Manageable Problems/Unmanageable Death: The Social Organization of Palliative Care

by

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We accept this thesis as conforming to the required standard

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ABSTRACT

This thesis is an exploration of the social construction and organization of community palliative care. The author's personal experience as the wife of a dying person is used to explicate the social relations of palliative care, through the feminist and constructivist methodology of institutional ethnography. The data analyzed includes a personal journal, working texts of the palliative care team (e.g. recording and reporting forms) obtained through Freedom of Information, and the *Palliative Care at Home* manual.

The author argues that the work of palliative care is text mediated, and carries into the helping relationship ideas from the discourse, for instance about the necessity for a multidisciplinary professional team. These work practices construct the dying person as a set of manageable problems, in a way that objectifies the patient and family members.

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I dedicate this thesis to my sons Josh and Gabe, and the spirit and memory of their father Jim.

Introduction

In late 1994, while I was in the middle of graduate course work, my husband became suddenly and fatally ill. I temporarily withdrew from the graduate program and cared for him at home until he died. During the four months of his illness, at the same time as I was preoccupied by practical details and struggling to understand what was happening, I also discovered myself as a relentless observer. I mentally noted, filed and speculated upon my own and others' reactions and behaviour. My encounters with the community health care system were particularly intriguing and sometimes troubling.

I was especially puzzled by the way in which we were frequently encouraged to utilize more services than we were requesting; this seemed odd for a health care system generally supposed to be on a shoestring budget. My initial speculation was that we were not being accurately perceived by the workers who interacted with us; that the people we knew ourselves to be were somehow overshadowed in their view.

In this study, I set out to explore what was happening along the line of fault between my lived experience as the wife of a dying person and my experiences as a recipient of palliative care. I wanted to understand more fully what it was that resulted in my shrugging off most professional help like an ill-fitting jacket. What I discovered was the transformation of the person into an object of professional work, through complex interactions of discourse, documents and organizational practices. Each shapes and is shaped by the other, to construct the palliative care patient as a multi-problem situation

requiring the services of a multidisciplinary team. I argue that the interests being served in this process are primarily those of the organizations involved.

This study is presented in seven chapters. In Chapter One, "You should go away for the weekend", I describe in detail how the problematic of the inquiry arose out of a specific experience, as well as introducing the reader to my own view of our family.

Chapter Two examines the discourse on palliative care through a review of recent literature, both professional and popular, related to care of the dying. This reveals both the persistence of death denial in our culture, and the problem-solving orientation inherent in medical and psychosocial models of health care. The imposition of these models on care of the dying, I argue, results in the basic contradiction of palliative care: the idea that dying is at the same time a natural process and one which requires multidisciplinary professional services.

In Chapter Three I discuss institutional ethnography, the methodology used in the study. This feminist methodology, which fits within the constructivist paradigm, enabled me not only to study my own experience as data, but to understand it by making connections with the social relations which organize community health care. I then describe the study itself and how I undertook to analyze the data.

In Chapter Four, "Receiving the Holy Binder", I explore the way in which the dying person and family are initiated into the category of palliative care patient. I analyze the consent forms used to register with Hospice, as well as work practices of the home care nurse, which serve to acknowledge that the patient is dying, and accept workers into the home. I also analyze the Palliative Care at Home

Manual as a "Holy Binder" or authoritative instruction manual for the patient and family, and I discover a consistent emphasis on the necessity and importance of accepting help, as defined within this discourse-oriented domain, from the palliative care team.

Chapter Five, "Wife Rena Teary", focuses on one document used by home care nurses to track their contacts with our family. I contrast my memory of a particular visit with its representation in the document, and identify the line of fault as the problem orientation of the document. I discuss the way that the discourse conceptualizes palliative care as the reconstruction of an unresolvable problem as a set of manageable problems, and the way that the work of the team must be understood and recorded as problem-solving in order to count as work. I argue that this process results in the objectification of persons which I experienced.

In Chapter Six, "For Fifteen Minutes a Day", I examine the transformation of the home into a workplace. I analyze the assessment carried out by the Long Term Care case manager, both documentary and in terms of work practices, to show the potential conflicts involved in this transformation. I discuss the ways in which, at these points of conflict, organizational needs dominate those of the individual.

Chapter Seven, "What I Learned", summarizes the conclusions which I reached in the study. In addition, I reflect on the ways in which my experience has changed my practice as a social work educator and as a family counsellor.

Chapter One

"You should go away for the weekend."

On March 14, 1995, a social worker was sitting where I am sitting now, in a green pleasant room with a sunny south window: my home office. Today I'm staring out the window, half watching, half listening to a soccer game in the Vic High school yard. On March 14, 1995, the social worker sat with her back to the window, talking to me as she filled out forms. She was employed by the Capital Regional District as a Long Term Care case manager, and she was conducting an assessment to determine how many home support worker hours would be allocated to us, and how much we could pay for this service. She was at our house because my husband, Jim, was dying of cancer.

"You know," she said softly, "you should think about going away for the weekend."

I looked at her with some confusion. We were meeting upstairs in my home office because the living room had become Jim's bedsitting room; he could no longer climb the stairs. "Jim can't travel," I replied.

"No, you should think about getting away on your own," she persisted. "Caretaking is such hard work, and the pain and heartache can become too much to bear at times. You could go away and refresh yourself, and we could have a home support worker cover every single hour of the weekend."

My confusion turned to alarm. Jim's cancer had been diagnosed at last as a metastatic round cell liposarcoma, developed as a result of exposure to Agent Orange in Vietnam in the late sixties. After quietly incubating for over twenty-five years, the tumour had, doctors explained to us, "reached critical mass," and was now spreading "like wildfire". It had also been described to us as "extremely malignant," "vicious," and "widely metastasized". Jim had first seen his family physician on December 7, 1994, and had been hospitalized immediately. His deterioration was cruelly swift; by March he was not only restricted to downstairs, but not moving around very much at all. I couldn't have known when the social worker told me to go away for the weekend that Jim's death was only three weeks away. But I knew that everything was happening really quickly and thought that anybody reading the case file or looking at Jim would be able to see that too. We had been best friends, lovers, spouses for twenty-five years, and now we were losing each other. The idea that I would want to go away by myself for the weekend was bizarre. The notion that if I did go away, Jim would be better cared for by a home support worker, or a number of workers providing twenty-four hour coverage, than by our sons, our friends and our neighbours, was just as absurd.

But before the social worker would drop the topic, I had to say I would think about the idea, I would bear it in mind. She "gave" us over one hundred hours of service a month, although I had said that all I could possibly imagine needing was a male worker who could help with Jim's personal hygiene when I couldn't lift him. The social worker suggested that the home support worker could do housework,

shopping, meal preparation and provide companionship, as well as personal care. Again, I shook my head. The housework in our cooperative townhouse could easily be handled by my sons and myself; I liked getting out of the house to do the grocery shopping (I always bought special treats and bouquets of flowers for Jim); our friends in the co-op and the neighbourhood were cooking for us constantly. And as for companionship, because of his waning energy I was having to reluctantly decline visits on Jim's behalf with all but our closest friends (who themselves could fill our small house). "I'll think about it," I assured the social worker, who seemed unhappy to leave this topic. "I promise I'll let you know if it turns out I need anything like that."

After she left the house, I thought, "If I were seventy-five years old and isolated, and if Jim had been sick for a long time, these would be very helpful services." It was neither the first nor the last time I had this thought, which became a familiar feature of my encounters with the community health care system. The thought was sometimes invited by guilt over my irritation with people "who were just trying to help me". It seemed, however, that they offered either much more help than I needed, or nothing. The Home Care nurse was willing and able to come to our house every day, but there was nothing for her to do there. The Hospice Palliative Response Team was available to make house calls all night, but when I initiated non-emergency contact with a Hospice counsellor it took over two weeks for my call to be returned. And I could go away for the weekend - have someone do my shopping and housework for me - make the adjustment to having our home become a workplace. But these weren't services I was requesting - the only reason anyone could suggest to

utilize them was that they were available. "If I were seventy-five years old and isolated, or if Jim had been sick for a long time, these would be very helpful services," I would tell myself to calm my irritation. Sometimes I would whisper resentfully back to myself - "But we're not!"

Who Were We?

Jim was a California kid who dropped out of school and enlisted in the army in 1968 because they told him that was the way to avoid going to Vietnam. He ended up as a clerk at a base camp called Xuan Loc, a defoliated rubber plantation. After his tour of duty he went AWOL from Oakland Army Base and came to Toronto. I had grown up there in a middle-class Jewish community, and had drifted downtown to make myself more comfortable in what was then called the counter-culture. We met at a porno book store on the Yonge Street Strip in 1970: he was giving out change for the dirty movie machines in the back room, and I was rolling Easy Rider posters in the basement.

When my kids asked me if I was a hippie, I said yes, but we called ourselves freaks. When we lived in a small town on Northern Vancouver Island, having joined a migration "back to the land," we became community members. Our two sons, Josh and Gabe, were born there in a ten bed hospital in 1974 and 1976.

We moved to Victoria in 1979. We never made it back into the middle class, economically speaking. For ten years one of us was in school - I finished a B.S.W. and a family therapy training program; Jim studied music and became a guitar teacher at the Conservatory. We raised our kids in Spring Ridge Housing Co-op, where we moved

in 1981. Our income-indexed rent helped us exist on one pay cheque and student loans. For most of the eighties our income was below the poverty line, but I seldom felt poor.

We almost split up over issues of power and control, and then decided to keep struggling. Later - years before Jim got sick - I felt intensely grateful for this decision.

We rarely talked about Vietnam.

In 1994, when Vietnam sneaked up on us, we were both self-employed. He was teaching guitar, and I was expanding my private practice with teaching, supervising, and graduate studies. I had been involved with the social service network in Victoria for fifteen years. We were old-timers in the co-op. Our older son had just moved into his first apartment, our younger son had graduated from high school. We went hiking almost every Saturday, and hung out with our pals in the neighbourhood on Friday nights, where we were known to consume illegal substances. We could never afford the time or money for all the live music we wanted to hear. We liked to dance, but lately Jim didn't seem to have the energy he used to.

He was almost forty-seven. I had just turned forty-four.

We Become Patients

Jim's sudden illness was really our only experience of being in serious trouble. I knew we were in trouble from my very first conversation with his doctor, Dave, who had been our family doctor on the North Island and delivered both our sons. Dave immediately started using words like "grim" and "grave". The news just kept getting worse over the next few weeks of testing.

I was so used to *us* being the people that others turned to. Now everyone was giving us advice. At first we were the recipients of their favourite miracle cancer cures - herbal remedies, coffee enemas and juice consumption, camphor injections, ozone therapy, psychic surgery - we heard and read about them all. We had never been true believers in the wonders of Western medicine, after all, and none of the three mainstream cancer treatments - slash, burn and poison - were very appealing. But Jim had a tumour the size of a cantaloupe on his liver and he was having a hard time eating and drinking. It became evident that cleansing himself with juice and enemas would be the end of him. We decided to focus on calorie consumption instead. This was difficult for some of our friends who favoured alternative therapies to understand, and actually created some conflict. One friend was very upset that we were using filtered tap water for drinking and meals rather than distilled water, and that Jim was eating ice cream and butter. It was impossible to convey the futility of dietary or nutritional cures without being more negative about the future than we wanted to be at that time. I had a sense of confusion in trying to reconcile the power of positive thinking with the acceptance of reality.

No cancer was found in Jim's lungs, stomach, esophagus, colon or bowel. A laparoscopy performed on December 29, however, found that his abdominal wall was "studded with white tumour throughout the peritoneal cavity". At that point Jim was given a terminal diagnosis, though neither Dave nor the surgeon used the word "terminal" or "dying". Surgery and radiation were impossible; chemotherapy could have only palliative results. Alternative therapies were either too

dependent on consumption of herbs and liquids to be useful, or too "flaky" for Jim to believe in them.

People's advice changed. They stopped suggesting miracle cures and started suggesting services. An acquaintance whose husband had died the previous year called me up and told me, "Get registered with Hospice right away. You never know when you'll need them. The PRT [Palliative Response Team] is wonderful; they'll come to your house in the middle of the night and make everyone comfortable." A close friend who worked as the coordinator of a home support agency, agreed; she also advised requesting Long Term Care as soon as possible so that the assessment would be completed before I actually needed service. A friend who had been a social worker at the Cancer Clinic talked to me about the doctors and the counsellors there and told me about the assistance available through the B. C. Cancer Society.

Because of my position in the health and social services network in Victoria, I considered myself to be very well-informed about what services were available, and capable of accessing the system through the specific individuals I preferred to deal with. I was expecting that I would need these services; everyone (except Dave) told me that I would. I was also expecting to find the services helpful - after all, I was a social worker and a counsellor, I thought that *I* helped people. Dave kept saying it wasn't necessary to contact Hospice or Long Term Care; he said we didn't need them but that we could access them swiftly if it became necessary. "The old-fashioned way is best," he said. "You and the boys can look after him."

I Become Puzzled

This proved in the end to be true. However, we did become involved with various programs of the community health care system; some by choice, and some inadvertently. Certain services were very helpful: the Cancer Society paid for all Jim's medications, and the counsellor at the Cancer Clinic focused on visualization techniques and a kind of Buddhist mindfulness that seemed to fit for Jim, as well as teaching us therapeutic touch techniques. We visited this counsellor weekly for six weeks or so, and he came to our house once. I had two appointments with a counsellor from Hospice that I experienced as vaguely helpful. We never called the PRT, mostly because our doctor was available to us around the clock.

Our encounters with Home Nursing Care and Long Term Care were somehow less benign. The first was not requested by us but "ordered" by a physician who performed a palliative procedure on Jim in January. The second began with the scene I initially described. I came away from certain encounters shaking my head in puzzlement at the gap between what they were offering us (daily services) and what I was requesting (practically nothing).

I know that I was sensitized to these experiences because of the nature of the graduate studies I had started on a part time basis the previous year. I was becoming interested in the social construction and organization of knowledge, and the textual mediation of work processes and discourse. In November I was studying the organizational context of policy and practice through analyzing the same assessment form and procedure that I experienced as a client the

following March. So many of the issues that had been discussed in class were now being experienced directly by Jim and me. Jim's observation, for example, when in hospital, that the nurses who were over forty gave more care and comfort than the younger ones who just "ticked off boxes", reminded me of our discussions about changes in nursing training and job descriptions.

I began to think, when I had unsettling or puzzling experiences, that I could eventually turn my research to these questions. I even began to keep field notes, at first just in my head and jotted briefly in my day book. After Jim died I used these notes to write a chronicle of his dying, trying to include every encounter with the health care system.

Now it's time for me to begin my search, my re-search, for some way to make sense of these puzzles; to explore some of the questions that I was left pondering.

Why, in this era of health care reform and budget cuts, were so many workers willing and able to perform services that were either unspecified or unwanted? Why did these professionals seem to be operating from the assumption that I had no personal support or resources? Why did they seem to think that their professional services were somehow superior to the loving care of our friends and neighbours? Why did I perceive some of them as obsessed with forms, signatures and manuals? Why did they not see *us* ? What did they see instead?

Chapter Two

Conceptual Framework: The Palliative Care Discourse

The conceptual framework that I needed to make sense of my experience contained several interlocking components. I wished to understand more about how palliative patients and palliative care have been socially constructed as categories of persons and professional practice. I began by reviewing literature relating to death and dying, focusing on material that had been written over the past fifteen years, seeking common themes and assumptions which inform this discourse. I thoroughly examined both professional literature used as educational texts, and popular guides for providing palliative care in the home. This material translated sociocultural attitudes and beliefs about dying into principles and practices, and provided a bridge to another area of my conceptual framework, which pertained to the organization of bureaucratic structures such as community health services, and the interaction of the individual with these structures.

