

MANAGEMENT OF BREAST CANCER PAIN IN THE HOME SETTING

A PATIENT PERSPECTIVE

by

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ABSTRACT

MANAGEMENT OF BREAST CANCER RELATED PAIN IN THE HOME SETTING A PATIENT PERSPECTIVE

This study's purpose was to describe, from their own perspective, the experience of individuals coping with metastatic breast cancer-related pain at home. Understanding how individuals cope on a day-to-day basis, in their natural setting, is essential in order to facilitate effective management of cancer pain in the home setting.

Using a qualitative approach and multiple case study design, data was collected by means of unstructured, in-depth interviews with six female co-researchers. All interviews were audiotaped and transcribed verbatim. Transcripts and field notes were analyzed for common themes, which were then reconstructed into a case study format and validated by the co-researchers. Finally, co-researcher accounts were integrated into one coherent description.

This study adds an extensive description to existing literature, providing an explicit portrayal of the experiences lived by these women. There were many

commonalities in their stories, yet each person's story was unique, with each woman managing cancer pain in their own way. This study suggests that women did not commonly achieve adequate pain relief through the use of medications. A multitude of factors, including the severity of medication side effects, influenced their decisions not to take increased doses of pain medications. However, women acted from a position of choice by electing to tolerate pain in order to maintain control of the life they valued. This study leaves little doubt that the impact of pain related to breast cancer is potentially devastating to a life. The challenge of describing and managing cancer pain effectively continues to be a serious problem for both professionals and individuals coping with breast cancer-related pain.

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CHAPTER 1

Introduction

Background to the Research Problem

Pain is whatever the experiencing person says it is, existing whenever they say it does. (McCaffery, 1979)

Despite advances over the past twenty years, there continues to be limited understanding of cancer-related pain, or its impact on the life of the individual. Cancer-related pain afflicts approximately nine million people worldwide annually (Bonica, 1990). Estimates indicate that 60 to 90 percent of cancer patients experience moderate to severe pain at some time during the disease process (Coyle, 1989). Although cancer pain often responds to drug therapy more effectively than other types of chronic pain, it continues to be inadequately treated despite the availability of effective pain relieving drugs (Stjernsward and Teoh, 1990). It is well documented that cancer-related pain is often under treated and that multiple deterrents result in needless human suffering (Bonica, 1990; Elliot and Elliot, 1991; Jorgensen, Mortensen et al., 1990; McCaffery, 1989; Schug, Zech et al., 1990; Toscani and Carini, 1989; Weissman and Dahl, 1990). Metastatic breast disease is

one of the most common sources of cancer-related pain. Breast cancer is a leading cause of death for women in Canada. Assaulting an organ of significant personal, interpersonal, and symbolic value; its course is frequently protracted and unpredictable (Pfieffer and Mulliken, 1984). Because metastatic breast cancer is an indolent process, women may survive for several years or more with painful metastatic disease.

It is important to address the problem of cancer pain management in the home setting, as current economic trends decrease hospital stays and increase management of patients at home. Current knowledge about the management of cancer-related pain, by patients at home, is not well established. Findings suggest that pain is not adequately managed by patients at home (Bonica, 1990; Ferrell and Schneider, 1988; Lander, 1990). An in-depth review of related literature indicates that few studies have focused on pain management from the patient's perspective (Arathuzik, 1991; Bonica, 1990). Clearly, research in this area is vital in order to adequately meet the needs of individuals coping with cancer-related pain at home. Addressing the experience of managing cancer-related pain at home will make a significant contribution by adding to currently existing knowledge.

Statement of the Research Problem

The purpose of this research study is to provide a description of the experiences of women who are coping with metastatic breast cancer-related pain in the home setting, from their own perspective. How do these women manage their pain in the home setting, on a day to day basis? Using a qualitative approach and multiple case

study design, the researcher conducted interviews to explore the ways in which women cope with cancer-related pain; how they make decisions about managing their pain; their perceptions on pain control efficacy; their awareness and utilization of personal, community, hospital resources; the roles of significant others in pain management; and the effectiveness of specific pain management strategies.

Understanding how these women cope on a day to day basis, in their natural setting, is an essential foundation for the provision of quality care and resources. It is anticipated that a better understanding of this phenomenon will help professionals identify individual needs, and plan strategies to facilitate effective management of cancer-related pain in the home setting.

Definition of Terms

In order to provide a frame of reference for the terms used in this study, the following definitions are provided:

Chemotherapy: treatment of cancer with drugs.

Metastasis: action during which cancer cells break from their original site and spread through the body.

Oncologist: a doctor trained to treat people who have cancer.

Opioid: narcotic drugs including natural poppy derivatives (such as Opium, Codeine, Morphine, Heroin) and synthetics which mimic the properties of opium.

Radiotherapy: treatment of cancer using high energy x-rays.

Remission: disappearance of signs and symptoms of disease.

Approach to the Research Problem

The qualitative approach to research theory and methodology has been selected as the most appropriate method of describing, from their own perspective, the experiences of women who are coping with breast cancer-related pain at home. Qualitative research differs from experimental research in that it attempts to "describe what is, not to manipulate or change it" (Haberman and Lewis, 1990). Rather than test hypotheses, it attempts to understand phenomenon by permitting the data to speak for itself (Osborne, 1990). The qualitative or phenomenological method fulfils the goal of seeking to understand an experience, rather than looking for causal explanations (Colaizzi, 1978). It describes in order to know, rather than the experimental method's attempt to know in order to predict or explain. It also emphasizes the perspective of the individual living the experience, rather than the researcher's perspective.

Qualitative inquiry is particularly useful in examining phenomena that vary and change, since it is based on the assumption that "existing patterns can never be assumed to remain stable" (Haberman and Lewis, 1990). Thus, it is well suited to examining how women cope with cancer-related pain, an experience that fluctuates and changes over time.

Because pain is "whatever the experiencing person says it is" (McCaffery, 1979), the individual coping with pain is most qualified to describe the unique experience that has become his or her reality. According to Colaizzi, "experience with the investigated topic and articulateness suffice as criteria for selecting subjects" (Colaizzi, 1978). By providing an accurate and rich description of the phenomena under investigation, the qualitative approach offers the means of making explicit the lived experience of women who are coping with breast cancer-related pain at home.

Summary

The problem and purpose of this research study have been introduced in this chapter, followed by a brief summary of the rationale for the research approach selected. Chapter Two examines the literature relating to the management of breast cancer-related pain. Research methodology is outlined in Chapter Three, including a description of the research design, participants, interviews, validation procedure and analysis of participant accounts. Chapter Four presents all participant case studies, constructed from verbatim transcripts. Common patterns and themes identified in the case studies are discussed in chapter five. Chapter Six contains a summary of research findings, and implications for research and practice.

CHAPTER 2

Literature Review

Introduction

How do women with metastatic breast cancer manage their related pain in the home setting? This specific problem has not been adequately addressed in the literature. A review of related research provides background information about the nature of this problem.

Significance of Cancer Pain

Pain, or fear of pain, is a significant element of a cancer patient's experience. It is not surprising that, for the nine-thousand Canadian women who develop breast cancer each year, this diagnosis triggers enormous fear. Surveys of patients in major cancer centres indicate that 60 to 90 percent of patients experience moderate to severe pain at some time during the disease process (Abram, 1989; Coyle, 1989; Foley, 1987).

Cancer pain has been described as all-consuming and overwhelming for patients and their care providers, a sometimes "crippling force for family and professionals in their frustration of managing this complex symptom" (Ferrell and Schneider,

1988). According to Spiegel and Bloom (1983); the pain experience includes the meaning of pain to the patient, expectations about progression of illness, emotional state, degree of family support, and results of pharmacological, medical, and psychological interventions to control the pain experience. McCaffery (1989), meanwhile, views pain as "whatever the experiencing person says it is, existing whenever he says it does".

The World Health Organization (WHO) has estimated that 3.5 million people worldwide suffer from cancer pain (Abram, 1989). Global attention to the cancer pain problem has been focused by WHO since 1982, when research and development of the WHO Cancer Pain Relief Program began, establishing cancer pain as a significant, complex and potentially devastating worldwide problem (Stjernsward and Teoh, 1990).

Breast Cancer-Related Pain

Metastatic breast disease is one of the most common sources of cancer-related pain (Bonica, 1990; Coyle and Foley, 1987; Kanner, 1988; McGuire, Foley et al., 1989; Pfeiffer and Mulliken, 1984; Watson and Evans, 1982). Breast cancer-related pain is most often due to tumour invasion of the bone. Pain is experienced in 77 per cent of breast cancer patients with bone metastases, and bone pain is present in 56 per cent of all breast cancer patients (Bonica, 1990). Publications discussing breast cancer pain are extensive, with research falling into three main categories: theory, prevalence, intensity and assessment of pain; drug and non-drug modes of pain relief; and health professional behaviour

and attitudes in the management of cancer pain. Results have been variable, and few studies focus on pain management from the patient perspective. Despite advances over the past twenty years, an overview of research in the field suggests that there continues to be limited knowledge of cancer pain, or its individual impact.

Management of Cancer Pain

As current economic trends reduce hospital based services, more and more patients manage their cancer pain at home. Increasingly, drug and non-drug modes of pain management are implemented in the community setting. Since much of the available information on cancer-related pain and its management comes from hospitalized patients, the extent of the problem for patients cared for at home is largely unknown (Coyle, 1989). This is corroborated by Ferrell and Schneider (1988), who state, "there is a lack of data to support the effectiveness of home management of pain by cancer patients and a need for improved measurement techniques for such interventions". Coyle (1989) suggests that, unless pain is treated at the level of significance experienced by patient and family, enormous suffering and inadequate pain control may occur. Coyle stresses the importance of bridging the gap between hospital and community, so that the expertise of the hospital is brought home to the patient. She identifies outpatients as a high risk group for poor pain control, with high levels of physiologic, psychologic, and social fatigue as the norm. Ferrell and Schneider (1988) emphasize the importance of the pain management problem in outpatient and home populations, where complex symptom management is often provided by family members of patients. Current literature

supports the importance of addressing the problem of women managing breast cancer-related pain at home.

Research results suggest that knowledge and technology exist to effectively control cancer pain. Findings infer that 80 to 90 percent of cancer pain can be controlled by implementation of the WHO Cancer Pain Relief Program's recommendations to give "the right drug, in the right dose, at the right time intervals" (Stjernsward and Teoh, 1990). The WHO Analgesic Ladder (Bonica, 1990) provides a three step incremental structure prescribing combined opioids and non-opioids for the control of cancer pain (increments move from non-opioids at step one to strong opioids at step three).

Recent studies examining the efficacy of the WHO Cancer Relief Program suggest it provides satisfactory pain control and improvement in quality of life (Toscani and Carini, 1989; Schug, Zech et al., 1990; Wenk, Diaz et al., 1991). In an Italian hospital district, Toscani and Carini (1989) applied the WHO guidelines to fifty-two persons suffering with chronic advanced cancer pain. "Considerable reduction in pain" was reported among patients during the first two weeks of therapy, with pain reduced to a "relatively even level" regardless of pain intensity at initial assessment. Still, "only a very few" patients were able to achieve short periods during which they were totally pain free. Toscani and Carini conclude that the WHO strategy "has proven extremely effective with simple, easy-to-use techniques requiring few means of continuous patient control".

Another study citing the effectiveness of the WHO Program was conducted by Schug, Zech and Dorr (1990). At the beginning of the study 92.5 percent of the sample (175 cancer patients) described their pain as "far more than moderate" on a six point verbal rating scale. Following introduction of drug therapy based on WHO guidelines, 80 percent of all patients described their pain as ranging between "none" and "moderate" at all times. An "acceptable level of pain relief" was maintained throughout therapy in about 90 percent of patients, whereas 11 percent had to be treated by other methods. Schug et al. emphasize the importance of using strong opioids, especially Morphine, in the treatment of cancer pain. They found 50 percent of overall treatment time spent at Step III of the WHO Analgesic Ladder.

An Argentinean study (Wenk, Diaz et al., 1991) reported improvements similar to those described in the two previous studies, in a sample of ninety-eight patients, 69 percent of whom reported "strong" or "unbearable" pain prior to the study. Complete data collection occurred for only 28 percent of the original sample. On the basis of Karnofsky performance scores (Karnofsky performance scale classifies patients according to physical status, with zero representing the dead client and one hundred representing normal activity with no complaints) and data collected from patient charts, these patients "obtained at least acceptable pain relief at rest" after commencing drug therapy according to the WHO regime. Wenk, Diaz, et al. (1991) state that "successful pain control can be achieved with very limited resources if the pharmacologic approach and oral medication are used". Conclusions derived from

this study's results are limited due to unexplained inadequacies in the data collection.

All three studies investigating the efficacy of the WHO Program measured the patient's experience of pain by interpreting self-rated pain intensity scales (Verbal Response Scale, Integrated Score); self-reported changes in hours spent sleeping, resting, standing, lying and sitting; and/or changes in Karnofsky scores. Although changes were apparent in the performance status scores and pain intensity scores of a significant number of patients in each study, the results must be viewed cautiously. Using a unidimensional tool such as Karnofsky's performance scale to measure quality of life or pain is problematic, considering the multidimensional nature of the pain experience and quality of a life. Further, the validity of the Integrated Score, developed by Ventafridda and colleagues, has been substantiated only indirectly as a technique for quantifying pain (Bonica, 1990).

Pain measurement instruments used in these and many other quantitative studies assess pain intensity, but lack information about location, quality, associated symptoms, pattern, patient's preferred methods of coping, or factors that relieve or aggravate pain (McMillan, Williams et al., 1988). The difficulty of obtaining an adequate and reliable report of an individual's pain is documented throughout the literature, and it is commonly suggested that patients tend to under-report or minimize their pain (Bonica, 1990; McMillan, Williams et al., 1988; Syrjala, 1987). One of the most challenging aspects of pain measurement and subsequent management is that of understanding what pain means to the person experiencing

it. If the experience of pain is misunderstood, it is not likely to be managed effectively.

The previously mentioned studies do, however, confirm Sjernsward and Teoh's (1990) premise that application of existing cancer pain management knowledge and technology is both inconsistent and inadequate throughout the world. Sjernsward and Teoh comment:

It is widely known what the obstacles are to obtaining effective cancer pain relief. Many patients accept pain and suffering as part of their disease. There is a fear of addiction. Doctors under prescribe and nurses under dose, and the drugs are not given regularly at scheduled intervals. There is lack of education in cancer pain therapy for health professionals.

Bonica (1990) notes that little progress has been made in the incidence of unrelieved cancer pain over the past twenty-five years, even among the medically advanced nations. He states:

In view of the great advances in biomedical scientific knowledge and technology, and especially the great amount of interest in and effort devoted to cancer research and therapy, why is cancer pain inadequately relieved? I have seriously considered this important question over that past 36 years and have repeatedly suggested that it is a result of inadequate appreciation or outright neglect of the problem of pain (in contrast to the problem of cancer) by oncologists, medical educators, research institutions, and national and external cancer agencies.

Elliot and Elliot (1991) conducted a survey of all physicians in Duluth, MN, in order to explore the often cited belief that "insufficient physician education in

cancer pain management is one of the major factors contributing to inadequate pain relief of cancer patients throughout the world". Responses from 150 physicians (62 percent of original sample) reveal that only 16 per cent of physicians learned about cancer pain management in medical school.

A study of 2459 nurses' knowledge of opioid analgesic drugs and psychological dependence confirms that the majority of nurses attending education programs on pain have inaccurate knowledge about "what is and is not an opioid drug" and the incidence of addiction in their use as analgesics (McCaffery, Ferrell et al., 1990). The sample likely represents the most knowledgeable of health professionals, leading to the conclusion that basic nursing education has not provided nurses with knowledge that enables them to assume an active role in pharmacological management of pain.

Many research studies suggest that a combination of drug and non-drug strategies promote the most effective pain management (Bonica, 1990; Coyle, 1989; Ferrell and Schneider, 1988; McGuire, Foley et al., 1989; Spiegel and Bloom, 1983; Watson and Evans, 1982). Bonica (1990) states, "More recently the importance of treating the whole person (rather than just the lesion) has been appreciated". He advocates that multimodal therapy is essential in the treatment of cancer pain, considering the numerous mechanisms of chronic pain in general, and cancer pain in particular.

Despite inferences that pain is most effectively managed through multifaceted therapy, research about drug therapy far outweighs that pertaining to non-drug

modes of therapy. A literature review of psychological approaches to cancer pain management by Ahles (1987) reflects that although these approaches appear to hold promise for reducing pain, further research is needed to validate the efficacy of techniques with cancer patients. Further, because psychological treatments require time, energy, and concentration on the part of the patient; the presence of intense cancer-related pain and fatigue are viewed as barriers to the success of psychological intervention (Ahles, 1984).

Several studies have examined the application of relaxation, hypnosis and biofeedback to the management of cancer pain, but results remain inconclusive (Blanchard and Ahles, 1990; Bonica, 1990; Ewan, 1986; Spiegel and Bloom, 1985; Syrjala, 1990). Of great current interest is the use of relaxation and imagery in the treatment of cancer, not only as a means of relieving pain, but as a treatment approach used in conjunction with traditional cancer therapy (Simonton, Matthews-Simonton et al., 1978; Siegel, 1989). Available research on the effectiveness of relaxation training for pain management has been confined to the study of non-malignant pain, primarily among patients with tension headaches (Syrjala, 1990).

In a review of biofeedback therapy literature by Blanchard and Ahles (1990), one study was conducted on patients with cancer pain. Results indicate that five out of ten patients achieved a short term decrease in pain. It is also reported that older patients over 60 tend to receive less benefit from biofeedback and relaxation techniques (Ahles, 1984).

It has been well documented among persons with chronic debilitating non-malignant pain, that hypnosis can dramatically alter an individual's perceptions of pain (Barber, 1990). In recent years, hypnosis has been applied to cancer pain with apparently promising results, but the few systematic investigations available focus on children and adolescents. Ewin (1986) observes that the hypnotherapist proposing to end a cancer patient's experience of pain may be a threat to the patient, in that pain is associated with life. He states, "Being alive and in pain is better than being dead without it . . . as long as the pain is present death cannot have occurred, and the pain gives subconscious reassurance of this" (Ewin, 1986). Ewin voices caution about using deep hypnotic suggestions with individuals experiencing chronic cancer pain. It is commonly recommended that hypnosis is used as an adjunctive tool for symptoms associated with pain, such as stress and fatigue (Ahles, 1987; Ewin, 1986).

Cognitive-behavioral methods are frequently utilized to reduce cancer-related pain, with the purpose of learning new cognitive and behavioral responses to pain and stress, thus providing a sense of control over pain and minimizing negative emotions and thoughts about pain. This, in turn, may further reduce pain, suffering, and pain behaviours (Turner and Romano, 1990). Cognitive-behavioral strategies include distraction, cognitive restructuring, and coping skills training. Empirical study of the efficacy of these techniques for the treatment of pain is still in its infancy, as evidenced by the lack of studies documented in the literature.

Williams and Keefe (1991) examined the degree to which 120 patients' beliefs about chronic pain related to their use of and perceived effectiveness of cognitive-behavioral coping strategies. Results indicated that 70 percent of the sample believed that pain was "enduring and mysterious", and were less likely to use cognitive strategies, more likely to catastrophize, and less likely to rate their coping strategies as effective in controlling and decreasing pain than subjects believing their pain to be understandable and of short duration. Patients who believed their pain was "enduring" and of a permanent nature failed to comply with physical therapy and psychological pain management strategies. Patients who believed they understood their pain and that it would be for a short duration rated their ability to decrease pain as significantly greater than the other groups. These findings suggest an understanding of patients' beliefs about pain may have implications for the process and outcome pain management strategies.

Fishman and Loscalzo (1987) used case studies to illustrate the application of cognitive-behavioral techniques for pain cancer management. Their main objective was to provide experiences of personal control that would increase symptom tolerance and counteract feelings of helplessness. Their findings suggest that psychological interventions can be very effective in the management of cancer pain. The fundamental philosophy of their approach is that:

Persons have, or can acquire, substantial control over their conscious experience and behaviour, and can therefore limit their suffering and enjoy aspects of their personal experience even in the presence of cancer pain.

At present, there is a lack of empirical data pertaining to management of pain among cancer patients, with the focus on psychological study results obtained from non-malignant pain population.

Management of Breast Cancer Pain

Pain experiences of eighty-six women with breast cancer were evaluated over a period of one year by Spiegel and Bloom (1983). Level of mood disturbance and belief that pain were indicative of worsening illness were significantly correlated to reports of increased pain. Surprisingly, measures of social support, social functioning, and coping strategies were not found to be significantly related to the pain experience. This is in direct contrast to Coyle's (1989) findings, which infer that good support systems and established coping strategies are significant to the pain experience. Meanwhile, other researchers emphasize the importance of support systems in the management of pain (McGuire, Foley et al., 1989; Bonica, 1990). Loscalzo and Amendola (1990), writing from a social work perspective, view psychological and behavioral approaches as significant synergistic adjuncts to drug and medical treatment for pain. They claim that psychological techniques have been useful in reducing the actual pain experience, managing emotional responses to pain, and in supporting health behaviours to enhance efficacy and function. Their assumptions appear to be based on research with non-malignant pain syndromes. It is vital to determine the significance and relationship of these factors to the experience of cancer pain.

Spiegel and Bloom's (1983) study substantiates that pain represents not only physical discomfort, but also a preoccupation with disease progress and a statement of psychological as well as physical distress. Their data suggests that use of drug therapy coupled with treatment of emotional distress and anxiety should result in less pain. This premise is supported throughout the literature (Abram, 1989; Bonica, 1990; Coyle, 1989; Ferrell and Schneider, 1988; McGuire, Foley et al., 1989). Although Spiegel and Bloom's research suggests implications for pain management strategies in the home setting, inferences are inconclusive, warranting further investigation.

Watson and Evans' (1982) study of 210 subjects assessed breast cancer-related pain over twelve months. Results of pain management strategies were subjective patient responses classified by the researchers as "good", "poor" or "unchanged". "Good" relief meant there was minimal or no pain, whereas "poor" relief meant there was less pain but that it was still significant. They found that analgesic drug therapy provided "good" relief in 68 percent of instances used, and that psychotropic drugs were helpful in 59 percent of instances. The study's main focus was to describe pain by site, etiology and type. They concluded that minor pain is relieved by drug therapy or radiation therapy, or supportive care such as physiotherapy or psychotherapy, while psychogenic symptoms are best treated with psychotropic drugs.

Far-reaching conclusions such as Watson and Evans' should be viewed with caution. Methodology is vague, assessment tools are not described, and the

rationale for pain classifications (good, poor) are not established. There is no discussion of subjects classified as having "poor" relief. Further, since a large number of patients were lost to follow up (eighty-three died, fifty-four lost to follow up) it is not possible to know how the effects of therapy in that group would have affected the overall results.

McGuire, Foley et al. (1989) describe pain control in breast cancer from a medical perspective. Their description provides an in-depth review of drug and medical measures for management of pain, with reference to the importance of support systems, teaching patients cognitive approaches to pain management, and helpfulness of group support. McGuire et al.'s information is limited by its exclusive focus on the medical role in managing pain, and lack of discussion about effectiveness of treatment for pain. Like other authors (Spiegel and Bloom, 1988; Watson and Evans, 1982), limited information is offered about the actual experience of managing pain, from the perspective of the patient.

Arathuzik's (1991) recent study describes the pain experience of eighty advanced breast cancer patients and the coping responses they use to manage pain, from the patient perspective. Data collection tools include a Pain Intensity Scale, questionnaire, and a coping response measurement tool, which were administered in a private interview. The majority of patients had pain lasting an hour to several hours at a time, while many others had pain lasting most of the day.

Findings demonstrate that patients rely on a variety of behaviours and strategies to manage their pain. Those patients who seemed to cope more

effectively with their pain used several responses to manage each episode. In addition to taking medications, patients tried to remain as active and ambulatory as possible. They also used distraction, relaxation, visualization, and cognitive restructuring to manage pain. A list of common concerns contributing to their pain experience included: interferes with housework, causes fatigue, causes determination to get well, causes appreciation of good health, interferes with daily activities, and affects body functions. Arathuzik's study provides the most complete description of the impact of the breast cancer pain experience and patient coping responses available in the literature to date.

Management of Cancer Pain in the Home Setting

Several studies have indicated that cancer pain management in the home setting is less effective than pain controlled within the hospital setting, and that there is a trend toward higher pain scores at home upon discharge from the acute care setting (Dobratz, Wade et al., 1991; Ferrell and Schneider, 1988; Jorgensen, Mortensen et al., 1990).

Miller and Walsh's (1991) study of 100 patients with advanced cancer demonstrated that 57 percent of the sample were having difficulty or were unable to manage in the home setting. Emotional upset, financial stress, and home management problems were cited as primary concerns. Miller and Walsh conclude that patients and families trying to manage advanced cancer at home have major psychosocial needs in addition to physical problems. Further, they found that

community resources were inadequate and suggested that traditional cancer services do not commonly address the complexity of the cancer patients' needs.

Oleske, Heinze et al.'s (1990) study investigating the quality of life among cancer patients receiving home nursing care cites pain as the most common specific problem described by patients at home. Their study results were based on data collected from personal diaries completed by patients at home. An average of 35 percent of the recording days contained documented health problems, with 75 percent of the concerns pertaining to physical complaints. They also reported an unexpected finding, that women with breast cancer reported a high frequency of problems referable to psychological and mental disorders. Otherwise, breast cancer patients managing at home described feeling most concerned about general physical symptoms, medication administration, digestive symptoms, and musculoskeletal symptoms.

A study conducted by Ventafridda (1989) and colleagues at the National Cancer Institute of Milan's Pain Clinic examined the efficacy of a home care program for cancer patients managing pain at home, using an approach that extended multidisciplinary expertise and support into the home setting. A team composed of doctors, nurses, psychologists, social workers, and volunteers relied on a relationship based on trust to collaborated with patients and family members in the home setting. They endeavoured to fully inform patients and families regarding the disease and its progression, treatment methods and goals, purpose and effects of medications. In a sample of 50 patients, 33 were enrolled in the program and the

remaining 17 (living outside the treatment area) were assisted only by family members. A deterioration in quality of life among patients not enrolled in the program was indicated, whereas quality of life measurements remained constant among the home care group. Decreased pain was evident among both groups, but a statistically significant difference was apparent in favour of the home care group. Ventafridda and colleagues assert their conviction that a multidisciplinary approach is a vital necessity for the cancer patient and family coping with related pain at home.

Coyle (1989) describes a continuity of care program model that provides community based care for cancer patients with chronic pain, and meets the needs of community professionals faced with the care of cancer patients with pain problems but who have limited experience in such management. The model is patient and family centred. Coyle provides case reports that illustrate the effectiveness of the program in helping individuals and their families maintain adequate pain control in the home setting. Following one hundred patients over three to 662 days, Coyle found that managing cancer pain at home demands multifaceted community resources and interdisciplinary liaison. A pain management and supportive care hot line seemed useful in providing community professionals access to resources of the hospital pain management team. Her study suggests that, once recognized, such programs are well utilized and provide effective support for the management of pain at home. Her study is one of the few to address the problem of pain management in the home setting, and offers insight into the patient experience. It also gives an

interdisciplinary perspective of varied pain management strategies, in contrast to previously mentioned studies (McGuire, Foley et al., 1989; Spiegel and Bloom, 1988; Watson and Evans, 1982). Limitations include her lack of reference to problems preventing effective pain management, and strategies that patients use to manage their pain at home.

Ferrell and Schneider (1988) addressed the problem of cancer pain management in outpatient and home care settings in their study comparing pain management in hospital and at home. Using quantitative and qualitative methodologies, they explored difference in pain experience and intensity in hospital and home, and described drug and non-drug management of pain.

Ferrell and Schneider's findings suggest a possible trend toward more intense pain experienced at home. Forty-six percent of hospital patients and 70 percent of home patients stated that they immobilized themselves to decrease pain. Common reasons for not taking prescribed medications included fear of addiction, fears of tolerance, misunderstanding of doses, and feeling that pain was untreatable. Almost half of all patients felt that nothing could be done for pain other than taking medication. Remaining patients described many creative, non-drug methods to decrease pain. There was marked absence in both settings of non-drug intervention by professionals. This focus on drug management of pain is not surprising, considering its focus in the literature (McGuire, Foley et al., 1989; Spiegel and Bloom, 1988; Watson and Evans, 1982).

In Argentina, where cancer pain patients are treated in their homes in collaboration with relatives and the primary physician, it is reported that the majority of patients receive ineffective pain and symptom control (Wenk, Diaz et al., 1991). The researchers conclude that physicians and other health care professionals in Argentina lack knowledge of the proper use of analgesics. This finding is consistent with research results in North America (Arathuzik, 1990; Bonica, 1990; Coyle, 1989; McIntyre, 1988). Wenk, Diaz et al.'s recommendation that patients' families are educated in the use of drugs and techniques to improve patient comfort is supported by Miller and Walsh (1991). Toscani and Carini (1989) suggest that open communication with the family and patient are a key element in the effective management of pain in the home setting.

Schug, Zech, and Dorr (1990) provide further evidence of inadequate pain control among patients managing at home. Seventy-seven percent of their sample (174 cancer patients) were experiencing significant pain despite analgesic therapy. Findings demonstrate that the efficacy of treatment by general practitioners and other physicians prior to the study was "appalling low", due to patients being prescribed drugs on an "as needed" basis, in too-long intervals, or irregularly. It was also found that physicians hesitated to use strong opioids, especially Morphine, in the management of even moderate to severe cancer pain.

McIntyre's (1988) qualitative exploration of the cancer pain experience from a patient perspective concurred with many of the previous findings regarding ineffective pain control among patients managing their care at home. She

interviewed twelve patients undergoing treatment at a British Columbia Cancer Pain Clinic, and found that patients interpret and manage their experiences of pain in unique and individual ways. Patients frequently did not take medications for fear of addiction, discomfort of side effects and loss of personal control. In spite of unique differences among patients, common concerns of the client group were identified. Patients shared a common belief that others do not understand what it is like to live with cancer pain, that resources available for pain management are inadequate, and that controlling their pain and lives is a tremendous challenge.

McIntyre's findings also suggest that inadequate understanding by health professionals interferes with patients seeking help with their pain. This supports data in the literature that a lack of knowledge among health professionals is an obstacle to obtaining effective cancer pain relief (Arathuzik, 1991; Bonica, 1990; Stjernsward and Teoh, 1990).

Many of McIntyre's findings have been further supported in Arathuzik's (1991) descriptive study of the pain experience among breast cancer patients managing pain at home. In this study 66 percent of outpatient subjects used only mild analgesics for pain relief despite experiencing moderate to severe pain, even though they would likely have benefited from stronger opioid analgesics. Patients often did not take their analgesics on a routine basis. Arathuzik found many patients lacking basic information about medications and their effects, despite having been instructed by doctors and nurses. Patients refrained from taking medications for various reasons, including: not knowing stronger medication for the pain was available; not

wanting to bother the doctor for stronger pills or being unaware they could do so; not wanting to complain about ineffective medications that had just been prescribed; resolving to bear the pain; and fear of addiction. These studies provide a valuable exploration of the experience and management of cancer pain at home. While the literature (Coyle, 1989; McGuire, Foley et al., 1989; Spiegel and Bloom, 1988; Watson and Evans, 1982) suggests that pain can be effectively managed in any setting, study results indicate this is not the reality. Barriers to effective pain management have been identified. Future research is needed to further explore pain at home and to test interventions for improved pain management.

Summary

In summary, the literature suggests that women should be able to manage breast cancer-related pain at home, achieving adequate pain control, by combining appropriate drug and non-drug strategies. Current research, however, does not establish that women are managing their pain effectively at home. A major limitation of available literature in its present scope is its emphasis on management and experience of pain within the hospital setting, where pain management is largely controlled by health professionals. The experience of pain outside this setting and the management of pain by patients themselves has been shown to be largely unknown. Minimal research reflects the patient's contribution to managing pain. There is little data about efficacy of medications and other strategies used for pain control, from the patient perspective. Study findings based on hospital patients warrant cautious interpretation when applied to community based populations.

Finally, much of what is presented in the literature is anecdotal, rather than empirically sound.

This writer's critique of the research literature on pain management is substantiated further in Lander's (1990) recent review of research on the "extent of under-management of pain", spanning 20 years. She criticizes the research on pain management as suffering from important methodological weaknesses, suggesting that study samples are often small and non-representative, and that data analyses are often poor. She also suggests that tools for assessing knowledge and judgements about pain management are not consistently reliable and valid. Landers concludes that much of the current research--focusing on patient or health professional traits as correlates of poor pain management--does not contribute to an ability to more effectively manage pain. She recommends that further research attend to factors that are appropriate for intervention.

Review of current literature raises many questions and establishes the need for exploring the problem of cancer pain management at home. Addressing the problem of how women manage breast cancer-related pain in the home setting will broaden the scope of knowledge in this area. It is this knowledge that will help professionals identify individual needs and facilitate effective management of pain at home.

CHAPTER 3

Methodology

Research Design

As discussed in Chapter One, the qualitative approach to research theory and methodology has been selected as the appropriate method for describing and interpreting, from their own perspective, the experiences of women who are coping with breast cancer-related pain at home.

A qualitative study's exact structure is only broadly defined at the study's onset, with the expectation that concepts will emerge without prior influence by what the researcher regards as the significant elements of the phenomenon being studied (Haberman and Lewis, 1990). Researchers often combine several qualitative approaches into a suitable methodology. Common assumptions underlying qualitative research include (Haberman and Lewis, 1990; Leininger, 1984):

- 1) Human beings create personal and social meanings as they transact with their environment.

- 2) A natural environment--including socio-cultural, physical and historical aspects --provides rich, meaningful data concerning people.
- 3) Multiple views of the same reality exist; realities are constructed, dynamic and holistic.
- 4) Cognitions help people make sense of their reality, and it is the role of the researcher to discover and attempt to comprehend these cognitive world views.
- 5) Researchers and participants are interactive, influencing each other in inseparable dialectic.

This approach contrasts and complements the quantitative or experimental approach, which is shaped from the beginning by a theoretical concept or structure which is stated prior to collecting data. The quantitative approach seeks to establish causal and measurable correlations among the variables under study, while the qualitative strives to document "as fully as possible the totality of whatever is being studied in particular contexts, from the persons' point of view or frame of reference" (Leininger, 1985). An attempt is made to illuminate the human experience through description.

The present study employed a descriptive multiple case study design. According to Yin (1989), case study designs are the preferred methods of investigation when "how" or "why" questions are being posed. He defines the case

study as "an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (Yin, 1989).

Sources of descriptive data may include interviews, written field notes, participant observation, direct observation, physical artifacts, personal diaries, and archival records (Yin, 1989). This research study relied on systematic interviewing, direct observation, and written field notes to construct a description that accurately reflects the experience of each participant.

Yin contends that the skills required for collecting case study data are "much more demanding than in experiments and surveys", because data collection strategies are "not routinized". He suggests case study researchers possess these skills: an ability to ask good questions and to interpret related responses; effective listening skills; adaptability and flexibility; understanding of the phenomenon being studied; and an openness to contradictory findings (Yin, 1989). Cochran (1985) emphasizes the need to "explicate one's presuppositions about the phenomenon in question in order to prepare oneself for research". Cochran (1985) describes:

If one were full of bias, one would hardly be in a position to stay faithful to another's experience. Ideally, one becomes presuppositionless, but this is not possible and probably not wise either. . . . In practice, phenomenological psychologists do not attempt to eliminate presuppositions, but to become aware of them, to develop a reflexive consciousness of one's own approach. Presuppositions are "bracketed" or isolated from experience for singular examination. The presupposition is stripped of context, and this allows or helps one to stand back and reflect on it, to hold a presupposition in a kind of suspension.

The researcher in the present study explored her own beliefs, values, and assumptions related to how women might be managing their breast cancer-related pain at home. The resulting awareness provided the foundation upon which the study was created. Prior to data collection the researcher attempted to "suspend" her presuppositions in order to be fully present to the participant's experience. The researcher's previous experience and expertise in the field of cancer nursing, complemented by her professional counselling skills and training, made her a worthy candidate for the case study researcher role described by Yin (1989).

The qualitative approach, using a descriptive multiple case study design, has been selected for this research after considering the research problem to be examined, purpose of the study, a review of related literature, and the researcher's attributes. It seems clear that if "pain is whatever the experiencing person says it is" (McCaffery, 1979), this is the only approach that will faithfully illuminate, from their perspectives, the lived experiences of women who are managing breast cancer-related pain in the home setting.

Co-researchers

Role of Co-researchers

The terms "co-researcher" or "participant", often used in qualitative study, highlight the co-operative nature of the research approach (Osborne, 1990). This contrasts with the traditional mode of scientific inquiry, in which the "interviewer-interviewing relationship is marked by a striking asymmetry of power" (Mishler,

1986). The qualitative approach aims to empower co-researchers, encouraging them to express their thoughts and feelings openly, and in their own way. Mishler (1986) states:

... respondents are likely to tell "stories". In sum, interviewing practices that empower respondents also produce narrative accounts. . . Through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests.

An atmosphere of trust and equality between co-researcher and researcher is necessary in order to obtain genuine descriptions of the co-researcher's experience. It is the researcher's role to establish the conditions of the relationship and record the co-researcher's story.

Selection of Co-researchers

A convenient, purposeful sample was used to select co-researchers among British Columbia registered breast cancer patients managing their pain at home. The intent of purposeful sampling is to acquire small samples of information rich cases. Omery (1983) explains that qualitative studies typically employ small numbers of participants and that it is not uncommon to describe a single case in great depth. Initially, co-researchers are selected according to these criteria: they are viewed as expert witnesses to the experience being studied; they are articulate; and they have sufficient involvement as well as distance from the experience (Colaizzi, 1978;

Cochran, 1987). As the study proceeds, co-researchers are purposefully selected on the basis of their ability to validate or refute emerging themes. Sampling is terminated when a saturation point is reached, that is, when new co-researchers provide a minimal amount of new information (Cochran, 1985).

Co-researchers in this study were identified according to their expertise and willingness to provide insight into the experience of managing breast cancer-related pain at home. Selection criteria included all of the following:

- 1) medical diagnosis of metastatic breast cancer;
- 2) current or recent experience of related pain, managed in the home setting;
- 3) initial experience and/or treatment for pain at least six months prior to study;
- 4) British Columbia Cancer Agency registered patient;
- 5) eighteen years of age or older;
- 6) resident of the Greater Vancouver or Lower Mainland area;
- 7) proficiency in the English language, and ability to participate in the interview process; and

- 8) informed decision to participate in the study, as evidenced by signed consent.

The participant was excluded if, in the opinion of the attending physician, they were in the terminal stage of the disease process.

Ethical Considerations

Participants were fully informed of the nature of the research study. They were also informed that their participation was voluntary and their refusal would not, in any way, compromise their care. Participants were informed they could terminate participation at any time. Consent forms were signed prior to entering the study and participants were informed that taped materials would be kept anonymous and confidential, and that tapes would be erased after transcription. Written materials do not identify co-researchers by name.

Participation in this study involved no known risks. Participants may benefit from the therapeutic process of "telling their story". Although participants may not benefit directly from study results, it is possible that other individuals managing breast cancer-related pain will benefit directly from the involvement of co-researchers in this study.

Selection Procedure

Co-researchers were selected through a major cancer treatment centre. The researcher consulted the chairperson of a group of professionals responsible for the

care of breast cancer patients at the centre, and a doctor was mutually agreed upon to facilitate the participant selection process. The designated breast cancer specialist (radiation oncologist) identified potential participants to the researcher, including those recommended to him by other group members. Decisions regarding the suitability of individuals for the study were made jointly by the doctor and the researcher. The designated doctor made initial contact with each potential participant, providing basic information about the study. Interested individuals were then contacted by the researcher, who provided further explanation regarding the nature of the study. If the individual consented to participate in the study, the researcher provided written information (see Appendix A), ensured consent forms were signed (see Appendix B), and made arrangements for an interview session. Potential co-researchers generally responded positively to becoming involved in the study. They commonly felt willing to participate in order to "help someone else down the road", and in the hope that patients and health care professionals alike might learn from what they had "been through". Only one individual declined to participate when she was approached by the doctor. As a result of the selection process, six co-researchers constituted the study sample.

The first co-researcher's interview transcripts were analyzed prior to selection of the next co-researcher, according to the theoretical sampling process described by Cochran (1985). Then, the next co-researcher was interviewed and her narrative description was compared with the first. This process continued until minimal new information emerged in the description provided by the fifth co-researcher. A sixth

participant was selected and interviewed to validate the common themes extrapolated from the five original co-researcher descriptions.

Characteristics of the Co-researchers

Demographic information is documented in detail within the case studies and was not a factor in the selection procedure. The sample comprised six women ranging in age from fifty-three years to seventy-three years. They included three Caucasians of Canadian origin, one Caucasian from New Zealand, and a Japanese-Canadian who viewed herself as multicultural in origin. Three participants lived alone, and three were married and lived with their husbands. One participant had two young children living at home. None of the participants were actively employed at the time of interviews, but three women described themselves as retired.

All participants had metastatic breast cancer and experienced pain related to bone metastases, as well as pain from other sources. The length of time that participants had been aware of their cancer diagnosis ranged from four to fifteen years. The period of time during which participants had experienced pain ranged from one to six years.

The participants resided in two suburbs of the city, the downtown area, and the east side of the city. All women received radiation treatments at the city's major cancer treatment centre. Cancer-related treatment was received through local general hospitals by four of the six women.

Interviews

The Qualitative Research Interview

Qualitative research interviews require that the researcher be fully present to the rich experience of the co-researcher, listening "with the totality of his being and the entirety of his personality" (Colaizzi, 1978). Cochran (1985) describes interviews as taking on "the flavour of a potent encounter". Researcher and co-researcher engage in a "meaningful dialogue of equals" (Cochran, 1985), with the purpose of obtaining an understanding of the experience as lived by the co-researcher.

Osborne (1990) suggests that the researcher establish good rapport and fully inform the co-researcher regarding the nature of the research during the initial interviewing phase. A description of the experience being studied is then obtained, using open-ended and minimally structured interviews. In the second interviewing phase, the written transcript and apparent themes are presented to the co-researcher for validation. At this time, further elaborations of experience are gained and general impressions are discussed (Cochran, 1985). The purpose of the final interviewing phase is to validate common themes reflecting each participant's experience, and to invalidate that which does not fit, until an accurate description of the co-researcher's experience has been completed (Cochran, 1985; Osborne, 1990).

Overview of Interview Process

In the present study, the researcher established initial rapport and explained the nature of the research through telephone conversations and an informal meeting with each potential participant. The researcher introduced herself as a graduate student in the field of counselling psychology and explained that she was also a nurse. Upon consent to participate in the study, two to four in-depth and minimally directive interviews were conducted with each co-researcher in their home. Interviews were informal and lasted from fifty minutes to two and one-half hours. Length of interview was determined individually by co-researchers. Interviews were often concluded due to the co-researcher's experience of pain, and the interval between interview was sometimes prolonged because co-researchers were experiencing treatment side effects or pain that prevented them from participating in the interview process.

It took four to nine weeks to complete each individual's initial set of one to four interviews, and all were completed in a five month period. In order for the researcher to validate perceptions and emerging themes in each subsequent interview, data was transcribed and analyzed concurrently with data collection.

All participant accounts were then reconstructed in a case study format, in order to protect the confidentiality of the co-researchers. As each case study was completed, co-researchers were interviewed one more time to provide final validation of content. The third co-researcher was unable to validate her final case study due to her death.

A total of twenty-one interviews were conducted in this research study, all occurring within an eleven month period. They were tape-recorded and transcribed verbatim, and the researcher maintained a log of field notes documenting her observations.

Initial Interviews

The first interview was prefaced by a statement of purpose, confidentiality, and researcher intent. Then, the lifeline exercise (see Appendix C) was used as a tool to help the co-researcher outline the period of life during which she had been managing pain. The co-researcher was then asked to describe her experience as if she were telling a story, beginning at the time when she first experienced breast cancer-related pain. Using a preamble similar to the following, the researcher invited the co-researcher to "tell her story":

We have used the lifeline to outline the period of your life I am interested in learning about, the time in which you have coped with pain related to your cancer. I am interested in developing an overall perspective of what it has been like for you since you first had pain. What has your life been like from the time you first experienced pain up until the present?

Throughout the interview process, open-ended questions facilitated description of what co-researchers thought, felt, and did in order to manage their pain. Sample questions (see Appendix D) developed from the literature review and the researcher's own presuppositions provided an initial framework for interviews, with no attempt to standardize the interview. Questions were reminders to the interviewer regarding

information that needed to be collected, and in some instances were used as prompts for co-researchers who were unable to respond spontaneously. Modification of sample questions occurred throughout data collection, in order to explore themes that emerged as significant from the co-researcher's perspective. These questions served to frame the interview, but remained focused on the participant's "story", letting the experience unfold as it existed for the participant in an unbiased manner. Probes were used for elaboration and clarification. The result of this in-depth exploration was a rich description of each co-researcher's experience.

During each subsequent interview this process continued, as the researcher and co-researcher reviewed previous interview content and themes. The co-researcher validated or refuted the researcher's ongoing analysis of emergent themes. Upon completing interviews with five consecutive co-researchers, one final participant was interviewed to validate common themes identified across all co-researchers.

Validation Interview. Following completion of first and second phase interviews, each co-researcher was sent a copy of their own descriptive case study for review. All co-researchers, other than the third participant, then participated in a final interview to validate the description, and to invalidate aspects that did not fit.

Validation Procedures

Emerging themes and a description of experience were validated by the co-researchers during all sessions subsequent to the first interview. Then, the researcher

reconstructed the verbatim co-researcher accounts and researcher's field notes into a case study format, according to common themes. Verbatim accounts were constructed in this manner so they could be included in this manuscript, while ensuring co-researcher confidentiality. Participants were invited to review their descriptive case studies and take note of errors, omissions, or areas where the researcher had inaccurately perceived the meaning of their experience (see Appendix E).

During the final validation interview the co-researcher generally began by updating the researcher on their experiences. Then they were asked how accurately their case study reflected their experiences of managing cancer pain at home. All co-researchers agreed that case study descriptions reflected their experience. Since they had already validated content and themes in previous interviews, co-researchers tended to make only minor changes to their stories. Their comments are documented in a postscript at the end of each case study.

Analysis of Co-researcher Accounts

After tape-recorded interviews were transcribed verbatim, they were analyzed according to Colaizzi's (1978) phenomenological analysis:

- 1) Verbatim transcripts of co-researcher interviews were read and re-read in an effort to grasp their general meaning. Repeated listenings of taped recordings during the many hours of transcription ensured the researcher's complete immersion in each co-researcher's story.

- 2) Verbatim transcripts and field notes were reviewed throughout data collection, extracting and listing significant phrases or sentences directly relating to the experience of managing cancer-related pain at home.
- 3) An attempt was made to spell out the meaning of each statement.
- 4) Meanings were clustered into themes, allowing for the emergence of themes and patterns common to all participants. Themes were validated through a process of re-examination and comparison of identified themes within original verbatim transcripts.
- 5) Results were then integrated into extensive and coherent descriptions of the experiences of women managing breast cancer-related pain in the home setting.
- 6) Findings were confirmed by each co-researcher in turn, to validate the descriptive results.

