The Silent Struggle of Family Caregivers of In-Home Palliative Care Patients

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ABSTRACT

Since the 1980's, against a backdrop of a need to contain health care costs, there has been an ever increasing shift to providing health care services in the home and a resultant increase in in-home palliative care.

The guiding question for this study was to describe how the Closer to Home policies affect caregivers in their everyday work of providing care in a home setting. A case study design was employed. This design was selected to support a desire to learn from the family caregiver's perspective. Four family caregivers were interviewed and asked to describe their everyday experiences of facilitating in-home palliative care.

The interviews provided the primary data source for the study. Other data sources drawn on to contextualize the analysis were: the Capital Health Region patient health file, my knowledge of Home Nursing Care services, the history of home care and palliative care services.

Four major themes emerged from the data. Descriptions of these themes contribute to an understanding of caregiver burden by "limiting generalization" (Stake, 1995). Closer to Home policies are presented in the thesis as generalizations about in-home palliative care. The four major themes emerging from the data, the constant, heavy demands of the caregiving role, role shifts and reversals, the caregiver's narrowing world and a change in the patient's character, specify what the experience of caring for a spouse or friend is

like. The strength of case study design is in it's effect on generalizations found in policies such as the Closer to Home policies. Implications for policy development that attend to specific client experiences are addressed in the recommendations section of the thesis.

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CHAPTER ONE

INTRODUCTION

> If people cannot speak of their affliction they will be destroyed by it, or swallowed up by apathy. It is not important where they find the language or what form it takes. But people's lives actually depend on being able to put their situation into words, or rather, learning to express themselves, which includes the nonverbal possibilities of expression. Without the capacity to communicate with others there can be no change. To become speechless, to be totally without any relationship, that is death.
>
> Dorothee Soelle (1975, p.22)

As a front-line manager for the Capital Health Region (CHR)[1] Home Nursing Care (HNC) Program, I work with staff nurses problem solving patient/family issues. Often the most complex and ethically difficult issues involve palliative patients.[2] I visit terminally ill patients who are receiving health care services in their home from CHR HNC nurses, and see the joy of remaining at home to die, but I also hear from the nurses and patients about the hardships that can arise when care is provided in the home. Recently a nurse came to me to discuss a patient situation:

> Two family members living together were receiving palliative care services. The family consists of a fifty-five year old husband terminally ill (his doctors had given a prognosis of six months or less, over a year ago); a thirty-one year old son with an inoperable brain tumour with a prognosis

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[1]. On April 1, 1997 health care services within the Capital Regional District (CRD) are amalgamating with a number of other health care agencies into the Capital Health Region (CHR). This change in name explains why the employer title is not consistent throughout this thesis. Work on this inquiry began in January, 1997.

[2]. "Palliative care is a program of active compassionate care primarily directed towards improving the quality of life for the dying. It is delivered by an interdisciplinary team that provides sensitive and skilled care to meet the physical, social, spiritual, cognitive, cultural, economic and emotional needs of both the client and the family" (Victoria Hospice Society, 1990, p.30).

of a couple of weeks; a second son who is a drug addict and cannot be relied on to help; and a wife/mother who is the main caregiver. They live in a two-story home with the husband being cared for in a hospital bed in the dining room, as he wants to be close to his wife. The son is being cared for in a bedroom upstairs because he needs a quiet environment due to severe headaches. He has seizures regularly and wants his mom with him when these are happening. The wife/mother has asked for 22 hours of home support worker help daily, through the CHR Long Term Care (LTC) program as each man is 200 pounds and difficult (to impossible) for her to move. She also wants some time to spend with her horses. She told the nurse that she is afraid that if she does not receive more help she will have to choose between her husband and son and have one of them placed in a LTC facility. If forced, she would choose to place her husband as she feels she has already cared for him at home and now it is her son's turn. She hopes she will not have to do this, because she worries her husband will die more quickly, and that she will be at fault.

read his

Assessments completed by LTC Case Managers have determined the family's home support needs as two four-hour periods per day. Informally, concern has been raised by the LTC case managers and LTC management because this family is using so many LTC paid hours of home support, and no one can say when the husband will die. According to LTC policy, an "end-stage palliative" is eligible for 150 hours of home support help per month, for up to three months.

> This family is currently receiving 240 hours and the wife/mother is requesting 660 hours each month. The wife/mother threatened to go to the press and local politicians unless LTC increases her home help. The help in the home was subsequently increased after the Medical Health Officer and a CHR Social Worker became involved.

This story, although extreme, is not atypical of what is happening with the changes occurring under British Columbia's (B.C.) 'New Directions' in health care policy. The nurse was coming to me in frustration as she felt the wife/mother was not being unreasonable. The 'system' was hesitant to provide her with the help she needed because the husband was not dying when expected.

It is noteworthy that CHR LTC policy for home support hours for palliative care patients is more generous than the Ministry of Health policy. Ministry guidelines provide for 120 hours per month while CHR provides up to 150 hours for the last weeks of life. It has been explained to me by the managers of LTC that their program receives a global budget for the purchase of home support services from the Ministry of Health (MOH). CHR LTC has decision making power about how this sum of money is spent within this region. With the aging population of CHR, the decision to encourage care in the home, particularly in-home palliative care, the budget is strained.

The need to contain health care costs gained a higher profile across Canada in the 1980's. Since that time the trend has been to provide more and more in-home health care services (Rachlis & Kushner, 1992). Policy makers were of the belief that palliative care

in the home would result in a win/win situation - enhanced quality of life for dying patients as the person would be in familiar surroundings with family around them, and reduced health care costs for the terminally ill (Emanuel & Emanuel, 1994).

> Everyone wins- the patient, the family, and society as a whole (Lundberg, 1993, p. 2554).

Hospice programs with a strong home care component began to be authorized.

Policy makers recognized that savings could be gained from a reduction in inpatient hospital usage. In 1991, Closer to Home: The Report of the British Columbia Royal Commission on Health Care and Costs, reaffirmed the Province's commitment to care being provided 'Closer to Home.' Within the Capital Regional District, palliative care at home is encouraged and accepted as appropriate care by community agencies and local hospitals. Hospitalization is encouraged for symptom management issues not controllable in the home and some end of life situations.

'Success' in evaluations of such programs is frequently quantified using statistics of numbers of patients who die at home or in hospital, within 48 hours after admission. In evaluations in which I have been directly involved, it was written that quality of life had been enhanced for the patients and family members who were able to die at home. It is presumed dying at home equates to enhanced quality of life. HC nurses are encouraged to talk with their patients about their choice of where they wish to die but on the other hand, praise is given for the numbers of people who die at home.

I am concerned that a burden is being transferred to the palliative care caregiver. In the hospital setting all activities of daily living are provided. Medications, supplies, and

equipment are provided. Health professionals come to the ill person and the caregiving role is assumed by the health care system. With care in the home, the opposite is true. It appears this burden is being ignored. I do not see this burden recorded in the standardized chart forms used by the nurses, unless the nurse chooses to document these concerns in a narrative section of the chart. I have not seen these issues addressed in the standard evaluations of palliative programs.

Staff report that families are hesitant to talk about the pressures they experience because they feel they are betraying their family member. My own personal experience as caregiver for my terminally ill mother-in-law and being mother of three pre-school children supports this statement. I remember not wanting to ask anyone for help as I felt I was so fortunate to have had such a supportive mother-in-law, but I was silently relieved when she was admitted to hospital. Running my already busy household, caring for her and preparing tea for people visiting her was heavy work.

I want to determine how the Closer to Home (CTH) polices for palliative services affect the every day life of family members. In particular, I wish to examine the affect on family caregivers when they 'accept' the responsibility of palliative care for their relative in the home. It appears to me that the CTH policy is affecting some families more than intended. It does not look like all family caregivers are winning. I want to determine how the facilitation of in-home care by family members is being obscured or taken for granted. In order to explore the contradictions, I want to understand what it means from their perspective to take on the responsibility for the provision of all the patient's needs including- medications, supplies, equipment, getting to and from appointments and the

assumption of the caregiving role.

Chapter two of this thesis reviews the literature on the development of home care and palliative care in Canada, background information leading up to the CTH policies and Dorothy Smith's (1991) concept of social organization of knowledge. This framework is used to provide insight into why and how palliative care services are provided as they are in the CHR. The concept of social organization of knowledge assists with understanding the ideology behind the CTH policies and how the values and beliefs of the organization, are taken for granted by health practitioners. This concept assists with exploring how family caregivers understand and carry out their role as caregivers.

The third chapter describes the case study approach taken to gain understanding about the research problem and provide an overview of the procedures used for the inquiry. Using the case study approach allows this inquiry to base its findings on family caregiver's reality. The ensuing four chapters introduce the reader to the four family caregivers who served as informants for this project and their terminally ill relatives, an analysis emerging from their stories and how these findings compared with my preconceived ideas. A discussion of the findings forms the basis for the recommendations offered to influence nursing practice and decision making for policy development for the provision of palliative care services.

CHAPTER TWO

LITERATURE REVIEW

A review of the literature on the development of home care, palliative care in Canada and the CTH polices is presented in order to reveal some of the rationale used by policy makers to support and challenge the home as a viable location for providing health care. The values driving in-home health care as the preferred site for caring for the terminally ill person will be made evident. The reader will come to see how ethics and economics have come to be linked with the provision of in-home palliative care. Dorothy Smith's (1991) concept of social organization of knowledge is discussed because thinking about knowledge as socially constructed allows the researcher to question how practitioners tend to pay attention to what they do, to question why their documents are structured as they are and why the family caregivers understand their role as caregivers as they do.

HISTORY OF HEALTH CARE IN THE HOME:

Reviewing the history of in-home care and in-home palliative care provides insight into why and how palliative care services are provided as they are today. Prior to this century, virtually all health care in Canada was provided in the home (Risse, Numbers & Leavitt, 1977; Reverby, 1987). Most sickness, birthing and dying took place in the home with care provided by immediate family and neighbours. The importance of home care waned and people 'learned' to turn to care in hospitals and physicians offices (Benjamin, 1993). Medical leaders promoted the limitations of the home as a site for modern medical practice. The hospital, with all it's economies of scale, came to be the

favoured site for illness care. Wide variations in educational levels, language and culture, were seen by decision makers as reasons to doubt the efficacy of training family members to assume nursing care roles (Benjamin, 1993). By the 1940's, most health care was no longer delivered in the home. Hospitals came to be seen as necessary in every community.

After World War II, the increase in persons with chronic illness and an increase in the number of aged, caused this trend to be questioned. Physicians were finding they could do little to treat illnesses such as heart disease and cancer, and yet, do much for conditions which responded to surgery or antibiotic therapy. They voiced concern about hospital beds being occupied by the incurable and chronically ill, thus reducing the availability of hospital beds for the potentially curable. New interest in care in the home arose.

In Canada, home care seems to have been rediscovered in the 1970's (Federal/Provincial/Territorial Subcommittee on Home Care, 1990). The move to providing health care services in the home was driven by economics because home care was seen as a way to substantially reduce utilization of costly inpatient beds. Throughout the literature, the recurrent themes are concern for rising health costs and reduction of these costs by increasing the use of home care (Weissert, et al, 1980; Beck-Friis, et al, 1991; Reiser, 1992). The legitimacy of home care has depended, and still does depend on its relationship to acute hospital care with funding being dependent on claims for relieving utilization and costs of institutional care (Benjamin, 1993). I believe this dependence is a contributing factor for costs for in-home palliative care not being addressed.

Home care, throughout its' resurgence as a site for health care, "has been considered a residual set of services, to be provided after other care was delivered and to persons whose conditions were not amenable to mainstream medical intervention" (Benjamin, 1993, p. 130). Care in the community has been seen to suffer from an absence of consensus about its' principal goals, the essential elements of comprehensive home care and the place of these services in a continuum of care. Benjamin (1993) suggests the lack of consensus has been due to the presence of two models of care- the medical post-acute and the social-supportive. This author suggests the medical model has been the better defined of the two models. The medical model has been supported by the need for care in the home continuing to need to legitimize its continuance by its claims to relieve utilization and costs of institutional care. In summation, 'home care' has been constructed by the medical system to meet the system's needs and then, the needs of patients and family members.

DEVELOPMENT OF IN-HOME PALLIATIVE CARE:

The pressure of ever increasing health care costs has not let up and attention has focused on proposals to control costs at the end of life (Emanuel & Emanuel, 1994). Statistics since the 1960's have consistently shown that 27 to 30 percent of health care dollars are used by 5 to 6 percent of the population, who die in that same year. Many see reducing expenditures at the end of life as an easy and readily justifiable way of cutting wasteful spending and freeing resources to ensure universal access to health care (Emanuel & Emanuel, 1994; Mahoney, 1994; Singer, 1994).

Ethics and economics have been linked together. Hospice programs, which allow

people who are dying, to die without pain, in peace and at home, are described at the same time as benefiting society as a whole, by reducing medical costs (Emanuel & Emanuel, 1994). Numerous surveys have shown that people do not want to be kept alive if their disease is irreversible (Singer & Lowy, 1992; Fries, Koop & Beadle, 1993; Godec, 1993). It is argued that if doctors would stop using high-technology interventions at the end of life, the person's autonomy would be respected and millions of health care dollars could be saved. Everyone would win- the person, their family and society as a whole.