Thinking about Death and Dying

The early ideas of Elisabeth Kubler-Ross, first published in 1969, continue to permeate the discourse about death and dying. She was one of the first to identify North American society as a *death-denying culture*, reflecting a widespread refusal to confront death. In addition, her research with dying persons resulted in her development of a five-stage theory of psychological adjustment to death, a theory

which has attained remarkable predominance in the popular and professional understanding of the process of loss and grieving. More recent writers on this topic pay considerable homage to Kubler-Ross for breaking *the last taboo* by researching and openly discussing death and dying. At the same time, acceptance of death as a part of life remains low in our society. "Despite the rhetoric of the last 25 years, the denial of death continues to dominate the allocation of resources for palliative care," claims a Canadian researcher (Scott, 1994, p. 35), while an American psychologist refers to her society as going to "practically any extreme to avoid accepting death for what it is - a cessation of life, a natural part of the life cycle," (Rando, 1984, p. 7). The "core paradox" according to a Globe and Mail article of May 18, 1996, "amid physiological decay at 50, political debates on euthanasia, the resurgence of palliative care and the bloody explicitness of popular culture is that this is *still* a death-denying society," (Alaton, 1996, p. D2). This author also points out that even Dr. Kubler-Ross, "psychiatry's great shaman of death and dying," (p. D1), has titled her most recent book <u>On Life After Death</u> and is declaring that death does not really exist.

The discussion of our difficulty in dealing with death frequently mentions the exclusion of the aged and dying in hospitals and nursing homes. This is both symptomatic of our discomfort and constitutive of it : "A process of life that for thousands of years was handled by people who mattered to each other is now delegated to professionals - strangers. Thus, the process itself has become estranged. Distant. Unknown. And because it is unknown, it is feared

in ways that previous generations would not have imagined," (Ventura, 1996, p.27).

Although it is generally accepted that given the opportunity, most people would prefer to die at home, approximately 70% of people in Canada and the U.K. die in hospital (Dossetor, 1994, Copperman, 1983). This is not only due to a societal wish to distance and exclude the dying, but also to persistent medical efforts to prolong life by means of high-technology resources (Scott, 1994, Rando, 1984). Physicians are trained to think of all death as defeat, reflecting our culture's unwillingness to see death as an inevitable experience for which we should all make preparation (Dossetor, 1994, Morris and Christie, 1995).

Dossetor's discussion of the ethics of palliative care describes the medicalization of death:

> Up to a century ago, death, even when it was painful, was perceived as a process controlled by the dying person. Its eventuality was often seen as a relief. Dying was often seen as a form of solemn celebration in which all those with a relationship to the patient participated. Through participation young and old could show their respect and express their love and affection and celebrate the meaning of a dying person's life. Dying took place in bedrooms at home, not in side wards in institutions behind white screens. How this has changed! (Dossetor, 1994, p. 40)

Our inability to confront and accept death as a natural part of the life cycle is, I believe, key to this transfer of control from the dying person and family to the professional community. When medical efforts to defeat death are unsuccessful, another group of professionals

take over, whose efforts may end not in the acceptance of death but in its trivialization.

Thinking about Palliative Care

Despite the persistence of this cultural aversion towards death and dying, the past thirty years has also seen the rise of the hospice movement, and the development of palliative care as an area of professional practice in medicine, nursing, social work and psychology. Hospice is generally understood as a *holistic, patient-centred* program of care, providing not only a physical facility for dying patients, but also psychological and spiritual support for patient and family. Dame Cicely Saunders of St. Christopher's Hospice in London is generally credited with introducing the concept of hospice care to North America (Neigh, 1995, O'Connor, 1989) in the 1960's. Initially a grassroots volunteer service in local communities, government funding has led to steadily increasing professionalization. A pilot project undertaken by the Health Care Financing Administration of the American government in 1979 was aimed at assessing the cost effectiveness of hospice care and defining what a hospice is and should be. A study of twenty-six hospice demonstration sites proved that hospices not only cared for the terminally ill within the given budgets but did so with much less money than anticipated (Neigh, 1995).

The definition of hospice created through this demonstration study expresses the elements found most frequently: "comprehensive, patient-oriented care with the focus on what the patient require[s] to remain comfortable and at home. The plan of care [i]s to be created by an interdisciplinary team," (Neigh, 1995, p. 13). Victoria Hospice

similarly defines itself as a program of care rather than a place, and continues:

> The care offered is called 'palliative care', which means it is oriented toward comfort rather than active treatment of your disease. Our goal is that each family member will be supported through this time of illness, death and bereavement according to their needs and wishes...Our team includes nurses, doctors, counsellors, volunteers, spiritual care and administrative staff. (Victoria Hospice Society, 1993, p. 5)

The elements I consider significant in this definition are: acknowledgement of terminal diagnosis (implicit but softened in the wording "oriented toward comfort rather than active treatment"), focus on symptom management, and the need for an interdisciplinary team approach. Each of these elements, which organize the discourse around palliative care, will be discussed in more depth below.

There is clearly an ethical basis in the intention of palliative care programs to assist terminally ill persons to die comfortably at home. However, there is also an economic motivation for the acceptance of palliative care at home by mainstream health care structures. The global population of terminally ill people is rapidly increasing, because of the general aging of the world's population, the effectiveness of cancer diagnosis technology, and the increase in tobacco and environment related cancers, as well as widespread HIV infection. The size of the population requiring palliative care in North America is estimated as increasing by at least 50% in this decade, at the same time as western health care systems are being downsized by as much as 20% (Scott, 1994). Palliative care at home reduces institutional costs, "albeit with a shift of expenses to the family," (Dossetor, 1994, p. 39), and has been demonstrated as being cost

effective. Thus the financial concerns which are the driving imperative behind health care "reform" in Canada are satisfied through the support of home care for palliative patients.

But does this really mean returning control of the process to the dying person and the family? Does the way in which palliative care is currently organized represent deprofessionalization, the reintegration of dying into the community? Or is it more accurately seen as merely transferring control of this process from hospital-based professionals to community-based professionals? Certainly in my own experience, we had to contend with assumptions that our case (i.e. our lives) would be managed by someone else. A closer look at some of the key principles organizing the palliative care discourse assisted me in unpacking its social construction.

The Palliative Patient as a Problem

Much of the literature regarding palliative care focuses on the problems of the dying patient and family. Each of the key elements identified previously - acknowledgement of terminal diagnosis, alleviation of distressing symptoms, and need for a multidisciplinary team approach - are related to this view of terminally ill people as struggling with the problem of dying, the problem for which there is no solution (Rando, 1984). A social work text on palliative care also conceptualizes dying as a problem which cannot be modified or changed; the task of the social worker becomes to "break down the apparently insurmountable series of problems into manageable parts," (Smith, 1982, p. 95).

The focus on problems extends to the family of the palliative patient as well. A 1994 survey of the membership of the National Family Caregivers Association in the U.S. asked "about the emotions of caregiving, what caused them stress, what they did to relieve it, how they viewed the future, and what they saw as the burdens of caregiving," (Mintz, 1995, p. 8). It is not surprising, given the assumptions revealed by these questions as well as the restriction of the survey to those who are members of support groups, that the profile that emerged was of a frustrated, sad, overworked, depressed, largely female population. In a more academic study, a British researcher examining the quality of life for terminal cancer patients at home and their relatives, after measuring both patients' and relatives' levels of concentration, fatigue, anxiety and depression, admits in his conclusion: "Courage has not been recorded, but that was my failure not theirs," (Hinton, 1994, p. 196).

The Problem of Acknowledging Death: Stage or Task?

Kubler-Ross' five stages in the psychological adjustment to death, as summarized in the text Social Work with the Dying and Bereaved (Smith, 1982), reflect the conceptualization of the dying patient as a problem. Before reaching acceptance, it is considered likely that persons will experience denial, anger, bargaining (a variant of denial in which the individual attempts to stave off reality), and depression. Anticipating this difficult passage, some texts (Benton, 1978, Smith, 1982) give considerable space to a discussion of how and whether to inform dying persons of their terminal diagnosis. It is

difficult to tell in reading these works whether the denial of death is more operative in the patients or in the professionals involved.

When admission into a palliative care program requires an acknowledgement that the patient is dying, health care workers need to ascertain levels of understanding reached by the patient and family. My assumption is that discomfort around open discussion of death leads to excessive reliance on forms and signatures in order to confirm that patients know they are dying. This helped me to understand incidents involving forms that occurred during Jim's illness, and which will be analyzed in subsequent chapters.

While the stage theory has fallen out of fashion in the field of palliative care because of its inherent suggestion of an orderly progression from stage to stage, others who work and write in this area find other but remarkably similar ways to conceptualize the same problems. Rando describes the dying patient as needing to accomplish seven sets of tasks (Rando, 1984, p. 203), mostly dealing with either practical preparations for the future or coping with losses of many different kinds. In her framework, denial is a coping mechanism which should be respected rather than broken down, and persons are seen as vacillating between denial and acceptance throughout the dying process. The emphasis in the discussion, however, remains on emotional reactions which are considered undesirable in our culture: anxiety, fears of various kinds, depression, anger and hostility, guilt and shame (Rando, 1984, p. 232-244). Coping mechanisms listed, besides denial, include regression, repression, suppression, rationalization, depersonalization, projection and introjection, intellectualization, obsessive-compulsive mechanisms, counterphobic

mechanisms, and sublimation (Rando, 1984, p. 253-266). This type of naming successfully pathologizes the dying patient and constructs the person as the needy object of psychotherapeutic interventions. For example, the altered time sense in which the dying person takes the future on a day-to-day basis is described as regression by the patient to a childlike state, though it might just as easily be understood as an enviable mindfulness of each moment achieved through meditation. The passage on suppression of anxiety through diversionary activity uses the examples of "excessive" talking or sleeping, or "shutting out the world through solitary word games" (Rando, 1984, p. 258). The idea that activities such as listening to and playing music, reading, writing - or word games - could be satisfying and fulfilling is totally absent from this description.

Acknowledgement of the terminal diagnosis is the entry point of a person into the category of palliative patient. Because of the way in which this category is conceptualized and constructed, this entry also involves the acceptance of a problem-saturated identity, largely featuring anxiety and depression. Palliative care, however, as will be shown below, has an impressive repertoire of solutions for the problems which have been constructed as its framework.

The Problems of Symptom Management

The most consistent principle across the literature on palliative care is that the symptoms of terminal disease can be controlled. Pain management is discussed in depth in almost every resource I examined. Nursing texts emphasize use of analgesics, especially current trends in morphine medications (Copperman, 1983, Robbins, 1989), while those

which focus more on psychosocial care give greater attention to alternative pain therapies such as hypnosis, relaxation and visualization techniques, and biofeedback (Rando, 1984, Smith, 1982).

The nursing literature and the popular literature on palliative care at home (Carroll, 1981, Duda, 1982, VHS 1993) also discuss the alleviation of other common physical symptoms: swallowing difficulties, nausea and vomiting, poor appetite, constipation, skin breakdown, and respiratory problems are most frequently mentioned. The presentation is one of a set of problems to be solved; again, certain aspects of our cultural attitudes towards death and dying are revealed. If caregiving professionals can do nothing about the central problem of death, they can create a more manageable set of problems which call for clinical intervention of one sort or another. Rando agrees that, "the major problem for many caregivers is that they are trained 'to do', to find the correct technique, to perform the proper action," (Rando, 1984, p. 272). The commitment to symptom management provides a lengthy list of things to do, especially if we include management of the psychological symptoms referred to in the previous section. In this context, even the maintenance of control by the patient and family over their lives and environment becomes a clinical intervention performed by the professional (Rando, 1984).

The persistence of pain and other physical symptoms, despite the effectiveness of new medications and treatment procedures, is somewhat glossed over. However, recent studies in Britain show that many cancer patients do not receive optimal pain control in the last weeks of life (Addington-Hall & McCarthy, 1995), and that improvement of symptom control is the most frequent reason for the

hospital admission of terminal patients from home care (Hinton, 1994). While these studies conclude that management of pain and other symptoms must be improved, the emphasis is on analgesic and other medications. Only in the self-help literature (Duda, 1982) and in a personal sociological narrative (Ellis, 1995) did I find a mention, for example, of the use of marijuana to control symptoms such as nausea, poor appetite and respiratory difficulties, and to potentiate morphine so that less is needed.

The experience of dying persons and those who care for them makes common sense of research findings regarding the critical importance of pain control. It also makes nonsense of the promise that all pain and other distressing symptoms can be alleviated. Perhaps it is more important for those who work in palliative care to believe in this promise than it is for patients and families.

It is also worthwhile noting that, except for prescribing analgesic drugs, and possibly instructing the family to administer non-oral medications, a comparison of the professional and popular literature yielded no great differences in terms of symptom management. If anything, the professional literature (e.g. O'Connor, 1976, Rando, 1984, Robbins, 1989) offered fewer options for treatment of symptoms, being more constrained by the medical model, while the popular or self-help literature (e.g. Duda, 1982, Carroll, 1991) ranged more freely through folk remedies, herbs and other alternative treatments. The medicalization of palliative care proceeds, therefore, not only because of the constructed psychopathology of patients, but also because of the creation of a body of so-called expert knowledge regarding the alleviation of physical and psychological

symptoms. General acceptance that this *is* expert knowledge (rather than locally available, intuition-based knowledge) may be based in part on attitudes towards those who work in this field. They are often "viewed as angels of mercy and considered above reproach because of their devotion to the needs of their patients," (Neigh, 1995, p. 13). Our cultural reluctance to confront death makes heroes of those who choose this work.

Michael Ventura, in his article on death, claims that, broken down to essentials, there are three officially sanctioned methods of solving problems and healing:

> 1. You talk to people (and hold their hands).
> 2. You give them drugs.
> 3. You give them drugs and talk.
>
> In the face of death, all three are pretty lame, in and of themselves. (Ventura, 1996, p. 27)

Are these "lame" activities properly the province of a multidisciplinary team, possessed of expert knowledge?

Multiple Problems and the Multidisciplinary Team

When I considered the social construction of the palliative patient, I began to understand the perceived requirement for palliative care to be carried out by a multidisciplinary team. The *dying person* has, perhaps, the huge and unresolvable problem of dying. The *palliative patient* has a multitude of manageable problems, including physical problems, psychological problems, legal problems, social problems, spiritual problems, economic problems and interpersonal problems. As Burucoa (1991) points out, one professional alone

cannot meet all these needs or solve these myriad problems. The principle which emerges from this assumption is that, "care requires collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussions with a common purpose," (Rando, 1984, p. 293).

The requirement for a multidisciplinary team is consistent throughout the professional literature I examined. One article described routine palliative care as including "at a minimum, the core services of medical direction, nursing, social services, and spiritual care," (Hirsch, 1995, p. 21). According to Rando, "the team usually involves the patient and family, physicians, nurses, psychologists, social workers, clergy, pharmacists, volunteers, and representatives of other professions involved in the care of the dying patient, such as dieticians and physical or occupational therapists" (Rando, 1984. p. 314). Mentioned elsewhere are home health aides and respite care workers (Morris & Christie, 1995); in B. C. both of these functions are carried out by home support workers. As I reflected on my own experience, I realized that in the short four months of Jim's illness, we had utilized the services of many different physicians, nurses, social workers, and pharmacists, as well as brief encounters with the B. C. Cancer Society, a dietician, a physiotherapist, and a home support worker. But when I tried to envision all these individuals as a team, I could not understand the need. What was wrong with the way we used these services, at our own discretion and initiative? Why would they need to form a team and be organized? Would that not indicate their lack of confidence in our ability to organize and manage our own lives? Certainly that was the impression I received whenever there was some attempt on the part

of community health workers to function as a team; I interpreted their actions as "talking behind our backs" in their efforts to influence us to need them more. However, the literature reveals an unquestioning acceptance of the idea that the patient and family's needs can best be met by a multidisciplinary team (Hirsch, 1995).

My experience leads me to believe that the existence of the multidisciplinary team results in the creation of much of its own work. If a team exists, its activities must be coordinated. This task is usually assigned to the palliative care nurse or community health nurse (Morris & Christie, 1995, Caie-Lawrence, Peploski & Russell, 1995). Team members must communicate with one another; in fact, "this is one of the primary reasons to convene an interdisciplinary team," (Rando, 1984, p. 314). The team must engage in team building practices and provide both formal and informal group support for professional caregivers (Morris & Christie, 1995).

