s really not going to be back in that chair.
The grieving experience of this participant, as expressed during the bereavement interview, provided inspiration for the following poem.

*The Empty Chair*

I look at your empty chair  
My heart still aches to see your smile  
I know you are no longer there  
Yet I feel your presence all the while.

The Christmas tree sheds its light  
That only last week you watched me prepare  
You were warmed by the sight  
As you sat in your favourite chair.

I am so glad that you died at home  
You found the peace you wished for  
With mom and I and the nurse by your side  
We felt your spirit depart and soar.

We kept you with us for awhile  
As friends kept coming to say good-bye  
You still had such a beautiful smile  
I can’t believe you are gone, as I cry.

The night is cold and I am tired  
My heart still aches for your love  
I long for spring to watch the flowers grow  
That you planted before you died.

I look at your empty chair  
My heart still aches for your love  
I’ll remember all that we shared  
As you watch over me from above.

Another participant could feel her mother’s presence when she hugged her housecoat, at the same time being aware of her absence. She described these emotions:
I still feel like she’s here, especially in the living room. I had her bedroom door shut for a long time. I’m getting braver now. But we haven’t gone through all her stuff and that doesn’t matter. Sometimes I go in and I hug her housecoat and I just have a good cry.

For these women, the strong reminders of their parents created a sense of connectedness, which helped to ease the pain of separation in the process for grieving. For other participants, such reminders were painful, and they chose to sell the family home, keeping only a few cherished belongings.

Exhaustion set in once the immediate responsibilities were met. One woman described herself as crashing: “I don’t feel strong anymore. I’m sleeping twelve to fourteen hours a day.” Another woman described her exhaustion in this way:

I don’t know what to feel just, okay, that’s another day. And do something. I try to pack my schedule. That’s all. Every day. And I’m exhausted. And I don’t think, I just do.

Eventually they succumbed to the need for sleep and rest to restore their energy. Some people spoke of taking one day at a time and doing only what was essential, while others were able to move forward by returning to their former routine and catching up on what they had not been able to do while they were caregiving.

As discussed previously, nurses and families recognized the need for timely and appropriate bereavement care to bring some sense of closure to the palliative care experience. For many reasons, the home care nurses were unable to engage directly with most families for bereavement care. In addition, they spoke of their own grief, while recognizing that it was very different from the family’s personal experience. They described accumulative grief and loss from their work in palliative care. One nurse described the experience of exhaustion that several colleagues demonstrated following the deaths of many clients:
I know one nurse recently who had five deaths in eight days and this was an experienced nurse who’s great, and really likes palliative care. But she’s exhausted. I mean how do you measure exhaustion? I think if you’re good and you care, that you’re going to have some exhaustion from it. And I don’t know how we address that. I guess that’s on my mind because there have been two nurses in the last two days who have spoken to me that were in tears. There’s anxiety and despair almost the first two years of working in palliative care. I remembered nurses who were so hard on themselves about what they could have done or might have done. It always could have been a little bit better or a little bit different. Always.

Some home care nurses noted that there was no regular forum for them to discuss their ongoing grief and loss. They did so informally among colleagues as time permitted. Peer support varied greatly with some nurses meeting on a daily or weekly basis, and others working long hours on their own with limited support.

At the hospices, the nurses had regular memorial services for the staff and the residents. They kept a memorial table in the hallway with pictures, remembrances, and a logbook for people to write about those who had died recently. One hospice nurse explained how she dealt with all the loss that she experienced:

I always think of the time that it was good to know them because I know they’re all going to die. I often help them to go out to special events. But I’m sad that they’re gone. I try to come together for the next one. The younger girls have a bit of trouble with death, but I’m a bit older.

All nurses, but especially those who were younger and inexperienced in palliative care, explained how transcending grief and loss was an ongoing challenge in their practice.

The depth and intensity of grief played a vivid part in the experience of caregiving for a loved one, and in supporting that caregiving. The families and nurses grieved alone and together, their lives transformed in their journey with death. In time, the pain of grieving became part of the process of moving beyond.
Client, family, and nurse participants expressed shared views on how they were able to transcend the experience of dying and death. For clients and families, the dying experience connected them to the larger focus of living and dying, to some ultimate purpose, to a sense of lives well lived, and an awareness of completion. Their existential moving beyond reflected death as part of the cycle of life. There was a profound sense of peace for all involved in this study when a death occurred naturally at home or hospice. For nurses, moving beyond the many experiences of death in their practice was an ongoing challenge, leading to their own personal and professional development and growth.

Summary

When clients and families can be supported to live their dying in the home or hospice setting, they can share hope and meaning, while preparing for the end of life. They can move to a place of peace, of grief, and of loss, while recognizing death as part of life and being transformed along the journey. These aspects of living one's dying and moving beyond are ideals shared by nurses to which they devote a lot of their care and attention. Their hope is that the living will be as good as possible and that the moving beyond will enable clients and families to accept death as well as to rejoice in life. The traditional model of palliative care worked well for families in the mainstream context, who were focused on living with dying and making meaning of this experience.
The Client Experience for Marginalized Populations

Current palliative care models were developed for the mainstream population living in homes, supported by family, friends, and neighbours. People living on the margins of society, such as the Vancouver Downtown Eastside neighbourhood, present unique challenges to this traditional view of palliative care services. In this study, there were three research participants to whom I will refer as marginalized. The three men were living with AIDS, and two of them were also addicted to drugs. The man with AIDS is still living; the others have died. In this section, I will discuss the changing social trends in relation to care for people living with AIDS, drug addiction, and related illnesses. The merits and limitations of specialized models of care will be explored, as well as the day-to-day struggles of home care nurses in providing timely and appropriate care from a harm reduction perspective. Findings that highlight the marked differences in marginalized and mainstream populations and in nursing practice for these disparate groups will conclude this section.

Changing Social Trends

These are Vancouver’s throwaway people.
They are used to being invisible.
(A home care nurse participant)

Vancouver has the highest concentration of drug users in Canada and the highest known rate of HIV among intravenous drug users in the developed world. It has been reported that there isn’t a city in the western world that still has this kind of open drug market. The Downtown Eastside is home to an estimated 5,000 active drug users, 50% of whom have HIV/AIDS (Bramham, 2000; Bula, 2000). For most people, drug use is the
symptom of a tragic life. Drug dealing, crime, assault, illness, shooting up in the alleys, and daily deaths from overdoses are a way of life in this neighbourhood. Most people live in slum rooming houses or small decrepit hotel rooms in the inner city, called SROs (single room occupancy), with shared bathrooms and minimal, if any, kitchen facilities. It is the least expensive available housing, with rents for $325.00 a month, the maximum allotted through social assistance. Because sheltered housing has been recognized as a determinant of health, the health board has taken an active role in funding the conversion of hotels to safe housing units.

The demographics of the city’s hotel residents have shifted dramatically in the past ten years demonstrating a sicker, younger, and poorer population. Sixty per cent of the residents are now under the age of 45 years. Women comprise 15% of the population, are much younger, and tend to be hospitalized more than men. Poverty is a reality of life, with employment rates of 7%, a decrease in welfare rates, and an increase in hotel room rents. About 20% of the hotel residents have been hospitalized in the past year, four times the national average, and almost half of that group have spent over two weeks in hospital. Health status has declined with increasing length of stay in the hotel rooms. People are experiencing serious illnesses at a very young age (Main & Hastings Community Development Society & Tenants Rights Action Coalition, 2000). First Nations persons are of particular concern, as they seem to become sicker sooner, spend more time in hospital, and have a shorter survival time (Vancouver/Richmond Health board, 2000).

People living in the margins of society have special needs. Many community services are available in the Vancouver Downtown Eastside including: a downtown clinic, street nurses, a hospice, family assistance workers, mental health services, an
inter-ministerial program for people with mental illness who are on parole, mental health services, and the Native Health Society. A newly formed organization, the Vancouver Area Network of Drug Users, actively engages its members to speak out on local issues.

Criteria for a home care referral include having a place of residence. Street nurses, who are funded by the Communicable Disease Department, see people who do not have a home. They also operate a health van and visit each night in the neighbourhood. Home care nurses are available during the day for those who require end-of-life care, which is usually crisis care. Due to safety concerns, home care nurses and shift care nurses are unable to visit clients in this neighbourhood during the evening and night hours. If the person requires immediate medical and nursing care, admission is arranged wherever a bed is readily available, preferably the hospital palliative care unit or a hospice setting. Admission criteria are flexible to meet priority needs. Care for people living with AIDS and with drug addictions poses the greatest challenges for home care nurses.

Care for People Living with AIDS

When AIDS first became an epidemic in Vancouver in the mid-1980s, the client population was comprised mainly of young gay males who lived in the West End. One nurse who has been involved in AIDS care since that time described how the Home Hospice Program developed based on the needs of the AIDS community. She explained:

What would happen was that people were diagnosed here in Vancouver and they deteriorated very quickly. Then they decided they’d like to go home and be with their families. But we had a large number of them dying at home. Then we ran into a problem during the last three to four days of life when the partners or the families couldn’t manage, because the symptoms got out of control and they would go to hospital or they would panic. St. Paul’s Hospital was the center of expertise. They usually died within three or four days.
So I was involved in a research study to examine the clients’ care requirements at the end of life and as a result of that work, we were funded for shift care nursing. Somewhat later came our on-call physicians. We had a huge number of patients wanting to die at home, probably about a third of our patients died at home. So that was quite new. So these are examples where I see AIDS really pushed the system.

She continued to elaborate on how the scenario has shifted dramatically and that there has been a major change in AIDS care within the last five years due to advances in treatment:

People suddenly weren’t dying. They were living. And what really was a very difficult time for many of them was that they got so well that all of a sudden they had to start thinking about going back to work again. And how would they be trained and resume their life when they had thought their life was over. A lot of them had spent all of their money. They had decorated their places or taken trips because they were dying. There was no cure for AIDS, but now it was a chronic disease. There were a lot more aggressive treatments such as TPN (total parenteral nutrition) and blood transfusions to support quality of life. There was more symptom stability. You couldn’t assume that they were dying.

One participant living with AIDS shared his personal experience on how he has outlived all forecasts. Eleven years ago, he was preparing for suicide because the doctor told him he had about five years to live. Many of his friends killed themselves before their predicted time was up. He recounted these details with great emotion:

I got very ill and the doctor did the worst thing he can ever do to a person who is terminally ill. He turned around and came in my room with his entourage. He was actually a dermatologist and I thought, how lucky doctors have their clipboards to hide behind, and he said, ‘Everybody look at this, a textbook case. Oh you’re still becoming HIV positive. But we’ll draw blood. Now it could be negative. But in six months it could positive.’ And he reached over, and said ‘But don’t worry it’s okay. You’ve still got a good five years left’. Then he walked out of my room.

Tell someone they’re going to die in two years and they will die in two years. They could be perfectly healthy but they’ll die. But I lived to five years as if I should be dead. Five years, ten, what, you didn’t die? It was after five years I started living like I wasn’t dying.

This same man was also struggling with dementia. He shared his fear: “The one thing that scares me is dementia. I’ve seen people with it. I’ve been diagnosed with it. That’s not a
nice way to live. I know I’d be looked after. I don’t think I’d be very happy even if I wouldn’t know it.” He was gay and had become estranged from his family and his partners. His priority was to resolve some of these relationship issues while his cognitive ability was intact. He was able to leave hospice, and is still living in supportive residential care at the time of this writing.

Due to the chronicity of AIDS, more people require long term care and have multiple diagnoses such as dementia, strokes, hepatitis, trauma from motor vehicle accidents, endocarditis, and liver failure. Another major change has been that the care teams, originally an integral part of the AIDS community, have diminished, as this nurse explained:

Initially, they had teams of friends. Gradually all the people looking after each other died. And so, then you would get the second round of survivors coming along and being sick. And they did not necessarily have supports because they had lost so many friends. It wasn’t unusual for people to say, ‘Oh I’ve lost between seventeen to thirty friends’.

This situation has also led to an increased need for respite and long term supportive care.

People living with AIDS represent a younger and more diverse group, as one nurse described the current culture: “Well the average now for sero-conversion is twenty-three years, which is a drop. Whether they’re gay or straight, they’re marginalized. You know, they’re isolated, disadvantaged people.” The man I visited at the Dr. Peter Centre was only 35 years old. He was celebrating his birthday the day we met, and died two weeks later.

Nurses reported that more clients with AIDS are now involved with substance abuse and there is no predictability in health status. Deterioration is closely related to social conditions such as isolation, and lack of food and medications. AIDS dementia has
become an acute problem, especially in conjunction with drug addiction, and often results in the person being evicted from a housing complex because of violence, or the inability to care for oneself.

Another man spoke frankly about his experience living with AIDS and drug addiction. He saw death everywhere he went, on the streets, in the palliative care unit, and in the hospice. He had lost many friends over the past years. He refused to go to any more memorial services, because they were too upsetting. He was on multiple medications, up to 25 pills a day, which he often would forget to take when he was living on his own. He was very knowledgeable about the disease process and could quote his viral load & CD4 count. He had lost 32 pounds in six weeks from diarrhea and nausea, which resulted in his admission to hospice on the referral from his home care nurse. He said that people with AIDS at the hospice found it difficult to relate to people with cancer. At 51 years of age, he was younger than the other residents and was able to return to independent living, while most of the people with cancer at the hospice had a steadier decline in their condition and were there to die. This man’s experiences reflect the complex characteristics of people living with AIDS today, as well as the long-term nature of the illness and the range and number of services that are utilized.

Care for People Living with Drug Addiction

Although I am writing separate sections for people living with AIDS and people living with drug addictions, the reality is that many people lived in both worlds. The nurses reported that active drug users were comprised of a young population with complex care needs related to their intravenous drug use, such as hepatitis C, mental
illness, malnutrition, tuberculosis, and alcohol abuse. One nurse described the lifestyle of drug addicts as follows:

People are controlled by their drug cravings. They're not lying in bed – they're out hustling and scoring. We call it dying with your boots on. They usually go to the PCU when acutely ill. We know them as sick, but not palliative. So they go in hospital and they die. They don't really get to the palliative care part.

Drug use was the main factor in providing care and health care was really a small part of their lives.

There were many other basic day-to-day survival issues, such as obtaining food and safe housing, and avoiding crime and assault. One participant living with addiction explained that “it was an every day struggle not to use” because most of his friends were addicts. He talked about how he managed his pain before coming to hospice:

And the only relief I was getting was when I started using drugs. I mean I was getting instant relief. It's medication. Right. But it was just short-term. Right. Heroin stops pain and you get high on it. Cocaine, you just get high. You don't notice the pain. Then I'd really pay for it, whenever I come down, because I'd twisted something or stressed something.

Being, drug free is the only way to go with HIV, right. It takes me long enough to get that in my head. It's to do it, right. And it's tough. And I slipped a couple times, so what. I get up and I'll walk again, right. Or I can whine and end up OD'ing or whatever, right. If I decide to use, I want to use. Nobody can stop me.

He used fewer hard drugs when his pain and AIDS-related symptoms were under control, but then the cravings would return when he felt better. This man did leave the hospice and returned to his habits of drug addiction and crime. His health deteriorated over the next six months until his death in the palliative care unit.

Like many other drug-addicted individuals, this man had a long criminal record for theft to support his drug habits. This was certainly a factor in providing care to drug addicts, as they could be evicted from their hotels for criminal activity and they would
not receive adequate health care when in prison. If they were found stealing in a hospital
setting, they could be discharged quickly. The nurses in hospice were less judgemental
but acknowledged that theft was certainly a problem. One hospice nurse described this
situation:

We’ve had a few of the real down andouters, the ‘hard to house’ from the
Downtown Eastside hotels. And our last one just walked out with all our money.
He was a likeable guy, but he needed it for drugs.

The nurses tried to prevent theft by ensuring that the person’s pain was controlled and
that they hopefully wouldn’t require hard drugs, but with drug addiction, the cravings
would always return.

The nurses who worked in this neighbourhood said that they never ceased to be
amazed at the survival skills of the street people. With lack of the basic necessities in life
such as adequate nutrition and housing, drug addicts survived crime, substance abuse,
and squalor on a daily basis. The nurses often met generations of people who lived in this
manner for years. Although some people did succumb to overdosing, many did not, as
this participant explained:

And the biggest thing for me was getting over the idea that when I got sick I’d kill
myself, right. That’s what I figured. It just happened one night that I was thinking
about it and I didn’t want to die. Not yet. I don’t know why. No big reason. But I
was pretty sure of myself.

This man described himself as having many friends, and having a quality of life that he
enjoyed. Clearly he found life valuable, and was not yet prepared to embrace dying.

Care for people living with AIDS and with drug addictions is complicated and
demands a flexible approach to meet individual needs in times of crises and in times of
lengthy illness. Basic necessities such as safe housing and food are often priorities. There
is limited if any support from friends and family. Nurses have to understand a very
different social reality, a different outlook on life, and a different set of complex relationships with systems and services. In addition, they need to develop skills to be able to work within a context where circumstances change on a frequent basis in terms of care requirements. Planning is an entirely different issue, and the kinds of plans that are made are qualitatively different from those made on behalf of mainstream clients. Short term and long term needs are best met in community settings where people have some freedom to live their life as they know it and to obtain timely, accessible care when required.

Specialized Models of Care

In response to the particular needs of marginalized people, various models of care were established during the 1990s. There are now two hospices for adults with priority access for people living in the Downtown Eastside. An alternative model of care is provided by the Dr. Peter Centre, which offers a day program and a residential program specifically for people living with HIV/AIDS. The three research participants, who were marginalized, had been involved with the Dr. Peter Centre and two of them had stayed for a period of time at both hospices.

Community hospices

The first hospice in Vancouver, The May Gutteridge Community Home, fondly referred to as May’s Place, has been operating since 1990 in the Downtown Eastside. Cottage Hospice opened in May 1999, and is located outside of this neighbourhood in a former orphanage, overlooking the Fraser River. There is a total of sixteen beds in both hospices with four reserved for referrals from the Native Health Society. Criteria for
admission include having a prognosis of weeks or months of life, and priority is given to people living on their own in the community, and then to those in hospital. The average length of stay is 50 days. The majority of referrals come from home care nurses. Both hospices strive to create a home atmosphere. Families and friends are welcome, although many people have no visitors. Residents and staff eat together at meal times and food is available when requested. A hospice nurse described the hospice philosophy and the diversity of residents as follows:

We aim to make it a home, to advocate for them and to listen. To let them choose whether they really want to live here or whether they don’t want to live here. They are marginalized ones, people with mental illness, drug addictions, or even transgendered. And we certainly are not out to try and cure their drug addictions, just support them and to advocate for them. To make sure they get the best care. To make sure they get the care that everybody else would get too. I really feel strongly about that too. That they should be up there at the front line of care like everybody else whether they’re native, or whether they’re addicts.

We get all kinds of people. One woman who just died was transgendered, native, a drug user, and a sex-trade worker. She was at the palliative care unit for a year before coming to hospice. Her one wish was to go to the PNE, so we took her and she really had fun. She then got very ill afterwards and just died last week. There were about 70 people at her memorial service yesterday at the church downtown. For many people, the hospice became their home, and the staff and other residents became their family.