Rhymes (1991) noted that death is never easy to accept, and in Canadian society this is especially true, death is regarded as an unnatural act to be hidden rather than as an inevitable part of life. HNC nurses say some palliative family members feel concerned that they will be seen as negligent if hospital medical care is not obtained for their loved one, when death is imminent.

A 1992 study conducted at the University of British Columbia concluded that the four top reasons for final admission to hospital are: pain, weakness, caregiver burden and shortness of breath (Lubin, 1992). CHR HNC nurses believe pain is often the ostensible reason for admission, but in reality it is caregiver burden. The nurses think family members find it easier to say pain control is the reason they are seeking hospitalization for their relative rather than that they are exhausted caring for their terminally ill loved one.

Lubin's study (1992, p.20) concluded "one cannot simply say that home care is better than in-hospital palliative care or visa-versa", but it can reduce health care costs and minimize demand on acute care hospital beds. Lubin stressed the need for 'adequate'

home support services, respite care and regular visits by trained nurses, physicians and social workers. He noted that in-home care necessitates family caregivers shouldering a greater 'burden' than hospitalization demands.

SOCIAL ORGANIZATION OF KNOWLEDGE:

Dorothy Smith's concept of social organization of knowledge is grounded in the belief that social relations are embedded in people's everyday activities (Smith, 1991). Thinking about knowledge development, using this concept, assumes social organization and social relations are orchestrating our daily activities and are continually expressed in ordinary ways. Forms of consciousness are socially organized. The shifts in understandings of the best location to provide palliative care from home to institution and now in the home again suggest that individuals beliefs about palliative care being organized through broad societal structures.

Gregor (1997) proposes three ideologies which serve to underpin this shift of care into the home. She sees the ideologies of familialism, community care and separate spheres as models of social organization which establish institutional care as being less desirable than care being provided in the home. Familialism or the return to family values assigns women the major responsibility for care of family members. Gregor feels this is based on the notion of a nuclear, middle class family. It assumes women are available to provide care in the home. The ideology of community care establishes care in the home as preserving independence and receiving care by family members as preferable to institutionalization. Gregor's third ideology, separate spheres, organizes the way we think about caregiving in the home in terms of gender. The idea of separate spheres suggests

men and women are seen to 'best' operate in different realms of social action with, "men in the public sphere of competition and action, women in the home and family" (Gregor, 1997, p.33). Gregor claims this has major implications for caregiving and the value attached to it. Caregiving is now seen as removed from the public sphere and is firmly located in the private sphere of the female world. The home becomes defined as the place of care and comfort. It is devalued, as Canadian society defines work in terms of measurable output and wage rate.

Explication of the ways in which caregivers understand the work they are doing forms the basis for the data analysis for this inquiry. Thus, I examine the ideologies driving the family caregiver's choices and their experience as caregivers. How priorities are set, how relations are drawn between family members, the caring establishments and the actual work of caring for someone as they die, is revealed in people's everyday actions (Smith, 1991). The study undertaken for this thesis follows this line of argument then, by seeking out details of everyday activities of family members who are facilitating in-home palliative care. The study seeks to reveal how choices to provide care in the home are conditioned by forces operating on, and through, family members.

Uncovering how the organization's ideology is translated, and relayed, through practitioners to caregivers and patients, will help me as a researcher to understand the caregiver's viewpoint. My knowledge as a HNC manager, and my understanding of the concept of social organization, will help me understand how ideology drives policies and what policies have an impact on palliative family caregivers. Being aware of this concept will raise my awareness to keep looking at myself and ask how I 'know' something. As

an example, teaching patients and family members self care is a highly valued concept of CHR HNC practice. Nurses are asked to document the patient's file when they determine that teaching a particular nursing task is not feasible.

I believe the timing is right for my inquiry to be a valued resource within the health care community. I would like to see my findings used in decision making related to the provision of services for in-home palliative care. Currently, questions are being asked about the role of the experts in the health care system, both as providers and policy makers. Policies are seen as never quite fitting the needs of individuals (Reiser, 1992). Professional providers and managers are seen as not being able to establish adequate polices given the magnitude of unique individuals needs. Across Canada there is a widespread shift from the medical model to a consumer model of care (Jackson, 1995; Gregor, 1997). Consumers are being involved in a consultation process for the reform of the health care system and in the governance of health services. With the rise in interest in individual needs of people, and the belief in public participation in policy development, the viewpoint of palliative family members needs to be heard.

In the discussion which follows I use four case studies as the method of inquiry. I am committed to learn from the family member's perspective for a number of reasons. The literature reviewed reveals that the majority of studies on palliative care have been based on interviews with professional health care providers or analysis of their documentation (Lubin, 1992; Boyd, 1993; Ross, 1994). Findings are grounded in the standpoint of the health care provider. By contrast, my research explores the daily reality of family caregivers.

In particular, guiding questions for this study are: How do CTH polices affect particular caregivers in their everyday work of providing care in a home setting? What happens in their day to day lives? How is the shift from hospital care to in-home palliative care experienced by them?

CHAPTER THREE

METHODOLOGICAL APPROACH AND PROCEDURES

Case Study as a Methodological Approach

A case study method has been used for this project because there are strong naturalistic and holistic interests and it will allow for a greater understanding of this project's real-life problem (Stake, 1994). A case study approach will, "concentrate attention on the way particular groups of people confront specific problems, taking a holistic view of the situation" (Merriam, 1988, p.11). Taking a holistic view of each family member's experience provides an opportunity to take into account the politics, socialization, culture, economics and personal contexts, all of which have an impact on how the informants view the world. The inquiry is therefore focused on their reality. Qualitative inquiry assumes multiple realities, with each person's world as a function of personal interaction and perception. It is important for deeper understanding that this inquiry take these influences into account. Each person's ideas, beliefs and knowledge set up conditions for them to 'know' differently (Smith, 1987). I am interested in gaining understanding about what the every-day experience of caregiving is like for family caregivers. What is their reality of the caregiving role? I will focus on gaining an understanding about how they come to know what they know. Both 'how' and 'why' questions are answerable using this approach (Yin, 1984).

For Stake (1995), case study design involves the researcher making a choice regarding the focus to be studied. As a form of research, it is defined by interest in individual cases, as in this project, family members who are facilitating in-home care for

their terminally ill relative who is a HNC palliative patient.

Stake (1994) defines a case as a specific and bounded system. In this thesis each of the four families is treated as a case. Stake (1994) describes a case as an integrated system of which "the parts do not have to be working well, the purposes may be irrational, but it is a system" (Stake, 1994, p.236). On examination, there is consistency and sequentialness to the system's operations. In addition, there are features within the system, such as the context within the boundaries of the case and other features outside of the specific boundaries of the case that constitute a system. It is in attending to the systemic ordering of a case that makes such a study holistic.

Stake (1994) describes three types of case study, each with a different purpose: intrinsic, instrumental and collective. The intrinsic case study is used when the goal is to better understand one particular case, usually looking at it's particularity and ordinariness. The specific case is of interest. The intent is generally not to build on theory, but the intrinsic interest in the case itself. With the instrumental case study, the purpose is to gain insight into an issue by studying a particular case. Refinement of theory may be wanted. The particular case is of secondary interest. The study intent is to gain deeper understanding about the external interest. "It is looked at in depth, it's contexts scrutinized, its ordinary activities detailed, because this helps us pursue the external interest (Stake, 1994 p. 237). The third type of case study is the collective case study which involves a number of cases as in this inquiry. It's purpose is the same as the instrumental case study but extended to a number of cases. Like this project, the cases are selected because it is believed that understanding them will lead to better understanding

and better theorizing from a larger collection of cases. In this instance, the experience of palliative in-home caregiving by family members living within the CHR is the external interest.

Each case is seen as a complex entity operating within a number of contexts relating to the physical, economic and cultural environment (Stake, 1995). Interpreting the meanings of demographic and descriptive data in terms of cultural norms, community values, attitudes and notions, provides for rich, 'thick' description of phenomenon.[3]

The researcher using this methodological approach chooses issues for study regarding the specific cases. Problems are posed, and issues to concentrate on, are chosen to aid with choosing the cases to be studied, what to observe and to help interpret patterns of data. The researcher's ideas are consequently reformed through studying the cases. Each case is treated as an 'exemplar'. The issues chosen serve to organize the case.

The research problem and the issues to concentrate on were identified through my experience as a HNC manager. I sensed that there are both direct and indirect costs being assumed by family caregivers. The nurses that I work with, as their direct supervisor, report concerns about the costs of purchasing medications, nursing supplies and equipment, and the cost and energy used travelling to and from appointments. I am concerned about the burden that arises for some family caregivers when they take on the role of caregiving for a terminally ill relative and the apparent lack of attention to this burden by health care professionals.

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[3] Thick description, according to Merriam (1988), is a research term referring to a complete, literal description of the incident being investigated.

By choosing to let each of the four cases tell their own story, Stake (1995) suggests that researchers may enter the inquiry expecting certain problems will be important, and discover that preconceived problems are of little consequence.

Qualitative case study is characterized by substantial time being spent on site in personal contact with the activities of the particular case in order to see what is naturally occurring. Understanding is gained through seeing what is important about the case in its own world (Stake, 1995). Learning is reflexive in that the researcher is spending time personally observing the activities of the case, asking questions, listening, reflecting and revising meanings of what he/she is seeing. Meanings are developed in their natural contexts.

A strength of using a case study approach is that it offers a variety of data sources- in this instance, the interviews with the caregivers, field observations and the HNC health care file. For this project, the interviews were audiotaped and the field observations were notes written about the nonverbal cues, following the interviews. This included body language of the informants while they talked about their experiences, a description of the home environment, and my own feelings, reactions and hunches (Merriam, 1988). Using the interview technique offers opportunity for new learning and for confirming what is already known.

CASE SELECTION:

Using an instrumental or collective case study approach requires the researcher to choose the cases to be studied. As stated earlier, in order to choose well, an understanding of the issues critical to the research problem, must be identified. Both Stake (1994) and

Yin (1984) suggest choosing informants who seem to offer opportunity for learning. They suggest being reasonably pragmatic when selecting potential informants. The researcher identifies the issues that she wishes to learn about and then chooses cases that appear to offer the most opportunity for learning. I chose families who the HC nurses assessed as experiencing a burden or hardship as a result of a dying relative, receiving in-home palliative care. The nurses and I looked for a variety of situations. It was my ethical duty to select those not in crisis and those the nurses assessed as having the energy to partake in an interview. I did not want to be an additional burden to them.

Stake (1994) suggested that finding the case the researcher can spend most time with, may provide for the best learning opportunity. More may be learned from an atypical case than from a typical case (Stake, 1994). Balance and variety are encouraged rather than a sampling of attributes. "Opportunity to learn is of primary importance" (Stake, 1995, p.244).

ETHICAL CONSIDERATIONS:

Consideration of privacy of others, being a guest in the home of the informants, confidentiality, informed consent and coercion are very important considerations to this inquiry. Being sensitive to not ask probing, sensitive questions is the responsibility of any researcher. My being a HNC manager puts me into a position of unequal power with the caregivers and patients, and the HC nurses. The gravity of these relative positions and the home situation necessitates ethical considerations being carefully attended to. Understanding that someone listening can be supportive, I hoped the informants would find talking with me helpful to themselves (Merriam, 1988).

The ethical tension between believing that learning from the caregivers themselves is important and concern my interview would cause them additional 'work' was an significant consideration in planning the interviews. I relied heavily on the nurse's assessment skills in selecting those family members they determined as having sufficient energy. The caregivers were asked to telephone me to set a time to meet, after their nurse talked to them about the project. During the selection process one caregiver did telephone and offer to talk to me about his experience and then called back latter to say he wanted to cancel as he had decided talking about caring for his wife would add to his situation.

PRODUCING GENERALIZATIONS:

This descriptive research study draws on Stake's (1995) methods for case study design in which cases are understood as having identifiable boundaries that can be specified in order to obtain a research sample. In this study the identifiable boundaries include:

* individuals who were on HNC palliative care services who also had an identified non-paid caregiver,

* home situations which HC nurses determined where there may be caregiver burden,

* caregiver's who the nurses assessed as having the time and energy to potentially take part in an interview of up to two hours duration.

Analysis of data collected regarding each of these cases involves developing themes relating to the research question. Such development involves seeking patterns within the data to develop the themes and seeking ways to triangulate the data by identifying different ways the phenomenon is being represented through different data

sources. To reiterate, the different data sources used in this study are: the interview with the caregiver as the primary data source, triangulated by the literature, my experience as a HNC manager and personal experience as a palliative caregiver, and the HNC patient care file.

Stake (1994) asserts that using this approach to research can help to refine theory, suggest opportunities for further study and assist in establishing limits of generalization. It may not be suitable for representing a population or provide grounds for advancing grand generalization. Nevertheless, it can establish limits to grand generalization. "The utility of case research to practitioners and policy makers is in its extension of experience. Case study can also be a disciplined force in public policy setting and reflection on human experience." (Stake, 1995, p.245). Stake also asserts that the findings will not provide for entirely new understanding but refinements of understanding. It will offer modification of understandings found in the literature. He calls this progressive focus. By using the informant's own stories, verifying my progressive analysis during the interviews, talking with the HC nurses, referring to the literature, and using my own experience, rigorous interpretation is the objective.