The multidisciplinary team of caregivers becomes a third focal point in the social construction of palliative care, along with the patient and family. The emotional needs of the team and the provision of emotional support in the workplace are considered an integral part of the program of care (Rando, 1984, Weatherill, 1995). Moreover, the development and maintenance of relationships with the team becomes a vital task for the dying person and family. In outlining the tasks of the family, Rando lists "establishing relationships with caregivers" as second only in importance to "denial versus acceptance of the illness" (Rando, 1984, p. 333). This involves family members learning "how to be assertive," and "how to express constructive anger and discontent with health caregivers, in ways that will not jeopardize either their

future relationship with the caregivers or the care of the patient," (Rando, 1984, p. 334). Rando seems to have a somewhat pessimistic outlook regarding the interaction of family and the health caregivers! Perhaps this is related to her expectation of complexity, as well as to her concluding comments about the team concept:

> If members are chosen carefully and communication is open, an interdisciplinary team can provide invaluable assistance to the patient and render peer support and opportunities for debriefing and ventilation of emotions to caregivers. However, in practice most teams are not carefully chosen to reflect the patient's needs. They are usually thrown together by chance, if they are put together at all. Communication among members may be minimal at best. (Rando, 1984, p. 314)

Another area of work which is created by and for the team is the preparation of advanced directives, such as power of attorney documents, living wills and Do Not Resuscitate Orders, which describe the circumstances under which CPR and other life-prolonging measures will not be initiated by medical staff (Hirsch, 1995, Morris & Christie, 1995). The DNR is needed, it was explained to me, because of the large number of caregivers on the team who might otherwise summon paramedics in a crisis. It also represents a tangible acceptance of terminal illness, in addition to the signed consent for palliative services. Completion and review of the forms thus becomes an important activity which would not be necessary if the team were not involved. As our physician said, "You don't need the form if you don't need the nurse - and you don't need the nurse."

When reviewing the professional literature on palliative care, it seems almost incomprehensible that a dying person and family would

not need the nurse. The nurse's position as coordinator of the multidisciplinary team gives her services some presumption of necessity and inevitability. However, in a review of nursing intervention studies with bereaved families, a core set of needs was identified which centred on information and the assurance of patient comfort (Weatherill, 1995). Families who are able to access information independently and who are managing to control pain and other symptoms by whatever methods may *not* need the nurse. The self-help manual A Guide to Dying at Home, unlike most of the professional literature, refers to this possibility: "The hospice nurse visited three times, not because we needed her, but because it was required by the program...It made me laugh with love to see the family worrying about not hurting the nurse's and social worker's feelings because we needed so little outside help," (Duda, 1982, p. 49).

While the need for emotional support of family members is key to palliative care, research indicates that, "Interventions cited as least helpful across studies focused on the specific emotional needs of the family such as 'encourage me to cry' or 'let me express my emotions.' Knowing that families received greater comfort from direct support of the patient than from their own emotional support may help professionals in prioritizing interventions," (Weatherill, 1995, p. 51). It might also cause professionals to reflect on whom they are really serving when they offer psychosocial interventions to family members. In a British study on which dying patients are admitted to hospital from home care, it was noted that, "with relatives, the association of greater emotional control with keeping patients at home was statistically stronger and apparent from the first interview...The evidence begins to

point to relatives' demeanour apparently influencing the course of care, their stoicism favouring patients remaining at home," (Hinton, 1994, p. 208). If this area of intervention is perceived as least helpful by family members, and may actually work against the control required to keep the dying person at home, why engage in it? Perhaps the provision of emotional support to family members becomes yet another *thing to do* when there is nothing to be done. Moreover, the therapeutic value of expressing feelings seems to be an unquestioned assumption in this field; Rando mentions encouraging expression of feelings over and over in her chapter on the family of the dying patient (1984, p. 327-365).

The Contradiction of Palliative Care

As I explored the way in which palliative care has been constructed in our society, I was struck by a contradiction that seemed to be present throughout the professional literature. On the one hand, there are the declarations that death is a natural process, a part of the life cycle, an experience which we will all inevitably share. It is suggested by many authors that our ancestors handled death more wisely than we do, through families caring for dying persons at home. On the other hand, death is conceptualized as an unresolvable problem, and dying as a set of multiple problems requiring the interventions of a team of professionals. Can palliative care really have it both ways? Philosophically, we may choose to regard death as the great problem of human existence (though we might easily prefer metaphors of mystery or completion). But in terms of thinking about dying persons and their families, how is it possible to simultaneously hold the belief that dying

is a natural part of the life cycle, and that dying requires the services of a multidisciplinary team of professionals? Do natural processes require professional intervention? Or even "appropriate therapy"? It seems contradictory that "appropriate therapy", the U. S. National Hospice Organization's No. 1 Standard, is listed in its mission statement right alongside its No. 1 Principle: "Dying is a normal process," (Rando, 1984, p. 297).

I began to suspect that the puzzle of my experience was located somewhere in or around this contradiction. The social workers and nurses whose behaviour confused or offended me were both skilled and compassionate; it was something about the translation of the contradiction into work practices that ended by troubling me.

Research Questions

What happens when community health care workers intervene in the lives of a dying person and family members? What is the experience of being a recipient of palliative care? Whose interests are being served in this process?

Chapter Three

Conceptual Framework: Methodology

The Constructivist Paradigm

The nature of my conceptual framework points towards, and flows into, the methodology used in this inquiry. Grounding the inquiry in my own experience, and using this experience as data, mean that both - conceptual framework and methodology - are situated within the constructivist paradigm. The conceptual framework grows out of this world view, and both point out a methodological direction. The constructivist paradigm or world view (which can also be named non-positivist) conceives of knowledge, not as a singular reality, but as the outcome of human activity, shaped by history and culture, and therefore necessarily partial. Truth is not universal and context-free, but rather "the best informed and most sophisticated statement of understanding for which there is a reasonably high degree of consensus," (Epston, 1992, p. 1). It follows that methodologies in this paradigm cannot be concerned, as are positivist methodologies, with prediction through proof and certainty.

In the research approach known as social organization of knowledge, which informs this study, the subjective experience in which the inquiry begins is understood to be linked through social action with phenomena in the world outside the individual's subjectivity. Even though experience is central to knowledge, "there is more to knowing than studying experience," (Campbell, personal

communication, November 1996). Unlike some interpretive methodologies, the intent is *not* to understand experience in a way that elevates subjectivity or illuminates individual motivations, but rather to understand how everyday experience is inextricably bound to regimes of ruling (Smith, G., 1995).

Institutional Ethnography

The methodology developed by Canadian sociologist Dorothy Smith, institutional ethnography, fits into the constructivist paradigm and the social organization of knowledge approach. In a recent paper, Campbell asserts that, "experience is the ground zero of [institutional ethnography]. The analysis begins in experience and returns to it, having explicated how it happened in the way that it did," (1996, p. 2). She discusses the grounding assumptions of the methodology as it was used in her research with a health care organization, summarized below:

1. that organizational knowledge in contemporary society is textually mediated;
2. that the process of textually-mediated knowledge production can subordinate or erase experiential knowing;
3. that such documentary and work practices are central to the exercise of power and control in advanced capitalist societies.

The commitment of this type of research is to examine the way in which specific events or aspects of knowledge have been socially organized so that people experience them as they do: "how ruling

affects people whose everyday/everynight lives come under the influence of specific ruling practice," (Campbell, 1996, p. 5). By explicating the social relations that organize experience, institutional ethnography seeks to make sense of that experience and to explore the broader implications of such an analysis. While the particular experience will be specific and localized, the social relations which organize it are general; to that extent knowledge about local experience is generalizable.

"Objective knowledge is no longer 'the truth', but a form of knowing used to rule society that contingently, but inextricably, incorporates the standpoint of men," (Smith, G., 1995, p. 23). The exclusion of women from a full share in the making of culture has resulted in the standpoint of men being represented as universal and general. Smith's feminist sociology seeks to take up the standpoint of women, to authenticate women's voices and stories by an inquiry which begins in their direct experience (Smith, D., 1984).

I paid attention to my reluctance to indict nurses and social workers for being the unconscious replicators of dominant ideology, as well as my reluctance to understand dying persons and their caregivers as multidisciplinary problems. I realized that my membership in both groups was important to the conceptualization and analysis of my experience. I am a social worker; I was a family caregiver; both groups are made up mostly of women. As a feminist social worker, I am committed to acknowledging the experience of women and opening space for our voices to be heard. Trying to understand palliative care from the standpoint of women involved exploring the experiences of nurses and social workers as well as the experiences of women caring

for family members in the home. I had no desire to see these two groups of women as adversaries, or to make villains of the women whose work it was to help me.

As George Smith points out, "This is not a shift from an objective to a subjective epistemology...but rather a move from an objective to a reflexive one, where the [researcher]...inhabits an actual world, the social organization of which she is involved in investigating...In terms of my research, the epistemological shift operated in two ways: first, it meant treating informants' knowledge as socially organized and therefore as constituted reflexively. Second, it meant beginning reflexively from my own, actual location in the world rather than from an objective standpoint." (1995, p. 22).

Unlike traditional social science research, which abstracts, categorizes and generalizes from the experiences of others, Smith's ethnographic methodology requires that the researcher discard the illusion of scientific detachment, grounding the inquiry in her own experience and remaining cognizant of her participation in what is being studied. She proposes a reflexive sociology that "will look back and talk back," (Campbell and Manicom, 1995, p. 5), rather than one in which we, as women, become objects to ourselves as subjects.

> Those of us who have had the experience of being members of a category that is the object of sociological inquiry can recognize the strangeness of finding ourselves as subjects transformed...into objects and of the unspoken sociological stipulation instructing us to disregard what we know of ourselves as embodied subjects. (Smith, 1987, p. 121)

Having already felt objectified by the palliative care discourse, I refuse to think about either the helping professionals or palliative patients as

the objects of my inquiry; to do so would be to further objectify *myself.* Smith's feminist sociology helped me to validate the grounding of my research in my own experience, and to rely on my embodied knowledge as trustworthy data.

Smith's methodology also offered the opportunity to answer questions in which I was interested - questions about how things happened as they did. To answer these questions, Smith theorizes about the relation between experience, texts, discourse, and the social organization of power and control. Using her methods of textual analysis, it is possible to show "how working up individual experience so that it is objectively administrable is a practice of domination. Altered irretrievably and *subordinated* in the process is the experience of the subject about whom the professional was initially concerned," (Campbell & Manicom, 1995, p. 10).

Smith locates the line of fault in the social relations which organize our experience and determine the nature of its transformation into an administrable category. She points out that the social relations in which our dominant modes of knowing developed were, and remain, *ruling relations.* She describes the ruling apparatus as, "that familiar complex of management, government administration, professions, and intelligentsia, as well as the textually mediated discourses that coordinate and interpenetrate it. Its special capacity is the organization of particular actual places, persons, and events into generalized and abstracted modes vested in categorial systems, rules, laws and conceptual practices," (Smith, 1987, p. 108). Ruling is accomplished through work practices which both shape and are shaped by dominant discourses, or modes of knowing.

Experiences I had when encountering the community health care system, in which ruling took material form, could be used as entry points into my research. How did work practices, the palliative care discourse, and the requirements of local government (of which community health care was a part) interact to organize my experience? How were these mediated and coordinated by texts or documentary practices, such as manuals, written policy, forms, case files? Such texts are critically important to the practice of social work, which can be described as engaging in "socially organized practices of power: the power to...assess, to produce authorized accounts, to present case 'facts,' and to intervene in peoples' lives," (de Montigny, 1995, p. 209). "Texts impose an ordered, manageable, and controllable character onto the equivocal, messy, chaotic worlds presented to social workers by clients," (de Montigny, 1995, p. 217). De Montigny goes on to demonstrate how the facticity of a particular entry in a case file depends upon "a complex organizational division of labour, elaborate professional knowledge, everyday organizational relationships, and a multitude of cultural and class assumptions [in his example] about proper and improper smells," (p. 210) (in my own case, about death, dying and palliative care). He explores the idea that in order to get on with the practice of social work, he disregarded the obvious disjuncture between his own experience and that of his client. Only on reflection was he able to reconstruct the documentary work processes which drove his actions. I became curious about what documents might reveal that would assist me to understand how helping professionals had been so unhelpful to me. De Montigny said:

> Files purport to represent the lives of clients. In my office the information on file had the appearance of a series of documentary facts. However, inside the spaces of the file, the actual voices of the clients were silenced...how was it that I was the proper interpreter of reality? What gave me a sense of certainty and authority?...What devices did I employ to report my experience as a series of facts?...What were the organizational sources of power which authorized social work accounts over those of clients? (1995, p. 213)

This seemed to be a promising way of thinking about my own experience. My review of the literature had helped me to unpack and examine some of the beliefs and assumptions framing the palliative care discourse. Our sociocultural tendency and ability to deny death seemed important in the transformation of the dying person into the palliative patient. The *issue* of death could be organizationally administered by community health care professionals if it were transformed into a set of more manageable problems calling for nursing and psychosocial intervention. This also made the work more emotionally sustainable for workers, especially if they were organized into multidisciplinary teams for mutual support and communication.

As I began to comprehend the work of team members as constituting a different set of meanings from mine, I became interested in studying the way in which *texts* shaped and were shaped by the palliative care discourse, and the way in which this textually mediated discourse interacted with the work practices and the social relations of the community health care apparatus. A critical ethnography by Diamond (1986, 1992) explored similar questions with regard to residents and workers in nursing homes, exposing the socially organized construction of patients as passive recipients of care. Like Diamond, I would enter my inquiry from the standpoint of my own

experience - my particular standpoint of the outsider, the reluctant object, the standpoint of women.

The problematic was presented by the disjuncture I perceived between my world as I directly experienced it, and the world of palliative care and community health services. In the first world, we struggled to understand and accept Jim's dying, to live each moment together lovingly and mindfully, and to provide maximum care and comfort for him with the support and help of our friends and family. In the second world, we were constructed as a multiproblem situation, requiring the intervention of a multidisciplinary team of professional problem-solvers, supposedly possessed of expert knowledge in the area of death and dying. While this construction never fit well with Jim or me, I recognize my participation in its functioning, as well as those times when I resisted. I wanted to explore what was happening.

The Study

Personal Experience

The primary resource for this inquiry has been my own experience, as I lived, remembered and recorded it. As I lived it, through that winter and spring, I was already puzzled by certain experiences and reflective about them. I began to make notes in my day book about visits and appointments, especially those with helping professionals. These notes assisted me in organizing my remembered experience in an accurate chronology. Three weeks after Jim died, I started to write a narrative account of the four months of his illness. I did not have a clear picture at that time of what I wanted to do with

this narrative; I hadn't yet considered it as a thesis topic. But I knew that I wanted to write about it in some way.

Carolyn Ellis, explaining the use of her own lived experience with her husband's chronic illness and death in a sociological narrative, writes:

> I felt I had to write about this experience. Not only did these notes and recollections serve as an anchor preventing me from being swept away by this epiphanic event, but it also seemed important to describe and bring meaning to this experience for me...and for others who will go through similar losses. As a sociologist, I thought it was imperative to personalize and humanize sociology. (Ellis, 1995, p. 9)

I worked on this narrative for several months, trying to reconstruct the past. I tried to focus on those aspects of the experience which I thought might be useful to others: our encounters with the palliative care system, and the support we received within our own community and neighbourhood. I wrote not only about what happened, but how I felt about what happened, and what Jim and my sons and other people told me about their perceptions. Conversations with doctors, nurses and social workers were recorded as closely to verbatim as possible. It wasn't too difficult to remember these interactions word for word, as some of the most puzzling or disturbing statements had a tendency to haunt my sleepless nights, playing and replaying in succession.

It was my assumption as a researcher that the social relations which organized my experience were embedded in the talk and the actions which I had recorded. As Campbell explains, "Observations of everyday life, where the researcher captures the language used by the participants, can...be used to gain entry into the social organization.