The main task of the analysis, according to Cochran (1985), is that "one attempts to rather exhaustively identify the various aspects of what a person says about his or her experience".

Summary

This chapter summarized the essential components this study's research methodology; including research design, selection of co-researchers, ethical considerations, research interviews, validation procedures, and data analysis. Chapter Four focuses on the research study results, presented as descriptive case studies organized according to the common aspects that were described in relation to managing breast cancer-related pain in the home setting.

CHAPTER 4

Case Studies

Introduction

This chapter will present the co-researcher accounts, presented as descriptive case studies organized according to the common themes that were described in relation to managing breast cancer-related pain in the home setting. Co-researcher accounts have been structured in this manner to ensure confidentiality. Anonymity is assured through the use of pseudonyms for all persons referred to in any way. Verbatim quotes are documented to most accurately reflect actual conversation. Words that were emphasized by the co-researcher are underlined. Words that were very strongly emphasized are underlined and presented in upper case letters.

Co-researchers described the experience of managing breast cancer-related pain at home in relation to ten major themes: history of the pain experience, description of pain, impact of pain on daily living, coping strategies, attitudes and feelings, significant relationships, seeking knowledge, negotiating the health care system, and future goals and expectations.

Case 1: Ann

Demographic Information

Ann is a fifty-four year old caucasian woman living with her husband and children in a Vancouver suburb. Neither Ann nor her husband Bob are Vancouver natives. She had a rural Canadian upbringing, and he came from a large British city. Married for many years, they began their family eight years ago with the adoption of their first child, a thirteen month old baby boy from Korea. Three years later they adopted a six year old girl from Korea. The children are now nine and ten years old.

Although not currently working outside the home, Ann was previously employed as a school teacher. Bob drives a bus for the regional public transportation system, and was on extended leave at the time of our interviews. Ann and her family live in a large house in a quiet neighbourhood a few minutes from the town centre.

Preface

I met with Ann in her home three times over a four week period. Her house stood on a hill several blocks from an ocean beach. Whether by foot or by car, travel from the house in any direction demanded negotiating steep hills. On my initial visit, Bob greeted me at the door and immediately expressed interest in the research I would be discussing with his wife. His speech and body movements were rapid, as if he were in a hurry. He led me up a small flight of stairs to the living

room, where Ann stepped into the room from the adjoining kitchen area. She was smiling, a seemingly pleasant woman, dressed in a bright cotton skirt and summer blouse. She was rosy cheeked, tall and slender, her greying hair neatly styled and groomed. Ann did not appear to be in distress. In direct contrast to her husband, her words and movements were slow, unhurried. I felt at ease in her company, somehow calmed by her air of self-composure.

Ann and her husband sat on chairs facing the couch I sat down upon. The living room was large, bright and uncluttered. From my seat I noticed a collection of pictures in the hall way, photographs of the children taken at different ages. Dominant features in the room included a fireplace and an unobstructed ocean view from the vast picture window. The area looked clean and orderly, with several vases of multicolored flowers adorning the furniture.

Suddenly, a little poodle bounced into the room, barking and demanding our attention. Seconds later, a small boy ran into the room and tumbled onto the carpet, grinning widely. I recognized him as one of the children in the photographs. After being introduced as "our son", he was asked to play quietly in his room. The child seemed momentarily disappointed and backed out of the room with a curious expression on his face. I knew the young girl beckoned from the kitchen to meet me would be the other child in the photo. Their daughter greeted me quietly, her head bowed toward the floor.

Bob continued to ask questions about the study. He said it sounded "very interesting" and assured me his wife would like to participate. He wanted to know

if they would be interviewed together, as Ann did not always "remember the way things really happened", and said it might be helpful if he was available to fill in the gaps. Ann sat quietly, occasionally interjecting questions and thoughts. She said she was "not a talker" and wondered about her ability to take part in the interview process. Despite her concerns, she volunteered to participate in an interview the following week. Bob requested the opportunity to ask some questions after our interviews were completed.

A week later Bob again answered the door and ushered me inside. Upon reaching the living room, I was surprised to find Ann sitting rigidly in a wheelchair. Her face looked strained and pale, a stark contrast to the previous week. Bob positioned the wheelchair so that she could look directly at me, minimizing the need to move her head and neck. She had lost the ability to bear weight during the past week, leaving her unable to walk. Bob was learning to transfer her to the bed, the toilet, and back into the wheelchair. I was struck by the dramatic changes a week had brought into their lives. Ann's ability to manoeuvre her wheelchair now determined her independence. She was confined to the main floor, and was even further imprisoned because the living room carpet made it difficult for her to move the wheelchair unassisted.

Bob went grocery shopping while I spent the following hour with Ann. She appeared physically uncomfortable, though she neither complained nor brought attention to the discomfort she may have been experiencing. I noted that her body

was tense and stiff throughout the hour. Reluctant to complain, she said she was "just a little bit tired and uncomfortable" at the end of our interview.

Her voice was soft, words articulated in a slow and careful manner. Once during the interview her manner shifted. Talking about her Christian beliefs, she spoke quickly and without inhibition. She seemed immersed in what she was talking about, taking on a trance like quality. Her face appeared relaxed and contented. At the end of the interview, Ann said that she was surprised that she "talked so much", saying she found it difficult at first, not having a structured set of questions to answer. She said she looked forward to our next meeting, and I sensed that she had enjoyed the experience of being a co-researcher.

The second interview took place two weeks later. The children were at school, and Bob was in the kitchen doing dishes when I arrived. He looked tired and said he was "finding it very hard". Speaking quickly, he described feeling overwhelmed with the number of errands and organizational activities he was doing because of Ann's immobility. He was trying to get some support in the home so he could return to work, expressing concern that he was losing his confidence about performing job related skills. Bob seemed nervous and fearful of the future. After sharing his concerns with me, he quickly gathered his things and left.

Ann's condition had improved considerably in two weeks. Now able to walk short distances with support of crutches, she voiced pleasure with the progress she had made. She expressed optimism and hope about her future. I noticed she was more spontaneous during the interview. She cried as she spoke about how her

death might affect the children. It seemed difficult for her to share her tears openly, and she apologized several times for being emotional.

After the interview, I answered Ann and Bob's questions about available resources, explaining appropriate channels for arranging home making and home care services. I referred them to their doctor for help with further arrangements. They also requested literature about helping children cope with an ill parent. They said this was their biggest concern and they needed help. Bob felt that it was important for him to establish good communication with his children now, so that he could support them in the future.

They were especially worried about their little boy, who at nine years of age, was wetting his pants at school. Bob found this particularly upsetting and said he was at a loss as to how to help the child. They described him as "quiet and reserved", and were worried because he did not show his feelings openly. Because tests had not indicated there to be a medical problem, they wondered if his problem was emotional. Bob became tearful describing his frustration. He expressed distrust in the doctors who had offered no recommendations, other than that the child might grow out of the problem. Listening empathically, I suggested they seek medical advice from their family doctor. As requested, I also gave them the name of a nurse clinical specialist at the cancer treatment centre, who would be able to provide information and support related to helping their children cope effectively.

Leaving their home, I found myself thinking about the tremendous impact Ann's disease was having on this family. Every corner of their lives was turned upside

down, and they were each struggling--in their own way--to find stay on this unpredictable roller coaster ride.

History of Pain Experience

Ann was diagnosed with breast cancer in July 1985. In August of that year she had a mastectomy, followed by a course of chemotherapy and radiation that was completed in the spring of 1986. Her experiences with pain began as follows:

- A: I guess it was about three years later in October [1988] that I had the hip [pains] and you know how you think, "Oh it will get better, it'll just go away for a while", not dreaming it was related at all to uh, uh, cancer. But finally . . . I went to the doctor and she said, "I really don't think it's anything". . . . she gave me some anti-inflammatory pills thinking that maybe--you know--so that went on for a while. Then I went back again and they didn't do anything, really, and then I went back again and she said, "Well I'll send you to physiotherapy". So I went to physiotherapy for a while. That didn't help at all. So then I went back to her again. This is over a period from October to the end of January. . . . we took an x-ray, and she couldn't see anything. . . . I went back again . . . so the end of January I had a bone scan . . . and that's when it [cancer] showed up. . . . in the pelvis that is, more on the right than on the left . . . So it was from October through to the end of January.

Upon confirmation that breast cancer had spread to her bones, Ann was referred to the cancer treatment centre to begin therapy. Around the same time, Ann became aware of promising treatments available in Mexico, and decided to go to there for additional therapy. She recounted the course of her cancer and treatments over the next twenty-one months [January 1989 to September 1990]:

A: . . . so we went to Mexico. We had the treatments as well--so we had the Tamoxifen [hormone therapy] and then we had the uh, Laetrile treatments and the other supplements that they give you down there. And we were there for three weeks, and then returned, and some things certainly lessened. And uh, I was feeling well until about October, November of that year--that was in eighty nine . . . then I wasn't feeling too great so I went to the clinic in Vancouver and uh, they changed my medication from Tamoxifen to Megace. Then that wasn't making a lot of difference--the pain--in fact, uh, as far as all things were concerned. So in January of uh ninety, we went back to Mexico again--for two weeks--and uh found that when we returned that uh there was some relief for about a month. And then it seemed to--the pain seemed to increase again . . . went to the clinic again and they uh, treated it as sciatic nerve and so I had radiation at that time. And also I think it was at that time that uh they decided to take me off Megace and not bother with that but go on with . . . radiation. And uh, that was certainly a relief. And uh, then--that was in January, February--of ninety. And uh, then the pain started up again and so in May . . . I was in the clinic hospital for four days hoping to get radiation at that time. But they had such a shortage of technicians . . . so I was unable to get uh, much radiation other than one session of it uh, on the left side. . . . I needed to wait another five weeks before I could get the radiation for the uh sacrum. . . . And uh that seemed to relieve it to quite an extent. And then, um, that was in June . . . in that area anyway. Then, um, it uh, seemed to come back again so we went down to Mexico again for a third time and that was the end of June and into July. And uh again, after that there was a relief coming along, it was getting so I could walk without crutches and doing quite well. And then about two weeks ago [August 1990], this last week--and I don't know the reason--it just seems to have come through again, and uh its been quite painful . . . you know, I was really functioning well, until I think, two weeks ago.

Description of Pain

Ann's primary experience of pain was in her pelvis and lower back. Location, duration and intensity varied. She struggled to find words to capture the fluctuating character of her pain:

A: Up to two weeks ago when I was immobile--just sitting or lying--I really didn't know I had any pain at all. It was really endurable. But . . . when you're moving and you're trying to be mobile, that's when you notice there's something there. The last two weeks it's there, and constantly. But sometimes if you get into just the right position you're okay. And with the help of some of the painkillers it takes the edge off. . . . The most severe pain's in the last couple of weeks and it's hard to describe really. It seems more to be in the muscles and nerves than actual bone. A HARD DEEP PAIN--almost like a toothache and yet not like a toothache. It just HURTS. A lot. You move and sometimes, you know--just they way the angle is--you just have to kind of find the comfortable position, to release that pressure.

K: And is that pain still in the same area? Although it sounds like the quality has changed a little bit.

A: Well, um, it does move within surroundings. For instance, this morning I can feel it more on the right side in the right hip, where two days ago it was more on the left. And sometimes it's down in the lower back. But within that area it kind of shifts, um, from the left over to the right or vice versa. But still in the context of that area. I don't know how else to describe it really.

K: If you had to choose a colour to describe it, could you? . . .

A: [laughs] I'm not very imaginative, so I can't really say. I suppose when one thinks of red as being danger. Perhaps an orange red would come to mind you know. . . . It just HURTS. So it's hard to--I don't know how you describe it. It's not exactly in the bone, but it kind of travels down the leg sometimes. . . . Because you're moving, it almost makes you think, well, maybe it's in the muscles. And uh, like injured muscles would be. . . . So sort of a variety of types of pains, and yet they're all pain.

K: My sense is that the pain is always there in some quality, right now.

A: The last two weeks it has been I would say, yes. Prior to that no. You know, I could sit or I could lie and not--and just think everything was fine until I started to move, you know. . . . up to then I was perfectly comfortable. But for the last two weeks it's there constantly. It's sort of, not as severe when you're sitting or lying usually. It's when you try to get up. . . . just moving intensifies it. You know, moving from the chair and then . . . going into bed is very, very painful. Other than that, most of the time I just have to sit immobile

in the wheelchair, which still lets me get around. It has been quite painful. Especially in the mornings when I first become mobile. It's worse in the morning and then at night again, when I'm tired, that's when it hurts.

In the second interview, Ann recalled a troubling episode of intense neck pain she had the previous weekend:

A: . . . trying to get up those stairs, it was really very awkward and I felt like I was really pushing myself to the limit, kind of thing. And I think maybe that's what caused a very, very sore neck you know. And then from the neck it kind of gave a headache from the back of the head, and causing nausea. And so that was not very pleasant over the weekend. But it's much better again now . . .

Ann's pain reflects a pattern of alternating intervals of stability that vary in duration, distinguished by minimal or absence of discomfort, with episodes of flare up. Flare ups are unpredictable and disabling, with chronic pain more familiar and "endurable".

Impact of Pain on Daily Living

Ann talked about the changes her pain has imposed on her life. "I'm on an up swing and then you know, I go back a bit, and then it's up swing." "Ups and downs" are now routine. She reflected on the disruptions to her normal activities:

A: Yes, [my life has changed dramatically], it really has. In fact, it's sort of brought home to me time and time again by the children, who say, "Mom, remember when we used to do this?" . . . You did all these

kinds of activities! Physical activities we used to do--go for walks--and oh just a lot of things together, you know. And now it's inhibited and kind of hampered by this. And so, yes it has changed a lot. Because I was, of course, quite an active person, being engaged in work for at least fifty percent to seventy percent. And then since the children came even. And so you know, with going to work and then doing these extra things with the children, it was a lot of fun . . . we kept busy and active and, as well as some things with the church work. Which I didn't get that involved with . . . I felt school and the family was really about all I could handle . . . YAH, it HAS changed and I don't like it! I like to be like, "COME ON, let's get going like we used to"!

Ann's physical abilities fluctuate in relation to her disease and pain experience, demanding perpetual adjustment to changes in herself. Physical surroundings have to be modified to accommodate her needs. For example, Anne went from "walking without crutches and doing quite well" one week, to "sitting immobile in the wheelchair" two weeks later. Two weeks after that she was able to walk short distances with the crutches again. The large steps to her home became a physical barrier and a wheelchair accessible ramp had to be built. Living in a house with stairs and several levels made her feel like a "prisoner" in her own home. Ann related the effect that feeling unwell and housebound had on her:

A: You don't even feel like reading, you don't feel like listening to the radio, or watching TV. It all seems like such a bombardment, you know. And you just can't do it, you know. So, anyways you really think, "Well, what can I do?" Well, you always feel like sleeping.

Ann was especially concerned about not being able to perform domestic activities and the extra demand it placed on her husband. She said that domestic help would be the most useful resource to herself and her family, elaborating:

- A: You don't realize the things that you do when you're healthy and well, and then when you're not able to do them . . . you wish somebody would be able to come in and do those kinds of things for you . . . somebody that would come and do the housework that I just can't do. And you see the dust sitting there, you see those fingerprints on there, and you know you can't do them. And the meals, you know, making the meals that are interesting for the family and for yourself. . . . when you're not feeling well sometimes the foods aren't quite as appealing . . . it would be nice to be able to have somebody come in and be able to cook interesting meals for you. That's what I would really appreciate and that would free [Bob] up more to do other things . . . he could go to work and feel that I was fine, there was somebody here doing some things, sort of thing. Even enough not to think that, "Oh dear, after work I need to come home and do this and this and this", it would be done. It would free him up a bit more and I think when you're fed well, you know, it makes a lot of difference too with the children, you know, if they have interesting meals and that kind of thing. And I think it just makes it easier all around and more pleasant.

Treatments have brought further disruptions to the daily life of Ann and her family. Therapy and appointments with specialists in Vancouver involve a thirty to forty-five minute drive each way. Trips to Mexico involve flying to San Diego, and commuting by van each day from the border town of San Ysedro, California to Tijuana, Mexico. Ann participated in three week long treatment programs three times since 1989. She said it was "very expensive" and wished the therapy was offered in Canada.

Coping Strategies

Ann identified a variety of coping strategies she employs to manage her pain. Those that initially stood out for her included taking medications and having treatments. As she explored further, she became aware of the significant role her spiritual beliefs and attitudes play in managing pain.

Medications and treatments. Ann had several courses of radiation treatment in an effort to relieve symptoms of pain. She responded to those treatments with varying degrees of relief over relatively short time periods:

A: . . . with the uh radiation . . . that was certainly a relief, and uh, then--that was in January, February of ninety--and uh, then the pain started up again, and so in May . . . then four more radiation treatments. And uh that seemed to relieve it to quite an extent. And then that was in June . . . Then it, uh, seemed to come back again.

Ann wanted more than her treatments in Vancouver offered. When she met a woman who had "very positive results" from going to Mexico, she sought treatments there as well. After her second trip to Mexico, she felt "fine for about eight or nine months". She wasn't sure which treatment was responsible for her well-being--hormonal treatment received in Vancouver, or therapy in Mexico. She continued therapy in both places. She was "doing really, really well without any medication here at all" after her most recent trip to Mexico. Ann talked about the treatments she had in Mexico, and what motivated her to go there for therapy:

A: . . . they didn't seem to be able to do anything here, other than the radiation. . . . And then they took me off the Megace, so I was on nothing other than the, uh, radiation. . . . they also had the live cell shots . . . in Mexico. . . . They get the cells from the calf embryo . . . they inject it into the human along with thymus . . . they feel that that is a way of getting the immune system going, and their theory in Mexico was that the reason one becomes ill is because the immune system isn't functioning at it's uh, level that it should be? And so they try to build up the immune system with all the vitamins and enzymes and you know, all kinds of things. . . . two reasons that kept us going there. . . . they weren't able to do much up here seemingly, that was effective for me . . . we went down there for the live cell shots. . . . I guess for one thing, I guess laetrile was to be the effective--the most effective ingredient--and that I know is not allowed to be practised, at least as far as I know in Canada or United States.

At the time of our interviews, Ann was taking the following medications at home: Aminoglutethamide, a hormonal therapy; Didrinal, an experimental drug prescribed in Mexico; calcium syrup; and Dilaudid, a strong opioid painkiller. Her cancer specialist had suggested going on painkillers at her last appointment. She followed his advice about dosage and frequency of administration, and found them "helpful", saying:

A: I've been taking it as he suggested, just taking a half a dose first . . . just get a tolerance for the drug that's in it, and then gradually build up. You know, the tolerance, so that you don't feel nauseated and that. But that's what [the cancer specialist] suggested, a half dose for a while and gradually increase it.

K: So how is it that you decide how often then, and how much to take?

A: . . . he was quite free with it because I've always had a resistance to taking painkillers. Apparently he has too, [laughs] so we kind of understand each other . . . on the directions it does say every four to six hours and so, uh, I'm pretty well doing it four or six hours. Just

using half a pill for each--this one hip. I'm not sure when I start taking a little bit more, uh, we haven't specifically got to that.

The "resistance" Ann mentioned hinted at her attitudes about pain. Later, she went on to tell me about how she understood the purpose of her pain, and how that influences her decisions to use painkillers. Though able to take the "edge" off her pain with painkillers, she said she had never achieved complete freedom from pain, elaborating:

- A: I've resorted to painkillers when I needed to, which are a help, but I don't like to be on them . . . And they take the edge OFF but they don't take the pain away.
- K: It sounds to me like you prefer to live with a certain amount of pain than to have to depend on taking the medications.
- A: I think probably you're right. I think I like to know . . . naturally, you know, where I am in this whole thing, you know. If you've taken painkillers I think you could fool yourself, in a sense, and then when they're removed, then, "OH! I'm really not feeling that well", you know, sort of thing. I guess I like to know the real nitty gritty, but I will take them when I absolutely need them.
- K: So effective pain management for you is being able to take the edge off the pain, and still being able to be in touch with what is really happening in your body?
- A: Yah I guess so, you know. Or maybe it would be nice if there was something that would take the pain totally away. Um, maybe I wouldn't mind that EITHER, really. But then, how would you know? If you were really getting better? I mean, am I really feeling better? Or is that just the painkiller doing it, you know? I like it to be for real. I feel a painkiller is not a for real thing, you know. It's needed at times, but like it, I guess it just doesn't really, I guess I'm for a cure rather than a painkiller. I guess that's really what it comes down to. And I don't want to think that just because I don't have pain, that's

getting better, you know. Does that make sense? You know, and yet sometimes it's so nice to have that relief from pain, because if there's been constant pain it really tends to make you not a very pleasant person. . . . a painkiller can be good too, in the sense that, "phew", you can relax and you're not in all that pain. And I think maybe when you've accepted the fact that nothing is going to improve--that it's not going to get better--then probably you know that painkillers are very welcome.

K: So in a way what the pain means to you, it sounds like the pain has a definite meaning in terms of the pain being a symbol of you getting better or not getting better.

A: YES. Actually, yes. And I need to credit that to [the cancer specialist]. He kind of indicated that, with this kind of disease that I have, in my situation, that was sort of a thermometer. And so I guess I kind of like to know what the thermometer is reading. . . . And yet when you are in such, such pain --like the sciatic nerve or something like that--then "AAHHHH", you DO welcome [relief]. Even though you know it's just a temporary relief . . . what was helpful too, was that when you were looking forward to getting the radiation . . . you knew you were doing this for a short period of time . . . I'm not saying that I'm against painkillers at all. But I guess I still like to know . . . well, you're not really in control, but you like to know what's going on in your body.

Ann perceives her pain to have an important function in helping her to monitor her disease. She said she is willing to accept a certain amount of pain, resorting to painkillers when pain becomes intolerable. She implied that submitting to painkillers for complete pain relief signified giving up hope, or giving in to the disease.

Self-care behaviours. Ann also uses a wide assortment of non-medicinal strategies to cope with pain. Some strategies are directed at adjusting to pain, rather than eliminating it. A recurring theme in Ann's story is the significance of prayer in

her life, a source of strength that helps her make decisions and cope with chronic illness. She described:

A: In prayer, it's not just a petition thing that you're asking. It's not like a Santa Claus sort of idea. But you're focusing on the greatness and the awesomeness too, of this great Creator. And a Creator that created the world, created our bodies and also everything around us, and He knows what hurts in our bodies, and what's going on in our mind. And the strength He gives us to help there, He doesn't say that He can make life super easy for everyone just because we become Christians or anything. But He does promise to stay with us, and to give us strength to go through them. And I have found that so helpful. . . . prayer's kind of like, uh, almost a two way street. Yes, you do have your requests. And yes, you do make conditions, but you also . . . think about Him and thoughts of His greatness and that too.

.....

K: I'm interested in hearing how it is that you make decisions about how you're going to manage.

A: Well, again, you know, prayer is first and then you sense the Lord's leading uh somehow. Sometimes it's very difficult. . . . "What's bothering me?" "What do I do?" Then you do what your knowledge tells you to do and what's best, what you know is available. Uh, for instance I mentioned the Mexico thing, that would have been the sensing of the Lord . . . We just felt that was the right thing to do, we had peace about it and so on.

K: . . . you have almost a sense, or an inner feeling about decisions?

A: Yes. Yes, I would say that was. You know . . . you feel good about it? You know, you feel at peace about it, sort of? And there isn't that uh, "Did I do the right thing?" Or, "Did I do the wrong thing?" But sometimes it's not difficult. You just, you have to go by what you think is the thing to do.

Ann also tries to keep her mind active by writing letters, reading, and keeping busy with other similar activities. She says, "The less you think about it, the less

you're likely to feel the pain". Ann found it helpful to read about others who have coped with suffering, reflecting:

A: I'm reading books that are encouraging and uplifting, rather than books that might cause me to be depressed. I find that not at all helpful. I read some articles, I don't know if you've heard of Joni Erikson, but she had an accident when she was swimming and broke her neck. Totally quadriplegic, but yet has made a very full life you know. She's not a person who sits around feeling sorry for her self. . . . you think well really, she's worse off than I am . . . I think things like that, when you read uplifting things, help you.

.....

A: I really draw a lot from the bible because it has very encouraging words too. . . . I think that this does give us strength. I'm thinking about how Job suffered and the way Paul suffered, how David cried out to the Lord. He wasn't perfect. He sought help from the Lord. He wasn't beat down, and sometimes he wasn't a great man of God. He still had his down times . . . just to know that these men of God, who God used so greatly, had their valleys as well, you sort of think, "WOW!". You know. Then it's okay for me to have some valleys too. And then you know, you pick it up again and sort of go. Yes, I would say the scripture is very, very helpful. It's been very, very helpful.

Ann also developed some practical ways to manage physical limitations. A cordless, portable telephone was a distinct advantage when she wasn't able to move around. She also discovered that wearing a satin like nightgown in a bed fitted with satin sheets really helps her to position herself more comfortably in bed.

Another way that Ann takes care of herself is to watch her diet carefully, following guidelines provided by her therapist in Mexico. The recommended diet is essentially a vegetarian diet with some fish and poultry, eliminating animal fats,

red meats, sugars, dairy products, white flour, and refined products. She commented, "It certainly means changing your whole palate, because it's a whole different way of cooking, which I've tried to carry out some at home here".

Interaction with the outside world helps Ann maintain a perspective beyond her home environment. She suggested:

A: I think it's helpful perhaps too, to get out of the house . . . especially on nice days. You know, and go for a drive and go, you know, on the beach like we did yesterday. And that was very pleasant and very nice. And it gets you thinking, I said to [Bob], "OH, this world is bigger than just my house"! . . . I think that's important too, because you can get quite drawn in and that's not helpful.

.....

A: Otherwise you spend all that time in the home, so it's nice when you can get out . . . I think it just gives you a brighter look on things altogether. Not being dismal and depressed and that kind of thing, it's helpful for the whole family, you know. The children like to see me being cheerful and happy and that too. And so I think it has a lot of positive effects.

Attitudes and Feelings Related to Controlling Pain

Ann feels the way she copes with her current illness and related pain is influenced by what she learned from childhood experiences. Because she had never experienced illness before, she was having difficulty perceiving herself as "sick". She said:

A: I've never been in the hospital you know, or needed it. Other than [having] my tonsils removed, and one day as a day patient. And then the mastectomy surgery, you know. So in . . . forty nine years I've

always been a very healthy person . . . and I think that's why I still find it hard to really accept the fact that I am ill, you know.

.....

- A: Like I still haven't--I don't know if you'd call it accepted it. In a sense I have accepted it, but in a sense I haven't, you know.

Ann has developed an independent style of managing her life, something she began to learn in early years. This self-reliant manner is reflected in the way she chooses to cope with pain. She discussed the factors that influenced her to become the independent, determined woman that she is today:

- A: We lived on the prairies . . . at least twenty miles from a doctor in those days . . . And then moving to British Columbia, we lived on a farm. And again, my mother--who was a widow at this time--brought us children up basically without medical interference as much as she could. When there was a necessity, of course, then she would. But having come from a rural setting like that, I guess we learned some independent skills.
-

- A: When we first married . . . it was difficult, for an adjustment period, where I was independent. I had been teaching for a while and I had been on my own for a while . . . so I had definite ways with things . . . also I think when you grow up with just a mother--you don't have a father--and she's working hard to keep the family together . . . and she didn't have any additional financial support. She was a very determined lady and a very self-reliant lady, and I guess that's passed on to me. She's a very proud lady, in the sense that she wouldn't accept, uh, welfare or anything like that, you know. That was not her style, and she just felt that she should make her own way in life and I guess I've come from that stock. And to me that's the way you operate, you know. And so I guess that's reflected in many areas of one's life, you don't really realize that until you sit down and talk with you, or someone like you.

Her father died when she was about the same age as her own children. She has a strong sense of what her children are going through as they struggle to cope with her life threatening illness. Ann reflected on her own childhood:

A: I lost my father when I was ten or eleven. He'd been ill . . . for quite some time. And I know it was difficult. It was really difficult. In fact, there was almost the sense of [deep sigh] release, or a sense of, what shall I say? When he did go, you know, it was like, "Well, now we can get on with things". You know, sort of thing. It's a drain on the family. It's a drain on the children . . . I don't like that kind of thing going on. Because, having had that kind of experience myself. So if I could choose, I would choose to be healthy and strong, and just help the children grow up to be the best kind of people that they can be.

When Ann is feeling particularly uncomfortable, her thoughts turn toward her children and how her illness affects them. She becomes less optimistic and contemplates her own mortality. She cried as she discussed the possibility of dying and leaving her children behind:

A: You think very soberly, of course, that you know you may not be around very long. And that, I think, especially with the children, for me that's difficult. Because we all know that we're not going to be here forever. And if my children were grown and on their own, I think it would be easier. Now I don't know, because I've not been in that experience. But when they're nine, and then the other one's nearly eleven, they still need a mother around, you know. And they express that . . . especially my daughter, she expresses it quite frequently. The son is more quiet. He doesn't express it, but you know, deep down . . . and he'll say, "Remember, Mom when we used to?" "Remember when we used to dance around in the kitchen?" . . . So those are very HARD thoughts. When you're not feeling well you think, "OH, won't I ever be able to do that again?" "How will they accept their mother leaving them?" . . . Those are hard things.

They're a little hard to even talk about. [tears welling up in her eyes] But yes, those things do enter when you're not feeling well. [crying] . . . like I say, if it wasn't for the children, uh, [crying] . . . a husband, he's mature and he can handle things. But the children, who haven't got the skills, and who are reliant on you, depend on you--that's where I hurt the most.

On "good days", her outlook is more optimistic and she looks to the future with a feeling of hope. She tries, as much as possible, to have a positive attitude. When she compares herself to others less fortunate, Ann feels more positive about her own experience. She also focuses on her hope for a cure, rather than "giving in" to her disease.

Ann's religious convictions are a main source of strength and hope. Her belief system helps her maintain a sense of control, and it is within these beliefs that she searches for the answers to help cope with pain on a day to day basis. Although her Christian faith has been important since about the age of sixteen, Ann became increasingly aware of her "need for the Lord" when first diagnosed with breast cancer. She discusses the role of faith in her life:

A: . . . and when everything's going well for you here, you tend to become more independent of the Lord. . . . you just manage things on your own and you go along. And when crises do hit in one's life then yes, you definitely focus more on the Lord, because your help comes from the Lord. There is no other way you can get help in certain times. And when you've exhausted all areas that you know--I think it's natural for most people in a crises, when they've done all they could and there's nothing more--then they'll cry out to the Lord. And, even in a Christian's life--by Christian I mean somebody who has been born again, has accepted the Lord and answered His calling--we tend to go along quite lightly, perhaps, when things go well. You still

have your relationship with the Lord . . . you're not pursuing it as ardently perhaps . . . then when problems do arise, I think your focus changes and the things that you were so involved in suddenly aren't as important as the eternal things.

Ann's belief in eternal life gives her hope and helps her cope with her fear of the future. She said she could not imagine facing death without the assurance of eternal life. She discussed her spiritual beliefs and how they help her deal with her cancer and her pain:

A: I guess my greatest help is spiritually . . . well first of all, it takes the fear away . . . And so you become more accepting, perhaps, of the situation. And you know one day you will be free of the pain. . . . I guess that's about where it's at . . . you're not fearful of the future. . . . What helps make me be not fearful is the fact that, uh, I believe that the scripture so clearly states that we have eternal life . . . absent from the body, we're present with the Lord. And there's no more pain or weeping or that in heaven. . . . And so, with that to look forward to, it takes the fear away really. Because you know that if you're leaving one beautiful life you're going to something else that's more beautiful. So that's where . . . the greatest peace of mind that comes in . . . if one is called to leave this life at any time, to know that your accounts are settled and that you're fine.

K: . . . your feeling of hope for the future is one of the things that helps . . .

A: DEFINITELY, that is THE MOST [helpful] I suppose. Oh, I don't suppose. I know it is because, as you said, without that I would feel that there really isn't very much hope.

As well as providing hope, Ann's religion offers a forum for exploring the meaning of illness and suffering. Within that context, she struggles to understand and accept her own experience of pain:

A: . . . There are miracles that do occur but whether God will choose to do that for me, we don't know. . . . His ways are not always our ways and . . . He may not choose what we want . . . and there are a lot of questions as to WHY. You cannot explain all these things, but our trust is in the sovereign God who . . . does what is best for us even though we don't understand. . . . I think that has to be . because if that's not there, what is there? There is nothing.

.....

A: And then you say, "Well then, why did He allow you to suffer like this?" . . . when Adam was made, he was made perfect and Eve was made perfect. . . . but they chose to sin, to do what God asked them not to do. And with that came all the fall, the sin, the sickness and the diseases . . . so the natural thing is that there is sickness in this world and I'm part of that. But even in the sickness God promised to be with us, to be our strength. He's promised never to leave us or forsake us, to walk through the difficult times with us. . . . I still don't understand why I am the one that is here. But I'm not the only one. Lots of people are suffering and so on.

.....

A: He's going to come again and get us. . . . I think what a GLORIOUS hope that is, you know, as a believer to have that happening. [crying] Actually you're leaving ones here that are very dear and that's what makes the going so difficult.

As she talked about "what makes the going so difficult", Ann cried openly and shared her grief, as well as her fears:

A: . . . It is difficult to let go of that and to see [those left behind] hurt, but at the same time you know that there is love and hope there. . .

I don't know how people who don't have that hope and that assurance of eternal life--how they cope with it--with death. I really don't know. Because to me, what is there then? . . . It's certainly not pleasant what the scripture says about people who shun God and they don't accept Him as their Saviour. It's very scary and I would be most fearful. . . . I've thought of that often and . . . I fear for them, if they don't accept the Lord as their saviour . . . WELL, I don't know how to express that really, Kathy, because that's something that's so very, very important and gives you so much peace. And just removes the fear. . . . there is still a loss that you feel when you're leaving. . . . it's like when you're visiting somebody you love a lot and you're saying goodbye to them. There isn't any fear or anything like that, but you miss them . . . I just sense that I'll miss them and they'll miss me. Perhaps they'll miss me more--maybe that's how it is--than me missing them. Because I'm not sure if--once I'm in heaven--if I see what's going on on the earth or not. . . . Just having had the experience of losing my parents, you know, you know you miss them. And that hurts them. And anything that hurts your children hurts you. [crying]

Ultimately, Ann feels that one must work through their feelings alone. Even with support of family and friends, Ann believes:

- A: . . . basically I think you have to work things out yourself a lot. You can't expect others to work out the very deep feelings. Perhaps it's helpful to discuss, as, you know, with someone. But really, you have to sort those things out. You think so? You know?
- K: What I'm hearing that you're saying, is that despite having friends and support and not wanting to work on something alone, ultimately it is you alone [A: Yah.] that must work out it out.
- A: That's right, that's right. . . . you put it so succinctly. Yah, I think that kind of says it!

Significant Relationships

Ann often referred to the supportive role of friends, family, and professionals in helping her cope with pain. She said she couldn't "imagine going through this alone", though she tends to rely on her own resources before reaching out for others.

Personal relationships. When asked which people in her life she was most likely to seek support from, Ann responded:

A: I guess my husband. . . . my husband and my family. And we have a little group of--well actually two groups of women--bible study groups. And they are very supportive. And the little group from our church . . . the prayer group. And, uh, they're very supportive. And then, uh, in my extended family, a sister. Uh, she's very supportive too.

.....

A: . . . My husband of course is very supportive, and I certainly need him. . . . So I have the whole family's support. And a lot of friends support . . . So I guess I'm blessed, really, that way. Rather than having to, kind of, do it on my own totally.

She went on to describe what she perceived to be the most helpful support offered by friends:

A: . . . anytime when the church family hears I'm not feeling well, casseroles come in by the dozens. Uh, baked goods and things like that, which I can't do right now. But WHAT A HELP, you know, to just go to your freezer and pull out a big casserole that's been prepared. That is a very practical way, uh, that they have shown that they offer their support . . . other ways, just the friendships you develop through bible studies in the church and in the church group are very helpful. And they drop in and come in for perhaps for just

half an hour or so, an hour, and a word of encouragement, and off they go again. And that's been very supportive too. Very helpful. Of course, the prayer support is very helpful.

K: When you say prayer support, what exactly does that mean?

A: That means that they have sort of an intercessory role, they pray FOR me with the Lord. Sometimes when you are in such great pain, it's difficult to pray because you can't really concentrate, you're distracted! And it's nice to know that there are others out there who are suffering with you, but not, perhaps to the degree that you're suffering. And they can intercede for you . . . that's kind of reassuring too, because you know that if you can't pray, somebody's out there praying for you. So that's certainly a big help.

The importance of prayer support in Ann's life is evident when she talks about her initial meeting with the woman who told her about treatments available in Mexico. It was no coincidence to her when she suddenly met this stranger--with the same disease as herself--at church. This woman played a significant role in Ann's life, offering new hope for a successful treatment:

A: . . . we went to church that morning and we were rather down after the service [this lady], she came to me . . . that's when she told me that what she had done, was to go to Mexico. But she said, "For some reason, I needed to come to this church this morning. . . . I've not been here before, and I really was going to go to my own church, but there was such a drawing power that I should come here. So, I'm here and I'll just tell you what I did". And to me that was like, "WOW", you know, somebody is obviously praying and brought this person into our life. 'Cause we had not contemplated Mexico. . . . And so that, I would say, was a definite answer to prayer there.

Ann became teary talking about her relationship with her family. It seemed difficult for her to share her hurt openly. When asked whether there were people in her life to share her tears with, she responded:

A: I think I could if I chose to. You know. But, uh, I generally try not to. But there are times, yes, when, uh, there are friends around . . . [crying]

Her tears suggest the impact of her pain and disease her family relationships. Acknowledging that her life centred around her role as mother to her children, Ann expressed sadness about her many losses in that role:

A: I guess basically my life is kind of wrapped up in the children . . . And my husband too . . . it's not like, that I ignore him for the children, you know. He too, just loves the children and wants the very best for them. We've been blessed with very beautiful children.

.....

A: They're getting more into their own independent ways, which is of course very good . . . especially in my situation, where you're not sure just how things are going to go. . . . I like to spend time, oh, going for walks, and chatting, and sharing our bible times together, which has been very meaningful, I think, for all of us. We have a little time together with the children before they go tuck into bed and [crying] they often ask questions about spiritual things that are on their minds, and they feel free to ask, and we chat about them. And things that come up at school, or with their friends, or something opens up. So, you know, it's just a beautiful time of just letting Mommy and Dad know--if Dad's around, mostly he's been at work--but just letting us know what's hurting them or what their concerns are and bouncing them off me, and sharing . . . but very beautiful times that we spend around that time of day too. But we also like to, you know, do things like go swimming together and cycling, you know. We used to cycle together and go for walks on the beach and just go to the library. In

fact, [our son] was just saying this morning he couldn't wait to go to the library again. We haven't done that for a while . . . So those have been very precious times. And you like to carry on things that are meaningful to the children.

The children help to do the things Ann is no longer able to do. Of her ten year old daughter, she said:

A: She's been a tremendous help. We took her to, you know, to try to enrich her life somewhat. And our own, you know. But it's ended up that she's done, I think more for us. Yah! [laughing] For me, than what I could do for her.

Ann talked about the struggle that she faces as a mother, trying to nurture her children through the ongoing uncertainty of her illness. While trying to prepare herself for the loss of her children, she tries to ready her children for the potential loss of their mother. At the same time, she maintains hope for their future together:

A: . . . we encourage prayer of course and faith. And yet, we, at the same time, must let them know that God doesn't choose to heal everyone . . . yet we also know that prayer changes things and that there are miracles that do occur . . . And so with little children, praying, they of course, have such faith and such expectations. You know. And when it doesn't occur, when the healing doesn't occur immediately, there tends to be--I suspect--a disappointment, you know. There may even be anger . . . so you talk about them, you do what, you know, you discuss with them, and you share with them. And there have been some very sad discussions, you know. There've been tears, uh, on both sides, you know. But at the same time, we don't want to make it sound like it's all going to be well, because we don't know.

Bob assumes responsibility for many domestic chores Ann is unable to perform. His role within the family has changed dramatically, even necessitating a temporary leave from his working role. Ann discussed how she and Bob--with their different backgrounds and styles of coping--make decisions about her pain management:

- A: Sometimes the spouse goes through a lot of things for you when you're going through that. [pain and nausea] So I'm fortunate to have somebody that is as tolerant, and as understanding, and as kind as he is, really.
- K: It's interesting, when I'm listening to you . . . it also sounds like both you and your husband handle things quite differently.
- A: You're right. You're very right. . . . I guess from my background . . . my mother . . . brought us children up basically without medical interference, as much as she could . . . where [Bob] came from the city . . . it was, I guess just so much more accessible for medical help. . . . Yes we do. We do have different ways of handling things.
- K: How do you find a common ground that works for you?
- A: [laughing] That's interesting because he'll give his suggestions and I'll say, "No, I don't think so. Not yet. Not really". You know. So then, he's pretty good. Unless he's very, very convinced that . . . there needs to be some medical interruption here, sort of thing. And then I'll go along for a while. And if I find that, indeed, I'm not being successful in my way of handling it, which is mostly doing NOTHING [laughing] about it, but letting nature kind of take its course, you know. Then I'll say, "Yah, I guess maybe it's time you should", you know, sort of thing . . . But if he feels very strongly, he'll really push it. And sometimes he'll do it when I would rather he didn't do it, you know. But sometimes he's right. Sometimes that is the best thing to do. You know, so I think it's just bouncing things back and forth on each other, and see how it feels.

Ann said she is painfully aware of the many adjustments she and her family have been making in order to cope with her pain, incapacitation, and other disease related symptoms.

Professional relationships. In order to manage her care at home, Ann has had to establish and maintain workable relationships with health care professionals. At the time of interview, her primary professional contacts were with doctors. She also talked about nurses who had cared for her during hospitalization. She described the criteria she used to find the qualities that she values in a family doctor:

A: . . . we have just changed family physicians . . . for the reason that we just felt she had a very cold perspective on things . . . and in discussions she expressed herself as being, really, an atheist. When it really comes down to the nitty gritty of life I find it's important to discuss, to have that spiritual perspective? And it just wasn't there. And she admitted, you know, her thoughts on that area too, so we've had different discussions but she was not at all helpful when I needed that kind of a warm kind of help. So we changed family physicians and now we've made the decision to go to someone who is born again. . . . and found him ever so warm and so caring. . . . And you sense there that there was a sincerity of real caring. . . . I feel now that if I do have a real problem I can discuss it with him, where I couldn't--I didn't feel at liberty--to do that with the previous one. . . . So I'm very happy, and I don't know why I didn't make the decision earlier you know, way back. But anyway, some of us are slow learners. And so, now I do feel that I can ask him questions and get more information from him. And, uh, he already has expressed that he . . . believes in the conventional way of treating cancer, but when--if and when that fails--that he would be supportive of alternative ways. Where, uh, that was never expressed by my former physician. So with that thought already expressed, I do feel more comfortable with him.

She views cancer specialists as "very busy people" who are very knowledgeable in "their particular field", saying, "A patient perhaps goes for specific questions, specific problems, rather than perhaps, your general areas. You're kind of focusing". Ann said her doctors are generally very helpful and "try to do their best" to provide effective medical treatment, but expressed frustration about the unhelpful relationship she experienced with her previous family doctor:

- A: I think one of the most frustrating things is the fact that this whole diagnosis [took so long] . . . I felt she should have been on the ball in that area. . . . I always felt more depressed coming out of her office than I did going in. . . . I never stopped to think about that either, prior to this, but she must be quite a kind of pessimist herself. And so that's always been frustrating.

Ann went on to describe the attributes she finds most helpful in doctors and other health professionals:

- A: I'd like them to--what am I looking for?--to be very competent in their field. . . . I'd like them to be able to give me that confidence that they are very competent people. To me that's important.
- K: What is it that they portray that makes you have faith in their ability?
- A: I think perhaps their discussion of alternatives, that they're aware of. And perhaps including me a little bit in making the decision. . . . a nurse that I certainly felt was very competent when I was in . . . I felt was just a wonderful nurse . . . she knew what I needed before I asked. You know. For instance, she said, "Would you like some help turning over on your side now?" . . . How did she know that I would like to turn? . . . Various little things like that, uh, they weren't so little to me. They were big at that time. . . . You just sensed a very real sense of caring and love . . . the expression on the nurses' face is very

important. Gave you the feeling that she's not just rushing in and rushing out, but she actually has a few moments of time for you. Maybe even just a touch on the shoulder . . . the way she just carries herself and her whole tone. Her whole expression is very important to a patient when they're not feeling well. And for a doctor, it's a little more difficult, because you don't have that much time with them. You're only in the room, you know, a short period of time usually.

Ann provided some examples that demonstrated the quality of "caring" she values in her doctors:

A: [The cancer specialist] really tried to get it [radiation treatment] done earlier. I really respect him. Because, in him, I felt he was a very caring person. You know, that he thought, "This lady is suffering, let's do something for her. And I'll try my best to get it done as quickly as I can". And he put his arm on my shoulder and you know, just those kinds of things. Like in him I really sensed a warmth, and a very caring professional person.

.....

A: [The cancer specialist] came in while I was in the hospital, just for a social visit, too, which was very nice. I thought, "He didn't have to come in". . . . That was a very nice thing to do, which was beyond his call of duty kind of thing, I'm sure.

Ann also talked about how important it is for her to feel a sense of hope and encouragement, and how doctors can instill and cultivate realistic hope in their patients:

A: I know that the news is not always positive news. The doctors do have to be honest and they want that, of course. But not to leave you absolutely devastated, if possible. . . . a little encouragement, that goes a long way, too. And in my situation, which is perhaps a little

unique in the sense that, the doctor says, "Well, I'll be praying about that". Or even in the room he says, "Well, let's pray together". To me that's a real uplifting feeling . . .

K: And if the physician didn't have the same spiritual faith as you . . . what other things could they do that would be helpful to you?

A: I think just how . . . they give you the information that they have to give you--which is sometimes negative--has a bearing on it. . . . I think it is just a way of sharing the information that they have to share. You can somehow say hard things, but saying them without a real down spirit. For instance, when I left [the cancer specialist], I felt uplifted, in a sense. Even though there wasn't a great lot of encouraging news that he gave. But he said, "Let's try this third hormone"--after discussing the options--"and go for the bone scan and we'll go from there". You know, he could have just said, "Well, we'll try this", and with a negative kind of expression. . . . They don't want to give you a false hope, so it's a very difficult area for them as well. But I think if they can sort of say, "Well let's try and see".

Ann perceives that her active participation in making decisions about medical treatment is vital. She discusses the manner in which she likes to take part in decision making with her doctors:

A: I just feel he has so much more knowledge and information about the disease and about the medication and so on that, I'd like, to trust him. But the fact that he shares the information with me, and says, "Well, you know, there is a fifty-fifty percent chance that this may work", or . . . "These are the side effects that may occur". And he shares that with you and gives you some statistics about the medication or that kind of thing. And then you kind of feel like, "Well, okay, if it has a fifty-fifty chance of working do I want to try that? . . . to be open and sharing the facts, but still kind of saying--well he didn't just say, "It's up to you", either. And I don't think that's what I want, because I don't feel I'm that competent to make the ultimate decision. But the fact that he kind of shared the options, I guess, was enough to involve me in the decision. I mean, if I was to make all the decisions then why go to a physician? You know. So, no, I certainly don't want that.