Most of the residents at May’s Place are living with mental illness and AIDS and are active drug users. They often require crisis care, and come and go as their health condition changes. A hospice nurse described the facility with these comments:

We haven’t defined respite, but we have people who come in here for what we thought was terminal care and have just done so well that within a few weeks they want to go back out. There’s always a hotel room you can put them into and set them up and keep an eye on them. But they know there’s always an open door here. They can drop by any time of the day or night if they’re having problems or if they want a meal or if they just want to sit in front of our TV and catch up with us. Some have come in to have a bath and a meal. And maybe had their clothes washed. And most of them have come back in at a later date to die.
Since many of the residents come and go based on need, the hospice staff are part of a collaborative community network which includes hotel operators and the Native Health Society. Together, they arrange for appropriate accommodations and follow-up through the many available services and with home care nurses.

In one hospice setting, the residents were permitted to use street drugs. One nurse explained:

Once they eat and feel better, the cravings return. We also allow them to inject their own morphine. We have even given them money for a fix if other medications don’t work in order to decrease theft. It’s amazing how sick someone can be and walk off with your portable TV. That’s not dignified for them to have to steal.

The new Cottage Hospice does not permit people to use drugs on site, so the resident population varies accordingly, with most people having cancer. One man described it as “a palace in the middle of nowhere”. He was from the Downtown Eastside and it was an unfamiliar neighbourhood for him. For others, the beauty of the peaceful surroundings was a welcome retreat and change from their former neighbourhood.

The hospices offer a community-based, flexible, client-centred model of care for people on the margins of society. Because they rely largely on funding from private sources and the assistance of volunteers, they are restrained in expanding their services. Beds are limited with a waiting list of up to 30 people. Care for people living with HIV/AIDS and drug addictions remains a challenge as they are often in and out of hospice and require interim services sometimes on a long-term basis.
The Dr. Peter Centre

The Dr. Peter Centre is an innovative, flexible, comfort care model for men and women living with HIV/AIDS whose multiple health and social circumstances put them at risk for chronic and life-threatening health deterioration. The mandate is broader than palliative care. The centre is a non-profit group home funded by the Ministry of Health and the Vancouver/Richmond Health Board that offers a day program and a residential program. The interim centre is in a former hospital building situated in close proximity to St. Paul’s Hospital, which is the Centre of Excellence for HIV/AIDS care. A permanent new facility is being planned nearby with public and private funding (Dr. Peter AIDS Foundation, 1998).

This is one of the few programs that serves the population of the Downtown Eastside outside of their neighbourhood, and is a place of refuge for those who want to get away from that area. Unfortunately, as one nurse explained, there is much competition between various organizations to keep services in the designated community:

In my view it’s like everybody would really be happier if the whole marginalized HIV population would stay in the downtown eastside and the urge seems to be to put the services in there. And my own feeling, there seems to be a lot of services down there. I think everybody is working very hard to keep their turf.

Although the centre is well established, there is still some outside criticism stemming from competition for funding.

The day program offers meals, medication supervision, and social activities on a drop-in basis five days a week and is often the transition a person needs to residential care. The goal of the program is to improve the health of the hardest to reach people and help give meaning to their lives through improving their ability to manage their own care.
and to increase their involvement in decision-making. Currently, about 60 people visit the
day program with over 100 people on the waiting list.

The ten-room residence provides 24-hour supportive, compassionate care
including palliative care, respite, and stabilization for individuals who no longer
find it possible to live independently. There is an increasing number of people
with AIDS dementia who are referred to the residential program for long term 24-
hour monitoring of medications and meal provision. Drugs are not permitted on
site, so drug addicts must be motivated to come to the centre.

In 1999, the length of stay varied from five months to one year, with an average of 20
people on the wait list. Admissions to the residence are primarily from St. Paul’s Hospital
palliative care unit when people get better and then have nowhere to go. Others are
admitted from the day program or referred by home care nurses. Although the program is
regional, people come primarily from the Downtown Eastside.

Guided by a shared-care model, the staff encourage residents to participate in
their own care as much as possible. Comfort care focuses on living, and dying as part of
living. Community-based health care is available through the resident’s family physician
and the Home Hospice Program team of home care nurses, hospice physicians, and shift
care nurses as needed. For acute symptom management, the person would be admitted to
the hospital palliative care unit and their bed at the centre would be held in the interim.

A major benefit is that the residence provides a continuum of care. If a person’s
condition stabilizes, or if their care is long-term, they do not have to leave the residence.
A nurse working at the centre explained:

The questions now in hospice and the palliative care unit are, what do you do with
the people there who are not dying tomorrow? Or what do you do with the people
who get better? And where do they go? Because for so many, I mean particularly
if you’re talking about the AIDS population, if you send them out they will
deteriorate.
This nurse was critical of the community hospice program, which she believed was developed as a middle class model for palliative care. "It's palliative care in a certain way for certain people." She was also concerned about the medicalization of palliative care: "It's all about good nursing care. As time has gone by, I have seen it become more physician intensive and treatment focused and interventionist."

As previously mentioned, I visited one of the residents at this centre who was living with AIDS and drug addiction. The nurse described him as "a career criminal, a crabby little guy, but really likeable". He had moved away from the Downtown Eastside and was commuting to the day program. He then went to jail, became very ill, and was admitted to a regional palliative care unit. After being discharged, he continued to visit the day program, but became very ill again, and was admitted to the downtown palliative care unit. Again his condition stabilized, but this time, he had given up his apartment and had nowhere to go. He was admitted to the residence where he lived until his death. Even when he was very ill and could hardly walk, his friends would carry him to take the bus to the Downtown Eastside, where he would have a fix, and then return to the Dr. Peter Centre. His life was typical of the long term, unpredictable nature of AIDS and drug addiction, and the involvement of multiple services and agencies over time.

For many residents at the Dr. Peter Centre and at the hospices, it was the most positive and caring home-like environment they had experienced and a welcome change from being in a hospital palliative care unit for an extended period of time. Participants appreciated receiving regular meals and careful monitoring and administration of their medications, which had become a tremendous burden for them. For the most part, their pain and symptoms were under control. One significant difference for these individuals,
however, was that they were “surrounded by death”. People were dying all around them and they shared their grief and loss with each other. There was the constant reminder that they would soon be going to the same unknown place.

The models of care provided at the two hospices and the Dr. Peter Centre do fill a gap in palliative care services for marginalized populations. However, the number of people on the waiting list at all places is testimony to the demands for and limits of the programs. The nursing administrator reported that evaluation of services at the Dr. Peter Centre has identified that the greatest demonstrated need is for the drop-in day program providing food and supportive care. The strength of the residential program at the Dr. Peter Centre is that multiple levels of care are provided so that the residents do not have to leave if their physical condition improves, as is the case in a hospice setting.

**Challenges for Home Care Nurses**

Home care nurses working in the Downtown Eastside described their nursing role as developing a relationship with clients based on a harm reduction model of care. This meant that they had to be non-judgmental, clarify their own values related to illicit drug use, and maintain hope for all clients, valuing their intrinsic worth. The nurses regarded people in this neighbourhood as having incredible strength and determination to have survived the many hardships in their past and to continue to live day to day under such difficult circumstances.

I accompanied two experienced home care nurses as they visited clients in the run-down slum hotels. Excerpts from my field notes describe how their work was very different from that of nurses in other neighbourhoods:
The nurses explained that palliative care was different here and that they worked from a philosophy of harm reduction. They worked together as a team, not only for safety, but also for consulting with each other, as decisions had to be made quickly. They talked about how hopeless these people were but it was very important not to give up on them. One nurse said that in her 20 years of experience, she had only met one person who was still “recovering” from drug addiction.

They walked quickly through the neighbourhood, knowing their way automatically, as I kept up, trying to take in all that we were passing by – the decrepit buildings, full of graffiti and posters, the iron barricades on most shops, the many boarded up storefronts, and the array of people on the streets – all ages, some very distressed, some looking quite “ordinary”, most in old dirty tattered clothes.

The nurses would enter doorways at the various hotels, ringing to gain entry or acknowledging the attendants as they walked by. Several places were secured and we needed to be let in. They talked all the way about whom they were to see and what their plans would be. They constantly answered their cell phones – usually a hotel worker asking them to visit someone else today. They replied promptly and obliged all requests. We climbed the stairs at all the hotels (whether there were elevators or not) sometimes 4 or 5 flights. The smells were overwhelming – stale smoke, urine, and indescribable stench. Due to asthma, I had to take my Ventolin inhaler en route. They teased me, and said I would never be an Eastside nurse. They worked quickly, pausing only to wait for the clients to answer their door. Some were out; some did not answer, still asleep. One man’s room was unlocked and his wheel chair was still there but there was no sign of him. The nurse knew this was unusual because the man couldn’t go out without his chair. She cautiously looked on the far side of the bed to make sure that he wasn’t dead on the floor. The nurses were both concerned and contacted the hotel attendant immediately to learn that the man had recently been admitted to a palliative care unit. Their anxieties were relieved.

Most of their care involved administering several medications, usually anti-retroviral drugs and analgesics, such as the Duragesic patch. They carefully dressed arm and leg wounds and abscesses, gave insulin injections, while making skillful general assessments. With all clients, they were respectful, explained fully what they were doing, and were reassuring. They advised some clients to see a doctor or dentist that day and knew where to refer them. They were well known and respected by the people, which wasn’t always the case, as they recounted past incidents with some angry clients. I was surprisingly unafraid in this strange environment and was comfortable in the company of these very competent nurses as we greeted people in the hotel hallways and lobby, and on the street.
These two nurses were exceptionally competent and highly respected by their clients and their colleagues. They had worked together as a team for many years, and believed that their work was meaningful and relevant to the population they served. However, recent challenges from their administrator made them believe that support for their practice of working together might not be continued, and they were consequently angry that the nature of their work was not recognized for its complexity and social relevance.

Basic care was a priority, especially the provision of food, but even that could be a problem. A canned nutritional supplement was a very effective means of providing food, as it required no preparation or refrigeration. Unfortunately, it had a high street value and was easily sold or exchanged for drugs. The nurses had to be creative in the distribution, such as giving the supplement with medications or after wound care to ensure the client took it. As for anyone at the end of life, food was very important. One nurse shared this experience:

With him, palliative care is making sure he has his ice cream because that’s what he really loves. We had a big meeting to get him ice cream. It was difficult since he didn’t have a fridge or freezer. It doesn’t sound like much – pouring a few pills and making sure he gets ice cream, but that’s palliative care for him.

The nurses recognized such basic needs as important for quality of life. Unfortunately, even simple requests for food often entailed much planning and consultation.

Wound care was never a straightforward procedure either. The wounds from repeated intravenous drug use were painful and infected. The clients’ accommodations were unsanitary and healing was delayed. Many people were reluctant to remove their clothes or to be touched, often because of their experience with physical and sexual abuse or because they didn’t want anyone to see their wounds. The nurses did their best under the circumstances to work quickly, reassure the person, and apply the most practical
dressing, all the while teaching about safe shooting and saving a vein. These excerpts from my field notes describe the situation of two women and the care that the nurses provided.

We saw a woman complaining of swollen eyes since yesterday – she could hardly see out of the left eye. Her older male partner left the room. Of more concern was a large draining ulcer on her left leg with redness down to her foot that the nurse observed immediately. The woman said that it was better that it had been, and the nurse asked her if it was from a fix. She said ‘yes’. The nurse dressed the wound and advised the woman to see a doctor at the clinic for her eyes and her leg. She was having her leg dressed by the street nurses in the Health Van at night, but she said that they didn’t show up last night. She told us that she would go to the doctor today.

The next woman was a return visit. The nurses had seen her last night at the drop-in for street women. She was complaining of a painful vulvar abscess and went to the Emergency Department on their advice. The abscess was incised and she had a packing in place. She said that it felt better, but it was still sore. We had seen her earlier that morning and came back after she had a Sitz bath. The nurse had suggested she use it on the toilet, but she did it in the privacy of her room and soaked the carpet. The washrooms are quite unsafe especially for women. Together, the nurses removed the packing carefully, but the woman was writhing in pain. I sat at the head of her bed and held her hands and talked to her. She needed a lot of reassurance and repeated explanations of what we were doing.

A wound care procedure was an occasion for a thorough assessment, as well as for teaching, planning, and meeting other requests, and for these nurses, required a team approach.

Another difficult challenge for nurses was to manage pain. People with addictions have a high tolerance for narcotics and can require exceptionally large doses for pain relief. A hospice nurse described the difficulty controlling pain for one woman who was a drug addict:

She had cancer in her mouth and her legs were full of ulcers and her liver was failing. It was just a terrible death. It shouldn’t happen to anybody, that kind of thing. She had a tumor pressing on all the nerves in her neck, so she couldn’t use her hands. So many things to give up. So many things to let go of. It was difficult to control her pain because of the tolerance. We changed narcotics so many times
for her. She was on two thousand units of Dilaudid a day with a syringe driver when she died.

In these situations, it was a challenge for nurses to administer and monitor an appropriate dose of narcotics that was usually well beyond recommended levels, in order for the client to have even moderate pain relief. The nurses could not rely on recommended dosages, and had to closely observe the clients not only for pain relief but also for potential dangerous side effects. On the street, the nurse worried that the client would overdose or sell the drugs when they had a supply to take as required, and they never knew exactly what other hard drugs the person was taking. In supervised hotels, all drugs were locked and distributed by the hotel attendant. Nurses did not carry narcotics for safety and legal reasons, and were obliged to obtain frequent renewal orders from the family physician. Family doctors often under-prescribed narcotics because of the high street value. Clients would subsequently have to visit the doctor more often to be assessed and to renew their prescriptions.

Nurses reported that it was a typical pattern for drug addicts to end up in crisis situations on a regular basis and to be transferred by ambulance or police to the hospital. Most often they refused, and it was always an ethical dilemma for the nurse to send people to hospital against their wishes. One nurse summarized the problem as follows:

Their needs are so great. It all happens so quickly and it’s so dramatic all at the same time. You know they need acute hospital care, but the main problem is their willingness to go. They don’t recognize that they need to go.

Unfortunately, the policies and practices of institutional hospitals do not always serve this population well, especially those living with HIV/AIDS, drug addiction, and mental illness. There is a reluctance to go to hospital for it is seen by many as a jail. If admitted
to hospital, especially a general medical unit, street people often discharge themselves after a short period of time, usually in very poor condition. One nurse told this story:

One woman went out of the hospital and landed in the community because the nurse caught her using drugs and cut her visitors off. She’s like probably eighty pounds. Very advanced HIV. She can’t walk or anything. Her boyfriend put her on his back and took her down to the hotel and she was in this bed with nothing. And we couldn’t get her anything. You know we couldn’t get her a homemaker. They couldn’t facilitate that.

And you know that we would need to respond immediately. Because all of a sudden they don’t have a doctor in the community, they don’t have a pharmacy in the community. They have nothing. And you have to pick the pieces up somehow. We had to send her back to the hospital. But a lot of the times they don’t treat their addictions quickly and efficiently like they should. And so immediately the person is sending somebody out to get them something.

Nurses reported that clients are frequently discharged or leave hospital on their own without receiving adequate care and with no plans for follow-up. These are situations when the nurse has to intervene to access resources if possible, or send the person to a hospice or back to hospital.

Continuity of care is always a challenge as the clients are transient and not easily accessible, especially during daytime hours. It is often the home care nurse who walks the streets and visits in the hotels who is the first contact that individuals have with health care services. Because women are notably more difficult to access, the nurses visit the WISH Drop-in Centre for women in the sex trade every Monday night to establish and maintain contact in a safe place.

Although street nurses employed by other agencies also work in this neighbourhood, there are no administrative or formal connections with the home care nurses. However, the nurses do refer to each other and they find out from the people which nurses have been involved in their care. Some street nurses are hired primarily for
STD prevention, screening, and treatment. Others operate the Downtown Eastside Health Outreach Van and visit the street people every evening, primarily women, to offer nursing care.

The home care nurses reported that they had developed excellent collaborative professional relationships with the neighbourhood family physicians who were readily available and very experienced in care for people with AIDS and drug addictions. They worked collaboratively to respond as quickly as possible to provide complex care that was acceptable to the client. There was never much time for advanced planning. The nurses expressed anger and frustration on a daily basis when resources were limited to meet even basic needs and, more so than in any other neighbourhood, they worked closely with social service providers. Unfortunately, the demands of the nurses’ daily work responsibilities did not permit them time to become involved in addressing complex system issues through more formal intersectoral collaboration.

It is evident from these findings that palliative care for marginalized populations, specifically people living with long term illnesses such as AIDS, drug addiction, and mental illness, is complex and involves multiple levels of interdisciplinary and intersectoral collaboration. Palliative care for this group of people differs from that for people with cancer, as there is no predictability of imminent death. Their specialized needs result in major challenges particularly for home care nurses who strive to maintain contact, provide essential care, and coordinate other service providers often in overwhelming circumstances. Barriers to accessing of mainstream healthcare services continue for many reasons, but primarily the unwillingness of marginalized people to seek institutional care. Thus, in times of need, they frequently end up in the hospital.
emergency departments for crisis care and are promptly returned to the cycle of poverty and despair. Quality palliative care is available in the two hospices and at the Dr. Peter Centre. The highly specialized model of multiple levels of care at the Dr. Peter Centre demonstrates the most appropriate and creative response to the challenge of providing short-term and long-term care for people living with AIDS. However, there remains a gap in accessible 24-hour crisis care in and beyond the Downtown Eastside neighbourhood.

Summary

Findings suggest that quality of life and quality of care are dramatically different for mainstream and marginalized populations, as reflected in the client and family experiences, nursing practice, and program models of care. All of the mainstream clients in this study had cancer, with a steady decline in their health, and had the support of numerous family members, friends, and health care providers up until their natural death at home or hospice. For the people living with AIDS and/or drug addiction, their illness trajectory was much more long term and complicated by many other serious diseases. As their condition changed, they moved frequently from unsafe housing conditions to hospital, to hospice, to residential care, and sometimes in and out of jail. Family was far removed, and friends were few and unreliable due to their own socially complex problems. Dying at home was not an option, even if they had a home, and suicide was reported to be a common occurrence. Quality of life certainly had very different meanings and was based on disparate values.

Nursing palliative care practice in the mainstream context focused on working collaboratively with clients and families to avoid end-of-life crises, throughout which
nurses established long-term meaningful relationships and felt rewarded. The nurses carried the majority of responsibility for care in the home with inconsistent support from family physicians. Ethical issues centered on family disagreements regarding treatment, place of death, and end-of-life care. In contrast, nursing practice for marginalized populations was based on the principles of harm reduction and crisis care in extensive collaborative partnerships with neighbourhood family physicians and social service providers. Clients were rarely identified as being palliative. Basic care and the social determinants of health were priorities and ethical issues involved personal and moral challenges related to illicit drug use and crime. Nurses believed that they were making a contribution to the quality of life for the people they served, but they were continually frustrated by the complexity of social problems for this population.

Program models of care and patterns of utilizing health care and social services are therefore quite distinct between the two population groups. In mainstream society, palliative care services are provided primarily at home through the Home Hospice Program with brief hospital admissions for respite, acute symptom management, or end-of-life care. In contrast, marginalized people are frequent users of acute care services, especially emergency departments and palliative care units. Nurses are limited in the types of services they can provide in the home and readily refer clients for more appropriate care in hospital or hospice.

In conclusion, care for marginalized populations, especially for people living with AIDS and drug addiction, is not palliative care as it was in the past. The traditional model of the Home Hospice Program is no longer appropriate for the majority of marginalized
people. There is a dire need for creative and flexible programs to provide highly specialized crisis care and long term care.
4.3. Increasing Tensions within the Health Care System

The changing context of the system within which health care is provided and nurses work has had a tremendous impact on palliative care in the community. Unfortunately, the practice of home cares nurses and client and family experiences of palliative care are often discussed outside of this context. Considerable tensions exist from increasing demands for community-based programs and limited resources with which to deliver them. Knowledge of this larger context will help us more fully understand the role of the nurse and quality of care issues, and in so doing, we can better grasp the complexities inherent in community-based palliative care.