The case study approach to research and learning is one familiar to health care professionals. It is a common approach taken for teaching those new to the health professions. It is expected that this familiar approach to learning will enhance the credibility of my research findings for fellow health care professionals.

Stake (1994) explains that two forms of learning can occur from a particular case. Didactic teaching from telling the story and what the researcher has learned, and

discovery learning which occurs by the researcher providing opportunity for readers to learn on their own. By using an approach health care professionals are accustomed to, readers will have an opportunity to learn by vicarious experience. They will extend their memories of happenings. Stake (1994) calls this a process of naturalistic generalization. "The reader comes to know things told, as if he or she had experienced them" (Stake, 1994, p.240). The researcher uses the case study to assist readers to construct knowledge.

Procedures

PRE-INTERVIEW:

Once approval was received from the university ethics department, I obtained a letter of permission from the Medical Health Officer to interview the informants and to access the CHR HNC health files. Although reading the HC nurse's documentation on the patient health files and visiting patients in their homes is part of my daily work, I sought permission from my employer as my purpose in reading the files and visiting the family members fell outside my CHR work.

HC nurses were asked to assist me by selecting suitable palliative families. Their assistance was vital as the nurses know their families and patients in depth.[4] I relied on their skills of assessment to determine which families had the energy to take part in an

[4] Analysis of the caregiver's stories reveals the research findings and my pre-interview concerns differed. The issues of burden of costs for medications, nursing supplies, equipment and transportation to appointments were not as I had expected. The concept of social organization of knowledge is used in the following chapters to understand the reason the nurses' and my knowledge is organized differently from the caregiver's personal experience .

interview of up to two hours duration, with the possibility of a second interview. [5] The nurses knowledge and skill allowed them to choose families where the home situation was relatively stable. The project was discussed at a staff meeting and a one-page summary (see Appendix A) describing the project was given to the nurses. When nurses expressed interest, I discussed the project with them individually. We talked about the purpose of the inquiry and what had sparked my interest on the issue of 'hidden' costs. I felt confident I could rely on the nurses to be sensitive to select only families who were not in a period of crisis; had the desired knowledge; and were apt to be open to talking with me (Hammersley & Atkinson, 1993). I asked the nurses to select families where they saw direct and/or indirect costs to in-home care as an issue.

Hammersley and & Atkinson (1993) caution quality and relevance of data produced by interviews can vary considerably, so initially I was not sure about the number of families to interview. It depended on how illuminating each of their accounts would be. As I proceeded I decided the four informants' stories contained sufficiently rich data for gaining a better understanding about the research problem. To ensure the caregivers had ample time to tell their story, I allowed each of them to set their own time frame for setting the length of the interview. When they seemed to have finished I asked them if they felt they had had an opportunity to say all they wished and whether they wanted to add anything. Merriam (1988) suggests the researcher note the 'feeling' during

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[5] A second interview may have been suggested, if I felt I was really unclear about the informant's story. The duration of the second interview was to take no longer than 30 minutes. I felt I had been able to obtain clarity during each of the interviews, and it became evident during the interviews that each of these people were very busy. I did not want to add to this situation. One of the informants requested a second interview to provide more opportunity to add to his description of his every day activities.

the interview itself as an indication of the informants' sense of comfort to share their story.

Once each potential family was selected, the nurse delivered a letter of introduction and an Informed Consent form to each (see Appendix B and C). Family members were asked to phone me to set an appointment if they felt open to participating in the study. At the opening of my visit, I invited their questions and discussed my need for their voluntary participation.

CONDUCTING THE INTERVIEWS:

"One of the most important sources of case study information is the interview" (Yin, 1984, P.82). Using an interview technique allowed me to get the benefit from feedback while still in the field. Within the interviews, I asked questions to clarify my understanding of each person's story. Using a case study approach emphasized the importance, during fieldwork, to observe, to ask seemingly stupid questions, and to write down what I saw and heard. Constantly cross-checking, comparison to previous data collected and the literature, occurred throughout the interview period.

An audiotape and participant observation technique was used for each of the interview sessions. Taping the interviews allowed me to focus my attention on listening and observing the informants. Just prior to each of the interviews I read the HNC health file for each family. This helped me better understand the family members' accounts. By understanding the stage of their relatives' illness process and the community services they were said to be receiving, I was triggered to ask clarifying questions. I was cognizant that organizational polices and values structure the nurses' documentation (Smith, 1987).

Following each interview, I immediately wrote field notes. Tape-recording the interviews did not remove the necessity for observation and writing field notes. Non-verbal behaviour was noted and the 'fine grain' of speech which was not evident on the recordings. Who was present at different sections of the tape was recorded. It was helpful to use the informant's body language to cross-check what they said verbally.

Keeping in mind that I wanted to provide the informants the opportunity to speak of their experience in fully open-ended ways, I had a list of questions available to guide me through the interview process and to help focus the informants on the topics in which I was interested. The questions were not fixed but open ended to shape the flow of the interview in a direction related to the provision of care in the home.

Interview Schedule:

I asked, -my informants to walk me through their day, explaining that I was interested in what it means in practice for them to care for a loved one at home.

-if their description of their day was typical?

-how has taking on this caring role changed their everyday lives?

-what kinds of household tasks are provided by other family members and friends?

-what is involved with getting medications, equipment and supplies?

-what is involved with getting to and from appointments?

-at the end of the interview, if they wanted to add anything?

Each interviews came to a natural end, when the informants finished telling their story.

<u>THE HNC HEALTH FILE AS A SOURCE OF DATA:</u>

Reading the CHR HNC patient health care file served two purposes. It assisted me to better understand the families' stories and it provided secondary data for the project. The usage of jargon by practitioners is often unconscious so reading the health care files helped me understand what the caregivers were trying to explain to me. Rather than being viewed as a biased source of data, these records were treated as social products of discourse (Smith, 1991). Following the interviews, the HC nurses tended to want to know how the sessions went. This provided the opportunity to ask them for their clarification about my growing knowledge.

DATA ANALYSIS:

Many authors recommend that analysis and data collection be simultaneous (Fetterman, 1989; Merriam, 1988; Yin, 1984). Following this approach allows for emerging insights and hunches to direct the next phase of data collection. Refining findings occurs. Rigor was added to the study by the interactions between myself and the participants, the verifying of perceptions, the rich description gathered and triangulation of data.[6]

Analysis of the interview data involved using the knowledge gained from reading the CHR health file, my knowledge of CTH policies, the history of the home care and palliative care services, and using the lens of social organization of knowledge. I looked for ideological positions informing the family members' construction of their daily work. What ideas, beliefs and knowledge, characterized the informants' language was important

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[6] Triangulation involves checking my interpretations with the informants, asking the nurses to comment on the emerging findings and clarifying my own biases and assumptions (Merriam, 1988).

to recognize. The theory was that my gaining understanding about what is informing the informant's understanding of their world, would help me see how palliative care polices are affecting their every day life (Campbell & Manicom, 1994).

Data analysis consisted of reading and rereading the data to look for differences and regularities, things that happened over and over (Merriam, 1988). A process of mind mapping was helpful for pulling out the major themes.[7] This entailed using a large piece of paper with the research problem written in the middle. As each theme arose from the data it was written down. The informants words relating to each theme were then written under it. Four major themes emerged from the regularities found in the data: the heavy demands of the caregiving role, role changes, the caregiver's narrowing world and a change in the patient's character. Concepts that emerged from the literature search helped with the categorization of data. While Merriam (1988) suggests not developing too many categories to separate the data, she cautions the fewer the categories, the greater level of abstraction. A large number of categories is more likely to reflect an analysis based on concrete description. She suggests using the frequency a theme occurs, and knowing the categories important to your audience, as a guide to determining the number of categories to use.

Data collected was coded to protect the confidentiality of the informants, the patients and the CHR staff involved with providing care in the homes studied. The home situations have been altered to this end.

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[7] Tesch (1987) defines a theme as, a brief statement that describes the content of individual units of data text.

CHAPTER FOUR

OVERVIEW OF THE FOUR PALLIATIVE FAMILIES

Before moving on to data analysis, an overview of the four families studied will help readers gain an understanding of the context of the four case studies. This overview is formulated from three sources, information from the HNC health files, the tool provided by CHR HNC for HC nurses to document the services they provide and to guide the care provided by other visiting HC nurses, my own observations during the interviews and the demographic information provided by the informants.

The families selected by my HNC colleagues for this project provide a broad range of circumstances. There were differences in the gender of the caregivers, the socioeconomic status and the relationship of the caregiver to the terminally ill person. All the families were Caucasian and had lived their lives in Canada.

Research tends to divide the dying process into three time periods between the time of diagnosis of a terminal illness until death: the first period is called the initial or diagnostic phase, which represents the time of the initial diagnosis; the second period is the living-dying or adaptation phase and is characterized by the ill person's increasing dependency on family as the disease progresses; and the final period is called the terminal or end-phase which usually consists of the final days and hours of the person's life (Stetz, 1987; Biegel, Sales, & Schulz, 1991). The terminally ill family members in these four families are in the living-dying phase of their illness. Three of the four are dying of cancer, while the fourth has pulmonary fibrosis, a terminal lung disease.

Each of the caregivers speak highly of their relative/friend. Each expresses

gratitude for the community supports which assists them in keeping their relative/friend at home. All the caregivers express strong feelings about supporting their loved ones to live for as long as possible.

The informants seemed comfortable talking with me. Initially, they focused their stories around their loved ones and needed encouragement to talk about their own experience. However, as each discussion ensued the four informants had no shortage of information about which to talk. None seemed eager to end our discussion. In fact, the informant from the second case study said she felt better following our time together, just as she had after talking with the hospice counsellor. The fourth informant phoned me the day after our interview to ask if I would make a second visit, as more information had come to his mind which he felt would add to my study.

Recognizing the interviews as providing comfort for the caregivers and not simply a way for me to gather data was very satisfying for myself. The enormity with which they were coping had a profound effect on me.

All the interviews took place in the month of March, 1997.

The caregivers and the patients have been given pseudonyms to protect their privacy. Table 1 provides a list of each of the code names and the year each patient was diagnosed with a terminal illness.

Table 1

Codes for Caregivers and Patients and Dates of Diagnosis of Terminal Illness

Case Study	Caregiver	Patient	Dates Of Diagnosis Of Terminal Illness	Age of Patient
1	Mrs. Jan	Mr. Jan	1993	86
2	Ms. Sue	Mrs. Fife	1996	57
3	Mrs. Kate	Mr. Kate	1995	84
4	Mr. Nat	Mrs. Nat	1993	65

Case Study #1- The first informant is an articulate, well-groomed woman living with her dying husband in a single family dwelling in an upper middle class residential area. The home was spotlessly clean with nothing out of place, inside or out. This is a second marriage for both, Mr. and Mrs. Jan. They have been married 35 years. Mrs. Jan appears to be in her early 70's.

Mr. Jan is an 86 year old retired businessman. He was an executive in a telecommunications firm. Mr. Jan has a son and daughter from a first marriage. The son and daughter live a considerable distance from Mr. and Mrs. Jan. Mrs. Jan speaks highly of both. The daughter is in close contact by phone, and had just visited for a few days prior to the interview.

As Mrs. Jan says, they have been living with the "cold hand of death on their shoulders," for a long time. In 1991, Mr. Jan had surgery for prostate cancer. At that time, he was told all the cancer was gone. In 1993, he began experiencing symptoms of heart disease. After tests, they were told he would probably die within a few months. By July 1995, the prostate cancer had reappeared and metastasized to the bones in his spine, shoulders, pelvis and left femur. Mr. Jan was admitted to HNC services November, 1995 with a life expectancy of three to six months.

Prior to my interview with Mrs. Jan, I read the HNC health file to help me to come to the interview with some understanding of their situation. The nurses had written in Mr. Jan's HNC file that his present symptoms include: difficulty in controlling pain, skin breakdown to the buttocks, loose bowel movements, nausea, loss of appetite, shortness of breath (Mr. Jan is on continuous oxygen) and drowsiness. He needs assistance to get in and out of bed. With much determination and considerable assistance, he manages the stairs between the main living area and their bedroom. Mrs. Jan uses a wheel chair to move him around downstairs. She bathes him each morning, in bed or on a stool in the shower stall, depending on how he feels. Leaving the home is no longer an option. Mrs. Jan says his vision is less acute and his power of concentration is reduced.

The nurses' notes say Mr. Jan has periods of feeling anxious, sad and generally poor. They quote Mr. Jan as saying he is not afraid of death. Late in 1996, he expressed feeling, "too weary for further treatments". A summary written in November, 1996 says he was feeling profound periods of weakness accompanied by a feeling that the end was near. Twice he has thought he was dying and said his goodbyes to Mrs. Jan. Emotional

strain in both Mr. and Mrs. Jan has been recognized by visiting nurses. The nursing care plan directs other visiting nurses to be supportive of Mrs. Jan and notes she has been caregiving for many years.