I like to believe he knows a lot more than I do. And that's the trust that I'd like to have in him.

Seeking Knowledge

Ann relies on her doctors as the primary source of knowledge regarding her disease and treatment. Their provision of information has generally been confined to medical treatments and medicines to control pain. Information collected from them is also influenced by time constraints. When asked how she seeks the information she needs to effectively manage pain at home, she responded:

- A: I don't think that I have as much information, perhaps, as maybe what I should have. I don't know, because when I think of it, certainly as a family we sort of like to consult with each other, discuss the options that we know of and so on. I may even contact a friend to, uh, get more knowledge about it. But other than that, I think we do rely a great deal on our doctors' advice. We don't know much about the topic. I've not really gone out to the community to search, there's not much help there.

Although she was knowledgeable about her treatments and medications, Ann felt her awareness about the potential progress of her disease had, at times, been inadequate. For example, when her hip started troubling her three years after her mastectomy, she thought, "It'll just go away . . . [I was] not dreaming it was related at all to cancer. . . . I wasn't aware that it moved to the bones that way". In another

example, she was reassured to know the fluctuating nature of her disease was "normal":

A: I don't know if this is characteristic of the disease or whether I'm kind of different along that line, but I find that I'm on an up swing and then, you know, I go back a bit. And then it's up swing.

K: It's very normal.

Without knowledge of other women in the same situation, Ann lacked a "norm" group with which to compare herself. She felt it would be helpful to know the experiences of other women coping with breast cancer. She showed interest in our research, saying, "It would be interesting to read what some of the other women have expressed, the different things or the similarities".

Ann felt she had limited knowledge about available resources and how to access information about them. She had not felt a need for additional resources until recently. Regarding services available through the cancer treatment centre, she said, "I'm not really aware of much going on there". She thought she knew about the social worker's role, but wondered:

A: . . . if that's the lady that did come to my room while I was in the clinic there? And, like, do they provide for instance, home makers? I think she came around and then I think the suggestion was to contact your local representative here.

She was not aware of other professionals from whom she could solicit support or information. Although she said she had not been informed about cancer information/support groups, Ann had seen a newspaper advertisement about a local cancer support group in her community. She also remembered seeing a pamphlet about "living with cancer" in the cancer treatment centre waiting room.

After our last interview, Ann and Bob asked for information about available resources and appropriate channels for arranging home making and home care services. They also asked about helping children cope with a parent's illness. Given the time and opportunity, Ann and Bob had many questions to ask about managing her illness at home.

Negotiating the Health Care System

Ann voiced frustration regarding hindrances presented by the health care system and related procedures. In light of the medical expertise and technology currently available, Ann expressed concern at the length of time it took to accurately diagnose the spread of her cancer:

- A: It seems strange that it would take that long when you've already been diagnosed having had a mastectomy and all that. So it was from October through to the end of January. It took that time. And I think it does seem, if indeed this is, you know, it's characteristic of this disease to move to the pelvises or to the bones, it seems strange it would have taken that long for a physician to get the bone scan done or whatever. I wasn't aware that it moved to the bones that way, so I just really didn't figure it was related at all until the bone scan came along. Well, when it goes for such a long time, you begin to get a little suspicious too.

Inaccessibility to much needed radiotherapy treatments was a real problem for Ann. She repeatedly referred to the frustration and helplessness of waiting, in pain, for treatments meant to offer relief of her discomfort. She said:

A: I was in the clinic hospital for four days, hoping to get radiation at that time. But they had such a shortage of technicians at that time, that they cut back on the evening staff, and just had the morning staff. So I was unable to get much radiation, other than one session of it . . . So then I needed to wait another five weeks before I could get the radiation for the sacrum. And then, that was a painful time of course, waiting for five weeks. I guess it's the waiting periods . . . that was a long waiting period, when you are in a lot of pain. And just to be told you have to take painkillers until you've got the radiation, that was frustrating.

Ann said she felt "powerless" in the face of long drives into the city that are compounded by long waiting periods at the cancer treatment centre, commenting:

A: It's frustrating to have to drive all the way to Vancouver when you're not feeling well . . . and to wait in the waiting room for your appointment, which is maybe, you know, at a certain time. And then find that sometimes you don't get in to see the physician for another hour, you know. That's frustrating. But then, you think, "Well, what can be done about it"? It's just a very difficult problem, unless there were lots more funds.

The nature of health care funding impacts significantly on Ann's ability to manage her care at home. She referred to the financial stress of managing illness at home:

- A: To me it seems a little bit strange, in a sense, that if you're in the hospital . . . you're under very expensive care there, and yet that's all taken care of, you know. But if you're at home and looking after yourself and you need a little help, then you have to pay for it out of your own funds. Even though you've paid all the medical fees and so on for insurance and so on. And I don't know if that's quite the way the system ought to operate, you know, and I know it's the way it does.

Future Goals and Expectations

At the time of our interviews, Ann maintained hope that her treatments would be effective and that she would get better. At the same time, she was experiencing and exploring feelings related to the potential losses facing her and her family. Her goals were primarily focused on spending the kind of time she enjoys with her children and husband, and in maintaining some semblance of normal life with them. She spoke of "carrying on things that are meaningful to the children" and "getting on with things", as she had always done before.

Postscript: Seven Months Later

Ann and I arranged to meet again in April 1991; seven months after completing our research interviews. She had received a copy of her case study several weeks prior, and said she would be prepared to discuss it with me. In our telephone conversation she indicated it had been "a difficult winter" for her, but now she was feeling "better" and looked forward to our visit.

Bob welcomed me at their home several weeks later, reporting that Ann was "having a bad day" and had requested him to meet with me on her behalf. He

seemed calm and relaxed, quite a change from his previously frantic manner. He told me Ann had reviewed the case study and found it true to her experience. He had read it too, and commended the effort and painstaking detail that had gone into the document. Reflecting on "her story", his face took on a sad, empty expression. The stark reality of the words he had read were evidently painful for him to discuss.

Bob proceeded to recount the chain of events that had taken place over the previous seven months. Apparently, Ann's cancer continued to spread, her condition progressively deteriorating over the fall of 1990. Just before Christmas her pain became "so incredible" that she was hospitalized for a month. At the time, he was told she had "about six weeks to live". He said Ann still "had hope" that chemotherapy treatments would help her, so he supported "her choice to go ahead with chemotherapy" even though he "didn't see the point" of her suffering further. Apparently their family doctor told Bob she would "die anyway". Tearily, he reflected on the difficulty of supporting a wife who was "still hopeful" when his own hope "had been taken away". He commented, "It was very hard for me to look at her as a dying woman while she was still struggling with a strong hope to live".

Ann completed her course of four chemotherapy treatments a month prior. Apparently, she experienced minimal side effects after the first three treatments, but was still coping with "severe nausea" from the last treatment. Bob said he felt "shocked" at her recovery--that she "is even still with us" after he had been advised to prepare for her imminent death.

Bob expressed "resentment" over the management of his wife's care during the time when "she was supposedly dying". He remarked, "I don't think much of doctors, their attitude is one where they know everything". He voiced anger that the doctor "took away" his hope, saying "it was Ann's hope" that kept him and their family "going".

Bob also vented frustration regarding the hospital care Ann received when she was coping with "intolerable" pain. Apparently she was initially hospitalized on a "chemotherapy ward that wasn't used to bedridden patients". He perceived that his wife was treated as an "outcast" due to her immense pain and need for basic care, which he felt the nurses were neither interested nor capable of providing.

He described coping with the circumstances by remaining at her bedside and "learning to be her nurse". He perceived that he was "labelled as disruptive" by hospital staff, explaining that he learned to "demand" what he needed for his wife. He said he found it "difficult to assume the aggressive role", but felt he "had to" in order to ensure appropriate care for his wife. He felt relief when Ann was transferred to the palliative care unit in their local hospital, where she received "excellent care" from nurses devoted to--and specializing in--the care of patients like Ann.

Overall, Bob felt that individuals and their significant others were "very much on their own" in the management of their pain, and that his learning occurred through "trial and error". He felt frustrated that "people need to learn to defend

themselves at a time when they are most vulnerable and have the least energy", claiming that he felt "absolutely exhausted".

After some time Bob refocused on the present. He said the family had settled into a routine, with the help of a home maker he described as a "Godsend". She spent four hours each weekday doing housework, preparing dinner and helping with child rearing. Bob felt their home maker was especially supportive because she was a widow with children similar in age to their own.

When he began discussing Ann's present condition he became teary, saying, "She's just not the same person that she was". He explained that she had become intolerant, complaining of things that "would never have bothered her before". He held her painkillers responsible for her personality changes, saying, "I desperately wish there were painkillers that weren't mind altering". Bob perceived that Ann was in pain "most of the time", but that, because of her independent nature, she tended not to complain. He said she had difficulty walking, and that the slightest activity or exertion "absolutely exhausts her". He felt she was having "a hard time psychologically", that it was very "trying" for her to have to "depend on others".

After talking about Ann for a few minutes, Bob said he would like me to see her for myself. It was as if I needed to witness the change in her in order to grasp it's believability. He went into the bedroom to ask Ann if I could come in to see her, but she insisted on getting up and coming into the living room. It was about fifteen minutes before she was dressed and making her way down the hall way with the support of a walker.

A sense of despair accompanied my first glimpse of her. She had aged significantly and lost a tremendous amount of weight. She was a mere shadow of her previous self. Her posture was stooped, giving her the appearance of a very old and frail woman. She sat in the chair across from me and chatted pleasantly, but her eyes were glassy and her eyelids drooped, occasionally closing for a few seconds. At times, her face took on a blank stare and her conversation wandered. Then, suddenly, she would jolt back to the discussion she had left trailing.

Ann said she was "delighted" to read her case study, verifying that it was a faithful representation of her story. She had managed a thorough review of the material and pointed out two minor corrections she had made.

Ann denied feeling pain as she sat visiting with me, but said her slightest movement triggered pain. She acknowledged that she had "been having a very difficult time over the past while", filling her days with hours of "dozing", something she found frustrating. A hospital bed had been set up in the bedroom so she could rest in various positions. She was taking Gravol and Morphine regularly, for nausea and pain. She complained about the constipating effects of her painkillers.

Ann felt the health care system lacked support for individuals trying to cope with pain at home, saying it had been "very hard to get the information you need in order to cope with day to day life". Echoing her husband's sentiments, she said, "You are really very much on your own, even when I was in the [cancer] hospital, they're not that helpful".

Despite her obviously deteriorated state, Ann said she had made an astonishing recovery since the "terribly painful time" before Christmas. She expressed hope that she would continue to "get stronger", and soon be "up and walking". Her determined spirit was evident in her comment, "My friends are wanting me to go out for lunch but I just can't manage the stairs, so I just HAVE to get better!"

We cut our visit short when Ann suddenly became nauseated and rushed to the bathroom. After spending a few minutes in the privacy of her bathroom, I assisted her back into bed, and said good-bye.

Case 2: Betty

Demographic Information

Betty is a sixty-two year old caucasian woman living with her retired husband Bill in a large Vancouver suburb. She has three adult sons living outside her home. Betty was employed as a sales clerk until about one year ago, when she quit work because of pain related to her cancer.

Preface

I met with Betty four times over a period of nine weeks. Our meetings were held in her home, part of a townhouse complex tucked away from other residential areas. On my initial visit Betty was unwell following a recent chemotherapy treatment, and her husband asked me to go up to her bedroom. I climbed the stairs to a spacious, fresh smelling bedroom where Betty lay in bed with covers tucked up under her chin. She appeared younger than her sixty-two years. Her pale complexion against the vast whiteness of the bed sheets made her seem frail and tiny. Her thinning hair remained in patches that revealed her scalp underneath. Betty greeted me with a big smile and asked me to sit on the edge of the bed beside her.

She said, in an eager voice, "You're a nurse, aren't you?" and told me she was having waves of nausea and needed an injection of Gravol. Betty asked if I

could give her the injection. She explained that it would be too late by the time the home care nurse was contacted and able to reach her home, leaving her to retch and vomit for several hours. She said she no longer called the home care nurse because the injection offered no relief unless given with the first waves of discomfort. Her husband had not learned to administer the injections.

After considering my legal obligations, I contacted the home care nursing department and confirmed the doctor's order. After giving the injection I observed Betty's relief as she settled back on her pillows. She voiced enthusiasm about participating in the study although she "could not imagine her story being much use to anyone". Willing "to give it a try" she agreed to meet again for our first interview.

I arrived three weeks later in the early afternoon because Betty wanted to rest after her morning activities. I was struck by the difference in Betty's appearance, compared to our previous meeting. She looked larger and stronger dressed in slacks and a sweater. Her complexion was rosy and most of her hair was gone, other than a few grey-brown wisps. She was tall, thin, and walked with a cane in her right hand. Although she walked with a limp, she was in no apparent distress.

The interview took place in her living room, which looked out on the trees and provided a sense of seclusion. Sitting beside each other on the couch, I noticed a few pocket books sitting on the coffee and end tables--opened face down--as if the readers had been interrupted. I saw no other personal articles.

Initially Betty expressed apprehension about being interviewed. At times her manner was abrupt and I wondered if she was angry. Given time, she seemed to get caught up in the story she was telling and I sensed she appreciated the opportunity to talk about what was happening to her. She expressed frustration and discouragement related to her cancer and its treatment. She also asked many questions about cancer, bone metastases, chemotherapy, hair loss and regrowth, and how to access various health related services.

During the interview I noticed her reposition herself on the couch from time to time, as if she were having pain. Towards the end of the hour her face looked strained. She confirmed that she was beginning to feel tired and uncomfortable, so we ended the session. After the interview Betty asked questions about physical symptoms she was experiencing, as well as some financial concerns. I referred her to a social worker at the cancer treatment centre, for information about wigs and finances.

A week later when Betty greeted me at the door for our second interview, her distress was apparent. The tone of her voice was sharp. Before I had a chance to step into the foyer she was expressing anger and frustration about her inability to "get through to the cancer treatment centre social worker" I had referred her to. She said she had been "put on hold about four times" and described her experience of being told she was ineligible for social services offered through the cancer treatment centre. After providing the information and assistance she requested of me, Betty

seemed satisfied that she would be able to access appropriate resources without further problems.

Betty then broke into tears. She explained that she had seen her cancer specialist the previous day, and I was the first person she had seen since--other than Bill. Sobbing, she said her cancer specialist had given her "one year at the most to live", that treatments were "not working", and there was "little hope of anything else working". She understood they "might try one more chemo anyway, even though it would probably do nothing to help". Voicing feelings of discouragement and helplessness, she admitted feeling shocked and out of control. She also reported an unexpected increase in physical pain.

Respectful of her emotional distress, I suggested we cancel our session. I stayed and offered empathic support as she expressed her feelings. After about thirty minutes Betty insisted we carry on with the interview. She remained teary throughout the session, and appeared uncomfortable. Her face looked tense, and she shifted her position every few minutes. She talked about her pain management for much of the session, asking frequent questions about taking painkillers and controlling their side effects.

She was particularly concerned about being able to manage her pain while driving to the prairies in a few days. Despite her discomfort, Betty was determined to go on the trip she had been so looking forward to, and was prepared to fly home at once if her pain increased. By the end of our session she decided to approach her

doctor about options for more effective pain management. We agreed to meet again after her holiday.

Our third interview took place two weeks later, following her return from a "great" trip. She said she "survived" the journey despite some difficult moments along the way. I was aware of a change in Betty, a contentedness that had not been apparent in previous sessions. Her pain had diminished considerably in response to stronger painkillers she had asked her family doctor to prescribe. She looked relaxed and comfortable, despite the aftermath [nausea and fatigue] of recent chemotherapy. She indicated that she was tired of enduring the ravages of chemotherapy, and that she yearned for some quality time in her life again. She hoped she would soon find out whether the treatments were "doing any good".

History of Pain Experience

Betty was diagnosed with breast cancer in 1976 when her doctor discovered a lump in her breast. After recovering from her mastectomy she experienced no problems until January 1977, when she had a lump removed from "underneath the arm". Again she had no further problems. In August 1989 her current troubles began. She recalled:

B: I thought I had [the] flu and a leg ache. . . And then all of a sudden my hip started to hurt and I thought it was arthritis. I went to see [my family doctor] in September--at last--because it was hanging on so, and I was limping quite badly.

Her family doctor ordered x-rays that apparently "showed nothing". She was then referred to an orthopaedic surgeon who took x-rays that also "showed nothing". According to Betty he asked if she "drank [alcohol] and had fallen". She recalled having a bone scan some time later that "showed something but they didn't know what it was" and "they didn't pursue it".

Her pain persisted and in December 1989 she was sent to an arthritis specialist who "thought it was arthritis" and gave her a cortisone injection, which she did not find helpful. She perceived herself to be "a real pain in the neck" during this time because she kept going to her family doctor and complaining about unrelieved hip pain.

In January 1990 Betty returned to the arthritis specialist because her hip was "very, very sore" and she was having difficulty working. She recollected:

B: I said I didn't want any more cortisone . . . [the doctor] said he wasn't really sure if it was arthritis or not. And just as he was leaving the office as I was getting dressed I said, "Well do you think it could be cancer?" And he said, "Oh heavens no". He said, "Cancer has to be in one of the other parts of your body". And when I came out he said for me to go down the hall and get some x-rays. And the next day [my family doctor] phoned me and said I had cancer. It just turned up that quickly.

Betty quit work and saw a cancer specialist in February 1990. She remarked, "I certainly did have cancer and at that point they thought there was a spot on my lung and over this [left] eye, besides the hip".

In March 1990 Betty commenced monthly chemotherapy treatments and had five days of radiation therapy. She also had a bone biopsy performed to confirm that breast cancer had spread to her left hip. She elaborated:

B: I was going to be in just overnight and [the doctor] did the bone biopsy, but obviously didn't go into the right place, or he hadn't taken a big enough piece. And so they decided to do it again the next day. And then that's when they took out a large piece of the bone, which [he] said had just turned to mush. And they put in epoxy. I've got a big ball of epoxy in my hip now.

At the time of interview Betty had just completed six months of chemotherapy treatments, as well as four radiation treatments for cancer spread to her lower back, spine and right hip.

Description of Pain

Betty's first experience of pain was in the "front part" of her left hip, extending down her leg. She described:

B: . . . it ran down my leg, the pain . . . I still get it but they still say it's sympathy pain. . . . The pain has never left . . . And try as I might I couldn't walk without limping. . . . kind of a jagged--always there. Just never left.

She described enduring this pain for a "long time" [August 1989 to January 1990] before being diagnosed with cancer. "In September it was really especially bad, the

pain . . . I was having a terrible time moving around". Her pain also tended to intensify during the night.

In the following passage she described the nature of her pain at the time of our first interview:

B: Funny, this hip with the cancer--the right hip that was just diagnosed--isn't sore. . . . but the lower back and spine are very sore. . . . Not painful, painful sore, but sore. You know--if one had a toothache or headache. . . . It doesn't come and go and it doesn't jag . . . it's there. . . . This hurts a bit [pointing to left groin area] . . . And then this [left] leg aches all the time. . . . It aches constantly. [rubbing thigh towards knee] Right down the front. Mm hm.

During our second interview three weeks later, Betty related, "The pain is getting a little more all of a sudden, which I didn't expect". She appeared to be in pain and expressed disappointment that radiation treatments had not relieved her discomfort. She described enduring pain throughout the day as well as waking during the night:

B: The pain isn't horrendous. It's just that now it's waking me up at night. But it's nothing you can say, "Oh my GOD I can't stand it any longer. It's not that".

By our third session her pain had diminished considerably in response to stronger painkillers she was taking. She described no longer having the pain previously described, other than an occasional "shooter" down her leg. She also

found herself having very sore buttocks "every once in a while" upon sitting. She commented, "I don't know where it is really but it just HURTS".

Impact of Pain on Daily Living

Betty portrayed herself as being socially and physically active prior to her problems with cancer-related pain. She worked as a sales clerk and went to aerobic exercise classes every day. She said she "felt useful". Betty explained that her experience with pain had impacted immensely on her life, both physically and emotionally. In this excerpt she reflected on the ways she felt her pain and treatments had disrupted her daily life:

B: I had to quit work and I don't clean house as well. And that upsets me, I was Mrs. Neat. . . and I tire very quickly. [Bill] and I like to go away on day trips, just jaunt around and quite often I can't do it. It's just too tiring. . . . I'm either feeling nauseated or just so tired that I can hardly move. And of course, I used to walk a great deal and I can't walk now. I haven't shopped--I was born to shop--and I haven't shopped now, except for the basic staples of life, since January. In fact, [Bill] was doing most of the shopping for the groceries for a while because I couldn't make it around the store. I don't have people in for dinner. I used to have dinner guests at least twice a week and I really miss that, but I can't do it. I get too tired. . . . a late night and I'm gone. And we don't take dinner invitations now. That's changed a great deal, I really enjoyed the social life. But I find too many people around me . . . I can't take a room full of people.

.....

B: It's too confusing and it's like I've changed into a different person. I don't know why. I have no idea, but as I said, I really miss entertaining--but I don't think I miss it, because I can't cope with it.

Betty often mentioned her persistent fatigue. She said that pain made her feel "very tired", reflecting, "I can hardly get myself up the stairs to get into bed, I get so tired". She also complained of significant disruptions to her sleeping patterns. In the following excerpt she described the "terrible nightmares" she had until recently:

K: Are the nightmares about anything in particular?

B: YES. That the cancer's all gone. And I wake up and to me, it's so real that I haven't been asleep, that the cancer's gone and the pain is gone! And I always jump out of bed and I think, "Isn't that marvellous! There's no pain!" And I trot into the bathroom, and I can walk without limping and then I get back to bed and I can't get back to sleep--you know--just weird. You doze off and often you wake up kind of terrified and you don't know why you're terrified, but you're terrified. And you [deep sigh] wake up in the morning and damn it all, the pain's there. It hasn't gone at all. [crying] And I was going to wake [Bill] up the other night and tell him that a miracle did happen! Thank heavens I didn't!

K: So what happens, is that you fall asleep and you have dreams where the pain and everything is gone?

B: Yah. [tears in eyes] I wake up but I don't realize that I've wakened up. I don't realize I've been asleep. It's so real that I haven't been asleep, that in my head I've heard the clock strike and everything, and it isn't, so I've fooled myself. [laughs] Then I don't sleep the rest of the night. I may have slept for an hour when I've wakened up with this dream that it's all disappeared and gone. And it hasn't.

When Betty started taking sleeping pills she began sleeping all night without dreaming or waking up "baffled or upset".

By our third interview she perceived the quality of her life had deteriorated significantly. Although she was "glad" to have more control over her pain, she was overwhelmed with uncomfortable symptoms she attributed to chemotherapy. She was tired, nauseated and "headachy" most of the time. Betty said she felt "worn out, tired and exhausted," and contemplated abandoning chemotherapy treatments in order to "enjoy what time I've got".

Coping Strategies

Betty used medicinal and non-medicinal strategies to manage her pain. She underwent a combination of radiation and chemotherapy treatments in an attempt to control her disease, and subsequently, her pain. Painkillers provided a direct method of pain management.

Medications and treatments. Once diagnosed with metastatic breast cancer [in March 1990] Betty received five days of radiation therapy and began a six month course of monthly chemotherapy treatments. At the time of our first interview in September 1990, she had just completed course of chemotherapy. She described having four radiation treatments the previous month, in an effort to control disease and pain in her back, spine and right hip. She claimed she was nauseated and "really quite sick" with each radiation and chemotherapy treatment.

At the time of our first interview [September 1990] Betty was taking a Percocet tablet every evening for pain. This opioid analgesic had been prescribed two weeks earlier. She said, "It's doing the job well, I just take one at night and it's

really great, you can just feel [the pain] leaving and you can go to sleep". She said she preferred to tolerate discomfort during the day rather than succumb to undesirable side effects of the medications, explaining:

B: The only reason I take the Percocet at night is so I can get comfortable in bed because I can't sleep on my back without a Percocet. But I don't want to take it during the day because I like--well if I take a Percocet when I'm up and about I get sick--so that means I have to take a Gravol and if I take a Gravol with the Percocet then all I'm going to go to sleep and so it's a lost cause, you know. I've got other things to do besides sleep all day--unless I really do want to! . . . I take a Percocet a day and that's always at night, it's at bed time.

According to Betty, night time is the most important period for her to be able to manage her pain. By minimizing her pain at night she can "sleep the night away" and get up in the morning to do whatever she wants to do. She accomplished this by taking a sleeping pill each evening with her painkiller. She remarked:

B: I wouldn't be without it. I rely on it. Maybe eventually I can get off them, but right now I need it. . . . I sleep the whole night through. . . I wake up so refreshed in the morning that I can get right up and have my shower and feel great!

Up until two weeks before our first interview she had not taken painkillers for about five months, despite having pain. Although she had a prescription for Leritine--an opioid analgesic--Betty "just quit taking it" because she "vomited and vomited and vomited" whenever she took it. Taking medicine to control her nausea

caused drowsiness she found "unacceptable". She talked openly about her decision to quit taking painkillers:

B: Well, I didn't think there was anything else. I didn't think to ask if there was anything else. That was my own problem. I mean, no one [health care professionals] said to me, "Are you sick?" And I didn't say to them that Leritine was making me sick. Oh yes, I did! I told [my family doctor] and he said, "Well you should always take Gravol when you take Leritine". And that's when I decided. Well then, you know, I was out to lunch all the time if I do that! So uh, but he hadn't prescribed anything else.

By our second interview Betty was no longer able to control her pain as she had done three weeks earlier. She was waking up at night, feeling nauseated and uncomfortable. She felt painkillers were causing the nausea. She contemplated doubling her dose of evening painkillers but voiced concerns about related nausea. She viewed her options for managing nausea as unacceptable. The first was to remain flat in bed all the time, and the second was to tolerate the sedating effects of Gravol. She described what she found most bothersome:

B: "Not being able to manage the nausea and not being able to function with a clear head--I hate being fuzzy headed all the time".

At the time of our third interview in late October 1990, Betty was taking a new painkiller and had completed her third treatment of a new round of

chemotherapy. She discussed her decision to approach her family doctor for a change of pain medication:

B: I couldn't quite decide if I really WAS in pain or not and then I decided that I really was and it was silly taking suffering with the pain when something could help it. So [my family doctor] started me off on the liquid [Morphine] first . . . he's got me on the pill now--it's the slow release [MS Contin]--twelve hours.

Betty had achieved an improvement in her pain relief since taking Morphine.

She elaborated:

B: I can sit up and read right now. . . . and that's a big help.

K: So you're not walking with a cane and the fact that you can spend a little more time in the evening...

B: Yes. With my husband it's much more nice, uh, a little more sociable even! I'm not feeling as though I'm spending all my time in bed now. . . . I was glad I started on the Morphine. It's made it much nicer. It really has.

Her only complaint was that she was having a "terrible time with constipation".

Despite her daily regime of stool softeners and laxatives, she gave herself an enema approximately every three days "to prevent things from getting too bad".

Although Betty seemed satisfied with her improved pain management, she expressed discouragement regarding chemotherapy treatments. She wondered if the treatments were helping, and talked about quitting them altogether. She

contemplated whether the resulting nausea, fatigue and headaches were worth it, as she reflected on the quality of her life:

- B: I just wonder if maybe I'll quit it [chemotherapy] altogether and enjoy what time I've got. It makes more sense. . . . I'm going through four days, well this is the fifth of really feeling ROTTEN and by tomorrow--tomorrow will be Saturday--Saturday and Sunday I'll feel quite good, only to start in all over again on Monday. And I just don't see the sense in it. . . . right now the side effects are rotten.

Self-care behaviours. Betty has made use of various non-medicinal approaches to manage her pain, particularly during the five months when she quit taking painkillers altogether. At the time of our first interview she was only taking painkillers at night. She said she could "pretty well manage" without pills during the day and went on to explain how she was able to do that:

- B: I count. When it starts to hurt--you know--I'll start counting. And then of course when you start counting your mind goes off onto something else and before you know it, you forgot the pain. So I've always found counting helpful. I don't know why, [laughs] or where I got it from, it's just one of those things. . . .
- K: Are you able to relieve the pain completely by counting?
- B: Yes, I can, I guess. Because I can then pick up my book and start reading. . . .
- K: How--when you say that you count--how far do you actually end up having to count?
- B: I don't think I get too far because then my mind wanders. I'm not straight and narrow. I think I probably only get up to about eighty-five or eighty-six, something like that. And then I'm not sure if I've

miscounted, and I can't be bothered starting all over again, and then my mind will wander to something else, how the kids are or what's happening, or somewhere. And then I realize the pain's not bad. . .

Reading light fiction books provides another "very good" distraction from discomfort. She said she finds it helpful because she can "lose" herself in someone else's life.

Betty also uses other practical methods to cope with her pain. Because the intensity of her pain is directly related to her level of fatigue, she manages her time to minimize tiredness and get enough rest. She finds that having a sleep when she's tired and uncomfortable helps her to "get up and kind of cope again". At the time of interview she napped before having company or going out, and often retired early in the evening. She described, "I'm really good in the morning, by late afternoon and evening I'm not good".

Although able to walk independently, Betty used a cane [on her cancer specialist's advice] to prevent herself from falling and breaking her hip. She also needed the cane to walk beyond the main floor of her home, negotiate stairs, and walk more than a block. Using the cane for support helped relieve her left hip pain. Betty was able to stop using the cane when she started taking Morphine and having less pain.

During cool weather she used a hot water bottle on her sore leg, describing, "It was soothing, but of course you know hot water bottles are like a comfort blanket--but anything that works, use it". Because she finds it uncomfortable to sit

in one position for a long time, she "moves around and it shakes into place" as needed.

Attitudes and Feelings Related to Controlling Pain

Betty's assumptions about cancer began to evolve at least fourteen years ago, when she had her mastectomy. She talked about what it was like for her to cope with cancer at that time, and for the ensuing years:

B: Well, fourteen years ago, my mother always referred to my mastectomy as "that THING". And now she'll say, "When you had cancer", which she never would before . . . it was like I had a contagious disease . . . The word just wasn't brought up . . .

K: . . . once you had your mastectomy you really didn't have problems [B: No I didn't.] for a long, long time [B: Right.] and I'm just wondering--those fourteen years in between . . .

B: You forget about it. It's out of sight, out of mind. And especially after five years, you think hah! No, you really never ever dwell on it, at least I didn't. It was gone, over and done with. And in those days I believed that once the mastectomy had been done the cancer was gone. I didn't know that it would come back. No, I thought that once the surgery was done that everything was done.

That her cancer recurred after many years of being "free and clear" continued to evoke an emotional response from Betty. Eyes brimming with tears, she described feeling like she was "hit by a truck" when her cancer returned.

B: I really haven't any complaint except I just wonder why the hell I got it again after fourteen years! It really kills me! Because I really thought that I had it beat! . . . I keep thinking, "What did I do"? I

went to exercise class. Oh God, I took care of myself. Now I wish I'd saved the energy!

Betty discussed her views about cancer and her belief that "you've got to tough it out". She explained:

B: You think, "Well this is it, I've got cancer and so I'm going to be sick, or I'm going to be in bed". No one's told me otherwise. . . . It's one of those subjects that, oh, when I was a child no one ever said the word cancer. . . . I guess because it's so terminal, is that it? I mean, any other illness people generally get over. But there really isn't any cure for cancer. I mean, eventually it's going to GET YA, regardless! [laughs] So maybe that's why cancer is so hard to discuss, for the ones who aren't sick. I think that's probably it.

Betty perceived she was able to "handle it a lot better" before she found out her sore hip was cancer. Before her cancer diagnosis she worked, managing without painkillers. She said, "It was just something to put up with because you thought you had a sore hip". She went on to describe how her attitude shifted once she knew she had cancer:

B: Isn't it amazing--once you know what you've got--how you change your attitude?

K: So . . . when you found out it was cancer, it changed?

B: Yes. Yah, then I quit work and got some painkillers. So maybe it's all in the head. Maybe you can manage pain a lot more when you don't know what it is, than when you know what you've got. Maybe you become kind of a big boob!

K: Is that how you feel about yourself?

B: YAH, yah. When I stop and think of it. My goodness, I was a sales clerk . . . running around like fury!

Betty reported her recurrence, pain, physical limitations and treatment to have a profound effect on her emotional well-being. She described experiencing a wide range of feelings as she struggled through the ups and downs of her disease and treatments. She described getting "depressed", and often referred to her feelings of helplessness, frustration and anger. During our third session she felt discouraged about her treatments and said she had "kind of lost" faith. She perceived that she was in a "whiny" state and wondered if I "really" wanted to talk to her.

When in pain, Betty reported feeling "very upset", "weepy" and "angry". Often during our discussions she talked about her anger. She ventilated anger about the length of time it took to diagnose her recurrence, and many other aspects of her care and treatment. Her final comments in our last session referred once again to her feelings of anger:

B: I'm getting over it. . . I'm not as angry. Because all of a sudden you realize, who are you going to be angry with? Yourself? And you can go around mad forever, but it's not going to help anything.

Betty expressed concern about changes in her ability to concentrate and in her thinking processes. She said she had become "quite slow" in her thinking and had "quite a time" absorbing information. She found herself losing her train of thought

very quickly and was often unable to grasp "simple" explanations provided by doctors.

She also found it confusing to interact in social groups. She described being out with a small group of people for about half an hour when she found herself unable to "focus on the conversations" and wanting to go home. Betty wondered aloud whether she relied on her confusion as an "excuse" or "escape" to avoid entertaining. She referred to "escaping" several times in our discussions. In the following example Betty talked about escaping to bed as a way of avoiding that which she found difficult to cope with:

B: I get so tired. And then I lay down and I'll be asleep in nothing flat. So it's an escape mechanism I guess.

K: You feel that it's an escape mechanism?

B: I think it is. I think it probably is, that I think I probably have committed myself, and then I'm sorry that I committed myself to all this entertaining. And one way to escape it is go to bed! [laughs] THEY CAN'T GET YA THERE! . . . and all my friends seem to understand it, I'll just say, "I'm going to bed". And they say, "That's fine".

Betty described herself as someone who had never had to ask for help and therefore felt disadvantaged in her ability to seek appropriate support to address her needs. She commented that her nature is not one of assertiveness, that she doesn't "want a fuss . . . [I like to] keep things nice and calm".

She said she finds it helpful to be able to "talk openly" with others about what is happening to her. It is important to her that others listen in a nonjudgmental and accepting manner. She related:

B: . . . if I can tell them I feel rotten, or I feel good, or I have a pain, without someone saying, "Oh pull up your socks and let's go". If you can just talk about it and get it out, and then forget about it and go on. . . . then I'm not all inward. . . . And you can spend so much time being inward that uh, if you have someone else to talk to, you can get it all out in the open.

Betty also finds it beneficial to approach one day at a time. During our last interview she said, "I'm just going to get through each day and then worry about the next". She finds that reflecting back on fond memories helps to ease her discomfort. She especially enjoys reminiscing about her three sons. All in all, Betty said she feels very fortunate to have had "such a good life".

Significant Relationships

Betty talked openly about her relationships with friends, family, and health care professionals, sharing both the ups and downs of her experience. She emphasized that, for her, communication about cancer-related concerns--within the context of personal relationships--is one of the most difficult aspects of coping with cancer and related pain.

Personal relationships. As she reflected on her personal relationships, Betty stated that the most supportive to her are those that have gone "on as

normal". She likes to be regarded as a unique individual rather than being compared or likened to others with cancer, and likes her friends to be themselves--not "preachy", "critical" or too "sympathetic". She talked about her "very dearest girlfriends," whom she has known for twenty-five to thirty-four years, describing how they help her manage pain at home:

B: When they phone up we still talk about the same things we've always talked about. And we never skip over cancer words, or "how you're feeling". And they want to know if I'd like to have them come and pick me up, and take me over to their place for tea, or could they come for tea? And if I don't feel like it, fine. They drop off books for me, and little tasty titbits. And they just treat me like we've always treated each other. They just seem to know what to do. But those people are few and far between. . . . I supported [one friend] through her divorce and . . . she's just a very calm, quiet influence on a person. She never, never pushes her--well, she had a tough life, let's face it. She was in a Japanese prison camp during the war, so I guess she earned a lot of inner strength there. And she can just make you feel good. I really can't say explicitly what, but when she phones up I feel great after talking to her. And you never feel sad, you never feel upset . . . And [another friend] . . . she's funny and she makes me laugh, and always running over with things.

Betty also disclosed that some of her relationships had "deteriorated drastically" since her cancer recurrence and related pain. Voicing considerable frustration, she described what she perceived as inappropriate reactions from others:

B: You get mostly depressed at your friends stupid remarks. "Oh you look great!" "You're all over it!" . . . "You've got to get out and get moving!" "I'm praying for you a lot." That one really thrills me. . . "If you would come to the States you would get better ."

Betty said she felt tempted to respond to such comments, but did not want to hurt anybody's feelings. She was also concerned that if "anything did happen" to her after saying "something nasty" to someone, they might "never get over it". She voiced disappointment that she did not always feel in a position to share her feelings openly, and regretted that two friends had been "driven away".

Betty perceived that "friends seem to be more accepting than family". She said her sisters didn't "want to discuss" her cancer with her. She explained that her elderly mother and sisters reside in the prairies and that perhaps "it's too painful" to talk over the phone. Betty struggled to comprehend her sister's reactions, reflecting that she might behave the same way if the tables were turned. She said she felt "overpowered" by one sister who she perceived was always telling her how she "should" and "shouldn't" be feeling. This became especially troublesome when Betty was experiencing pain, and was told she "shouldn't" be having pain. Betty said she just "didn't seem able" to assert herself honestly with her sister.

Between our second and third interviews, Betty and Bill drove to the prairies to visit her mother and sister. Betty looked forward to seeing them and being able to talk with them directly. One thing she anticipated discussing with them was that she had "about a year to live". She returned from her trip with assorted stories about the "great time" she had. She recounted:

B: Yah, I did [talk to them about having about a year to live] and got it through to them. And they're not upset, you know, but that's their problem. I can only tell them and what they do with it is up to them.

. . . I guess they just don't want to [accept it] . . . They'll have to change their mind eventually, won't they?

Her voice softened as she spoke about her immediate family:

B: It's nice to be this age, frankly. I've had such a good life . . . I've got great kids . . . I've just always been very fortunate. . . . and the boys are all happy, and they all come and see me.

She went on to describe the support and attention she receives from her youngest son, a bachelor living nearby:

B: He comes over just about every day, or phones to make sure I'm still here. And rushes around and gets me my water and, "Don't move Mom, I'll get it for you", and does laundry and the vacuuming. [laughs] Really spoils me! He's a great kid!

Amid the joy of seeing her children grown and happy, Betty was anxious about them having to cope with her death. She said:

B: I guess the only disturbing part is, I guess, my youngest son. I really don't know how he's going to take it if--well of course I will die eventually anyway--but if it should happen sooner than we expect. . . . I really hope that he can handle it if anything does . . . Bless his heart. Yah, I don't know how he'll--I guess [he and my husband] will have to cling together like a pair of shipwrecked sailors, won't they? Because the eldest one is quite self-sufficient. [The middle one] isn't sentimental. Which is maybe a good thing. And then of course [the oldest] has [his wife], which is great because he'll need her. He's very, uh, very tender . . . they'll get by.

Her eyes filled with tears each time she referred to her relationship with Bill, her husband of forty-three years. She first talked about him at the beginning of our second session:

B: We are going home anyway [to the prairies]. . . Bill hates to hear it, but [my cancer specialist] thinks maybe a year that I've got, so uh, it will give us a chance to talk anyway. . . .

K: What is different about going away on a trip, than being here?

B: [crying] Um, I think as you're kind of driving along, you can talk a little more, you know . . . yah, you're really enclosed. You're not in one room or the other . . .

Betty hoped the long automobile journey would create an environment for them to talk with each other, and an opportunity for her to help him accept the bad news.

Several times Betty alluded to the difficulty Bill was having adjusting to the impact of cancer in their lives:

B: I don't want to whine to [Bill]. He's having a tough time, poor thing.

K: He's having a tough time.

B: Oh, coping with me. Not coping with me, but uh, what can be said?
[crying]

.....

B: Oh dear. [sobbing] What do I say? That uh, he's helpless.
[continues to cry]

K: So it's very hard for him. . . .

B: Yah. It is. Well. Well, um, I think it's harder for the survivor really. But hopefully the boys will be good and look after him. [crying]

She hoped to support her husband through "the time they had left" together, and for that time to be of a certain "quality". She elaborated:

- B: Just as long as I can keep him comfortable, and happy, and . . . uh, just make sure he's comfortable, that gives me great joy. [crying] . . . Comfortable in living, giving him food that he likes. And keeping him nice and neat and tidy! [laughs] . . . Yah. [crying] I want quality time. YAH. And it's nice that we have the time together, and we thoroughly enjoy the time together. We can spend all day just sitting here, reading, and it's very enjoyable. [sobbing] I do apologize.

Betty recognized that she and Bill were grieving their anticipated losses. She said, "You've got to, you can't just stick your head in the sand". At the time of our interviews she expressed concern about leaving Bill with burdens:

- B: . . . the one way that I'm really not helping [Bill], um, I'm just kind of leaving a mess. I don't know who to leave things to and I'm afraid I'm just going to have to leave that to him to decide.

Professional relationships. Betty's primary professional contacts have been doctors and nurses. She described her family doctor as the first person she would consult if she "really wanted answers", explaining, "I can ask him anything and I feel very comfortable with him". She especially valued his honesty and the time amount of time he spent with her.

From her perspective, Betty's interactions with her cancer specialists have not always been consistent with the "good rapport" she shares with her family doctor.

She commented, "Some of the specialists don't like to be questioned", explaining, "They want for you to do what they tell you to do, and take what they give you, and don't ask why".

Betty worried that asking too many questions would make specialists and other professionals upset or angry with her. She elaborated:

B: But then again, I can't fault them because I really don't know what questions to ask. Or maybe I know what questions I wanted to ask, but maybe I'm afraid of sounding stupid? You ask a typical lay person's dumb question . . . you would sound absolutely insane. And I guess we are all too worried about our facade and how we project ourselves. We want people to think that we know what we're doing when we don't. . . . I really do hate to be put into a position where I've asked a stupid question, and I get an answer and I think, "Ohhh dumb".

On the other hand, Betty said she was getting "to the point" where she no longer cared what doctors thought about her asking questions. She recalled a situation in which she stopped taking a new medication that she believed was causing "terrible" chest pains and shortness of breath, only to find out later from the doctor that she had to taper the medicine off gradually, rather than "go cold turkey". After telling the story she asserted:

B: And now I'm going to start asking an awful lot of questions . . . I don't know how it's going to go over. . . . I'm realizing I've got to question everything.

Throughout our interviews Betty voiced many frustrations about the relationship she had with her primary cancer specialist. During our second session she said she wanted to change doctors because she was having a "communication problem" with him. She elaborated:

- B: He always seems in such a rush . . . and he doesn't have the time.

- B: I'm not getting the answers I want. . . . I guess because I don't know the questions to ask. . . . But you seem to have to tear each little bit out of him. . . . he's not asked me any deep down questions. "Are you sick?" "Are you really nauseated?" "And how do you manage to get out of bed?" . . . But because I'm not a medical person, and I don't know what questions to ask, I guess it's my fault--partly my fault and partly his fault--but I don't know how to dig the information out . . . And he really gives me the short shrift in time. I mean, when he has decided that he's finished, he gets up and leaves the office, and you go home, and that's it!

- B: I don't think he's an unreasonable man and I don't want to build it up in my head and all out of proportion, because he's not a difficult person. I'm sure and he's a very caring doctor. . . it's just that you feel that you're a know nothing, and everything relies on his expertise and what he decides to do for you.

Betty said it would take "guts" to communicate her needs to her cancer specialist. She admitted feeling powerless to challenge "the authority".

Betty mentioned another cancer specialist who personified the qualities she values in the patient--doctor relationship. His informal and very "easy" manner made communication seem effortless. Ultimately, she wondered if it isn't just

"chemistry" that allowed effective and open communication between doctor and patient.

Betty mentioned a variety of ways that doctors could be more helpful to herself and others coping with cancer and related pain. She said she would find it especially helpful if doctors provided basic information about new medications and treatments. For example:

- B: When they give you a new bottle of pills, explain why you have to take them. And if it's necessary to see the doctor if you have a certain symptom or if you don't feel well.

She also emphasized the importance of doctors translating medical terminology into terms understood by lay people.

Other professionals Betty had frequent contact with were nurses, who she generally perceived as being "very good". She noted the hospital nurses were abrupt and "testy" at times, and attributed this to being understaffed. She recounted:

- B: There've been times that you think that they've really shoved the needle in a little harder than they needed to! [laughs] I mean, when they felt a little harassed.

.....

- B: And when I go to the [cancer treatment centre] for my radiation I have to go and find the nurse myself to give me the shot of Gravol before I have my radiation, 'cause otherwise I'd be sitting there 'til I grew horns! So I run up and down the hall, find a nurse and drag her in! [laughs]

Seeking Knowledge

Betty relied primarily on her doctors for information about her disease, treatment and pain management. Still, she lacked knowledge about many things related to managing her cancer and related pain. She identified various obstacles that prevented her from acquiring desired information. Most importantly, she perceived that she did not know what questions to ask, and feared sounding "stupid". She was also concerned about not understanding the "answers". Her concentration was poor and often she found herself unable to grasp even "very simple things". As well as having difficulty absorbing and retaining information, she felt self-conscious about having to have things repeated.

At the time of interview she was making changes in her expectations, behaviours, attitudes and role as a patient. In order to acquire the knowledge she needed to manage at home, Betty decided she had to start asking more questions and asserting her needs in a more forceful manner. This was in direct contrast to her usual "keep it calm", "no fuss" approach illustrated here:

- B: Before I just went along because when you're a new cancer patient, you really don't know beans. And they're not too forthcoming in the chemotherapy department, when they're giving your drugs . . . they just say, "This has been ordered for you and we're injecting this and you're not getting that one". Why aren't I getting it? "Because it wasn't ordered for you". Uh, that's kind of an obvious answer, but I'd like to know why. . . . now I'm realizing I've got to question everything.

Betty concluded that "you've got to take control of your own life if you want to know what's going on!".

Her transition toward a more active stance was evident over the course of our interviews. Our relationship provided a climate where she could think, feel and explore openly as her story unfolded. Betty evaluated herself and her situation, seeking information as she went along. In doing so, she became more aware of new possibilities and her own freedom to make choices about her care. For example, Betty shifted from a position of living with pain [because she didn't think there was any other painkiller than the one she had been prescribed], to one of seeking more effective pain control [by requesting her doctor give her stronger painkillers]. Her sense of empowerment was apparent when she exclaimed, "The more I talk with you the BRAVER I get".