Rising Demands for Palliative Care Services

A major theme in discussions about the health care system with all participants was concern for the increasing demand for community-based palliative care. The growing complexity of care associated with technology in the home and complicated family dynamics were important considerations. Nurses raised many issues in relation to equitable access and appropriate care for diverse and underserved populations.

Increasing Complexity of Care

The nurses reported that both mainstream and marginalized populations have increasingly complex palliative care requirements. Advances in technology have resulted in prolonging life with intensive treatment procedures including surgery, wound care, intravenous therapy, and medication administration. In addition, complex pain and
symptom management is fundamental to palliative care and requires skillful and ongoing assessment and supervision by nurses.

As cancer becomes a chronic illness, there are ongoing advances in technological and investigational procedures. People living with cancer are now supported by multifaceted and often long-term, treatment plans including radiation, chemotherapy, blood products, and analgesics that involve close monitoring and regular laboratory testing.

Nurses attributed the advent of antiretroviral drugs to prolonging life for people with AIDS, thus necessitating a long-term treatment plan. Intravenous administration of antibiotics, total parenteral nutrition, and maintenance of central venous catheters are now managed in the home, whereas a few years ago, people would have remained in hospital for these procedures.

Another trend is the growing numbers of referrals for children to the Home Hospice Program. Although the pediatricians are very involved, they are not usually experienced in palliative care. A home care nurse described why palliative care for children was very different and challenging:

I'm caring for a little boy who's six. He has a brain tumor. He doesn't have a good gag reflex. So he's not supposed to be fed orally. He had a naso-gastric tube. He kept pulling at the NG tube, and he pulled it out, and his mom's been feeding him orally. He's supposed to have a gastrostomy tube, but the mom refuses to have the surgery because he's just had quite a bit of surgery. He's just had four surgeries in the last couple of months. So right now, that's what she's doing. She's feeding him by mouth. And the physicians are all aware. I contacted the pediatrician when I realized she was feeding him orally. He said that if we don't support her, then she wouldn't trust anyone. He was fantastic actually. He was really good to talk to about it. The child has been okay so far and it takes her all day to feed him. So our role is quite different, in supporting the mom, you know, as opposed to really providing the care to the child, because that's her role. It's difficult because I just don't feel like I have the knowledge about pediatrics. I
haven’t had to deal with a lot of children. I imagine that’s going to be really difficult.

In addition to having children on the hospice program, the nurses noted that there were more referrals for young adults in their twenties and thirties, usually with cancer. Supporting young families was often a very difficult and emotional experience for nurses.

The second main consideration in complexity of care relates to individual client and family situations. Complicated family dynamics are common in palliative care practice and care requirements often extend beyond the original reason for referral. One home care nurse described her experience with the following family:

There was one situation recently where an adult son in the home had paranoid schizophrenia, and his paranoid behavior escalated as his father’s condition deteriorated. When his behavior became really unpredictable, we had to pull out the home support workers. We continued to visit but felt at risk, and didn’t feel that we could have shift care nursing in there either. So what happened was the father did go into the palliative care unit but it was less than 24 hours before he died. So we did manage to keep him at home. The primary nurse is keeping in touch with the mother.

This situation highlights how a referral for one person can involve taking responsibility for the other family members. There are similar concerns when caring for elderly couples, and the needs of an aging spouse must also be addressed. For example, one home care nurse explained this situation:

Actually one couple I visit both have cancer and they’re in their eighties. So their family is older and they have to deal with their own lives and their own children. It’s very difficult because they both need one another to keep on. So when one person dies, the spouse will probably require extended care.

With increasing complexity of care, home care nurses are becoming more involved in situations where they are caring for and supporting not only the client, but also several family members. Under these circumstances, families are limited in their ability to provide care for each other and the nurse assumes greater responsibility.
Nurses described palliative care for people with drug addictions as perhaps the most complex nursing practice, due to the many unknowns and the unpredictability of the client’s lifestyle. There was no detailed chart to consult and the client’s personal history was not always reliable. Multiple factors were considered in every decision about care, which was usually a crisis situation involving critical thinking and a quick response.

The increasing complexity of palliative care at home and in the community is a significant factor in the growing demand for services that have become highly specialized and require intensive involvement of nurses. In addition, the long-term nature of cancer and AIDS, in particular, places a new dimension on palliative care programs originally designed for people whose life expectancy was months, not years.

Access for Diverse Populations

Although Home Hospice Program services are available throughout the city, nurses reported that access to palliative care services was inequitable across different populations. Family and nurse participants shared high expectations for palliative care services with a common belief that dying persons have the right to stay at home and in their community as long as was possible and desirable.

In the neighbourhood with the highest number of palliative care referrals and home deaths, a home care nurse explained that many of the people had lived in the same area for several years and had a well-established community network. There was good family physician support, and the nurses were very experienced in palliative care as it comprised up to 80% of their practice. One home care nurse shared the following description of this neighbourhood:
In my neighbourhood, in one of the last probably eight deaths, one went into hospital for less than 24 hours. The rest have all been at home. I think that’s just the way people are in that area. They increasingly want to die at home, have high expectations for services and care at home, and are used to having control in their lives.

We’ve become too successful in our program. And I can’t see it getting any less. I mean we’re a part of our own success because we have expanded this role. And people are aware. The physicians are aware. Families are talking. Word in the community is that, yes, in fact, this is a viable alternative to dying in hospital.

Families expected to have respite and end-of-life care in the home, which was usually provided by shift care nurses. Based on the 1999 shift care nursing statistics for the six community health areas of the city, 45% of the clients were from this one community. In general, people in this neighbourhood knew how to access available services through their family physician and home care nurses, and they also had caregiver support which is one of the main criteria for admission to the Home Hospice Program.

In contrast to this pattern, there was a native reserve nearby that had few referrals to the hospice program. When the nurses were involved, it was to support the families and community members who assumed the full responsibility of caregiving in the home.

It has been reported that diverse ethno-cultural groups throughout the city tend to utilize acute care services rather than the Home Hospice Program. Suggested reasons for their restricted access to available community services included difficulties in communication; unavailability of caregivers in the home; poverty; and cultural beliefs that do not permit dying and death in the home (Vancouver/Richmond Health Board, 2000). Unfortunately, hospital programs are sometimes limited in their ability to honor ethno-cultural beliefs and customs. Nurses also noted that cultural influences accounted for differences in the number of home deaths by neighbourhood. For example, they
reported that two culturally diverse communities had the same number of palliative care referrals, but one had twice the number of home deaths. The neighbourhood with the most limited access to palliative care services provided by the Home Hospice Program was the Downtown Eastside. The primary reasons for this pattern is that clients have little family or community support, and their housing conditions are unsafe for health care providers. The reality of widespread poverty contrasted starkly with the resources available in other neighbourhoods. The residents of this community receive palliative care, if any, primarily in hospital palliative care units. Those who survive are then transferred to a hospice or residential care setting. Many nurses commented that access to palliative care at home was an issue for clients with long term chronic illness. Nurses had difficulty recognizing that palliative care was required for populations such as the frail elderly, and people living with end-stage renal, cardiac, or respiratory diseases or with multiple sclerosis, ALS, and Alzheimer's disease. For example, one nurse explained that there is a policy for the Home Oxygen Program that clients with chronic obstructive pulmonary disease are visited for assessment every six months. Unfortunately, they sometimes die between the scheduled visits. In another situation, a woman with ALS lived alone and was on long term care. As her health deteriorated, home care nurses were visiting her daily until she died. Regrettably, she was not referred to the Home Hospice Program and therefore was not eligible for additional home support services or shift care nursing.

Until recently, there have been few referrals for frail elderly people to receive palliative care at home. One nurse shared this experience:
We have very frail elderly who are just becoming palliative. I had one fellow last year who was diagnosed as ‘failure to thrive in the elderly’. And nobody could exactly figure out what was wrong, and we knew he was dying. So he was palliative.

The Home Hospice Program consult team has not traditionally been involved with the frail elderly population and is creating a partnership with the consulting gerontologist to address different end of life issues and system support development, by partnering palliative care with general care for the frail elderly.

Overall, people living with cancer were usually referred to the Home Hospice Program sooner than people living with chronic illness. The nurses believed that many clients with chronic illness were never referred for palliative care at home, or to the palliative care unit, and therefore were not aware of the full range of options and services.

Nurses reported that the highest utilization of services of the Home Hospice Program was for people with cancer who had adequate family and community resources. For many different reasons, access to the Home Hospice Program was limited for marginalized populations, some ethno-cultural groups, frail elderly, and people living with chronic illnesses other than cancer. Nurses questioned if the Home Hospice Program was the most appropriate model of care for these diverse populations.

In summary, there are rising demands for palliative care services as advances in technology and aggressive treatment procedures have resulted in prolongation of life especially for people living with cancer, and for people living with AIDS. As care becomes more complex and family involvement increases, expectations for services increase. Unfortunately, access to community-based palliative care is not equitably represented across different communities. These expectations and demands reflect growing tensions within the health care system.
Impact on the Role of the Nurse

Increasing expectations for community-based palliative care services present challenges for existing programs, which are functioning at maximum capacity and limited in their ability to expand. Other consequences include the negative impact on nurses’ quality of worklife, and the shortage of nurses experienced in palliative care.

Inability to Meet Increasing Demands

Nurse participants expressed concern about the inability of the Home Hospice Program to meet the current demands for services and described the health care system as being unstable and in turmoil. The impact of increasing numbers of referrals is widespread. Hospice physicians are delayed in their response capability and palliative care referrals are triaged on a daily basis. With only sixteen hospice beds for the city, people are either admitted to hospital or they die at home while being wait-listed for hospice. It has been reported that although the number of admissions to the palliative care units has decreased for the mainstream population, there is greater use by marginalized populations for crisis care, and for end-of-life care within 48 hours prior to death.

Increasing resources are required for AIDS care due to its long-term nature and loss of community support networks. This is quite a change in practice, as one nurse commented:

That means that people don’t have choice anymore in AIDS palliative care. My hope was we would never get to the point where people won’t have a choice. You can go into palliative care for symptom management or for end-stage because you’re dying and you just don’t have the support at home. That’s only the last three or four days of life pretty well.
Other nurses agreed that people requiring palliative care are beginning to have less control and choice over limited resources. Although going to hospital is always an option, there is often unavailability of beds, not only in the palliative care unit, but also throughout the hospital. One nurse explained this situation:

We used to give the option of going into the hospitals for palliative care. We’re giving that option far less or less easily now. But we still usually tell people that they can have respite in palliative care. But sometimes, if you put your foot down or if the doctor puts his foot down, it sometimes is a choice. Not like it used to be. And so now the nurses have to say, ‘We may be able to get a shift nurse if one is available. Or we put in a home support worker to be with them and have a home care nurse visit a couple of times on days, once on evenings, and then hopefully a shift care nurse at night. If not, then the on-call night nurse might have to go out to get medication or visit in the night. So that’s very disappointing. In a way, we’re almost going backwards to the way we were.

With admissions to palliative care units being primarily for acute symptom management, respite, or for end-of-life care, people are expected to manage at home in the interim or consider transfer to an intermediate or long-term care facility. Another impact of the growing demands on the program is that physicians with the Home Hospice Program are limited to consulting and are considering the policy of not accepting clients unless the family doctor agrees to be the primary physician.

The expectations of clients and families to be cared for at home and the increasing complexity of palliative care have dramatically changed the quality of worklife for home care nurses. One nurse who has worked many years in home care described these changes in practice, and the decline of respite for clients, families, and nurses:

We seem to see far more end-stage treatment than what we used to. So what it means for the nursing staff is being alert to really assessing for these changes and making sure that the physicians are really aware. And what it means is that the workload is just becoming very, very challenging for the nurses. I find that with the hospice care at home, people live longer but it’s really burning out our nurses right now. I question in my mind whether we’re putting unreasonable expectations on the nurses. As the client starts to deteriorate a little bit, instead of
having them to go to the palliative care unit and have it dealt with there, which
gives the family a bit of respite, and the client a bit of respite, and the nurses
respite, they’re doing everything at home with the support of the hospice
physician. That’s a change. I have a feeling that there’s an expectation that we
can handle it all and we don’t need to send them in to hospital.

Another nurse explained how working late hours was becoming the norm:

One of the nurses was always working so late and so hard and taking everything
home. And now I think other people are doing that too, like I think it’s become
the standard for practice. There used to be some other nurses working here who
didn’t do that and did what they could and then left it. A lot of these people we
see, you could keep doing things for 24 hours a day and it never would be enough.
We just get so involved and to get someone else to do something to help doesn’t
really help, somehow. So I see that happening more and more. We need some
more balance.

The traditional generalist model of practice to visit eight clients a day was becoming
problematic, as one nurse explained:

We usually visit eight clients a day and if seven of them are palliative, there can
be major problems. You are forced on a daily basis to set priorities and cancel or
postpone visits if a crisis occurs. There are more joint visits now with the family
and hospice physicians that could take up to two hours at a time. There are also
family conferences to attend at the PCU’s.

The nurses reported that they frequently had to adjust their daily schedule when a
palliative client’s condition suddenly changed. They would then assess priorities and
cancel or defer other visits. If this was not possible, then it meant working overtime.

Meeting increasing demands for community-based palliative care is becoming
extremely difficult for the Home Hospice Program. In addition, these trends are
negatively impacting the work environment of nurses.

Shortage of Experienced Nurses

The shortage of experienced home care and shift care nurses is of particular
concern to the Home Hospice Program. Casual and new home care nurses have little
palliative care experience. It is more difficult to recruit nurses to work in home care than in hospital because they were traditionally required to have a baccalaureate degree in nursing and two years of hospital experience. That policy is changing as experienced diploma nurses are now being hired. In addition, it remains difficult to attract experienced nurses, as they would not be able to transfer their seniority. The current vacancy rate is approximately 10%, with most new hires coming from the casual pool.

Administrative practices have also had an impact on the recruitment and retention of home care nurses. In the past, nurses had to work years in a casual position with no benefits until a full-time position became available. Although it now takes only a few months to transfer to full-time status, nurses do not understand why, with the shortage of nurses, a majority of entry-level positions continue to be designated as casual. Unquestionably, that more nurses are needed to meet the increasing numbers of referrals to home care in general, as indicated by intervals when no new referrals can be accepted.

Educational support for new nurses is limited in terms of formal preceptorship and mentorship programs in which they would be paired with experienced nurses for a period of time based on their individual learning needs. One home care nurse expressed these concerns:

I do think palliative care is hard also for our younger, newer nurses. We don’t let them get in too quickly or easily into taking over our palliative clients. I guess maybe we want to have more control over what’s going on. But that will change. I do feel that life experience is important, but I guess it would have to be taught too.

Experienced nurses are expected to increase their knowledge and competencies in order to be current and proficient in palliative care. Time and resources are not always available to reduce nurses’ work and enable them to participate in continuing education
opportunities for their own professional development or to preceptor and mentor novice nurses.

Nurses reported that their workload demands have contributed to a loss of service. In fact, one of the nurse participants resigned from her position due to burnout and what she perceived as a lack of administrative support. This had a negative impact on her clients receiving palliative care, as she was very experienced and an out-spoken client advocate, who was not easy to replace. Other senior nurses explained that they were working part-time or job sharing to ease the demands of full-time work. One of the clinical nurse specialists expressed her concern as follows:

I have a concern that our expectations are too high for the health of the nurses. We’ve recently hired a number of home care nurses who’ve got really good shift care experience and they are saying, ‘You know this workload is too heavy.’ Nobody’s taking coffee. They’re not taking their lunch breaks. And they’re working huge amounts of overtime. And it’s the expectation. It’s like being in ICU and going on forever and ever without having the staffing for an ICU. Palliative care units have a much smaller staff/client ratio than a general ward and I think that’s the issue we’re seeing happening right here, right now in the community.

Home care nurses have compared their work to that of nurses in hospital palliative care units, in which the nurse/patient ratio is lower, and there is more clinical and educational support.

To further complicate the nursing shortage, the number of shift care nurses, who provide 24-hour respite and end-of-life care, has decreased significantly within the past few years. This loss has contributed to a 30% decrease in the total number of shifts provided from 1999 to 2000. Because the nature of shift care is casual work based on fluctuating demands, most shift care nurses need to work casual or part time in other positions to obtain sufficient hours of work. Consequently, several shift care nurses
applied for permanent home care nursing positions. The number of referrals for shift care depends, in large part, on the home care nurses’ knowledge of the program. The shift care nurses believe that they are under-utilized in certain neighbourhoods and in seniors’ housing. They also reported that many families are referred very late when they are desperate and not well prepared. On the contrary, some home care nurses reported that they do not request shift care nurses because availability cannot be guaranteed and decisions need to be made quickly. In addition, many family physicians are unaware of this service.

The loss of experienced home care nurses and shift care nurses will continue to place stress on palliative care programs. Novice and experienced nurses acknowledged that educational and professional opportunities serve both as recruitment and retention strategies as well as directly benefiting quality palliative care.

Impact on Quality of Care

Further tensions in the healthcare system have been created for programs and families with shifting policies in resource utilization, and the escalating burden of care costs. Palliative care services are not well integrated throughout the continuum of care. Clients and families have limited options for palliative care at home and hospice, and appropriate alternatives may not be available when necessary.

Appropriate Resource Utilization

Throughout their palliative care experiences, clients and families posed many questions about allocation of resources. Nurses provided detailed explanations about the
Home Hospice Program policies, as they made careful assessments of the family situation and organized appropriate services.

The utilization-related goals for the Home Hospice Program are to: increase the number of days of palliative care at home from the time of referral to the time of death; decrease the inappropriate utilization of acute care hospital resources; and to decrease the length of hospital stay prior to a person’s death (Robens-Paradise et al., 1997). In this study, clients and families at home had lengthy involvement with home care nurses and home support services. In fact, nurses reported that they faced criticism when providing palliative care services for an extended period of time. These same clients also had short-stay hospital admissions for acute treatment as required, and were supported in a home death. These goals are achievable for people in the mainstream population who are referred to the program. The three clients with AIDS had several lengthy hospital admissions in palliative care units until they were able to find appropriate community-based care. The goals of the program are largely unmet for marginalized populations who continue to be high users of acute care services, especially emergency departments and the palliative care units.

The Home Hospice Program is one of several Community Health Services programs that is funded by the Vancouver/Richmond Health Board. It is a centrally coordinated consultation program in contrast to other services that are now decentralized to neighbourhood teams based at six community health centres. In the 1998/1999 fiscal year the Home Hospice Program spent approximately 50% more than the allotted funding. An update on the 1999/2000 budget was unavailable. One clinical nurse specialist expressed her concern:
And so now we are looking at how we can get that amount of money because we have had support from community health services teams to continue practice as it has been even though we’re over-extended.

When applying for additional funding, it is important to have accurate statistics for the numbers of clients utilizing palliative care services. Some nurses explained that many clients who receive palliative care at home and then die in hospital are often not recorded as being part of the Home Hospice Program, and are therefore not included in the actual number of palliative care referrals.

There is a considerable cost differential for palliative care in hospital and in community settings. The approximate daily cost of care by setting is presented in the following table.