The researcher asks what it is that conditions the participants' actions and talk?" (1996, p. 6).

In utilizing my personal experience for this inquiry, I paid particular attention to those moments which were recorded and remembered as jarring or confusing in some way, as these represented the clash between discourse and lived experience that served as the entry points to my analysis.

While I was writing, I was clearly aware of the therapeutic aspects of this activity. I had used journals before as a tool for making meaning of my experience, though I could only manage a few feeble entries during Jim's illness. But as I wrote about the past, the present kept breaking into the story as commentary, reflection and emotional expression, and I thought of the whole process as a way of mourning. When I first considered using this experience as data for my thesis, though, I had some doubt about its academic propriety. Carolyn Ellis reflects on her experience of this same conflict:

> When I returned again to my book manuscript, however, I wondered anew if "all I was doing" was self-therapy, the other critical response sociologists had offered over and over...It took awhile to realize that this was yet another dichotomy that I had accepted uncritically. Of course my writing was therapeutic. Isn't most useful research "therapeutic"? Because my research was helpful didn't mean it lacked intellectual substance. What I had learned from my own struggles for meaning was unique enough to be interesting, yet typical enough to help others understand important aspects of their lives. Don't we all need to know we are not suffering alone? Neither the therapeutic and scholarly nor the particular and universal are mutually exclusive. (Ellis, 1995, p. 308)

Unlike Ellis, I was not discouraged from this endeavour by any of my academic consultants. Perhaps the applied sciences of social

work and nursing are more amenable than the harder social sciences to acceptance of the active role and emotionality of the researcher, and the relevance of lived experience as data. While I half expected someone to suggest that I was "too close" in some way to my data, this never happened, and I was able to truly appreciate the therapeutic aspects of the work I was doing, especially as my perspective changed over time. Initially, I wanted and needed to tell my story; later, I reviewed and reflected on this story to analyze and interpret it. I found this latter process, surprisingly, to be as therapeutic as the first telling.

Documents

I have already stated as an assumption of my methodology that social organization is textually mediated. As Dorothy Smith says, "Advanced contemporary industrialized societies are pervasively organized by textually mediated forms of ruling...Essential to this capacity are the documentary bases that objectify knowledge, organization and decision-making processes, distinguishing what individuals do for themselves from what they do organizationally," (Smith, 1984, p. 61). Documents are recognized as constituents of a social course of action in which they are first produced and then become active themselves, standing in for the real actors in ordering subsequent social relations.

Through this inquiry I have reflected on my direct experience of the process Smith describes. The re-shaping of our experience into problems, which was so puzzling and sometimes irritating to me, began

to make sense when analyzed as document-based, organizationally relevant work.

It was my observation that community care for dying persons was organized around the manual titled *Palliative Care at Home,* produced by the Victoria Hospice Society. The manner in which this document was issued to us by a home care nurse led us to nickname it "the Holy Binder". I retained a photocopy of this manual, which includes several forms that seem significant to the organization of palliative care.

I requested a copy of Jim's files from the local community health unit, asking for files from both Home Nursing Care and Long Term Care. When the package arrived in the mail, I was actually surprised at how much was there - thirty-two pages of file material, including pages from the B.C. Cancer Agency and a private home health care agency.

When I first looked through the data, I noticed myself described as a "very supportive, caring wife", Jim as an "Intelligent, insightful man. Self-determining ++", and our situation as: "Close family. Devoted wife, sons. Many good friends, neighbours offering support." The guilt that I have frequently felt in pursuing my research question attacked me once more. How, after reading this, could I have the perception of not being seen for myself or truly heard by community health professionals? Was I just unleashing my anger on "the system"? Then I remembered that the social worker who wrote the latter two comments was the same person who, in the same encounter, advised me to go away for the weekend by myself even though she recorded Jim's prognosis as 4-8 weeks to live (in fact he

died three weeks later). The data then became even more mysterious to me, revealing that the worker had both a realistic idea of Jim's prognosis, and a realistic idea of our family and living situation. That she strongly advised me *anyway* to go away for the weekend and have a home support worker or workers look after Jim seemed contradictory. Her recommendation to me was not immediately apparent anywhere in the files.

This aroused my curiosity about the ways in which community nurses and social workers interacted with forms and documents to organize both their work and my experience. In the contradictions between the documented case and my transcribed memory, I began to search for work practices which were structured by the relevant documents, and for work practices which were made invisible through the lens of the documents. These documents all serve to organize the relations between the dying person and the community care system; the language of the documents operates as the conceptual coordinator of these social relations.

Campbell and Manicom, in their introduction to a collection of essays using Smith's methodology, suggest that: "These essays offer insight into how conceptual and objectifying practices for knowing about people, activities and/or events (that is, 'ruling knowledge') make it possible to put into place objective, impersonal and extra-local methods of control and ruling action," (1995, p. 9). Through my inquiry I hoped to offer a similar insight into such conceptualizations and practices at the local level of community health and social services.

The Influence of Guilt

The guilt that I referred to above occurred frequently enough for me to think of it as a perverse research associate, whose objections I had to overcome in order to keep working. As I reviewed aspects of palliative care in the community, I found myself feeling guilty for being critical of particular individuals or a particular service, just as I had felt guilty for my negative reactions to professionals during Jim's illness.

For a period of time it was difficult to discuss my research with colleagues in the helping professions. I wrote in my journal that people often responded by recounting a story from their own experience which painted a different, more positive picture of palliative care - what happened when their auntie was dying, or their friend. "I don't disbelieve their stories," I wrote, "and I usually feel guilty about my criticism. More than once I've ended up wondering what's wrong with me that I'm so unappreciative. Am I just being a bitch?" This same thought accompanied me as I obsessively read the obituaries, noting all the tributes to the professional caregivers whose care I had rejected.

Sometimes people responded by pointing out the ways in which our situation was different from many others. We were "lucky" because we had a caring physician with a personal interest in our lives, because we were a strong and close-knit family to begin with, because we had the support and protection of our housing co-op, as well as rich connections and support systems in the community. Guilt temporarily convinced me that I had no right to be critical from such a privileged position, and led me to question and doubt the validity of my

experience. But I refused to continue feeling guilty for circumstances of our lives that I considered as much the result of design as chance. It wasn't just luck that we had so much support, we had chosen our community and had created our lives in it.

Guilt also motivated me to dig deeper into the data - my memories, the documents - in order to argue back against it. I tried to understand how ruling relations organized the practice of the workers as well as the way I experienced their practice, often through looking for parallels in my own life as a social worker. In this way I tried to turn the tables on guilt, exploring it as data in itself. Paying attention to the context in which guilt arose became an important part of my research, and provided additional insight into the social construction of the palliative care patient.

Chapter Four

Receiving the Holy Binder

In this chapter, I will discuss my experience of the process of "becoming" a palliative care patient and family. I will show through documentary analysis how this process was constructed and managed in accordance with both organizational requirements and elements of the palliative care discourse. The documents examined in this chapter include the *Palliative Care at Home* manual - the Holy Binder itself - as well as assessment data from Jim's CRD file.

The above is one way of explaining what I am about to do in this chapter. I could say it differently: in this chapter, I will once more plunge into that whirlpool of grief and memory that both lures and threatens me; I will carry on my debates with guilt and with blame; I'll mine my own tears like diamonds for insight and understanding.

This is the background of all these endeavours:

The new year of 1995 began in desolation for my family. We had just received Jim's terminal diagnosis - although as I noted previously, the words "terminal" and "dying" were never used. The surgeon who performed the laparoscopy told me, "It's beyond surgery," and "We'll just have to keep him comfortable." Dave, Jim's physician and our friend, answered my questions about what was going to happen by saying that Jim would "just waste away". "If you wake up," he said, "and he's not there any more, call me right away." The oncologist at the Cancer Clinic said to us both in our intake

appointment, "This is trouble. You should get your affairs in order." Terrified, I wondered: What affairs? What order?

Of course we knew that these code words and phrases meant that Jim was dying. We had already begun our own bittersweet process of saying goodbye. But the doctors' reluctance to use the words *death* and *dying* seemed contagious. I remember one occasion when very close friends were visiting, and Jim was talking about the way the Conservatory was dealing with him and his guitar students. "They don't want to tell people 'Jim Miller is dying of cancer'," he said. I replied into the sudden silence that we ourselves hadn't been using those words very much.

It's difficult to decide, thinking about Jim and me, whether this represented denial - if we don't say the word, it won't be true - or acceptance - Jim's clearly articulated decision to focus his attention more on living in each moment than on dying in it. On reflection, I think that while we knew Jim was dying, he most often chose to concentrate his energy in mindful appreciation of each present moment, and I had made it my mission to facilitate what he wanted in every way possible. This could have been understood as denial by palliative care professionals, although they seemed no more eager to use the words death and dying than we were. Perhaps I took this as instruction in the art of euphemism; at any rate, I recall in many encounters with health professionals a sense that we were all tip-toeing around these words, waiting for someone else to speak them first.
In mid-January, Jim's tumour, which had resisted an easy diagnosis, was finally identified as a liposarcoma (one of two forms of cancer accepted by the U. S. Veterans Administration as resulting from Agent

Orange exposure in Vietnam veterans). We had a consultation with the oncologist just before Jim's forty-seventh birthday, which we celebrated with a houseful of loving friends and high calorie desserts. The chemotherapy treatment he was offered had a 20-30 per cent chance of slowing down, but not stopping, the spread of the tumour through his connective tissues. At the same time, the oncologist noted that ascitic fluid was building up in Jim's abdomen and seeping into his lungs, making breathing difficult. Dave drained off several liters of fluid but a few days later the condition was once again so severe that Jim could only rest or sleep sitting on a chair, leaning forward over a pillow onto this desk I am working on now.

He was hospitalized for three days so that a respiratory specialist could perform a procedure called a pleuradhesion which would prevent fluid from building up around his lungs again. In July 1995 I wrote about this hospitalization:

> When I saw Jim that night, he was in horrible shape. He was hiccoughing like crazy - now I know that the procedure actually caused the hiccoughs though no one said that at the time - and the hiccoughs hurt him really badly. He had been on a small dosage of 15 milligrams of morphine twice a day since Dave gave us the prescription in December. Although he said that it didn't have any effect on the hiccoughing pain at all, the nurses kept giving him more morphine whenever he complained. By the time he left the hospital, he was taking 90 milligrams of morphine twice a day, and was still experiencing intense pain from hiccoughs. He had a pressure sore on his tailbone, he hadn't had a shit in five days, and he seemed to be dozing a lot.

Just a few hours after I brought Jim home from the hospital, at about seven o'clock in the evening, I received a telephone call from a

woman who introduced herself as a home care nurse with the CRD (Capital Regional District, which at the time was the body administering community health services). She said that Dr. S, the respiratory specialist, had "ordered" home nursing care for Jim, and asked if she could come over that evening for an intake appointment. Although Dave had told us that we didn't need Home Nursing Care or other home support services, I wasn't sure. Jim looked dreadful and was hiccoughing painfully for about ten minutes at a time once or twice an hour. I hoped that the nurse would be helpful in some way, and agreed to have her visit that evening.

She seemed to arrive at our door almost instantaneously, probably because her office was only two blocks up the street. She introduced herself as B, and said immediately, "I'm not your regular nurse, I'm the after hours nurse." She added that she wasn't the regular after hours nurse, either, and that in all likelihood we wouldn't be seeing her again. At the time, I was confused by the urgency with which she contacted us to perform an intake assessment, only to never see us again. It only began to make sense when I encountered the intake in the case file as a discrete piece of work, represented by signed consent forms and a completed Patient Data Base. If no crisis calls were coming in to B that night, an intake appointment just two blocks away from the office would seem a sensible thing to do and a savings of the regular nurse's time.

B's next question was, "Will we go to another room or will these people be leaving now?" The "people" - our two sons and a close friend - were watching a hockey game. There wasn't another room to go to downstairs, and I was reluctant to drag Jim up the stairs, which

were starting to become a chore for him, so the family volunteered to leave. I remember feeling some resentment at B - who wasn't even our regular nurse! - "taking over" our living space as though it were her office. Of course, she had asked my permission to come over, and I had invited her. But, I wondered, had this been like an invitation to the vampire, with unforeseen consequences?

Now, in reflecting on this moment, I recall that when I made home visits as a school-based counsellor, I would sometimes request that the television be turned off or that people sit down and pay attention. Like B, I needed to reconfigure the environment in some way as my work space. This, I see now, involved the establishment of hierarchical social relations where I, the worker, had the right to set the conditions for the work to be done; I who supposedly knew "the right way" to do this work, even in someone else's home. That this was likely perceived as "taking over" my clients' homes was no more evident to me than my own silent steaming was to B.

The three of us sat at the dining room table, and B produced a large navy blue binder titled in pale blue *Palliative Care at Home*. "This binder is the property of the CRD," she said. "We'll make it -" (her eyes swished back and forth from Jim, who was nodding and drifting with morphine, to me) " - *your* responsibility." She handed the binder to me. It seemed such a momentous transfer that we later nicknamed its object the Holy Binder.

B proceeded with our intake and assessment. After introducing us to the Holy Binder, she completed the drug profile form (listing off medications was beginning to be a dismally familiar task) and a baseline assessment form with twelve categories, bolstered by a page of

handwritten notes about the initial visit. Reading through these notes now, I'm struck by the way they substantiate my memory that this Friday night was Jim's lowest point until perhaps the day before he died. He was in pain from the hiccoughs, the pleuradhesion, and the pressure sore as well as from the tumours; he was constipated, nauseous and dozy from the elevated morphine dose. B told me what laxative products to purchase for the constipation and suggested Gravol for nausea. She noted about the hiccoughs: "Sometimes severe - becoming more bothersome. States dr. knows but nothing prescribed. Will try honey, warm fluids. Will talk to GP re: Largactil if becomes more of a problem."

My hope that B would be immediately helpful to Jim was in vain. Honey and warm fluids were well and good, but he had a very limited ability to take in fluids. I wrote in my journal, "I was glad B wasn't going to be our regular nurse because I didn't like her very much." Even now, when I can regard her work more objectively, my memory finds her somewhat humourless and officious. But she efficiently completed the process of our intake to both Home Nursing Care and Hospice, in accordance with the Physician's Order Form, which stated, "Patient needs supervision of pain control, hospice referral." B described this in her notes: "HOSPICE - registration done. Pt and wife aware of palliative nature. Introduced to Hospice manual and protocol to phone." Her use of the word "protocol" suggests that this introduction is actually an induction into a routinized system of care. Clearly two different purposes for our interaction that night existed: mine, to obtain practical help which did not materialize, and hers, to induct us into the program..

At the very front of the Holy Binder are a number of pages which both introduce the patient and family to the manual and the palliative care system, and also activate their referral to Hospice. The information pages include the first one, headed "Your Home Manual", a list of contributors, dedication page, preface, and a page headed "Hospice Registration Information". The two forms which are filled out at the intake meeting, removed from the binder and sent to Hospice, are headed, "Request For Victoria Hospice Service" and "Consent for Victoria Hospice Service". On most of these pages, as I will show, there is some evidence of the transformation of the dying person into the palliative care patient in a way which maximizes patient and family neediness and, therefore, opportunities for helping interventions. This meets both organizational requirements for the existence of work (the nature of this work will be more closely explored in a subsequent chapter) and the ideological requirements of the palliative care discourse. The social relations embedded in both discourse and practice are not egalitarian or collaborative. As shown in my review of the literature, the palliative patient and family are constructed in terms of multiple problems, as objects requiring the attentions of the multidisciplinary team members, who become the active agents of the process.

How this actually comes about is the topic of this whole thesis. In the rest of this chapter, I explore the messages conveyed in the manual, and reflect on the way Jim and I were entered into the discourse-defined relations of palliative care. Our lives, our home, our experience of Jim's dying, were to be shaped in congruence with the ideas contained and carried by the Holy Binder, ideas that began to

emerge from the data as I read it with more analytical eyes. Dorothy Smith claims that, "Discourse develops the ideological currency of society, providing schemata and methods that transpose local actualities into standardized conceptual and categorial forms," (1984, p. 65). Organizational ruling proceeds through the textually mediated action that subordinates the particular persons in local settings to these categories. In our case, the Holy Binder transmitted the ideology of palliative care and began to weave us into its social relations.