Mrs. Jan describes herself as very healthy with some arthritis in her hands. She finds washing Mr. Jan's hair a little difficult as this causes her hands to hurt.

Both Mr. and Mrs. Jan want him to die at home.

Case Study #2-

This case study involves two friends, Ms. Sue and Mrs. Fife. Ms.Sue, the caregiver, is in her mid fifties. She is single with a daughter who is a young adult living on her own. Ms. Sue works full time as an administrative clerk with a community health agency. She met Mrs. Fife nine months prior to our interview. They are neighbours in a trailer home park. Ms. Sue says their dogs brought them together. Since meeting last spring they have spent considerable time together walking their dogs and enjoying taking day trips.

Mrs. Fife is a 57 year old widow living in a one bedroom trailer. Financial limitations are an issue. (At Ms. Sue's request, this interview took place at her office so I have not seen Mrs. Fife's home). Ms. Sue describes Mrs. Fife's home as small. If she has need to sleep over at Mrs. fife's, she sleeps on the chesterfield.

Mrs. Fife is originally from B.C. but moved to another province two and one half years ago with her husband so they could be closer to his grandchildren. When he died suddenly from a heart attack last spring, she moved back to B.C. Mrs. Fife has no children of her own. She has a nephew living locally who Ms. Sue says has pulled back

from Mrs. Fife's life since she has become ill.

In 1988, Mrs. Fife had a cancerous lump removed from her left breast and the following year she discovered a lump in her right breast. Following surgery to remove both breasts in December 1989, she was told cancer was found in one of the lymph nodes under her arm. Oral chemotherapy was prescribed. As a side effect of the chemotherapy drug, her bowel was damaged resulting in more surgery to remove a large tract of her bowel in 1992. In October, 1996, Mrs. Fife started "to feel poorly" again so she returned to the cancer clinic to find the cancer had spread through her lymphatic system to the bones in her spine, ribs and pelvis.

HNC services began in January of 1997. Mrs. Fife is expected to live to the summer or the fall of this year. On admission she told the nurse that she did not wish to die at home. She asked for assistance to arrange for entering a LTC facility and sell her home and car. The nurse notes that Mrs. Fife speaks openly about death and being aware her life expectancy is limited to the summer or fall of this year. She is quoted as saying she is ready to die. During the interview, Ms. Sue told me Mrs. Fife has decided to live and no longer wants to sell her home. Ms. Sue talked about attending the cancer clinic with Mrs. Fife, and seeing Mrs. Fife's x-rays showing the cancer in the bones but also talked about Mrs. Fife getting better and taking little trips together this summer. This change in attitude is not reflected in the HC nurses' charting. Repeatedly the nurses note Mrs. Fife is depressed when her symptoms are not controlled. On admission to hospital with uncontrolled nausea, she is quoted as saying she would rather be dead.

The HNC file says her current problems are: controlling pain in her back and rib

area, diarrhoea, drowsiness, loss of appetite, nausea and vomiting, feelings of depression and reduced vision. The nurses note that she does not take her medications regularly. From the notes, it seems she does not take her pills for nausea and pain when she is feeling well.

Mrs. Fife has arthritis in her knees and back which causes her ongoing discomfort. She uses a cane to walk outside and still drives her car locally. She manages her own hygiene, including travelling to have a weekly bath at an adult day care centre.

Ms. Sue considers herself healthy but has needed to take time off from work for severe headaches that seem to follow Mrs. Fife's bad nights. Ms. Sue spoke of feeling concerned as she had the flu a few weeks ago, and is suffering with an ear infection that is hampering her hearing. She is taking antibiotics for it.

Case Study #3-

My third informant is a woman in her late 70's caring for her husband of 55 years. They live in an upper middle class socioeconomic area in a single dwelling home which appears well kept indoors. The outside of the home is showing signs of neglect. Considering how this couple kept their home on the inside, the walkway at the entrance to the house made me think I should be more attentive to how Mrs. Kate was managing. They have four children and numerous grandchildren. A son and daughter live locally. The others are scattered throughout the province. The daughter who lives locally, visits every day to help her dad with his bathing. The family seems to plan their visits so one offspring and family visits each weekend. Numerous family pictures are in the living room.

Mr. Kate is an 84 year old retired antique dealer. In 1964, he had surgery for renal cancer and in 1984, one lung was removed as being cancerous. In 1989 cancer reappeared in the form of a facial tumour. He was very well until September 1995, when Mrs. Kate says he experienced pain in his upper chest, weight loss, night sweats and loss of appetite. He was told in December 1995 he had cancer of the spine. He received a series of radiation treatments.

Admission to HNC palliative care services occurred in December, 1996. His prognosis was projected to be three to six months. His present problems according to his Home Care nurse include: pain, a urinary catheter which plugs periodically, feeling very weak, sleeping a lot, difficulty swallowing, coughing, loss of appetite and a reduced ability to concentrate. Mr. Kate needs help with all aspects of his personal care and daily activities. He needs assistance to get from his bed to the wheelchair. Going for rides in the car has not been possible for the past month. Mr. Kate has cataracts on both eyes and uses bilateral hearing aides. The nurses note he "can be very demanding of his caregivers" and "tends to be irritated easily". It is documented that he is aware that his illness is terminal but he does not want to talk about it. One of the latest notes on the HNC file quote him as saying he feels like a "concentration cancer victim". A history written by one of the Cancer clinic oncologist states Mr. Kate is a charming man.

On admission to HNC, Mrs. Kate has advised her physician she wants HC nurses to teach her about the caregiving role and help her plan for the future. She was feeling anxious.

Mrs. Kate describes herself as being very fortunate with her health. Her only

health problem is some arthritis in her knees which prevents her from gardening. She likes to go swimming a few times each week. Mrs. Kate has been a bank manager.

Case Study #4-

My last family includes a husband who retired from work last year. He is the main caregiver for his wife of 44 years. He is 66 years old and she is 65. They live in a modest two-story home in a working class neighbourhood. They live downstairs and their daughter, who is a single parent of three elementary school aged children, lives upstairs. Their other two children live out of town. The second daughter is single, suffers from a chronic condition which limits her stamina. She is just able to work full time in an administrative job. Periodically they help her out financially. Their son has had a troublesome early adulthood and has just started working full time. Mr. Nat hopes his son will decide to further his education, and has offered to help him if he does. Their home is modestly furnished. It is very clean and tidy inside and out.

Mr. Nat worked for the government for most of his working life. Mrs. Nat has always worked in the home. He describes them as having a 'traditional' relationship. She ran the home and looked after the children and he "worked". They both enjoyed playing golf.

During our first interview Mr. Nat said Mrs. Nat was healthy until 1993, when she started to find it difficult to complete routine activities such as vacuuming and playing a full game of golf. She was diagnosed with terminal Pulmonary Fibrosis. A lung transplant was not deemed possible as her bone density is reduced because of osteoporosis. She has minimal lung capacity. She uses continuous oxygen to help her

breath. They were told to expect her to live three to four months. At the second interview, I learned from Mr. Nat that his wife had actually felt unwell since the mid 1980's. In addition, she has non alcohol induced cirrhosis of the liver, high blood pressure and thyroid problems.

In September 1994 she was referred to HNC for palliative care services. Presently Mrs. Nat is suffering with breathlessness on exertion, lack of energy, periods of pain in her bladder area, angina, poor appetite and an inability to sleep for any length of time. She is able to get herself up and walk with a walker for about 15 feet but is breathless following this. Mrs. Nat can go out in the car but it leaves her exhausted, so she only goes out for necessary appointments.

Both Mr. and Mrs. Nat want her to die at home. They talk openly about death and see death as a time to go to a better place. Mr. Nat says he does not have any health problems but feels some concern about his tendency toward being emotional. He says he never used to cry but now will cry in a sad movie. This was something he never used to do. He was obviously upset by his crying at the end of our first interview.

CHAPTER FIVE

THE FOUR MAJOR THEMES ARISING FROM THE DATA

Analysis of the data collected from the interviews revealed four major themes. The caregiving role was clearly demanding for all four family caregivers. Changes in the family caregiver's role within the relationship to their loved one were evident. Mrs. Jan and Mrs. Kate saw their role as changing little. Ms. Sue has taken on role of helper as Mrs. Fife has no one else to turn to and Mr. Nat is profoundly effected by his wife's illness. All see their relative's world narrowing and consequently, their own social world narrowing. The fourth theme related to a change in their loved one's character. This last theme seemed to have the greatest impact on all of them.

THE CONSTANT, HEAVY DEMANDS OF THE CAREGIVING ROLE

The constant, heavy demands of the caregiving role was a consistent theme in all of the caregiver's stories. This is not surprising because research has shown on average family caregivers of home hospice patients spend 10.2 hours a day providing patient care (Biegel et al, 1991). Stetz's (1987) American study of 65 home care spousal caregivers of terminally ill, adult, cancer patients found on average, spouses reported spending approximately 23.2 hours daily, at home, with their bedridden patients. Mrs. Jan repeatedly told me how busy she was. She described how her friends and family had learned that if they phoned when Mr. Jan was awake, she would probably have to hang up and not find free time to call for a few days. Mr. Nat said, "I rarely sit down for any length of time and just relax. Things take about three to four times longer that they used to." If he did sit down his wife might ask for something five to six times.

One researcher reports, "Over time, most family caregivers develop a care regime and a knowledge base so attuned to the care recipient's needs, that their skill rarely can be matched by nurses" (McKeever, 1995, p.17). I cannot help but wonder about the justice of home caregiving if it requires family caregivers to give up so much of themselves. The goal of in-home palliative care is to provide quality care for the dying person but this should not be at the expense of the family care providers. I take ownership of this assessment because none of the informants spoke at any time about wanting to stop the caregiving role. Only Mr. Nat said he would like more help from his daughter and LTC home support worker time.

Each informant seemed to measure caregiving demands or the burden of providing care differently. Mrs. Jan impressed upon me that she was very busy, but did not convey it as being beyond what she could, or was prepared, to do. From an outsiders viewpoint, each of the informants appears to have a very different work load. Mrs. Jan has private housekeepers and a gardener as she has always done. Ms. Sue said Mrs. Fife "needs lots and lots of help". Unlike the other three patients, Mrs. Fife manages her personal hygiene, other than her bath, which she receives at the day care centre. Unlike the other patients, she is independently mobile. Ms. Sue's role does not include helping with personal hygiene, being there 24 hours a day, or meal preparation. Like the other caregivers, she helps with laundry, dinner clean up, driving to appointments and staying with Mrs. Fife when her symptoms are not controlled. Mrs. Kate said she feels "drained". She described one evening when, after helping her husband with his nightly hygiene activities and returning him into bed, he said he would like some warm milk and bread. She then,

proceeded to get him up to the kitchen where she prepared this for him. Mrs.Kate's daughter comes daily to bathe and shave her father. All the care demands of each of the patients are different but to each of the caregivers the requirements of the role are demanding.

In the article *Social Divisions in Caring* Hilary Graham (1993), argues that social class gradients are reflected in informal care. She sees material resources sustaining independent living in the face of disability and illnesses. Mrs. Jan's circumstances reflect this premise. Her description of her everyday activities suggest that she has the resources to manage caring in a way which suits both herself and her husband. Mr. Nat on the other hand does not feel that he has sufficient financial resources to hire help to the point where he would feel adequately supported. He talked about feeling torn because he is juggling the finances to help his single-parent daughter, a chronically ill daughter and his son who he would like to go to university.

It is evident from these findings that a single definition of what constitutes caregiving 'burden' would not be accurate. The meaning of burden, is individual to each caregiver. Assistance with the same activity might cause one person to report feeling, 'very burdened' while another might cite experiencing 'little stress.' Hooyman and Gonyea (1995) have looked at the task of defining caregiver burden and suggest a concise definition will be difficult due to it being a multidimensional concept. They talk about objective and subjective burdens. Objective burden refers to physical and financial demands and subjective burden relates to the psychological, emotional and social problems relating to family caregiving.

From the discussions with Mrs. Jan and Mr. Nat, it is not evident to me how their workloads differed but they certainly defined them very differently. Mrs. Jan describes her day as being consumed with caring for Mr. Jan but does not want more assistance right now. She felt she was managing. Mrs. Jan has options from which to choose. Mr. Nat on the other hand wonders 'how long' he can carry on.

Being on standby or on constant vigilance seems to be part of the feeling of burden. During the interviews, I could see Mrs. Jan and Mr. Nat were keeping an ear open for their spouse. Mrs. Jan said she had taught herself to not "panic" when friends stopped to talk to her at the mall. Up to this time, she has been able to leave her husband and go grocery shopping. She described sitting him on the chesterfield with the phone and warning him to not answer the door bell. She estimates she can be away safely for about 20 minutes. Mr. Nat carries a cellular phone when he goes out. Both he and his wife find it comforting for Mrs. Nat to be able to contact him.