Table 6. Approximate Daily Cost of Care by Setting (Dec. 2000)

<table>
<thead>
<tr>
<th>SETTING</th>
<th>DAILY COST PER PERSON</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Unit at Vancouver General Hospital</td>
<td>$1000.00</td>
</tr>
<tr>
<td>Cottage Hospice / May Gutteridge</td>
<td>$275.00</td>
</tr>
<tr>
<td>Dr. Peter Centre Residence</td>
<td>$195.00</td>
</tr>
<tr>
<td>Dr. Peter Centre Day Program</td>
<td>$65.00</td>
</tr>
<tr>
<td>Shift Care Nursing at home (24 hours)</td>
<td>$600.00</td>
</tr>
</tbody>
</table>

Because the hospices and the Dr. Peter Centre are continuing care programs, the residents pay a per diem rate from $25.00 to $50.00 based on their income, which is applied to the cost for basic care. For those who receive social assistance, their cheque goes to the facility and they are given the balance of $85.00 a month for comfort money. The cost of hospice care and residential care is approximately 20% to 30% of the hospital rate.

Although the community programs are cost effective, they can only accommodate a
limited number of people. Residents at the Dr. Peter Centre have had dramatic reductions in their use of acute care services and, if admitted, their length of stay is considerably less than if living on their own. Plans are under way to build a new facility for the Dr. Peter Centre that will increase the number of residential beds from 10 to 24, and expand the day program to accommodate 70 people a day from five days a week to seven days a week.

Nurses consider individual and family circumstances to balance their plans with the appropriate utilization of scarce resources. Long term use of home support workers can no longer be supported due to increasing demand for their services and the high costs incurred to the Home Hospice Program. In one participant family situation, the client, an elderly woman, was receiving short-term home support hours for 20 hours a day from Monday to Friday for a year. Her sons visited from out of town on the weekends to care for her. She had metastatic cancer and her condition fluctuated, while recovering from several crises and acute care episodes. Eventually, a decision was made to reduce home support hours and plan for admission to a long-term care facility. One son described the situation:

However, what I did find a bit intriguing was the reason mom isn’t getting as many hours or as much home care dollars directed towards her anymore is because she used up too many. It’s sort of like this is the penalty for living longer than they had in their books. Now when her condition is worse and she needs even more care, it’s all taken away.

Unfortunately, by the time the woman was reassessed, she was imminently dying. The sons felt that the long-term care assessor and home support agency supervisor made decisions based on resource allocation rather than on the family’s current situation. Furthermore, the sons had not been involved in the decision-making process. The home
care nurse reversed the decision and supported the woman to die at home. Although home support hours for palliative care are intended to be for short-term utilization, many clients now live much longer than expected.

Determining the appropriateness and consistency of home support and shift care nursing resource allocation are ongoing challenges for home care nurses. Variability exists in practice throughout the region and policies keep changing, as this nurse explained:

It would be helpful to have management or the hospice CNS or social worker go over this occasionally to make sure that we are all approximately using these resources in the same way. And it should probably be repeated once every six months so we can keep up on things. People should have a review, not so much even about what to do, but what our policies are for shift care, home support, and calling in hospice physicians.

Nursing hours have increased. I often visit people at the end of life a couple of times a day and will have the evening nurse go in if we don’t have shift care. You know, sometimes we don’t need shift care. We need home support workers but we also need some sort of nursing monitoring or more frequent nursing monitoring. Sometimes what happens is you could have the person at home with home support if the home support worker was comfortable and skilled enough. But you don’t have that so then you need a shift care nurse. Well that’s not a good use of shift care. It’s also not a good use of going to hospital, so you end up going to a higher resource level than what you need.

For example we practically routinely send in now, if we can, a shift care nurse when medication has to be given sub-cutaneous or something like that. You know sometimes it is necessary, sometimes it isn’t necessary. Sometimes the family can do it. Some of our nurses will do it on a drop of a hat. Another nurse won’t do it. They have to be reminded and reassured that they’re doing the right thing. Either way. And it’s hard if we don’t know the policy as it’s constantly shifting. All of a sudden we’ll hear, ‘Oh we have no more money, so please stop’. Well officially shift care nursing was only for 72 hours and it changed because we gave such good nursing care and people lived too long.

Policies for shift care nursing have changed in the past few years, as the clinical nurse specialist explained:
So what we’ve tried to do actually is define the boundaries. For example when I look at where shift care gets off track in relation to resource utilization, is when we have people come out of hospital who require 24 hour shift care because they are coming home to die. And they need that level of intense resources but who knows when they’re going to die. Sometimes the judgement around the kind of support that they need in hospital isn’t the same as what we would put in. So what we’ve said is, ‘If you have somebody coming out of the Palliative Care Unit, we can make a commitment to, at the outside, two weeks of care.’ We probably should be saying a week, but a week’s not long enough. Then the family and the Palliative Care Unit need to be prepared for that person to go back in two weeks, because we have to have a limit. Then if you’re at the two weeks and the person’s imminently dying, fine. But if you’re after two weeks and things have stabilized, then the family is prepared. The Palliative Care Unit is prepared that the community doesn’t have the resources for that. And so then the person goes back into the hospital.

Shift care nurses were initially scheduled for a maximum of 72 hours per family but now are being utilized for respite and end-of-life care up to a maximum of two weeks.

At times there is an unfortunate waste of resources, as a home nurse shared:

And then there are people who are working. It’s very difficult to draw the line. I had a young woman, a teacher, who lived in a very nice house. Her husband worked long hours. She came home after chemotherapy and we provided homemaking for twice a week on short-term hours. She had a nanny that looked after her kids on the days that she used to be teaching, but she felt that she needed this extra help, and we gave it to her. But a couple of times she wasn’t even home, and the home support worker couldn’t get in the house, and we would have to pay for it. I didn’t even know about it until I found out later. So that’s aggravating and it’s costly.

Part of the nurse’s role is to assess the client and family situation and their changing requirements for home support throughout the palliative care experience.

One common waste of resources identified by both nurses and families was prescription drugs that remain unused. At the end of life, regular medications are usually discontinued, and the type and dose of narcotics change frequently. Remaining medications must therefore be discarded, as they cannot be returned to the pharmacy or
utilized by someone else. Over-prescription of drugs can be a tremendous waste of health care dollars.

Some nurses suggested cost sharing for nursing and home support services with families who had extended health benefits. No additional costs would be incurred by the family, and substantial savings could be realized for the Home Hospice Program. One nurse explained:

I think we need to be more creative than we’ve been before. If the person has some kind of health plan that pays for RN support, let’s tap into it. We aren’t even asking those questions lots of times for shift care. We had a family where they had a really good policy. They wanted consistency and so what we did was connect them with an agency with good palliative nurses, and said, you can get your support there and what we will be is a backup to you. So that worked because the family had the ability to take on that stress of scheduling the nurses. I think we do need to be pursuing that cost sharing more than we have done up until now.

Nurses believed that simple creative cost-saving strategies were often overlooked and that more could be done to address inefficiencies in the system. The nurses had difficulties dealing with the economic issues because of ongoing problems in communication within the system creating unfamiliarity with changing policies. When made forward suggestions for improvements, a slow bureaucratic process that did not facilitate quick decisions frustrated them. Nurses were so overwhelmed in their daily obligations to clients and families, that there was little time to become involved with lengthy processes in changing policies.

Throughout the course of a terminal illness, individuals and families can incur high financial costs. Costs of equipment rental, prescription drugs, and private home support workers or nurses can be burdensome. Loss of income from time away from
work or leaving a job can be considerable, even when the family is very committed to caring for their loved one at home.

In one participant family, a daughter was caring for her father with a brain tumour for a year. She was a teacher, and her mother was a hairdresser. The daughter used her vacation and sick time when she was able. The mother’s hours were more flexible but she had no paid leave. They juggled their work to share the caregiving responsibilities, but this was difficult during periods of crises and at the end of life. It was important for the family and nurses to consider that resources were less available at home than in the hospital, as one home care nurse illustrated:

If you have a middle class family that has to pay for the hospital bed and the medications and if they’re young, it does cost a lot of money. And there is a point that, in hospital, you get it for free. If they’re on short-term hours or the palliative care unit, there’s no direct cost to the client. But if you’re on short-term hours and then you put them on the wait list for intermediate or long term care, and they’re placed, well then they have to pay even the minimum of six or seven hundred dollars a month. If there are two people living on a supplemental income, they’re both just making it on that basic level. Well if one of them goes and has to put up seven hundred dollars, that leaves the other one sometimes with nothing but rent and fifty dollars left over for food.

Nurses reported many situations where home costs for palliative care at home seriously strained finances and significantly impacted quality of life and quality of care. Moving to hospice or long term care was not usually a preference, especially when families were unprepared for this change in their life, and it was even more costly than staying at home.

The nurses were constantly aware of pressures to constrain costs. These pressures influenced their ability to provide quality care. Nurses developed strategies for better resource allocation, but they lacked confidence in their analysis, and were unfamiliar with the processes of policy decision-making and of how organizational decisions are enacted.
Managing Integration

Home care nurses communicated that a major and challenging responsibility was to integrate palliative care services across various health care sectors. Since the beginning of regionalized health care services, constant changes in administrative structures and neighborhood boundaries have resulted in decentralized interdisciplinary teams at six community health centres. This continues to have an impact on nursing practice as nurses struggle to redevelopment professional networks for providing care.

The continuum of palliative care can extend over years from diagnosis, through the ups and downs of treatment and supportive care, until approaching death, followed by bereavement care. Throughout this time, home care nurses search for and coordinate health care services available for individuals and their families, because palliative care program models vary in intensity and duration. The client and family participants in this study were involved with the following services: the provincial cancer agency for diagnosis and treatment; palliative care units for respite and symptom management; acute care hospital for short-term admissions; family physicians and specialists, including hospice physicians; hospices; home care and shift care nurses; home support worker agencies; allied health professionals; and equipment rental agencies. People in marginalized groups were additionally supported by several community, regional, and provincial services related to housing, mental health, native health, parole, and addictions. Those living with HIV/AIDS benefited from care through the Centre of Excellence for HIV/AIDS and the Dr. Peter Centre.
For marginalized populations, integration is an even greater challenge due to the number of providers on the care team, their long-term involvement, and the transient nature of the clients. As one nurse described:

Often times when there actually is a team meeting to address a client’s need, I’m always amazed at how many people there are for one person. So you have one of the IMP workers that may have known this person for fifteen years and a mental health team that may have been involved for eighteen years. Then they get sicker and besides their mental illness and going to jail, they’ve now started to become HIV positive and develop AIDS, so they are connected with the Centre for Excellence for their drugs. They’re difficult to house, so now they’re involved with staff in supportive housing. There are different providers that are involved with different population needs and what you have is a layering on of services. The one provider doesn’t check out because their expertise in relation to the person, for example someone with schizophrenia, is still really important. And then they need basic symptom management and nursing care for chronic illnesses in relation to wounds. There are multiple providers already involved by the time the person is referred to home care.

Even though many resources are available in this neighbourhood, nurses reported that there was often fragmentation of services by competing groups. The continuum of palliative care for this population is very short or non-existent. The usual pattern of care is years of being on and off treatment and then death happens quickly. Palliative care may not even be identified and bereavement care is seldom required as there are few friends and family involved in the person’s life.

Continuity of care among the nurses, other members of primary care team, and consultants is an ongoing challenge for both mainstream and marginalized populations. The home care nurse is responsible for coordinating care for clients and families and advocating on behalf of clients who are unable to do so. The family physician is expected to be actively involved and available for the client and family and to support the home care nurses. Many nurses and the hospice physician reported that lack of involvement of family physicians was a major gap in the integration of palliative care services. Although
referral to hospital is the family physician’s responsibility, the home care nurses and hospice physicians referred when necessary. One nurse explained why admissions could be difficult:

There are many patients that aren’t known to the palliative care units in the teaching hospitals, and then we are busy trying to figure out how to get them admitted. We can do it through consultation with the hospice physician, or we can call directly, but it’s supposed to be done through the family physician. So it’s harder this way and definitely takes more time.

Over the years, the palliative care units have established strong community links for admission and discharge planning. Other areas in acute care have been less responsive. The lack of or incomplete home care referrals from some hospital physicians were reported as problematic.

Although the goal of the Home Hospice Program is to provide palliative care services integrated across care settings throughout the continuum of care, the program cannot ensure the provision of multiple levels of care in the home. The hospices are also limited in this respect. It is increasingly difficult to determine when the client should be referred to acute care or long term care. These decisions cause considerable anxiety for clients and families, as unexpected changes in the quality of care can occur when a person has to be transferred to other settings.

Determining when a client requires acute care can be difficult for nurses in home and hospice. Home care, in general, has become acute care in the home, and palliative care is no exception. There are occasions when acute care treatments may be warranted for palliation. However, in time, home care nurses are guided by the client and family’s plans and ethical decisions related to stopping treatment.
Occasionally, in hospice, physicians order active treatment, which is not congruent with the hospice mandate. A hospice nurse expressed concern over the prescription of expensive drugs in the hospice setting:

We had a young man with AIDS. He had a lot of neuropathies. So the doctor wanted to put him on IV Gancyclovir. Well, we don’t do it. Well, the doctor was quite upset but I just said, ‘Well he can go to the hospital.’ So anyway it turned out that the guy did not need it. He did not have CMV so it was okay. We had a bottle of Gancyclovir here. I had no idea how much that costs - $2998.00 for an eight-day course. But it’s still an outrageous amount of money and wherever that money is coming from, it’s coming from somewhere. And I think sometimes, people say well money and medicine shouldn’t go together but the fact is they do. It’s a fact of life. It is. I think we’ve got to sort out what’s acute care and palliative care, and where we fit in the continuum of care.

If a resident in hospice requires acute care, they are usually sent to a hospital.

The question of when a person, who is palliative, should be considered for long-term care causes even more anxiety. In home and hospice, people’s physical condition often improves and stabilizes once symptoms have been managed and adequate nutrition is being received. After months of palliative care services by the Home Hospice Program, the nurse must reassess the client to consider if intermediate or long-term care placement is appropriate. This is very distressing for clients who are considered to be “dying too slow”. Three home care nurses expressed their concerns:

If they have a brain tumour, you almost don’t want to tell the Palliative Care Unit because they won’t want to take them, because they’ll be there too long.

This is a concern that a lot of the nurses have. It’s a real problem. In fact I think it's our care, because we go in and if things haven’t been so good, we take care of them and they plateau. But the problem is that their plateau is quite low. They’re not doing really well. They’re just being maintained. But we controlled everything, and we got homemakers in there and they’re probably eating better than they used to before. They’re getting much better care than they did before and they plateau. But it’s not at a high, high level. We’re helping them live.
The problem is the message when we say that maybe we’re going to put you in a long-term care facility. And so what we’re saying is, you’re not dying fast enough.

These comments exemplify the difficult decisions that impact quality of care. If a person’s illness is considered to be long-term, they may not be admitted to a palliative care unit, and if they are, then they might be subsequently transferred to a long-term care facility. Although a client’s condition often stabilizes when at home, nurses explain that the person is still dying and in need of palliative care. Admission to a long-term care facility may take months and it is very difficult for the client and family to alter their plans at this time. Unfortunately, people sometimes do not have a choice when their illness is prolonged. One nurse described this policy change:

The choice has changed in the last couple of years. People are going to facilities to die now, where they didn’t have admissions a few years ago if someone was dying within the last months of life. They would have stayed in hospital. They would never have been discharged if they were dying within the next month or two. And people are dying in the facilities, where they would have gone to the hospital. So that’s a big change and it’s a place that requires more support.

The quality of palliative care in intermediate and long term care facilities and the need for consultation and education were other concerns identified by home care nurses.

The same questions arise in hospice settings. A hospice nurse shared this situation about a young woman who had breast cancer and bone marrow metastasis, as well as a long history of mental illness:

So now I think she’ll end up going to long-term care. Now this is really distressing her mentally. And also she’s a fairly young woman. She gets a lot of attention here. So I can see why she doesn’t want to move. She’s moved in and yet it’s not a nursing home. I don’t know how long she’ll live. It may not be a year, but it may well be so, because she’s really quite stable.
Residents are assessed for long-term care referral if their condition stabilizes or if they have been at the hospice for a year. Fortunately, hospices have priority on long-term care beds and can usually transfer people in a few weeks.

Integration of palliative care services across for clients and families remains fragmented and challenging. Continuity of care is a major issue as numerous care providers are involved over the course of illness until death, especially with marginalized populations. Of most concern for clients and families are decisions related to quality of life and quality of care when they go to long term care settings.

Problems related to the appropriate allocation of resources and integration of palliative care services directly affect quality of life and quality of care for clients and families. Choices regarding place of care are becoming limited as policies change to restrain services at home and hospice in response to rising costs. Home care nurses will continue to be challenged to coordinate and integrate services so that continuity of care will be available throughout illness, dying, death, and bereavement.

Summary

Tensions within the health care system are seriously influencing home care nursing practice and quality of palliative care services. Although the Home Hospice Program is continually expanding, it cannot meet rising expectations for palliative care that is accessible to diverse populations in their own neighbourhoods. There is currently less choice and control over resources, resulting in care being provided in the most available place rather than the most appropriate place. Except for the Dr. Peter Centre, existing programs are unable to provide multiple levels of care, and are not well
integrated, necessitating numerous admissions or transfers to long term care or acute care settings throughout a person's experience of illness, dying, and death. Home care nurses are struggling to address the increasing complexity of care, which affects quality of care, and also strains their quality of worklife. The shortage of experienced home care and shift care nurses, coupled with loss of nursing service due to burnout, are placing considerable demands on an already burdened system and limiting further development of a cost-effective integrated delivery system for palliative care.

**Summary of Findings**

Findings of this study demonstrate that home care nurses contribute to quality of life and quality of palliative care through their abilities to integrate services amidst the complexities and challenges of the health care system. Nurses assume the major responsibility for coordinating palliative care for clients and families in the home setting. The nurse-client relationship and the abilities of the client and family form the underpinnings for the palliative care experience. Planned home deaths are increasingly preference for the mainstream population because of adequate support for individuals and family caregivers as well as for the home care nurses.

With respect to quality of life and quality of care for mainstream and marginalized populations, there are dramatic differences, as reflected in the client and family experiences, nursing practice, and program models of care. All of the mainstream clients in this study died from cancer at home or in hospice with support of family caregivers and health care providers. For people living with AIDS and/or drug addiction, their illness experience spanned years of fluctuations in health status, as well as many
other illnesses. During that time, they moved frequently among community, acute care, and residential care settings with little if any social support and suicide was reported as a common occurrence.

Mainstream nursing practice focused on working collaboratively with clients and families to avoid end-of-life crises, and to establish long-term meaningful relationships. The responsibility for providing and coordinating home care fell to the nurses, with inconsistent support from family physicians. Ethical dilemmas centered on family disagreements regarding treatment, place of death, and end-of-life care. Bereavement care was recognized as a significant gap in services. In contrast, nursing practice for marginalized populations was based on principles of harm reduction and crisis care in collaborative partnerships with neighbourhood family physicians and social service providers. Ethical dilemmas in this context were associated with the complexities of illicit drug use and street crime. Further, nurses were confronted with abstract moral challenges associated with society's responsibility for providing basic necessities of life for those who live on the margins. Nurses believed that they were contributing to the quality of life of the people they served, but were continually frustrated by complex social problems in this community.

Program models of care and patterns of utilizing health and social services are quite distinct between the two population groups. In mainstream society, palliative care is provided primarily at home through the Home Hospice Program with brief hospital admissions for respite, acute symptom management, or end-of-life care. In contrast, marginalized people were frequent users of acute care services, especially emergency departments and palliative care units. Nurses questioned the tendency to continue with
the traditional approach to care for marginalized populations, when it obviously wasn’t working. They knew that intersectoral collaboration and integration of health and community resources were required to develop creative and flexible programs for specialized crisis care and long term care, but did not know how to effect change.