Betty said she had never really "read up" on cancer, although she perused various articles and the newspaper to see "what's new in medicine". She occasionally learned about treatments like "laetrile" from friends, but preferred the conservative "medical approach", because "if the others were good there'd be thousands of patients there".

Betty asked many questions about managing her cancer and related symptoms at home. She requested information about drug and treatment side effects, painkillers and pain management, spread of disease, monitoring treatment response, and palliative care. She also sought frequent confirmation that her own experiences were "normal". Betty emphasized that she did not have a clear

understanding of many aspects of her disease and treatment, and she disclosed various assumptions and knowledge deficits that impeded her ability to manage her care effectively:

B: I never even associated bone cancer with breast cancer, I always thought if I got cancer again it would be the other breast. I don't know why, but I never thought it would be the hip. I never asked anyone either, and you know, they never explained.

B: I just wish I knew more about this bone cancer and how it spreads.

B: I'm really not too sure what's going on . . . is [the treatment] supposed to stabilize it? Or is it supposed to--I don't know what it's supposed to do!

B: Saying it's in remission . . . I thought the drugs do work. Because you know, even though you read about cancer cures, they say there's no cure--that it's never cured, well you really are wondering, is all cancer terminal? I guess it is. If it isn't cured it has to be terminal some place down the line, doesn't it?

B: I didn't think there was anything else [painkillers], I didn't think to ask if there was anything else. . . I just thought whatever [the doctor] prescribed was it!

B: I just assumed that I was given [a cancer specialist] and THAT WAS IT! I just assumed that everyone was assigned a doctor and you couldn't change. Not so?

Betty also felt she had inadequate knowledge about resources available to her and how to access information about them.

- B: OBVIOUSLY, I'm not aware of anything that is available to me. . . . we didn't know of the home care nursing that came and gave me shots except through our [family] doctor, [he] did that for us, or we would never have known about it.

Her awareness of professionals from whom she could solicit support or information was limited. She said she had never been given information about "cancer groups" or other resources, either at the cancer treatment centre or the local hospital. When asked what kind of resources she thought she might use if they were available, Betty asked for information about facilities that provided care for persons unable to manage at home.

Negotiating the Health Care System

Betty frequently spoke about what it has been like for her to depend on the health care system for treatment, information and support. Her greatest concern was the length of time it took to accurately diagnose her cancer recurrence. She recounted:

- B: It took so long to discover that I had cancer. And with all the sophisticated machinery, why did the radiologists take so long to see it? I mean, the whole hip was involved and I just can't understand . . . it took almost five months. And that's one thing that really disturbed me, that it should take so long. If I had had only one little wee spot some place, I could see . . . That's the only thing that really disturbed me, was that it took so long. In this day and age that seems rather weird, doesn't it? . . . and it certainly wasn't [my family doctor's] fault. He sent me to all sorts of specialists. But I haven't got too much faith in any of them . . . I guess a lot of cancers are difficult to diagnose, but I really think a lot of people are put through bad

times when they shouldn't be, by the medical staff. And I don't know if that's right, or not but that's how I feel.

Betty also voiced her annoyance regarding the impersonal atmosphere and long waiting periods at the cancer treatment centre, where she received radiation treatments:

B: When you get there for your appointment--and it's not their fault that they're short staffed--but then you when you wait and you wait and you wait and you wait and, [deep sigh] you know, I could've been doing something else. And you'll say, "Am I going to get my chemo"? "Oh yes, we'll get there, we'll get there".

She went on to describe how the hospital environment made her feel like one in a herd of sheep:

B: None of us, as patients, question anything. We all just lay there like sheep.

K: This is when you're having tests done?

B: This is when--well, having tests done, this is when I'm having chemotherapy done, and the same with radiation. You know. They just flop you on the guerny and have you marked, and say, "We're leaving the room and don't move". And that's it.

Betty referred often to the resourcefulness and persistence one needs to manage at home, isolated from the hospital and health care resources. Although she has gradually acquired knowledge and skills to get what she needs from the system,

she expressed frustration because she perceived there to be no "help" along the way.

She commented:

- B: We pick up the phone . . . go through the hospital and uh, don't get any answers there! . . . You [learn] to look after yourself, but you don't get any help. If you're self-reliant and can get around . . . that's the only way you're going to get things done!

Betty felt it would have been helpful, in the beginning, to be given basic details about "where and how to get the help you need" and "what to expect". She thought this kind of guidance would have enabled her "find her way around" and manage her pain more effectively, asserting:

- B: Let's face it, first time patients are also going to be the last time patient. They don't know where to go for the information and if the hospital doesn't give it out, which the [hospital] hasn't--and they haven't--how are you to know? . . . The sooner you have the information the better off you are!

She suggested an information booklet be provided to all new cancer patients as a means of helping individuals like herself cope more effectively.

Future Goals and Expectations

Betty's expectations regarding her treatment outcome fluctuated throughout the time we met, impacting significantly on her personal goals. Living with constant

uncertainty, she focused on short term goals, trying to "get through each day before worrying about the next one".

Some of her goals and expectations shifted as she became armed with new information. When she realized she had not exhausted the full range of available painkillers, she made plans to consult her doctor in an attempt to achieve more effective pain control. She said it would be "marvellous" if her pain and nausea could be controlled, and that she would "try it in a twinkling". Betty reflected on what it would mean for her to have less pain and nausea:

B: I would love it. I think it would be marvellous. It would make my day longer. I could do a little bit more. . . . If I found a combination of pills it would be marvellous, make a day trip a lot easier.

She was also in the process of experiencing and exploring feelings related to the many losses facing her and her family. Grappling with the news that she had "about a year" to live, she was evaluating the quality of her life. During our last session she was thinking of discontinuing treatments she perceived were diminishing the way she wanted to be living her life. She explained, "I can see that, if your kids are young, being willing to be subjected to that [treatment], but not now". Her hopes for the future centred around comforting her husband and enjoying quality time with him.

Betty also talked about the possibility of becoming more incapacitated in the future. She acknowledged having "a dread of being in a wheelchair", but otherwise had not "really thought that far ahead". She said:

B: I suppose I should start thinking about that because it may not be too far in the future--that I won't be able to look after the place, right? If it comes to that, I really think I would rather go to a nursing home of some sort. And are there places for someone like me?

Although she said would prefer being in her own home, she perceived that being cared for in a health care facility would ensure "everyone's life isn't ruined when it becomes a real BURDEN". Her wishes for the end of her life were simply stated: that she have no "life supports and so on", that her pain is controlled, and that she is kept "comfortable".

Postscript: Eleven Months Later

My visit with Betty, almost a year after our series of interviews, gave me a very pleasant and unforeseen surprise. The suntanned, freckle faced woman who greeted me at the door bore little resemblance to the frail, "dying" woman I had spent time with the previous year. The change in her was nothing short of incredible. She looked as if the phrase "a picture of health" had been coined for her. Dressed in a summery skirt and blouse, she seemed relaxed and contented, her reddish hair curling softly around her face. She walked easily, no longer limping or

using a cane for support. It was hard to imagine this being the same woman who talked about "having a year to live" almost one year ago.

Looking back over the past year, Betty said she finished her chemotherapy and had one radiation treatment shortly after our last session. Her anti-nausea medication had been switched from Gravol to Maxeran, achieving complete relief of her nausea. She continued taking long acting Morphine [MS Contin] for pain, gradually increasing the dose as needed. She described having a "great" winter during which she felt progressive improvement. Her pain was well controlled by painkillers, contributing to a "wonderful year".

Betty understood she was "on a plateau" and wondered, "What does that really mean?" She was taking a very high dose of MS Contin [300 mgm] twice daily for pain, with what she described as complete relief. Still, she complained the Morphine made her so "drowsy", she could "fall asleep at anytime and anywhere". She also disliked its constipating effects, for which she routinely took a fruit laxative, stool softeners, laxatives, suppositories and enemas. She had considered reducing her Morphine dose, but her home care nurse warned her not to because, "it's hard to get pain in control after it's been out of control".

Betty told me she "no longer feels ill" and doesn't "like to think about it". She commented, "The only time I really remember I have cancer is when I take my Morphine". Otherwise, she said she was able to do everything she wanted. Her only limitation was that the sedating effects of Morphine prevented her from operating a vehicle. She described her life as rich and full, saying she loved "being

independent" and able to "live a normal life again". She said her family were coping well and continued to be "very supportive". Because her husband was having some difficulty "getting around" [due to arthritis] Betty had taken on the role of supporting him. She reflected that their life had "changed considerably" since last year, and that she was grateful for the quality time she was able to enjoy "toodling around" with her husband. She pointed out that she doesn't "socialize as much as before", but enjoys "going out for tea" at least twice a month with friends. She described "no goals or expectations of the future", preferring "to take each day as it comes".

Betty took the opportunity to ask questions related to her cancer and what it meant to have "reached a plateau". She understood that if her cancer returned, it would "settle in the liver or lungs", and she wondered if it would be "treatable".

Regarding her case study, Betty said she "knew it was all absolutely true" but felt "amazed and shocked" at how she coped with her cancer and related pain the previous year. In fact, she said she felt "very embarrassed", commenting, "I didn't realize I was in so much pain, but I feel almost embarrassed to think I was so short-fused". She perceived that she "wasn't coping well at all" and felt "taken aback by the amount of anger" she had experienced. She voiced concern about "how upsetting it must have been for other people" to be around her. Finally, she disclosed that it had been difficult for her to read the case study because it reminded her of the pain and illness she had once lived with. She expressed little interest in reading any aspect of the completed thesis document, saying, "I don't want to be

reminded of being sick, I'm too busy enjoying feeling good!" She emphasized, "This is the real me! It's great to be normal again!"

Case 3: Carla

Demographic Information

Carla is a single, fifty-three year old Caucasian woman who was born and raised in New Zealand. She presently lives alone in Vancouver's high density residential area near the downtown core. Prior to her problems with pain Carla did a variety of different things for a living, including furniture upholstery, waitressing, and managing her own business.

Preface

During the autumn of 1990 I met with Carla four times over a six week period. Our first meeting--to discuss her participation as a co-researcher--took place in her home, a small one bedroom suite on the second floor of a low-rise building. Conveniently located several blocks from the beach and near downtown, the apartment block was otherwise plain and nondescript.

Noting the building's modest interior, I took an elevator to the second floor. Carla's suite was located at the end of a dimly lit corridor, where she welcomed me with a big smile and open display of friendliness. Upon entering her suite I was immediately struck by the bright atmosphere and strong sense of individuality reflected within the small rooms.

Carla's living space was organized to accommodate her physical limitations, with all her furniture pushed up against the walls. I noticed there were no obstacles to trip over, and wherever one stood there were only a few steps to a chair or resting place. Occupying one corner of the living room was a large futon, folded out on its frame. There were many personal items scattered throughout her home, including framed photos, baskets of handicrafts, children's art work, and books. During our visit we sat at a table nestled by the window, where Carla said she was most comfortable, sitting in a straight backed chair.

Carla appeared younger than fifty-three years of age. A petite woman wearing a bright red and white polka dot skirt with a white sweater, she used a cane and walked with a noticeable limp. Wrapped around her neck she wore a soft neck brace adorned with decorative broaches, a personal touch embellishing an otherwise restrictive looking piece of medical equipment. Despite her cane and neck brace, Carla looked hardy, as if she had been a physically strong and active woman. Her coarse blonde hair was natural and tousled around her tanned, lined face, and her voice was husky. She impressed me as a strong, yet vulnerable woman who had weathered some stormy times in her life.

Carla seemed comfortable talking and sharing her feelings openly with me. After voicing enthusiasm about taking part in the study, she discussed the changes cancer had imposed on her life. She cried throughout her conversation, sometimes breaking down in deep sobs. She also expressed excitement regarding an imminent visit from her daughter and four year old granddaughter, who were arriving from

New Zealand in a few days. Her daughter, who she had not seen in four years, planned to stay with Carla for about four months.

By the time we met for our first interview two weeks later, Carla's daughter and granddaughter had been visiting for a week. She arranged for them to go out for an hour, acknowledging that our time together offered a "welcome relief" from the strain of coping with company. She said it was a big change for her to "have a four year old child running around all day" and complained of feeling "very tired".

Throughout the interview her eyes brimmed with tears. Often she cried openly and, at times, she sobbed uncontrollably. Carla smacked her right thigh as she sobbed, as if trying to regain control. She also repositioned herself in the chair from time to time, as if she were uncomfortable. Otherwise she sat in a rigid manner, massaging her right thigh continuously. We ended our session when Carla felt too uncomfortable to continue, after about forty five minutes.

Our second interview took place two weeks later. Recovering from a bad cold, Carla reported she was having increased pain and felt "exhausted". She acknowledged feeling overwhelmed by the presence of her visitors, saying, "I'm getting a little edgy having them around". She talked about the challenge of living with "family" day and night, and of her need to establish a new routine to accommodate the needs of three people living in a tiny apartment. Although she cried continuously, Carla claimed she felt "much better" by the end of our session, saying she was grateful for the opportunity to talk openly about her experience.

Our final interview occurred two weeks later, on the eve of Halloween. Carla was dressed for the occasion, her face painted with glittery make up and her hair dusted with blue sparkles. Her manner was more animated than it had been previously, and she explained, "[My daughter and I] decided to get a bottle of wine tonight because we wanted to make this a fun little celebration!" Despite her acknowledgement that the pain was "not really improving", she seemed somehow more contented and at ease, weeping only occasionally during our session.

In her discussion Carla disclosed that she and her daughter had worked through some problems and established a "more workable" routine. Her expressions were buoyant as she chatted about activities they had shared during the previous week, and excursions she looked forward to on the weekend. Later in our discussion she became more sombre as she shifted the focus to her experience of continuing pain and its future implications.

After our session I wheeled her downstairs where I was invited to join the Halloween celebration taking place in the apartment lobby. I lingered only a few minutes but my last glimpse of Carla has stayed with me to this day. She waved an energetic goodbye from her wheelchair and then turned to join the Halloween merrymakers encircling her. With her daughter and grandchild nearby, she sipped wine and laughed heartily with friends and neighbours. Carla appeared to be the life of the party, and for a brief moment I saw no outward sign of the pain from which she was struggling to free herself.

History of Pain Experience

The story of Carla's experience with cancer-related pain began in 1986 when she was forty-nine years old. After falling down she started having persistent left shoulder pain, subsequently diagnosed as arthritis. She then consulted a physiotherapist who apparently advised her to "check into it" because it was "probably bursitis". Her story continued:

- C: Then it got more and more uncomfortable under the arm and I was kind of tired of it. It was a pain I've not experienced before and it ... was in here [pointing to shoulder joint] and so I went back to the doctor and I asked him if he would give me a full medical examination. Not because I was afraid of anything, it was just the age I was at, I thought it was important . . . I explained to him that the pain was different, it wasn't the same as the pain that was in my shoulder. So he checked it out and examined me and we found the lump in the left breast.

A needle biopsy confirmed the presence a malignancy in her left breast. Ten days later, in March 1986, she had her breast and some lymph nodes removed. After recovering from her mastectomy Carla continued to have swelling and discomfort in her left arm, symptoms she understood were related to removing lymph nodes.

About five months after her mastectomy Carla had the first of two breast reconstruction surgeries. She recounted:

- C: . . . so it was March, August and November [when I had surgery]. . . I just wanted to get it [the reconstruction] over and done with. . . they

took tissue from here [pointing to pubic area] for the areola? They lifted this [referring to mastectomy site], they took tissue from the stomach to build up this area 'cause . . . the cancer had spread quite a bit when they caught it, and there's an indentation there. And they took tissue--fat tissue from [the stomach]--to see if it would work to build it up. And that's where I had the recurrence, [pointing to the area just above her mastectomy site], there!

Her cancer recurred about two years after reconstructive surgery, in her reconstruction site. Carla's distress was evident as she showed me the shiny, tight scar tissue that remained after the "lot of radiation" treatments to the area. Nevertheless, radiation effectively eradicated her recurrent cancer [according to Carla] and she went back to work.

It wasn't long before problems with pain were disrupting her life again. Lower back continued to bother her and she began waking up at night with leg cramps. She recalled the events leading up to her second diagnosis of recurrent cancer in February 1990:

- C: I had gone back to work . . . on industrial machines. And I went to see the doctor about the cramps in my legs and he said, "Oh well, that's probably because you're back working". And it got worse so I went back again 'cause the pain-- actually that was a weird pain in the hip. . . . Then the pain started getting in the thigh more, so I went back to see him--the doctor--and he said, "Oh well, it's probably bursitis". [laughs] And he gave me a cortisone shot [laughs] and I was fine for two days! . . . but this pain, I didn't know what to do with it and I went and had my checkup . . . and [the cancer specialist] asked me how I was doing and I said, "NOW I've got this weird pain". . . . So he took x-rays and then he came back and told me the great news . . . [cancer had spread to the hip]

Although the cancer in Carla's hip "went into remission" following radiation treatments, her back pain persisted. She perceived that she "wasn't being listened to" as she sought medical help for her pain. Frustration was evident in her voice as she recounted:

- C: Each time I went back to the clinic they'd ask me, "How was I doing?" And . . . I would mention to him, "Well, have you looked any further into [my back pain]? . . . And [the cancer specialist] said, "Well there's nothing there, no it seems okay, you're not having any problems". But actually I was . . . and when I would go back to visit . . . one of the doctor's said, "What's the worst pain you're dealing with?" And I told him . . . I'd say, "Fine but I've got this lower back pain". And their answer kind of was, "Oh it'll go away . . . "

Meanwhile Carla was having physiotherapy treatments in an attempt to ease her back pain. Because she still had pain that "wouldn't go away" she decided to see a chiropractor, thinking that "maybe a chiropractor treatment would adjust it". Carla sobbed as she related her experience of seeing a chiropractor:

- C: There was my big mistake! I went to him and he cracked me, and he cracked a rib . . . that's why I'm having problems with the spine. He cracked one of the vertebrae where the cancer is . . . I went to him in pain, he got the x-rays from the [cancer treatment centre] and let me know when he had received that information, and said, "Okay you can come in, I think it's okay". But every time I left him I was in worse pain. And . . . I talked to a couple of friends, they said, "Well, it usually gets worse before it gets better". And I kind of listened to other people, rather than listen to myself! . . . [sobbing] I kept going back!

At the time of interview Carla still suffered with neck pain related to injuries sustained during chiropractic treatments. In addition, she understood that cancer had "set into the neck and back bones". She also complained of pain across her left breast region which she had hoped would be relieved by having her reconstructive surgery "redone". She elaborated:

- C: I was going to have this [reconstruction] redone, because it's not comfortable any more. It's got real hard . . . and I get sharp pains. . . . and we postponed [surgery] because of the cancer in the hip. And then they found cancer in the spine and the neck--so [surgery] has been put off.

Description of Pain

Carla described many kinds of pain related to her cancer. She began by trying to make the distinction between her emotional pain and her physical pain:

- C: Yah, [the physical and emotional pain are] very different. Physical pain, you can go to the doctor who can give you a pill and it'll sort of go away for a while. But the emotional pain takes longer to heal. I guess with every person it's different. Depends on what's underneath there that needs to be taken care of. . . . The [emotional] pain sat there [holding her fist tightly against the middle of her chest], and it was around fear, learning to let go.

.....

- C: How do you explain the different kinds of pains? . . . the physical and the emotional pain . . . you know, like, when you're a child--if you get a scratch--they put a little band aid on and if you've got any hairs there it hurts. Well, can you imagine the whole top part of your body, that [tape] all being ripped off [after your mastectomy], and then sort of looking down, and the disappointment because it doesn't

look like what you think it should be? And the pain involved around that . . .

.....

- C: Okay, [the physical pain], it's a dull ache. When you hurt it's like either an intense pain or a dull ache. And the intense pain, you need medicine for it. The dull ache, maybe you can mentally get rid of it by massaging it and working with it at the same time. The emotional pain is like a knot inside of you, like sometimes I would cry for a long time and it got scary. . . . Yah, the emotional is different, it just feels like this big knot in your gut that just won't go away, whereas the physical pain feels like a dull ache. Or it can be an intense ache. . . [crying] . . .

Carla considered her physical and emotional pain experiences to be interdependent—that the presence of one kind of pain intensified the other.

She went on to carefully describe the assorted pains she had experienced over the previous four years. Her first encounter with pain—in the left shoulder joint area—was described as "a dull ache, a warmth that wouldn't seem to go away". Once her cancer diagnosis was confirmed Carla recalled, "The pain seemed to intensify for a period of time, I think until the mind seems to accept that there's something wrong and there's something that needs to be done". She remembered having a "different kind of pain again" after her mastectomy:

- C: And when I came to, there was pain because I was all strapped up . . . they strap you up really tight, you know, for about five days. And it's real hard because it's elastic bandage . . . after they had taken off the bandages . . . the pain seemed to stay there and intensified at times.

After her reconstructive breast surgery five months later, Carla said she experienced a feeling of tightness and pain across both breasts that "didn't go away for a long time". After her mastectomy and other surgeries she also experienced painful swelling in her left arm, due to excessive presence of lymph fluid following the removal of her lymph glands. She explained:

- C: This [left] arm started swelling and it got very puffy. And it's like a different pain, it's like a dull ache. It feels like a balloon, somebody's blowing air into you, and it would blow up.

Her next painful episode led to finding cancer in "the hip bone", even though her pain was not localized there. Elaborating on the "weird pain" in her hip, she said:

- C: It was not a pain that stayed in one place. Sometimes I would wake up in the night with intense cramps in my legs . . . then the pain started getting in the thigh more . . . but the pain was sometimes in the thigh, in the butt and in the anus. And when it was in the anus it was a real--it was like, uh, haemorrhoids were on fire!

Following radiation to her hip, Carla's worst pain shifted to her middle and lower back. She said the lower back pain made it "hard" for her to walk, and her middle back hurt so badly, at times she felt as if she would "snap in half". Throughout our interviews her primary source of pain continued to be in her back. She also coped with residual neck pain which had gradually improved since the intense discomfort she described here:

- C: The neck pain, now we can spend a whole hour on that! The pain was really bad. And nerve pain is different again from like the pain that I was dealing with [in] the hip. It's not a throb, it just continually hurts. I would move my head, like just a fraction and it, uh, you know, you want to cry. You know, you just want to crawl up into a ball because it's a lot harder to tolerate, I think, a nerve pain. . . . Because you use your neck so much . . . and sometimes it was shooting down my back . . . that lasted too long, that pain, it really did.

At the time of interview she also had "spasms of pain" through her left breast area, in addition to "a constant band of tight pain" across her chest. The skin over her hardened left breast area looked tense and fragile.

Carla did not develop any new pains over the time we met, though her back pain gradually intensified. She attributed her increased experience of pain during our second session to fatigue, asserting that she always had more pain when she was tired. She expressed relief that her pain confined itself to the same areas for a little while, stating, "New pain is worse than old pain--old pain you get used to".

Impact of Pain on Daily Living

Carla felt that her lifestyle and independence had been altered dramatically by the effects of her cancer-related pain. Perceiving herself as having "always been a very healthy" person, she referred to the challenge she had coping with illness, "Not being sick in my life before . . . I didn't understand the ups and downs of having major surgery, losing a breast".

She cited the physical limitations imposed by her pain as causing profound disruption to her lifestyle. She said that much of her personal satisfaction had been achieved through the physical challenges of her work and leisure activities. Now there were times when she was not even able to do housework and related chores. She reflected:

- C: I've basically been an outdoors person. And it's hard for me to stay cooped up. And I don't want to be SICK! . . . It makes a very big difference for me because I am very much an outdoor person. Like, I used to play tennis and walk everywhere. And not being able to get out--I can go out for a walk around the block by myself, and that's kind of about as much as I can do on my own. But any more than that is really quite tiring, you know, staying comfortable.

Carla emphasized how much she valued her working life, both for the financial security and sense of productivity it provided. After her mastectomy, the physical demands of her waitressing job were more than she could manage, requiring her to find a less strenuous means of employment. She recounted:

- C: I used to do reupholstering . . . and enjoyed it. And I didn't have the strength any more because of the problem I had with this arm. . . . And I couldn't waitress any more so I needed to get into something. And I needed to have something kind of creative, so anyhow I went back to work and I was working on industrial machines.

She had completed a "travel agency course" the previous winter in order to broaden her employment opportunities, but at the time of interview Carla was unable to work

due to her pain and immobility. She remained hopeful about the possibility of working again in the near future.

Carla often focused on her diminished capacity for activity, as demonstrated in the following extract:

- C: I get tired. [crying] I still have pain in my back because I get tired. . . . So that I don't have the pain I make sure that I get time by myself, especially in the afternoon to have a sleep. . . . I'm pretty good until about nine o'clock [in the evening] and then I become a wimp again. . . . [crying] When I'm home I can take this [neck collar] off for a while, for an hour or so, as long as I'm not overdoing it. Like when I'm lying down in bed it's okay. 'Cause when I'm like this [sitting] I don't last very long. . . . I'm good when we go out in the [wheel] chair because I can LAST. I can't last very long if I have to walk, it gets too tiring.

Carla identified that her greatest day to day challenge was to manage her pain--and avoid using higher than her usual dose of painkillers--by getting enough rest. She said fatigue heightened her pain, and feelings of tiredness intensified in the presence of discomfort. Problems with insomnia further influenced her experience of pain and fatigue. Carla's pain resulted in problems getting to sleep, and staying asleep through the night.

Coping Strategies

In order to cope with her pain at home, Carla complemented her use of medicines and medical treatments with a variety of non-medical approaches to managing pain.

Medications and treatments. The chief medical strategies Carla employed to manage pain included having radiation treatments and taking medications. By the time of our interviews she had completed three courses of radiotherapy--to her left breast, hip, and spine. Although she "got better" after radiotherapy to her hip, she described only partial improvement following treatments to her breast and spine. She reflected on the experience of having radiotherapy in this passage:

- C: The first time for radiation treatments . . . I was scared 'cause I didn't know, I freaked out actually . . . you do get weak when you have the treatments. . . . [I've] been through it three times . . . the body's adjustment with the treatments, the vomiting . . . I can tolerate it, you know. It just means resting a bit more and stuff. . . . The first lot of treatments it kind of SAPS you. And I think you get better at it each time. You get better at it, but it still weakens you.

Carla had taken a variety of medications during the previous four years. Her anecdotes reflected the negative aspects of her experiences with drugs. For example, she remembered taking analgesics for post-mastectomy discomfort, only to have an allergic response to them. She described:

- C: It was a tough time. I found out I was allergic to Codeine, so then I was for a few days on antihistamines . . . that was a very druggy time, for about two days. I broke out in hives--or welts all over my body, all over the scar.

And for two years she had tolerated the side effects of hormonal therapy described in this passage:

- C: With the Tamoxifen I was growing hairs on my chin! And that used to really bug me because I have to wear glasses too. [laughing] Men can shave, but the more we shave, the more it grows. And it was like, every time I looked in the mirror . . . it frustrated me. [crying] . . . Then the cancer came back so I got quite angry and said, "NO", I didn't want [Tamoxifen] any more.

At the time of interview Carla was taking another hormonal therapy medication she understood was "supposed to keep the cancer from growing", and a strong opioid analgesic [Morphine] for pain. As illustrated in the following excerpts, her discussion often focused on her reluctance toward taking Morphine:

- C: Right now I'm on Morphine. And that keeps me going, but I don't want to have to spend the rest of my life [on it]. I mean, if that's the only answer, okay. [crying] 'Cause it's not painful to take the pills.
.....
- C: It took me a while before I would take it on a regular basis. . . . I was ill one day, I fell and I started having spasms. And that's when I seriously had to think about taking the Morphine on a regular basis, because I was having spasms in the breast too. But when they told me I had to take the Morphine, that's what they gave people, you know, when they're on their last leg. . . And it kind of scared me, so I had to work through any stress around the Morphine. [crying] . . . I don't want to have to take more Morphine if I can help it. I would like to work on healing whatever pain is there, so that I can take less dosage instead of more. . . .
- C: I was really scared about the Morphine being the last leg. Yah, there was a lot of fear behind that. And there probably still is.
.....

At the time of our first interview Carla was taking three long acting Morphine [MS Contin] tablets every morning and evening, supplemented with Morphine syrup

throughout the day for breakthrough pain. In the two week interval between our first and second sessions she "tried taking less" medication, and experienced more pain. By the time of our last session she had escalated her MS Contin dose to four pills twice daily in attempt to relieve her increasing lower back pain.

Carla's level of pain relief fluctuated in intensity over the five weeks that we met, but she described never being completely free from pain. At the time of our first interview she talked about the effectiveness of her pain control:

- C: The Morphine helps me sleep pretty good . . . so I'm fairly good in the morning . . . yah, it's a lot easier. Sometimes it used to take me about five or ten minutes to get from my bed to the bathroom. . . . [The Morphine], it takes the edge off it. Now I don't have a lot of pain in the day, because of the Morphine. That helps me to have my quality time in my day? I get tired. I still have pain in my back because I get tired. Yes, since the neck is [getting better] I guess the Morphine is--got that under control too. . . . By eight o'clock [in the evening] I have to be horizontal because otherwise I have to take more medicine.

By the time of our final session Carla was experiencing an increased level of persistent, unrelieved pain, even though she was taking a higher dose of Morphine. She expressed the following concerns:

- C: You know, until I'm sort of certain [about] what is causing this pain, I need answers for it. You know, 'cause [the Morphine is] really not making my life more comfortable. . . . The spasms--to me, the Morphine's just covering that. That's my fear. That it's just covering it up. And I'm hoping that maybe I'm wrong, you know. What else it could be I don't know, but this pain has been here for a long time and it comes and goes.

She also complained about both the sedating and the constipating effects of taking Morphine, elaborating:

- C: And I don't want to end up having to take more medicine because that's going to make me groggier anyhow. . . . And when I first went on the Morphine I had--OHHHH it was so much PAIN, OHHHHH--so much pain with bowel movement, and I had people here who didn't know how to help me and stuff, and I had to go to the bathroom. I would scream in pain. That was awful, that was. And that lasted, like a few days. . . . I used Preparation H. I used that to ease it and so I was able to get to the doctor. And that was a very PAINFUL experience, REALLY was, it WEAKENED you so much. People don't REALIZE just having a BOWEL movement, you know, just a normal one is such a HIGH! [laughs]

In addition to radiation and painkillers, Carla described having laser treatments that had been "helpful" for relieving post-surgery site pain in her left breast area. She explained that the laser helped break down the build up of scar tissue and adhesions responsible for her discomfort. She went on to talk about another treatment that provided relief of pain in her swollen left arm :

- C: This machine at the [cancer treatment centre], it's like a sleeve that they put on and it's got like teats, and that circulates all the fluids in the arm, and brings down all the pressure.

Self-care behaviours. Carla described many non-medicinal ways of managing her pain. She repeatedly emphasized the importance of "finding out what's available" and experimenting in order to ascertain "what clicks for you". She

elaborated on her own experience of discovering a pain management style that "fit" for her:

- C: I tried herbal things. I went to a herbalist . . . but he SAT there with one cigarette after another. . . . like he REALLY didn't CARE. But I TRIED, but I really didn't see any difference . . . I tried a few different things . . . and then I found what worked for me. And first I knew that my body needed more rest than it normally did. And to look at the different aspects of healing, and learning that one can mix with the other--the mind, the body, the spirit. I think I've known that all my life because I've taken fairly good care of myself. . . . I had not been around people who were sick, so I had to sort of basically learn, you know, what worked for me. . . . But yah, I think it's an individual thing? Something works for you may not work for the next person?

She stressed that one of the most helpful means of managing pain was to get enough rest and quiet time for herself, explaining:

- C: So that I don't have the pain I make sure that I get time by myself, especially in the afternoon, to have a sleep. . . . the rests in the afternoon certainly help. . . . When I'm in my bedroom I like to have that, for some quiet time for myself? . . . The rest is real important. I try to get to bed like by nine-thirty? Just so I can have like half an hour to read. I enjoy reading.

At the time of our first interview Carla was coping with considerable disruption to her lifestyle as she adapted to living with another adult and a small child. During our second interview she complained of worsening pain and fatigue:

- C: And I'm not finding time for [things like reading]. I'm too tired. . . . And it's a little hard sometimes, but [crying] I'm enjoying their visit at the same time, you know. But I know I have to learn to allow myself some more space. 'Cause I'm getting tired every day now.

By the time of our final meeting she and her daughter had established a routine that provided Carla with adequate time for herself. She remarked, "It's working better because we do like, maybe one thing a day, and we put [my granddaughter] in day care for two days a week".

Carla also practised meditation, a relaxation technique she had incorporated into her lifestyle long before encountering cancer-related pain. She explained:

- C: I was into meditation prior to getting sick, so that helped me a lot. . . . I used to just lie on my couch and just sort of get off in the mountains . . . the [relaxation] tapes were very much a part of my life before. I try to call them relaxation tapes rather than meditation tapes--because somebody like you, who's like minded, would understand. But some people don't understand that basically relaxation and meditation is the same thing. The relaxation is a more familiar word to them. . . . meditation conjures up a whole lot of things in some people's minds. Yah, airy-fairy religious stuff you know, so . . .

Carla viewed meditation as her most powerful tool for controlling pain. In this passage she illustrated some of the ways meditation assisted her to cope with pain:

- C: [In the beginning, meditation] helped me level out the stress and get myself together to get out there, to go to the doctor . . . stuff like

that. And then I would come back and I would rest some more . . . meditation for me is the biggest help, because it not only relaxes the mind, it relaxes the body. You can take a pill and it'll relax the body, but not always the mind? . . . the more you use the power of the mind I think, the more you're able to relax, and let go of whatever discomfort you're dealing with . . . it just lifts you up nicely. And then you get re-energized? . . . When I get kind of a little stressed out with having company all the time, that's what I put on, [a relaxation tape], just to help me keep things in perspective.

Massage therapy provided her with another means of easing her pain through relaxation. Carla professed that "laying on the hands is one of the most healing practices", and went on to discuss the benefits of massage in her own experience:

- C: I'm only seeing a physiotherapist now, once a week. And he massages my body, my back, you know from here down to there [motions from her shoulders to her waist]. And it helps. It eases whatever extra stress I put on myself, I guess, that the Morphine's not taking care of.

- C: I always felt that a massage helps an awful lot, because it shifts your energy and changes your energies. And helps you work through whatever it is that you're holding on to, you know. I went to rebirthers and in New Zealand, and I've gone to a couple here since and uh . . . they balance your energies and stuff . . . I found that worked a lot for me, and it was through massage. It seemed to make me feel more rested. And I felt I got value for my money. Ladies--if you work with them, you heal faster, I found.

Carla also relied on some practical approaches to lessening pain and managing physical limitations. For example, she minimized neck strain and discomfort by wearing her neck brace whenever she was up and around. She found it helpful to use a special neck pillow when lying down, and tucked cushions behind

the small of her back when sitting. A wheelchair increased her general mobility, and she supported herself with a cane when walking short distances. She also learned to sleep on her back to avoid laying on her painful left breast.

Despite her physical limitations, Carla said she liked to remain active and "get away" from the confines of her apartment regularly. She claimed that by "staying occupied" she prevented herself from "getting hooked back into the pain", reflecting:

- C: If somebody calls and asks me out I'm going to do the best I can to go out and enjoy. . . . When it's nice and crisp and sun's shining and all that beauty out there, you want to be part of it. . . . I can enjoy a day in bed maybe once a month or something like that, but not every other day. I'm an outdoors person . . . like we got out in the boat [with friends] . . . so that was very good for the spirit, to get out of this confine. And like, that'll last me, that trip will last me . . . It makes a very big difference for me, just getting out. Like, it doesn't matter to me if it's raining or anything like that . . . getting out, that to me is important so you can stay on a calm level. I think the getting out, this is high energy for me.

Carla confessed that her illness provided her with more time for "going out" socially than when she had been well. She remarked:

- C: It's almost better than when I'm working! [laughing] I never found time for social life too much when I was working! You know, people ask me, "How do you deal with it?" I say, "Well, just say it's time out-you know, time out to catch up on some of the things, books you want to read . . .

She also participated in regular swimming sessions with friends, asserting, "I have to watch that I don't over do it, but I do get some exercise". She found aquatic exercises much easier on her body than "getting down on the floor and trying to do exercises".

Carla tried to do as much of her own light housekeeping as possible even though a cleaning lady performed basic household chores every week. She had depended on home care services several times in the past, when she had been unable to manage on her own. She explained, "I was not able to get around and they had to bath me and I was having problems with my balance and it was painful". Carla contended that it had been more disruptive than helpful to her, vowing:

- C: That's why I'm working on doing as much around the house, so that it'll help me get stronger and I don't have to deal with that ever again. Because that was an awful experience. It's okay when you're OLD and you are weak and you've got nothing much to look forward to anyhow!

Other aspects of what Carla referred to as her "healing process" included consultations with a psychic healer, homeopathy and using "runes" [an ancient alphabet surrounded with an aura of magic and mystery, giving a magical effect to what is stated in them; often used for healing and warding off disease]. At the time of interview she was taking a "dream analysis" course to open yet another avenue

for healing. Carla said she had been devoted to "New Age healing processes for many, many years".

She also incorporated "healing" foods and substances into her cancer and pain management program. She claimed that aloe vera and vitamin E applied to her mastectomy wound "healed the scar quite well". Her diet included fruits, vegetables, and a small amounts of meat, because she felt it was the most "healthy way to eat". As well, eating plenty of fruits and vegetables offered her an "easy way to make lots of nice things without even having to cook". Finally, Carla quipped, "And the odd drink helps too! I guess it helps me relax too!"

At times her treatments and medications required alterations in her usual diet. For example, during radiotherapy her intake was basically limited to liquid protein supplements [Ensure] recommended by a nurse. She prevented the constipating effects of Morphine by drinking berry teas and eating laxative fruits.

Attitudes and Feelings Related to Controlling Pain

Much of Carla's dialogue focused on the emotional aspects of living with cancer-related pain. Initially she talked about how she coped with pain in the beginning:

- C: There was a lot of pain in the beginning, to deal with . . . and that was frustrating as well. Sometimes I'd just sit there and laugh. . . . It was quite exhausting sometimes. But uh, sometimes I would find myself on the corner of Robson and not know why I was there. And that was in, like the first week, when you sort of go into a state of oblivion because you know, you don't know WHY? And it was kind

of strange, but I tried to keep myself busy in that time. But then, I didn't know why I was there or what I was doing.

She went on to discuss the emotional pain that endured for several months after her mastectomy:

- C: And the pain became more emotional [crying] because I didn't understand. Not being sick in my life before I didn't understand the ups and downs of having major surgery. . . . [crying] But I guess as the days went by, and I was able to share little bits with different people--because it was three months before I found anybody that I could talk to, who had been through the same experience. You didn't quite understand why, you know. What seemed to you no reason at all, you'd break into tears. . . . but I think mostly my search in three months was to find somebody that I could bounce off, who would understand the pain. . . . I think three months after that, and I met a lady and her and I started sharing, and uh [sobbing] I think it started to get easier then.

Carla perceived her cancer was especially difficult for her to deal with, emotionally, because she had never been sick before. She had always seen herself as a "very healthy person", a "strong person" who wasn't used to asking people for help. She remarked:

- C: I guess I'm what you'd call a tough broad and uh, you sort of hope that the pain is gonna go away. I'm a bit stubborn at times.

Overall, she felt her pain had imposed constant emotional upheaval in her life, as well as monumental shifts in her responsibilities, roles and life patterns. Carla recalled some of her reactions to the many changes pain brought into her life:

C: [crying] Sometimes I'd make the meal and then I'd run out of energy and I'd just sit on the floor 'cause I didn't have any energy to feed myself, you know. [crying] And that was kind of painful for me [sobbing] in a way.
.....

C: Sometimes I would cry for a long time and it got scary, you know . . . the emotions were strong sometimes. It was hard to know how to control them, because the tears came, and uh, you know, you cried for a little while, but it was like really deep SOBBING.
.....

C: It's hard sometimes to understand why [cancer] is still growing in your body? When you feel you're doing all the right things, like the meditation, releasing the emotion and stuff, and working on that. And you feel you're doing all the right THINGS, and then, you know, [crying] it's CRUEL sometimes. You don't know what to do, so you just do the best you can. [crying]
.....

C: All my life . . . I've taken fairly good care of myself and that was hard too. Because, you know, I went through the "WHY ME"? I had given up on cigarettes a couple of years prior to the cancer and that kind of made me angry. And I had not been around people who were sick so I had to sort of basically learn what worked for me.

She learned that for her, "working on the mind" was the "best way of dealing with the pain". She asserted that "relieving emotional pain helps physical pain get better". In the following passage Carla discussed the ways she first sought relief for her emotional distress:

- C: The [mastectomy] wound had healed quite well but there was still the emotional pain that I had to deal with, the crying and not understanding. So I went to an organization called Attitudinal Healing? And they had a grief and loss workshop and for me it was very interesting . . . I found it helped me a tremendous amount, to understand that you're not alone in the process. And I think it got easier.
-
- C: I found it easier to call the crisis line any time I got to that line where you didn't know where to go? . . . because I felt that helped me more, I was talking to a complete stranger? And I would let them talk and I would listen. Whereas with friends it becomes too involved? And becomes sometimes too intense? With a stranger it's easier, because, for me, you're more able to let go. With a friend you're inclined to take on some of their stuff as well, and it doesn't always help. It intensifies the situation too much sometimes and it's harder on your body.

As time went by Carla began to address emotional issues she felt were rooted in her childhood. She explained:

- C: I never thought about cancer even though my mother had died of cancer and my sister had surgery for cancer, but her's . . . was benign. . . . My mother was ill when I was young and she was kind of a hypochondriac. She took a pill for everything. But that was just her way of coping with all the stress that she had to deal with and uh [crying] I sort of swore when I was younger that I wasn't going to be--you know--and here I am, fifty three and dealing with cancer. It's kind of scary in a way 'cause my mother died when she was fifty four. And so I try not to think about that . . . 'cause I'm going to be [fifty four]. I can stress myself out thinking about it.
-
- C: And MY big fear, because my mother died . . . when she was fifty four. And I'm fifty three, so I had a big FEAR around that too, you know, is my time gonna to be up? . . . The emotional stuff I think was harder for me than, say another person, because there was a lot of childhood stuff that came up, that was quite painful to deal with.

As well as attending grief and loss workshops to work through her emotional pain, Carla sought help from a psychic healer named "Aurora". During our interviews she frequently referred to the healing power of her sessions with Aurora, as illustrated in this excerpt:

- C: WHEW! Very powerful healing with her. But that's kind of scary . . . It was a lot to do with stuff from my childhood and basically I feel that's what this [emotional pain] is all about. . . . I've known of a lot of [healers], but didn't feel RAPPORT!? But with Aurora, she has such a sense of humour around what she does. . . . Like this was a weekend seminar, that I did . . . [crying] It was a lot of childhood stuff that came up. Like, she hardly touched me and I could FEEL--I was sitting down actually--she was sort of working through the chair . . . but I could feel the heat, the energy of her. And it's faith, you know. Belief. And she just works with you on such a level that you want to clear? 'Cause you can sort of feel it here? [her fist held tight between her breasts] And you want it to move, because if it doesn't move you feel you're going to explode. Like, she touched on a lot of my childhood stuff. [crying]

Carla viewed her "childhood stuff" as being responsible for her emotional pain. In the following account she elaborated on how she began to ease that emotional pain through her work with the psychic healer:

- K: When I was here the last time you had said that you felt that it was the childhood stuff that was really underneath the cancer and the pain.
- C: Oh yah. Oh yah, I think so. I think so. I don't know if you've heard of Louise Hay? . . . She talked about cancer being resentment. And I don't know if I felt that. I know I missed out on a lot as a child, but I don't know if I felt resentment. To me resentment is you know, something that's pretty severe--envious, jealous. [sobbing]

- K: Have you found it helpful to go back and look at some of those childhood [experiences]?
- C: OH YAH! OH YAH, that workshop released so MUCH. Like I can't put it in WORDS. It was like I went to sleep and I woke up ten years younger. That was hard to explain. Like . . . there was a lot of deep sobbing, and it came, and she sort of explained stuff after--that we hold it here. [holding her fist against her chest, between her breasts] We hold a lot of stuff here, and she showed us . . . what areas to work on. I was willing to try it because I was fed up with not being comfortable. You know, I wanted to get back playing tennis and stuff, and wanted to get back working and--you know--being normal. . . . And Aurora . . . helped me release a lot of--I've been a lot better since then. MENTALLY, a lot better. I'm a little tired now, because you know, the company and stuff, but I'm doing a lot better since I went to see her. [sobbing]

Carla felt her cancer played an important role in helping her come face to face with painful childhood issues. Speculating on what triggered the onset of her disease, she spoke of her illness as an opportunity to make changes in herself:

- C: Just before [the diagnosis] I'd been in business for myself. And I think a lot of the stress that I was dealing with then triggered off probably to this. I don't know, I mean you can't really prove any of that stuff. But there was a lot of stress involved, stuff I hope I never have to go through again. Yah, very much so. Very much so. It's like I'm a different person in many, many ways. A lot easier to be around I would say. Because I think I've got rid of a lot of the pain? Gotten rid of--I've faced the hurt and the pain and worked through it? I would say.
- K: And in what way are you different now?
- C: I'm just easier to be around! Because there's not that unknown. I couldn't talk about it. I couldn't talk about my childhood to anybody. When I did try to, people would say, "Nah, things like that don't happen". You know? No, I couldn't even--couldn't even talk about it.

K: So in a way it provided an opportunity for you to work through and accept that part of yourself . . ?

C: Mm hmmm. Oh yes, very much. Very much.

As well as working through her emotional pain, Carla felt her attitude played a vital part in assisting her in managing pain more effectively. She said she had always approached her life "one day at a time" and found it especially helpful to do so at this time. She approached her pain with an attitude of determination, saying, "If I give in today I'm going to give in tomorrow and the next day". Carla also found it helpful to maintain a sense of humour about her pain. She felt that her humour had sustained her through "painful times". Another way of encouraging a "healthy" attitude was to dress in attractive, brightly coloured clothing that made her "feel good" despite her illness.

Carla reported that, at times, she found herself "playing the woe is me's" in response to her pain. To prevent feeling sorry for herself, she found it useful to view difficult experiences from a positive perspective. For example:

C: When you vomit you can play woe is me, you know, "I've been vomiting you know da da da da". Well, I try and . . . I don't see any sense in hanging on to anything stressful? Making more out of it than what it was? So I just kind of tell myself that it's cleansed me out, so now I can put some good things in my body . . . looking it as a cleansing rather than thinking of all the PTHHHHHH [sticking her tongue out] around it.

Carla also practised setting realistic goals for herself to make specific achievements, describing:

- C: I'd started setting goals for myself so that I could get well, in order to work through the pain. I meditated every day, every night. In the morning that seemed to help me get through at least a couple of hours--go out around the block or do something. Because I'd promised myself that I would go out at least once a day.