Biegel et al (1991) report on a study which showed 67 percent of family caregivers of palliative patients do not get adequate sleep. Five to six hours of sleep is the average night's rest (Lemkin, 1995). I asked each of the four informants if they were getting adequate sleep. Mrs. Jan said her husband tends to have periods when he sits on the side of the bed and rocks back and forth. Their physician thinks this may help him to breathe easier. Mrs. Jan feels fortunate as she is able to go back to sleep once she determines that he is alright. She thinks that an "inner alertness" is keeping her going. She finds herself going to bed about ten and getting up at five in the morning. When asked if this was a normal time to get up, she said it gave her a sense of control to get up at

that time. Her routine is to get dressed, have breakfast and pay bills or write to friends before her husband wakes.

Ms. Sue thinks she is "fine", but has needed to report in for a sick day from work. She got a "splitting headache" after being up with the visiting nurse at midnight one night. Mrs. Fife had been vomiting. The nurse had asked her to stay as Ms. Fife was frightened. She described the nurse telling her she might need to give Mrs. Fife a medication by needle if her nausea reoccurred. Ms. Sue describes the nurse as saying, "you wipe, stick it in and throw it away" when she instructed her on how to give the injection. She said she felt so scared, she "prayed" her friend would not need the medication. It was after midnight but she still stayed up after the nurse left to practice handling the syringe.

Mr. Nat said he usually gets six and a half hours of sleep. This is not what he is accustomed to but he says it is alright. When his wife is not well, she might need help six to seven times during the night.

What become evident to me as I talked to each of the informants was that I was seeing a gender difference in how they reported the demands of the caregiving role. Mr. Nat looked strained. He reported wondering how long he could continue like he was.

Both Graham (1993) and Hooyman & Gonyea (1995) see caring by unpaid caregivers as socially constructed. For women caregivers, caregiving is motivated by a number of socially constructed traits: emotional attachment to care receivers; caring as central to a female person's identity; by their capacity for self-sacrifice; and their sense of altruism. Women learn to think in these ways. If a women's roles in family caregiving

are socially constructed and if the work women do in the home is largely invisible, we can expect that the female informants will not see caregiving as new work in the same way as the male caregivers would. Through interactions with others they have 'learned' to not see it.

For Mr. Nat, most of what he is now doing is new work. Prior to his wife getting sick, she ran the home. He could remember occasionally helping by putting the children to bed but on the whole, he described himself as not being "able to find the sugar" before his wife's disability. When he called me to come for a second visit he had prepared a list of all the new tasks he preformed and the tasks he now preforms prior to Mrs. Nat's illness (See Appendix D). The majority of his old tasks related to playing golf. It is no wonder he feels the strain of the role changes he has had to assume.

I must confess Mr. Nat's feelings about taking on the home-making role raised strong feelings in me. When he said he did not like the role, I responded by saying I get tired of it at times as well. Once I recognized this as a gender issue, my negative feelings subsided as I was able to understand his reaction to doing, what I and many other women do on a daily life-long basis.

ROLE CHANGES-SHIFTS AND REVERSALS:

Caregiving causing role changes for the informants is seen as less of an issue for both Mrs. Jan and Mrs. Kate. Both said they had always managed the house and the finances. Mrs. Kate said she would need help to fix the screen door this year. Mrs. Jan has always managed the bills and managing their investments has come to be her job over time so she feels quite confident. She sees their bank manager as a big support. With Mr.

Jan being diagnosed as terminally ill with months to live in 1993, Mrs. Jan feels the changes in their relationship have occurred over time.

Ms. Sue says she took on the "helper" role because there was no one else to help Mrs. Fife. For example, Mrs. Fife asked her to take her ashes up island and spread them there. When asked how she felt about this, Ms. Sue said she thought she could do it.

Mr. Nat said, "it's not the life of retirement, I expected". He has accepted it as a necessity but it had not been what he looked forward to or what his wife looked forward to.

Role shifts and role reversals are explained Biegel et al (1991) as occurring as the terminally ill person's dependencies require greater responsibility and initiative from family. McKeever (1995) sees the home as a site of caregiving as adding to the strain imposed on family caregivers for two reasons. First, the home is traditionally considered a refuge from work and second, taking on the caregiving role is not one of choice. Mr. Nat felt "government officials" should recognize this. He wondered why there was no assessment of a family caregiver's skills for delivering care in the home. "Whose to say everyone can 'do' this job ?"

Frances Gregor, a nurse teaching at the School of Nursing at the University of Dalhousie, has been reviewing the current strategies of Canadian health reform. She sees reform as shifting care to the 'family' and to the 'community'. She argues that policy makers are relying on a return to 'family values'. She sees deinstitutionalization as relying on the care of the sick and disabled by kin groups. If caregiving is socially constructed, family members will tend to see it as their moral duty to care for their family member.

Others reinforce this assumption.

My informants' accounts support Gregor's analysis. None of them questioned if it was their 'job' to care for their loved one. Mr. Nat said he feels it is his duty to care for his wife and as such he would do whatever it takes to ensure that she never sees herself as a burden. He is afraid she would die if she ever felt this way. Their doctor has told him he does not know what he is doing but he is sure this is why Mrs. Nat is alive today.

The negative ramifications of the role changes were most evident with Mr. Nat's situation. This is due to numerous reasons. The fact Mr. Nat is male, their lack of financial resources, the traditional roles they held prior to Mrs. Nat's illness and the length of time Mrs. Nat has been unable to function to her full capacity, are all adding to his burden. Family members report being able to care for a family member over a short term, but months and years of caregiving take a tremendous toll (Baginski, 1995).

Normal family equilibrium is disrupted and renegotiation of well-entrenched patterns of nurturance, dependency, initiative and power are forced on families (Biegel, et al, 1991). Mr. Nat said their hopes for the future were not as they had planned. Mrs. Kate said that on one hand she hoped her husband would die soon so he would not need to suffer, but on the other hand, she is concerned about her own future without him. She would miss his "companionship". Mrs. Kate went on to talk about their being married 55 years ago at the ages of 21 and 22. She described their life together as "good".

The demographics of our population are changing and with these changes in-home care may not have family members to provide assistance as they do today. The structure

of the family is changing. There is an increase in single-parent families. In 1970, only 10 percent of households with children under 18 were maintained by one parent whereas by 1990, this percentage had risen to 30 percent (Hooyman & Gonyea, 1995). Blended families are increasing with the high divorce and remarriage rates. Two the families in study are not the traditional nuclear family. This was a second marriage for both Mr. and Mrs. Jan. Mrs. Jan spoke warmly about her step-daughter, but also, said that she was thinking about her options after Mr. Jan died as she does not want to be a burden to her step-daughter. Ms. Sue has been Mrs. Fife's friend for only nine months, but as Mrs. Fife did not have family support, Ms. Sue is assisting her to be at home. Mrs. Fife's husband had children but she has none of her own. Mr. Nat's daughter, who lived in the same house, is a single parent with two small children. He feels that she takes more of his time than he takes of hers.

Families are mobile (Bakker, 1996). Due to the need to move to new employment opportunities, people move away from their home town. This leaves parents with no family able to help them on a regular basis. As a percentage of the total Canadian population, the number of people over the age of 65 years is increasing. Canadians are living longer. In most instances, women are the primary family caregivers and with more women in paid jobs, they have much less time to care for sick relatives.

The informants seemed to be not maintaining a balance between their own needs and the caregiving responsibilities generated by their relative. Mrs. Jan said she had always valued regular exercise but was finding the only regular exercise she got was on her many trips up the stairs going to assist her husband or walking to the pharmacy to

pick up his medications. With his condition deteriorating this is becoming less and less possible because she does not feel safe leaving him the length of time it takes to walk. She explained that her walks were more than just enjoying her neighbourhood. This was a time she could be with "her God". Mrs. Jan did not talk about feeling she had inadequate time for herself and her body language confirmed she was being truthful. Only Mr. Nat reported personal loss. He had wanted to take an accountant's course when he retired, but had to stop his classes as his wife wanted him to be at home in the evenings. Prior to retirement he played golf three times a week, but is only able to play Saturdays now. Every Saturday, his daughter stays with her mother so he could get out.

Reimer, Davies and Martens (1991) reviewed eight years of research articles and found that caregivers' neglect for their own needs is a common theme. Their review suggested that caregivers neglect themselves because they focus on the ill person. Health care professionals reinforce this by attending to the patient and not the caregiver. The HNC health files support this finding. I found the caregivers' needs were seldom mentioned. I tend to think the support offered to the caregiver is offered with the intent to ensure the patients' ability to remain at home. At the start of each of my interviews the informants tended to talk about the day's activities from the perspective of the patient. It took considerable guidance from myself to encourage them to talk about their day's activities.

CAREGIVER'S NARROWING WORLD

The next broad theme to emerge from the informant's stories is related to the patients' narrowing world and consequently, their social world. The patients are said by

the caregivers to be withdrawing into more and more passive dependency. Mrs. Kate said her husband had been a great reader but at Christmas it was evident to the family that he could no longer read. His vision was getting less and less. A daughter tried to read him the newest edition of one of his favourite authors but, he had not been able to follow the story. Mrs. Jan said her husband had been a "great conversationalist" but he was too tired now. He did not like to watch the news on the television as had been their habit in the past. Informants from case study 1, 3 and 4 all said they tended to watch lighter shows on the television in the evening. This was often said with sadness. Mr. Nat said, "every day is like every other day". He spoke about his wife's friends no longer coming around to visit. He saw this as expected as their world was so limited. Mr. Jan's neighbours wanted to visit but he did not want them to visit. Mrs. Jan thought he just wanted to be with her.

As well as changing relationships with family and friends, the patient and caregiver, experience changes in their relationship. Relationships are built on reciprocity and equity but as the ill persons' dependency increases changes occur in their relationships to the caregivers (Biegel, et al, 1991). Ms. Sue said she had not told her friend that she was frustrated when Mrs. Fife asked her to sell her trailer. She found potential buyers but then Mrs. Fife said that she had changed her mind. "She's going to live now. It's like a yoyo type of thing. You get pulled one way and then another".

Biegel et al (1991) tell about a study in which found 9 of 15 caregiver spouses report feeling emotionally isolated. They said that they tended to withhold feelings from their ill partners which effectively cuts off their primary context for expressiveness. As

found with Mrs. Jan and Mrs. Kate, family caregivers have feelings of anticipatory loss. A seemingly big concern but both wives did not appear to have shared it with their partners. Ms. Sue is anticipating missing the companionship of Mrs. Fife. As well as emotional intimacy, couples lose sexual intimacy with their partner which can strain the relationship (Beigel,et al, 1991). I wonder if this may be part of Mr. Nat's emotional stress.

As well as the day to day demands eroding the energy and moral of caregivers, Reimer et al (1991) suggest the life's transition through which patients and caregivers are going takes considerable energy. Generally people resist change and are reluctant to relinquish old and comfortable views of themselves. As the terminal illness progresses, both the patients and caregivers are forced to redefine themselves and their situation. Adapting to change requires time and energy. The change process required with caring for a terminally ill person is not a one time thing. The redefining occurs over and over as the need to adapt to the ill person's disease processes.

Along with the relationship between the patient and the caregiver changing, their relationship with family and friends is changing. As my data reveals, restrictions on social and leisure activities are dramatic. It appears that the patient's increasing debility causes them to withdraw and the caregiver to decrease their involvement with others as their caring role becomes more and more consuming. The average caregiver spends 10.2 hours a day care giving, so there cannot be much time left to devote to their own mental well-being (Beigel et al, 1991). The activities most frequently cut back are those that contribute to the caregiver's mental health, like rest, exercise and talking with friends.

Mintz (1995, p.9) states that loss of self-image is, "an insidious by-product of caregiving. It comes about because both the patient and caregiver are no longer part of society's norm". Mr. Nat expressed this very clearly. He sees the day-to-day activities taking up all his time. He sees being part of mainstream of society closed to them. Reimer et al (1991) and Beigel et al (1991) call this 'social death'. "We're really I guess not that good company for them because our life is so narrow."

As the patient's self-image, self-control and self esteem are eroded, they start to feel that they are no longer part of the family or useful to others. Mr. Nat seemed to be cognisant of this concern for his wife. "They told us five years ago that she wouldn't live for six months and I think it's the home attitude that has helped her exceed that". He saw the value of his daughter and grandchildren living in the same house and their being able to visit regularly. It looked like he was being successful at ensuring she felt needed within the family. One grandchild stopped in to chat to his granny while I was visiting. Mrs. Nat spoke proudly of the little boy's good looks.

While talking with the informants, I was struck by the length of time each of the patients had been dealing with having a terminal illness (see Table 1). In the CHR HNC program, we have tended to define palliative care in a time frame of six months. This now seems narrow-minded and callous. The use of a six month time frame for defining palliative care is not found in the literature and I have come to think that it has been used within the CHR for policy development to put a time frame on the provision of services.

Looking back, Mr. Jan was first diagnosed as having heart disease which was not

treatable in 1993 and then in July 1995, he was told that he had prostate cancer which had metastasized to his bones. Mrs. Fife first discovered cancer in her left breast in 1988. The cancer reappeared in the right breast in 1989. Both breasts were surgically removed with chemotherapy treatment following. Metastasis to her bones was found in June, 1996. She was told by the oncologist no cure was available. Mr. Kate had surgery for renal cancer in 1963 and lung cancer in 1989. In December 1995, a diagnosis of metastasis to his bones offered no hope of recovery. Lastly Mrs. Nat was told in 1993, she had about three months to live due to severe lung disease.