Palliative care constitutes a specialized form of home care nursing, and one that requires considerable skill and commitment. Whether this is best supported in a system where nurses work exclusively in palliative care or in the generalist tradition remains controversial.

Tensions within the health care system seriously impact home care nursing practice and quality of palliative care services. Although the Home Hospice Program is continually expanding, it is unable to meet rising expectations for accessible and neighbourhood-based palliative care for diverse populations. Currently care is often being provided in the most available place rather than the most appropriate place. Difficulty in addressing increasing complexity of care, which affects quality of care, also strains nurses’ quality of worklife. Finally, the shortage of experienced home care and shift care nurses is placing a considerable demand on an already burdened system and limiting further development of a cost-effective integrated palliative care system.
CHAPTER 5
DISCUSSION OF THE FINDINGS

Findings from Chapter 4 will be discussed in relation to the current body of knowledge in palliative care, home care nursing, and health policy literature. Numerous studies on the relationship between nurses and people receiving palliative care have been conducted but few situate the nurse and clients within the context of the health care system. The intent of this research was to explore and interpret the contribution of home care nurses in the development and provision of integrated palliative care services for diverse populations. Detailed analysis of the complex and multidimensional elements of everyday nursing practice in caring for mainstream and marginalized populations can provide insights into policy by identifying service needs and gaps in the system.

My aim in this discussion is to examine three overarching issues within the study findings that have relevance for policy: the changing nature of palliative care; the complexity of home care nursing practice; and the challenges of integration. By considering the findings in relation to these issues, and examining them in the context of existing empirical and theoretical literature, as well as the theoretical framework for this study, I will draw conclusions about the contribution of home care nurses to the integration of quality palliative care services. Situating the discussion within this body of knowledge will enable further exploration of the findings that can contribute to an understanding of how home care nurses can influence the social, economic, and political processes that shape the provision of quality palliative care.
5.1. The Changing Nature of Palliative Care

The first major issue within the findings of this study is that two very different kinds of health care currently exist in this region under the overall umbrella of palliative home care. The goals, skill sets, infrastructure requirements and organizational challenges of what I have termed mainstream and marginalized palliative care services seem so radically distinct from one another that it is difficult to conceptualize a unitary and integrated palliative home care system. Because the marginalized group is increasing, both in numbers and in demands upon the health care system, this variation within palliative home care services requires thoughtful consideration from both a planning and policy perspectives.

The current national definition, philosophy, and standardized principles for palliative care were developed by Ferris and Cummings (1995) after extensive consultation with health care providers and palliative care associations throughout Canada. This document served as both a philosophical guide and a practice model for client and family centred palliative care programs across the country. In this vision of palliative care, the intended continuum is more comprehensive than in earlier models, extending from the time of diagnosis, through supportive care, dying, death, and bereavement. Thus it extends the understanding of palliative care from the more traditional medical model, toward recognizing the complexities of integrated health service delivery and processes. The fundamental beliefs underlying the document are that Canadians should have access to essential palliative care services, 24 hours a day, and seven days a week, and that these services should be equally available to all regardless of age, gender, ethnicity, geography, diagnosis, disability, and availability of a primary
caregiver. The Canadian Palliative Care Association is currently taking a leadership role to engage the provincial associations in a Revisions Work Group for a process of national consensus with regard to these standards (BCHPCA, 2000a).

As the findings of this study confirm, such a model for palliative care is necessary and appropriate. Its general principles and essential attributes are consistent with the needs identified and articulated in this research by both consumers and care providers. However, many aspects of the service needs for marginalized populations may be sufficiently distinct from mainstream needs to warrant different philosophies and models for palliative care delivery. A home care system based on assumptions of family support fails to recognize the extreme challenges posed by health care consumers who have no homes and/or families. Access to traditional services can become insurmountable for marginalized populations, and attempts to integrate their care into structures suited to a mainstream population can be frustrating for care providers trying to meet the needs of both populations. It is necessary to consider in more depth the specific needs and challenges associated with both population groups, and to consider how future developments in care delivery systems might be approached to make the best use of available resources and to provide the best possible care to both groups.

The Mainstream Context

When studying palliative home care for mainstream populations, a set of assumptions and structured approach of integrated and coordinated services based on family support and planning for end-of-life care is apparent. Increasing demands for services within this context reveal gaps in service needs.
Findings about mainstream populations within this study confirmed many assumptions reflected in the literature. Care towards the end of life presents an extreme variation from everyday life for the individual and family. During this time, families require additional supports to care for their loved one in a manner consistent with their values and beliefs. Traditional home hospice programs support family caregivers and provide services for people who have a home, a primary caregiver, friends, and community support (Stajduhar & Davies, 1998; Vachon, 1998). The vision for the proposed regional palliative care program is congruent with this traditional model characterized by “palliative care providers supporting primary care providers caring for the individual and family coping with a progressive, life-threatening illness or condition” (V/RHB, 2000, p.5). Such traditional models of care, as in the mainstream populations described in this study, plan and prepare the client and family for end-of-life care, while managing pain and symptoms and preventing crises.

Home-based palliative care is becoming more complex and often requires integration of acute and long term care services, home support, respite, and 24 hour home or inpatient hospice care at the end of life. The plans for a national strategy for end-of-life care acknowledge that the place of care may extend from the home to varied institutional settings (Carstairs, 2000). Coordination of family caregivers, home support workers, home care nurses, family physicians, hospice physicians and medical specialists, as well as allied health professionals is also needed. Appropriate services need to be assessed and balanced with fluctuations in the client’s and family’s care requirements, although there is usually a gradual, predictable progression toward intensive support in the final stages (McCorkle, Hughes, Robinson, Levine, & Numah, 1998).
Palliative care at home can be a very meaningful and relevant experience, consistent with people's desire to make choices in relation to death and dying. Although some prefer to die at home, others choose to die in a hospital setting, preferably a palliative care unit. Death at home can present significant challenges for families. Availability and accessibility of comprehensive and coordinated home care services are pivotal in making death at home a realistic option (Stajduhar & Davies, 1998). One Canadian study concluded that those most likely to die at home had cancer or AIDS, had a primary caregiver as well as other family members well enough to care for them, and had sufficient financial resources. Those less likely to die at home included people dying of more chronic diseases, cultural minorities, those who lacked a primary caregiver, and those whose family could not manage a prolonged burden of care (Vachon, 1998). These results emphasize that there are complex medical, social, and cultural considerations in determining place of care and place of death.

AIDS care has made a significant impact on the overall development of palliative care services and has been successfully integrated in many regions within mainstream hospital and community palliative care programs (Foley et al., 1995; Fraser, 1995). There is a growing distinction in care requirements, as evident in this study, between the mainstream gay male population and those who are marginalized, especially injection drug users and those with multiple diagnoses. It is no longer useful to generalize the AIDS care situation. Although these distinctions were first raised in the mid-nineties (Johnson, 1995; Smith, 1994), they are now gaining in importance (Cox, 1999; McAmmond, 1998; Millar, 1998; Stajduhar & Davies, 1998). The higher level of services
applied to AIDS care in the last decade must now be absorbed into the marginalized AIDS population needs.

While tremendous advances have occurred in the home based palliative care program in this region, services are unable to keep pace with needs, as in the numerous requests for bereavement care. Families in this study who had had extensive services in the home preferred contact with nurses or other health care providers who had been involved, rather than community-based programs, especially in the immediate period of grief. The early period following death can be especially difficult for families due to a high prevalence of depression (Wyatt, Friedman, Given, & Given, 1999), guilt (Demi & Miles, 1994), and particular vulnerability for elderly spouses and caregivers (Ross, Fisher, & Maclean, 2000). Some researchers acknowledge the importance of bereavement for providing a sense of continuity to both the nurse and the family (Sourkes, 1987) and to bring closure to the relationship (Rasmussen, Sandman, & Norberg, 1997). Although nurses in this study agreed that bereavement care was important, they have been unable to prioritize it due to high demands for care prior to and including death.

New challenges exist for providing palliative care at home for many segments of the population whose end-of-life care needs are often unrecognized, such as people with chronic illness, end-stage conditions, ALS, and Alzheimer's disease. The home hospice program continues to receive referrals primarily for people living with cancer. Although some health professionals view cancer as a long-term illness (McCorkle et al., 1998), the important distinction is that cancer is viewed as a life-threatening illness, whereas chronic illness is not. Roy (1999) questions if palliative care is only for the imminently dying,
and why it is taking so long to acknowledge the many other areas of human illness and suffering. The Vancouver/Richmond Health Board (2000) supports broadening the target populations to include people with end-stage cardiac, lung, and renal diseases. Although expanding palliative care to include a more diverse group of clients is admirable, findings of this study suggest that important challenges will have to be considered for this initiative to be successful.

In cultural minorities in this study tended to utilize acute care rather than home-based services for palliative care, due to difficulties in communication, unavailability of a primary caregiver, and beliefs that do not permit dying and death in the home. According to Woo (1999), it is common among cultures of traditional Chinese origin to believe that it is inappropriate to discuss impending death for fear of precipitating or hastening it. Thus, in meeting the palliative care needs of multicultural communities, it is important to understand their values and beliefs regarding death and dying and come to a mutual understanding of the experience (Hall, Fiset, & Stone, 1998). Other researchers have suggested that attributing particular characteristics or beliefs to ethnocultural minorities can be misleading and can create stereotypic assumptions about care needs. Therefore, it would be more appropriate to create models that are flexible to the attitudinal or organizational attributes that any individual family reflects (Lobchuk & Stymeist, 1999).

Palliative home care for seniors was described by home care nurses in this study as posing unique challenges, such as caring for aging spouses, and being involved in difficult decisions regarding the need for intermediate or long term care, especially for those who lived alone. These issues are congruent with work by Ross and colleagues.
(2000) who conducted an extensive review of the literature on end-of-life issues and challenges for seniors who face a life-threatening illness. They reported that Canadian seniors constitute a larger proportion of the population than any previous generation. Although many seniors prefer to die at home, family members have difficulty managing the intense care requirements without substantial financial resources. Palliative care for the elderly is a neglected area of service delivery, and growth in this population will seriously impact health care systems in general (Ross et al., 2000).

Thus, analysis of the findings of this study within the context of the work of other authors makes it clear that mainstream palliative care services are continually expanding to meet identified population needs and, as they achieve successes in this regard, expectations and demands continue to expand. Although traditional models are well established within the mainstream, their effectiveness in delivering optimal services to their original client groups is being challenged by recognition that more groups also warrant this kind of care delivery. Consequently, there is tremendous pressure on palliative care programs to increase with an ever-expanding population need.

The Marginalized Context

Palliative care for marginalized populations contrasts starkly with the service needs for people in the mainstream. The clientele within this local neighbourhood has paralleled that of low-income downtowns of many Canadian cities, with increased drug use among segments of the population causing earlier population groups to move elsewhere. These kinds of enclaves are becoming increasingly prominent in our cities and creating a new and unique kind of health care challenge. Although the numbers of
marginalized people requiring palliative care are small in comparison to the general population, their needs are complex and their behaviour can be disruptive and challenging to traditional care settings.

People on the margins of society often live alone, with few friends or family, who if available, are usually incapable of caring for themselves, and are unreliable as supports for the client (Griffiths, 1996). However, findings in this study suggest that many people possess incredible strength and skills to live everyday in a struggle for survival. Their world encompasses poverty, crime, violence, drug addiction, homelessness, and mental illness where a majority of persons are also living with life-threatening diseases, and dealing with death and dying at every street corner.

Nurses in this study described AIDS palliative care as extremely complex when it involved injection drug users, sex trade workers, transgendered people, women, native people, and immigrants (who were not mutually exclusive groups) who were intensely in need while extremely anti-social and untrusting. Studies in Vancouver and Toronto have shown that a common reality in AIDS populations is poverty amid non-traditional family units that are transient, living in chaos, and at most times, extremely suspicious of health care providers (Johnson, 1995; Smith, 1994). Although the nurses in this study recognized that the challenges associated with the diverse needs of these groups, the factor that most influenced the changing nature of the palliative care service they delivered was drug use.

Problems related to illicit drug use are a major concern for health and social service providers in marginalized communities. Injection drug use now accounts for the majority of new AIDS cases in the United States and Canada (Cox, 1999; Health Canada,
Overdose from illicit drugs has surpassed AIDS as the leading cause of death of adults age 30 to 49 years in British Columbia (Millar, 1998), thus shifting the focus of HIV/AIDS care to managing addiction.

As a result, the approach to palliative care, as illustrated in this study, is dramatically different from mainstream programs and traditional AIDS care. The primary focus is harm reduction, defined as “a policy or program directed towards decreasing the adverse health, social, and economic consequences of drug use without requiring abstinence from drug use (Canadian Centre on Substance Abuse National Working Group on Policy, 1997). Home care nurses working within this framework reported public and administrative opposition to their encouragement of safer drug use and reducing drug related harm. Drug users were limited in obtaining safe housing and health care that was based on an abstinence model. The most challenging principles are that: substance use should not be a barrier to receiving appropriate care; that the person has the right to make choices about their substance use and their lifestyle; no person should be pressured to receive substance use treatment; and care will avoid involuntary withdrawal and ensure provision of effective pain management.

From a public health perspective, Mathias (1997) urged that treatment and harm reduction strategies are not designed to resolve the root cause of drug use, and that decriminalization of narcotic use is the only solution that will bring this issue into the realm of public health and out of the realm of the law. This approach is being considered in British Columbia with the pending drug court initiative that diverts non-violent drug offenders from jail to a comprehensive treatment program.
For injection drug users with AIDS, crisis care was a way of life. The continuum of palliative care was often very short from the time of diagnosis, if there was a diagnosis, until death. Nurses were challenged to identify when the person was in need of end-of-life care. Needs ranged from primary care and short-term crisis care to acute care when pain and symptom management was beyond control, and then to hospice or long term care when they could no longer care for themselves. Dean Wilson, the president of the Vancouver Area Network for Drug Users calls this approach “health care by ambulance” (2001). There was little ability for planning implying that one is capable and willing to make complex decisions and to undertake responsibility for one’s own care. Judgemental attitudes of health care workers towards street people were a further impediment to seeking regular health care, and resulted in reliance on emergency services as the primary treatment site. Several researchers (Nicholson & Turner, 2000: Smith, 1994) have criticized established systems of palliative care that are unable to address the complex needs of marginalized people in receiving care and in finding a place to die.

Flexible, comprehensive approaches to palliative care, especially for people living with both AIDS and drug addictions, are possible in specialized residential and hospice settings. In this study, there was one hospice setting where people who were active drug users could receive short term and long term care, and be connected to a community network of health and social services. The other community alternatives, an AIDS residential program, and a community hospice, did not permit drug use on site because of legal implications and the associated problems of crime related to drug use. In a survey of hospices in the US, continued drug use by clients led to theft of prescription narcotics, pain pumps, and other items by clients and their visitors (Cox, 1999). Traditional AIDS
hospice settings in the UK are similarly unresponsive to the needs of injection drug users with AIDS (Nicholson & Turner, 2000). Tremendous challenges exist to work within social and legal structures to provide services that will be acceptable to society while meeting the individual needs of clients. There is an urgent need to orient care approaches to harm reduction, and to create systems and structures that avoid dehumanization, alienation, and illegal activity in palliative care settings.

In summary, there are two decidedly different kinds of palliative care contexts, mainstream and marginalized, with both populations having dynamic and changing needs. As we attempt to apply the principles that are now becoming accepted in Canada with regard to palliative care, we will have to address these changes. As end-of-life home care for people living with cancer and AIDS becomes more effective, those with other chronic conditions, the elderly, and cultural minorities will demand a similar level of supports. The greatest challenge yet will be to provide appropriate highly specialized primary care, crisis care, hospice care, and long term care for marginalized populations, especially people living with multiple, complex health and social problems.

We do a disservice to both mainstream and marginalized populations if we fail to make these distinctions in articulating our policy and service delivery requirements. The challenges of palliative care mirror the need to continually renew and adapt all aspects of the health care system to address the changing nature of society and its evolving health concerns.
5.2. The Complexity of Home Care Nursing Practice in Palliative Care

Findings in this study demonstrate that home care nursing practice is very complex as nurses provide quality palliative care in homes and diverse community settings while addressing the everyday challenges of societal, organizational, and health care system issues. Furthermore, nursing practice in palliative home care is dramatically different for mainstream and marginalized populations. These findings will be discussed in relation to the literature to explore the required competencies for palliative home care nurses and the multidimensional roles in their practice. Nursing practice in home-based palliative care is somewhat similar to palliative care in hospital and hospice settings and to community health nurses’ practice, which embraces the principles of primary health care. These bodies of literature show certain aspects of the role but fail to describe the changing nature of palliative care in the community. Influences on the quality of nurses’ worklife will be discussed in reference to national issues in nursing.

Nursing Competencies for Palliative Home Care

The overall goal of home care nurses is to provide quality of life and quality of care for clients and families wishing to remain at home as long as is possible and desirable. The focus on quality of life is consistent with research by Lee and Pilkington (1999) with people in hospice wherein they conclude that the human becoming theory provides nurses in palliative care settings with opportunities to uniquely participate in cocreating quality of life with persons living their dying. Nursing practice is holistic, extending beyond pain and symptom management, to support people throughout the continuum of palliative care. In describing contributions of nursing to palliative care,
Dicks (1990) concluded that their practice epitomized the essence of what holistic nursing. Because holism is fundamental to the nature of nursing, palliative care provides a context in which both nursing arts and sciences can be fully expressed.

The practice of home care nurses in this study was somewhat similar to that of nurses who care for the dying in hospice or hospital. Many palliative care nursing studies have focused on characteristics and competencies of experienced hospital and hospice nurses in their relationship with clients and families in the mainstream context, usually people with cancer. In her research of exceptional nursing practice of unusually competent oncology nurses, Perry (1998) described the mutual experiences of nurses and patients on a shared journey and the power and promise embedded in exemplary nursing care.

Exceptional nursing practice is more than being technically competent... Exemplary nurses have well developed nursing philosophies that... include a reverence for life and respect for the value of each individual... Exemplary nurses seem to be both motivated by their work and to draw satisfaction from it, especially by the opportunity to feel valued for what they do, and by the chance for personal and professional growth (p.155-156).

These human dimensions were an important aspect of what home care nurses valued in their role. The difference that nurses made in these intense and emotional life transitions confirmed to them the privilege of working in palliative care.

Some authors have attempted to describe the palliative care role in nursing by conceptualizing the personal qualities that the individual nurse must bring to the role. These authors have theorized that expert palliative care nurses demonstrate hardiness, critical competence, and compassionate care (Hutchings, 1997, 1998) as well as positive attitudes about death (Brockopp, King, & Hamilton, 1991). Several researchers have explored the impact of the emotional labour involved in palliative care. Sourkes (1987)
advised that care providers must assess their capacity to endure repeated cycles of attachment and loss and acknowledge their vulnerability. In other research with expert hospice nurses, sustaining oneself as a nurse was the foundation for the development of competencies for family caregiving (Zerwekh, 1995).

While many researchers have articulated the importance of personal qualities in palliative care, such qualities were sometimes lacking, especially among inexperienced or casual nurses. In one study, both negative and positive nursing behaviours in care of the dying were explored in nursing students and new graduates, as well as the consequences to patients and families (Degner, Gow, & Thompson, 1991). Clients and families in this study shared both positive and negative impressions of their relationship with home care nurses. Furthermore, research by Fisher (1996) on interprofessional hospice care emphasized that adjustment to hospice care is a continuous rather than a developmental process with an end point, necessitating ongoing professional development.