Carla said she also liked to feel a sense of "control over the situation", and did so by learning as much as possible about "the healing process". In this passage she described some of her ways of doing that:

- C: I read, all I can to help me have a much better day, you know, that I can work through the pain.
- C:
Like I had to put my faith in a strange man. . . . The first time I went to see [the breast surgeon] I went with one of these [tape recorders]. I guess it was my way of keeping it all together? . . . Anyhow, I don't know if it's being too in control of the situation, but I needed to feel that!?
.....
- C: I went to Unity and got into stuff like that. . . . It's a religion--more to do the Science of Mind. With the SCIENCE OF MIND and the healing process of unifying the mind and the body for the healing process. Yah . . . I guess I was into it, you know, already, because I had been fairly healthy most of my life.

At the time of interview Carla actively participated in the Unitarian Church, a spiritual organization similar to the one just mentioned. She elaborated:

- C: I go to different [spiritual groups] . . . there's the Unitarian Church which we've been going to now, and they're basically the same. They've all come from Unity, basically different branches. . . . I was brought up Catholic and I'm no longer interested . . . too many lies. I guess I'm like everybody else, just searching for a little niche. And I feel comfortable at the Unitarian Church there. Their speakers are female, and interesting and beautiful. . . . your everyday, basic people, who are trying to learn and enjoy, without these highs and lows and stuff. . . . just being with a big group of people is gratifying sometimes, too.

Carla's attitudes and beliefs about taking medications strongly influenced the manner in which she chose to manage her pain. She described growing up in a culture where "pills" were not seen as a remedy for illness, and declared, "I'm against taking medications, really". She continued:

- C: To me the best way of dealing with the pain is working on the mind. So okay, do I take a pill for this pain or do I just . . . need to slow down and relax and rest the body? Like I'm sort of from the old school in a way . . . with my friends [here] it's a big difference. As soon as you turn the TV on it's, "Take a pill for this, take a pill for that". And I wasn't brought up with that [in New Zealand].

Her resistance to taking painkillers also related to fears born out of past experiences. She recounted:

- C: It took me a while before I would take [the Morphine] on a regular basis. . . . [crying] My mother died of cancer and suffered a lot, and a friend died two years ago. I watched him take his medicine every day and it helped him, but it was also a struggle for him . . . It sort of scared me that maybe they weren't telling me the truth . . . when they

told me I had to take the Morphine, that's what they gave people, you know, when they're on their last leg.

K: Is that what you saw your mother having before she died?

C: Yah. Yah, it was all they could give you, in those days. And it kind of scared me so I had to work through any stress around the Morphine . . . [sobbing] I mean, right now I'm on Morphine and that keeps me going, but I don't want to have to spend the rest of my life on it . . . [sobbing]

Overall Carla described the emotional aspect of coping with cancer-related pain as "a big learning process" in which she had to learn to manage her own well-being rather than "have somebody else do it" for her. She reflected:

C: I was determined that I was going to be okay. . . . and I've learned to be more assertive in taking control of what I think is going to work for me. I haven't always been able to do that and think that clearly.

Carla commented that she was "always having to learn something new". At the time of interview she was learning to accept her daughter's help and support, something she said was "very difficult for someone not used to asking others for help". She remarked, "I should be giving in and letting her pamper me and stuff, but I'm not used to having that kind of attention, you know. Well, she does make me a cup of tea and toast sometimes and that's kind of nice". Other examples of learning she had yet to do included:

- C: The thing is, learning my space. Learning how much I'm able to cope with. It's interesting having [my daughter and granddaughter] here actually. It really is. And it's delightful at times but it's also exhausting at times.
-

- C: I'm just one of those disciplined people and it frustrates me no end when people don't honour themselves . . . one of my big lessons that I have to learn about is releasing and letting GO of old ways of thinking. But you have to honour yourself first.

Finally, Carla reflected how time and experience helped take away some of her fears about managing cancer-related pain:

- C: I think it's learning to--when you get sick--learning to be open to what's out there. And that's what it taught me. How much help there is out there. . . . There's not so much fear . . . each time I have to have the treatments I learn a little bit more about my level of TOLERANCE and how to take care of myself better . . . and I've learned more each time I've had to deal with it. And I think each time, I think I've been through the worst. Right now, I feel that, whatever comes up now is just the left overs!

Significant Relationships

Carla talked openly about the relationships she considered significant in her life, both professional and personal.

Personal relationships. Carla said she had established very good relationships with friends over the years, and that those friends had been especially important to her during times of crisis. In the following passage she shared her

perceptions of how friends and acquaintances responded to her cancer, and what it felt like for her:

- C: It was very hard at first, actually--with my friends--because a lot of them are lady friends. And a lot of them are a little younger than me, in their forties and stuff. And it's touching sacred grounds, you know, as far as my friends are concerned. . . . it was more hard with friends. It really was, because they always saw me as the strong person. [crying] Yah, I found it hard. A few people said--'cause at that time Ann Jillian had a double mastectomy--and they said, "Oh well, she was back at work in ten days, you can do it". And I got tired of hearing it. 'Cause the situations were totally different, and she was married, financially stable. And to me, they're like really important factors in one's life. [crying] I just got tired of people telling me to "be BRAVE". . . . My friends all say, "You're so BRAVE, we admire you". And sometimes I don't want to HEAR that 'cause it sounds like crap . . . and then sometimes I get angry and I think, "Well it's easy for you to say those words but why weren't you HERE a little more!?" . . . It's scary to other people, especially when somebody like me comes down with something like cancer. It scares them as much as it scares you. . . . One lady I used to do Yoga with, and I sort of told her and--we used to be quite friendly and stuff--and she just sort of said, "Oh I'm sorry, [Carla]" and sort of walked off. And I sort of felt an awful EMPTINESS.

Carla went on to discuss how she sought emotional support from her friends, while preventing herself from becoming a burden to them:

- C: [My friend] came by and he asked me what I was doing and I said, "Well, I've just found out I've got cancer and I need to have a cup of coffee with you". And I felt that I had to go to that level because I needed somebody to talk to. And then I'd walk down the street and I'd say, "Please Lord, let me run into somebody I know so I can handle this".

.....

- C: And not knowing anybody [with cancer], I went to the Y and to other women's organizations. . . I went down [to the Women's Resources Centre] and uh they gave me information from files of women who had cancer in the leg or somewhere else. Oh, there was one lady I talked to and she was willing to listen, to share. And that helped a lot. But I didn't call her a lot because I didn't want to be a burden to somebody else? And we had talked about getting together, but she helped me an awful lot and I guess that helped me keep it so that I wouldn't be a BURDEN to my friends. Even though they were supportive, they still had very active lives.

Carla said she liked it when friends offered their company after medical appointments, provided practical support such as transportation to and from appointments, helped her "get out of the apartment" to take part in outdoor activities, and sent flowers to "brighten up the place". Above all, she expressed appreciation for the help friends provided after hospitalizations. She recalled:

- C: [After the mastectomy] a friend came out from Australia, [Mitch], and he stayed with me for about ten days. That was very healing. It helped me get over a big--I had somebody there. You know, he helped me laugh. . . . I think he gave me the strength to get through the next operation. [crying]

.....

- C: When I came out of hospital, I stayed with [Benny and] them for a couple of days and that was a lot easier than going from being in the hospital, having people taking care of you and then going home. To me it would have been too much, to do that. . . . I was very grateful for that--that way that gave me the--they let me just rest. And they fed me. And I was able to go back, you know, in two days and get on with whatever. That made it a lot easier for me, and I've been lucky that I've had that support you know, each time.

During our interviews Carla often referred to an especially close friend from whom she had received support throughout her illness. Reflecting on her friendship with Benny, she said:

- C: I have a really good friend who I call my "brother" and he's always been very supportive. I always go to him first 'cause he's just a neat guy. Though I have good lady friends I still feel very much a need for a male friend, as well, in situations like that. So [Benny's] been very good to me over the years, but he's been one of the people I've known the longest too, here in Vancouver.

She also shared these thoughts about not being in a sexually intimate relationship with a man:

- C: I'm not even sure how I would handle it even . . . seeing a guy. . . . I haven't met anybody since--which is too bad in a way, because I think the sexual aspects of life can be very healing. And times when you're down, you know, 'cause you need that emotional--need the hugging, you need somebody to care, and not feel that you're just a sexual--you know, an object. I would like to be in a relationship, and I go out as often as I can, but I haven't really met anybody that turns me on. I don't know how I'd deal with it. I don't think it would worry me too much, 'cause if you like somebody there's so many aspects to a relationship.

Two of the most important people in Carla's life at the time of interview were her daughter Jane, and her little granddaughter. Carla and Jane shared a special relationship--one that began anew just five years earlier, after Carla's ten year search for the child she gave up for adoption at birth.

- C: I gave her up for adoption when she was a baby and when I went home the last time, I finally found her. [crying] . . . I gave her up for the right reasons, you know. Her father was killed in an accident and I couldn't afford--and I'd been brought up in a not so nice a situation--in an orphanage. And I just wanted her to have better than I felt that I could give her. I was only twenty two then. In those days at twenty two you were very young. . . . It took a few years, a few trips back to New Zealand . . . I had spent a couple of years sending money to different agencies to find out, and not getting any results. And then when I went home I guess it helped me cope . . .
- K: How long had you been searching for her?
- C: Oh years. Yah, from the time she was twenty one. So it's been a long time. I was only able to go home every three or four years . . .

Carla said her search for Jane was a "driving force" in her life for many years. She felt that her cancer diagnosis in 1986 intensified her determination to find Jane, providing a real "sense of purpose" in her life. She talked about the experience of finding her daughter that same year:

- C: The first day [Jane] and her husband and the four of them, we all spent together and then [her mother] came over the next day. And just the three of us, it was a neat experience, it really was. And we've been good friends since. . . . Her mother was here for a visit in May. . . . You hear of a lot of stories that don't work out that well, and I think I'm lucky. . . so this is like, kind of a big miracle in my life in many ways. That it HAPPENED 'cause I'd been looking for her, for many years and here she IS . . . [crying]

Carla and Jane had not seen each other since their 1986 reunion. At the time of interview Carla was in the process of re-establishing ties with family she barely knew, and spoke openly about the ups and downs of adapting to this new situation:

C: I should be like happy, happy, happy. Right? But I'm finding that it's exhausting. . . . It's very difficult when you have a child around who's wanting all the time, and you have a five minute conversation and it goes nowhere because there's these continual interruptions . . . she's used to having a brother around to play with all the time . . . it's hard to understand a child's mind sometimes . . . we're getting closer, really, we are. So it's really an interesting situation in many ways but it's quite exhausting, at the same time. And I love the idea of them being here.

C: [Jane and I] sort of talked through some of these things and we became a little closer. 'Cause we're strangers in many ways. But it's working good in many ways, it really is, you know. [crying] I don't know how many people would have the tolerance when you're fifty. . . . It's working a lot BETTER now than at the beginning, because we all had adjustments to make.

Above all, Carla hoped her daughter would find happiness in the relationship she herself had spent so many years searching to find. She elaborated:

C: This is Canada, this is her big trip, away from home. I want my daughter to just ENJOY. . . .and for me to try and make the most of teaching her to make the most of it. And not heavy energy down [for her] just because [I'm] not feeling a hundred percent. I don't want her to go home feeling that she hasn't DONE enough.

Another significant person in Carla's life was Annie, a three year old child residing with her single mother in a neighbouring apartment. Carla described

spending many enjoyable hours with Annie while her mother worked or entertained company. In fact, Carla said she felt as if she had "raised" little Annie. She said Annie helped keep her "going", regarding her as a "source of strength". She reflected:

- C: It's been wonderful for me, having [Annie] around. 'Course she's been around since basically the beginning, and I needed that?! . . . I think that's what I've been given, this OPPORTUNITY to take back some of what I missed in my own life. Yah, and I think that's helped ME through the healing process, being able to BE a child around her. . . . We'd be dancing and singing and carrying on and doing silly things . . . she was my best audience. I never heard anybody laugh so hard, and just enjoyed it more. That was very good for me and the other way too, me good for her.

Professional relationships. Carla's professional contacts with doctors included surgeons, cancer specialists, and her general practitioner. She said she found it difficult to "feel in control" when she had to put her life in the hands of doctors she barely knew. For example, she referred to the "leap of faith" she had to make in order to trust the surgeon performing her mastectomy, "I had to put my faith in a strange man".

Carla repeatedly vented feelings of anger and frustration regarding her relationships with doctors, including her cancer specialists. Her perceptions are reflected in these accounts:

- C: When I told the [family doctor] that I'd gone to the chiropractor he was quite angry with me. And when I told them at the [cancer treatment centre], they were angry too. And I'd said to [the cancer specialist]--I've had quite a bit of anger dealing with the various

doctors--I had mentioned to him that, "Let's look into it and see if it's okay, because I'm still having back problems". Because I wanted to go back to work, and the pain wouldn't go away . . . I could never get comfortable! And I thought, "Well bugger it, every time I go to the doctor all he does is offer me a pill, so I just have to take responsibility for my own life, right?" So that's why I went to the chiropractor. And he was recommended to me from a couple of friends. . . . What was I supposed to know? And [the doctors] sort of told me that, "Well, you know we set up appointments for three months". What am I supposed to do in between? So you know, it's not always easy having to deal with them. And they keep you waiting and they have other people in the room. So I used to be frustrated quite often when I went to see [the cancer specialist].

.....
C: I get pissed off at the [doctors] sometimes, I really do. Like, they offer you another pill and that's it! And when I . . . was taking the Tamoxifen for two years and then the cancer came back, I told [the cancer specialist] I didn't want to take any more pills. So he said, "Well what are you going to do?" I said, "I'm going to meditate". [laughs] Because you know enough is enough! I got real angry with him at that time!

.....
C: You go to a doctor, he gives you a pill, tells you to take it. And the PAIN can still be there because underneath the physical pain you're still dealing with emotional pain. . . . They just give you medication.

.....
C: Last time I saw [the cancer specialist] I felt okay with him, but lots of times I left there feeling really frustrated. Because I just felt that nearly every time I went to see him there was either one [medical] student, or two students. And it was very seldom a one on one. And all the questions that I had sort of got--I just felt that he talked over me lots of times. And many times I wanted to ask for a female and I didn't always feel comfortable with him at all. But I sort of feel frustrated because each time I went back they would ask me basically the same question, "Well where's the PAIN?" And I would say well basically, "I'm okay, it's the lower back". . . . "Why we don't look into what the lower back is all about?" And he--several times he said, "Oh no, you don't seem to be having too much of a problem with it, we'll let it go". And I think that's why I got frustrated this time, because I sort of feel that we could have looked at the SPINE and the NECK, sooner. Then would I be in the situation that I am now? I don't know the answers, but I guess it gave me something to be angry about. I feel that sometimes you have to direct the anger either at

yourself or somebody else. And it gave me kind of good reason to get angry at him!

Carla conceded that the affiliation she had with her family doctor, on the other hand, was unique. It had evolved into a social relationship with him and his family, elaborated upon in this passage:

- C: We're invited away this weekend, my doctor's got a place at Mount Baker. Yah, he's been very--I don't know if it's guilt because of the bursitis trips and stuff--but he's been very--he's tried to be very, very good. And I babysat his kids when they went away on their holiday. The kids are adopted except the youngest one is theirs. . . . [His wife], she sort of understands . . . we've become quite close, which is kind of nice, having a doctor on your side. Yah, kind of comforting!

Emphasizing that she liked to be treated as a unique human being, Carla expounded on how she felt doctors could be more helpful to their patients:

- C: I think [doctors should] be aware that they're treating individuals. One person's going to come in and know nothing and lean on him. The next person comes in is going to be more open and be more knowledgable, but still have the same basic fear that the other person had, but more open to honest answers. Down to earth you know, lay the cards on the table. Where the next person that comes in may not want to know the truth, may want to be spoken to in another language. And [doctors should] be comfortable with that. Just to be AWARE of the different individuals that come in.

Carla identified that nurses had an important role in helping her manage pain at home. Home care nurses provided support from "the beginning" by visiting or

phoning each week. When Carla felt particularly unwell the nurse telephoned every few days. She said the nurses approached her the way she "liked to be treated", elaborating:

- C: The nurses have been exceptionally good, just very caring, very compassionate . . . KIND and COURTEOUS. In a very caring way, asking questions. "Are you comfortable?" "Is there anything I can do for you?" "What is it you're not getting?" You know, those sort of things?

Frequently Carla mentioned a nurse who made home visits from the local hospital's palliative care unit. She described this nurse as being instrumental in helping her address her fears about taking Morphine. Carla said she preferred to "learn the basic facts about medications and treatments from nurses" because she felt at ease with them, explaining:

- C: [The palliative care nurse], she came and explained to me the benefits of the Morphine and stuff. She explained a lot more to me than the doctors did, actually. . . . I like to ask [the nurses] questions 'cause I find that I get better answers, clearer cut answers about whether the Morphine is just hiding what is there. I would rather know the basic facts and deal with them . . . answers seem to be more basic and clear cut. . . . She's been very helpful for me, because I wouldn't even take that [Morphine] a while back. I was really scared about the Morphine being the last leg.

Although she relied on professional home makers at various times, Carla expressed dissatisfaction with their services, saying:

- C: They seem to be very uncomfortable in the situation they were in. They didn't know anything and it was very frustrating for me. . . . And I had this really young girl, oh she didn't know what to do, and I called one of my lady friends and she came over and she showed her and helped her to do a few things, so that made it a little easier. . . . I don't want to have to deal with that again. I really don't. . . . You basically have to watch everything they do because they don't feel capable of playing out their own role . . . so I found it very frustrating when they came.

Despite her general feelings about home making services Carla acknowledged that there had been one exception to that experience, described here:

- C: One girl . . . the difference between her and the others, my goodness me. She was like one of the nurses, she was just so caring. As soon as I woke up in the morning she was there to help me and to get whatever. And with no fuss--just and did it in such a nice way. And she was pleasant to be around, and that was twenty four hours. She was usually here for three days at a time, and it was a very pleasant experience. And it's helped me get through the next two days of having another strange person come. And she helped me to sort of try and relax. . . . and she helped me to see that not everybody is the SAME and not to expect that.

Another professional whose assistance Carla appreciated was a social worker at the cancer treatment centre. She remarked:

- C: [She] has been very good to me, not just me but all the patients that she comes in contact with. She's just this very beautiful, gentle SOUL, that always takes the time to give you a few minutes if she can. And she made a tape for me that last time to get me through the treatments.

Carla commented that she had developed a close friendship with another social worker, explaining, "We're into the same things, kind of clicked, and she has been wonderful".

Carla also utilized the resources of several friends who were health care professionals. She had two friends who practised physiotherapy, providing her with information and physiotherapy treatments. Another valued resource was the emotional support and information provided by a close friend in the nursing profession.

Seeking Knowledge

Carla said she felt most able to "handle pain" when she understood what was happening to her and felt able to actively participate in the "healing process". She remarked, "It's kind of scary if you don't know what it is, but when you understand why the pain is there, you can work on healing it on a mental level and it'll become less intense". At the same time, she acknowledged that "sometimes not knowing helps". For example:

- C: In the beginning not knowing [the facts] helped--it helped me sleep better. Because the first time around there's a lot more fear that you have to deal with . . . not knowing how far it's gone.

Carla considered the knowledge needed by patients to be an "individual thing" dependent upon the amount of information one has to "work with at the beginning". She commented, "Some people are around people who've done for

them and have never had to learn, so it would be an opportunity for them to learn to do for themselves". She maintained that being informed about her disease helped her make crucial decisions regarding treatment of her cancer and related pain. For example:

- C: The first time was scary, with the radiation. I hadn't seen the machines, didn't even know what I was getting into. But I was scared. . . . I really didn't know if I really wanted to go out and find out what it was about? I don't know, maybe I wouldn't have gone through the treatments. Several of my friends were into new age stuff and feel that that is not good--having an operation and radiation treatments are not really good for the body, and the toxins and everything. I think you have to decide for yourself and take advantage of both, because I think you need the radiation. I know that my body needed the radiation. If I didn't have the radiation, further down the line it's possible the cancer could have spread could spread through more of my body.

She investigated the facts about her disease and treatment in a variety of ways. As well as collecting information from health care professionals she relied on her own resources to acquire knowledge from books, television shows, workshops, friends, other women with cancer, and women's organizations. She found it especially helpful to read books authored by healers and individuals experiencing cancer. During our interviews she often referred to things she had read:

- C: Several books that I've read have helped. . . . Jill Ireland's book. But different again--her life is different again, like she had the money, she had the husband. She had those things for support, though she was able to go and she did try lots of things. And I think probably one thing that killed her was the chemo--too much chemotherapy. I think

it weakens the body too much. And Gilda Radner too. You know Gilda Radner's book, when she had [chemotherapy], the first ones weren't too bad. I think they got through the first lot, but it was when they had to go back and have more again. I think that's what totally destroyed them.

.....
C: I'm reading Bernie Siegal and . . . he explains very clearly from a doctor's perspective, the different patients that would come to him and explain to him about the pain.

.....
C: Elizabeth Kubler Ross's book "Death and Dying", I'm really interested in her point of view. You know, who knows when their time comes?

.....
C: And I have a really nice book that I pass on to friends--by Jerry Jampolsky--called "Love is Letting Go of Fear". . . . I don't like to put anybody on the pedestal but I found that book was very helpful. And a lot of my friends have.

.....
C: Louise Hay, I've got one of her books. "You Can Heal Your Life" . . I don't know if I believe all of it. Some of it was pretty close. She talked about cancer being resentment. . . .

Carla pointed out the difficulties she had obtaining knowledge about managing breast cancer and related pain, especially at the time of initial diagnosis:

C: I went to the Y and two other women's organizations and they didn't have any info at all at that stage. I didn't know about the [cancer treatment centre] at that stage neither, because I didn't have to have radiation or chemotherapy until the recurrence happened.

Over time she discovered "how much help there is out there" and that "it doesn't have to cost an awful lot". She mentioned that resources available at the cancer treatment centre had increased since her first treatment there, to include support groups and a library of videotapes.

Carla perceived that at times, she lacked the basic information she needed to manage her care effectively. For example, she said it would have been useful to have someone show her how to make practical adjustments to accommodate her physical disabilities. She described other situations where she would have appreciated more information from her doctors:

- C: And the chiropractor cracked me! And he cracked a rib . . . he cracked one of the vertebrae and the cancer is metastasized in that area . . . I guess my timing was wrong and I never thought about the bones being brittle. . . . It never kind of entered my head . . . What was I supposed to know? I didn't realize that because I'd had cancer in the hip, that it would affect the rest of the bones in my body.
-
- C: I remember when I first got the Morphine, I was perturbed that they hadn't given me a little bit more information around it. They just said, "Well, take that and that'll help you with the PAIN" And there was no nurse or anything to explain anything. And the pain was so bad that time that I decided that okay, I would take it and then I would maybe talk to the doctor later, 'cause he wasn't around, but I would have appreciated that information.

At the time of our final interview Carla was once again seeking answers to her questions. She expressed concern about her persistent nature of her unrelieved pain, voicing that she wanted to "know what is happening". She reflected:

- C: I've got an appointment [next week] at the [cancer treatment centre] and what I feel I need to now, is to ask the doctor, you know, what are my chances? . . . like I'll sit down and talk to him and ask him what the odds are. . . . until I'm sort of certain what is causing this pain--I need answers for it. I don't know if it's cancer again or what it is? I'm hoping that the radiation has killed the cancer and there's lots I don't quite understand, like about bone cancer?

Carla asked me many questions about the potential progress of her disease. She requested information about pain management, spread of disease, monitoring treatment response, and chemotherapy.

Negotiating the Health Care System

Carla's main concern about dealing with the maze of professionals, hospitalizations, treatments and procedures that were part of her cancer care, was that the health care system provided inadequate support to individuals managing their care at home. She felt that "in order to survive" she had to assume responsibility for her own recovery and rely on her own resources.

She voiced frustration regarding aspects of the system she felt hindered instead of helped her cope effectively. For example, she found it difficult to adjust to caring for herself at home alone after periods of hospitalization. She cited the following example to illustrate her view:

- C: When I had [reconstructive surgery] done I had a close friend die of cancer. And they wanted me to go home. I had the operation on the Monday and they wanted me to go home on the on the Wednesday. And I said, "No", that I wasn't ready for it. And I said, "I'm not capable of taking care of myself". I mean, I wasn't used to all that heavy medication and stuff. Demerol is a real nice high but you know, it can be devastating coming down from it and not have anybody there. And I insisted that I stay another day and when I woke up the next morning I felt really good. I went home and I cleaned up and went to the funeral service and felt okay about it.

Carla also complained about hindrances experienced at the cancer treatment centre. She expressed annoyance about being kept waiting for scheduled appointments "alone in a little small room" for periods of thirty minutes and more. At other times she felt deprived of her privacy, commenting that there were often other people within sight or hearing distance of invasive procedures and private conversations with professionals. She also voiced this practical concern:

- C: I found the doors in the [cancer treatment centre] very heavy. And the more treatments I had the weaker I got. It was exhausting. Like when I had cobalt four . . . way down the end, that was bad enough because they didn't have the changing rooms that they have at the other end, and those doors are awfully heavy . . . they could make an improvement there.

Future goals and Expectations

During our interviews Carla contemplated her past as well as her future possibilities. Since being diagnosed with cancer her ambitions constantly shifted in response to her disease and its progress. Reflecting back on her life, she said, "It's so nice at this stage of my life, I feel that I've achieved so much in the last few years". She went on to talk about the "deep satisfaction" she felt about fulfilling her dream of being reunited with her daughter. As discussed earlier, Carla's primary goals at the time of interview centred around building quality relationships between herself, her daughter and granddaughter.

As she looked toward an unpredictable future, Carla maintained hope that she would continue to heal, enabling her to reclaim the strength and independence that

she felt had been robbed by her cancer and related pain. During our first interview she commented, "I want to stay around for a while, I want to get better!" Her vision of the future at that time focused on her hopes of resuming some semblance of her previous life. Considering future possibilities, she commented:

- C: What are my chances of ever playing tennis again? 'Cause medication's only going to do so much and I don't want to be a cripple for the rest of my life. . . . I have a couple of friends who've said that they know somebody who has been on Morphine for many years and is functioning fairly well. I don't KNOW what I'm going to be able to DO . . . the only thing I know is sewing and I used to waitress. So I don't know.

By the time of our last interview Carla had settled into a routine with her family, expressing great pleasure regarding their relationships. Despite her contentment, it was evident that her pain was not diminishing. She reflected, "It is really quite tiring staying comfortable . . . I don't know if I want to deal with it much longer".

As Carla acknowledged the reality of what might lie ahead, she explored some of her fears. She worried about her cancer "coming back" and having to have chemotherapy. She disclosed:

- C: The big fear for me is having to deal with chemo, the thought of chemotherapy really scares me. Everything I've seen and the people that I've known that have had to deal with it, it's just blown them asunder. And my friend that died of the same disease, she said if she had to do it all over again she would go without chemo.

Looking toward an uncertain future, Carla voiced mixed emotions. She remained optimistic despite the presence of unrelenting pain, hoping for a successful outcome that would enhance her functional capacity. She also expressed fear of increasing pain and dependence. Contemplating the outcome of a medical appointment several days ahead, she said:

C: It kind of scares me . . . I'm not sure what I'm capable of doing? Or WHAT I would like to be doing, to tell you the truth. [crying]

Postscript: Three Months Later

Several weeks after our final interview, Carla telephoned me in an obvious state of emotional distress. She reported that she had been referred to a "chemotherapy specialist" who recommended she have chemotherapy for progression of her cancer. She understood chemotherapy offered the "best chance" for a possible remission.

Carla apologized for calling me, explaining that she wanted to ask some questions, in order to make an informed decision about having chemotherapy. She perceived the doctor did not "have enough time" to provide the information she needed to realistically weigh the costs and benefits for her-- in her particular circumstances--to have chemotherapy. She declared she did "not want to have chemotherapy", but the alternative seemed much worse. In the face of a treatment that intimidated her beyond description, she admitted feeling "terrified" and "out of control".

Amid her tears and sobbing, Carla requested information about chemotherapy administration and effectiveness, how chemotherapy works, goals of treatment, management of side effects, and long term effects. She voiced particular concern about the possibility of losing her hair and experiencing nausea and vomiting. By the end of our conversation Carla said she remained "frightened" at the prospect of having chemotherapy, but felt "more in control" and able to think "more clearly" about her decision.

I never heard from her again until January 1991, when she left the following message on my answering machine, "I'm at home, but I've been in [the local] hospital and everything is all right". I tried to return her call several times, with no response. Several weeks later I tried to locate her through the palliative care unit of her local hospital, but her battle with cancer had ended several hours earlier. Carla died on January 18, 1991, three months after our last visit together.

Her friend Benny invited me to a memorial celebration in Carla's apartment a few days later. Apparently, this memorial to her life was being celebrated according to her wishes. Her small suite was jammed with friends, a wide assortment of people from various aspects of her life. All seemed to regard Carla as an individual with an extraordinary flair for life. According to her friends, she endured significant pain in the weeks before her death, finally relieved by very high doses of intravenous Morphine. Her daughter and grandchild had returned to New Zealand several weeks before her death. In a final tribute to her, Carla's many friends provided a loving testament to the exceptional friend they had just lost.

Case 4: Diane

Demographic Information

Diane is a seventy-three year old caucasian woman living with her retired husband in a Vancouver suburb. In 1987 they moved here from central Canada, where Diane was born and raised. Married for almost forty-four years, she and her husband have a forty year old son living near by. They also have two young granddaughters. Although currently retired, Diane has been employed throughout much of her adult life. She worked as a high school librarian, a book keeper, and most recently as a medical secretary.

Preface

I met with Diane twice over a period of eight days. We had talked on the phone several times so I felt as if we had met before I arrived for our first interview. Our sessions took me to a large home in a well established residential neighbourhood. As I approached the house for the first time I was aware of an elderly man gardening near the front entrance. He did not seem to hear me advance nor did he respond when I greeted him. Assuming he was preoccupied with the task at hand, I headed for the door. Before I could reach for the bell, Diane opened the front door and greeted me enthusiastically. Eagerly she ushered me into her home while excusing her husband's deafness.

Diane rushed about and spoke very quickly, as if bursting with energy. Plump, with a ruddy complexion, she looked much younger than her seventy-three years. It was hard to imagine this robust looking woman was coping with cancer-related pain. She was neatly groomed, with a short and simple hairstyle, and wearing bifocals. Over a pair of dark pants she wore a loose and comfortable looking print blouse. She immediately impressed me as a practical, "no-nonsense" woman. Her friendly outgoing manner assured me that I was welcome in her home and she was interested in conducting research with me.

Diane sat on a wooden chair beside the sofa I was sitting on, adjusting a small pillow behind her back. The living room was decorated with knickknacks, framed snapshots, paintings and bookcases that spilled over with books. Assorted pictures of her son, grandchildren, and friends were neatly arranged on the coffee table just within my reach. Diane pointed out a beautiful seascape she had painted years before, and a delicate water colour painted by a friend. She seemed to cherish the sentimental value of these treasures. Diane's home felt cosy, warm and inviting.

Throughout our first session Diane wiggled and repositioned herself often but did not complain of discomfort. She talked freely, interspersing her conversation with jokes and laughter. Not one to mince words, Diane expressed herself in an unusually frank manner. She seemed to take pleasure in sharing anecdotes about her life experiences. In fact, this appeared to be her main style of self-expression.

She had no difficulty taking part in an unstructured interview and I sensed she looked forward our next session.

Returning for our second interview a week later, I immediately noticed a profound change in Diane. She was experiencing obvious respiratory distress, her breathing rapid and wheezing. In order to maintain conversation she punctuated every few sentences with a gasping breath. I recommended we postpone our session but Diane insisted she was fine and wanted to go ahead. She assured me she had been to the doctor the previous day and was told there was "nothing wrong". She wondered if her symptoms were caused by an unknown allergen.

Entering the living room, I noticed an attractively set dining room table covered with a fancy tablecloth and fine china dishes. Diane was having a special lunch for her husband and his friends. She went on to show me an unusual looking stuffed beaver she had "dug out" for me to look at. Her son had given it to her years ago, from an Indian reserve in northern Ontario. I found myself chuckling at the fat little creature whose ears had been lost to tiny grandchildren long ago. Diane shared my laughter and showed me other trinkets given by her son over the years. As she chatted about her son I sensed she was very proud of him.

Diane was able to sit in one position throughout our second session. Her shortness of breath was distracting but did not hinder the interview process. Her speech was rapid and spontaneous except when she referred to her husband, who was pottering around the house. Upon mention of him, or their marital relationship, she glanced around the room and lowered her voice to a whisper. After a few

minutes of discussion she would throw her hands up in the air with a look of exasperation on her face, and change the subject.

After the interview Diane asked how to relieve her distressing respiratory symptoms. I encouraged her to seek medical advice immediately if symptoms worsened, and by the end of the day if symptoms did not improve. She called me several weeks later and said she was still being treated for a pulmonary embolism [obstruction of pulmonary artery] that had been diagnosed after consulting her cancer specialist the afternoon of our interview. She understood it had been caused by her "cancer medications" [Megace].

History of Pain Experience

Diane was diagnosed with breast cancer in 1975 during an annual check up. She hadn't "realized there was a problem, although one breast nipple looked a bit droopy" and she had felt "a mass or something underneath the surface". A modified radical mastectomy was performed to remove her right breast, followed by sixteen cobalt radiation treatments.

Over the next thirteen years [1975-1988] Diane went to her local cancer treatment centre for routine checkups. She believed that after five years she was free from any further threat related to her cancer. She said, "From then on I was fine. I didn't have any problems that I was aware of, other than being tired." In April 1988 she found out that she had "bone cancer in the ribs". She described:

D: I went to pick up something from the fireplace over there and I couldn't get up. I bent over and I was here alone and uh, I just sat on a chair until the seizure passed. It was pretty violent, I thought I was going to faint and I thought I would throw up but I didn't. . . . I said, "I think I better go and see the doctor . . . I've done something and I don't know what it is". . . my side was hurting and we had x-rays done . . . and he [doctor] phoned me and said, "They've found bone cancer in the ribs".

Diane started taking hormones [Tamoxifen] and "everything seemed to be going along very easily" until her hip began "bothering" her in June 1990.

D: My hip was aching. I had cracked my hip some years ago. . . . they found something . . . [the cancer treatment centre] couldn't see that what they had found had any bearing on my hip aching. . . . and from June to September there was some increase in the cancer somewhere or other, and I just realized it's there. They're trying to control it.

In September 1990 her medications were changed due to her ongoing discomfort and because the cancer specialist "didn't think the other medication was working". At the time of interview [about a month later] Diane understood that she had cancer in her arm, hip, ribs, lower back, as well as in her skull. She commented:

D: I have cancer in the skull somewhere, where it is in my head, I don't know. . . . I have never been able to find out where. I've asked but [the doctors] just talk around it.

Pain Description

In an attempt to describe her experience of pain, Diane clarified her interpretation of terms she used to portray the varying intensities of her discomfort. She used the word "discomfort" to describe pain equal to "four or five on a scale of ten", with zero being completely pain free and ten being the worst possible pain. She viewed "discomfort" as "minimal pain" that remained "bearable". To her, the term "pain" reflected discomfort of a "devastating" nature, measuring "over ten" on the aforementioned scale. Diane expressed that focusing on a "few little aches" wasn't as useful as concentrating "being able to use the body".

Diane described discomfort that "comes and goes" in her ribs, hip, back and head. She had lived with arthritis and "disintegrated discs" for years and said, "Aches and pains I'm so used to that I just ignore them". She felt her most "severe pain" was in her ribs and went on to describe the nature of that pain:

D: It's in the right ribs and it's a sharp pain. Acute pain, like something shooting through it, and sometimes it lasts for quite a while . . . sometimes . . . it is very severe, so whether something's touching a nerve . . . I don't really know, why or how? You know, why bones ache?

The discomfort in Diane's arm fluctuated "on and off", but generally "got worse" at night. Her back "hurt quite a bit" recently and Diane wondered if it was from "lifting suitcases". On occasion she had "terrible headaches" with "pain shooting through the skull", which she said "could be partly from drafts in the car

or wind or that kind of thing". She was more aware of her pain at night when it had a tendency to prevent her from sleeping. Diane perceived that she did not "get that much acute pain", although she lived with chronic "discomfort".

Impact of Pain on Daily Living

Diane has always regarded herself as an active individual. She was always "into sports" and enjoyed activities like skiing, bowling and badminton; as well as less demanding ventures such as playing the piano, oil painting, reading and sewing. Diane did not feel her disease and related pain had significantly changed her life. She simply adapted her activities to those she could physically tolerate. For example, she gave up knitting because of the discomfort it triggered in her right arm. Despite being unable to "go out and do physical things quite the same", she believes she is as industrious as ever. At the time of interview she was able to get around independently--by foot or car--and did not feel inordinately disabled by her disease.

Coping Strategies

Diane employs both medicinal and non-medicinal approaches to manage her pain. Those that stand out include taking medications and distracting herself from pain.

Medications and treatments. At the time of interview she was taking hormones to treat her disease, and mild analgesic painkillers to manage her pain.

She said, "I'm not inclined to lean on painkillers every time there's a little twinge".

Diane discussed how and when she chooses to take medicine for pain:

D: I really try to wait until it gets beyond being funny . . . yesterday my side was really aching . . . "Well, I'll take some Tylenol and be darned and get on with it". So I took it. . . it didn't do much and then I came down and got lunch ready and it was still aching. So I thought, "Well it's not four hours but this is still bothering me" . . . "I'll take two Bufferin, they're not maybe as strong as taking something with Codeine in it". I took the two Bufferin and eventually--an hour or so after--that eased off and it didn't bother me again.

Because of their side effects Diane "steers off taking too many" Tylenol #3.

She said she rarely took more than one Tylenol #3 per day and that sometimes "a week goes by without Tylenol". She elaborated further:

D: . . . why am I so against Codeine? Well when I was in the hospital and they were giving me painkillers . . . everything they tried I either threw up or I fainted or I was dizzy. Nothing seemed to suit me. So I've been a little bit frightened of that kind of medication. I don't WANT to be dizzy, I don't WANT to be nauseated. So if I can keep away long enough not to take anything . . . maybe that is when I was conscious of being careful what I took for pain. . . from then on I thought, "Well come on, let's be careful of, uh, I don't want any of those kind of side effects you know".

Although Tylenol #3 "didn't do much good" Diane said she was able to ease her pain by combining Bufferin with Tylenol #3. Asked if there were times when she experienced complete relief from pain, she responded:

- D: Oh, it's not there all the time. Oh no. No, no. It comes and goes. Now, I haven't taken anything since last--I went to bed last night about around eight o'clock and I took a couple of Bufferin . . . my back hasn't hurt today. So whatever, those couple of Bufferin must have done something.

Diane has always "been a light sleeper" and now finds her sleep disrupted by pain. She said she prefers not to take medication to help her sleep because she "doesn't want to become addicted" or tolerate the "dopey" effects she experienced when she tried taking sleeping pills in the past.

Self-care behaviours. The main non-medicinal approach Diane uses to manage her discomfort focuses on shifting her attention away from pain or disease, and on to activities that keep her mind otherwise occupied. She talked about "keeping going and keeping busy" in order to have "less time to think". She claimed, "I think the whole thing is to have a busy mind".

Diane's days are packed with activities and she is "never at a loss for something to fill in time, ever". She describes some of the ways she keeps herself busy:

- D: I like to travel and I like to read, I like to mix with people . . . this morning a lady phoned me, I said I would work in the office at the Cancer Society in [our community] . . . I belong to a book review club, a bunch of people get together and talk books, which I find very interesting. I like groups. . . . I like lectures and things like that. We go to Vancouver to symphony concerts and we go to concerts here . . . and I go to the Women's Canadian Club sometimes with some of my friends and those are mostly lectures or luncheons . . . I started to play bridge with a group of ladies . . . I just enjoy some of the activities and tomorrow there'll be some more music and then Tuesday there'll be some kind of meeting where a girl is going to talk about

house plants and then Thursday will be a book club meeting, and then the week after that there's a luncheon and just casual things like that . . . I always have a project of some kind, it might be a silly project. I send a lot of greeting cards to people, write a lot of letters, hear from people all over the world . . .

At the time of interview Diane was undertaking a big project putting together a book detailing her parents' families. She was also busy sorting, organizing and deciding the eventual fate of her belongings. Evidence of her many projects was everywhere. She had compiled an array of travel scrapbooks and a series of photo albums, collections of coffee spoons, stamps and tea cups. Surrounded by things that help keep her memories alive, she often finds herself reminiscing and telling stories based on her recollections.

Diane often focused our attention to her experiences as a traveller. She and her husband like going away on trips as often as possible. She shared several tales about a recent Alaskan cruise they particularly enjoyed:

D: There were birds and animals and there was one sunset at eleven thirty, just the sun was sinking in behind the mountain. It was superb. It was glorious. . . . it's so natural and so glorious and grand and uncommercialized.

Her fondness for travel was evident as she talked about the many trips she had enjoyed through the years, including trips to "Australia twice, Britain and Europe about six times, about five cruises, every state except Oklahoma and all across Canada".

Reading also absorbs much of Diane's time. She especially enjoys books about travel, history, and "achievers" such as pioneers. Reading provides a relaxing distraction from the pain that prevents her from sleeping at night. Other strategies that help her handle disrupted sleep include:

- D: If I'm uncomfortable at night and I can't sleep I don't lie there and toss around. I either read or I write a letter or I come down here and eat something or walk around. . . . I think sometimes if maybe when you're in bed maybe your body's leaning on something and causing a problem, you get up and you walk around you shake it out, your circulation is better.

Diane also finds it uncomfortable to sit in one position for a long time. She finds it increase her comfort if she can "wiggle around", reposition herself often, and tuck a pillow against her back.

Attitudes and Feelings Related to Controlling Pain

The way Diane copes with cancer and related pain is influenced by family role models and how she has come to view illness. The sick role is familiar to Diane, who as a child had diphtheria, measles and scarlet fever. She commented, "If there was anything to catch I was greedy and I caught it". She described having a "miserable childhood that way" and missed a year of school due to poor health. Other disruptions in her health included:

- D: I had my appendix out when I was seventeen . . . when my son was born I had an emergency Caesarian, the placenta had ripped off . . .

I had a bladder repair . . . a gall bladder operation . . . then in 1975 I had the mastectomy. So other than that I'm quite healthy.

Brought up in a home where there was "a lot of illness", it was her mother who most significantly influenced Diane's current attitudes toward illness. This was evident in the following excerpt:

D: My mother was always ailing, she always had something wrong with her. Of course I think a lot of it was PHONY because she wouldn't have lived til she was ninety nine and a half! She really enjoyed poor health. It was a way of--a Victorian way of--"Poor little me, be NICE to me", sort of thing. And I swore I would NEVER do that to anybody. . . . I think it's CRUEL. Mother was always running back and forth to the doctor and was going to die tomorrow, and I was very wicked, and that's why she was ill, and I thought, "I couldn't have been so wicked or she wouldn't have lasted that long". I'm glad I'm pretty hard shelled because that could really wound a little child or a teenager.

Diane believes she had to develop a "hard shell" in order to survive her mother "crying wolf all the time". As an adult, she vowed never to complain like her mother did and finds it hard to hear others complain unless they are "REALLY ill". She perceives that others do not "really want to know" and that "you can't bother everybody with all kinds of aches and pains and things".

Diane was also influenced by her mother's sisters. Two out of three sisters died of cancer in old age, while her mother survived for ten years after her mastectomy at eighty-nine years. While one aunt was a "very cheerful and lovely lady", Diane reflected her inability to identify with one of her aunts. She said, "I

could never get tuned in to her way of thinking, she was very frail and she said, IT'S A L-O-N-G C-O-L-D WALK TO THE GRAVE". Describing her mother and one aunt as "real tough nuts", Diane claimed, "Perhaps I am like that too".

Her father inspired Diane to be "strong and sensible". She seemed to recognize the ideal in her father's characteristics and now finds herself striving to embrace those very qualities in herself and others. She described "leaning towards solid types like him". Diane continually expressed admiration for her father and how he coped with chronic respiratory disease:

D: He was a very sensible person . . . never flared up and got dramatic like my mother did. . . . He was a very strong, quiet person. . . . He always went along very quietly and never talked about how he was feeling and anything like that. . . . And I hope that is what I'm like.

Whether discussing past or present, Diane regards herself as a "survivor". She said, "I think I'm a born survivor . . . I have to be tough or I wouldn't survive some of these things". Diane recounted many stories which illustrated her ability to "survive". She spoke about the ways that she has learned to be "strong" and how she rejects weakness in order to maintain her strength. These dominant themes prevail throughout most aspects of her life and seem to underlie her world view.

When asked what it was that helped her "survive", Diane said she was "more or less optimistic about everything". An important element of her survival is to identify with "achievers" rather than those who "feel sorry for themselves". She said:

D: I really enjoy people that have, I suppose, accomplished something. I'm not very strong on weak people. I'm afraid I don't have much time for them . . . I don't think that it's fair to other people to cry on their shoulders all the time about things.

Another way Diane "survives" is to avoid dwelling on her cancer. She said, "You have to live for today--you don't live in the past", and went on to say:

D: Once I've had something and I've got over it I don't think about it any more. I just say, "Well, that's it". Cause there's no point in dwelling on stuff.

Further exploration revealed that Diane chooses not to remember a lot of things because she doesn't "want to remember them". She admitted, "It is helpful to deny some of the things that might be happening" and shared the following example:

D: Maybe I'm playing a bit of ostrich in so much as I'm saying to myself, "Well it's not bone cancer, it's arthritis". Maybe I just don't want to think it's bone cancer. [laughs] It could be I'm fooling myself, or trying to fool myself. But it's not going to change anything. The cancer's not going to go away just cause I think it's something else.

Diane thinks keeping her mind busy prevents her from being afraid or worrying. She said, "If you're afraid of something then whatever that something is, it's going to hit you". When asked what she would fear if she stopped being busy

long enough, Diane responded, "I don't really know, I hadn't even thought about it". Later she acknowledged:

- D: I don't really know what kind of fears I would have, as long as I can use my arms and legs. I would hate to not be able to use them but I never even visualized the thought that it might be possible that I wouldn't be able to use--you know, it didn't strike--it just didn't register with myself at all.

Still later she contemplated her future for a moment:

- D: I have thought about the future only to this point, that I'm not blind to the fact that with cancer you can live a long time or you might not live a long time. . . . You have to consider what's going to happen although you don't dwell on it . . .

- D: I'm not even thinking beyond what would happen if I was incapacitated. I guess I'd have to go in a nursing home or something. Who knows? Nobody's told me what the possibilities are so I'll just have to deal with it as they get on, I guess.

Diane's attitude to her cancer and related discomfort is, "It's there and you can't worry". She refuses to feel sorry for herself or ask "Why me?". When very uncomfortable she admits, "I get almost whiny, but I don't whine to somebody else". She expresses her feelings by "stamping around and cussing and swearing, rattling pots or finding something to do".

Comparing herself to others less fortunate helps Diane maintain her optimism. She expressed:

- D: I think it's so sad when people can't do things that they would like to try to do. My one friend . . . she's had a stroke but she's bouncy and I think, "What an example she is". She's got something to deal with, going around in a wheelchair. I'd hate to do that! So when you compare yourself with somebody else there's always somebody a lot WORSE OFF. . . . So you look around, you think, "Aren't I lucky that I don't have that?"
- K: So by looking at somebody who has a worse situation you're able to make yourself feel . . .
- D: Oh I think so! I don't do it with any Pollyanna goody goody attitude at all. I just think, "I'm lucky I can walk and I can do a lot of things. . . when you look at these types of people . . . I think there are worse things than cancer although people are frightened to death by cancer.