One article claims that approximately 60 percent of cancer patients die within five years of diagnosis (Beigel, et al, 1991). I think this is a long time to live knowing you are going to die. Mrs. Jan talked about living with the "cold hand of death on her shoulder". I have limited this study to the second phase or adaptation phase of terminal illness, but as health care providers, we should not lose sight of the fact these families have lived through each of the phases of palliative care.

Each phase of the terminal illness, takes its toll on both the patient and the caregiver (Beigel, et al, 1991). Mr. and Mrs. Nat that said they talked openly about her death with all the family. Mrs. Nat said they believe "death takes us to a better place". Waiting for her husband's death is not as easy for Mrs. Jan. She said, "each time I go up those stairs, I don't know if Jan will be dead".

The day following our interview, Mr. Nat phoned to ask if I would come for a second visit because he felt he had more information that would help me with my research. The night before he had typed up a list of what he felt I had missed. Mr. Nat

gave me four pages of typed notes on my arrival (see Appendix D). The first part was a minute by minute account of what he called, The Normal Day in the Life of a Caregiver. In time intervals, he described his day. He noted altering the flow of his wife's oxygen tank 16 times. On the remaining pages, he had written two more lists. One was a list of ten tasks he has taken on, that do not occur daily and the last included the duties which he had done before her illness and continues to do. He said that he had asked his wife to read his summary and she had agreed they were accurate. From her words and body language, I did not detect tension between them, but I have to wonder if he was trying to tell her something or was he simply telling me to get some acknowledgement?

Lemkin (1995) advises that caregivers tend to not recognize their own exhaustion and burnout. She (1995, p. 42) lists some, typical signs of burnout:

*not eating properly, whether by overeating and undereating,

*appearing more emotional,

*feeling overwhelmed or frustrated,

*seeming to withdraw,

*interacting less with peers,

*having less mental focus at work,

*having a dishevelled or unkept appearance.

Lemkin (1995) has found that the duration of illness and the extent of care are factors in predicting burnout in unpaid caregivers. The more prolonged the illness and/or the heavier the physical care, the greater the chances of caregiver burnout. Mr. Nat's caregiving role has been extended and Mrs. Nat's demands are heavy. Mr. Nat

perceives his wife to be critical of his caregiving. His teariness is a clear indication that he is exhausted and certainly is not happy.

A CHANGE IN THE LOVED ONE'S CHARACTER

The last broad theme coming out of the data is the informants seeing their loved one's character changing. This finding seemed to be the most distressing change in their loved ones for the caregivers. Each of the informants described this change as a new way of being and not just a periodic moodiness. Mrs. Jan said that her husband had "always been such a charming man" and she felt very lucky because friends spoke of their ill husbands becoming so "nasty". Mrs. Jan says Mr. Jan is not nasty, but he does not seem to think of her. He wants to know where she is at all times. She has decided there is no point in her trying to nap because as soon as she puts a rug over her legs, he asks for something. Ms. Sue saw her friend as "kind of edgy". Ms. Sue talked about how she had felt very upset when Mrs. Fife "yelled" at her when she suggested she eat something more nutritious than jelly filled donuts. Mrs. Kate said, "the family think he should be saying profound things, but all he is, is angry".

During our interview, Mr. Nat said he wanted to make a recommendation. From his observations, he concludes that "sick" people change. They get "more and more demanding and critical of their relatives". He suggests that home help hours should have been increased when he retired rather than decreased as they were. While he worked, the LTC program provided three hours of home support assistance five days a week but when he retired, they were reduced to two hours three times a week. An example of Mrs. Nat being critical occurred while I was visiting. While Mr. Nat and I were talking, Mrs. Nat

was having her regular afternoon nap. Mrs. Nat called for Mr. Nat and in a harsh voice, asked him why the head of her bed was not raised. Mr. Nat apologized and said he had forgotten. Mr. Nat said before his wife was sick he would have "told her to go to hell" had she spoken to him in such a manner, but he feels she ever felt that she was not loved, she would give up and die.

A discussion of terminally ill persons changing character or being inconsiderate does not appear in the literature. Reading Reimer, et al (1991) study on what they have called the 'transition of fading away' could be a cause for the patient's character to seem to have changed. These authors theorized that terminally ill patients and family members go through a change process from the time of diagnosis of a terminal illness. They state as, "unrecoverable weakness, inability to get around, loss of independence in personal care, and loss of mental clarity " are visible signs of the patient's demise". The person's self image changes radically, as does their self esteem and sense of control (1991, p.323). The patients are constantly having to themselves and their relationships to others. Hope of recovery is being destroyed.

With the need to change how the ill person sees themselves come feelings of denial, anger, depression and fear (Biegel, et al, 1991). These are predictable responses for both patients and family members. As the patient's condition deteriorates to a point where the inevitable can no longer be denied, does this realization, this concern for what was, become so consuming that they forget to consider those they love? It would seem to be a human reaction for the person to feel anger with their situation and resentment towards others who are well.

In conclusion, as the patient's tendency to not express concern for their family members' feelings increases, other people's reactions reinforce this behaviour. Health care providers, friends and neighbours tend to focus their attention on the sick person. The caregivers may become almost invisible as everyone's attention is focused on the ill person (Mintz, 1995) This tendency by the health care professionals is evident in the HNC health files of Mrs. Fife and Mr. Nat. Neither of the two files mentioned Ms. Sue's concern about Mrs. Fife asking her to arrange for selling everything then changing her mind. Similarly, there is no mention of Ms. Sue feeling frightened when asked to give Mrs. Fife her nausea medication by an injection. None of Mr. Nat's feelings are documented.

CHAPTER SIX

COMPARING THE RESEARCH FINDINGS AND MY PRE-INTERVIEW CONCERNS

Prior to conducting the interviews, I had a sense of what I thought was causing stress for caregivers. As a front line HNC manager, I had anticipated what would be of concern for the family caregivers. My role necessitates my reading the documentation of the nurses on a regular basis. As their immediate supervisor, I visit patient homes with them and talk to patients and families.

I was concerned about the costs of medications. Although cost of medications over $350 per year can be claimed back from pharmacare, people have to pay for them up front. I wondered about families already fatigued, needing to pick up pieces of equipment and nursing supplies. Often the staff have expressed concern because they feel family members are tired and yet they are required to make numerous trips to pick up new equipment as the patient's condition weakens. I wondered if people were receiving sufficient assistance from home support workers. Is the cost for home support assistance high or even prohibitive? In hospital, health care professionals come to the ill person, whereas in the home the person must visit the health care professionals. Is this a problem for caregivers?

From personal experience as a family caregiver and through listening to the nurses, I had a sense that the physical demands of caregiving were heavy. The literature suggests non-paid caregivers assume approximately 85 percent of the caregiving role (Centre on Aging,1995).

Through reading and rereading the transcripts of the four interviews, I have been reminded of the importance of asking people directly about their viewpoint. My preconceived concerns were not the caregivers' prime concerns. As a manager, I am positioned within the organization in a particular way. This causes me to listen for and respond to some messages over others. My way of knowing causes me to filter information, often at an unconscious level. The HC nurses tell me certain things that they think I will be interested in, because they are also positioned and they understand me in a particular way. The discrepancy between my preconceived ideas about what it means to a family member to facilitate palliative care in the home, and the findings from this project demonstrate the importance of doing research with the caregivers themselves, and not only through the observations of health professionals.

MEDICATIONS:

Direct economic costs were not a priority issue for any of my informants. This may be related to the socioeconomic level of all the families except for Mrs. Fife. Mrs. Fife did have concerns about the cost of her medications but when the nurses became aware of this, assistance with the cost of medications was arranged. Once in Mrs. Fife's HNC file, she is quoted as expressing concern about the medications taking too long to be delivered by the pharmacy and fearing that she would run out before they were delivered. The other informants did not talk about the issues of cost or pick up of medications. I raised the issue of cost with each of them and always it was seen as a non-issue. Mrs. Jan saw getting the medications from the local pharmacy as an opportunity to go out for a walk. Her pharmacy had offered to deliver them. She thought this might

be helpful as Mr. Jan's needs demanded more of her time. Each of the patients are taking between five and eleven different medications daily.

EQUIPMENT AND NURSING SUPPLIES:

No one felt the direct costs or arranging for equipment and nursing supplies, has been a burden. Mr. Nat said the oxygen would be a problem financially if it was not paid for by the Ministry of Health. All the families except Mrs. Fife, had various forms of equipment in their homes, ranging from bath stools to an electric hospital bed.

HOME SUPPORT WORKER ASSISTANCE:

Home support worker assistance was a topic raised by the informants. Both the caregivers in the first and third case studies, said their husbands were not happy having home workers come into the home to care for them. Mr. Jan had asked his wife (in front of the home worker) to "send her away". She described how he had sat rigidly when the home support worker tried to rub his feet. Mr. Kate had refused to get out of bed when the home support worker came. Both wives talked about being fairly assertive with their spouses, saying they needed help in order to help them to stay at home. In contrast, the female patients were expressing positive feelings about having help come into the home. Mr. Nat said his wife enjoyed talking with the "ladies" and would miss them if they were to stop coming. He, on the other hand, felt the work they did was substandard. He feels they "take no pride in their work". He showed me three of his shirts to demonstrate their lack of ironing skills. He said they were not supposed to iron but some would. He thought he could probably hire help privately and get the house cleaning done more quickly and more thoroughly, but because his wife particulary liked one of the home support workers,

he probably would not change the arrangement.

An interesting question arises as to whether the gender difference in the acceptance of assistance, is related to the women recognizing the 'work' involved with running a home. Daniels (1987) talks about the 'invisible work' that traditionally women have done in order to run a home. In her article, Daniels says that in modern, industrialized society we tend only to recognize work for which we get paid. Perhaps the ill husbands were not 'seeing' the work their wives did to keep the home running. Both Mrs. Jan and Mrs.Kate described having divided the roles along traditional lines prior to their husband's illness. To the caregivers, traditional roles in a marriage referred to the husband working outside the home in a paid job while the wife was responsible child rearing and for the work involved in maintaining the home.

TRAVELLING TO AND FROM APPOINTMENTS:

Ms. Sue said she is using her vacation days to take Mrs. Fife to her appointments at the Cancer Clinic. Her holiday entitlement is 23 paid days a year. She did not voice any concern about using her vacation days in this way. Mrs. Jan and Mrs. Kate found health care providers have come to them. Mrs. Nat's family physician visits regularly, but she is finding that getting to the dentist is a problem. Getting new dentures has required her to make five trips to the dentist in the last two weeks. Mr. Nat says that although the appointments are brief, each trip takes about an hour, which proves exhausting for his wife. Walking just 15 steps causes her to be short of breath. He said she often refuses to go. I would think, from the location of their front door and the garage, it would be an exhausting endeavour for both of them, but Mr. Nat did not say anything to make me

think he feels this way.

A review of the HNC files for all the families reveals they are using formal community resources (See Table 2).

Table 2
Formal Community Resources Accessed While on HNC Program

Case Study #1- Mr. and Mrs. Jan
House cleaner, hired privately
Home support workers, hired privately
Community Rehabilitation therapist
Home subsidized oxygen
Hospice counsellor and Palliative Response Team
LTC case manager to assist with planning for future
HNC visits three times a week and as necessary
Case Study #2-Mrs. Fife and Ms. Sue
LTC home support workers two hours daily
Hospice counsellor, respite bed, Palliative Response Team
Adult day care bathing
Acute hospital
Nutritionist from acute hospital
Delivery of medications by pharmacy
LTC case manager for arranging home support workers and waiting for a LTC facility
Volunteer drivers
HNC visits daily
Case Study #3-Mr. and Mrs. Kate
LTC home support worker two hours two days a week
Hospice respite bed and Palliative Response Team
Community Rehabilitation therapist
HNC visits two times weekly and as necessary
Case Study #4- Mr. and Mrs. Nat
LTC home support worker two hours three times a week
LTC case manager to assist with arranging home support assistance
Acute hospital
Community Rehabilitation therapist
Home subsidized oxygen
Registered with Hospice with no services accessed to date
HNC visits every two weeks

Looking at the four families' usage of formal supports from the 'traditional health care system's' viewpoint , Mrs. Fife appears to be using slightly more than the other three

families. In Chapter Two, the notion of social forms of consciousness was introduced. Differences in uptake of community resources reflect these social forms of consciousness in that, as Gregor (1997) argues, chooses made represent societal beliefs and values about who should do the work of caring and where that caring is best accomplished. From reading Mrs. Fife's health file, it appears her pain, nausea and vomiting are not well controlled. This has required her to be admitted to the acute hospital and the involvement of a nutritionist. Her caregiver being a friend who is employed full time and there being no other informal supports would also suggest why she is at the adult day care for bathing and using volunteer drivers. The Jans' are hiring help privately because of their higher income level. Home Support worker assistance is subsidized by LTC based on income. They have had a LTC Case Manager assist them in planning for the type of qualified help they may need as Mr. Jan's dependency increases. Mrs. Jan said she did not feel she needed more assistance right now, but was confident she would know when she did need it. She spoke of how helpful her bank manager had been in helping her to arrange for money to be readily available for this purpose. Mr. Kate was in a respite bed at Victoria Hospice at the time of our interview. Mrs. Kate said Mr. Kate did not want to go until she promised he would come home.