When researchers study the role of palliative care nurses in hospice settings, they focus on the existential and experiential aspects of the supportive role, such as knowing the patient, preserving hope, easing the struggle, and providing privacy (Rittman, Paige, Rivera, Sutphin, & Godown, 1997). A study of shift care nurses described their experiences of nurturing the dying at home through the dimensions of opening, witnessing, connecting, and being present for the dying person and family (Knill, 2000). Research by Davies and Oberle (1990) on the dimensions of the supportive role of the nurse described the nature of the nurse’s support as very complex and emphasized the importance of the nurse as a person. Findings from the current study revealed some of these same dimensions, as well as ongoing needs to coordinate services, to predict and
prepare families for impending crises, to ensure that predictable problems could be
prevented, and to negotiate between caregivers and professionals with different rule
books and agendas.

A major finding in this study was that nursing practice for marginalized
populations was dramatically different from caring for people in the mainstream. In
addition the qualities and competencies required for palliative care nurses, home care
nurses working with street people were exceptionally non-judgemental, able to work and
react very quickly, and extremely well connected to other care providers. Their practice
was guided by principles of harm reduction in conjunction with principles of palliative
care. Daily challenges included first of all accessing the clients and then to provide
complex pain and symptom management, wound care for infected injection sites,
administration of antiretroviral medications, food supplements, and referrals for other
basic care requirements, especially housing, all within a gentle manner of respect and
understanding. It was difficult for nurses to determine when a person living with AIDS,
drug addiction, mental illness and various other conditions should receive palliative care
due to the extreme unpredictability and complexity of multiple disease processes. A study
of hospice care for marginalized populations described the Hotel Project in San Francisco
where nurses provide palliative care in the hotels. They reported an increase in the
number of residents receiving primary care, a reduction in the number of emergency
room visits, and improved pain control and management (Robb, 1994). Nurses working
in the streets reported that even though they are often discouraged by the overwhelming
social and health care problems, they are actively involved in developing and
implementing creative programs for accessing and caring for the difficult to reach (Giles
& Brennan, 2001). The constant challenges in working with marginalized populations require that nurses be assertive and persistent in their approaches to palliative care.

A major part of the home care nurses’ practice with individuals and families in this study was to explore and resolve complex ethical issues. The most common problems within the mainstream context stemmed from misunderstandings or disagreements among family members related to decisions about prolonging or declining treatment, and the place of death. Many nurses reported that dealing with planned suicide was also very difficult. Important considerations in treatment decisions are the expectations of the clients and families, their inability to change the focus of hope, and the timing of the DNAR discussion (Elwell & Fainsinger, 2000). Roy (1995b, 1998a) concurred that ethical issues can only be resolved by honoring the complexity encountered at the bedside of dying people, and that the experiential components of pain and suffering are multiple, diverse, and interactive. For marginalized populations, home care nurses faced significant ethical distress, such as witnessing people in pain and hunger because they sold their food supplements and prescription drugs for heroin and cocaine. Another moral dilemma was sending people to hospital against their wishes or leaving them alone because they refused care. Robb (1994) concurred that “caring with compassion and clinical expertise for such persons mandates clear thinking, a willingness to accept difference, and a moral outrage that such populations must live so close to the margin of society” (p. 528). A study of nursing practice with homeless persons in Montreal concluded that nurses are constantly challenged about the meaning of life, freedom, solitude, and social justice (Thibaudeau & Denoncourt, 2000). Kuhl (1994) proposed that ethical issues are best addressed through understanding the complexities of personhood,
of medical care, of a person's definition of quality of life, of the principles of bioethics,
and of the necessary role of other team members. Overall, the nurses addressed ethical
issues by being guided by client and family perspectives and respecting their choices and
value priorities for quality of life. This approach to nursing ethics extends beyond
biomedical and healthcare ethics and is consistent with suggestions of Milton (1999) and
Pilkington (1999) that nursing theoretical frameworks contain embedded ethical values
and principles that serve to guide decision-making in nursing practice.

In this study, the complex nature of the nursing role in palliative care was
described and understood from perspectives of nurses, clients, families, and a hospice
physician. Only a few studies have previously examined the palliative care nursing role
from the perspective of clients or families. One study of the perspective of home-based
family caregivers on the support of hospice nurses identified the families' priorities as
24-hour accessibility, effective communication, a non-judgemental attitude, and clinical
competence (Hull, 1991). These findings differ from the many studies focusing primarily
on competencies of the nurse. In exploring the nature, meaning, and impact of empathic
relationships with home hospice nurses from the client's perspective, one researcher
reported improvement in the client's well-being when empathic relationships were
established (Raudonis, 1995), thus recognizing the positive impact of the nurse-client
relationship. There has been even less research incorporating both nursing and family
perspectives. Stiles (1990) examined the experiences of both nurses and families to gain a
richer understanding of the meaning of the nurse-family spiritual relationship. Research
involving the client, family, and nursing perspectives of palliative care is critical for
planning effective nursing care and gaining a broader understanding of the complexities
of the nurse’s role. All of these studies on the perspective of clients and families took place in the home, emphasizing the importance of client and family participation in home care nursing.

There are major differences in the role of home care nurses in palliative care from that of their colleagues in hospice and hospital settings. Home care nurses make brief visits to about eight clients and families in a day, with the frequency of visits determined by changing palliative care requirements. For marginalized populations, the nurses visit clients in their hotel rooms, in makeshift clinics in hotel offices, at drop-in centres for women, or whenever they meet on the street. In all settings, nurses may be involved with clients and families over months or years. Although they assume responsibility for ensuring 24-hour continuity of care, they are seldom present at the time of death. The complexity and diversity of the home care nursing role thus encompasses a broad scope of nursing qualities and competencies including highly developed interpersonal skills, supportive care, and symptom and crisis management in order to access, coordinate and integrate appropriate services. These multidimensional aspects of home care nursing practice in palliative care can be further understood in relation to the principles of primary health care, which forms the foundation of community health nursing.

**Palliative Home Care as Primary Health Care Practice**

Although primary health care is a philosophy of health care and the core of community nursing practice in Canada, it is not often discussed in relation to palliative care. Principles of primary health care include accessibility, public participation, interdisciplinary and intersectoral collaboration, health promotion, and appropriate use of
technology (CNA, 1988, 1993). Many issues that nurses in this study considered reflected their orientation to primary health care and ensuring that it was available to clients and families.

Ensuring equitable access to palliative care remains a struggle for home care nurses. There are still barriers to the utilization of services at home, especially for marginalized populations, cultural minorities, and people living with chronic illness in Vancouver. These inequities in accessing to palliative care are congruent with the situation nationally where the principle of accessibility still does not apply to community-based care (Rodger & Gallagher, 2000).

In this study, clients and families receiving palliative care participated actively and established effective relationships with the home care nurse. They usually relied on the nurse to resolve care issues with their family physician or other health care providers and to assist in making ethical decisions or arranging for alternate levels of care. They often became resigned and frustrated by problems they encountered within the health care system. They seldom reached the level of self-reliance, strategic dependence, and creating networks to negotiate health care as described by Thorne (1993) in the context of chronic illness. Individuals and families are unlikely to have the energy and resources to negotiate the palliative care system on their own. Thus, nurses must advocate for clients to access the resources that they need throughout illness, dying, death, and bereavement.

Nurses in this study often took a leadership role in establishing and sustaining collaborative professional relationships on the palliative care team. One challenging aspect articulated by the nurse participants in this study was the difficulty in obtaining consistent and appropriate family physician involvement, especially for the mainstream
population. A survey of family physicians reported that family practitioners would be willing to provide palliative care if they had education, consultation, home care support, access to acute care and hospice beds, and appropriate reimbursement (Vancouver/Richmond Health Board, 2000). The report concluded that continuing lack of family physician involvement will negatively impact quality of care and the roles of home care nurses and hospice physicians. Collaborative models of care that have evolved in relation to marginalized populations have created more effective working relationships between doctors and nurses than was common within mainstream palliative care. In addition to interdisciplinary collaboration, intersectoral linkages are essential for addressing broader community health and social problems (Stewart, 2000). Nurses in this study were less involved in intersectoral collaboration in the mainstream context, but established extensive intersectoral networks with social service agencies in caring for marginalized populations.

Home care nurses enabled clients and families to participate as fully as possible in their own care, to have control in making decisions, and to enjoy quality of life from their own perspective. In caring for marginalized populations, however, nurses are guided by principles of harm reduction, somewhat in contrast to health promotion. Nurses advocated for early intervention and treatment programs, but only if and when the client was willing to participate. The trend in health promotion activities for community health nurses in Canada has been a shift from a focus on individual lifestyle to a concern for broader community concerns (Rodger & Gallagher, 2000). Home care nurses in this study, who provide care for people living with drug addictions, have supported an approach of advocating for comprehensive community programs which include safer
drug use practices, safe housing, and availability of basic and specialized health care. These efforts contribute to the regional plan for addressing drug problems in Vancouver which has four dimensions: prevention, treatment, enforcement, and harm reduction (Vancouver Coalition for Crime Prevention & Drug Treatment, 2000).

The fifth principle of primary health care is the appropriate use of technology, a major consideration for home care nurse participants because more complex and acute care is being provided in the home with a resultant rise in potential for crises. Examples of palliative care crises experienced by nurses in this study included uncontrolled pain and agitation in the client; sudden deterioration of the client requiring emergency hospital admission; and client and family distress. It is well known that medicalization of home care can create negative consequences for clients and families (McWilliam, 2000). A survey of palliative care crises in a community in southwestern Ontario (Mantz and Crandall, 2000) reported that intense care situations in the home caused undue stress for the client, family, and care provider. The researchers concluded that crises could be managed in the home with nursing expertise, appropriate drugs, and sufficient support. In the absence of adequate technological support, nurses had no choice but to utilize emergency and acute care services.

Home care nurses’ knowledge of existing barriers and gaps in palliative care, as well as strategies to provide care for diverse populations are important contributions to primary health care in Canada. Rodger and Gallagher (2000) have suggested that the principles of appropriate technology and intersectoral collaboration will require the greatest effort for community health nurses in the future. In contrast, home care nurses caring for marginalized populations in this study have been very active in intersectoral
collaboration. Overall, the greatest challenges were equitable accessibility, interdisciplinary collaboration, and increased technology, all of which contribute to increasing demands for palliative care nursing in the home.

Palliative Care in a Declining Worklife Context

Many home care nurses in this study reported a decline in their quality of worklife, which was difficult when the role was already complex and challenging. Reasons included the increasing volume of referrals, administrative concerns, and the shortage of nurses with home care and palliative care experience. These problems resulted in less time for nurses to care for clients and families, and limited opportunities for professional development. Growing work demands were taking a toll experienced nurses in full time positions, as several experienced nurse participants chose to work part-time to reduce the workplace pressures. Researchers have emphasized the importance of organizational supports, in addition to personal strengths to prevent emotional exhaustion in palliative care (Mulder & Gregory, 2000). These include reasonable workloads, educational opportunities, and supportive colleagues.

Home care nurses believed that working in palliative care was challenging in itself, without having to worry about lack of flexibility in work assignments and scheduling. Experiences of home care nurses in this study were congruent with other findings where nurses struggled with accumulated loss (Adams, Hershatter, & Moritz, 1991) and the harsh realities of hospice care (Bailey, Carney, Grodski, & Turnbull, 1987; Korda, 1987). Knill (2000) described shift care nurses’ expectations for hospice care on a continuum from congruence to dissonance depending on the reality of the situation. The
responses of nurses to the pursuit of meaningful hospice care and spiritual integrity have been described as either vitalizing or devitalizing experiences (Rasmussen et al., 1997). Vitalizing experiences occur when nurses feel challenged to use their abilities to promote dignity for the dying and to help family members endure suffering. Devitalizing experiences, such as not having time to provide care in accordance with one’s values, related to lack of staff and to the nurses’ personal endurance. Another hospice study reported that administrative concerns caused more stress for staff than issues related to death and dying (Dean, 1998). The home care nurses in this study enjoyed their work with marginalized populations in spite of the hardships. This was congruent with results of another Vancouver study of the nature of street nurses’ work, concluding that quality of worklife is related to teamwork, flexibility and creativity, and recognition and support from other health and service providers (Hilton, Thompson, Moore-Dempsey, & Hutchinson, 2001). For the most part, nurses embraced the many challenges of palliative care nursing practice, but they could easily become overwhelmed and burdened by administrative problems.

The lack of experienced nurses in home care and the declining quality of worklife are reflected nationally. The provincial shortage of nurses is critical and the majority of new hires are recent graduates. The problem is long-term and complicated by increasing demands for health care services (RNABC, 1999). Many Canadians agree that the shortage of nurses is getting worse and if left unchecked, could lead to deterioration in the quality of the nation’s health care system. The key focus of the national nursing strategy is to improve quality of worklife for nurses (Health Canada, 2000).
The role of home care nurses within the changing nature of palliative care is extremely complex, comprised of multiple dimensions. Working from the framework of primary health care, nurses are engaged not only in the provision of quality care, but also in ensuring access to and coordination and integration of services. They face unique and very different challenges in working with mainstream and marginalized populations, requiring specialized abilities within each domain of nursing practice. Furthermore, the shortage of experienced nurses as well as administrative issues are contributing to increasing work demands and a decline in the quality of worklife, impacting on the quality and availability of palliative care services in the home.
5.3. The Vision of Integration

Within the changing nature of palliative care, many challenges to developing an integrated approach to regional community-based services have been identified. In this section, I will discuss tensions within the health care system relating to literature on health care reform and policy processes. An important element in developing a vision for palliative home care is an understanding of the ethical issues involved. In this study, two distinct kinds of ethical issues emerged - those relating to death-and-dying decisions by individuals and their families, and those having to do with resource allocation within health care. Rising demands for palliative care services and appropriate resource utilization will be discussed in terms of establishing effective collaborative intersectoral networks within the context of the current debates in the development of national strategies for integrated health care, end-of-life care, home care, and harm reduction. Building the capacity of individuals, families, and communities to become more involved in palliative home care is also important to the vision for an integrated system of services. Strengthening their capacity will enable home care nurses to have a central role in the sociopolitical process, and to be more connected to the policies that govern their practice.

Creating Ethical Foundations

Individuals and families within the mainstream have asserted their rights to palliative care at home and to make decisions and choices about their care. At the same time, home care nurses have struggled to provide basic care for marginalized populations. These inequities lead one to consider larger societal questions. What is the health care system's responsibility for ensuring resources for basic health care? Is palliative care a
societal value and a right? In considering the larger ethical context within which palliative care philosophies have been articulated and programs have been developed, Roy (1996) argued that palliative care is based on the logic of humanity, whereas social, economic, and health care policies are shaped by the logic of exclusion. He explained further that:

Within the logic of humanity, there are no strangers to us among those who suffer, be it from poverty, social discrimination and marginalization, illness, or impending death...Palliative care, with its vision, its logic, and its mission, is on a direct collision course with that elite minority who today shape social, economic, and health care policy according to a logic of exclusion (p.4).

In the culture of exclusion, the needs of the living tend to surpass the needs of the dying. Herein lies the struggle for funding and political support. Findings in this study demonstrated that funding for palliative care is concentrated in institutional settings rather than in home and community-based care, and that criteria for palliative care programs exclude people on the margins of society as well as those with long-term and some chronic illnesses. This same perspective is shared by the Canadian Senate committee’s call for quality end-of-life care to all who need it, and that “as Canadians, we will afford what we value” (Carstairs, 2000, p.7). Wilkinson (1993) concurred and called for allocation of resources to be determined by fairness of provision whereby people receive an equitable share of services based on an assessment of their need.

Inadequate resources are one reason why palliative care services are not equally accessible to all populations. In identifying important ethical issues in palliative care, healthcare professionals described resource allocation to be the most fundamental concern, whereas suicide/euthanasia was ranked as the lowest, in contrast to media attention (MacDonald, 1994). In this study, many home care nurses reported that planned
suicide was a difficult ethical situation. Nurses also identified lack of resources as an important issue, more so for marginalized populations. The attention on euthanasia in the media however, has helped to emphasize the inadequacy of palliative care services, thereby gaining support for palliative care programs, national standards of practice, research, and education especially through work of the Canadian Senate (Neiman, 1995). In addition to inadequate resource allocation, the Senate Committee acknowledged that inadequate federal-provincial collaboration, and insufficient attention to end-of-life care needs have contributed to the slow implementation of the recommendations from the 1995 report (Carstairs, 2000). This ethical concern about resource allocation provides a lens through which to frame palliative care within the broad spectrum of health care and social services.

Establishing Effective Networks

This study’s findings suggest that integration of regional palliative care services requires the establishment of effective collaborative networks of providers and programs across the continuum of care and across diverse care settings. Palliative care programs are interdependent and no one program provides the full continuum of care (V/RHB, 2000). However, the palliative care programs in this region were not well integrated. Furthermore, inaccessibility of community based palliative care has led to continued reliance on acute care services. Hospice care and residential care were limited in this region, and many of the existing services depended on private sources of financing to supplement public funding. Funding was competitive and insecure; resource allocation was not equitably defined. No regional accountability for utilization patterns and system
development was apparent, despite increasing demands for services from the mainstream population and gaps in services for those who were marginalized. This situation mirrors the health care system in Canada:

Canada does not have integrated healthcare. Canada has a series of disconnected parts, a hodge-podge patchwork health care industry comprising hospitals, doctor's offices, group practices, community agencies, private sector organizations, public health departments, and so on. Each Canadian province is experimenting with different types of organizational structures and processes with the intent of improving the coordination of services, facilitating better collaboration among providers, and providing better health care to the population (Leatt, Pink, & Guerriere, 2000, p.13).

Attempts to integrate a health care system using a formally centralized mechanism can be problematic. Based on experiences with integrated health care in Australia, Leggat and Walsh (2000) advised that not everyone requires integrated health care but that integration can be best achieved from a "bottom-up" approach where communities demand the services required to meet their needs. Shamian and LeClair (2000) of Health Canada agreed, suggesting that marginal populations may not be best served through integrated models of care, but rather through primary health care reform. Responsibility for coordination of health care services in British Columbia resides with the regional health boards. Although major strides have been made in Victoria (Closson, 2000), the health care network within Vancouver has been problematic, within decreasing choice and increasing control over available resources. Findings in this study support a vision of integrated palliative care programs for certain populations, within the context of current debates for national approaches to end-of-life care, home care, and harm reduction.

As mentioned earlier, the most recent national initiative in palliative care has been the Canadian Senate committee's report on end-of-life care, based on extensive consultation with members of the Canadian Palliative Care Association and other key
stakeholders. The committee reviewed the 1995 recommendations for improvements in palliative care, in a response to a study on euthanasia and assisted suicide. There was agreement that end-of-life care should to be a core service integrated within the health care system, and extended in terms of the nature of a person’s illness and the time period of service eligibility. The development of integrated, accessible, and adequately funded services is intended to support clients and families in varied institutional and home settings (Carstairs, 2000). Based on identified gaps in services in this study, the home care strategy is inherently limiting unless it recognizes the lack of appropriate housing for the poor and marginalized in our society, who are in disproportionate need of these services.

Lack of linkages between institutional and home settings was another important theme in this study. Increased resources are insufficient without a comprehensive, integrated network of services to provide the most appropriate care, rather than the most available care, as demand for multiple levels of palliative care services will continue to rise. Improvements have been realized in linking care at home with the hospital palliative care units in this region where clients were admitted for respite, acute pain and symptom management, and end-of-life care. Unfortunately, serious deficits remain in linking palliative home care, hospice care, and long term care. Moreover, there is a regional shortage of long-term care beds and a survey of long-term care facilities suggests that there are major differences in their ability to provide quality palliative care (V/RHB, 2000).