Emphasizing her own good fortune, she asserted, "I'm seventy three, I have a husband that's still alive, I have a son that's still alive, my two granddaughters are normal, I have friends and I've travelled and I'm not starving. So I really have a very full life".

Diane also finds it helpful to have "a lot of interesting things to look back on" to sustain her through difficult times. During our interviews she frequently looked back and told stories about various life events. She said her sense of humour also helps "carry" her along. "A good feature is to be able to laugh, maybe that's a kind of religion as far as I'm concerned".

Religion does not appear to play a role in helping Diane manage pain or disease. Not a "deeply religious" person, she attends the Anglican Church regularly because of its familiarity. She likes "good music, a reasonable sermon" and above

all, the democratic right to freedom of religion. She does not believe prayer to be particularly helpful approach for coping with problems and becomes angry when others offer to pray for her. Diane offered her views about prayer:

D: Some of these church groups, they have prayer meetings . . . If I need prayers I can do it myself. They're no closer to God than I am . . . I suppose it's kind of them . . . But I think that you've got to do some of these things yourself. . . . you could ask for guidance . . . do whatever you're doing better. But you don't need Mrs. Jones and Mrs. Smith and their brother and everybody else running around saying, "Oh we'll pray for so and so". . . . it doesn't work as far as I'm concerned. I would pray at a church to say, "Well thank you, it's a nice day, thanks for the freedom in this country, or the fruit and the vegetables, and the birds and the bees". I'd pray for that kind of thing.

Significant Relationships

Diane's independent nature is reflected in her statement, "I guess I'm a liberated creature from a way back". She doesn't feel the need for "a lot of people to lean on in any way" and said, "Where I get support, I don't really know".

Personal relationships. Diane believes that having an active social life with old and new friends is critical to "keeping her going". Although she doesn't like to discuss her problems with others she says she might share them with friends. She talked about the role her friendships play in helping her manage pain:

D: I have one friend . . . she phones and chats . . . And then there's another girl . . . I don't lean on them but I mean they chatter away and say, "How are you?" and I don't mind talking to them and I have

a cousin nearby . . . we're going to a concert with her. . . . she's very casual about everything. I get along with her. I would draw strength from somebody like that, that's quiet. . . many of my friends I've kept for a very long time . . . I get a lot of mail from people . . . but two or three of my very good friends have died and I miss their mail. . . my one friend died a couple of years ago. She and I got along very, very well and I think about her and how she handled her situation.

Diane finds it most helpful when friends let her know they care without "having a long face". She likes people to be comfortable, relaxed and maintain a sense of humour. She said, "I don't want anybody making a big fuss. It's just nice to know some of your friends care about you".

Diane finds it unhelpful to be around people she views as "weak". She avoids those who "enjoy poor health". She also finds it frustrating to cope with people's fears about cancer. She has heard people say things like, "People with CANCER, they're SO SICK, I couldn't BEAR to go see them" and feels many people are "frightened to death by cancer". The following example portrays a friend's misconceptions about cancer:

D: [A friend] said to me, "Did I have any washing?" and I said, "Oh yah I have some here". "Oh just put it aside and you can do yours separately". . . . We got talking about leukaemia she said "Oh that's contagious". . . . I said, " . . . it's not a germ like cold or measles". "Oh no no no no no. It's infectious". I thought, "She's positive that this cancer business is catching". Even though this was five years after I'd had surgery and I'd had radiation. But she was not going to let any of my clothes touch any of her clothes.

Diane spoke often about her son, praising his accomplishments and voicing concern about his troubles. She said, "He is a very important part of my life". Her special relationship with him began at birth when she came close to losing him. "Just knowing he's around" provides strength for her.

Diane does not want to burden him with her illness because "he's got enough to sort out his own life" as he struggles through his divorce. She would prefer to support him through his troubles. Diane feels the real strength between them is their ability to communicate. She thinks they have a good relationship because he is "sensitive and kind" like her father was. She said, "My son is more like my father than his own father . . . he's strong".

Diane characterizes her marriage as one in which she and her husband coexist quite independently of each other. Other than their shared passion for travelling, "He just goes off and plays golf or billiards and does what he likes, and I go and do what I like". She went on to express feelings of dissatisfaction with her marital relationship and concluded, "If I'd had any brains, or I was living in this day and age I'd be divorced within about a week after [getting married]".

Still, she described feeling "protective" of him, saying she "has to look after him".

Diane described her seventy-six year old husband as "kind, generous and friendly" but said he offered her "NOTHING, very little" in the way of support. She feels, "He just does not understand illness". She referred to him as a "leaner", someone who "does not take the initiative to do anything". She feels unable to "rely

on" him and looks after all business and household financial matters. She admitted to enjoying this role, saying:

D: I don't need anybody else to do it. . . . I think this is part of being me, that if I see something that's got to be done well it's done. I don't want to have to ask somebody . . . if it pleased them.

K: So if your cancer was to become more disabling so that you weren't able to be the person to do that--that would be a very difficult thing between you [and your husband].

D: OHH! OH God! I just SHUDDER to think about it, I REALLY do!
 Oh dear. I don't know what would happen.

Another significant relationship Diane referred to several times spanned twenty nine years until her friend's death from cancer. She met him in 1944 and visited him overseas five times over the years. It seems she still draws on fond memories of their friendship.

D: He took me out to where my father was born and I saw where my mother was born and I felt very CLOSE to him. Closer than I did to my husband. I can't communicate with my husband. But some of these other people they just, well, I think we're on different lines you see. And then he died of cancer too. And so I have good memories.

Professional relationships. Diane's primary professional contacts are with doctors. At the time of our second interview she had just seen her family doctor about her sudden breathlessness. She remained confused about it's cause and struggled to find an explanation for her distressing symptoms. She said:

D: I thought he [family doctor] would have been more concerned. . . . But a couple of times I've gone to him--and I don't go very often--he says like . . . "Hmm well I don't know". . . . And I said to him, "What'll I do? Will I take some aspirins or something?" He says, "OH that won't stop you from being short of breath".

After some discussion Diane decided to "give it a few days and phone him again". Recognizing the severity of her symptoms, I encouraged her to seek medical advice by the end of the day if her symptoms had not been relieved. She did seek advice later that day for worsening symptoms, and was subsequently diagnosed and treated for a pulmonary embolism. She was hospitalized in her local hospital for a week, receiving intravenous anticoagulant therapy.

Diane said she had "lost faith" in her family doctor and wondered if she could "trust" him. She claimed that she never felt understood by him, explaining, "We can't communicate, he listen. He just says, 'Yes Mrs Brown, yes Mrs Brown'". She wondered if he was deaf and should be retired. Aloud, she contemplated switching to another doctor, saying she preferred a female doctor.

Although she felt she received "little help from the general practitioner", Diane reported that her "cancer doctor" provided "much better advice" regarding her care. She described him as having a "pleasant attitude" and said she "felt secure with him". She perceived the cancer specialists "seem to know what they're doing".

Diane outlined her expectations of the doctors she relates to:

D: I just listen to what they say and I follow whatever they suggest. I don't go in with any pre-conceived ideas about what I will do. I'm

going to see these professional people because they know what the best thing to do is and I follow it. I would do whatever they say. . . . I do what I'm told if the source is someone that I respect sort of thing.

.....
D: I like the feeling of the doctors caring without them saying too much. I like the doctor to take command and tell me what I should do. I like to know they listen.

At the same time, Diane feels she has a responsibility to inform the doctor of her individual needs. For example, she tells the doctor which medications she can and cannot tolerate. Diane believes that doctors sometimes blame patients for not "telling them things", so she tries to tell them what she can about herself.

Diane said doctors and other professionals do not provide helpful suggestions about managing pain, although cancer treatment centre professionals were "very nice, kind and considerate". She talked about how she thinks doctors try to help patients by protecting them:

D: . . . a lot of doctors, especially specialists--they always give trick answers just to see you work around it. I mean I've noticed that with them, you know, they never give you a STRAIGHT answer. They want you to tell them something so they can tell you something back. . . . I know sometimes they're protecting you. They're not telling you something either. It's quite likely they're talking around the point cause maybe they don't want you to get all hepped up about something.

Seeking Knowledge

Diane relies on doctors, friends and past experiences with cancer as information sources regarding her disease and treatment. Her previous work as a

medical secretary also helps her "recognize some of the things that are happening".

She perceives it would be unhelpful to seek reading material about her disease and refers to friends who "drive themselves and everybody nuts" reading about their cancer. Diane has access to a variety of cancer information resources. She writes to a friend who is a cancer specialist in England, and she has been active in various volunteer organizations aimed at helping other people with cancer. Diane does not use any resources through her local hospital or the cancer treatment centre, but knows that one can have somebody that will come in "and look after me and things like that if needed". For the present she is grateful that she does not need outside help and commented, "But if I did I'd ask, you know".

During our interviews Diane asked for information about several practical concerns. The following discussion revealed her knowledge level about her cancer:

D: One thing I wanted to ask you. On the driver's licence you sign a consent to give your body to--organ donor. Now if a person has cancer their organs could be contaminated with cancer. If you have bone cancer what would they do with a person? Would they use it, use your body for research?

.....

K: . . . they could use the body for scientific reasons, you know basically to study . . . they won't generally use any of the organs. [for donation]

D: Oh I wouldn't think so, in case any of the cells broke away. Because I said to them, "How did I get bone cancer?" and they said, "Well some of the cells that were dormant after the first lot of cancer had broken away and got into the bones". So I've seen two or three friends die a miserable death with bone cancer. But you just don't think about it. You keep saying to yourself, "Well every year the medication is improving". And that's how it is. And if you're

uncomfortable well then do something. If you're not don't worry about it.

Negotiating the Health Care System

Diane said she "feels grateful" for the services provided by the Canadian health care system, and considers herself "lucky" to have had the care she's had. She stated:

D: I'm very pleased that they can control my cancer. They're particularly good at the [cancer treatment centre]. Blood tests, x-rays, scans-- couldn't be better. Sometimes I think, "Am I getting all this on the medical plan?" I would never have been surprised if I received a bill. So I give donations because I am thankful.

She voiced "minor" complaints about some aspects of the health care system. Her primary concern was that "so far" her family doctor had "not been great". She also criticised the long periods of waiting that occurred during scheduled appointments at the cancer treatment centre, but went on to qualify her criticism:

D: I know they can't treat you first. I know that you have to wait due to the high volume [of patients]. I've been used to illness so I have a tendency to take these things in stride.

Future Goals and Expectations

At the time of interview Diane was trying to "live one day at a time". She was taking medications in the "hope that it's going to control it [cancer] for the time

being". She was also getting her "house in order", making practical plans in the event she became unable to direct someone as to what she wanted done. For example, Diane joined a memorial society that provides prepaid funerals at a reasonable price. She reflected:

D: I'm not thinking in terms of dying particularly, but it's there within the next year, two, five, ten--and it's not because I have cancer. . . . I can't complain after having so many years of health!

Diane was sorting "a lot of stuff" and commented, "I've got to live for a while to get rid of my junk". She was busy gathering details about her parents' families and putting it in a book for her son. Diane said she wanted to finish seeing her son through his long and painful divorce battle. She wanted to provide him with support and help him "survive in this world", and reflected:

D: So I suppose deep down maybe I feel I have to survive to maybe just be around and see the children and see [my son], I don't know.

In the face of cancer and related pain Diane continues to enact the role she assumed early in her life--that of being a "survivor".

Postscript: Six Months Later

Six months later, in April 1991, I met with Diane to discuss her assessment of the case study I had sent, based on the verbatim transcripts and other data collected during our interviews. Her review of the case study was methodical. She

corrected several minor errors and added snippets of information throughout. She confirmed that the case study accurately reflected her experience of pain, from her own perspective. She voiced enthusiasm regarding her role as a co-researcher, and said she especially liked the personal manner in which the case study had been written. Eagerly, she voiced interest in reading the other women's case studies when the final thesis document was complete.

During the previous six months she had experienced one episode of "grinding" left groin pain--a "spasm" that lasted about an hour. She required an "urgent D & C" to control bleeding she attributed to her anticoagulant therapy. Diane said she had no other problems. In addition to the same combination of analgesics for pain, she was taking "anti-clotting pills" [Coumadin], a new hormonal treatment [Aminoglutethamide], and a steroid [Decadron].

Diane looked better than when I had last seen her, no longer exhibiting any signs of respiratory distress. She said, "I feel good". In fact, she said she was more "afraid of the dentist" or becoming "disabled from a stroke" than she was bothered by her cancer.

Case 5: Emiko

Demographic Information

Sixty-three year old Emiko is a single Japanese woman living in Vancouver. Born in Vancouver, she moved to Japan at the age of twenty-three. Emiko lived in Japan on and off for more than thirty-five years before returning to Vancouver permanently in 1985.

Until her retirement five years ago, Emiko was a business woman working in the buying office of an American company. Her career allowed her to travel and live in various parts of North America, as well as returning to Vancouver each year.

Preface

I met with Emiko twice over a two week period in November 1990. We conducted our sessions in her small flat on the third floor of a low rise building near the downtown core. The surrounding neighbourhood--city streets lined with similar apartment blocks--was surprisingly quiet, considering its proximity to heavily trafficked thoroughfares.

When I arrived for our initial meeting Emiko immediately responded to the knock on her door. My first glimpse of her revealed a petite, smiling woman whose appearance was impeccable. Her dark hair seemed perfectly coiffed, her make up presented a "healthy glow" and she wore a simple blouse over her dark pants.

Emiko looked much younger than her sixty-three years. I was struck at once by her gracious and gentle manner. Her voice was soft, and despite a noticeable limp in her left leg, her movements appeared relaxed and graceful. I instantly felt a sense of liking for this apparently delightful woman.

Her apartment was small, simply furnished, and orderly. The warm temperature within lent an air of cosiness to her home, which was organized to accommodate her physical limitations. A love seat provided a small sitting area in one end of the living room. Tucked in the other corner was a hospital style bed, which could be adjusted to various positions with an electronic control.

Throughout our first interview Emiko sat beside me on the love seat. Although she admitted to being slightly anxious, her manner was consistently one of composure and poise. She smiled often and had a tendency to punctuate her conversation with pleasant laughter. Neither her face or behaviour revealed any outward sign of the pain she described living with. As I learned later, this was a reflection of her stoic nature.

During my second visit Emiko was noticeably more relaxed. She was also excited because she was having less pain and felt an overall improvement in her general condition. She chose to sit semi-inclined in her bed while I sat on a chair beside her. Her telephone sat within reach, her kleenex box was tucked beside her, and her slippers were neatly placed by the bed so she could step right into them as she got up.

I felt very welcome and completely at ease with Emiko, and could not help but admire the tenacity and strength I sensed underlying her delicate and gentle exterior.

History of Pain Experience

A year after her retirement to Vancouver--in 1986--Emiko found a lump in her breast. She was fifty-nine years old. Although her doctor told her he didn't "think it was cancer", she was sent for a mammogram which confirmed the presence of a malignancy in her left breast.

Her mastectomy was performed soon after. She understood that her "lymph nodes were clear" and therefore she required no further cancer treatment. Nevertheless, Emiko saw her doctor for routine checkups twice a year after that. She experienced no pain or other problems over the next four years. In her words, her cancer was "gone".

Emiko's difficulties with pain began in January 1990, ten months prior to our meeting. She "had a little pain" the previous year but it "had disappeared". She clarified, "So I guess the pain I would call pain would [have started] this January". Emiko began her story:

E: Well, I started noticing that pain early this year, I couldn't walk and I was hurting in here. [rubbing left hip and outer aspect of left leg]

K: That was in your left leg.

E: In my left leg. Upper leg. . . . and then [my leg] wouldn't move. So immediately I was at the doctor and I told him I was having a hard

time moving the leg, and it was in pain. And he moved it around like this [moving left upper leg back and forth with her hands] and he said it was bursitis. I thought "Ohhh maybe he was right". But I told him that I felt the pain in my bone. He said it was bursitis.

Emiko was prescribed what she thought were "painkillers for bursitis", saying, "They really didn't help". She took the painkillers regularly but continued to experience pain and difficulty walking. Because her symptoms were not worsening, she began to think about a trip she had been planning to Japan in May. According to Emiko, her doctor said "yes, okay" when she asked him if she could go on her holiday.

The day after her arrival in Japan, Emiko said she "couldn't even get up". She attributed her sudden immobility to being cramped in one position during the long flight. Her story continued:

E: I think that [immobility] was because of my spine. I didn't know that my spine was in trouble, I thought only my leg was in trouble. And pretty fast I went to the doctor there. He took an x-ray right away, of this part [left hip], and he said, "There's something very wrong in the bones up here". And so he wanted me to go into the hospital. And I said, "Well I'm going back to Canada". So he gave me some medicine too, and some plaster to put on. So he wanted me to come back to Canada right away. . . . I asked him, "Is it osteoporosis?" And he said, "NO". So I knew it was something other than osteoporosis.

She stayed in Japan for six weeks before returning to Canada in June. Unaware of what might be wrong with her hip, she recalled, "When the doctor tells you something's very wrong, and then he tells you it's not osteoporosis, I gathered

maybe it could be cancer". Upon suggesting to a friend that "it could be cancer", her friend "just laughed her head off and said it can't be". Her friends claimed she looked too well to be "that sick". Emiko said she would never have gone to Japan or stayed there for six weeks if she thought she had cancer.

Upon her return to Canada she went to her doctor right away and had a bone scan. Apparently it revealed cancer in her hip, spine and lower ribs. Emiko said sadly, "So [the cancer] was all over". She had lived with pain for six months before discovering it's cause.

Emiko was hospitalized immediately upon confirmation that her breast cancer had recurred. There, she received painkillers and started radiation treatments in an effort to control her pain. At the time of interview she was "having a little break" after many radiation treatments and several hospitalizations.

Pain Description

Emiko recounted how the quality of her pain changed over time, from it's onset in January 1990 to the time of our meeting ten months later. She described her initial pain as a "deep pain" originating in the bone of her left hip. The intensity of her discomfort was evident in her response to the following question:

K: If I were to ask you to tell me, on a scale of one to ten, with ten being the worst pain, and zero being completely free of pain . . . what number would you use [to describe your pain]?

E: Oh, more than ten!

K: It would have gone right off the scale?

E: Yah! Yah, it would be like a SKY ROCKET! [laughs] Arrow! [continues laughing]

.....

E: When you can't even lift your leg up to MOVE because of the PAIN, it's REALLY STUPENDOUS.

Emiko's pain intensified even more after returning from her trip to Japan.

She related her experience of that pain:

E: When I had that pain in my back, in order to get off the bed, I would be trying for five to ten minutes to get ready. . . . it was a burning sensation. I didn't know if it was burning in the bone or the muscles or the ligaments, but it was just--you burn. With a burning rock you burn your calf and it was just like that. It just burned and I wondered if it will ever lessen? It was just a TERRIBLE feeling. You just can't MOVE. You JUST CAN'T MOVE like this [shifts upper leg], it would take about five, ten minutes to get ready to get off the bed. . . . You had to stay to your bed, you couldn't go this way or that way. . . and then when you wanted to go to the toilet and you HAVE to move, then it takes you five, ten minutes to get off the bed. And then [the pain] it increased. It would just hurt me SO much. It would just jump out!

.....

E: I couldn't even walk, it was so excruciating. Each movement I made I had to holler. And then I came back [to Vancouver] in a wheelchair and then from the gate to my place the wheelchair wouldn't go . . . I had to go down and each step I took. It was so excruciating I had to holler, it hurt that much, you know. It was UNTHINKABLE! Oh, it was HORRIBLE! I just couldn't go on this way. . . I was in pain.

Emiko's pain had diminished by the time of our first meeting. Using the same pain rating scale mentioned earlier, she felt her pain had shifted from being "over the scale of ten" to a more tolerable "four or five" on the scale. Although she

was never completely free of pain, she found herself thinking back to "that bad time" and felt content to maintain the status quo. She said her pain was now "a stiffness around the bones" in her left hip, leg and lower back. She also described a constant "dull, achy" pain throughout her upper back, arms and hands that caused a "kind of shake" when she wrote. Her pain intensified at night, when she walked, and when she felt tired.

By the time of our second meeting two weeks later, Emiko was excited to report her pain had decreased even further. She said her pain was "maybe three" and "sometimes four" on the aforementioned scale. She described her pain relief as being "almost complete" except in her lower back. Occasionally she was overcome by a sudden "cramp" in her lower back, which prevented her from walking again until she had taken a rest. Emiko perceived her pain control had improved dramatically and expressed great relief, reflecting:

E: It's a GREAT relief! And if this can continue then I have nothing to say.

Impact of Pain on Daily Living

Emiko's experiences with pain precipitated many changes in her ability to carry on her daily life in the usual manner. Over time, she found herself coping with varying degrees of pain, and changing levels of incapacitation. She described her loss of independence as having the greatest impact on her. She frequently expressed concern about it in statements like the this:

E: I never thought I'd be using a wheelchair. EVER! Before I was so INDEPENDENT!

Emiko portrayed herself as a self-reliant person who had always been "busy working" and taking care of her own life. Now she felt "sick" and "not like" herself. She had "never had to rest, in fact, could never take a nap", and now she had to nap three times daily in order to get through a day.

She talked about the daily activities most meaningful to her and how they had been disrupted by her experience of pain:

E: I used to write a lot but I can't write any more. I used to write to friends. I haven't gone shopping, no, I haven't gone shopping at all. My friends stop here . . . they take me to the mall and then we take the wheelchair too now! Because I can't go on walking all the way. . . . house cleaning is out of the question for me now . . . Oh I can't [prepare meals], even cutting your vegetables, uh? I would have pain along my back. . . . It's too strenuous to go into the bathroom [for a bath] every time so I take a bath about two, three, four times a week. . . . when I first came back I couldn't even go down into the bath so I got this chair? And I had a bath on it. . . . Yes, it was bad this year when I couldn't move and I couldn't cook and I couldn't walk and even I couldn't even make my own bed! I thought, "What's going to HAPPEN?"

At the time of our second interview Emiko reported "feeling better" and "less tired". Although she wasn't "doing any more" than two weeks earlier she felt she "could do more" if she "had" to. She did experience an important change in her ability to walk. Not only was she walking more within her apartment, she had walked to a nearby department store and taken a taxi back. She was thrilled, exclaiming, "It really felt good, FIRST TIME--first time in eight months!"

Coping Strategies

Emiko's primary strategies for managing pain during the six months prior to her cancer diagnosis were perseverance and a "stoic" approach. Once diagnosed she relied mainly on radiotherapy treatments and medicinal means of pain management.

Medications and treatments. Emiko recalled having twelve radiotherapy treatments during hospitalization immediately upon diagnosis. After returning home she went to the cancer treatment centre for about fifteen more treatments. At the time of interview she was having a "break" and perceived she would "have to go in and have another radiation" if and when there was "some more pain".

She regarded radiotherapy as the most effective means of relieving her pain. After several courses of treatment her pain was "gone quite a bit". She asserted:

E: I think without that [radiotherapy treatment] I would STILL be in pain.
I think.

.....

E: [Radiation] treatment was the thing that was helpful because the pain went away . . . yah, I think the radiation treatments were the thing. Tylenol has helped me too, but mainly the radiation.

K: It sounds like the radiation has made the biggest difference for you.

E: Mm hm, yes. Yah, it's been effective for me.

As well, Emiko took medications to help relieve pain and control her disease. Upon initial diagnosis she was prescribed hormonal therapy [Tamoxifen] and a

strong opioid analgesic [Leritine]. By the time of our meeting those drugs had been replaced by another hormonal therapy [Megestrol]; and a mild analgesic painkiller [Tylenol #3].

At the time of interview she was taking one Tylenol #3 approximately every six hours during the day, and two tablets in the evening to help her sleep. Still, she was experiencing pain measuring "four to five" on a scale of ten. Reluctant to take more painkillers, she said she preferred to sacrifice some pain relief to minimize drug side effects.

Emiko had already taken it upon herself to decrease her dose of painkillers, explaining:

E: In the beginning I was taking only one [Tylenol #3] every four hours but I thought that would be too many and I decided to cut down then, that's how they made me feel. . . .

K: Were you having side effects . . . ?

E: Yah, constipation and everything. . . . I'm always drowsy. Mm hmm. . . . you feel like a zombie! It's almost as if you can't even do anything--just like a zombie--when you take too many.

She confessed that she "didn't want to get addicted", and so was "refraining from taking [painkillers] as much as possible".

Her decisions about taking medicine for pain were also influenced by unsettling experiences she had taking painkillers in the hospital setting:

- E: I was VERY drowsy at the hospital because of the painkiller, they gave me SO much. They gave me three at one time. . . . your head is not clear. . . . you see a vision in front of you. I had hallucinations. I could see something like a ghost, or something white through those people. And I just go like this [waving her hand in the air] every time when I'm in the hospital. Then I thought I was taking too much pills.

Emiko indicated that the public health nurse had expressed concern about her pain management, advising Emiko to take as much pain medicine as she wanted to gain more effective control over her pain. Apparently it had also been recommended to Emiko that she change her painkiller to Morphine, a much stronger opioid analgesic. At the end of our first interview Emiko requested basic information about painkillers and how they work, Morphine, opioid addiction and fundamental principles of cancer pain management. During our next session--two weeks later--she told me about a decision she had made regarding her pain pills:

- E: Next time I go to my doctor I thought I would get [my medicine] changed to Morphine. . . . Yah, then I might need to take less and I want to try it anyway.
- K: So you talked about that with your public health nurse?
- E: Yes, uh huh. And she said, "Yes, that's a good idea". She's been TELLING me to change it!

Self-Care Behaviours

In addition to medications and treatments, Emiko found many practical ways to handle her pain and it's effects on her. Above all else, she stressed, "Rest is very

important". She considered it her most valuable tool for relieving pain, and took her "rest" in the form of three half hour naps interspersed throughout the day. She described:

E: I notice that I get so tired that I just can't stand up. And I just want to lie down. [My ability to cope with pain] decreases.

Emiko generally experienced less pain and felt "very good" immediately following her rest periods.

Another useful method of easing her pain was to take a warm bath--physical ability permitting. She found the moist heat of her nightly bath particularly comforting. During uncomfortable periods she also liked to read, or talk with friends on the telephone.

Emiko organized her home environment to accommodate her physical limitations and problems with pain. Her bed was conveniently centred in the middle of her "living" area, a few steps away from the kitchen, living room and bathroom. The electronically controlled "hospital bed" was especially "handy" for lying and sitting in various positions. She enjoyed being able to visit with friends while "sitting" in the comfort of her bed. Finally, a wheelchair helped her get out of her apartment and participate in activities otherwise inaccessible.

Unable to do her own house cleaning, Emiko had a home maker come in each week to do the washing, vacuuming and floors. She also devised some approaches to help her manage the task of food preparation, a chore that had

become challenging due to the pain and tremulousness in her hands and arms. She prepared only simple meals at home and looked forward to going out for dinner with friends once or twice a week. This way she was relieved of having "to do everything" for herself. On occasion she took a break from making her own meals by having "somebody bring something like Chinese" for dinner.

Attitudes and Feelings Related to Controlling Pain

Emiko's style of coping with her cancer and related pain is influenced by her past experiences and basic beliefs about illness. Her cancer diagnosis came as an unexpected shock because she had always assumed:

E: I will never die of cancer because nobody in my family had cancer. My grandfather, grandmother--on both sides. I know--I saw them because they were living when I was in Japan and they never had cancer, and all my uncles and aunts, none died of cancer. They all died of high blood pressure, strokes, or heart attack. Things like that.

She believes her breast cancer is a direct result of major changes she made in her life in 1985, when she moved back to Canada, explaining:

E: Five years ago I came back to Canada and the following year I had mastectomy. So ever since I'm not that well. . . . I think that kind of thing, [the change between Japan and Canada] is the cause of my illness.

K: You do.

E: Yah, I think so. Because every time I change the life--living--I go through some kind of a illness. . . . it's such a change. Yah, it was a

big change. I didn't know whether I could live in Japan all my life or whether I should come back here. It's been a BIG decision. And finally I thought, "Well, maybe I'll go back in the spring time, if you've been away from that country so long I think you better stay in Japan". . . . but I got sick right away. . . . I didn't find it stressful but it was another change in my life.

Emiko has difficulty perceiving herself as sick or "dependent", roles previously unfamiliar to her. She described once being "REAL SICK" with hepatitis, enough so that she was hospitalized for five months. Still, she made the following comparison of her hepatitis and her recurrent cancer:

- E: That [hepatitis] was a very sickening time but I don't know, I think that this [cancer] was worse because more pain accompanies this. . . . if you have liver trouble it is very very devastating to you because you're so sick, you can't do anything. But this time I have lots of pain.

Her approach to illness has been to tolerate it until the severity of symptoms make it impossible to do so, or until they disappear. She elaborated:

- E: Usually I leave it to the last minute. That's not my fault, I think, "Well it'll cure itself, it will cure itself". And finally it gets so bad that I can't take it any more. . . . I could limp and walk so I thought, "No, I'll get better, it will get better". But it got worse and worse and worse and my friends were seeing me walking. They said, "You just can't go on like that". They got worried. They advised me to see someone right away.

Emiko's ability to be stoic and her capacity to endure are the basic qualities upon which she relies to manage pain. These traits are an integral part of her character, rooted in her socio-cultural background. Although a "Japanese-Canadian", Emiko said she lived primarily according to Japanese values. She described:

E: In Japanese there's a word called "GAMON" that means to endure. And when the children are naughty or they do something bad and are punished, "gamon" means to endure. . . . "Gamon" comes from within. You are taught to endure and not to cry. Women especially, must endure pain. [Otherwise] people will say, "My goodness, she can't even tolerate a thing like that!" When you become sick, people find out who you really are!

Emiko said that those who are unable "to endure" are "shamed" in the traditional Japanese culture. She portrayed how she has attempted to endure her own suffering:

E: I have suffered so much. You know, I'm quite stoic. . . . Yah, I'm very stoic, but this year I REALLY HAD IT! But I never cried or anything. But I really had it!

K: Where does this stoicness come from . . . ?

E: I think it's part of our culture and the way you're brought up I guess. You are told to endure a lot.

K: In Japan?

E: Yah, in Japanese. Because I never crab about anything. I think about the times that there's nothing to crab about anyway! . . . [But in this situation] I thought, "Gee, I can't take this any more. This time it was different, in my whole life."

When experiencing severe pain, Emiko found herself reflecting on what she had done to deserve such torment. The kinds of thoughts that ran through her mind included:

E: Why should I have this PAIN? You know? I haven't hurt a soul in my life and why do I have to suffer like this? . . . What did I do to deserve this?

Emiko's pain made her feel "very miserable", primarily because it prevented her from functioning independently. Initially, she did not know what to expect of treatments and said she "did not think" she would be improving. In retrospect, she said it would have been easier for her to cope with her most severe pain if she had had a more positive attitude". She felt that if she had known treatments might help, she would have been "in a better mood all the time".

E: I didn't know what is going to happen, so I'm sure I looked GLUM, glum and gloomy to everybody else. I was SCARED! . . . I was REALLY SCARED. And then in 1986 [the doctor] told me . . . the cancer had gotten into my spine and they said that I might become, uh, if there is anything, uh, if I should get uh, numb in my fingers or arms or legs I should let him know right away. So I thought, "GEEEEEE am I going to get PARALYSED?" And those kind of things scared me a lot. . . . So I was REALLY SCARED!

Emiko mentioned that although religion is not an important aspect of her life, at times she has resorted to prayer in an attempt to manage relentless pain:

- E: Prayer. I have a friend who's a very religious person. [laughs] She tells me to, you know, recite this um, it's in Japanese but I don't know what it means because it's in the old language. And she said to recite it. But I don't do it.
- K: You don't do it.
- E: No I don't. But sometimes when you're really suffering I do! [laughs]
- K: . . . and why is it that you don't do the prayer the other time?
- E: You forget about it! [laughing] That's how religious I AM!

At the time of interview Emiko expressed relief that she had "improved a lot" and said she would be content to maintain that status, despite persistent pain and limitations. She was "willing to endure" because she "had come so far". By comparing her progress "to that bad time" she was able to appreciate how far she had come and find the strength to go on. She reported:

- E: [The worst] is past. So this is something. It's a BONUS! I think it's a bonus and so therefore I'd be very happy the way I am now, even if I didn't improve.

She often looked back on her experience and wondered about various aspects of her medical care. As she gained knowledge about treatment of breast cancer Emiko queried the quality of her own therapy. For example:

- E: When I came back from the hospital, the first thing I saw was a health show on ABC and here they were talking about Tamoxifen. YAH, and they said that Tamoxifen was for breast cancer patients who had

operations--they'd been given Tamoxifen right after the operation because it is VERY effective in the patient with cancer, so the cancer will be gone. So I thought, "Ooohhhhh", at that time I sat down and thought, "Gee if they had given me that medicine right after the operation, I may not have suffered so much with this".

Emiko found it very upsetting to reflect on what might have been. She agreed to feeling very frustrated about the medical follow up she had after her mastectomy and asserted, "I shouldn't say this, but . . . I feel that my follow up, that my mastectomy follow up was basically inadequate".

Significant Relationships

Despite her self-reliant nature, Emiko frequently referred to the supportive role her many friends play in helping her manage pain at home. She also discussed the care provided by her doctors and other health professionals.

Personal relationships. Because she has only one unmarried brother and her parents are no longer living, Emiko relies mainly on her "very, very supportive" friends for assistance managing on her own. She shared what those friendships mean to her:

E: Friends are VERY important, you know. Mm hm. They are family. Yes, [when you have little family] then your friends are special. Yes, they are very important. For me they are very important. . . .

As well as the practical help she accepts from friends living nearby, Emiko appreciates the numerous telephone calls and letters she receives from friends outside Vancouver. She seemed to take great delight in speaking about her many long distance friendships:

E: I have good friends, even from the States. I get phone calls very often from Japan too. But they used to call me every Saturday so you know, it's so expensive I told them, "Please don't call me any more". . . . My friends have been very caring. And then I have calls from another friend in Nova Scotia, yah, and in Moose Jaw. . . . I have a friend from Virginia . . . he phoned me up . . . I have another friend, they were in Japan too and they live in San Francisco, Diablo, California? Yah, and she calls me often too. And Mr and Mrs Smith, they're worried that if I'm alone I won't be able to hear anything so if I needed help they call me often too.

K: So you have a lot of support from all sorts of different friends.

E: ALL SORTS OF DIFFERENT PLACES! One from Hawaii too, he calls often from Hawaii. . . . my friends are not localized.

Emiko feels able to talk openly with her friends about her cancer recurrence and it's treatment. She remarked, "There's no use hiding it and it's better that they know, so I told them what happens". At times she felt overwhelmed by the caring response of friends and acquaintances:

E: Most of my friends have come to think that this is fatal, you know. They think that . . . it's the second cancer and I can't recover. I think they all feel that way because I can tell by their ATTITUDE, the way they CALL me on the PHONE. From JAPAN it costs a LOT but they call me a lot so they think that I might not be able to SURVIVE!

.....

- E: When I was in the clinic I hear my girlfriends, they say . . . "You looked pretty bad". So I guess I must have looked very bad. They all say I couldn't have come out alive, so I must have looked very bad. Yah, my girlfriends are really shocked. They said, "Gee, it's really amazing how much you've come".
-

- E: [Neighbours] see me in a wheelchair and they were shocked! And they saw me going out shopping or visiting friends and I was always healthy, going out almost every day, because all I had to do [is] go out. And then next thing they saw me and they were shocked and they didn't know what happened.

Emiko enjoys the sense of community she has with the people she has gotten to know in her apartment building over the past five years. She portrayed her neighbours as "very helpful", "very nice", and "very friendly", and described the ways in which they are helpful to her:

- E: There's a lady upstairs and when she doesn't see me for a couple of weeks she gets worried and she comes knocking! [laughs] Yah, she comes KNOCKING in! . . . She's eighty three and her husband is eighty three. And then another lady, she's a widow. She's eighty six. And they are well you know, they are living on their own and they have time to come and look after ME! [laughs] . . . [It's a nice feeling] to have somebody to care about you.

Emiko's brother lives "not too far" away in the city. From the time she left home until her retirement Emiko had little opportunity to spend time with him. She stated, "We never lived together for a long time so we were more like a stranger than a brother and sister, but this illness has brought us together more!" Although she enjoys his visits, she relies more on her girlfriends for physical assistance. She

declared, "[My brother] comes also but men are men you know!" Further explanation revealed that she and her brother are both very independent people who do not rely on each other for support.

Professional relationships. At the time of interview Emiko was seeing her family doctor on a monthly basis to monitor her blood cholesterol. She was also seeing a cancer specialist at the cancer treatment centre every month. She assumed her family doctor would not know how to help her manage pain because that responsibility was "in the hands" of the cancer specialist.

Emiko focused much of her discussion on how she perceived her doctors could be more helpful to her. She asserted that the "doctor should advise the patient" and provide more details about disease and treatment. She also suggested that doctors should instill a realistic sense of hope in their patients. She elaborated:

E: Well the doctor usually he asks me, "Are there any questions?" But instead of asking me, "Are there any questions?" I wish he'd advise me what to do.

K: About anything in particular?

E: About anything. Advice over, oh, lots of things, tell me how much he thinks that I will be improved. Because I was in the blind because I didn't know what's going to happen. And then he wouldn't tell me, "You're going to be okay, you're going to be able to walk". He never told me those things. So really I was in the blind and I was telling my girlfriends, "I don't think I'm ever going to walk again". . . . I think [doctors] should advise us more. . . . like taking this [hormone], I used to sweat a lot and I was getting real hot but the doctor wouldn't tell me. He never even told me that I was going to get hot and flushes, so I didn't know . . . I used to be so HOT and I was DRIPPING like this, you know. I was WATERY ALL OVER so I asked him, "Is that drug

making me this hot?" And then he said, "YES". So those things he should TELL me beforehand. Side effects. Symptoms. Yes, I would like to--we would like to know the side effects and symptoms that I would have from the medicine.

Emiko expressed anger that her own ignorance may have contributed to her late diagnosis of metastatic breast cancer. She found herself looking back, wondering how long her "bones were depositing [with cancer]" while "being told nothing was happening". She reflected:

E: If I had been aware that it could be bone cancer, then I would have taken care more. The doctor should advise the patient about it. Any warning, any signs. That's VERY important! Because if I had known that bone cancer can come after the mastectomy I would have been more careful. . . . I wish that they would let you know. Because then if I had pain in any area of the bone I would be aware. I wasn't aware at all. Each time I went to my doctor who gave me the operation he says, "You're doing perfect". If I had been perfect I wouldn't be sick now!

Emiko spoke often about her own role as a patient and how it has evolved over time. She illustrated how she had altered her view of doctors and learned to assert herself within her relationships with them:

E: Before I didn't ask much. I just did what [the doctor] told me to do, and [took] what medicine he gave me. . . . Before I used to feel kind of scared of doctors and I didn't talk to them much. I wasn't nervous but I didn't think that I should tell the doctor this and that, because I thought that maybe they're the ones that are supposed to know what questions. But now I realize that they may be the experts but it's the

patient that knows their BODY, isn't that right? But now I would ask him.

-
 E: I was ignorant because I trusted the doctor so much before and what he said. So what they said was just like a God's word and I said okay. Now I have my doubts. [laughs]

Emiko went on to describe the responsibilities that she feels patients must assume in order to facilitate their own care. She emphasized:

- E: If a patient has pain they still have to let the doctor know . . . They say that the wheel that speaks the loudest gets the most oil so [laughs] you have to let them know because the doctor won't know. In my case I told the doctor that I had pain and I thought it was in the bone but even at that point he didn't think I had cancer, he thought I had bursitis. You know? So I should have pushed him on, tell him that, "Maybe you should take an x-ray for me". But I didn't do that. I trusted him so much I said, "Okay maybe it's just bursitis" and I got his medicine and I took it . . . You have to let them know because doctors don't know anyway because he can't read your body. You're the only one that knows what is happening inside you so . . . I think you have to let them know that you have pain and that you're improving and things like that.

Another professional who played a significant role in helping Emiko manage her pain at home was the public health nurse who visited or telephoned every week. Emiko said she usually talked to the nurse about what she was "going through" and found it "nice to talk to her". She found it especially helpful when the public health nurse spent time teaching her about her treatments and medications, recalling:

- E: I asked her to explain and to tell me . . . I didn't know what Megestrol was, so I had to talk to the nurse and she would look it up in the dictionary and tell me.

Seeking Knowledge

Although she likes to know essential facts about her cancer, Emiko reported that until recently her knowledge was clearly lacking. She expressed tremendous concern that she was not told about the potential of her breast cancer recurring after her mastectomy. Out of ignorance, she feels she ignored critical warning signs that her cancer had spread. Emiko has since learned how to gain the knowledge she feels she needs in order to care for herself as effectively as possible.

Emiko feels it is important to know about treatment and medication side effects and risks, explaining:

- E: When you're on your own you don't know what you're doing or what you're taking, so I like to know what I'm being given--so I ask . . . These days I know what to expect!

She emphasized the value of having enough information so that she has some sense of what to expect in the future. As well, Emiko worries unnecessarily when she does not know what was happening.

Her chief sources of information are her doctors and the public health nurse, as well as friends and the media. Emiko acknowledged getting "LOTS of advice" about treatment from various people, but did not feel swayed by others in this

regard. She assumed that "you can mostly tell" whether well meaning advice is "useful" or not. She recounted an instance where she was influenced by knowledge acquired outside relationships with professionals:

E: I had three friends in Japan who had mastectomy. One had it one year before me and the other had it about one year after me. And they told me--they all told me that they were on hormone therapy. See? So I thought, "I wonder WHY they don't put me on any kind of therapy?" And then I saw the ABC health show that says Tamoxifen is the hormone therapy that is very effective for mastectomy patients. And I thought, "My God, I'm a year behind".

At the time of interview Emiko was utilizing the services of a home maker and public health nurse, and had some awareness of other resources where she could seek support or information. She knew about a "mastectomy" group and "Cansurmount--some kind of cancer group", but had never attended them. She remarked, "I've been living alone for a long time so maybe I cope with everything by myself". She continued:

E: I think I can cope. But it's good to know that you can talk to people that have the same illness, uh? Then you can compare. Like, nobody among my friends had bone cancer before, I was the only one that knew what it was like. [If you can talk with another woman] then you will know, if she's having the same problems then I should be having it and it's only natural. Otherwise you have to worry by yourself because you might not see the doctor for two months.

At the end of our interviews Emiko asked about several aspects of her treatment, including questions about how breast cancer metastasizes, using Morphine to relieve pain, the safety of having frequent x-rays, and how radiotherapy works.

Future Goals and Expectations

Emiko's comments about dealing with the health care system and related procedures reflected her frustrations about the length of time it took to accurately diagnose the spread of her cancer, and how she has had to "educate herself" to use the system to her benefit. She said she felt the system had failed her. The following excerpt offers some indication of her disappointment in the "system":

- E: When I first saw the [cancer] specialist he asked me, "What were you doing going to see the doctor every time?" And they didn't test me at the doctor's office. . . . I've never been to the [cancer treatment centre] until just now . . . I didn't have the right, but I told my friend, see, if I had been to the [cancer treatment centre]-if my home doctor sent me to the [cancer treatment centre] when I first had this breast cancer then I wouldn't be suffering like this!

Future Goals and Expectations

At the time of interview Emiko was unsure about the journey that lay ahead. She wondered exactly "where she stood" and expressed concern about "how far I'm going to go or how worse I'm going to get". In anticipation of a medical appointment that would confirm her progress several days after our final interview, she contemplated the uncertainty of her future:

E: I think I'm improving. I feel a little different. but I'm not sure you know, I can't be sure unless the proof come from the blood test.

Emiko voiced fear that she might have to receive chemotherapy treatments someday. She said, "That's something I'm afraid of--I'm afraid of chemotherapy". Still, she maintained hope for her future, exclaiming:

E: I think I'm going to make it! Yah, I think I'm going to make it this time. . . . If I can maintain this status I'd be very happy. But if I can IMPROVE and if I can climb up the stairs like before instead of, you know, then I'd be HAPPIER. But if I can't do it I'll be content.

She said her greatest hope is to continue living in her apartment on her own, functioning independently for as long as it is possible.

Postscript: Eight Months Later

I visited Emiko again in July 1991, eight months after our interviews were completed. We had spoken several times on the phone during the previous few weeks, trying to schedule a time to discuss the case study I had sent her. In those telephone conversations she sounded very distraught, complaining of "severe pain" she had endured for weeks. She was particularly upset because she was on a "long waiting list" for radiation treatments and had "no idea" when she would be called for an appointment. When her pain lessened in response to newly prescribed painkillers, we were able to schedule our visit.

Upon seeing Emiko again, I was immediately aware of the discomfort reflected in her overall appearance. Her facial expression was strained as she hobbled along with the support of her cane, conspicuously favouring her left side. She looked weary, and a look of relief spread across her face when I suggested she rest in bed during our visit. Despite her obvious discomfort, her manner remained cheerful and stoical.

Her friends had moved her into a more spacious apartment, where she had put her bed into her bedroom. Pulling my chair up beside the bed, Emiko raised the head of her bed and wriggled into as comfortable position as she could. I noticed her wincing in pain as she made the effort to lift her legs up onto the bed. I found myself distracted by a brightly coloured mobile hanging from the ceiling over her bed--multicolored strands that shimmered beautifully in the daylight. She explained the mobile was of Japanese origin, made for her by a young girl. It consisted of one thousand delicate origami cranes, a Japanese symbol of "long life", traditionally sent to the very ill for "good luck".

Reflecting on the previous eight months, Emiko said she "had a good winter", but was "taken by surprise when the pain started coming back on the other side [left hip]" in the spring. Her discomfort gradually intensified, reaching an "intolerable" level by June. After seeing the cancer specialist, her body was marked for radiotherapy treatments. She had been waiting on "the list" for treatment about four weeks. Emiko expressed considerable frustration regarding her situation, saying:

- E: Just knowing there is a treatment available, but knowing I can't have it! It's like a third world country--it's amazing in a country that is so advanced, that this treatment is not readily available!

Other than medical appointments, Emiko had not ventured beyond the confines of her apartment during the previous month. She described spending most of her time "resting", anxiously awaiting the telephone call from the cancer treatment centre radiotherapy department. She now had a home maker coming in twice weekly to perform household chores, and relied heavily on her friends for additional support. She said it had been "terrible waiting for the phone to ring", always wondering if it would bring news of the radiation appointment she awaited.

Although she was suffering with considerable pain at the time of our visit, Emiko said her pain had "lessened a lot" since being prescribed long acting Morphine [MS Contin 120 mgm], which she had been taking twice daily for about three weeks. She said, "The pain was way worse at the end of June".

Emiko asked many questions about "what to expect in the future" and whether radiotherapy treatments would effectively control her pain. She expressed discouragement about her setback, saying, "I only want to be free of pain".