On the front page of the Holy Binder, under the heading "Your Home Manual", the following statements are addressed to the dying person:

> This Manual is for you, your family, *and your other caregivers* to use while you are registered with this Palliative Care Program and Home Care Nursing.
>
> The intent is to empower you by providing information and education which will allow you to make sound choices throughout your illness.
>
> The Manual will improve communication and planning around your care. Rather than explaining your situation to *every new person*, you will be able to refer them to the information already in this binder. *Each caregiver* will be able to quickly see what has been recommended or ordered for you, and the reasons for any changes that have been made. *It will be easier for the whole "team" to work together.* (Victoria Hospice Society, 1993, p. i) (emphases added)

Immediately upon receiving and opening the Holy Binder, the person begins to be instructed in becoming a palliative care patient. The assumption is made quite explicit that a number of different caregivers will be working in the home, and the first reference to a team is made.

At first I passed over the list of contributors and dedication page in my deconstructive efforts. On further reflection, I realized that even a superficially benign list of names is not a neutral document, but may be a point of entry which reveals something of the social relations of palliative care. The contributors to the manual, which is *for* the dying person, are listed alphabetically by surname, along with their educational and professional credentials, position and employing agency. All fifteen contributors are professionals - nurses, physicians, social workers, administrators, counsellors - working for Victoria Hospice Society and CRD Home Nursing Care. Although Hospice has an active volunteer component, input from this sector appears only through the volunteer coordinator, who is listed with his B.A. and M.A. The composition and nature of the list reveal that the Holy Binder is securely fixed within the palliative care discourse, which prescribes such care as work to be done *for* (or on?) patients and families by a multidisciplinary team of professionals in possession of specialized, expert knowledge. The dedication page likewise focuses on "two groups who work in most homes throughout the Region"(p. iv) - home care nurses and home support workers. This was a clue to me, suggesting the possibility that the Holy Binder was, at least, as much *for* these people as for the patients - the caregivers, the "every new person" predicted on the first page of the Binder.

Further instruction to the patient is given on the page headed "Hospice Registration Information", where the criteria for receiving services are outlined, as follows:

- You live in an area of the Capital Regional District served by Hospice

- The intent of your care is palliative (i.e. comfort-oriented only and will not involve life-prolonging procedures)**
- Your Family Physician agrees that Hospice services are appropriate and desirable
- You are willing to accept added care in the home, if necessary, from community support systems, including Home Care Nursing and Home Support Workers
- You are currently residing at home or in a Personal Care Facility

** If there is uncertainty about the stage of your illness or confusion about the nature of palliative care, a Hospice Medical consultation is available to assist and clarify prior to deciding on registration. (p. vi)

In order to complete the transformation into the category of palliative patient, besides meeting residency requirements, the person must have the approval of his/her physician, must be willing to accept community workers in the home, and must acknowledge the terminal diagnosis. The special attention given to this last criterion through the asterisked note is an indication of its discourse-driven centrality in effecting the referral; at the same time it is noteworthy that this happens without using the words "death" or "dying". Only in the very first, defining sentence on this page are the "d words" employed: "Victoria Hospice is a community-based palliative program which enhances the quality of life and death for people facing death and bereavement," (p. vi). Perhaps in part because of such guarded and euphemistic language, it becomes important to ensure that the patient knows he is dying. Therefore the patient is asked to sign a consent form, including demographic and medical data, as well as this statement:

> I understand that my care will be palliative only, i.e. it is comfort-oriented and will not involve life-prolonging procedures. My care will be coordinated by my Home Care Nurse in partnership with my Family Physician and Victoria Hospice.
>
> Victoria Hospice has my permission to:
> 1. Collect current and personal information from me &/or those identified by me.
> 2. Obtain appropriate health information from other health care agencies (e.g. X-ray, Lab reports, medical records) and providers.
> 3. Share this information with the palliative care team members who are involved in my care, and with those individuals identified by me.
>
> (p. viii)

The signature on this consent form is the most tangible evidence of the patient's acceptance of his terminal diagnosis. It also firmly establishes the existence of a palliative care team, and the home care nurse as team coordinator.

In a viewpoint article published in the Victoria Times Colonist on November 9 1995, the husband of a palliative care patient described their experience of being admitted to the program.

> A nurse visited the house and said to my wife, "I am your Home Care nurse and I will visit you twice a week. I want you to sign this form consenting to palliative care only and to read this book, the *Palliative Care at Home* manual." Since a terminally ill person does not expect to be cured, the need for such an agreement was obscure, but the negative effect on my wife was quite apparent. She referred to it as "my official death warrant."

This reaction on the part of the correspondent's wife makes it evident that the intent - and intensity - behind the consent form was conveyed by the nurse, again without having to use direct language.

The referral to Hospice also requires completion of a form headed "Request For Victoria Hospice Service". This form may be generated by a home care nurse, physician, hospice staff or "other", but is obviously intended to be filled out by a professional, probably most often the home care nurse. The referring person fills out a checklist of services required and the urgency of the situation. Does the palliative patient require this service within 24 hours, 1-3 days, 4-6 days, or 1-2 weeks? (In the case of bereavement support, a note indicates time delays "beyond two weeks".) Other services offered by the multidisciplinary team are: community care nurse consult, community volunteer, counsellor consult, Hospice physician consult, out patient clinic, Palliative Response Team - crisis intervention and support for home death, spiritual care consult, and in patient assessment.

Now I sit in puzzlement, trying to remember if B went through this list of services with us, or if she clearly explained that in signing the consent form Jim was agreeing to what seems now a high level of information sharing. I don't think this happened; I only remember the sense of a heavy weight around signing the form - his "official death warrant".

As I leaf through my copy of the Holy Binder, I see that it can be viewed as a textbook, instructing people on how to be palliative patients. The manual is divided into sections: General Introduction, Planning for Care, Patient Care, Professional Care, and Bereavement Care. In each of these sections, the professional contributors have specific guidance for the patient and family members. Our Times Colonist correspondent referred to the manual as "stuffed with every

conceivable detail of the dying and mourning process...reams of printed literature with lists of emotions one might, may, or perhaps by implication, ought to feel." The instructional aspect of the Holy Binder was clearly not lost on this individual.

The basic message given to the palliative patient in the Holy Binder is familiar from the literature review: "You need help! You have problems in all aspects of your life and you need a team of professionals to help you." This message is conveyed through statements such as the following: "When you get into any kind of difficulty, you should ask for help immediately. Little problems are much easier to solve than big crises, both for you *and the others on your team*," (p. 2) (emphasis added). Family members are similarly instructed, "It is important that you accept some help with care. If you don't look after yourself, you run the risk of becoming sick and exhausted, and you may be unable to look after the patient or yourself," (p. 2). This idea was echoed by a nurse manager in Home Nursing Care who told me in a casual conversation, "If we can just keep in contact with them [palliative patients] we can avoid a crisis. Sometimes we don't hear from them, and then they call us in a crisis. It didn't have to get that bad!" This remark, like the quotes above, left me wondering who had the privilege of defining a crisis and its nature. Was a crisis an event which could not be readily documented as managed or resolved? Might it be preferable to some patients to maintain their privacy, to resist the transformation of their home into a workplace, until such a time? Yet the message is definite in the Holy Binder: "You need help! Even if you don't think you need help yet, you do."

That this help will be delivered by the professional multidisciplinary team is made clear on the first page of this section, which consists of a graphic "wheel of support": a circle divided into four quadrants, representing all the sources of support available to the palliative patient. In this chart, "Patient and Family" are given one quadrant, while the other three are filled by "Home Care", including home care nurse, long term care case manager, home support workers, home support supervisor, quick response team, and physio/OT; "Physicians", including family physician, specialists, hospice physician, cancer agency, acute care and LTC hospitals; and "Victoria Hospice", including Hospice unit, counsellors, home consult, out patient clinic, Palliative Response Team, volunteers, and bereavement. The one quadrant assigned to the patient and family includes relatives, friends, religious community, AIDS Vancouver Island, and others. Without even delving into the puzzle of why one specific non-profit society and no others are included in this sector (revealing an assumption that persons with AIDS are more lacking in social or familial supports than others?) the patient's personal support system would appear fairly thin on the ground in comparison with the plethora of professional supports and services ranged around the other three quadrants. This type of depiction graphically emphasizes the importance of professionals and gives no indication of the way in which friends, relatives, and a caring family physician can virtually run the wheel themselves in many situations.

It is also true that the Holy Binder contains many statements about patients' rights, self-determination, and the value of family support. A page on Advocacy lists the rights of patients and indicates

Hospice's willingness to act on behalf of patients, as well as inviting people to express any dissatisfaction with the services. Another example, from the section on planning for care at home states:

> While the nurses, doctors, counsellors and volunteers on your team can help with many aspects of care at home, the support that comes from people in other parts of your life is also very important and makes a big difference to how you are able to manage. (p. 6)

The patient is given another wheel divided into four quadrants, labelled Family, Community Groups, Community Individuals, and Organizations.

> Look at the groups of people listed in this wheel/circle. If you are getting support in any of these areas, put the person's name on the line adjacent to who they are. For example, if you have someone from your bridge club who does shopping for you, find "social clubs" on the wheel, and write *"Ann Moore (bridge club)"* on the line beside it. This may be a way for you to see where your support comes from and any gaps that exist. (p. 7)

In my journal, I referred to this aspect of the manual as seemingly "designed to keep the patient and family extremely busy filling out charts and diagrams". At first it seemed merely pointless to me. If Ann Moore from the bridge club goes shopping for you, surely you know that and don't have to write it down. This led me to wonder once again who the document was created for. It seemed to have been designed to *create* space, those "gaps that exist" to be filled by the team. Further reflection clarified my distaste for the circle diagram, as I described its condescending language to colleagues. I began to see it as an incursion into our experience of a planning mode that was mechanical and intrusive - making a chart of our lives and our friends.

This invasion and mapping of our lives can be understood as their colonization by the ruling regime, the transformation of our lived experience into a format which, when entered into the Holy Binder, justified the need for such localized imperialism.

The part of the Holy Binder that I found most useful was a medication chart. B showed me how to write down Jim's different medications and then check off boxes as they were administered. This initially helped me to get organized and ensure that Jim took everything he needed at the right time. Eventually, however, I was remembering to give the medication and forgetting to check the boxes. So this too, went unused after a few weeks.

On that Friday night, though, I accepted the message of palliative care. I was sure that we needed help. I was hoping for some of the promises of palliative care regarding symptom management to be fulfilled. I wanted B to stop Jim's hiccoughs, heal his pressure sore, wake him up. Although she was unable to do anything whatsoever about these symptoms, she effectively completed her own organizational tasks of an intake assessment and hospice referral. When she packed up and left, our status had changed; we were now palliative patient and family caregiver.

The Holy Binder was indeed our instruction manual for becoming members of these categories. The consent forms, the charts and graphs, the introductory information, are all examples of the palliative care discourse in textual form. These texts are built on the same assumptions about dying people as were identified in the professional literature: assumptions about the multiplicity of problems and the need for early, comprehensive, professional intervention.

Similarly, the "protocol" introduced by B, as well as my observations of her interaction with us and the forms, demonstrate how the discourse had penetrated and directed her work practices. The process of our induction was completed by a worker who would play no role in our continuing care; her primary tasks appeared to be signing us up and explaining the rules.

Again, I thought of Jim and myself as the indigenous inhabitants of our own territory, consenting to interaction with a colonizing force without a clear understanding of its imperialistic purposes. In signing his official death warrant, Jim agreed not only to accept professional help, but also to allow that help and our need for it to be defined by a textually mediated discourse and discussed by a multidisciplinary team. Thus we were pulled from the painful and triumphant world of our experience, and entered into the problem-saturated, discourse-driven, multidisciplinary world of the community palliative care system.

Chapter Five

"Wife Rena Teary"

After the crisis which precipitated our intake, or induction, into the community palliative care system, things began to settle down again. While Jim continued to decline in strength and energy, some of his most troubling symptoms abated. The pressure sore on his tailbone gradually healed. When I worried about his drifting, Dave suggested cutting back on his morphine and, though he prescribed medication for the hiccoughs, told me that, "The best thing for him might be a puff of weed." Jim had been unable to indulge in this - his preferred method of relaxation - since the fluid had built up around his lungs; now, after the pleuradhesion, I filled the pipe again. Marijuana seemed to be an almost magical cure for the hiccoughs, as well as contributing to Jim's improved appetite and ability to be comfortable on very little morphine.

Something else had changed for us: after the last hospitalization Jim and I were both determined that he should stay at home. He said, in a discussion with Dave, that going back to the hospital was his greatest fear. He decided to forego the chemotherapy, which would have to be administered in hospital in forty-eight hour admissions every eight weeks, and which was described by the oncologist as "very rough chemo" with very limited potential to help. I decided that I wanted Jim to die at home, not at Hospice. Because I wasn't sure exactly what that would be like, or when it would happen, I wanted to maintain some connection to the palliative care services which were

available to us. My interactions with the system's representatives, though, continued to puzzle me.

In this chapter I explore the ways in which my interaction with Home Nursing Care was organized by documents; specifically by a form used by the nurses to record their work. Reflecting on this document's problem focus, I recognize now the significance of the nurse's recording of the interaction amongst the three of us. The form required that the nurse find, and record, manageable problems. It is my contention that the nurse's recording constructed Jim and myself as problems. I argue here that the nurse's work process, organized around the discovery and documentation of problems, was oriented to organizational interests rather than ours. As a helping professional myself, I can speculate that those organizational interests might involve the demonstration of accountability and objectivity. While I recognized that the nurses were conducting their work competently and professionally, indeed using the concepts and language that I found in the palliative care literature, I show in this chapter how this was unhelpful to us, and resulted in my feeling objectified by being treated as a problem with a solution. This document-organized, problem-focused approach fit comfortably within the medical model and the palliative care discourse, and may well have fit with the needs of the organization. The only place this world of manageable problems did not fit was the world of our house, and the experience we lived there.

I found ample evidence of this problem-building process in the document which is the focus of this chapter, a form with the printed title "Open Flow Sheet". This document was used by home care nurses to record their visits and telephone contacts with us. The document's

"openness" appears to relate to its use as a shared communication tool by various staff members. Each one who had contact with us contributed notes to the same document. As a "flow sheet", the document seems to work by providing an overall sense of the flow or progress of the team's work from contact to contact. It consists of a grid of squares or boxes. At the top of the document Jim's name and Direct Care Number are handwritten, above the typed heading "Palliative Flow Sheet". Down the left-hand side of the page are two columns with printed headings: "Assessment Category Number" and "Problem Name and Parameters". Six more vertical columns to the right are each headed by a handwritten indication of the date and time of the contact. The horizontal columns are headed by typed assessment category numbers and problem names. The home care nurse then writes comments in each box documenting the visit or telephone contact. At the bottom are boxes for the visit number and the nurse's signature. Four different signatures appear on the two pages of the form, over three visits and nine telephone calls.

The nurse, through this form, is led to structure each contact with the palliative patient around problems. Every comment she makes relates to a specific "problem name"; presumably she is being asked to say something about the "parameters" of the problem. This fits with my conceptualization of the palliative care discourse as problem-saturated. While this may be considered a feature of the medical model generally, an extra urgency exists around palliative care. I have described this in my conceptual framework as an effort to resolve the unresolvable by breaking down the process of dying into a set of manageable problems.

This is graphically illustrated by the Open Flow Sheet, which lists the following ten items under the heading "Problem Name and Parameters": 1. Medication; 2. Skin Integrity; 3. Pain Control; 4. Signs & Symptoms; 5. Elimination, Voiding & B.M.; 6. Coping with A.D.L.; 7. Nutrient Intake; 8. Nausea and Vomiting Control; 9. Feelings & Attitudes; 10. Report to Doctor. It is instructive that these categories are defined as problems; that in order to comment on any of them, they must be considered as problems. The flow sheet structures the nurse's contact with the patient and caregiver by listing the areas which must be addressed as potential problems. The palliative care team therefore find themselves relating to the patient and family in a particular way that depends on the existence, indeed, the construction through documentation, of manageable problems with prescribed interventions.