Integration is also important in the development of a national home care program. Home care is within context of provincial continuing care service systems, also including
long term care and home support. Provincial and territorial governments have committed increased investment in home care and community care as critical components of a more fully integrated health care system (Canadian Intergovernmental Conference Secretariat, 2000). In an extensive review of the most policy-relevant information about home care in Canada, MacAdam (2000) reported that “mounting evidence of cost-effectiveness, in combination with demographic, health delivery, technological changes, and consumer demand are bringing home care to the forefront of Canadian health policy” (p.9).

Intensive lobbying is underway to include home care services under the Canada Health Act in order to remove inequities in the current system, move home care from its marginal position, and ensure integration with acute care and long term care sectors. MacAdam (2000) argued for strong federal leadership in establishing a national home care program. She wrote:

... savings from one sector do not move easily to another sector unless there is strong leadership at the policy level... I am concerned at this point in home care development about too much integration. I am worried that unless there is separate funding for home care, the much more powerful acute care sector will starve home care of needed resources, especially in the areas of long term care substitution and home support services (p.110-111).

Several Canadian researchers have argued that we do not necessarily need a national program for home care, but rather a national home care approach with a special federal/provincial fiscal arrangement to allow for integration of home care into continuing care (Beland & Bergman, 2000; Thompson, 2000). Alcock (2000) went one step further to call for an accountability framework. The Canadian Nurses Association (2000) also proposed a national approach to quality home care and community care, integrated with the health care continuum and rooted not only in the principles of the Canada Health Act but also of primary health care. Although there are differences in how
a national approach would work, all researchers and policy makers agreed on the need for federal leadership to move home care issues forward (MacAdam, 2000).

Unfortunately, current discussions on national strategies for integrated health care, end-of-life care, and home care are based within the mainstream context. Although there is no specific reference to marginalized populations, MacAdam (2000) emphasized that actual home care delivery systems should be developed at the local level within a framework of national principles and accountability mechanisms. Other policy makers support a community-based approach (Legatt & Walsh, 2000) and recommend primary health care reform (Jeans, 1999; Shamian & LeClair, 2000) to address the health care requirements for diverse populations.

Findings in this study demonstrated that traditional programs of palliative care were unable to address the specific needs and social circumstances of injection drug users. The most appropriate approach to palliative care was in home and hospice settings and was based on harm reduction philosophy wherein abstinence from illicit drugs was not a requisite for care. This approach to care for drug users is advocated by the Association of Nurses in AIDS Care (Fisk, 1998) and other nursing experts (Bradley-Springer, 1996; Schmidt & Williams, 1999) whose aim is to prevent the spread of AIDS and other infectious diseases among the drug using population, and to expand harm-reduction-based interventions and policies. Harm reduction is also supported among public health researchers in Canada who have evaluated the cost effectiveness of a needle exchange program in Edmonton (Jacobs, Calder, Taylor, Houston, Saunders, & Albert, 1999), some of whom advocate for a heroin prescription program trial (Fischer & Rehm, 1997). Decriminalization of illicit drugs has been advocated by several international
organizations including the Canadian HIV/AIDS Legal Network (1999) and the CATO Institute, a public policy research foundation in Washington, DC (Boaz, 1999). The Canadian Harm Reduction Network (2000) was established with funding from the Drug Policy Foundation in the USA to lobby for changing the direction of Canada’s national drug strategy from heavy reliance on prohibition to harm reduction and to participate in the international network of harm reduction organizations. The Canadian Senate established a Special Committee on Illegal Drugs in October 2000 to conduct an extensive review of Canadian drug laws and policies to which members of the Canadian Foundation for Drug Policy (2001) have made presentations. These current initiatives highlight the international problems with illicit drugs and have created intense debates about non-traditional approaches to policy development. Decriminalization and/or legalized medical prescription of illicit drugs would be important for development of palliative care services sensitive to the drug-using population.

There are many areas of agreement for the development and integration of national health care programs in the mainstream context. Strong federal leadership is a prerequisite for developing provincial and regional programs based on population health needs in both urban and rural communities. Federal/provincial consensus, on integrating home care and palliative care across the continuum of health care services, and on supporting family caregivers and health care providers is also needed. Integration of existing programs and services that exclude segments of the population is inadequate. These proposed networks must also consider safe housing and federal drug policies, in order to influence future development of specialized palliative care programs appropriate for marginalized populations. A vision of integration is one that has creative, flexible, and
equitable programs for diverse populations within a regional framework and organizational structure to ensure accountability for resources and quality of care.

**Building Community Capacity**

Building community capacity is a means of integrating palliative home care services with various community services. Home care nurses in this study have been extensively involved in intersectoral collaboration with community services to address the social determinants of health in marginalized neighbourhoods. Individuals and community organizations in Vancouver have contributed also to developing creative hospice and residential care services. Although there is support for community participation in the planning, implementation, and evaluation of palliative programs and services at the national level (Carstairs, 2000), there has been no discussion as to how home care programs can be expanded beyond a medical supportive function to assist in building supportive communities (Chappell, 2000). The grass roots approach by nurses and communities in this study as well as identification of individual, family, and community needs is consistent with the development of community competence described by Eng et al. (1992).

Supporting the capacity of individuals and families in providing palliative care at home was another important theme that creates challenges for the integration and future development of palliative care services. Many researchers who advocate for a national home care strategy emphasize the importance of the family’s role. MacAdam (2000) reminded us that 80% of home care is provided by family members, without which the publicly funded programs would be completely overrun with requests for care. Chappell
(2000) proposed that all home care services should be viewed as potentially providing respite and support to family caregivers. From an international perspective, Hirschfeld (2000) reminded us that we can learn from the approach in developing countries in which the first priority is to preserve community solidarity and family care to keep people at home and only later develop other service elements.

A major challenge in supporting families is to provide financial support especially for home support services. Inequities in funding between hospital and home were most remarkable at end-of-life when families were responsible for the cost of care at home. Cuts to home care affect some of the most vulnerable people in society, such as seniors living in poverty (Vogel, 2000). Non-professional services have been slashed across the country, yet it is these services that home care recipients believe are essential to helping them remain independent and within their community (Chappell, 2000). Other burdens for families are direct costs for drugs and supplies, and indirect costs related to loss of employment or unpaid absence from work. Following extensive lobbying at the national and provincial levels, a new Palliative Care Benefits Program, effective February 2001, was recently announced that will cover the cost of drugs, medical supplies, and equipment for British Columbia residents who have a life expectancy of up to six months (BCHPCA, 2000b). With regard to indirect costs, there is support from the Senate committee to explore income assistance and income security programs for family members who leave their jobs to care for dying relatives. Building family and community capacity in the provision of palliative home care is crucial for programs to sustain increasing demands for services.
Strengthening the Capacity of Nursing

Nurses can be a valuable resource to policy development as they have substantial knowledge and understanding of client and family’s needs as well as what works and does not work for diverse populations. For a number of reasons, home care nurses in this study were limited in participating or providing input to decision making and policy development affecting their practice. Their priorities were client and family care, and with the shortage of nurses, there was little time for committee involvement. Another concern was lack of professional nursing leadership in senior management to represent nursing issues in practice.

There is a noticeable absence of discussion on the role of nurses in planning national health care strategies and policies, except by nursing leaders. Judith Shamian, executive director for nursing policy in Health Canada, and Stephen LeClair, senior advisor, argued strongly for reform of organizational structures and corporate decision making to reflect partnerships between health care professionals and administrators. Throughout the 1990’s, nursing management at the corporate level almost totally disappeared as regionalization and restructuring of health care shifted the decision-making framework from professional administrators in favour of management. They explained other dynamics as follows:

Furthermore, the regionalization, restructuring, and downsizing of the 1990’s left us with the serious crisis of a highly dissatisfied nursing workforce, a nursing exodus, and a growing nursing shortage... It would appear that issues of retention are more serious than recruitment (Shamian & LeClair, 2000, p.73).

Findings in this study support these trends of a decreasing quality of worklife, as well as a shortage and loss of experienced nurses.
Nurses have a unique and complimentary role in health care delivery systems (Jeans, 1999). Several examples of effective collaborative partnerships between nurses, clients and families, and physicians in this study ensured a seamless system of palliative care through integrated community-based services. Home care nurses experienced in palliative care are seeking to advance their nursing practice and to strengthen the primary care team through improved relationships with family physicians. Although advanced practice nursing roles and nurse/physician collaborative projects are well established in other provinces (Rodger & Gallagher, 2000), restrictive scope-of-practice legislation does not permit nurse practitioners in British Columbia at this time (Mass, 1999). However, as the supply of nurses and other health care professionals diminishes and the demand for health care increases, creative solutions to community-based collaborative practice will need to be considered (Mass, 1999).

Home care nurses in this study played an important role in the integration of palliative care services. Allocation of limited resources was dependent not only upon availability, but also upon the knowledge and decisions made by home care nurses with expertise in accessing and coordinating cost-effective palliative care services. Leadership skills are required to transform knowledge about health into action and to use evidence to plan programs and policies (McWilliam, 2000). Home care nurses must be enabled to take leadership roles in moving beyond the support of individuals and families to becoming involved in health and social policy (Reutter, 2000). The capacity of nurses can be strengthened and enhanced through creating and sustaining a stable workforce, a supportive organizational infrastructure, and strong collaborative partnerships with physicians.
In summary, a vision of integration for community-based palliative care services must be based upon an ethical foundation of humanity through inclusion of diverse populations. Strong federal leadership for national approaches to the integration of health care services, end-of-life care, home care, and harm reduction can provide direction and funding for the development of regional networks offering creative, flexible, and equitable palliative care services that address the needs of both mainstream and marginalized populations and ensure accountability for resources and quality of care. Increasing demands for services can be addressed through building family and community capacity for involvement in the planning, delivery, and evaluation of palliative home care programs. Strengthening the capacity of nursing will ensure that home care nurses actively contribute to ongoing program and policy development.
Palliative care within the mainstream context must address specific needs of extended segments of the population, including people with long-term and chronic illness, the elderly, and cultural minorities. For marginalized people, the challenge will be to provide specialized services based on principles of harm reduction for primary care, crisis care, hospice care, and long term care. The complexity of home care nursing is reflected in the multiple dimensions of personal qualities and competencies required for providing quality palliative care and coordinating and integrating services. The most significant consideration is the vast difference in approach to care for mainstream and marginalized populations. A vision of integration for community-based palliative care services entails the development of regional networks that address the needs of diverse populations and ensure accountability for resources and quality of care, within the framework of national initiatives for the reform of health and social policies. Building family and community capacity and strengthening the ability of home care nurses to contribute knowledge and expertise will ensure the future development and integration of quality palliative care services. These challenges are consistent with the need to continually renew and adapt all aspects of the health care system to address the changing nature of society and its evolving health concerns through public participation and active involvement of nurses.
CHAPTER 6
CONCLUSIONS AND IMPLICATIONS

Summary of the Study

The purpose of this study was to explore and interpret the contribution of nurses in the development and provision of integrated palliative care services for diverse populations. This issue has emerged as a relevant policy challenge, as reflected in the literature on nursing, palliative care and health policy. Many researchers and policy makers have recognized barriers to access and gaps in the utilization of services. The specific elements of quality palliative care in the home are not well understood. Ethical issues are challenging for nurses and families. Another major gap was to determine appropriate services to meet the care requirements for marginalized populations. The role of the home care nurse on the interdisciplinary team and within intersectoral collaboration is important to determine their sociopolitical responsibilities within the context of the health care system. The theoretical framework which guided the method, data collection, and analysis for this study was based on the principles of primary health care, nursing theory, social theory, and policy process.

Ethnographic approaches are ideally suited to the study of health services such as palliative home care to develop a comprehensive narrative description and analysis of the experiences of a particular group of people, as well as events, and trends. In total, there were 52 participants including home care clients, their family members, home care and shift care nurses, clinical nurse specialists, nursing administrators, and a hospice physician. Data collection methods included participant observation, fieldnotes, interviews, and documentary review during fieldwork that occurred over a two-year
period. Analysis of fieldnotes, as well as interview and documentary transcripts, involved processing strategies of an inductive nature and constant comparative analysis wherein preliminary data analysis occurred simultaneously with data collection. This was a cyclical process that directed the researcher to conduct more focused observations and interviews while noting theoretical observations and questions to project next steps in the constantly emerging design. The data were developed into an analytic structure and further refined into meaningful descriptions having significance to related theory and concepts as well as the research questions. Conclusions became explicit through increasing analysis grounded in and verified by the data.

Findings of this study are organized into three major themes that emerged from the data. The first was that home care nurses made valuable contributions to quality of life and quality of palliative care through their coordination and integration of services amidst the complexities and challenges of the health care system. The second theme illustrated dramatic differences in quality of life and quality of care for mainstream and marginalized populations as reflected in the client and family experiences, nursing practice, and program models of care. Critical tensions within the health care system comprised the third theme, which showed that current programs are unable to keep pace with rising expectations and demands for services.

By examining these findings in the context of the existing empirical and theoretical literature, several policy issues became evident. The nature of palliative care is dynamic and changing. Within the mainstream, programs are less responsive to specific needs of extended segments of the population including people with long-term and chronic illness, the elderly, and cultural minorities. For marginalized people, the system
is challenged to provide highly specialized services based on principles of harm reduction for primary care, crisis care, hospice care, and long term care. The complexity of home care nursing practice is reflected in the multiple dimensions of personal qualities and competencies required for providing, coordinating, and integrating quality palliative care services. Integration for community-based palliative care services requires regional networks to address needs of diverse populations and ensure accountability for resources and quality of care, within the framework of national health care and social policy reform initiatives. Building family and community capacity and enabling home care nurses to contribute their knowledge and expertise will ensure future development and integration of quality palliative care services. These challenges are consistent with the need to continually adapt all aspects of the health care system to address the changing nature of society through public participation and active involvement of nurses.

Limitations of the Study

Upon reflection on the data analysis and consultation with committee members, the following limitations of the study are presented.

Theoretical Framework

The framework *Partnership Model for Primary Health Care* was derived from nursing theory, social theory, policy process, and principles of primary health care. The model was developed to situate the literature review and to frame the research questions which subsequently guided data collection and analysis.

Several principles and concepts from Parse's theory of human becoming were supported throughout the data. Nurses described their practice in terms of quality of life
from the client and family perspective and emphasized the importance of the nurse-client relationship. Client and family members were freely-choosing human beings, living their lives according to value priorities as shared in hopes and dreams. They created personal and shared meanings and were able to transcend the experience of death and dying.

Limitations of Parse's theory relate to the complex role of the home care nurse, which extends beyond the relationship with clients and families, and includes ensuring access and coordination of services as well as intersectoral and interdisciplinary collaboration.

The importance of community competence and social determinants of health was upheld, especially in reference to differences between mainstream and marginalized populations. A limitation of this perspective is that it failed to define the scope of the nurses' responsibility for social change.

Although the Advocacy Coalition Framework was supported by significant contributions and involvement of the Canadian Palliative Care Association, it fails to address the importance of extensive collaborative networks for policy development, as evidenced in discussion in the findings. Analysis of changes within and external to the health care system were key considerations. However, there is a lack of direction in how nurses and others can become involved to effect policy development.

Study findings challenge the Partnership Model for Primary Health Care because relationships among nurses, clients and families, and other health care providers are inequitable and varied within the community. The important role of government was supported and further defined. Principles of primary health care were important throughout data analysis, yet were limited to the complexity of home care nursing practice and the principles of harm reduction.
Selection of Participants

This research focused on nursing practice and the experiences of clients and families. I considered involving family physicians if I encountered them in participant observation situations, but the opportunity did not arise. A limitation of this study is the omission of senior administrators or members of the regional health board. This decision was based, in part, on extensive changes in administration throughout the study period. However, I was consulted by the project coordinator for the regional palliative care program proposal to share my interim findings. As well, I had access to notes from the consultation process and current regional reports. I plan to consult with regional, provincial, and national policy makers through dissemination of the findings.

Transferability

Findings of this study are transferable to similar populations in large urban centers, but would be limited with respect to rural communities where populations are less diverse and palliative care services are minimal. The theoretical framework could be revised based on these findings and considered for further research.

Conclusions

These conclusions are based on interpretations of the findings and of the discussion regarding relevant literature in palliative care, home care nursing, and health and social policy.

1. The complexity and diversity of the home care nursing role encompasses a broad scope of nursing qualities and competencies including highly developed interpersonal
skills, supportive care, ethical decision making, symptom and crisis management, and coordination and integration of services within the context of the principles of primary health care.

2. Clients and families can be supported to stay at home as long as possible and die at home if desired with accessible and available comprehensive palliative care services, including home care nursing, family physician commitment, hospice physician consultation, shift care nursing, and home support services.

3. Gaps in palliative care services and barriers to access exist within the mainstream context for people living with long term and chronic illness, the elderly, and cultural minorities.

4. Bereavement care within the immediate period of grief is a major gap in the continuum of palliative care for mainstream populations.

5. Quality of life and quality of palliative care are dramatically different for mainstream and marginalized populations, as evidenced by the client and family experiences, nursing practice, and program models of care.

6. Traditional programs of palliative care services do not work for marginalized populations, specifically people with multiple health and social problems associated with injection drug use and AIDS. There are insufficient appropriate program models of care based on harm reduction to meet the highly specialized care requirements for marginalized people.

7. The increasing demand for palliative care services in conjunction with a shortage of nurses is impacting negatively on the quality of worklife for home care nurses.
8. There are systemic problems in the coordination and integration of palliative home care services with acute care and long-term care institutions, resulting in care often being provided in the most available place rather than the most appropriate place.

9. Effective and integrated systems of palliative care require coordinated regional networks with flexible and equitable services that address the needs of both mainstream and marginalized populations and that ensure accountability for resources and quality of care.

10. Quality palliative care services depend upon building family and community supports and strengthening the capacity of nurses to contribute their knowledge and experience to ongoing program and policy development.

Implications

There are several implications for nursing practice, nursing education, organizational and policy development, and for research that were derived from interpretation of the findings.

Nursing Practice

Quality of life and quality of care are basic goals of nursing practice. Specific implications for palliative care at home relate to having appropriate nursing services available and accessible when required. There is a need for lower home care nurse/client ratios in palliative care than in regular home care to allow more time at each visit and flexibility to increase the number of visits to meet changing care requirements. More shift care nurses are required for end-of-life care to avoid inappropriate utilization of home support workers or unnecessary transfers to hospital.
To address the specific needs of underserved segments of the population, there needs to be earlier recognition of palliative care services for the elderly and people with chronic illness. Furthermore, home care nurses must assess and understand the circumstances and distinctive requirements of cultural minorities in relation to death and dying. The gap in bereavement care could be addressed through a more formal program, recognizing the intense involvement of nurses with families, and the specific needs of many families for continuation of some contact with those care givers with whom they have been so intimately involved.