THE CAREGIVING ROLE:

Lastly, I wanted to learn about the physical demands of the caregiving role from the caregiver's perspective. All the informants talked about the role being all consuming. It is interesting that the informants from the first, second and fourth cases, said the same statement verbatim, they "rarely sit down". They all talk about having little time for

themselves, to socialize with others, or do the things they have always enjoyed.

Looking at the data collected from the four interviews revealed four major themes. As I had suspected the heavy physical demands of the role was an issue as was their narrowing world and the role changes for both caregiver and patient. They each saw their loved ones' character changing.

CHAPTER SEVEN

DISCUSSION OF FINDINGS

The four informants' stories have proven to be rich in information for enhancing understanding about what it means to be a family caregiver for an in-home palliative patient. Each has a voice in their similarity and variety. The four themes occurring to some extent in all four situations add to their value and trustworthiness (Stake, 1994). Their occurrence has caused me to reconceptualize my original conceptualization of hidden costs for family caregivers.

The informant's concerns about the heavy demands of facilitating palliative care in the home, the new roles demanded of them and the narrowing social world for the dying in-home patient reinforce the findings of other researchers (Mintz, 1995; Hooyman & Gonyea, 1995; Biegel, et al, 1991). Changes in the palliative care patient's character has not been reported. The informants describe this change as permanent and not merely a periodic mood change. As all the informants spoke of this, I came to think practitioners should consider it a potential stressor for caregivers. Further, the assumption of household chores being viewed differently by men and women has not been reported in the literature.

Hooyman and Gonyea (1995) talk about how difficult it is to define caregiver burden because each situation will be viewed differently by different people but the findings from my four informants lead me to think male caregivers may experience the burden of role shifts differently than women. The degree of burden experienced seems to be related to the way 'housework' was divided prior to taking on the caregiving role. If

the male partner was used to seeing himself as contributing to the relationship by working outside the home and the wife's role was to run the home, taking on the household tasks may be seen by them as a greater burden.

The literature on caregiver burden reveals that the stressors for a caregiver with their relative in hospital differ from those where the patient is being cared for at home. Wright and Dyck (1984) found 45 next-of-kin of hospitalized adult cancer patients' primary concerns related to dealing with the ill person's symptoms, fear of the future, waiting and trying to obtain information. Only fear of the future was mentioned by my in-home caregivers. They talked about feeling supported by the health care providers and how they felt confident dealing with the symptoms because of the teaching and praise they received from the professionals.

Interviewing the four caregivers was a very moving personal experience. They talked only in terms of supporting their spouse/friend. In *Social Divisions in Caring*(1993) by Hilary Graham, the concept of family caregivers attending to the emotional as well as the material needs of the ill person is addressed. Family caregivers care about those they care for. So simple yet so profound. Finding the 'caring' with in-home caregiving has been especially important for me because as a community health care provider, I have worked with a strong belief that in-home care enhances the dying person's quality of life.

The negative side for family caregivers is that this 'caring' leaves them potentially in a silent struggle between their personal needs and their love and duty. I talk about it being a silent struggle because I see health care providers and society in general assuming that families want to care for their dying relatives. Examining what causes the caregivers

to be put in positions of stress has been the strong focus of this research project. The research to date on family caregivers is limited and most of what has been done, focuses on caregivers of the elderly or measures overall caregiver stress without identifying the aspects of the role that causes the problem (Mintz, 1995; Beigel et al, 1991). This thesis provides insight into the causes of family caregiver stress.

With the shift to the home as the primary site for palliative care, the family is being held as responsible (McKeever, 1995). McKeever's research points out issues which lead to caregivers having feelings of ambivalence about their caregiver roles. The moral duty to care for a terminally ill relative/friend and balancing caregiver' needs often leads to conflict. In each situation, the four palliative caregivers in this inquiry are putting the needs of their spouse/friend first.

Glazer (1993) in her book on *Women's Paid and Unpaid Labor: The Work Transfer in Health Care and Retailing* raises questions about how work is being reorganized. She asks about whose interests are being met with the move to valuing patient self-care and independence. Although self-care and independence appear to reject the notion of dependency on other people, in practice the unit of self-care or self-support is not the individual but the family. From this article and my findings, it is evident that not all families experience the transfer of palliative care to the home identically. My work would suggest the work load or the burden of care varies according to gender, financial resources, family support and the relationship to the ill person.

I found a familiar but disturbing parallel in the literature on caregiver abuse and some of the findings of this project. Criner (1994) provides a list of potential indicators

of caregiver breakdown leading to an abusive situation: long term caring leading to possible depression, hostility and anger, physical, psychological, financial, and emotional problems adding even more stress on the caregivers as well as increasing dependence of the patient and limited internal resources. Jill Pitkeathley emphasizes that health care providers, "must remember that caring issues are enormously complex and full of inherent conflicts" (1995, p. 30). She reminds us that caring takes place within a relationship and family relationships are variable in their history and quality. Pitkeathley reaffirms that the unit of care in practice is the patient and not the family.

The recurrent discrepancies found in the caregivers stories and the HNC health files confirm this statement. There is no mention in the files about Ms. Sue being terrified when asked to give Mrs. Fife the injection, about Mr. Nat's feelings about the home support workers or about Mrs. Kate's concerns for her own future.

Why is it that as a society we put the needs of the patient above the needs of the caregiver? In a study investigating the experiences of families living with AIDS, one family member said he wanted his lover to die, for his sake, "but also in order to get on with his life" (Cody, 1995, p. 108). This study revealed some people are able to take on the role of caregiver and yet still focus on living, whereas for others the caregiving role produces strong conflicts. Mrs. Jan seems to be focusing on living each day as it comes. Mr. Nat on the other hand has strong feelings of conflict.

In summary the findings from the stories of the four informants provides much information for clinical practice as well as valuable information to enhance policy. The final chapter will make recommendations for future decisions for palliative care in the

CHAPTER EIGHT

RECOMMENDATIONS FOR POLICY MAKERS AND NURSING PRACTICE

Earlier, Stake (1995, p. 245) was quoted as saying, "the utility of case research to practitioners and policy makers is in its extension of experiences". Findings from a research project using a case study approach can help to refine theory and assist in establishing limits to generalization. The findings will not provide for entirely new understanding. Instead, they can offer refinements for understandings found in the literature. Stake called this progressive focus (Stake, 1995).

Recommendations are offered for policy decision makers on the provision of palliative in-home services and for nursing practice. Knowledge of Smith's concept of the social organization of knowledge has made this possible by explaining how the ideological underpinnings of an organization's policies organize the way practitioners do their work. The accounts of the four informants demonstrate how the ideological concepts of the CTH polices for in-home care of familialism, community care and separate spheres are setting conditions for how the practitioners do their work and how the caregivers' daily activities are organized (Gregor, 1997).

The findings from this study provide a rich source of insight into causes of family caregiver burden when they are facilitating in-home palliative care. First, and foremost, it cautions health care professionals never to assume that we can know the viewpoint of our clients. Some of my assumptions about the burdens of caregivers are probably correct but if I had assumed I 'knew' what the issues were for these four caregivers, I would have modelled my interventions as a professional health care provider inappropriately. I

would have reinforced feelings that I did not value them as people and I would have wasted limited resources.

Care in the home for the terminally ill person was reaffirmed as a model of care which can enhance quality of life for the patient. The loving care exhibited by the informants was beyond what I ever imagined. It was evident that family caregivers attend to the emotional as well as the physical needs of the ill person.

The family caregivers gave their full support for the professionals providing palliative care services in the CHR. They felt supported and experienced a sense of control. They 'knew' that the nurses and doctors all felt they were doing a good job. Analysis of the data strengthened the importance of medical equipment being available for home use and the appreciation of family for a professional to help them choose the most appropriate equipment for their relative's needs. Ms. Fife's situation demonstrated the importance of having financial support and home delivery for medications. It is likely her ability to be at home may not be possible without this support.

While it is rewarding to hear the system praised, the object of research is to learn and improve. From reading about the research of others and the findings from this inquiry, it is evident there are numerous ways professionals in the CHR can modify policies for in-home support and offer better support for palliative caregivers.

At the beginning of this thesis is a quote from Dorothee Soelle's book entitled, *Suffering*. The reason this has been included is that it puts into words what happens to people when they have no-one to listen when they express how they are feeling. Initially, I was concerned that my request for the caregivers to take time out from their daily lives

to talk with me would be solely for my purpose, but with each interview it became apparent that they welcomed an opportunity to have someone listen to their own experiences as caregivers. None of the informants seemed keen to end the interview. Each expressed appreciation for my interest and their desire for my research to be used by health care professionals. The therapeutic value of simply listening was reinforced. It appears that in-home palliative care is in many ways robbing them of their personhood. The needs of family caregivers are not being addressed by the nurses and certainly not by the health care system. Although the health care system is increasingly concerned about the costs of providing care for terminally ill patients, the findings from this study suggest the needs of caregivers are being ignored and should be addressed.

A fundamental principle of care found in the literature is that both the patient and the family be considered the client (Baginski, 1995; Glazer, 1993; McKeever, 1995). The works by these authors and analysis of the four HNC health files, reveal that health care professionals tend to focus their interventions on the patient. Their interest in the caregiver is primarily in terms of their ability to assist the patient in being cared for at home. If the standards for documentation included provisions for the caregiver, it would legitimize the focus of care on both the patient and the caregiver. Restructuring the health care record to include an assessment of the needs of the caregiver, would let the HC nurse know that the organization recognizes both the patient and the caregiver as recipients of care. The nurse's interactions may then be relayed to the caregiver. The caregiver's feelings of self-worth would be reinforced and enhanced. Family and friends would learn from the nurse's interactions to turn their support to both the patient and the family

member's needs. If caregivers felt their contributions were recognized, voicing their personal concerns would be encouraged. Health care professionals need be cognizant of the power of listening.

Continuous reassessment is vital to providing adequate support for in-home care. The issues for the caregivers are ever-changing for a multitude of reasons. Each new situation brings change. As the patient's dependency increases, caregiving demands increase. Family members are being asked to assist their relatives in ways they may never have dreamed possible. As in the situation of the Kates. Mr. Kate's daughter bathes and shaves her father every day. Privacy boundaries have changed drastically for them. Nurses need to recognize the corresponding relationship between increasing dependency and care demands. They must also assist the caregiver in utilizing community resources.

Reimer et al (1991) encourage nurses to assist families through the transition of their family member 'fading away' and the emotional work of having a loved one dying. As the dying person's condition deteriorates, massive adjustments are forced on family members. How each person faces the work of transition, is often related to their past ways of coping (Reimer, et al, 1991). It is well documented that people resist change. It is much more comfortable to stay with old ways of thinking and doing. Resistance to change was demonstrated by Ms. Sue. Although she had been with Mrs. Fife when the oncologist talked to her about the cancer having spread to her bones and her life expectancy being in terms of a few months, Ms. Sue spoke at our interview about going on a holiday in the summer with Mrs. Fife.

Energy is used in the feeling of being on standby 24 hours a day. Nursing

assessments of caregiver burden should take into account the emotional aspects draining the caregivers' energy, as well as the concrete demands being placed on them. Adapting to new and unfamiliar views of themselves and their loved ones make demands on caregivers' energy.

Policies need to be written which recognize both the objective and subjective demands of caregiving. The nursing assessment should include providing caregivers with an opportunity to assess their need for respite support. In addition to the emotional and the daytime demands, lack of adequate rest is common. Research by Beigel et al (1991) found 67 percent of family caregivers were not getting adequate sleep. Three of the four informants spoke of being wakened at night by their spouse/friend. Mrs. Jan was getting up at five in the morning. She said this gave her the opportunity to dress and have breakfast before she became busy attending to her husband's needs. During the night he often sat on the side of the bed for periods of time, rocking. This frightened her because she feared he would fall.

Recognizing each person's individuality is vital in supporting these people. Each of the informants described or measured their caregiving demands differently. Potential causes for care demands to be viewed differently by caregivers are numerous: gender interpretation, family fiscal resources, and relationship to the patient. An exhaustive list is impossible to articulate. What about the patient/caregivers previous relationship? Has it been positive as it was in these four cases? A poor relationship may influence a person's willingness and ability to support an ill family member. Life is never simple and there is no guarantee the illness of one family member will be the only pressure being put

on a family. The family scenario in the introduction of this research project is a real one. The family has two family members who are terminally ill, a son in trouble with the law, and a caregiver concerned with her own ability to work outside the home after her husband and son die.

Ms. Sue's story about her fears when she was asked to give her friend a 'needle' demonstrates that professionals must not become so concerned for the patient that they forget that non-health care providers may find medical interventions threatening or frightening. Ms. Sue was fearful she would hurt her friend if she was called upon to give Mrs. Fife her injectable nausea medication. It is not clear whether the nurse's teaching may have been rushed because it was late at night. The incident happened at midnight when historically there are fewer professional supports available. Palliative care patients and family members require support systems to be in place 24 hours a day, seven days a week. Teaching family caregivers medical procedures needs to be paced to their needs with time provided for practice and return demonstration. Caregivers need to be given the right to consent to assuming the task without pressure.