My experience as one of the objects of this work begins to make sense when overlaid by the grid of the Open Flow Sheet, which is reproduced on the next two pages. The first visit, by Nurse B, is described in the chapter, "Receiving the Holy Binder". The second visit, by Nurse V, was in response to my request for assistance with the pressure sore Jim had developed on his coccyx after three days in hospital. V's notations for that visit suggest that describing our situation in terms of problems was a stretch. She commented on the other "problems" listed in a way which indicated that they weren't really problems. For example, under Feelings & Attitudes, she wrote: "Cheerful, wife and client managing care at present." (There is something ominous about that "at present", forecasting a future inability which never actually materialized.) V did address the real

problem of Jim's pressure sore, though we did not find her intervention very useful. The duoderm dressing which she applied to Jim's tailbone not only came off almost immediately but tore skin away in the process. I had more success healing the sore with Sunlight soap, a treatment suggested and demonstrated by a friend who had worked as a care aide in residential facilities. Though he told us this method was now considered primitive in hospitals, it worked well for us. (This was yet another reason to doubt in the Holy Binder and the palliative care team as the only repositories of the specialized professional knowledge we needed. Indeed, I came to be skeptical of the concept of specialized professional knowledge itself, when folk remedies and common sense proved equally effective for us.) However, unlike later visits, V's was related to a problem which was observable to all of us.

After V's visit there were two telephone contacts by our "regular nurse", N. N questioned me about each of the problem areas and wrote comments such as, "[coccyx] dry and healing?", "wife says things are stable", and finally, "would like HNC visit Mon. a.m. to assess". What I remember about these two phone calls was N saying that she "really should" have a home visit with us, since she was our regular nurse, and she hadn't met us face to face. I distinctly recall her telling me that the visit would take about an hour. I don't think I requested it, but she may have asked me something like, "Would you like me to come on Monday morning?" to which I must have answered, "Yes." Perhaps it seemed inescapable. My clear memory of the visit being required by N was translated in the official record into a statement that I would like a visit. This translation relates directly to the dependence of her work on the existence of manageable

problems. In this instance, we see the nurse reconstructing our interaction into a formulation which is both ideologically correct and organizationally relevant: one in which we have the problems for which we require her professional assessment and intervention. If I had declined visits and insisted that there were no problems, would there be no work to be done on us? Would this create an organizational problem for the nurse in whose caseload we fell?
N's visit took place on February 20 1995. I wrote about it: "She stayed for about an hour, which was way too long for Jim, who actually got a bit testy with her towards the end." I remember sitting on the couch with N, Jim facing us in his easy chair, as she worked her way down the list. Now that I know she was looking for problems to record, her persistent gentle probing and sad compassionate gaze are more coherent to me. I look down the column on the flow chart which represents this visit: "Medication: done - see med list; Skin Integrity: Healed; Pain Control: MS contin 30 mg. BID; Signs & Symptoms: Abd. more distended; Elimination, Voiding & B.M.: Reg. with colase." So far, no real problems had been identified. Finally, under "Coping with A.D.L.", N found a problem to report: "Wife Rena teary. She has requested counselling."

Somewhere in our conversation, I told N that I was curious about the services available through Hospice. The weekly caregivers' support group was not convenient for me to attend, and I wondered about other groups. I was also looking for an individual counselling session, assuming that this would be helpful to me. I mentioned that I had telephoned Hospice asking for a counselling appointment over two weeks previously, and that I hadn't heard back. It's possible I became

Province of British Columbia
Ministry of Health and Ministry Responsible for Seniors
COMMUNITY HOME CARE NURSING SERVICES

OPEN FLOW SHEET

NAME: Miller, Jim

DIRECT CARE No. 6 0 1 6 2 4 2 1 7

PALLIATIVE FLOW SHEET

ASSMNT CATEGORY NUMBER	PROBLEM NAME AND PARAMETERS	DATE	95.01.20	95 c 124	95.02.03	95.02.15	95.02.20	95.02.22
		TIME	2100.	0915	PC.	PC	1100.	PC.
1.	MEDICATION Review q 6 Days & p.r.n.		See PN	/	Spoke to wife.	wife says "things are stable"	done off Med list	No chge.
2.	SKIN INTEGRITY		Assess data base	Decubitus + tenderness to 1" shallow slit at coccyx	Dry + healing?	area healing	Healed.	Bath seat helpful.
3.	PAIN CONTROL			Controlled	Good	good.	M.S Contin 30mg bid	No chge
4.	SIGNS & SYMPTOMS			No hiccuppy this am Moves c ease	Ø		Abd more distended	same
6.	ELIMINATION, VOIDING & B.M.			Bowels moving x2. On regular Colace/Senokot regime	Reg.		Reg & Colace.	To decide re bottle & commode
7.	COPING With A.D.L.			Wife will monitor coccyx.	Wife managing		Wife Rene she Tearfully requested Has requested counsellor	Still able to go upstairs
8.	NUTRIENT INTAKE			Fair	Has been Good but		Good.	No Chge
	NAUSEA AND VOMITING CONTROL			Controlled	nausea this am.		Ø	Ø
11.	FEELINGS & ATTITUDES			Cheerful, wife clear managing care & coping		would like HNC visit mon am to assess	Weaker	Getting out for short visit & friends
					—			Wife to see Hospice counsellor
5.	REPORT TO DOCTOR.				—		PC to Hospice Dr tonight.	
	VISIT No.		1	2	3/	2	3	4
	NURSE'S SIGNATURE		[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
			B	V	N	N	N	N

HLTH 306 e REV 92/05

OPEN FLOW SHEET

NAME _____ DIRECT CARE No. _____

ASSMNT CATEGORY NUMBER	PROBLEM NAME AND PARAMETERS	DATE / TIME	95.03.02 0900	95.03.13 1000	95.03.21 PC	95.03.22 1030	95.03.27 0850	95.03.[illegible] PC
	ADL's		Hospital Bed being set up.	Wife managing	Rena @ work.	Rena at son Rena working about 1/3 caseload.	wife reports no changes and they are managing full	↓ HSW Started.
	Pain Control		↓ uncomf.	No problem				
	Skin Integrity			Good.		No problem	-will phone if need help	
	Bowels		No problem	/		No problems		
	Nutrient Intake		Low intake	No change.		Decreasing		
	General Status		Declining Weaker	Will PC if problems.		Declining strength		Very low.
	Family Coping		Rena's OK but shows stress	Rena feels better seeing [redacted]		F. Good		HSW started today
			Seeing [redacted] today Jim does not want more people.					
			Visit declined.	LTC [redacted] to visit 03.14		LTC assessed & Med's adjusting		
VISIT No.			5 PC	PC		6 PC	5 PC	
NURSE'S SIGNATURE			N	N	N	N	W	N

teary at this stage of N's visit, though I didn't record that in my journal. What I wrote about crying was that I seemed to cry frequently for days at a time, so much that I reminded myself of Alice in her sea of tears. This was followed by a dry, arid, empty period of several days. Being teary, in my view, was not a problem but a welcome relief from this emptiness, and a regular means of expression - part of what my son Gabe called "the new normal". It was not how I would have primarily characterized myself, yet it was how I was characterized by N, who needed problems to record and work on. The recording of the problems fixed us more securely within the framework of the palliative care discourse and the requirements of the organization. We could become her "work" readily within this problem context.

During this visit and afterwards, N worked on the problem of "Wife Rena Teary" in several ways. In the immediate moment, she encouraged me to express my emotions. This type of intervention was rated by families of terminally ill patients as "least helpful" in research I cited in my conceptual framework, and was similarly unwelcome to me. She also began to look through the *Palliative Care at Home* manual for the information I was seeking about groups. "It's on a page with a flower," she repeated several times, while leafing through the Holy Binder. Jim and I sat patiently waiting for her to complete this task which we could just as easily do ourselves. In the end the task was futile; "the page with the flower" was not to be found, though N used a good portion of her hour with us in searching for it. This was not the way in which we would choose to spend our very precious and limited time, and Jim later referred to "the page with the flower" derisively

when refusing further visits from N. "I don't need her over here looking for the page with the flower," he said.

At the bottom of the column of problems, under the heading Report to Doctor, N wrote: "PC to Hospice. Dr. to visit tonight." I assume that the first part of this comment, the phone call to Hospice, was also work performed by N on the problem of "Wife Rena Teary". This work fit with her role as the coordinator of our care, a role sanctioned for home care nurses throughout the palliative care literature and discourse. N, having successfully located and identified a problem (though how "Wife Rena Teary" relates to "Coping with Activities of Daily Living" remains somewhat mysterious), performs work on this problem, both directly on me, and indirectly through her phone call to Hospice. I suspect that this telephone call motivated the subsequent call I received from a Hospice counsellor to make an appointment. In the recording of my next contact with N, a telephone call one week later, she notes at the bottom, "Wife to see Hospice counsellor." The manageable problem of "Wife Rena Teary" has been thus documented and resolved, even though it was not a problem in the world of my experience.

Conversely, the part of the visit that I reacted to most strongly and wrote about in my notes, was only faintly alluded to by N in her final comment, "Dr. to visit tonight." My journal reads:

> N was very keen that we should fill in and sign the Do Not Resuscitate order. This was a form at the back of the Palliative Care manual. We'd been told by everyone not to call 911 if anything happened to Jim, unless we wanted the paramedics who came with the ambulance to undertake life-saving measures. They had to do this unless a DNR order was signed and waved in their faces. We were told to call Hospice instead,

> where a Palliative Response Team was available after hours...but N kept going on about the DNR order and how important it was. She said that if many different people were in the house providing care, someone might call 911 by mistake. We said we would discuss it with Dave [Jim's G.P.] when he made his home visit that night.
> When Dave showed up, he told us that N had called him at his office to inform him that we hadn't yet signed the DNR order and suggest that he encourage us to do so. It pissed us all off that she called Dave "behind our backs".
> "What do you need her for?" Dave asked me - Jim had already made it clear that he didn't need her for anything, and didn't want her to come over.
> I said that I wanted somebody to see Jim, look at him, on a regular basis.
> "Why? What do you think she'll see?" Dave was soft-spoken but insistent.
> "I don't know...how he's doing...if he needs anything..."
> "He isn't going to need anything that he can't tell you about himself," Dave said. "Or if he can't tell you, you'll see for yourself what he needs. You don't need to bother with the DNR order if you don't need the nurse, and you don't need the nurse - you've got me."
> This was very affirming. Dave convinced me that I could manage without N, without the Palliative Response Team, and without Long Term Care. This was a big relief to Jim, and it allowed us to keep our home full of people who loved us, and not people who were working on us.

It is interesting that this aspect of the visit and follow-up, which was so significant to me, becomes invisible in N's account. "Dr. to visit tonight," - but no record of "PC to Dr." or of the DNR order itself. Perhaps this is because of the difficulty in assigning the event to any of the pre-determined problem categories. Perhaps it was not perceived by N as a problem, but somehow subsumed into the undocumentable, unrecordable part of her work. After all, as a friend familiar with the forms pointed out to me, the boxes to write in are quite small, so the nurse has to be selective in recording. N's

"harping" (our perception) on the DNR order and "tattling" on us to the doctor was selected out, in favour of the problem of "Wife Rena Teary".

To Jim and me, the significance of the "harping and tattling" was that it resulted in our declining further visits from Home Nursing Care for the foreseeable future. The behaviour which N probably saw as so routine that it wasn't necessary to record it, was perceived by us as intrusive and disrespectful. It is only since I have researched the palliative care literature that I have begun to understand this behaviour differently. I see now that N was fulfilling her role as the coordinator of the multidisciplinary team, which was itself a standard, almost institutionalized, model of service. Our brief experience of being the objects of such teamwork threatened us with the loss of self-determination and decision-making power. I wrote in my journal, "Dave's not a team player, he wants to be the kingpin - and I'm glad." I was fortunate that both Jim and Dave were so sure that "the old-fashioned way is best"; without Jim's quiet strength and Dave's unconditional support, I might not have been as assertive as I needed to be in declining further visits from N, as well as other services.

N continued to work on the problem of "Wife Rena Teary" through two subsequent telephone contacts. On March 6 she started a new open flow sheet, without the typed in problem names. She omitted some of the previous categories, and added "General Status" and "Family Coping" as problem names. In the latter box she observed on March 6: "Rena's OK but shows stress. Seeing E [Hospice counsellor] today. Jim doesn't want more people." One week later, March 13, she wrote, "Rena feels better seeing E."

These notations are puzzling to me except as the representation of work performed to solve a manageable problem of her own construction. I first of all wondered how I "showed stress" over the telephone. Guilt - familiar companion of my research - tempted me to dismiss this query as semantic quibbling. After all, there was no doubt that I was under stress, which was probably evident or "showing" in my voice. Consulting my day book, I saw that March 6 was not only the day of my counselling appointment with E, but also the day that we were setting up a hospital bed in the living room. Jim had become too weak to climb steps, and we had to make the difficult decision to move downstairs. He would sleep in the hospital bed, and I would use a foamie on the floor; it was a wrenching loss for both of us to be unable to sleep together. No wonder I was stressed.

Reviewing the open flow sheet, I realized that what was jarring to me about "Rena's OK but shows stress" was its total separation and distinction from the issue of the hospital bed. In the very first problem category, ADL's, N wrote on March 6, "Hospital Bed being set up." This entry is physically separated from Family Coping, which is the very last problem category listed. Nothing links them together on the flow sheet, and my perception remains that "Hospital Bed being set up" was entered as a solution to the manageable problem of Jim's declining strength. To me, "Hospital Bed being set up" was a problem: a separation foreshadowing the impending and final separation, and thus an integral part of the huge unresolvable problem of Jim's dying. There's something belittling about seeing this graphically reduced to separate manageable bits in the open flow sheet, something smug and

self-serving about the tidy solutions provided for these constructed problems.

The final resolution to "Wife Rena Teary" is the entry "Rena feels better seeing E." Looking at this entry, I once again feel bemused at the way my experience has been altered to appear in this guise. First of all, I found it a challenge to get to see E; as already pointed out, I made two phone calls and N made one before she contacted me. After our appointment at Hospice on March 6, E went on holiday, and though she did give me her home number, I didn't use it. I met with her again sometime after Jim's death; I wasn't "seeing" her regularly as suggested in N's note.

I wrote in my journal about the appointment with E that "it was good to have a place to just cry unreservedly without making myself stop too quickly...Usually when I start to cry with my friends, they start to cry too and then my impulse is to stop sniffling and pat them on the back." I am sure that "Rena feels better seeing E" resulted from N's invisible questioning. At the end of a telephone interview which otherwise elicited comments such as, "Wife managing", "No problem", "No change", and "Will pc if problems", I must have replied politely and positively to the questions: "Yes, I saw E. Yes, I feel better now." And, though I can't confirm this through my memory or notes, I suspect that she reached me at a non-teary moment. This allowed N to wrap up the problem she had identified. There was no more work for her to do, although there were four more telephone calls before Jim's death; three from N and one from Nurse W. Almost nothing is recorded on the flow sheet from these calls except, "No problems", despite Jim's steady decline in strength and rapidly approaching death.

This again illustrates the way in which the palliative care discourse, the open flow sheet, and the nurses' work practices interact to construct the situation from the standpoint of the intervenor, in terms of manageable problems only.

I asked Jim, after my appointment with E, whether he would like her to come to the house to talk with him. I said that she was a pleasant and interesting woman who had a great deal of experience being with people who were dying. Perhaps she could answer some questions for him. Jim smiled and said quietly, "I'm not very interested in what happened for other people. I'm content for this to be my own unique experience."

I am thankful that we were able to live out our own unique experience, the last one we would share outside the bounds of memory. My examination of the Open Flow Sheet confirms my intuitive knowledge about the impact that community health care services could have had on this experience. Like capturing a delicate, fragile being by forcibly restraining it, altering and distorting its shape.