Emiko reported her case study was "very real life", emphasizing that there were no words to accurately portray the extent of pain she had experienced. She expressed concern about the personal nature of her story, something she would not usually share beyond her immediate family. She said she had very much enjoyed

the informal manner in which she was invited to talk with me, but that it was out of character for her to talk about herself in such a personal way. Emiko said the only person she had really confided in was her family doctor, who she had known for many years. She said she shared herself and her story because she trusted my respect for her confidentiality, and valued the intent of the research she was participating in.

Case 6: Fran

Demographic Information

Fran is a fifty-four year old caucasian woman. Recently widowed, she lives by herself in a senior citizen's complex located in a large Vancouver suburb. Prior to troubles with cancer-related pain she was employed in a variety of jobs.

Preface

Although our first telephone contact took place in late November 1990, I did not meet Fran until mid January 1991. During the weeks prior to Christmas she felt unable to take part in an interview because she was having considerable pain as she awaited radiotherapy treatments. She expressed interest in meeting with me once her treatments commenced and she felt more comfortable.

I spoke to Fran on the phone several times while she waited for her radiotherapy to start. In those conversations she voiced her feelings of distress about having to endure weeks of pain, while waiting for the treatment she hoped would free her from pain. Apparently the radiotherapy department was short staffed, limiting treatment availability. By the time Fran felt able to take part in an interview I felt as if we had already met.

Our session took place at her home, in what appeared to be a well maintained twin tower complex on a quiet city street. As she welcomed me into her

small, fifteenth floor suite, I surveyed the comfortable looking surroundings, decorated with numerous leafy house plants and overlooking the city skyline. I felt relaxed and at ease in the presence of Fran and her inviting home.

Petite and well groomed, Fran's eye glasses complemented the short grey hair that framed her face. She expressed self-consciousness about her noticeably swollen "belly", caused by her cancer. Her general manner was quiet, polite, and at times, slightly apprehensive. She spoke in a soft, faint voice that occasionally faded to a whisper.

Throughout the several hours of our interview Fran sat motionless beside me on the couch, her back positioned against a pillow. She claimed to be comfortable though her breathing was shallow and, at times, she was notably short of breath. Overall, she seemed to be a gentle and somewhat reserved woman.

History of Pain Experience

The story of Fran's experience with cancer-related pain began in November 1984--six years ago--when a painful lump in her mouth began causing discomfort that prevented her from wearing lower dentures or eating solid food. The pain was localized in her right lower jaw bone.

When Fran initially became aware of her pain she was away from home. She had decided to stay on with her father for Christmas after attending her mother's funeral. Upon returning home at the end of January 1985, she consulted her doctor, who sent her for a biopsy. The results of that biopsy revealed she had cancer.

Further tests confirmed that breast cancer had spread to her jaw bone and her liver. She explained:

F: When they did the biopsy on the jaw bone, they said then, that it didn't start there and it didn't start in my liver. It started somewhere else. . . . And they think it was the breasts. But I have no lumps, even now. But now I'm troubled with lymph nodes on the right side.

She immediately began radiotherapy, followed soon after by chemotherapy. Since that time she has had "a lot of treatments on and off" for cancer spread to her pelvic, hip, spine and rib areas. At the time of interview she had just completed a course of radiotherapy for what she described as incapacitating pain.

Pain Description

The elusive nature of Fran's cancer and related pain is evident in her observation that, "It feels like they get it in one place and shortly after it pops up somewhere else--that's the way it's been". She outlined the course her pain had taken over the previous six years:

F: First was the jaw bone, then the pelvic and hip bone on the right side. Then I had the pelvic and hip bone on the left side. And at the spine in three places. . . . and there was another spot, the ribs on the right side.

At the time of interview Fran reported having pain in her liver region, right arm and lower back. Although her liver "bothered" her when it became enlarged,

it was in her right arm that she experienced what she perceived as "real pain". It was especially painful for her to perform tasks that required lifting her arms above her head. She reported:

- F: If I use my arm too much it aches. If I lay with my arms up there [above my head] I can feel it later, you know, so they feel like lead. So I have a good excuse to go to the hairdresser! . . . [The pain is] maybe like a toothache. I don't know what it's like. Just some pain. Not sharp or--it's just --it's there. . . . It's never totally gone.

Fran went on to talk about the worst bouts of pain she had weathered. She described having pain "so bad" several years ago that she was almost completely confined to bed. The memory of her most recent episode of intense pain, just prior to Christmas 1990, remained vivid in her mind:

- F: I can remember very well the last time as it's less than a month ago. . . . the pain was very bad. I couldn't stand, couldn't sit . . . when the doctors saw me they said, "The spine has collapsed". And this is the pain that was so terrible. And it felt like pressure--pressure on the abdomen, on the left side . . . like I could put a PIN there and I'm sure it would burst, because there was just so much pressure there.

.....

- F: This is the WORST I've felt, you know, with the collapse. . . . when I was in bed all that time and . . . I couldn't sit for more than twenty minutes or so at a time . . . I really thought, "I can never sit again".

By the time of our meeting Fran was pleased that she could once again sit quite comfortably, propped against pillows. The severity of her back pain had subsided and she claimed to have sufficient pain relief to "get by".

Impact of Pain on Daily Living

Fran's lifestyle has been significantly altered in the face of a disease that demanded her continuous adaptation to ever changing levels of pain and incapacity. The onset of her pain and subsequent diagnosis of cancer also coincided with traumatic events taking place in her life. She conceded that her cancer occurred at a time when her life had been "turned upside down", explaining:

F: It seemed like everything happened at once, at the same time. My mother passed away and then, it was like six months later my husband passed away, both with cancer. And I already had cancer. And when my husband passed away, we knew I had cancer about six months. So, like everything changed almost at the same time. I used to go . . . first to the [cancer treatment centre] for blood work and then I would go to the [hospital] and visit with him. Then I'd go across the road and have the treatment. . . . And then a year after--about in April--my dad passed away as well. Then I moved in this building. .

Fran portrayed herself as a "busy" woman who worked and led an active life prior to her problems with pain. She discussed some of the ways that coping with pain has disrupted her daily life:

F: . . . I've been in bed so much, which is fine, it's just impossible to do anything else. Even knitting you have to sit up more or less.

.....

F: [In the beginning] I couldn't eat anything. Well, maybe baby food but that's about all I had. So they gave the treatments there . . . I lost about fifty, sixty pounds in a month 'cause I couldn't eat.

F: Several years ago . . . I couldn't eat because this [painkiller] made me sick. I was just dizzy and there was no way I could get up. Somebody stayed there with me at the time 'cause I couldn't stay alone. . . . until I had the treatments.

F: I can't open my mouth real wide, like say, to eat a hamburger or hot dog? I have to cut it . . . it's like a lump there inside the cheek.

F: The treatments tire you. You feel so tired after treatments, you feel very tired. And you can feel weak, you know, your legs just feel--you just feel like RUBBER. It's just OHHHH, you've got to lay down. Like you just WILT, you know, you feel the only place is in bed.

At the time of interview Fran was having shortness of breath that increased on exertion, limiting her ability to walk or climb stairs. In order to get through her day she had "a lot of rests". She was also dependent on public transit or volunteer drivers for transportation to and from the cancer treatment centre, a trip that generally takes thirty to sixty minutes. She was unable to use the nearby ferry link to downtown because of the long walk through the connecting terminal.

Fran referred to the six weeks she spent on the radiotherapy treatment waiting list as being the most disruptive to her daily life. Suffering in pain and unable to "do anything", she spent the time "lying in bed" and "WAITING". Reflecting on that experience, she said:

- F: I couldn't . . . go anywhere. I wouldn't talk to a friend on the phone 'cause I was thinking [the radiotherapy department was] going to phone me. So I didn't want to tie up the phone. . . . Then when I found out my son and family were coming, I thought, "Well I've GOT to get these treatments OVER with before they COME". Or I'll be in bed all the time! What's the use for them to come?

Coping Strategies

From Fran's perspective, radiotherapy has been the most useful means of controlling her pain. As well, she has relied on chemotherapy, medications and other non-medical strategies to help her manage pain at home.

Medications and treatments. She recalled that as soon as her cancer was diagnosed "the doctors got together and decided that they better treat the face first". She commenced four weeks of radiotherapy "right away, that same day". Because her treatments "went right across the throat" Fran was able to eat very little and lost considerable weight during the course of her therapy. She was given a month to recover before starting chemotherapy treatments for her liver. Over the next six years she underwent further chemotherapy, as well as radiation treatments to her hip and pelvic bones, ribs, and several regions of her spine.

Fran lives with some residual effects from radiation, but does not seem to find them troublesome. For example, she described, "My mouth will always be dry . . . [the doctors] said [the radiation] damaged your saliva glands". Her bite is also restricted, preventing her from opening her mouth wide and biting into large pieces of food.

She felt the radiotherapy treatments consistently helped relieve her pain.

Throughout our interview she remarked on the effectiveness of those treatments:

F: I had treatments in the middle of September . . . just recently. It was just the one treatment for fifteen minutes. And I find now that I get out of bed very easily, since I've started. So the treatment has helped.

F: It's surprising, the treatments work that quickly. . . . It was just maybe four days, five days, and then I could stay up a little longer. And things were easier to do, just the walk was a little easier. The treatment was helpful.

F: EVERYWHERE that I've had it [radiation], it has helped. Yes. Mm
 hmm, it's helped me every time.

Considering herself very lucky to have responded so well to radiotherapy, Fran commented:

F: [The radiotherapy technicians] did say that I was fortunate that the treatments have helped me. Some people have them and they don't help at all. I've got that on my side!

She also expressed realistic concern about her future. She wondered what would happen if her response to treatments lessened, and what options were available if and when she reached her maximum dose of radiation.

Chemotherapy provided another approach to treating her disease and helping her manage pain. Fran devised her own strategies to cope with chemotherapy treatments, as evidenced in the following excerpt:

F: When I went for chemo I found that I wouldn't eat before I went. If I did eat it was just a light breakfast. . . . And then I didn't need to take the pills that they give you for nausea. 'Cause they made me more woozy, and I'd get all woozy when I was coming home. So I would always tell them, "Don't give me that" . . . They said, "Well that's the only one you can refuse, you've got to take the others". And I never got sick then. . . .

At the time of interview she was taking Tamoxifen, a hormonal therapy aimed at controlling her disease; and Tylenol #3, a painkiller she used "to follow up" other treatments for pain. The only other painkiller she had taken for cancer-related pain was several years earlier, when she took liquid Morphine--a much stronger opioid analgesic--for severe pain. Although Morphine helped relieve her pain, she said it made her feel "sick" and "dizzy", confining her to bed rest. The following account illustrates how Fran used painkillers to manage pain at the time of our meeting:

F: [Doctors] say to take it [Tylenol #3] about every four hours. Four to six hours. But I find I just take it when necessary. But if I'm home and I'm not doing anything, just lying around, then I slow down and I just take one at a time. And I could go three hours or four hours with one. But if I'm out shopping then I will take two.

K: So when you're more active you take a little bit more.

F: That's right. I usually carry a small jar of water in my purse so if I need to take a pill--if I'm on a bus or it doesn't matter where--I could

take it. I take it soon as it starts. 'Cause it takes about twenty minutes, half an hour to work.

K: And once you've taken it do you find that it relieves your pain completely?

F: Well enough so you can get BY. You know, enough. It's never totally gone.

Fran described how she experimented with the painkillers in order to establish their most effective use. Although prescribed by the doctor to be taken every four hours, she discovered that:

F: If I'm shopping then [four hours] it's too long, I find three hours is fine. But I've even tried taking one every TWO hours rather than two every four hours like they say. Because at first until I got used to them they made me kind of woozy. So I thought, "Well, I'll take one every two hours or three hours until I get used to them". But, like last fall there, when the pain was so bad the doctor said, "Well take two at a time, that's more effective than one every two hours". . . . I started doing that, but every three hours. But if I'd taken any more than that--like any closer than that--then it makes me nauseated, I feel sick to my stomach. . . . and if there's a lot of pain and I take them close together, then I find I get nauseated.

Despite lingering pain, Fran said she prefers not to take any more painkillers than she has to, in order to avoid feeling nauseated. She agreed that she would rather live with discomfort than tolerate "being sick" from painkillers.

Self-care behaviour. Fran supplements the medical management of her pain with some practical strategies of her own. She remarked, "Surprising the little tricks

you find when you have to". Above all else, she emphasized the importance of managing pain by getting sufficient rest:

- F: I get a lot of rest. It seems like I can pull through anything as long as I get a lot of rest. If I don't get enough rest then I--I'm just--I'm BLAH!! I can't do anything. I get so irritable. . . . can't stand the TV. I NEED MY REST. That's important. If I get enough rest I'm okay. That's half the battle, right there!

Fran went on to discuss how she manages time to accommodate her increased need for rest:

- F: I lay down [during the day] but I don't sleep. I save that for night time! [laughs] And I do rest in day time. I mean if I feel tired, it depends what I'm doing.
.....
- F: But if I have anything I want to do, even shopping, I do it in the morning after I'm well rested . . . As far as doing things too, you know, if I feel great in the morning I'll just go and do the laundry or go for a walk. If not, well, stay in bed another hour or two! [laughs]
.....
- F: And then always with treatments I'll just stay home and get to bed early. . . . I'm early to bed every night! I'm just early to bed, early to rise!

Fran's pain increases when she is unable to get enough rest. The following example illustrates the consequences of inadequate rest:

- F: Over Christmas time when I had company [I was] a little busier and [there was] not enough time to rest and things sort of--I have to take more [painkillers]. And finally it made me nauseated. I was sick then.

Another practical coping strategy is Fran's selection of living accommodations, which enhance her ability to manage on her own, both physically and financially. The seniors complex she lives in is subsidized according to income and offers a host of amenities, such as the following:

- F: They have meals twice a week . . . they have special apartments for people in wheelchairs. . . . we have our grocery store deliver to here and on the fourth floor you can just walk across [the sky walk to the other building]. It's very handy and a lot of people who can't get out of their apartment, you can just phone there and he will deliver whatever you want. Or if you can make it there and if you can't carry a bag, they will deliver it. And my hairdresser is there and that's where I go.

Despite being under age Fran became eligible for a suite in the complex because:

- F: We had our name in here when my husband was still alive and so after four years they decided to let me come in anyway, although he had just passed away. They let me in because I have the disability and I have cancer but I can't work. And they do a lot--disability people--so that people can come in. That's the only way you can come in if you're under age. I was able to get in that way, but it took four years on the list.

She acknowledged the facility and its services to be well suited to her changing needs, saying, "I could never have managed in the other place, I stayed there a year but couldn't have managed it on my own".

Finally, Fran mentioned several useful "little tricks" that she finds helpful for easing her discomfort. She "babies" her painful arm and finds it especially beneficial to elevate it on a pillow at night.

Another comfort measure she enjoys is lying on her couch, warmed by heat radiating from a nearby heater. She described:

F: Just lying here [on the couch], usually if I'm visiting--if somebody's here. Like, the heater is behind here. And when I had the pain in my back I could lay on my side and heat would come up.

K: Oh! Through the back of the couch.

F: And that was JUST SO NICE!

Fran used a heating pad several years ago for "pain in the spine" and thought "the heat was a BIG HELP", until:

F: I fell asleep with it on! . . . I fell asleep with it on and then I had a spot which was burned! So the doctor I went to [said], "WHAT HAPPENED THERE?" I had it on too hot--well, it was just a new one, a new heating pad. But I mean, after that I put it away and said, "Well I'm not using it any more".

Attitudes and Feelings Related to Controlling Pain

Fran's experiences coping with her cancer and related pain were foreshadowed by her own husband's struggles with cancer, which ended with his death in 1985. It was her husband's disease that introduced her to the experience of managing a major illness. Supporting him through his sickness helped Fran prepare for the journey that was to become her own.

F: Of course my husband, at the time [of my diagnosis], he had cancer too. He had a laryngectomy . . . from there it spread to the lungs, that's what he died from.

F: They showed me in the hospital how to take care of him and things to do for him, and I just got used to it. . . . So when it hit me I just didn't go into it blindfolded. I knew what to expect, although we had it in different places. But it was like I was ready for it.

F: My mother had [breast cancer]. But she lived in the country and when they found out . . . it was too late to give her treatment. But I wasn't around her . . . to learn that much. Well, [I] went for visits but it wasn't the same as being right with her, as with my husband.

Fran's initial diagnosis and treatment of cancer occurred during an especially difficult period in her life. With herself and her husband coping with illness, she found herself balancing her time and energy between her own and her partner's special needs. She described the first few years of her illness as being further stressed by a series of significant losses: her mother's death in 1984; her husband's death in 1985; and her father's death in 1986.

Fran related how she first responded to her cancer and eventually came to terms with it:

- F: When I found out that I had it, well, it wasn't easy at first. I must have cried for two weeks, day and night. And after that, well, what can I do about it? And once I accepted that, there's nothing I can DO about it, let the doctors do what THEY can. Then I just kind of gave up, you know, I just felt better afterwards. Well, they're doing what they can, there's nothing I can do. Except do what they TELL me.
- K: Mm hm. So that was a turning point for you, when you were able to accept that it wasn't something that you had control over . . . ?
- F: That's right. It was hard, 'cause I had never been sick before. Never. . . . Another thing that was hard to accept, because, like you say about smoking, I had never smoked. But then, like my husband thought that I got it from him. And I didn't get it from him 'cause I had breast cancer!

Fran said the best approach to her pain and its effects is to have a determined and optimistic attitude. The success of her radiotherapy treatments has contributed to her confidence and inspires hope for the future. Her persistence is evident in this passage, where she talks about her reactions to having pain:

- F: I just get really--I just get angry at myself. I feel that, "OH WHAT AM I DOING HERE WITH PAIN?" I could be out DOING something, you know. It bothers me in that way.
- K: You get frustrated and angry with yourself.
- F: Yah. Mm hmm. . . .Yah, that's true. Mm hm. Yah, that really bothers me. . . . I get up and do what I have to DO even if it's only washing dishes. I might try three times, you know. And lay down,

and go back to it and . . . then I FEEL better, I've ACCOMPLISHED it. I DID what I WANTED to do.

Her discussion went on to reflect how much she values her independence and daily achievements:

F: I didn't want [a home maker]. I said, "The time will come soon enough for that". As long as I can manage, myself. Both doctors--my general doctor and specialist at the [cancer treatment centre]--have offered me, if I wanted a home maker. And I just--I turned it down. They asked me a few times and I've turned them down every time. As long as I can manage. I need to give it THREE TRIES to get the dishes DONE, but as long as I can manage!

Another important aspect of coping is for Fran to shift her focus away from her disease and discomfort. She discussed how she accomplishes this:

F: I even do a little volunteer work now . . . It keeps my mind off things. And it makes me feel that I've DONE something! I feel GREAT! . . . if I stayed here by myself, it would really--to just think about all this. And I don't think then I could cope with all that. . . . I don't care too much, even for TV . . . I have got in the habit of reading a bit now, since I've been in bed so much.

Although "born and raised Catholic" Fran explained that she has "been away from it for a long time". She reported that religious/spiritual beliefs and practices did not play a role in helping her cope with pain. Overall, she concluded, "I would

think that it's probably different for everyone, [you] just have to learn--you've got to do what's best for you".

Significant Relationships

Fran talked about the loss of significant personal relationships in her life, as well as the support provided by various professionals participating in her cancer care.

Personal relationships. At the time of interview Fran was still grieving the loss of relationships she perceived as being most significant in her life. She referred repeatedly to the deaths of her mother, father and husband, all of which occurred in the last six years. She emphasized the strain she felt losing two loved ones from cancer while coping with it herself.

Fran was also mourning the death of a close friend who died two months before our interview. Tearily, she reflected on that friendship:

F: And then a year after [my husband's death] . . . I moved in this building and I met a very nice person here. And he just passed away . . . and he was a big help to me here. When I couldn't cook he'd do the cooking. You know, he could always put a pot of soup on. And when he was sick, well, I helped him. And so that was very hard too, and that was the end of October. I went to the service one day and the next day I went to the [cancer treatment centre] and found out I had the collapse [in the spine].

She went on to mention other significant people in her life and how they support her to manage her pain at home:

- F: Since my husband passed away, I was for a year in the other place. And there's some good friends there, but I'm not there in that place. They helped me a lot. They still are here, these people . . . they're the ones that took me to the airport to pick up my kids when they came for Christmas. They're still around and I can call them any time. If they know I'm going to see the doctor, they phone up that night, "Well, how did you make out?" Yah, they're very nice. And this person that passed away a couple of months ago, his kids come over and see me too. His daughter was just here Sunday.

Separated geographically by three provinces, Fran maintains a long distance relationship with her three sons from her first marriage. At the time of interview she had just enjoyed a Christmas visit from one of her sons and his family. Speaking about them, she said:

- F: They phone maybe once a month to see how I am. They don't coax me to go to Winnipeg and stay . . . they feel that I have better doctors here. I'm in better hands here.

Professional relationships. Fran's primary professional contacts have been with doctors, nurses and radiotherapy technicians. She remarked that they are "very good with pain" and have always been helpful to her. She said, "I usually let them tell me [what to do] and it's worked". Fran has experienced health care professionals to be most helpful in providing information and helping her understand what to expect from treatments, medications and other aspects of cancer care.

She emphasized the importance of her relationship with her "breast cancer specialist", in whom she expressed great faith. The impressions she shared about

that relationship reflect the basic qualities of trust and honest communication she values in her interactions with doctors:

- F: The breast specialist--one time I went down to the lab and somebody around there said, "Well did you hear he's leaving?" . . . I said, "No, I didn't hear that". Well THEN, that UPSET me! I was SO UPSET! . . . They say, "Oh, he's the best!" and then they say in the next breath, they say, "Oh he's leaving, he's retiring". NOW, who will I GET? To start all up with a different one again! . . . I've had him right from the start. And he knows how I feel about everything. . . . He said right off the start, "Well, I'll tell you like it is". I said, "That's the way I want it". He's not holding SECRETS on me! I don't like that. I like to KNOW where I stand!
- K: So you found a good match with [him]!
- F: Yah! Yes, he's open to where I stand. Yes, the way I've always wanted it.

Fran explained that, at the same time as she liked her doctor to be honest about what to expect, she appreciated him refraining from giving information that would worry her unnecessarily. She shared an example in which her doctor had seen the progression of her cancer on x-rays before she experienced any signs or symptoms:

- F: He knew that [I] had this [pain] coming . . . through x-rays . . . He didn't want to worry me about it. He knew I'd be worried about it. . . . He knows through x-rays that, okay there's [cancer] spots there, there's going to be pain there shortly. They don't treat it until you have pain.

Fran also talked about the crucial role her radiotherapy specialist had in assisting her in managing pain at home. She proclaimed, "I have a lot of confidence in him" and then elaborated on how much she valued his skill and optimism. These excerpts reflect the extent of her willingness to rely on his expertise:

F: On the spine, it's covered with [cancer] spots. And if they treated each spot, then there's nothing left for support. Which is probably why it collapsed this time. There's not much between each treatment for support. The last time was very close to another one I had previously. The doctor was very good to find it. I guess he knew I was worried about it, he phoned me. And he said, "Oh, don't worry". He said, "I've got it all figured out in my mind, it's going to work". It has worked. I feel better with it. . . . he gave me a lot of hope when he called.

.....

F: When I needed treatment on the ribs, in the fall, the [breast specialist] doctor said, "If we can wait for the radiation doctor to get back". He was on holidays at the time. He said, "We have other doctors, but I'd like you to have him". Because he's the one I've had all along. And I said, "I'll wait. I know that I can wait. I can come home and stay in bed most of the time, and just take it easy". I'm not going to go and do things and make the pain worse, in that way, I could manage to wait. So that was good, he got back.

Others whose services Fran depended on at the time of interview were volunteer drivers, who provided transportation to and from her cancer treatment centre appointments. She commented:

F: I've been going [to my appointments] with a volunteer driver. . . . And they are just wonderful! Especially in December, I had evening appointments and the co-ordinator didn't think he could get drivers

for evening. But he DID! And they got me there and back, which is nice.

Seeking Knowledge

Fran reported that she assumes responsibility for seeking the information she needs to manage her pain at home. One of the ways she acquires knowledge is to request it from health professionals involved in her care. Remarking on that experience, she described the roles she perceives professionals have as providers of information:

F: [The doctor is] quite helpful if I ASK him things. And the only way to do that is if I make a list, because when I get IN there I'm NERVOUS and I CAN'T THINK! And of course he doesn't know what you want to know so--it's like they don't VOLUNTEER information! Because I suppose they don't know. I mean, everybody might want to know something different. So they don't know what to tell you unless you ask them.

K: So you ask for the information that you need.

F: Well, I find it's BETTER and they'll ANSWER you. Otherwise they could be there all day with you, if they're going to answer questions. They don't know what you want to know. . . . But if there's something I want to know [I bring a list of questions]. Yes, it helps. Or even the nurse is very helpful. The nurse can answer things.

Fran said it is especially important for her to know enough about treatments and medications to be able to anticipate and manage their effects. In the following excerpt she illustrates the kind of information that is especially helpful in managing her self-care:

- F: The [radiotherapy] technicians, after treatments, they always tell us, you know, "Don't wash that area, don't rub it and . . . [put] corn starch [on] that flesh". Otherwise, you know, it could break and get infection. Like when I had the treatments on the ribs, that was a heavy treatment, thirteen minutes all in one shot. This was all at once and they explained it all, that it would be inflamed inside. It's like having a sunburn, the next day, that's what it's like. And so they explained all that, and I'm glad they did because if not I probably would have went to emergency . . . The next day . . . I couldn't move, couldn't STAND it. Just the PAIN was just terrible. I stuck it out. What else can you do? I thought, "Well, it's a good thing they told me what to expect". You don't know what to expect, you know, the first time. . . and it seems the different machines for radiation react differently.

As well, Fran has had experiences where inadequate knowledge contributes to erroneous assumptions and anxiety on her part. She recounted these examples to portray the consequences of trying to manage with too little information:

- F: There was such a long WAITING list for [radiotherapy] treatments. And I phoned the radiation desk and they didn't seem to know much about it, it was up to somebody else. And then I got the feeling, "Well I guess they don't want to give me any treatments, so THIS is why they're just putting it off!" And so I didn't know what to THINK!
- K: So you were interpreting that long wait that you had as them really not wanting to treat you.
- F: YES! Well this is the way I felt, because . . . this, where it's collapsed, I mean you'd think they'd RUSH this. And then I heard on the TV that there is a waiting list of up to TWELVE weeks!
-
- F: The doctor gave me pills, you know, for appetite. . . . And I didn't know what they were for. . . Didn't know what they would do. But then all of a sudden I started having such an appetite I could eat anything in SIGHT! . . . At first if I'd of known, I could have ate things maybe, that aren't FATTENING to eat. But at first I thought, "Oh well, that's just me. I'm hungry, I'll eat what I want". By the time I found

out it was too late. I was so embarrassed. I didn't want to go any where, I'd put on so much weight.

Fran also relies on information sources other than health care professionals. She first began to educate herself about cancer when her husband was coping with his throat malignancy. In her desire to support him, she tried to learn as much as she could about cancer. Fran carries on that learning today, collecting information about her own cancer. She described:

F: Well with him I did all the reading that I could on it at the time. . . . I did reading on everything I could find at the [cancer treatment centre], read it all. [laughs] . . . when I started with it, I still did read a few things, you know, on breast cancer, which is different then what I had read about for him. If I notice something on TV concerning cancer I'll be sure and watch it too. Different articles in the papers too . . . like even in the Enquirer, about Jill Ireland. I find it interesting because--to compare things, how they feel and how I feel.

Fran also spoke about the value of learning from other women coping with metastatic breast cancer and related pain:

F: There has been a few [women] when I was going for chemo, we always ended up going on the same day. Don't know their names, just faces. But it was interesting to talk, just to compare things. . . . Or even in the car when the volunteer driver takes us, quite often you notice two or three of us going at the same time. So then you get to talk to them, get to know them. I find that quite helpful. Especially at first. At first, you know, I didn't know what to expect.

Although she contends that it is helpful to hear about the experiences of others, Fran has not attended cancer support groups she learned about through the cancer treatment centre. She commented, "How would I get there? It's a long ways to go from here". As well, her need to settle for bed in the early evening prevents attending groups scheduled at night. Fran supposed she would attend a group "once in a while" if it was available at a convenient time and place.

Negotiating the Health Care System

Several times during our interview Fran voiced her frustrations regarding the lengthy waiting period she coped with prior to Christmas 1990, waiting for radiotherapy treatments. Reflecting on that time, Fran recalled the feelings of powerlessness, confusion, and anxiety she experienced dealing with perceived shortcomings in a system responsible for providing cancer treatment:

F: This, where [my spine is] collapsed, I mean you'd think they'd RUSH this. . . . And then I heard on the TV that, there is a waiting list of up to TWELVE weeks!

K: How long did you end up waiting for your treatment?

F: It was around six weeks. . . . This is the LONGEST I've ever had to wait. And this is the WORST I've felt, you know, with the collapse. The PAIN, that was worse than what I had EVER had! And the WAIT was LONGER! . . . [Then] they decided to have evening appointments, which was a big help. 'Cause other than that, you know, I might have waited eight or nine weeks! Or more. . . . So they decided to put some night workers on and did it that way. And it was just up to me to find a way to get there. I thought, "Well, I'll get there!"

She also complained of long waiting periods related to scheduled appointments at the cancer treatment centre. She said a typical appointment, if she had to have x-rays, required about two hours of waiting time. Fran expressed frustration about having to endure long periods of "sitting and waiting" while experiencing pain. It was especially annoying for her to wait, often up to an hour, for chemotherapy related medications dispensed only through the cancer treatment centre pharmacy.

Future Goals and Expectations

At the time of our interview Fran anticipated her cancer and related pain would continue to recur in a pattern similar to what she has been accustomed. Her primary ambition was centred around continuing to manage her care independently, until such time that she must depend on others. She maintains hope that radiotherapy will offer ongoing pain relief.

Her hopes for the future were tempered with caution, as she contemplated the potential reality of managing pain without the benefit of radiotherapy treatments. In the following passage she discusses coping with the uncertainty of her future:

- F: [I needed that last treatment], and really not knowing if it would work or not, or what would happen after that? Because . . . like the one doctor, he didn't think I should have any more treatments on the spine. [K: Mm hm.] And this was kind of scary too, you know. Would having that last treatment, would it work or NOT?

- K: So as time goes on . . . that's something that's entering your mind, whether the treatment will work this time or not?
- F: Well, it's--if they would get the right spot. 'Cause there are so many spots there. Would he get the right one to treat? And if you don't get the right one then maybe it's the one right next to it and you can't treat that one because it's too close. . . . the only thing I'm concerned about is if it comes up some where that they can't treat it any more. 'Cause I've had a lot of treatments. And I did pick that up, a couple of months ago when one doctor felt the treatment would help, the other one felt it wouldn't. I knew then that one of these days they won't be able to treat it. 'Cause on the spine it's...it's covered, said it was covered with spots.

Reflecting on her future aspirations, Fran mentioned a goal she hopes to achieve while she is still able:

- F: I thought, "If I can ever sit again for three hours without too much suffering, I intend to go back to Winnipeg on one more trip!" Before I have too much . . . too much PAIN!

Postscript: Six Months Later

Fran and I met again six months later, in July 1991. I was instantly struck by the change I noticed in her. Without the lines that had previously betrayed her fatigue, her face appeared young and relaxed. She also seemed to have gained a little weight. The greatest difference I experienced, however, was in her manner--formerly quiet, reserved and somewhat apprehensive. Now, as if she was a woman transformed, she was outgoing and energetic, laughing and smiling throughout our conversation. She seemed delighted to have company, sharing anecdotes and stories

openly. When I expressed my surprise at the changes in her, she acknowledged that she had not been her "usual self" at the time of our interviews. She recalled feeling drained of energy and "utterly exhausted" after many weeks of enduring unyielding pain.

Bubbly and animated as she chatted, she gave me an account of her progress over the previous six months. She described feeling better as time went by, saying she felt "thrilled" that radiotherapy had so effectively relieved her pain. She had required no further treatments and said she was living her life in a "pretty well normal" manner. Initially she denied having pain, but on further exploration she said she always had some level of discomfort, but not of an intensity that was unbearable. She described her pain as "seven" on a scale of zero to ten [zero being pain free and ten being the worst pain]. She was still taking painkillers in the same manner as she had been six months earlier.

Fran also found it helpful to use a cane for support when she went out walking, although she said it made her "feel stupid". She continued to refuse home maker services that had been offered by her doctor, saying, "Once I have help, then that will be the end--it's like giving up".

Fran voiced excitement about her case study, saying, "As soon as I received it, I couldn't wait to go right upstairs and read it!" "Amazed at how real it was", she found herself immersed in her past experiences. She said "I couldn't believe a person could suffer so much--it's hard to believe, and yet I knew it was true". As she read her story Fran felt "amazed" at what she had coped with. She described feeling

very moved by the story, and found herself crying as she "relived" her experiences.

Fran expressed great interest in reading the final thesis document.

CHAPTER 5

COMMON PATTERNS

Introduction

Individual co-researcher accounts were presented in Chapter Four, organized in descriptive case studies according to common themes and patterns evident among the accounts. In the present chapter an integrated description of themes and patterns common to the co-researchers' experience of managing breast cancer-related pain in the home setting will be presented.

Common themes have been identified and clustered accordingly:

I. Threat to a Life

History of Pain Experience

- Diagnosis story
- Length of time for accurate diagnosis

Description of Pain

- Different kinds of cancer-related pain
- Varying intensities of pain
- Locations of pain
- One is almost never free from pain
- Factors that intensify pain
- Old pain is easier than new pain

II. Disruption of a Life

Impact of Pain on Daily Living

- Fatigue and increased need for rest
- Sleep disturbances
- Changes in self-concept
- Living with incapacitation
- Loss of valued experiences and activities
- Living with uncertainty

III. Taking Control and Managing a Life

Medicine and Treatments for Managing Pain

- Radiation therapy
- Chemotherapy
- Taking painkillers to manage pain
- Managing side effects of painkillers
- Factors hindering use of painkillers
- Alternative treatment and medicines
- Laser therapy and compression pump

Self-Care Coping Strategies

- Getting enough rest and sleep
- Establishing a flexible routine
- Using physical aids to enhance activity
- Remaining active and busy
- Distraction
- Positioning
- Application of heat
- Relaxation techniques
- Maintaining contact with the "outside world"
- Prayer
- Diet
- New age healing strategies

Attitudes and Feelings Related to Managing Pain

Emotional responses to pain
 Past influences
 Feeling a sense of control
 Finding meaning in pain
 Having a determined approach
 Hope, optimism and a positive attitude
 Willingness to live with pain
 Living one day at a time
 Not dwelling on the pain
 Maintaining independence
 Cancer as learning experience
 Developing assertiveness
 Talking openly with others
 Looking back on a life
 Maintaining humour
 Spiritual beliefs
 Denial and avoidance

Significant Personal Relationships

Impact of cancer on relationships
 Friendships
 Ways that friends help
 Ways that friends hinder
 Spouses
 Family members

Significant Professional Relationships

Assumptions about doctor roles
 Satisfaction within doctor-patient relationships
 How doctors help manage pain
 Hindrances within doctor-patient relationships
 How doctors can help more
 Perceptions of the patient role
 How nurses help and hinder
 How home makers help and hinder
 How social workers help
 How a psychic healer helps

Seeking Knowledge

Perceived lack of knowledge
 Obstacles to acquiring knowledge
 What women want to know
 Helpful sources of knowledge
 Assuming responsibility for learning

Negotiating the Health Care System

Hindrances imposed by the system
 Assuming responsibility for one's own recovery

IV. Looking to the Future

Future Goals and Expectations

Quality of a life
 Having purpose and hope in a life
 Fears

I. Threat to a Life

The first major theme related to being called attention to the threat of one's life. This threat was understood as a cancer diagnosis being the source of an experience with pain, and was met with feelings of shock and disbelief.

History of Pain Experience

Co-researchers began their accounts by providing a spontaneous chronological account of events leading up to the diagnosis of cancer or its recurrence as the

primary source of their pain. This story served as a beginning point from which to describe their present experience of managing pain.

Diagnosis story. Co-researchers typically reported a detailed history of their pain experience, recalling exact dates, numerous investigations and treatments, and a plethora of medications. It was commonly a story they had told over and over again, to various health professionals providing them care over the years. Histories spanned five to sixteen years.

Four women experienced no problems with pain following their initial breast cancer diagnosis and treatment with mastectomy. Their problems with hip pain began from three years to thirteen years later, and eventually led to the discovery of recurrent breast cancer. One woman's shoulder pain led to her diagnosis of breast cancer and subsequent mastectomy, while pain in her hip just over two years later resulted in her diagnosis of metastatic breast cancer. The sixth woman's metastatic breast cancer was diagnosed following the appearance of a lump and related pain in her lower jaw.

All women expressed shock that their experiences of pain were eventually determined to be cancer-related. The five women who had mastectomies following initial diagnosis had no idea their breast cancer could recur in an area of their body other than the remaining breast. Their comments included, "I never dreamed it was cancer pain", and, "I thought the cancer was all gone!"

Length of time for accurate diagnosis. Four of the six co-researchers voiced frustration and anger regarding the length of time it took to accurately diagnosis their breast cancer recurrences. In response to their complaints of hip pain, all four were given treatments for bursitis and/or arthritis. Length of treatment time prior to accurate diagnosis of cancer recurrence ranged from four to six months. One woman perceived her doctor was not really "listening" to her when she kept telling him about her experience of pain.

Description of Pain

Descriptions of cancer pain consistently portrayed a pattern of alternating relapses exhibited by periods of intense pain, and treatment-induced remissions distinguished by intervals of minimal or absent pain. Post-treatment intervals of functional stability varied in duration and were associated with chronic pain that was considered "tolerable". Relapses were distinguished by episodes of unpredictable and disabling pain considered "acute" and intolerable. Three women exhibited a progressive pattern of deterioration in which post-treatment recovery following each relapse of pain resulted in a lower level of functioning than before.

Different kinds of cancer-related pain. Co-researchers described experiencing more than one kind of pain, saying it was difficult, if not impossible, to find words to accurately capture the nature of the various pains associated with metastatic breast cancer. One woman also made a clear distinction between her physical and

emotional experiences of pain. She described physical pain as an "intense pain or a dull ache", and likened emotional pain to a "big knot" in the gut.

Varying intensities of pain. In their descriptions of pain, co-researchers spent considerable time and effort attempting to describe what their pain felt like. They all reported experiencing an endurable level of continuous aching pain on a day to day basis, punctuated by intervals of acute, intense, intolerable pain. Episodes of very intense pain were reported to have lasted up to six months. Thus, the pain these women lived with on a day to day basis was a continuous aching sort of pain, with episodes of acute, intense pain. The onset of acute, intense pain was typically sudden and unexpected.

Co-researchers focused primarily on their experiences of intense pain. The most common descriptors used repeatedly by all six women to describe their most intense pain were the words hurt, pain, dull, and ache. Other expressions used to reflect very intense pain included pressure, acute, sharp, nerve, terrible, severe, devastating, intense, very bad, on fire, excruciating, burning, weird, jagged, and stupendous. Each co-researcher emphasized at least one episode of very intense acute pain, perhaps the worst they had experienced to date. Such episodes were reported to have been uncontrollable, lasting from a few days to several months. Less intense pain was expressed differently by each woman, but was consistently referred to as a chronic type of aching pain that persisted continuously over time. This level of pain was considered "tolerable" in comparison to the more intense pain already described. On a scale of zero to ten (zero being pain free and

ten being maximum pain), two women rated their less intense pain as "four or five" and one woman rated it as "seven". Terms used to distinguish less intense pain included endurable, dull and achy, chronic, discomfort, very sore, and tight.

Location of pain. Co-researchers commonly experienced several locations of cancer-related pain. All had pain in one or both hips, as well as in other locations, including the abdomen, liver area, skull, back, neck, arms, ribs, legs, and buttocks. Pain was reported to shift from site to site with each relapse, and co-researchers routinely tried to find explanations for their pain. The experience of pain in a new location generated fear that cancer had spread to another site. This was a constant source of anxiety for most women.

One is almost never free from pain. Although their pain fluctuated in intensity over the time of our interviews, none of the co-researchers experienced times when they were completely free from pain, despite the use of medications, treatments, and other pain management strategies. Persistent, unrelieved pain was the norm, with individuals determining their own level of tolerable, acceptable pain. For example, Emiko perceived pain rated as three to four on the aforementioned pain intensity scale as acceptable, and "almost" completely relieved. One woman reported complete freedom from pain in her the validation follow up eleven months later.

Factors that intensify pain. Pain was consistently reported to worsen with movement and on weight bearing. It also intensified at night, with the least painful

period occurring during the morning hours. Severity of pain tended to increase with fatigue.

Old pain is easier than new pain. Co-researchers developed some tolerance for "old" or familiar pain, providing the pain was of the chronic, low intensity type.

- C: New pain is worse than old pain--old pain you get used to.

 D: Aches and pains I'm so used to--I just ignore them!

 E: And if this [pain relief expressed as four on a scale of ten] can continue then I have nothing to say.

II. Disruption of a Life

The second major theme concerned the overwhelming intrusion cancer-related pain imposed on a life. The consequences of pain, compounded by untoward effects of painkillers, were perceived as the most significant disruptions to daily living. Effects considered most debilitating included physical incapacitation, fatigue, loss of personal control and independence.

Impact of Pain on Daily Living

All co-researchers but one shared the perception that cancer-related pain had significantly altered their day to day lifestyle, with varying levels of physical incapacitation imposing the most profound disruption to activities of daily living.

Cancer-related pain was perceived to disrupt every possible aspect of a life, from the ability to manage within a previously familiar physical setting to the loss of one's valued roles in life.

One woman did not feel her disease and related pain had significantly changed her lifestyle. She reported she was "used to being ill" and was therefore able to "take these things in stride". In fact, she refused to allow her cancer to have an impact her life by using "denial" to prevent the intrusion of cancer-related pain on her life.

Fatigue and increased need for rest. Persistent feelings of tiredness and an increased need for rest were the major concerns emphasized among all five women who considered cancer-related pain disruptive to their daily life. They expressed significant distress regarding the number of rest periods they had to have each day in order to conserve energy and cope with pain. As a result of chronic fatigue, many previously valued self-care behaviours, roles, and activities requiring energy expenditure had been relinquished or were in jeopardy. As well, fatigue was reported as part of an endless and vicious cycle with cancer pain. Fatigue was experienced as a response to intense or continuous pain, and fatigue lessened the ability to cope with pain.

Sleep disturbances. Co-researchers commonly cited problems both falling and staying asleep. Pain caused loss of sleep which further magnified suffering, leading to still more sleeplessness. Sleeping pills and increased doses of painkillers were

commonly taken during the evening, in an attempt to sleep throughout the night, thus enhancing daytime functioning and ability to tolerate pain.

One woman experienced particularly serious disruptions to her sleeping patterns. Recall the "terrible nightmares" that wakened Betty about an hour after falling asleep, leaving her "baffled", "upset", and unable to sleep the "rest of the night".

Changes in self-concept. The next major impact felt by five of the six co-researchers pertained to changes in self-concept, including effects on body image, self-esteem, and valued roles. All perceived themselves as active, independent women prior to their problems with pain. Without previous experience coping with illness, they reported having difficulty perceiving themselves as "sick". One woman reported feeling comfortable and familiar in the sick role, though she admitted she was "not able to go out and do physical things quite the same".

The consequences of pain resulted in role losses, strains, and adjustments. The acts of adjusting, retaining, or letting go of valued roles presented a significant challenge, especially when those important to a woman's self-esteem were lost. For example, Betty and Carla were unable to retain their roles as wage earners and expressed feeling a loss of "productivity" and "usefulness".

Living with incapacitation. Loss of independence and incapacitation were repeatedly referred to as the most significant and far-reaching consequences of cancer-related pain. Women who so highly valued their autonomy and ability to

manage on their own found themselves struggling with varying levels of dependence and incapacitation. All six women said they most feared increasing pain and dependence.

Three women indicated that their most trying experience so far was the period of waiting, in pain, for radiation treatments. During the five to six weeks of waiting, individuals commonly described intense suffering, almost complete incapacitation, and reliance on others.

Loss of valued experiences and activities. Fluctuating levels of incapacitation were perceived as interfering the most with previously valued experiences and activities of daily living. All were especially concerned about their inability to perform their house work. Co-researchers were also distressed about not being able to perform routine activities such as shopping, socializing with friends, walking, going on day trips, exercising, and enjoying recreational activities with their children.

Living with uncertainty. Co-researchers referred repeatedly to the challenges of managing the "ups and downs" or "roller coaster" pattern of cancer-related pain. Feelings of anxiety and fear, frustration and anger, powerlessness, and loss of control were expressed in relation to the presence of pain and an uncertain future. Co-researchers described developing a more flexible attitude in order to accommodate the constantly changing effects of their cancer and related pain. Goals were set and adjustments made on an ongoing basis, depending on the individual's health status at the time.

III. Taking Control and Managing a Life

The third major theme concerned what women did to manage their pain and live a life that was meaningful to them. The most significant aspects of living a worthy life focused on maintaining a sense of normalcy, having control, feeling a sense of hope, and maintaining independence. Women commonly wanted to continue on as usual, despite the presence of pain.

Medicine and Treatments for Managing Pain

The major strategies most relied on by co-researchers to manage their pain included having radiation treatments and taking medications. All women took opioid or non-opioid painkillers. Some women also received hormonal therapy or chemotherapy, in addition to medications aimed at combatting nausea and constipation. One woman sought treatments in Mexico to complement her treatments here.

Radiation Therapy. Overall, radiotherapy was regarded as the most effective means of managing cancer-related pain, providing varying levels of relief in relatively short periods of time.

A: With uh, radiation . . . that was certainly a relief.

.....

E: Tylenol has helped me too, but mainly the radiation.

.....

- F: EVERYWHERE that I've had it [radiation], it has helped. . . . It's surprising, the treatments work that quickly. . . . It was just maybe four days, five days.

Despite its effectiveness, radiotherapy caused significant side effects in some of the women. Recall Betty and Fran experiencing considerable nausea and/or vomiting with treatments. Most co-researchers made reference to intense fatigue believed to be associated with radiotherapy. One woman described, "It kind of ZAPS you, weakens you".

Chemotherapy. All but two co-researchers had undergone chemotherapy treatments. Two of those women were able to manage chemotherapy side effects with minimal disruption, while the other two women suffered persistent nausea, vomiting, and fatigue. In one case, the treatment was perceived as more devastating than the disease itself. Recall Betty's feelings of discouragement regarding the profound impact of untoward side effects on her quality of life, "I just wonder if maybe I'll quit it [chemotherapy] altogether and enjoy what time I've got." The other two woman feared the prospect of having chemotherapy.

- C: The big fear for me is having to deal with chemo, the thought of chemotherapy really scares me. Everything I've seen and the people that I've known that have had to deal with it, it's just blown them asunder.

.....

- E: That's something I'm afraid of--I'm afraid of chemotherapy.