Collaborative partnerships with other health care professionals are essential in palliative home care nursing practice, especially with family physicians. There are several means of establishing positive working relationships including contacting the family physician as soon as a client is referred and arranging joint home visits. With increasing demands for palliative care services at home, alternative arrangements will have be considered if the family physician is not available as required. New collaborative models of home care nurse / family physician practice ought to be explored such as outreach teams. In addition, the community interdisciplinary team can be strengthened with the inclusion of allied health care professionals. More flexibility in advanced practice roles for nurses would meet the challenge of providing 24 hour, 7 days a week care as proposed for the national programs for end-of-life care and home care. However, before considering such changes in professional practice, approaches to reimbursement for collaborative practice would need to be implemented to eliminate the paralysis caused by different payment methods for physicians, nurses, and other health care professionals.
The quality of worklife of home care nurses has a direct impact on their ability to provide quality palliative care. In addition to hiring more nurses, there needs to be time for nurses to have a regular break during the day, and for informal and formal peer support through regular team meetings. A visible nursing infrastructure is required to address issues in practice and concerns about larger system problems. The declining quality of worklife for home care nurses is a serious consideration for recruitment and retention initiatives and will have an impact on future contributions from the nursing profession. Resolution of many challenges to the development of integrated community-based palliative care services is contingent upon building a stable and highly qualified nursing workforce, with opportunities for professional advancement and strong collaborative partnerships with family physicians.

**Nursing Education**

Because of the lack of home care nurses experienced in palliative care, formal orientation and mentorship programs for new staff are a priority. Continuing education should include nursing competencies required to provide quality palliative care for people of all ages in both mainstream and marginalized populations and appropriate resource allocation and service utilization. New competencies such as lobbying, social and political activism, and formulating policy are also needed. Educational leave must be budgeted to permit nurses time to participate in opportunities for professional development in palliative care.

Home care nurses also need release time from regular client care responsibilities to mentor students and new staff. A nursing educator position for palliative care could be
created. Senior experienced nurses who have chosen to work part-time could be encouraged to return to full-time employment with teaching and program development responsibilities. In addition, increasing involvement of home support workers in palliative care will necessitate appropriate educational preparation and supervision.

Another teaching opportunity for experienced home care nurses is with staff in long term care institutions. Palliative care courses and regular group consultation sessions with hospice physicians are ideal for interprofessional education of family physicians, nurses, and allied health care providers.

Policy and Program Development

There are several implications from the findings of this study for future policy and program development for regional palliative care services. The first recommendation is to create a systematic and accessible process for ongoing data collection of palliative care services utilization. A large amount of information is currently collected, but the data are not accessible. Other significant data could be collected through centralization of wait lists for hospice and long term care. Availability of current and meaningful data is important to ensure accountability and to secure funding. For example, having accurate utilization data could be the basis for assessing the need to increase beds in the palliative care units and hospice as opposed to increasing home support hours and considering alternative models of care such as day hospice. Sharing this information on a regular basis with staff would enhance their knowledge and decision making. Policy and program development should also be based on research, the experiences of other regions, and national standards and guidelines for end-of-life care and home care.
Building family and community capacity is essential to keep pace with service demands. Increasing home support services for those in greatest need and cost sharing with people who have extended health benefits can reduce some of the inequities.

Home care programs maximize their potential when closely linked to referral processes for acute care, hospice, and long term care. Developing palliative care consultation teams in intermediate and long-term care facilities would improve continuity of care between home care and long term care.

Flexible, accessible, and appropriate services need to be developed for the care of marginalized populations in their own neighbourhoods. Health care requirements are inseparable from social service needs. Housing is the most critical necessity so that people can be accessible for service provision. Varied models of stable, safe housing are required within and outside of the neighbourhood, including supervised residential care with three meals a day and medication administration. There is a dire need for safe housing and hospice care for women who are very hard to reach and the most vulnerable.

Appropriate palliative care services require a comprehensive harm reduction approach including 24-hour access to community-based drop-in centres for food, shelter, medications, needle exchange, assessment, treatment, and referral. Such a model could improve the health and quality of life of people on a daily basis and prevent serious complications from pre-existing illnesses. It would also enable health care and service providers to maintain access with such a hard-to-reach population. Another recommendation is to develop a palliative care consultation team for the neighbourhood and designated hotel suites for crisis care, or “in and out palliative care” that would be
quickly accessible 24 hours a day, 7 days a week. Finally, there is an urgent need for addiction services including treatment and detoxification centres.

**Palliative Care Research**

Comprehensive research methods that include the perspectives of nurses, other health care providers, and clients and families are important for future program and policy development. Researchers should endeavour to include diverse populations. Research is needed in the ongoing assessment of individual, family, and community palliative care needs, especially for underserved segments of the population such as people with chronic illness, the elderly, cultural minorities, and marginalized populations.

Program evaluation is another research priority to identify trends in utilization of services, place of death, client demographics, and referral patterns. Comprehensive cost analysis studies, including short term and long term cost of care in various settings, and costs to families are needed. Pilot studies and evaluation research of primary health care models of practice and alternative models of hospice and palliative care are also important. Interdisciplinary research opportunities should be fostered, such as harm reduction program trials and evaluation. Another area of needed research is the context of suicide in home deaths, as the dynamics are not well understood by nurses. Qualitative methods would be appropriate to explore these situations with family caregivers.

The final recommendation links to all implications and that is to lobby for a regional palliative care centre of excellence, as in other major Canadian cities, to act as teaching, research, and consultation units for the region and as a base for specialized
palliative home care. Such a centre would also facilitate the transfer and uptake of research into practice and policy formulation.
REFERENCES


British Columbia Hospice/Palliative Care Association. (2000a, December). *Hospice news,* Vancouver, BC.


Dicks, B. (1990). The contribution of nursing to palliative care. Palliative Medicine, 4, 197-203.


Roy, D. J. (1994). A day soon must come when... *Journal of Palliative Care, 10*(3), 4-5.


Appendix A

HOME CARE AGENCY ANNOUNCEMENT
Appendix B

INFORMATION FOR HOME CARE NURSES
Following the observations, I will plan a formal interview at a time convenient to the nurse. This should take approximately an hour and will be audiotape recorded for the purpose of analysis. I would like to interview each nurse on at least two occasions to learn about their experiences with families receiving palliative care.

The nurses' participation in this study is voluntary and will in no way affect their employment. Participants are free to withdraw from the study at any time, refuse to answer any questions, ask for any taped message to be erased, and ask for any sensitive information not to be divulged. A signed consent form will be obtained for each participant.

Confidentiality will be maintained by assigning each nurse a code name or number. Similarly other staff, clients, families, and institutions will remain anonymous. Biographical details will be altered as necessary in published and unpublished work to mask identifying characteristics of the participants, clients, families, and institutions.

The names of participants will not appear in any materials, and observational notes, tapes, and transcriptions will not be made available to any employers or administrators. The data will be kept secured in a locked filing cabinet and be available to the researcher and the members of the researcher's dissertation committee for the purpose of analysis and writing of the research report. The researcher will utilize the data for future publications, presentations, and possibly secondary analysis at a later date.

Follow-up interviews, group meetings, and/or educational sessions will be offered to all participants to make the study results available once it is completed. Participants may access their own interview transcripts as well as the complete dissertation. A summary report of the findings will also be available for all participants.

I PLAN TO BE AT YOUR UNIT DURING THE MONTHS OF JANUARY-MARCH. PLEASE CALL ME IF YOU ARE WILLING TO PARTICIPATE.

Sincerely,

Frances Legault
Appendix C

CONSENT FOR HOME CARE NURSES
I am aware that my participation in this study is voluntary and will in no way affect my employment. I know that I am free to withdraw from the study at any time, refuse to answer any questions, ask for any taped message to be erased, and ask for any sensitive information not to be divulged.

I understand that confidentiality will be maintained by assigning each nurse a code name or number. Similarly other staff, clients, families, and institutions will remain anonymous. Biographical details will be altered as necessary in published and unpublished work to mask identifying characteristics of the participants, clients, families, and institutions.

I have been assured that the names of participants will not appear in any materials, and observational notes, tapes, and transcriptions will not be made available to any employers or administrators. The data will be kept secured in a locked filing cabinet and be available to the researcher and the members of the researcher's dissertation committee for the purpose of analysis and writing of the research report. The researcher will utilize the data for future publications, presentations, and possibly secondary analysis at a later date.

I understand that Frances will offer follow-up interviews, group meetings, and/or educational sessions to all participants to make the study results available once it is completed. I will have access to my own interview transcripts as well as the complete dissertation. A summary report of the findings will be sent to me. If, during this study, I have any concerns about my treatment as a research participant, I may contact Dr. Carol Jillings, the researcher's supervisor, or Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598.

Signed ____________________________________________

Date ____________________________________________

I CONSENT TO THE TAKING OF PHOTOGRAPHS YES/NO

(please circle)

Receipt of:

"Information for Home Care Nurses" acknowledged ______

Copy of "Consent Form for Home Care Nurses" acknowledged ______
Appendix D

INFORMATION FOR INDIVIDUALS AND FAMILIES
Your participation in this study is voluntary and will in no way affect the care you are receiving from the Home Care nurses. Participants are free to withdraw from the study at any time, refuse to answer any questions, ask for any taped message to be erased, and ask for any sensitive information not to be divulged. Confidentiality will be maintained by assigning each person/family a code name. Similarly the nurse and the institutions will remain anonymous. Biographical details will be altered as necessary in published and unpublished work to mask identifying characteristics of the participants, families, and institutions.

The names of participants will not appear in any observational notes, tapes, transcriptions, or written reports. The data will be kept secured in a locked filing cabinet and be available to the researcher and the members of the researcher's dissertation committee for the purpose of analysis and writing of the research study. The researcher will utilize the data for future publications, presentations, and possibly secondary analysis at a later date.

Participants may access their own interview transcripts as well as the complete dissertation. A summary report of the findings will also be available for all participants. Please call me if you have any questions.

Sincerely,

Frances Legault
Appendix E

CONSENT FOR INDIVIDUALS AND FAMILIES
I am aware that my participation in this study is voluntary and will in no way affect the care that I receive. I know that I am free to withdraw from the study at any time, refuse to answer any questions, ask for any taped message to be erased, and ask for any sensitive information not to be divulged.

I understand that confidentiality will be maintained by assigning each participant a code name or number. Similarly other staff, clients, families, and institutions will remain anonymous. Biographical details will be altered as necessary in published and unpublished work to mask identifying characteristics of the participants, clients, families, and institutions.

I have been assured that the names of participants will not appear in any materials, and observational notes, tapes, and transcriptions will not be made available to any employers or administrators. The data will be kept secured in a locked filing cabinet and be available to the researcher and the members of the researcher's dissertation committee for the purpose of analysis and writing of the research report. The researcher will utilize the data for future publications, presentations, and possibly secondary analysis at a later date.

I understand that I will have access to my own interview transcripts as well as the complete dissertation. A summary report of the findings will be sent to me.

If, during this study, I have any concerns about my treatment as a research participant, I may contact Dr. Carol Jillings, the researcher's supervisor, or Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598.

I CONSENT TO BEING OBSERVED        YES/NO (Please circle)
I CONSENT TO BEING INTERVIEWED      YES/NO (Please circle)
I CONSENT TO THE TAKING OF PHOTOGRAPHS    YES/NO (Please circle)

Signed ________________________________________

Date ________________________________________

Receipt of:
"Information for Individuals and families" acknowledged _____
Copy of "Consent Form for Individuals and Families" acknowledged _____
Appendix F

INFORMATION FOR HEALTH CARE PROFESSIONALS
I would like to spend a few hours to observe and interview you in your workplace setting. The interview should take approximately an hour and will be audiotape recorded for the purpose of analysis. Your participation in this study is voluntary. Participants are free to withdraw from the study at any time, refuse to answer any questions, ask for any taped message to be erased, and ask for any sensitive information not to be divulged. A signed consent form will be obtained for each participant.

Confidentiality will be maintained by assigning each participant a code name or number. Similarly, other staff, clients, families, and institutions will remain anonymous. Biographical details will be altered as necessary in published and unpublished work to mask identifying characteristics of the participants, clients, families, and institutions.

The names of participants will not appear in any materials, and observational notes, tapes, and transcriptions will not be made available to any employers or administrators. The data will be kept secured in a locked filing cabinet and be available to the researcher and the members of the researcher's dissertation committee for the purpose of analysis and writing of the research report. The researcher will utilize the data for future publications, presentations, and possibly secondary analysis at a later date.

Follow-up interviews, group meetings, and/or educational sessions will be offered to all participants to make the study results available once it is completed. Participants may access their own interview transcripts as well as the complete dissertation. A summary report of the findings will also be available for all participants.

PLEASE CALL ME IF YOU ARE WILLING TO PARTICIPATE.

Sincerely,

Frances Legault
Appendix G

CONSENT FOR HEALTH CARE PROFESSIONALS
I understand that confidentiality will be maintained by assigning each participant a code name or number. Similarly other staff, clients, families, and institutions will remain anonymous. Biographical details will be altered as necessary in published and unpublished work to mask identifying characteristics of the participants, clients, families, and institutions.

I have been assured that the names of participants will not appear in any materials, and observational notes, tapes, and transcriptions will not be made available to any employers or administrators. The data will be kept secured in a locked filing cabinet and be available to the researcher and the members of the researcher's dissertation committee for the purpose of analysis and writing of the research report. The researcher will utilize the data for future publications, presentations, and possibly secondary analysis at a later date.

I understand that Frances will offer follow-up interviews, group meetings, and/or educational sessions to all participants to make the study results available once it is completed. I will have access to my own interview transcripts as well as the complete dissertation. A summary report of the findings will be sent to me.

If, during this study, I have any concerns about my treatment as a research participant, I may contact Dr. Carol Jillings, the researcher's supervisor, or Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598.

Signed __________________________

Date __________________________

Receipt of:

"Information for Health Care Professionals acknowledged ______

Copy of "Consent Form for Health Care Professionals" acknowledged ______
Appendix H

SAMPLE INTERVIEW QUESTIONS FOR HEALTH CARE PROFESSIONALS
HOME CARE NURSES' CONTRIBUTION TO THE INTEGRATION OF PALLIATIVE CARE SERVICES

Researcher: Frances Legault RN PhD(c)  
Student, UBC School of Nursing  
Supervisor: Carol Jillings RN, PhD  
Associate Professor, UBC School of Nursing (822-7479)

SAMPLE INTERVIEW QUESTIONS FOR HEALTH CARE PROFESSIONALS

1. What has been your involvement with individuals and families receiving palliative care?
2. Can you tell me of a situation where there was quality palliative care?
3. What factors contributed to this situation?
4. Can you tell me of a situation when there was not good palliative care?
5. What problems were present in this situation?
6. What are the special needs of people in marginalized populations?
7. What ethical issues do you experience in palliative care and how do you deal with them?
8. How do you view the role of the nurse in palliative care?
Appendix I

SAMPLE INTERVIEW QUESTIONS FOR INDIVIDUALS AND FAMILIES
HOME CARE NURSES' CONTRIBUTION TO THE INTEGRATION OF PALLIATIVE CARE SERVICES

Researcher: Frances Legault RN PhD(c)
Student, UBC School of Nursing
Supervisor: Carol Jillings RN, PhD
Associate Professor, UBC School of Nursing (822-7479)

SAMPLE INTERVIEW QUESTIONS FOR INDIVIDUALS AND FAMILIES

1. What has been your experience of palliative care at home and in hospital?

2. What has worked very well for you?

3. What has been difficult for you?

4. Where would you like to be at this point in time?

5. What are your hopes and dreams?

6. How does the nurse help you?
Appendix J

DESCRIPTION OF OBSERVATIONS
HOME CARE NURSES' CONTRIBUTION TO THE INTEGRATION OF PALLIATIVE CARE SERVICES

Researcher: Frances Legault RN PhD(c)
Student, UBC School of Nursing
Supervisor: Carol Jillings RN, PhD
Associate Professor, UBC School of Nursing (822-7479)

BRIEF DESCRIPTION OF OBSERVATIONS

Observations are the key to ethnographic research. The ethnographer begins with broad observations moving in time to more focused observations to answer specific questions that have risen from the data. Detailed observations also guide the researcher to questions for interviewing.

My role as participant-observer is described as the first distinct activity of the ethnographer which involves participating in the daily routines of the setting, developing ongoing relationships with the people in it, and observing all the while what is going on. In this study, participant-observation will begin with nurses during their day-to-day contact with individuals and families receiving palliative care. I will observe how the nurse interacts verbally and non-verbally with the clients, what the main issues of concern are for the nurse and the clients, how the clients respond, and what the nurse-person relationship is like. A detailed description of the physical setting will also be included.

Observation of other health care professionals in the hospital and community settings will take place either at their work site or more often at committee meetings. My role as a participant observer will be to observe the group dynamics, differences in viewpoints, and the strengths and limitations of the group. I will participate as much as possible in the discussion and in committee work.

The production of fieldnotes is the second distinct activity in ethnography. These fieldnotes describe experiences and observations the researcher has made during participant observation. Sanjek (1990) describes these written accounts as: headnotes (evolving written analytic notes and memos); scratch notes (the first step); fieldnotes proper (chronological fieldwork notes); and fieldnote records (information organized separately in sets). In addition, the ethnographer's journal is a record of personal experience, reactions, and assessments of life and work in the field. In this study, time will be planned for daily processing of scratch notes to field noted and for writing of headnotes and journal entries.

Appendix K

AGENCY CONSENTS
Dr. Carol Jillings,
Associate Professor,
UBC School of Nursing,
T-201,
2211 Wesbrook Mall
Vancouver, BC
V6T 2B5.

Dear Dr. Jillings,

Re: Frances Legault - PhD Student

This letter is to support the application for funding of the dissertation research proposed by the above student: Integration of Palliative Care Services: A Nursing Perspective.

With the current change in the structure of health care it is critical that the needs of service delivery for the terminally ill be looked at in more detail. This thesis not only proposes to identify the barriers for people with cancer to the access and utilization of palliative care services but will also look at the success factors that nurses have developed for enhancing quality of life for cancer patients. The research will contribute data and theory to highlight the valuable contribution of nurses in shaping health care policies wherein community and hospital partnerships and a shared vision of the goals of palliative care are imperative. Although data collection is based on the patient with cancer the information will serve as a valuable basis for individuals dying from any illness.

I will be very pleased to be interviewed as part of the data collection process and to participate in an advisory capacity.

Yours sincerely,

Tyleen Katz
Director, Hospice Programmes.
11 March, 1997

Frances Legault
1406 54th Street
Delta, BC
V4M 3H6

Dear Ms Legault:

Re: Integration of Palliative Care Services: Nursing Perspective

This letter will serve as notice that the Vancouver/Richmond Health Board agrees in principle to participate in the conduct of the above project under the terms outlined in your submitted proposal.

Would you please contact Jo Wearing at 734-1661 regarding the logistics of arranging staff meetings etc.

Sincerely,

Guy A. Costanzo
Research Officer
April 18, 1997

Frances Legault
Doctorial Student
University of British Columbia
School of Nursing
2211 Wesbrook Mall
Vancouver, B.C.
V6T 2B5

Dear Ms. Legault,

Thank you for sharing your doctorial dissertation proposal with the Vancouver Palliative Care Coordinating Group (VPCCG). As we have discussed, the VPCCG is willing to have you attend meetings in the capacity of participant-observer. Participation of individual committee members will be dependent on your data requirements and their individual consents.

Your research topic "Integration of Palliative Care Services: A Nursing Perspective" is of utmost interest to us, especially in these times of change to both hospital and community services. The research findings will be of help to us as we work to envision changes within palliative care services in Vancouver. Of particular importance is your research question "identifying barriers for people with cancer to the access and utilization of palliative care services". We understand that you are seeking an NHRDP operating grant, and we wish you every success in your application.

We look forward to working with you.

Sincerely,

Pat Porterfield, RN, MSN
Chair, Vancouver Palliative Care Coordinating Group
Appendix L

UBC ETHICS APPROVAL