I heard something on the radio recently that reminded me of this process. A palliative care doctor was being interviewed about research he was undertaking into the spiritual needs of dying people. He said that he had been inspired to do this work by one of his patients with AIDS, a well-known writer and director who had thanked him for all his help, saying that he now had to involve himself in a spiritual journey which did not require the doctor's professional skills. The doctor realized that he indeed knew nothing about his patients' spiritual needs. He then decided to research this by interviewing dying persons

about their spiritual needs, so that professional interventions in this area could be developed by palliative care teams.

Dorothy Smith's article, "The Social Construction of Documentary Reality" (Smith, 1975) describes in minute detail the kind of documentary process which I experienced in my encounters with community palliative care services. Although not describing the same organization, her analysis of documents and the text-mediated work of professionals provides insight into my experiences with palliative care. She points out that reporting and recording practices are a socially organized method of constructing knowledge, and that though these practices are "decisive to its character, their traces are not visible in it," (Smith, 1975, p. 257). Techniques of eliciting information by questions or other strategies structure the account in definite, though invisible, ways. Smith further argues that the social relations which are embedded in these structuring procedures, and the documentary reality itself, are those of ruling and domination. While it is unpleasant to think about the helping efforts of N, E, and B as exercising ruling and domination, it would certainly seem that in order for us to have used their services, we would have had to let their documentary reality overcome and manage our lived experience. Documentary reality was organized by social relations whose relevances originated elsewhere - in an office two blocks down the street, a very different world from the one I experienced in my home. These organizational relevances, while not immediately apparent during our interactions, were in part revealed to me as I studied the recording of their work. As Smith says, in reference to the collection of demographic data by hospitals, "How their practice intersects with the lives of those they treat and the

character of their practice, constitutes that birth (or that sickness or that death) very differently from how it is constituted by those for whom and to whom it happens," (Smith, 1975, p. 265).

Jim's dying was constituted by the palliative care system as its work, and the work was constituted as the resolution of a set of manageable problems. The Open Flow Sheet was an instrument of this construction, and the nurse its active agent. Even as the recorded problems dwindled, and consequently the work to be done, the last few notes refer us on to another service for which our situation might provide work. In much the same way as I had perceived us being "handed over" to Hospice by the Cancer Clinic after Jim refused chemotherapy, we were now being "handed over" to Long Term Care, a program like Home Nursing Care housed by the Capital Regional District. On March 13, N wrote at the bottom of the column, "LTC to visit 3/14" and on March 22, "LTC assessed and HSW set up." In order to access a home support worker (HSW) our situation had to be assessed by a case manager from Long Term Care. This process will be described in the next chapter.

The three visits and nine telephone conversations with home care nurses ranged in my perception from satisfactory to irritating. While I was aware of my resistance to using more services, it was only when I began to study the documents that I realized I had been resisting the objectification that results from being absorbed into the system. I saw how the palliative care literature, and other aspects of the discourse active in popular culture, established and supported the problem orientation of the organizational document, and how both discourse and its textual manifestation directed the work of the nurse.

This work is defined as the identification and resolution of the multiple problems assumed to be experienced by dying persons and their family caregivers. We may also assume that the performance and documentation of this work must be articulated to the organization's systems for control and accountability.

In our experience of this process, the intertextuality of discourse, document and work practices resulted in N's construction of a problem - "Wife Rena teary" - that was not a problem to us, as well as her construction of a solution - "Hospital bed being set up" - that was deeply problematic to us. This distortion of our lived experience to fit a context supplied by discourse and organization seemed even more objectifying to me as I read and re-read the file than it had at the time I lived it, when my energies were preoccupied. What both Jim and I were intuitively resisting was the loss of autonomy that comes from being turned into a problem and worked on. Shaken to our roots by uncontrollable events that were changing everything for us, we resisted being reconstructed as a set of manageable physical and emotional problems to be solved by the multidisciplinary team.

Chapter Six

For Fifteen Minutes a Day

This chapter brings me back to the place where I started my journey: sitting at the window and thinking about the visit of the Long Term Care case manager, the person who thought I should go away for the weekend. When I first had this experience, I labelled it as odd or puzzling, but filed it away as a low priority. When I first wrote about it, I speculated that L, the social worker, hadn't really "seen" us or understood the depth of our personal support system. As I have previously noted, her recorded assessment partially contradicted this notion. There were many points in the five page assessment where L commented on my ability to care for Jim and the support available from our sons, friends and neighbours.

I had carefully thought about our need for a home support worker, and decided that it would be helpful to have a male worker come in to help with Jim's personal care when I could no longer lift him. Although our sons were available much of the time, I worried that having to lift and support their father might be too emotionally taxing for them. After Jim was restricted to living downstairs, I had to confront the reality that he would at some point be restricted to bed. Only then, I thought, would it be useful to bring in a home support worker. Even so, I could not imagine needing a worker for more than fifteen minutes a day. L, however, authorized 150 hours a month of home support, and encouraged me to use those hours even though I was

not requesting this level of service, and she could see that we didn't need it.

In this chapter, I explore the organizational and social relations embedded in this disjuncture. It seemed so peculiar to me. At a time when public decision-making operated on the unquestioned assumption of the insufficiency of health care dollars, why was I being offered so much home help? I will argue that organizational interests and relevances are so compelling of individual workers that it is virtually impossible to allow client self-determination. The social worker, trained and motivated to help by "doing something", was doing what was within her mandate and authority. For us, this was experienced as unhelpful and unpleasant, even domineering. Although we resisted such "help", in various ways we were subordinated by the palliative care system, an outcome that Smith (1990) and others (Campbell and Manicom, 1995) refer to as "ruling".

As I read and re-read L's assessment, I also remember that in an indirect, small town way she was connected to us. Another CRD social worker is a long term mutual friend; I'd passed word through this friend that I would prefer L to do the assessment rather than her job sharing partner. When she came to our house, I was glad I had asked for her. She quickly obtained Jim's signature on a couple of forms, and then asked if we could go somewhere to complete the assessment without bothering him. My friend M, who is the coordinator of the home health care agency we used, told me later that L really wanted to help us, and I know that is true.

L worked her way through the sections of the assessment form: Medical Background, Mental Health, Dental Care, Communication,

Activities of Daily Living, Housing and Social Context, Self Care, and Financial Affairs. This certainly seems an appropriately inclusive list, and at first glance the assessment form is less problem-focused than the nurses' open flow sheet. At least there are no columns headed Problem Name. However, closer examination reveals the multiple problems in small print. For example, the section on Medical Background includes two items to be checked off: Client Smokes and Client Drinks. L checked the No box on both of these, thus eliminating the need to tick a box on the next line: Degree of Problem - none, moderate or major. Similarly, the section on Mental Health offers ten categories in each of which the assessor can select either normal/appropriate, or from a whole range of presumably inappropriate and abnormal possibilities. My favourite category is Affect, in which one may either be checked off as appropriate, inappropriate, anxious, blunted, euphoric, depressed, labile, angry or having a history of mood swings. "All of the above" does not appear to be available as a choice, though it would have described me!

L's comments in the Activities of Daily Living section forecast our need for home support: "Bed in living room. 2x/week bath, introduce bed care. No equipment as yet." It was in the section on Housing and Social Context that she wrote, "Wife and 1 son at home. Close family." "Devoted wife, sons. Many good friends, neighbours offering support." I wonder now how much of that "true" picture L deduced from our assessment interview, and how much she knew beforehand from our mutual friend and because her step-son lived in our housing co-op. Can it be a coincidence that the documentary

version of ourselves that seems most like us was constructed by someone who had informal, non-expert knowledge about us?

L's recommendations, on the last page of the assessment, were: "Respite care as requested. Auth. 150 hrs, but due to late involvement, may exceed 150 hrs. Personal care 2x/week (2 hrs initially) then daily. Respite as requested." (Her interest in my receiving respite is evident!) This is followed up on the first page of the assessment, with a summary and indication by checklist of approved services and care level. L's summary reads: "46 yr old man [he was 47] assessed EC level, palliative [Extended Care, the highest level]. CA pancreas, stomach - liver mets, pleural effusion. Ambulatory, weak, continent, eating 'small amounts of everything'. Devoted wife and two sons in Victoria. Reports no pain, MS Contin 45 mg BID [it was 30]. HNC maintaining phone checks. Clients prefer X agency. Respite to be offered, assist with personal care to begin 95.03.20. *HPIA application completed." The last sentence, asterisked as significant, referred to an application for GAIN for Handicapped, to cover the client portion of the cost of home support services. While I had heard other Long Term Care case managers describe the financial data and income testing as the most important part of the assessment process, L had skipped over this part very quickly. I had copies of our tax forms ready to show her, but she never asked to see them. In fact, she had to call back the next day to obtain a figure for my current income, which she had forgotten, she said, to ask me. This was likely another expression of our indirect connection, and her wish to spare us any unpleasantness that she could.

The application for GAIN for Handicapped crosses a bureaucratic boundary from the Ministry of Health to the Ministry of

Social Services (now Ministry of Human Resources). It consists of two parts: the applicant's report, which L filled out and had Jim sign, and the worker's report. It is interesting to me that, on this form, L's description of Jim's situation is subtly different from the version in the assessment form. In the applicant's report which she wrote for Jim, she stated that he "requires 24 hour care, assistance to mobilize, to bathe, all personal care. Requires food prepared, some assistance with feeding, medication administering, toiletting. Requires 24 hour home supports - cost $220.00/day." This doesn't much resemble the other Jim from the assessment summary - "ambulatory, weak, continent, eating". In Part II, the worker's report, L reiterated the need for "between 4 & 24 hrs/day homemaker service depending on family back-up...bed care, bathing, assist to transfer & ambulate, assist with medication, food prep and feeding. 24 hr supervision required. Family are able to provide some support - varying as wife is working." I don't sound quite so devoted in this description! At the time I was working perhaps two afternoons a week; whenever I was working Josh or Gabe were at home.

I understood that L was constructing a different documentary reality through this form for a different organization and different organizational intentions. L made sure to describe us in a way which would unquestionably qualify us for funding. (She even listed as expenses, "Equipment - commode, walker, hospital bed, medications. Approx. $600./month," - all of which we were receiving at no cost from the Red Cross and the Cancer Society.) The Jim that she constructed, while not an accurate reflection in the present, represented a reasonable forecast of his condition in the very near future. In order

to grease the organizational wheels, L had to present this probable future as the present, and to downplay the family and other support available.

I reflected on my own experience of trying to ensure funding for clients. In writing assessments for criminal injury compensation claims, for example, I often focused on the harm suffered by victims and glossed over their strengths. My ethics were troubled not only by the compromise this represented to my values and beliefs, but also by the fact that I would benefit financially from the approval of funding. At the same time I truly believed that counselling was helpful to people recovering from criminal injuries, and thus rationalized the means to this end. However, I now see that the risk of constructing this kind of organizationally relevant identity is that *its* needs and demands may come to dominate or subordinate those of the individual it was created to help.

The evidence indicates that L was similarly affected by conflicting organizational relevances and requirements. While the GAIN for Handicapped payments would not end up in her pocket, they *would* help to make work, for home support workers and their administrative support system as well as for Long Term Care. I don't know if L suffered from any ethical twinges in this process, but I am sure she wanted to ensure that we would receive the services that she predicted we would need, at no personal cost to us. The need for this forecast becomes evident when I look at the dates on some of these documents. The application for GAIN is dated March 13 1995; the approval of handicapped benefits is dated April 13 1995 and arrived in L's office on April 25. It would have been short-sighted of L to

downplay the needs and inabilities which Jim was likely to experience in the six weeks between application and approval.

As it happened, he died on April 5. By that time he did require the intensive care predicted by L - though he fed himself and brushed his teeth up to the day he died. L recommended that home support services for personal care begin on March 20, but I waited until April 3 to call on the agency. That was the day that Gabe and I had a lot of difficulty helping Jim to stand. He had needed some assistance to "mobilize" for awhile. The location of his tumours made it impossible for him to roll over on his side. He was most comfortable sitting up, supported by pillows, but this was taking a toll on his tailbone where the skin was breaking again. He had been standing less and less - only to use the commode, and to have the pressure sore tended - but on this day as Gabe and I struggled with his fragile weight, I realized that it wasn't just a matter of helping him to get to his feet; he suddenly wasn't able to stand on his own. He wasn't going to be getting out of bed again, and I remember seeing my own grief and panic reflected in Gabe's eyes. I wasn't sure how to properly bathe Jim in bed, though we had successfully moved this activity from the shower in the upstairs bathroom, to the side of the kitchen sink, to his bedside. I was worried about how to wash his shoulder-length hair, and how to elevate his hips in order to keep him clean and change his clothes. These were the tasks which I thought a home support worker could do.

Although nothing happened exactly as I imagined, these tasks were much the same ones I'd envisioned when I had spoken to L three weeks earlier. She originally suggested that a worker come in for a four hour shift, but I couldn't imagine what he (I was asking for a male

who could transfer Jim) would do in our house for more than fifteen minutes. Not only did I not want respite, I didn't need help to clean the house, go shopping, prepare meals or provide companionship.

It wasn't that I was doing everything by myself. A steady stream of support arrived on our doorstep - mostly food, but also flowers, videos, money, music, as well as offers to shop, do laundry, clean, keep Jim company, and to be available in the middle of the night - this last from a registered nurse. Sometimes I felt, coming home to our co-op townhouse tucked into a corner of Fernwood, that although I was in pain, I was literally cushioned by the support of my friends and neighbours. It was good to be surrounded by people who cared about us; I often thought how different it would be to come home to a house on a street where I didn't know my neighbours.

I suppose a home support worker could have taken over the cooking that five or six people were sharing. But then we might not have had the Great Lasagna Contest. And would the worker have offered to satisfy any of Jim's food cravings, and whipped up a dozen deviled eggs within a few hours of his request? And how could a worker's companionship be as valuable as, for example, the visits of the four little girls who lived in the co-op? Their hugs and drawings and music tapes "dedicated to Jim"? I became more and more appreciative of the kind of support and caring that could never be professionalized. I began to think of the palliative care system as providing services which were a less preferable substitute for true community care. Of course, it is difficult for any community of people to sustain such a high level of support for a long period of time, and back-up from "outside" may be necessary in some situations. But

the discourse insists on viewing professional support not as back-up but as intrinsic to the care of the dying, a view that translates into work practices which encourage patients and families to utilize their resources.

I was looking for as little service as possible, and L was trying to make sure that we could have as much as possible. This echoes my own experience as a social worker, when I considered it a part of my advocacy role to ensure that my clients had maximum access to resources. Like L, I assumed that people preferred - or needed, whether or not they preferred - to have access to more rather than less service. Now I see this differently.

My friend M told me that 150 hours a month was the standard for palliative patients, and that L was doing good professional work in authorizing as many hours as possible, which I could then use or not. "She's just telling you what's available," M said, "she's not putting pressure on you." But I *experienced* pressure, to go away for the weekend, to use those resources. In L's talk about going away for the weekend, I thought I recognized the "use it or lose it" thinking so common in a threatened public service. As I described this, M compared it to the pressure she experienced from the school system to utilize all the resources available for her children's special needs, whether or not they were appropriate. In class discussions I had heard home care nurses admit to feelings of resentment towards patients who had access to resources they didn't use, while others who desperately needed services often couldn't obtain them. The message came through clearly that since this service was available to us we should take

advantage of it. No consideration was given to the possibility that the service could be detrimental rather than helpful.

I realized that the transformation of the dying person into the palliative care patient also involved the transformation of the home into a workplace. The potential for conflict between the person's requirements for a home and the worker's requirements for a workplace exists in a number of areas. This conflict may occur although the needs and requirements of each party are entirely reasonable.