Nurses need to keep in mind that caregivers tend to neglect their own needs for mental health activities. This tendency will potentially increase as the patient's dependency on the family member increases. Normalizing this reaction for the person and helping them to see their own health as vital to their continuing support to the patient, will assist in addressing their needs.

"Knowing when and how to talk with families about death-related issues, continues to be a problem for health care providers" (Reimer, et al, 1991, p. 321). No neat and tidy

rules about communication can be written when the course of events is ambiguous and uncertain. Nevertheless, providers need to be open to negative discussions with caregivers. They need to ensure opportunities are made available for caregivers to talk in private. Letting the caregivers know that their situation is 'normal', will reduce the tendency to feel guilty about any feelings they may be having. Mrs. Kate said her family had expected their father to be saying profound things but all he was, was angry. She was concerned about her life after her husband died.

Nurses need to open the door for caregivers to talk about their concerns for their own future. With the family member's illness, they will tend to try to protect their relative and therefore lose their main source of expression. Caregivers may want information about options for themselves after their loved one dies. They may need someone to be open to listening to their feelings of anticipatory loss and encouraging them to open other avenues for communication. Some may feel supported knowing that caregiver self-support groups or peer volunteers are available. Nurses need to have information on assisting caregivers in finding ways to reduce their emotional isolation.

A review of the literature reveals that the issue of 'caring' in the home is gender defined. Gender differences come into play in the female caregivers' stories very differently than for Mr. Nat. Although the women describe themselves as feeling very busy, they do not recognize their roles as changing very much. The male patients tended to decline outside assistance from home support workers. Nurses must be aware of these factors and offer women caregivers the opportunity to talk about their own needs for respite. As a professional person, the nurse may be able to offer female caregivers support

in introducing someone else to assist in the home. The important thing for nurses is to listen to the family caregiver and help them define their own needs for assistance.

Policies which define palliative care service eligibility in terms of a limited time frame should be questioned. CHR polices for providing LTC funded home support worker assistance are presently limited by time frames of three and six months. It needs to be recognized that patients and family members live with the terminally ill from the time of diagnosis. Each family situation should be looked at individually.

Finally, public education is needed to raise the public's awareness about in-home palliative care. The supportive role non-health care community services can offer families is vital. Mrs. Jan felt that the support of her bank manager, her husband's barber and the pharmacist were all important. She tended to talk about their supportive role more than that of the paid health care professionals. She spoke highly of her mechanic who was advising her on the upkeep of her car.

In conclusion, much has been learned by listening to the four family members talk about their experiences as palliative caregivers. The terminally in-home patient is receiving loving care, but massive shifts in the caregivers' lives need to be recognized when developing in-home health care policies. In listening to the four caregivers talk about their experiences and in reviewing the research done to date, it seems that the CTH policies for in-home palliative care are creating a third tier to the health care system. The work of this third tier is being done in relative silence by family caregivers. Policies need to be written to allow practitioners to conduct their practice in a way that allows for the individuality of each family situation.

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APPENDIX A

SUMMARY FOR CRD HNC NURSES

Analysis of the Hidden Costs for In-Home Palliative Care

Part of the University of Victoria Masters in Nursing Program is a research project in the form of a thesis. I am asking for your assistance with my research.

As Home Care nurses you are aware the direction of health care is to provide more and more services in the home. You have raised concerns that care in the home is not without costs for family caregivers. For some families the purchasing of medications, equipment and supplies is a burden. For other families assuming the caregiving role is causing fatigue.

I am interested in gaining more understanding about these concerns from the family member's perspective.

By talking with them and reading the current literature, I hope my thesis will be helpful for future planning for health care services within the CRD.

This project has been approved by the University of Victoria Human Research Ethics Committee and Dr. Richard Stanwick, CRD Medical Health Officer.

I am hoping to interview family members providing help with daily activities for about three terminally ill HNC clients. I am asking you to volunteer to help me with the selection of families. Would you please determine if any palliative families in your district meet the following criteria ?

* Client's family are providing assistance with daily activities;

* Family member(s) have the energy to take part in an interview of up to two hours duration. A second interview, if needed for clarification will take less than 30 minutes;

* Client's condition and home situation is relatively stable;

* Family member(s) must be adults and able to provide informed consent to participate.

If you think any of the palliative families in your district meet these criteria and may be willing to talk with me, I will provide you with a letter of introduction and a Consent Form to give them. Once they have reviewed these materials and are wanting to talk with me, I have asked them to phone me at my home phone number- 721-0217- after 6 o'clock in the evening.

Please see me if you have any questions or concerns.

Thank you for your assistance.

Once the project has been completed, I will have a summary report of the findings available if you would want to read it.

Vicki Jacques

January, 1997

APPENDIX B

LETTER OF INTRODUCTION FOR INFORMANTS

3933 Sandell Place,
Victoria, B.C.
V8N 5R4
Date

Name of Informant
Address
Victoria, B.C.
Postal Code

Dear :

My name is Vicki Jacques, and I am a student of the University of Victoria Masters in Nursing Program and an employee of the Capital Regional District (CRD). I am an Assistant Manager of the Home Nursing Care Program, working on a research project for my thesis.

The direction of health care is to provide more and more services in a person's home when they are ill. I am interested in gaining more understanding about concerns you may have about costs which have arisen for you, when care is provided in the home. The Home Care nurses have raised concerns because they see direct fiscal costs and the assumption of care giving causing some families a burden.

I will be asking to hear about what a typical day is like for you.

By talking with you and reading the current literature, I hope my findings will be helpful when planning for health care in the CRD for the future.

This project has been approved by the University of Victoria Human Research Ethics Committee and Dr. Richard Stanwick, CRD Medical Health Officer.

Please read the enclosed consent form. If you are willing to talk with me please call me at my home phone number, 721-0217 after 6 o'clock in the evening so we can make an appointment. I anticipate my interview will take about 2 hours. If you would like, when this project is completed I will mail you a summary report of the findings.

Thank you for your consideration.

Yours truly,

Vicki Jacques, Phone 721-0217

APPENDIX C

CONSENT FORM FOR PARTICIPATION IN THE STUDY ENTITLED, 'ANALYSIS OF THE HIDDEN COSTS FOR IN-HOME PALLIATIVE CARE'

I understand that the purpose of this project is to gain an understanding about the concerns family members may have about assuming the costs of health care, when care is provided in the home. The findings from this project are to be used to assist with future planning of health care services in the CRD area. I understand that I will be asked about my impressions and experiences with care in the home and that the researcher, Vicki Jacques will be reading my family member's Capital Regional District (CRD) Home Nursing Care chart. The researcher is a student of the University of Victoria, Faculty of Human and Social Development Masters in Nursing Program, working on her thesis. She is an employee of the CRD as an Assistant Manager of the Home Nursing Care Program. It is anticipated participation will take up to two hours.

I understand that:

a. I am free to refuse a visit at any time, to refuse to answer any question asked of me, and to discontinue an interview, without explanation.

b. The researcher's thesis will not include my family names or any information that will identify my family.

c. The interviews will be audiotaped. The tape, transcripts and all identifying data will be destroyed immediately after the researcher's thesis is accepted by the University of Victoria. This is anticipated within the year. All documentation will be kept in a locked filing cabinet in an locked office. Only the researcher will have access to the documentation. If I decide to withdraw at any time, during the interview all data collected will be destroyed at that time.

d. Involvement will include a maximum of one to two visits during the months of February and March, 1997.

e. Information I give during the interviews and collected from CRD patient health chart kept by the Home Care nurses may be used in the researcher's thesis to be submitted to the University of Victoria and to be submitted to the CRD Medical Health Officer.

f. Whether I participate or choose not to participate will have no bearing on the services received by the CRD Home Care Nurses.

Please sign as indicated to show your willingness to participate in this project.

DATE:_____

NAME:_____

SIGNATURE:_____

I, _____ understand that you will be interviewing _____with respect to the project outlined above and on the conditions noted above. I consent to your obtaining information about my care and to your using the information in your thesis.

RESEARCHER: VICKI JACQUES TELEPHONE NUMBER- 721-0217

UNIVERSITY OF VICTORIA FACULTY SUPERVISOR:
DR. MARY ELLEN PURKIS TELEPHONE NUMBER- 721-6284

Thank you for agreeing to participate in this project. I appreciate your taking time to talk with me. If you have questions or concerns please raise them with me at any time.

APPENDIX D

The Normal Day in the Life of a Caregiver

6:30 Rise, close window and shutters so wife can continue sleeping.
Put up heat for her comfort.
Shower, shave, make and have breakfast.
Put out her water, pills ready for her to rise.

7:15 Put up oxygen, assist her to washroom.
Discuss with her how she feels. Find out if she wishes to get dressed or have breakfast in her house coat.
Depending on decision to get her housecoat or determine what clothes she wishes to wear and take them to washroom.
Put on her Nitro patch and help her dress as needed. Put out anti-persperant and powder.
Open curtains in family room, put on her light and get paper for her to read after her breakfast.

7:30 Return to washroom, get her a warm face cloth and towel and put away anti-perspirant and powder.

7:35 Get her breakfast then her socks and put them on.
Put down oxygen.
Make bed, empty commode.
Gather and do breakfast dishes.

8:00 Set out - her tooth brush with paste, her tooth pick and her salt solution to rinse her mouth.

8:05 Put up oxygen. Clean her false teeth.

8:10 Wash days (Mon. Wed. Thur. Fri.) gather dirty clothes, towels and put on wash.

8:15 Put down oxygen.

8:30 Put wash into extra rinse.

8:45 Put wash in dryer and hang up those items not to be machine dried.

10:30 Take clothes out of dryer and fold for ironing.

10:40 Put up oxygen.

10:55 Put down oxygen.

11:00 Get water, fix shades, get calcium. Read part of paper and visit with wife.

11:45 Take out garbage, sweep garage and driveway, polish shoes.

11:55 Prepare lunch.

12:00 Have lunch and listen to news.

12:30 Put up oxygen, prepare sofa for her rest (get pillow and blanket), close window blinds. Do dishes.

12:40 Put down oxygen.

2:00 Put up oxygen. Get coffee and biscuit.

2:10 Put down oxygen.

2:15 Finish reading paper.
Play game and visit with wife.

3:00 Spare time. Leave her to watch T.V.

3:30 Put up oxygen.

3:40 Put down oxygen.
Get water and calcium.

4:00 Start to get ready for dinner.

5:15 Put up oxygen.

5:20 Put down oxygen.
Dish dinner.
Listen to news and T.V.

7:30 Prepare tooth brush, pick and salt solution for her to do teeth.
Prepare bathroom for her shower. Put up oxygen.
Get house coat and night gown.
Assist her with her shower including washing hair and help her to get dressed for bed.
Start doing dinner dishes. Put down oxygen.
Clean up bathroom and clean and put away tooth brush etc.
Put away her clothes. Continue with dinner dishes.
Put down oxygen. Return to dinner dishes.

Turn down bed and get special pillows for her to sit and listen to tapes in bed.

8:00 Go to computer. Email.

8:30 Spare time.

9:00 Turn up oxygen.
Help her to bed.

9:10 Spare time.

10:00 Spare time.

11:00 Retire for the night.

Extra Duties to be Completed Since wife's Sickness.

*Send in medical bills
*Pick up prescriptions
*Go to cleaners
*Return clothes purchased and found unacceptable
*Prepare 60 Christmas cards, including 30 letters
*Purchase Christmas presents and wrapping for family and special friends
* Complete preparations for visitors and clean up afterwards (6 times a year)
*Iron clothes (3 hours per week)
*Change bed and night attire in middle of night following sickness.

Duties Which Continue to be Completed

*Put in golf times for 20 players
*Phone golfers and inform them of their times
*Wash car
*Polish car
*Cut grass
*Take garden refuse to dump
*Manage Seniors golf at golf course (50 golfers)
*Phone 15 senior golfers once or twice a month
*Go to Lodge one night a month
*Play 9 holes of golf Friday mornings
*Play 18 holes of golf on Saturdays when coverage can be arranged
*Paint house inside and out as needed
*Tend garden
*Water flowers

Changes in lifestyle Since Wife's Sickness

*Work normal 8 hour day

*golf 4 times a week: Tue. and through. evenings, Saturday with men friends, Sunday and holidays with wife.

*Act as Secretary for Masonic Lodge

*Attend 3 evening meetings a month with Lodge

*Act on committees with golf course

Prepared by Mr. Nat March 13, 1997.

VITA

Surname: Jacques Given Names: Vicki Joanne

Place of Birth: Duncan, British Columbia, Canada

Educational Institutions Attended:

University of Victoria	1993 to 1997
University of Victoria	1981 to 1985
Royal Jubilee Hospital School of Nursing	1965 to 1968

Degrees Awarded:

B.S.N.	University of Victoria	1985
Nursing Diploma	Royal Jubilee Hospital School of Nursing	1968

Honours and Awards:

University of Victoria President's Scholarship	1985

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Title of Thesis: The Silent Struggle of Family Caregivers of In-Home Palliative Patients

Author [redacted]

Vicki Joanne Jacques
September 4, 1997