For example, the home support workers required each job assignment to be of a reasonable duration. L's recommendation of two hour blocks of home support worker time seemed excessive to me. I still thought that what I wanted the worker to do would take about fifteen minutes (maybe thirty on a hair wash day), but M pointed out that workers could not be paid for less than an hour, and that they tended to prefer longer shifts because they were not paid for travel time from one workplace to the next. These are reasonable requirements, especially given the low wages paid to home support workers. However, these requirements conflicted with our need for privacy in a peaceful, quiet environment. Jim had the most energy in the morning, and our routine generally followed breakfast and hygiene with time together, listening to music, looking through our photograph albums, reminiscing, reading stories, meditating, being physically and emotionally close. While Gabe was at home, he generally slept late and didn't inhibit these activities anyway. But it would have been very different in the home-as-workplace, if a home support worker had

been hanging around washing the dishes or vacuuming or doing our laundry.

Unlike the workers, our friends could easily drop in for short visits. The proximity of our co-op neighbours made it simple for them to bring us food or other treats; often they didn't even knock, but left things on our doorstep. The necessary care which they gave us fit more smoothly into our lives than that of the home support worker whom I called in my journal, "the dreaded stranger in the house."

And what would the stranger in the house think about Jim's steadily increasing use of marijuana to stay comfortable and stimulate his appetite? I asked M if that would be a problem. She said with some discomfort that it couldn't really be discussed openly; an employer couldn't knowingly send employees into a workplace where illegal activities were taking place. Although she would look for someone tolerant and open-minded, it would be better if Jim didn't smoke when the home support worker was there. This made sense from the perspective of the employer and worker - I remembered similar conversations I'd had with adolescent clients about not smoking pot at school or in front of me.

At the same time, I wrote in my journal that, "Dave thought the marijuana was working in conjunction with the morphine to produce a pain-free state in Jim. We called it the morphijuana effect." While Jim experienced some abdominal discomfort, he had none of the extreme, intense pain often associated with aggressive cancers. This to me was miraculous, and I would do anything to maintain his comfort. This included opening all the windows to air the place out, and burning

incense before receiving what I referred to as "emissaries from the service network".

It wouldn't have been difficult to restrict Jim's smoking for the one hour of daily home support which we eventually accepted. But this was yet another reason why I wouldn't go away for the weekend. Even if I had needed respite, it wouldn't have been acceptable to us for our serene and pain-free home to become someone's drug-free workplace. Indeed, M told me, even clients' cigarette smoke was beginning to be regarded as a workplace hazard by the Workers' Compensation Board and by some home support agencies. WCB also insists that the agencies carry out safety assessments of clients' homes. Such organizational requirements and relevances, when in conflict with the needs and preferences of individuals, will always outweigh them. That is how the relations of ruling are experienced in our everyday lives.

Organizations such as Long Term Care, through the media of the documents I have discussed in this chapter, translate palliative care services into specific work objectives with time frames. The number of hours approved is derived from organizational relevances and requirements, not from the expressed needs or wishes of the patient. 150 hours a month is the standard for persons in the palliative category, and therefore readily available. Longer shifts are preferable for both home support agencies and workers. These organizational requirements, while outwardly invisible in the documents, may appear in the guise of the patient's assessed needs, such as L's recommendation that we have "between 4 & 24" hours of home support a day. This amount of home support, like the standard twice

weekly visits of the home care nurse, was not only unnecessary, but could have actually been detrimental to Jim's comfort and care.

Whose needs and interests, then - if not ours - were being served by the construction of a documentary reality in which we needed this much home help? L's suggestion, for example, that I go away for the weekend, is incomprehensible except in the context of the availability of worker hours. This context, I would argue, must have been related to the needs, interests and priorities of the participating organizations, and to the real life organizational issues involved in managing a labour force and a client population in times of budget restraint and cuts. Similarly, the text-mediated categorization of needs and eligibility, which I found to be practices of objectification, can be understood as serving organizational requirements for accountability in the process of allocating resources. In these ways, I realized, my experience had been bent and shaped to a framework determined by the organizations whose task it was to intervene in that experience.

Our need for professional palliative care was far less urgent than our need for professionals to tread lightly on our lives. Yet this latter need was never fully acknowledged by any of those involved, except for our physician. For the others, we were as the discourse constructed us, palliative patient and family caregiver, consisting of multiple problems requiring the services of a multidisciplinary team. And, as I discovered in my perusal of the files, we unwittingly collaborated in the construction of an altered version of ourselves and our needs, through the interaction of discourse, documents and work practices, which then assisted in the subordination of our own knowledge and experience.

Chapter Seven

What I Learned

What I learned from my analysis of the data has influenced me both personally and professionally. While this is only a part of the life-changing learning that I experienced in Jim's dying, it is the part most relevant to my practice as a social worker.

I began this study from the "ground zero" of my lived experience: the irritation and disappointment with community palliative care professionals that signaled a clash or disjuncture between my world and theirs. The guilt which accompanied my criticism of their work practices or of the Holy Binder recurred as I set out to analyze the social organization of the documents. Now, in reflecting on the process, I realize that guilt was in part inspired by my sense of the nurses and social workers involved as skilled and compassionate professionals. I knew that they were trying to help me, and the guilt was for being ungrateful. However, my study and analysis of the documents showed me how these efforts by workers were mediated by a discourse-driven organizational process which could clearly be seen to objectify the recipient of services. Our induction into the category of palliative care patient by Nurse B was our first experience of such an objectifying practice, in which Jim's signature on the "official death warrant" established him as an object of the work of the multidisciplinary team. Even after he died, this work object lived on a bit longer, as his file circulated through the GAIN system back to the CRD and the home support agency.

The Holy Binder, our palliative care instruction manual, reflected the assumptions of current palliative care literature that dying persons and their caregivers are experiencing multiple problems which can only be addressed by a multidisciplinary team. This assumption is textually represented by the document analyzed in Chapter Five, the Open Flow Sheet. The breakdown of our situation into the manageable problems required by the organization was another example of the objectifying nature of the process.

What I learned helped me to dispel, forever I hope, the guilt that dogged my research and made me reluctant to discuss it. I saw that the construction of "palliative care recipients" - a category into which we didn't fit properly - was not intended to address individual needs and feelings, but those categorial needs and feelings sanctioned by discourse and amenable to tending by the palliative care team. My discomfort is comprehensible to me as the sense of being squeezed to fit as an object of work into the organizational context.

I contrasted the guilt I felt in relation to the community care providers with the pride and gratitude which filled me when I thought about the support of my family and community. In the end it seemed crazy to feel guilty about my research when, despite the ominous forecasts of the literature, I experienced no guilt about my final four months with Jim, or for anything left undone or unspoken between us. The workers would go on to minister to others, some of whom would truly find them to be the angels of mercy thanked effusively in obituaries. But we had just this one chance to experience Jim's dying; we couldn't try to do it better next time. So I've resolved to be

finished now with guilt, though it pushed me into my analysis as much as it pulled me away.

My analysis also helped me to see how the textually mediated process of helping constructs the workers involved as much as it does the clients or patients. This bridged the gap between my sense of most workers as competent and caring, and my overall experience of being objectified and misinterpreted. The organizational and discourse-oriented constraints and limitations on the worker's practice, as I have demonstrated through documentary analysis, may result in her own conscription as an agent of a process which I have described as both colonizing and objectifying. The worker's caring and helpful intentions can be overwhelmed by a process that is unable to address individuality in any useful way.

At several points during my discussion of the data, I have written about my own social work practice as a way of extending my understanding of how this process takes place. My experience as a recipient of service, and my reflections on that experience, have greatly *deflated* my previously held assumptions about people's need for professional helping, as well as further developing my ideas about the value of such professional help vis-a-vis localized community support.

These ideas, whose influence on me preceded Jim's illness by several years, have had a profound impact on the way I work; my personal experience as an object of helping has strengthened and anchored my beliefs. As I worked on this study, I thought about the many ways in which professionals create their work by defining people's lives in terms of problems to which they (the professionals,

the multidisciplinary team) also have the solutions (Ferguson, 1984, Mueller, 1995). I realized how I too might construct my clients according to particular organizational contexts, in a way which benefits me at least as much as them. When I find myself building for a person an alternative identity of "damaged victim" in order to secure criminal injury compensation, when I hear myself using the words, "you need to...", or catch myself making assumptions that more service is preferable to less, I intervene in people's lives in ways that have real effects; effects which in my experience as a client were objectifying. My entitlement to intervene in this way is founded in the professionalization of helping, and my own supposed possession of professional expertise. There's a certain irony to my disclaimers in an academic context which is key to the construction of this notion of expert knowledge. Nevertheless, I have for several years been considering ways of detaching myself from ideas about social workers as experts, and thinking about my "expertise" as experience and skill in listening and asking questions. The work of White and Epston (1990, 1992) has been most influential in terms of my actual work and language practices in attempting to be helpful to people.

When Jim became ill, I immediately stopped taking new referrals, and wound down with most of my active clients. A few months after his death I started working again, but on a greatly reduced scale. I soon realized that I felt more comfortable with my practice when it wasn't my sole source of income! As I increasingly tried to work from a standpoint of acknowledging people's strengths and capacities for self-care, I tended to see people for fewer sessions. The ebb and flow of the marketplace could, I decided, act as a

constraint on my ability to work in this way; I, like the palliative care professionals, could be tempted to create work by looking for problems. Although initially I curtailed my practice because I was doing the work of grieving, I discovered that it was easier for me to trust in the capability of those I worked with when I didn't need them to be my work.

I did, however, need other work, which I found primarily as a social work educator. In this role the dilemmas of professionalized helping are also inescapable. Professional training does not successfully address the way social workers are incorporated into ruling practices as they become agents of organizations. While some schools, including University of Victoria's, teach a structural approach to social work which addresses the impact of dominance and oppression on groups and individuals, practice applications of this approach are often fuzzy. Students sometimes assume that their critical analysis itself will be therapeutic to people; when I asked once, "What is the difference between telling people they are oppressed and telling them they are sick?" the reply was, "One is true and the other isn't." More often they are anxious to acquire "skills" which they have been told will function as the "tools" of their trade. Rossiter (1993) has described the teaching of social work skills and competencies as a technological approach based on control and predictability which reproduces the very patterns of domination it seeks to oppose. She proposes alternative methods based on understanding meaning, reflection and encouragement of uncertainty, rather than the reproduction of skills and the idea of "getting it right". Rossiter's ideas about how to help students practice taking another's perspective have

been useful to me in teaching practice oriented social work courses, as have the ideas and questioning practices of White and Epston.

However, even as I seek out alternative ways of working with students and with clients, I'm aware of the risk involved in seeing any method, technique, or even way of thinking, as a solution to the dilemmas of professionalized helping I have discussed in this thesis. We may come to believe that we have found a way of doing helping work that is not objectifying to persons, that if we have the correct political perspective and the latest technology of questioning, we are not complicit in ruling processes. This would be a mistaken belief. It is important that students understand their co-optation into these practices as both an inevitable result of employment in the bureaucracy of caring, and an identifiable and resistible force. Darville (1995) refers to the professional privilege of "organizational literacy" as specialized knowledge in how bureaucracies operate. By rendering this privilege transparent, professionals can use their knowledge and expertise to provide the maximum choice for people, rather than the maximum service. For example, if the social worker had said to me that she was approving 150 hours a month of home support because that was organizationally expedient, I think that would have been preferable to her efforts to convince me that I needed the help.

These are issues that students do not always enjoy confronting, because there is no way to "fix" them, but what I have learned from this study only deepens my commitment to continue presenting them as requiring ongoing attention from all of "us professionals".

For awhile after Jim died, I went around saying that if I followed my heart I would quit counselling and become an advocate

for co-op housing. Perhaps it's fortunate for the continuity of my career that the harmony and goodwill uniting our group during Jim's illness and death was eventually frayed once again by familiar petty issues. Though my idealism may have been rebalanced with gritty reality, I still see co-op housing as an effective means of creating community. This community, of which we were an organic part, had a much more delicate and knowledgeable touch in supporting us than the professional service network, as did our other friends in the neighbourhood. My appreciation for community, and for the help which springs up from it spontaneously and which is not professionally applied, will also have a lasting impact on the way in which I live and work.

Epilogue

On the Sunday that Jim couldn't stand up by himself, I called M to arrange for the "dreaded stranger in the house". The next morning we received another "emissary from the service network", an R.N. who was the field supervisor for the home support agency and came to discuss the details of care. Her report shows that she found Jim mentally alert, fully awake, and "keeping spirits up" during her morning visit. Later in the day, though, he drifted into a strange sleep which lasted far longer than his usual naps.

He was still sleeping when Dave came over that evening and pointed out to us the changes in breathing that indicated "things will reach a conclusion soon."

Gabe said tearfully, "Do you mean tonight?"

"Maybe tonight," Dave replied, then asked, "Why isn't there any music on?" There was always music on.

"Jim and Gabe were going to watch the basketball championship tonight," I said. "We turned it off when you came over, it's half time now."

"Half time?" Jim said suddenly, opening his eyes. "You mean I've missed half the game?" He seemed to return from the shadow lands so clear, so present and alive and disappointed that we all laughed with weak relief. As Dave left, though, he said quietly, "It won't be long now."

The next morning Jim was still clear and awake as we had our breakfast, smoked and talked. He brushed his teeth and I washed his

face and brushed his hair, not wanting to relinquish these loving tasks to the home support worker who was due at 9:00 for his first visit. I wrote about this person that he was "young, a bit nerdy, very efficient". I watched as he gave Jim a bedside bath, just to see if there was anything he did better or differently than me. There wasn't, and I mentally crossed bedside bath off my list of his duties. He lifted Jim so that I could clean and dry the pressure sore on his tailbone, which was now the size of a loonie. It looked bad to me, and I thought I could see more skin breaks on his upper thighs. I told the home support worker that he could leave - we'd wash Jim's hair the next day. He had been in our house for perhaps thirty minutes, some of that spent chatting.

After that Jim started drifting again, his flame flickering, then at times burning bright. Sunshine streamed through the living room windows as we sat with our sons and the friends who came to say goodbye. M and I still laugh about how Jim came back to us dancing in his seat when Gabe put on a James Brown CD, snapping his fingers and singing along. But as the day wore on, he was longer and longer in the shadows, less and less with us. He didn't eat or drink very much, and wouldn't lie down for a nap in the afternoon. He said that he was really comfortable just as he was; it seemed to me that he wouldn't lie down because he knew he wouldn't sit up again. At one point Josh said, "This is torture. We're just waiting for him to die." I answered, "I'm not waiting for him to die, I'm keeping him company until he dies. But it *is* torture, and you can take a break if you need to leave for awhile." But Josh didn't go, and a few minutes later Jim said in his weak croaky voice, "I'm keeping *you* company." It wasn't until evening that we turned him on the hospital bed, stretched out his legs

and covered him with a blanket. He woke briefly and said with a smile, "This is a surprise."

That night I didn't lie down on the foamie or turn out the lamp but slept fitfully on the couch. Whenever I awoke through the night, I could hear his ragged breathing. It wasn't until morning, when I was curled up in the chair by his side and holding his hand, that his breathing just...stopped. I know he waited for me to be there, just as I know that his letting go of life had something to do with his reluctance to be cared for by anyone else. One of the first calls I made was to cancel the visit of the home support worker.

Later I wrote: "When Jim died, when his spirit passed from his body and didn't return, I was too tired and numb to be aware of any supernatural experience. I've thought about how I was sitting beside him and holding his hand, and as his energy left his body, perhaps some of it entered my body. But Jim's energy soaked this house, soaked me, anyway, just as mine soaked him."

Jim's death wasn't quite the end of my misadventures with the palliative care system; I struggled even more with the discourse, documentation and work practices around bereavement. But that is another story.

I'll end this story with my final contact with N, our "regular" home care nurse. She called the day after Jim's death to ask when she could come by and pick up the Holy Binder. I predictably found it odd that she should want it back so quickly, especially since it contained a whole section on Bereavement, but at the time I was anxious to see the last of it. In fact, later that day I went for a walk and dropped the manual off at the community health centre which housed N's office.

This was irresponsible treatment of the Holy Binder on my part, and it certainly never reached N, who came over the next day anyway.

I didn't ask her in.

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