Taking painkillers to manage pain. Co-researchers relied primarily on painkillers for pain relief, but generally perceived them to have limited value in managing their pain. The goal of taking them was to keep pain at a tolerable level. At the time of interview not one woman reported experiencing complete pain relief. Eleven months after initial interviews Betty described achieving complete relief of pain with very high doses of Morphine.

Painkillers used by co-researchers at various times included Dilaudid, Morphine, Leritine, Tylenol #3, and Bufferin. Eventually five of the six co-researchers relied on Morphine to manage their pain. Gravol, Stemetil, and Maxeran were used to minimize nausea.

Managing side effects of painkillers. All co-researchers reported experiencing unacceptable side effects upon taking painkillers. Although they acknowledged pain control to be more effective when painkillers were taken regularly, concerns regarding side effects prevented them from taking them regularly or in larger doses. All co-researchers preferred to tolerate a certain level of pain in order to minimize distressing effects of painkillers.

Co-researchers were most concerned about the sedation and severe drowsiness caused by Morphine and other painkillers. Their descriptions included "being fuzzy headed all the time"; being "out to lunch"; feeling "woozy", "dizzy", and "dopey"; and "feeling like a zombie". Despite strategies used to prevent constipation, it remained a significant problem among the women. Nausea and vomiting were also

consistently reported as a consequence of "taking too much" medication. Co-researchers typically refrained from taking any more medication than needed to "take the edge off" their pain. All suggested they would welcome the opportunity to become pain free, providing they did not have to endure effects they perceived as uncomfortable or diminishing to their life's quality.

Factors hindering use of painkillers. A variety of factors influenced the decision as to whether or not to take painkillers as directed by health care professionals. Issues common to all co-researchers in their decision to refrain from taking painkillers included: the unacceptable nature of side effects; "not feeling in control"; socio-cultural background; previous negative experiences with medications; fear of addiction; lack of understanding regarding painkillers; fear that Morphine is "just covering up" the disease process; and lacking awareness regarding the range of potent painkillers available.

Taking painkillers was commonly viewed as "giving up" or "giving in to the cancer". Recall Ann's comment, "I'm going for a cure rather than painkillers". One woman's resistance to taking Morphine was based on experiences with her mother suffering a painful cancer-related death while taking Morphine. This woman associated Morphine as "being the last leg" of a journey she did not want to take.

Alternative treatments and medications. Generally, co-researchers preferred to rely on traditional approaches to managing cancer and related pain. Recall Betty's comment, "if the [other treatments] were good there would be thousands of

patients there". Two of the six co-researchers complemented their use of traditional medical pain management strategies with non-traditional treatments and medicines. Recall that Carla "tried herbal things" but didn't "really see any difference. On the other hand, Ann perceived the treatments she underwent in Mexico (Didranol, Laetrile, enzyme injections) were effective in helping control her cancer and related pain. She sought treatments in Mexico because she perceived her doctors in Canada were not able to offer effective treatment.

Laser therapy and compression pump. One woman found laser treatments helpful for relieving the "tight band of pain" across her chest, caused by scar tissue and adhesions. She also reported achieving relief of pain and swelling (lymphedema) in her arm by having treatments with an inflatable sleeve that applied alternating pressure to her arm.

Self-Care Coping Strategies for Managing Pain

Co-researchers used a wide variety of cognitive and behavioral coping strategies in an attempt to reduce or control their cancer-related pain and its effects. Some strategies were directed at adjusting to pain rather than eliminating it. Strategies were highly individualized according to each woman's personal coping style. The most common and highly valued strategy for managing pain was that of acquiring enough rest and sleep, followed by establishing a flexible, but familiar routine.

Getting enough rest and sleep. The role of rest in relieving and controlling pain was the most heavily emphasized among the co-researchers. Several rest periods or naps were taken throughout the day, especially in the afternoon. Women commonly felt more tired and uncomfortable during evening hours, and tended to settle for sleep at an early hour.

Establishing a flexible routine. Considerable time focused on how women organized their daily activities to accommodate their increased need for rest, in order to conserve energy for coping with pain. Most women liked to have a routine which they could flex according to how they were feeling. Morning was consistently a "good" time for accomplishing tasks and going out, whereas evening was considered a "bad" time in relation to energy and ability to manage pain.

Using physical aids to enhance activity. Co-researchers tried to organize their home environments to accommodate physical limitations and problems with pain. Recall Emiko locating her bed in the middle of her "living" area, a few steps away from the kitchen, living room, and bathroom. And Carla's living space was organized so that wherever one stood there were only a few steps to a chair or resting place. Meanwhile, the stairs and varying levels in Ann's house imposed physical barriers that made her feel like a "prisoner" in her own home.

Other means of enhancing activity and minimizing pain included using a cordless phone, cane, neck brace, hospital bed, wheelchair, special neck pillow, and wearing a satin like nightgown in a bed fitted with satin sheets.

Remaining active and busy. Remaining active and busy were reported as a key strategies for successfully managing pain, in order to minimize the time one has to think about cancer and related pain.

- A: The less you think about it, the less you're likely to feel the pain.

 C: Staying occupied keeps me from getting hooked back into the pain.

 D: Keeping going and keeping busy give you less time to think. I think the whole thing is to have a busy mind.

Distraction. Co-researchers also used distraction techniques to shift their attention away from pain or disease, and on to specific activities that keep the mind otherwise occupied. The most common diversional activity used among the co-researchers was reading. Other activities included listening to music, talking on the telephone, praying, and counting. One woman said she could "pretty well manage" without pills during the day by "counting".

- B: I count. When it starts to hurt--you know--I'll start counting. And then of course when you start counting your mind goes off onto something else and before you know it you forgot the pain. So I always found counting helpful., I don't know why or where I got it from, it's just one of those things . . .

Positioning. The use of positioning was a common and effective strategy used by all co-researchers in an attempt to alleviate pain. Co-researchers found it uncomfortable to sit in one position for a long time, and needed to reposition themselves often. Each woman learned to position herself in a way that would minimize her unique pain experience. For example, Carla learned to sleep on her back to avoid pressure on painful breast tissue, and Fran elevated her painful arm on pillows when lying down. Cushions were commonly tucked behind various parts of one's back when sitting.

Application of heat. Application of heat to the painful area was another commonly used pain management strategy. Co-researchers found heat "soothing" and "comforting". Sources of heat included a hot water bottle, heating pad, hot bath, and lying on a couch warmed by heat from a nearby heater. One woman stopped using a heating pad after she fell asleep on it and sustained burns to her skin.

Relaxation techniques. Various methods of relaxation were used to manage pain and related stress. Co-researchers generally tried to engage in leisure activities they found pleasurable, such as reading, travelling, swimming, watching television, and talking with friends. One co-researcher viewed meditation as her most powerful coping strategy. Massage therapy provided yet another means for easing her pain.

Maintaining contact with the "outside world". Regular interaction with the outside world was stressed as a helpful way of coping with pain, by maintaining a perspective beyond the home environment and cancer pain experience.

A: I think it's helpful perhaps too, to get out of the house . . . especially on nice days. . . It gets you to thinking, I said to [Bob], "Oh this world is bigger than just my house!"

.....

C: When it's nice and crisp and the sun's shining and all that beauty out there, you want to be a part of it . . . [it's] very good for the spirit, to get out of this confine.

Prayer. One co-researcher emphasized the significance of prayer as the primary source of strength that helped her cope with cancer and related pain, by placing her faith in God and eternal life. Although religion did not play an important role in other womens' lives, one woman resorted to prayer when her pain became intolerable. The use of prayer as a pain management strategy evoked these spontaneous responses among several co-researchers:

B: You get mostly depressed at your friends stupid remarks. . . "I'm praying for you a lot". That one really thrills me.

.....

D: [Prayer] doesn't work as far as I'm concerned.

.....

E: Prayer. I have this friend who's a very religious person. [laughs] She tells me to you know, recite this . . . But I don't do it.

Diet. Some co-researchers incorporated special guidelines or "healing" foods into their diets to facilitate healing and indirectly manage discomfort. Recall that Ann followed dietary guidelines recommended by her therapist in Mexico. She maintained an essentially vegetarian diet; eliminating sugars, dairy products, white flour, and refined foods. Carla followed a similar diet, perceiving it was the most "healthy way to eat". Carla also reported that the occasional alcoholic beverage helped her to relax and control pain. Co-researchers commonly supplemented their diets with laxative fruits and bulky foods in order to minimize the pain and distress of severe constipation afflicting most of them.

New age healing strategies. One co-researcher included homeopathy, analysis of dreams, and use of the runic alphabet in her "healing processes".

Attitudes and Feelings Related to Pain Management

All except one co-researcher reported their cancer recurrence, related pain, and physical limitations to have a profound emotional effect on them. They described experiencing a wide range of feelings as they struggled through the ups and downs of their cancer. They also identified attitudes and beliefs that helped or hindered pain management.

Emotional responses to pain. Co-researchers commonly described feeling "shocked" regarding their initial and recurrent cancer diagnoses. Emotional responses included "crying for two weeks", "feeling scared", feeling as if "hit by a

truck", and alternating between "tears and laughter". Four women continued to feel anger and frustration regarding the length of time it took to accurately diagnosis the cause of their hip pain. At different times during the process of managing their pain, feelings included alternating hope and despair, fear, terror, worry, anxiety, optimism, sadness, depression and helplessness. Responses to severe pain were unique to each individual.

A: You think very soberly, of course, that you know you may not be around very long. . . . especially with the children, for me that's difficult.

.....

B: I get very upset. Weepy and angry.

.....

C: [I] play the woe is me's.

.....

D: I get almost whiny . . . I get my feelings out stamping around and cussing and swearing, rattling pots . . .

.....

E: It makes me very miserable. . . glum and gloomy.

.....

F: I just get really--I just get angry at myself. I feel that, "OH WHAT AM I DOING HERE WITH PAIN"?

Past influences. Coping styles were consistently influenced by childhood memories, past experiences, and learned attitudes regarding illness. Each woman's coping style was highly individualized according to her unique background. For example, one woman's childhood experience of watching her father die following a lengthy illness gave her a strong sense of her own children's suffering, intensifying her feelings of grief for them. Another woman's experience of supporting her husband through his cancer and death helped her prepare emotionally for the journey that was to become her own. In another case the cancer diagnosis triggered an overwhelming emotional response related to unresolved childhood issues.

Finding meaning in pain. Co-researchers invariably searched for explanations for their cancer and related pain, attempting to make sense of their suffering. One woman perceived her cancer played an important role in helping her face painful childhood issues. Several women explained that their cancer was caused, in part, by stress and transition in their lives. Another searched for answers within the context of her spiritual beliefs. Commonly, individuals asked themselves, "Why me?", "Why now?", and "What did I do to deserve this?"

Feeling a sense of control. Co-researchers commonly perceived their coping to be effective when they felt a sense of control, and ineffective when they felt out of control. Loss of control was generally associated with very intense pain, loss of hope, new pain or symptoms, lack of information, and unfamiliar treatments. Individuals achieved a sense of control by acquiring knowledge, making informed

decisions regarding pain management, participating actively in their care, and maintaining independence. Control was also achieved by surrendering it to another person or spiritual being.

Having a determined approach. Pain was approached with determination and persistence, as in the spirit of battle. Even in difficult times co-researchers refused to "give in" to their cancer.

C: If I give in today I'm going to give in tomorrow and the next day. . . I was determined that I was going to be okay.

.....

D: I think I'm a born survivor . . . I have to be tough or I wouldn't survive some of these things.

Hope, optimism and a positive attitude. The importance of hope, optimism, and positive attitude in achieving a sense of control over pain were repeatedly emphasized. Co-researchers shared the common experience of comparing themselves to others less fortunate, in an attempt to strengthen their optimism. Negative experiences were often reframed in a positive light. Hope was also inspired by reading about: people who had endured suffering or were living with cancer, successful treatment outcomes, and confidence in health professionals. Two women relied on spiritual beliefs as a source of hope.

Hindering the ability to maintain hope and optimism were periods of intense and uncontrolled pain, severe treatment effects, and lack of information. Recall the

case of Emiko, who said it would have been easier to cope with her most severe pain if she had a more "positive attitude". She felt that if she had "known treatments might help", she would have been "in a better mood all the time". At times health professionals were perceived to "take away" hope. Consider Betty's "loss of faith" when she was told she had about a year to live.

Willingness to live with pain. Co-researchers consistently expressed a willingness to endure some pain in order to feel a sense of control over their bodily functions, their faculties, and the cancer they battled against. All women believed, in varying degrees, that pain is an unavoidable companion to the cancer experience.

One woman's willingness to tolerate pain seemed more dramatic than the others, based on her Japanese cultural values. Recall that Emiko's stoicism and capacity to endure were more highly valued than comfort.

Living one day at a time. Adjusting the time frame of personal goals was consistently reported as one of the most effective ways of managing cancer and related pain. Goal setting became concrete, tentative and short-term, dependent on the health status of the individual.

B: I'm just going to get through each day and then worry about the next.

Looking back on a life. Co-researchers commonly engaged in some sort of life review, or looking back on the events in their life. It was found that reflecting

on fond memories helped sustain them through difficult times. Those with families especially enjoyed looking back on times spent with their children. Women also expressed appreciation for the life that had been lived to date.

Not dwelling on the pain. Women commonly kept themselves busy in order to avoid thinking about their pain. Several women found it helpful to do volunteer work to keep their mind off themselves.

F: If I stayed her by myself--to just think about all this. And I don't think then I could cope with all that.

Maintaining independence. Despite physical limitations, co-researchers consistently fought to assert their independence and self-reliance in activities of daily living. Women commonly resisted accepting help unless they absolutely needed it.

F: Once I have [domestic] help, then that will be the end--it's like giving up.

Cancer and related pain were perceived as being especially difficult to deal with if one had never experienced illness before. None of the co-researchers perceived themselves as having effective skills for asking others for help.

Cancer as learning experience. Managing cancer-related pain was considered a learning process in which co-researchers were "always having to learn something new" in order to maintain responsibility for their own well-being.

Developing assertiveness. Co-researchers commonly described the need to develop assertiveness in order to get the information and support they needed to manage their pain. Awareness of the need for assertiveness often occurred through trial and error, and within the doctor-patient relationship. Often, the motivation to become more assertive was ignited by anger toward some incident in which the individual suffered physical and emotional consequences, perceived to be the result of inadequate provision of information by health care professionals.

Talking openly with others. It was considered especially helpful to be able to express feelings openly with people, to those who listened in a nonjudgemental and accepting manner. One woman called the crisis line to seek relief for her emotional distress, feeling she was "more able to let go" with a stranger.

Maintaining humour. The ability to laugh and find humour in their experiences was often used as a means of coping with pain.

Spiritual beliefs. One woman's spiritual belief system helped maintain her sense of control, and provided a framework within which she sought answers to help her cope with pain. Her spiritual beliefs also helped reduce her fears and cope with thoughts about dying.

Another woman actively participated in a spiritual organization expounding on the healing process of unifying the mind and the body. She found that "working on the mind" was the most effective means of managing pain.

Denial and avoidance. One co-researcher felt it was helpful "to deny some of the things that might be happening", explaining that she chose not to remember many things because she did not "want" to remember things. She also found it helpful to tell herself she had arthritis instead of "bone cancer". Other women used avoidance, at times, to cope with effects of cancer and related pain. One woman avoided fear and worry by keeping her mind preoccupied. Another woman talked about escaping to bed as a way of avoiding entertaining, an activity she found difficult to cope with.

Significance of Personal Relationships

Personal support networks varied greatly from person to person. Friends and family were most commonly cited as sources of support--or strain--to the individual managing breast cancer-related pain. Half the women also referred to social networks, such as church groups, as highly valued means of support. One woman was still grieving the loss of four personal relationships she perceived as being the most significant in her life.

Co-researchers tended to rely on their own resources before reaching out to others. Communication about cancer-related concerns within the context of personal relationships was perceived as one of the most challenging aspects of coping with

cancer and related pain. The perception that ultimately, one must work through their pain and related feelings alone, was also common.

Impact of cancer pain on relationships. The diagnosis of cancer often had a profound impact on friends of the individual coping with cancer-related pain. Friends frequently responded with "shock" and "fear". In some cases the stress of cancer brought about more meaningful and caring relationships, while, in other instances, friends became alienated.

The overwhelming impact of cancer experienced by co-researchers was often perceived by co-researchers to be equally devastating to their family members. In light of this, co-researchers attempted to manage their pain and symptoms in a manner that would not "burden" family members. Women often tried to protect their family by limiting disclosure of pain related concerns.

Friendships. Co-researchers talked more about the helping nature of close friendships than they did of family support. To one woman, friends were her family. Another woman perceived that "friends seem to be more accepting than family". Women commonly expressed that the greatest support came from those friendships that had endured over many years. These were the friends with whom the co-researchers felt most able to openly discuss their cancer and accept support. Two women said they did not prefer to discuss their concerns with others, but would discuss them with a friend if needed.

Ways that friends help. Friendships in which co-researchers felt most supported were those that had continued on "as normal" despite the intrusion of cancer.

B: When they phone up we still talk about the same things we've always talked about and we never skip over cancer words . . . they just treat me like we've always treated each other.

Co-researchers liked friends to be genuine and sincere, maintain a sense of humour, and show their care without making a big fuss.

Appreciation was commonly expressed for the following sorts of practical help offered by friends: transportation, housework, help with chores, baking and cooking. They also enjoyed receiving flowers and treats, being taken out somewhere, having friends drop in, and receiving phone calls. During periods of increased incapacitation, some women depended on close friends to help them manage at home.

Ways that friends hinder. Most commonly, co-researchers identified that friends and acquaintances hindered their relationships by withdrawing or reacting inappropriately to the experience of cancer. Responses perceived to be inappropriate were those that were excessively sympathetic or lacking in genuineness: "You're so BRAVE"; "We admire you"; "Oh you look great!" One woman found it frustrating coping with people's unfounded fears about cancer. Women who did not value prayer expressed irritation when told their friends were

praying for them. Meanwhile, one woman considered her friends' prayers a primary source of support. Being compared or likened to others with cancer was also considered unhelpful.

Spouses. Of the three women who had spouses, two women described their husbands as "very supportive", but perceived them to be experiencing difficulty adjusting to their situation. Both women expressed concern about the extra chores and household demands placed on their husbands as a result of their pain. An additional concern was for the husbands' ability to cope with the potential loss of a loved one.

A: Sometimes the spouse goes through a lot of things for you.

.....

B: I don't want to whine to [Bill]. He's having a tough time, poor thing. . . . He's helpless [continues to cry] I think it's harder for the survivor really.

Recall Diane's perception that her husband offered "very little" in the way of support, because he lacked understanding of illness. She perceived her role was to "look after him" and "shuddered to think" what would happen if she were to become disabled, having to rely on his support.

Family members. The significance of family members in helping women manage their cancer-related pain at home varied from woman to woman. Those who were mothers commonly referred to adult or young children as a primary

source of pleasure and pride. They also shared a common struggle in their attempts to nurture their families through the ongoing uncertainty of chronic illness. This was especially true for the one woman with young children living at home. While trying to prepare themselves for the potential loss of their families, women tried to ready families for the potential loss of their own lives.

Some women had limited family systems from which to seek support. One single woman's only living relative was a brother, on whom she relied very little for support. The other single woman was in the process of re-establishing ties with a family she barely knew. Yet another woman was a widow, who maintained long distance relationships with her adult sons.

Significance of Professional Relationships

Doctors and nurses were perceived to have the most significant role in helping women manage breast cancer-related pain at home. Co-researchers typically focused most of their attention on their experiences with doctors.

Assumptions about doctor roles. Co-researchers commonly articulated their views regarding the roles and responsibilities of the various doctors they consulted with on a routine basis. Family doctors were regarded as "front line" professionals from whom individuals could seek general medical care and advice. It was commonly perceived that they had more time than specialists to spend with their patients. One woman assumed her family doctor would not know how to help her manage cancer pain because that was the cancer specialist's domain.

Cancer specialists were commonly viewed as very busy, knowledgeable, and competent doctors who had limited time to spend with each patient. Co-researchers perceived that cancer specialists were to be consulted for specific, cancer-related health problems. Three of the six women felt that it was more challenging to communicate with the specialists.

- B: Some of the specialists don't like to be questioned. They would [like] for you to do what they tell you to do, and take what they give you and don't ask why.

.....

- C: A lot of doctors, especially specialists--they always give trick answers just to see you work around it . . . they never give you a STRAIGHT answer.

Satisfaction within doctor-patient relationships. Five of the six co-researchers voiced varying levels of dissatisfaction with the relationship they had with either their family doctor or their cancer specialist. On the other hand, one woman expressed a high level of satisfaction regarding relationships with her doctors, while another was dissatisfied in all her relationships with doctors.

Four women voiced anger and frustration regarding what they perceived as inadequate medical care or follow up provided by their family doctors. Recall the delayed diagnoses reported by Ann, Emiko, and Carla. As well, consider the perceived response of Diane's doctor to her shortness of breath. All four women reported a diminished sense of trust in their doctor, and two women felt

misunderstood by their doctor. One of these women changed to another family doctor, and the other was considering doing the same. Another woman was thinking about requesting a new cancer specialist. Two women said they would feel more comfortable if they had a female doctor.

The two women who described feeling dissatisfied in their relationships with cancer specialists cited ineffective communication as the main problem, perceiving their doctors didn't really listen or understand their complaints. The one woman who felt very satisfied within both of her relationships with cancer specialists felt a high level of trust in their expertise, clinical skill, and straightforward manner. She said they had always been empathic, honest, and skilled their provision of care.

How doctors help manage pain. Co-researchers commonly reported that they had been most helped when they felt a genuine sense of caring from their doctor. For example, Ann described her cancer specialist "trying to get radiation treatment done earlier" when he witnessed the enormity of her suffering. Women typically perceived it had been helpful when their doctors: communicated openly regarding disease and treatment; demonstrated clinical skills; refrained from giving information that would worry them unnecessarily; let them know what to expect of treatments and medicines; spent time with them; had an optimistic attitude and instilled realistic hope; discussed options; included them in decision-making; and gave advice. Several women liked the doctor to "take command" of their care. One woman found it helpful that her doctor was open to alternative treatment approaches, and that he shared a common spiritual faith.

Hindrances within the doctor-patient relationship. Women commonly reported having been hindered in their ability to manage pain at home because: doctors were perceived to provide inadequate information about disease, treatment, or medications; women had not known the warning signs of breast cancer recurrence; they felt awkward asking questions and did not know what to ask; they did not feel like an equal in the doctor-patient relationship; their doctors did not give them hope; doctors did not speak in a language they understood; doctors neglected to provide helpful suggestions for managing pain; doctors were always in a rush; and they perceived doctors to frequently have an impersonal approach. One woman felt especially hindered by the medical profession's narrow emphasis on "giving pills".

How doctors can help more. Co-researchers commonly made individual suggestions for doctors who are helping patients cope with cancer-related pain. They suggested that doctors: be aware that they are treating unique and different individuals; provide basic information about new drugs and treatments; explain why pills are being taken and what side effects to expect; explain exactly what is meant when using medical terminology with lay people; give more details about disease; instead of asking patients if they have questions, advise them on what to do; advise patients regarding warning signs of cancer recurrence and what to expect in the future.

Perceptions of the patient role. Co-researchers commonly discussed their roles as patients, and how these roles evolved and changed over time. Womens' perceptions of the doctors' role tended to shift as a result of their experiences as patients. Commonly, women were in the process of learning how to more effectively assert their specific needs within the doctor-patient relationship.

E: I used to feel kind of scared of doctors and I didn't talk to them much. . . . I was ignorant because I trusted the doctor so much before and what he said. So what they said was just like a God's word and I said okay. . . . I thought that maybe they're the ones that are supposed to know what questions [to ask me]. But now I realize that they may be the experts but it's the patient that knows their BODY, isn't that right?

Women commonly felt they had a responsibility to inform doctors regarding their pain and their individual needs, in order to facilitate their own recovery.

How nurses help or hinder. Three of the six co-researchers were visited or telephoned every week by a public health or home care nurse. These nurses were perceived to have an important role in helping women manage pain at home. Women commonly felt at ease with their nurses, and enjoyed being able to talk openly with them. Visiting nurses helped most by answering womens' questions and providing information about medications and treatments. It was commonly felt that nurses gave information in a way that was most understood by patients.

- C: I like to ask [the nurses] questions 'cause I find that I get better answers, clearer cut answers . . . she's been very helpful for me, because I wouldn't even take that painkiller a while back.

.....

- E: I had to talk to the nurse and she would look [the medication] up in the dictionary and tell me.

One woman also relied on the home care nurse to give antinausea injections in the home setting. At times, this was not an effective means of help, because the nurse was not available at the time the injection would have been most helpful for controlling nausea.

Five of the six co-researchers also spoke of nurses who had helped them within the hospital setting. Four women perceived that hospital nurses had generally been very helpful to them. Commonly, these women referred to the nurses' kindness, caring, and ability to anticipate their needs. One woman noted that nurses were abrupt and "testy" at times, and attributed this to being short staffed. The fourth woman felt very helped by nurses in her local hospital, but perceived care received in the "cancer" hospital was less helpful. Although she described isolated incidents of being very well cared for by nurses there, it was her overall view that the nurses were "not that helpful".

How home makers help or hinder. Three of the six women utilized the services of home makers at various times during their illness. Two women found these services beneficial in helping them to stay at home and effectively manage

pain, by relieving them of basic housekeeping chores. One woman expressed dissatisfaction with their services, feeling they were a burden and intrusion on her life.

How social workers help. One woman's pain management had been assisted by the emotional support of her social workers. One social worker played an important role by making special relaxation tapes for the woman.

How a psychic healer helps. One woman experienced a release her emotional pain--and subsequently her physical pain--through healing sessions with a psychic healer. This woman perceived the psychic healer as being instrumental in helping her work through unresolved childhood issues.

Seeking Knowledge

All co-researchers expressed a desire for knowledge regarding their cancer and related pain, although the nature and quantity of that knowledge varied from person to person. One woman felt "most able to handle pain" when she understood what was happening to her and felt able to actively participated in her "healing process". Meanwhile, another woman perceived it was helpful to "deny" some of the things that were happening. There were times in each woman's experience when "not knowing" about something had been helpful.

- C: In the beginning not knowing helped--it made me sleep better. Because the first time around there's a lot more fear that you have to deal with . . . not knowing how far [the cancer has] gone.

Perceived lack of knowledge. Co-researchers focused most often on what they "didn't know" rather than what they did know. They commonly perceived that they lacked sufficient knowledge to manage their pain effectively at home. Frequent examples were cited to clearly demonstrate the consequences of trying to manage without appropriate knowledge.

Prior to their recurrences, five of the six women never knew their breast cancer could eventually metastasize to their bones. Typically, they wished their doctors would have told them what warning signs to look for. They expressed considerable frustration and anger that their own ignorance likely contributed to their current situation.

Co-researchers also cited common experiences in which they lacked important information about medication side effects. As well, most women did not feel they had a sufficiently clear understanding of their disease processes and treatment plans. One woman lacked awareness that there were many painkillers were available, in addition to those she had already tried.

All co-researchers used the opportunity of the research interview to ask questions about their cancer and related pain. Most commonly requested information regarding the following concerns: how and where breast cancer spreads; managing side effects of treatments and painkillers; future possibilities and treatment options; chemotherapy; monitoring treatment response; and available resources.

One woman spoke of the value of learning from other women coping with metastatic breast cancer and related pain. The remaining co-researchers lacked knowledge of a norm group with which to compare their experiences, and used the research interview to seek frequent validation regarding the normalcy of their experience.

Two women perceived themselves as lacking information about available community resources, and used the opportunity of the research interview to request information they felt might be of use to them. One woman emphasized how many resources were available in the community and at the cancer treatment centre, but that it had taken her much time and effort to discover them. The remaining women had some knowledge of available resources, but did not feel a need for them at the time.

Some of the co-researchers' requests for information required referral to appropriate health care professionals. Such referrals were commonly met with enthusiasm at discovering another source of knowledge and support.

Obstacles to acquiring knowledge. Several obstacles were identified that prevented women from acquiring desired information. Most commonly, co-researchers felt constrained because doctors appeared to be in a "rush", because women were not always sure of the appropriate questions to ask, and because they were concerned about not understanding the answers to their questions. One woman was having difficulty absorbing and retaining information, and felt self-conscious about having things repeated. Women were commonly prevented from

attending support groups, often scheduled at night, because of their increased pain and need for sleep during evening hours. A further barrier to accessing resources was imposed by the distance co-researchers had to travel to the cancer treatment centre, where many cancer-related resources were understood to be centralized.

What women want to know. Women commonly cited the kind of information that was most helpful to them in managing their self-care at home. Most of all, women wanted to know enough about treatments and medications to be able to anticipate and manage their side effects at home. Women repeatedly emphasized the importance of having some sense of what to expect in the future. They also expressed a common desire for more information about using narcotic painkillers to manage pain. Those who had waited on lists for radiation treatment wished they had been told why they had to wait, and approximately how long the wait would be. One woman said it would have been useful to have someone show her how to make practical adjustments to accommodate her physical disabilities.

Helpful sources of knowledge. Co-researchers commonly relied on their doctors as the primary source of information regarding their disease and treatment. Nurses were the next most commonly utilized knowledge source. Books and articles were frequently mentioned as valuable information sources. Books authored by persons who had survived cancer were considered of particular benefit. For example, Jill Ireland's book was cited several times as being very helpful. Women also gained knowledge from media sources and friends. One woman began

educating herself about cancer when her husband was diagnosed with it. In her desire to support him through his illness, she tried to learn everything she could about cancer from available literature at the cancer centre library.

Assuming responsibility for learning. Commonly, women came to believe that they were responsible for seeking out the information they needed to effectively manage their pain at home. They typically perceived that health professionals provided information primarily on request, rather than offering it spontaneously. Women had to learn how to be active participants in their care, rather than passive recipients of care provided by others. Assertiveness was considered a necessary strategy for a successful outcome in the quest for knowledge.

Negotiating the Health Care System

Co-researchers commonly identified that learning to deal with the health care system and related procedures was one of the most vital components of managing their pain in the home setting. Upon engaging with the bureaucratic structure of health care facilities, co-researchers commonly felt a loss of privacy, independence, and control as they accommodated to the system. This imposed very little difficulty for one co-researcher, but was considered a major source of anxiety among the others, who expressed their feelings of powerlessness and frustration openly.

Hindrances imposed by the system. Co-researchers commonly discussed what it was like for them to depend on various aspects of the health care system for treatment, information and support. Four of the six women shared a common

concern regarding the lengthy interval between their first report of pain and eventual diagnosis of recurrence. They typically questioned the apparent difficulty of diagnosing such problems, considering this "day and age" of sophisticated medical technology.

Three women strongly criticised the system that did not have radiation treatments readily available, causing them to endure weeks of pain while they waited on a list, for the treatment proposed most likely to offer relief of their pain.

E: Just knowing there is treatment available, but knowing I can't have it!

F: This, where [my spine is] collapsed, I mean you'd think they'd RUSH this . . . And then I heard on the TV that, there is a waiting list of up to TWELVE weeks!

A common complaint among all co-researchers concerned the long waiting periods experienced at the cancer treatment centre. Women described waiting, in pain, up to sixty minutes for pre-scheduled appointments. Some women felt further hindered by the impersonal nature and lack of privacy at the cancer treatment centre. Recall Betty describing how the hospital environment made her feel like one in a herd of sheep. Two women pointed out that the heavy doors there were especially difficult for patients to handle. For some, the commute to the central cancer treatment centre was very taxing. One woman expressed frustration that Laetrile, the drug she sought for treatment of her cancer, was not available through the Canadian health care system.

One co-researcher qualified her complaints about the system as "minor", saying she felt very pleased "they could control" her cancer. She also felt better able to deal with the system because of her familiarity with illness.

Assuming responsibility for one's own recovery. Co-researchers frequently referred to the resourcefulness and persistence one needs in order to care for one's self at home, isolated from the hospital setting. Four of the six women asserted that resources and support were inadequate for those managing their breast cancer-related pain at home. They also spoke about the process of educating themselves, through trial and error, to use "the system". Although in different stages of acquiring the knowledge and skills they needed to manage at home, women commonly perceived there was limited help along the way. Each woman eventually concluded that it was up to the individual to assume responsibility for their own recovery, according to their own personal values.

A: You are really very much on your own.

.....

B: You've got to take control of your own life if you want to know what's going on!

.....

B: You [learn] to look after yourself, but you don't get any help. If you're self-reliant . . . that's the only way you're going to get things done.

IV. Looking to the Future

The fourth major theme related to the co-researchers' future. Despite coping with the threat of death, women looked to the future with determination and hope. Most commonly, concerns for the future included goals and expectations, quality of life, and fears.

Future Goals and Expectations

Despite managing various levels of disruption and disability, co-researchers described individual goals and expectations regarding the future. Even in the face of a "death sentence", one woman decided to do whatever she needed to do in order to enjoy a certain quality of life with whatever time she had left. Just short of a year later, she reported being alive, pain free, and living a fruitful life.

Quality of a life. When contemplating the quality of their lives, co-researchers most commonly valued their ability to maintain independence and whatever they perceived to be "normal" life. The value placed on normalcy in their day to day lives was repeatedly emphasized. Management of pain was viewed within the context of these issues, with careful consideration given to whether pain relieving strategies were likely to enhance or diminish the quality of their lives. Goals were not so much to obtain complete freedom from pain, but to manage pain at a level where life was livable, according to individual standards. Most co-researchers elected to tolerate a certain level of pain in order to continue managing their daily lives.

Only one woman was eventually able to report living a "normal" life while achieving complete pain relief from painkillers.

Having purpose and hope in life. Co-researchers commonly felt a sense of purpose in their survival. For example, Diane wanted to see her son through his divorce, and Ann wanted to resume the full responsibilities of her role as a mother. Hopes for the future were often tempered with caution, shifting as women considered the potential realities of their future. Recall Carla contemplating her future, after fulfilling a goal that had kept her going for so long, "It is really quite tiring staying comfortable . . . I don't know if I want to deal with it much longer". Six weeks later she died.

Fears. Co-researchers commonly expressed fears regarding the uncertainty of their future. All feared the prospect of increasing pain, dependence, and becoming a burden to their loved ones. Both women who had not previously had chemotherapy expressed great fear about the possibility of needing chemotherapy in the future.

Summary

This chapter presented an integrated description of how women with breast cancer manage related pain in the home setting. Chapter Six will present a discussion of research findings, implications for theory and practice, and a brief conclusion.

CHAPTER 6

Discussion

Introduction

This chapter will discuss study findings in relation to other research, followed by a discussion of implications for theory, research and practice, and a conclusion.

Discussion of Major Findings

As indicated in the review of cancer pain research presented in Chapter Two, cancer pain is a complex experience about which professionals are just beginning to learn.

Threat to a Life

In this study, four of the five women who originally underwent mastectomies for primary breast tumours, subsequently lacked critical knowledge regarding the warning signs of breast cancer recurrence. These women reported seeking medical advice repeatedly before the discovery that recurrent cancer was causing their persistent complaints of hip pain. Angry and frustrated that their own ignorance may have contributed to delayed diagnosis and treatment, they commonly ruminated about "what might have been", if only they had been better advised

regarding the potential spread of cancer to areas other than their remaining breast.

These findings are consistent with recent study results, in which 75 percent of patients reported being given no information regarding the source, or expected course of their cancer (Bonica, 1990). Carnevali and Reiner (1990) suggest that integration of health-monitoring behaviours into daily life occur most often when one feels a threat to life, such as cancer. They also stress the importance of knowledge as a motivating force in self-monitoring activities. The presence of self-care agency (the ability for engaging in self-care) develops through the process of learning and using knowledge in day to day life (Orem, 1985). Thus, knowing about early symptoms of cancer recurrence is critical for self-care agency. Without being aware of the warning signs to look for, the effectiveness of self-care among women with breast cancer is limited. In addition, the length of time it took for accurate diagnoses of metastatic cancer was considered unacceptable, causing significant personal distress for the women involved.

Co-researcher reports of physical pain were typical of metastatic breast cancer pain caused by tumour invasion of pain-sensitive bones and nerves (Arathuzik, 1991; Bonica, 1990; McCaffery, 1979). Women had difficulty finding words to effectively communicate a description of their pain. One woman's statement that there simply "were no words" to accurately portray the extent of her pain, is echoed in Bonica's (1990) assertion that the experience of chronic cancer pain is "almost beyond comprehension, let alone description".

As previously indicated, pain relief strategies are largely based on assessment and understanding of verbal expression of pain. The manner of expressing pain, and the means by which that expression is understood, are crucial to effective pain management. Recent studies show that approximately ten word descriptors account for 67 percent of words used by patients to describe pain and its intensity (Gaston-Johansson, Albert et al., 1990; McIntyre, 1988; Norvell, Gaston-Johansson et al., 1990; Tearnan and Cleeland, 1990).

The current study concurs with previous studies suggesting the words "pain", "hurt", and "ache" as the most commonly used descriptors of very intense pain. However, in this study, the term "ache" was also commonly used to describe much less intense pain. The implications of attempting to quantify pain by single word descriptors or numbers are obvious, especially considering the large gaps that have been found between patient and care giver understandings of language used to describe pain (Grossman, Sheidler et al., 1991; Norvell, Gaston-Johansson et al., 1990).

Cleeland (1990) documents poor correlation between care giver perceptions and patient reports of pain, concluding that the common practice of administering pain medications based on observing patient behaviour has little to recommend it. This is further supported in the present study. Despite her expertise and experience in the area of cancer nursing, the researcher failed to realize the full extent of each woman's pain until development of trust and considerable exploration had taken place.

This study confirms previous indications that patients tend to minimize the severity of their pain, and even neglect to report it (Bonica, 1990; Carnevali and Reiner, 1990; Cleeland, 1990; Grossman, Sheidler, et al., 1991; McMillan, Williams, et al., 1988; Syrjala, 1987). In-depth knowledge of each woman's experience invariably revealed that all six women were experiencing significantly more pain than they initially described.

Disruption of a Life

This study confirms previous suggestions that cancer-related pain commonly imposes overwhelming intrusion on a life (Arathuzik, 1991; Bonica, 1990; McIntyre, 1988; Syrjala, 1987). It is also consistent with other studies identifying loss of mobility, persistent fatigue, loss of personal control, and loss of independence as the most disruptive and far-reaching consequences of cancer pain. (Bonica, 1990; Arathuzik, 1991; Ferrell and Schneider, 1988; McIntyre, 1988). Existing literature, however, does not provide detailed insight into the personal and emotional aspects of living with cancer pain.

Fluctuating levels of mobility and independence were perceived to be among the most profound disruptors of daily life. Consistent with previous findings, women experienced a wide range of emotional responses regarding immense losses related to valued roles, experiences, and activities. Diminished feelings of usefulness were experienced primarily as a result of losing vocational and domestic roles. This elaborates on Arathuzik's (1990) recent study, in which women managing pain perceived the inability to perform routine housework as a most significant loss.

Relationships between cancer pain, fatigue, sleep deprivation, and emotional distress have yet to be established in the literature (Arathuzik, 1991; Irvine, Vincent et al., 1991; McIntyre, 1988). In this study, women described pain and fatigue in relationship to each other, as part of a vicious, cyclic pattern. They also referred frequently to the interrelated nature of pain, fatigue, sleep disturbances, and emotional distress. Persistent fatigue caused the most distress, concurring with McIntyre's (1988) suggestion that the problem of fatigue associated with cancer-related pain is more significant than previously thought. This elaborates on Arathuzik's (1991) study, in which 73 percent of women with metastatic breast cancer described fatigue as a major contributor to their pain experience. Although the finding of fatigue as a primary concern among cancer patients is well established, research investigating the subject is limited and has been criticized for its lack of sound methodology (Irvine, Vincent et al., 1991; Pickard-Holley, 1991). Sleep disturbances were also a serious problem for women in this study, corroborating previous research citing sleep disruption as one of the most disabling consequences of chronic pain (Bonica, 1990; Morin and Gramling, 1990).

This study validates earlier research indicating that cancer pain has a profound impact on friends and family of the person with cancer, contributing to supportive and/or strained relationships. It also confirms Arathuzik's (1991) findings that women with breast cancer do not always discuss pain and related concerns with significant others for fear of distressing them; and that they are very concerned about how family, especially children, are coping. In this study women perceived

their spouses were having more difficulty coping than they were themselves. This is further substantiated in one study in which spouses reported greater distress than did cancer patients (Keital, Cramer et al., 1990).

One woman's experience stood apart from the others, in that she perceived her cancer and related pain did not disrupt her ability to carry on as usual. She differed from the other women because she had previous experience managing chronic illness, and reported frequent use of "denial" as a means of coping. At times she pretended to have arthritis, not cancer. Although current research seems to perpetuate the belief that all patients with cancer pain suffer serious physical, psychosocial, and behavioral consequences; several studies emphasize that not all persons suffer major disruption in their lives due to cancer pain (Bonica, 1990). One study suggests that some individuals cope more effectively by blocking out, or denying illness and related effects (Keitel, Cramer et al., 1990).

Taking Control and Managing a Life

The main purpose of this study related to what women were actually doing at home to manage their pain. Women were primarily concerned with the task of living a "normal" life in spite of pain, and in the abnormal presence of an unpredictable, debilitating disease commonly viewed with fear and social stigma. All efforts to manage pain were considered in relation to keeping control and living a normal life.

These findings are best understood within the context of psychological concepts of personal agency and causation. Personal agency refers broadly to the

existence of intentionality, or purpose, in an individual. The individual acting with intentionality "has a sense of capability" and "can respond in the moment to changing life situations" (Ivey, Ivey et al., 1987). The concept of self-efficacy, rooted in behavioral psychology, also embraces the view of persons as agents. Persons are seen to progress most effectively when they feel a sense of control over their own destiny (Ivey, Ivey, et al., 1987). Personal agency also refers to having the ability to use personal and external resources successfully (Kobasa and Pucetti, 1983).

DeCharms (1976) views people as having the capacity for, and being positively directed towards, self-determination. Persons are perceived to have the ability to control and influence the events of their lives through their own actions and personal commitments. In his theory of personal causation persons are motivated according to what is personally meaningful to them. They are referred to as "origins of their actions" or "pawns at the dictates of others" (Cochran, 1988). "Origins" perceive themselves to be the product of their own free choice, feeling a sense of control over their fate. "Pawns", on the other hand, view their locus of control as being external and beyond grasp. "Origins" are typically determined, optimistic, and accepting of challenge; while "pawns" feel powerlessness and impotent (deCharms, 1976). Whether one assumes a stance of "origin" or "pawn" towards the experiences of life strongly influences one's behaviour and consequences in that life.

In light of these theories, interviews indicate that all co-researchers were in various positions of assuming an "origin" stance towards their experience of

managing cancer and related pain. Some were in the gradual process of shifting from previous "pawn" positions to more active, "origin" stances. This was evident in the shift from being passive recipients of care, to the position of assuming responsibility for their own care. One woman's movement away from a position of powerlessness and passivity was particularly dramatic. In the beginning, she felt helpless in the face of cancer, related pain, and even death. She believed she had a year, at the most, to live. Her transition toward a more active stance seemed to begin over the course of our interviews, which provided a climate for her to think, feel, and explore freely as her story unfolded. As she evaluated herself and her situation, she sought new information. In doing so, she became more aware of new possibilities and her own freedom to make choices about her care. She shifted from a position of being resigned to a life of pain, to one of seeking more effective pain control. Her sense of empowerment was apparent as she began assuming responsibility toward her vision of a good life. A year later she had achieved her goal of freeing herself from pain, and was living what she perceived to be a good life. Looking back on the previous year, she expressed embarrassment regarding the "pawn" like role she had been enacting.

Women commonly assumed "origin" like qualities, managing their pain in ways that enabled them to maintain or enhance personal agency. These were the coping strategies they consistently found to be most effective. Interviews indicate that knowledge was an empowering, and essential, component of agency. Thus, the most helpful means of managing pain were those that provided a sense of control,

knowledge, and the means to live a worthy life. The most significant aspects of living a worthy life focused on maintaining a sense of normalcy, having control, feeling a sense of hope, and maintaining independence. These findings are consistent with those of two recent studies (Arathuzik, 1991; McIntyre, 1988) and suggest that controlling pain cannot be viewed in isolation from the life encompassing it.

Consistent with previous research, medications were used as the primary method of pain relief, and were not taken regularly or as prescribed. Some of the reasons cited for resisting medications have been documented in earlier studies, including: fear of addiction; socio-cultural beliefs regarding illness and taking medicine; previous negative experiences with medications; and lack of information about painkillers (Arathuzik, 1991; Bonica, 1990; Ferrell and Schneider, 1988; McCaffery, 1979; McIntyre, 1988; Bonica, 1990; Stjernsward and Teoh, 1990).

Most often, women refrained from taking painkillers in order to maintain control and enhance personal agency. This finding has had limited exploration in the research. In a recent qualitative study of cancer pain from the patients' perspective, patients perceived keeping control as being more important than controlling pain, and their decisions not to take medications were often kept from health care professionals (McIntyre, 1988). Arathuzik (1991) found that, even when counselled by doctors and nurses to do so, some patients experiencing moderate to severe pain failed to take stronger pain medications on a routine basis. The current study confirmed and further explicated these findings.

This study indicates that women took just enough medication to reduce their pain to a level that they perceived tolerable. Most commonly, concerns regarding serious side effects prevented them from taking painkillers regularly or in larger doses. Although their pain was better controlled when medications were taken regularly, all women preferred to tolerate some pain in order to minimize the distressing effects of painkillers. These findings concur with those in another study, in which patients provided "vivid descriptions" of what side effects meant for them (McIntyre, 1988). Despite a plethora of literature on the management of drug side effects, little could be found to further understand how patients experience side effects, from their own perspective. In contrast to the indications of this study, available research on the efficacy of opioids suggests that side effects are few, or are managed with little difficulty (Schug and Zech, 1990).

This study indicates that the patient's experience of opioid side effects is far more dramatic than suggested by the literature. All women complained of untoward side effects, with sedation or extreme drowsiness causing the most concern. Women reported feeling "out of control", "dopey", "dizzy", "like a zombie", from the effects of painkillers. Severe constipation was also a significant problem, and intense nausea was a frequent consequence of taking increased doses of medication. Antinausea medications commonly caused even more drowsiness. Medication side effects were often considered worse than the pain itself.

Taking enough medication to completely eradicate cancer pain was commonly viewed as giving control over to the cancer. A typical meaning attached to the pain

was that it provided a gauge for monitoring the underlying disease. Taking painkillers implied a risk of losing that measure, or sense of control.

The literature frequently refers to the importance of past influences and meanings given to cancer pain (Arathuzik, 1991; Bonica, 1990; Ferrell, Schneider, et al., 1988; McIntyre, 1988). This was further validated and elaborated on in this study. The meanings women gave to cancer and related pain were highly unique and individual, often based on past memories and experiences. This study also confirmed previous research suggesting that cancer pain provokes fear because it is believed to be a warning sign of progressing disease (Bonica, 1990).

This study's cases add to previous research by providing a deeper understanding of the patient's hesitance to take medications on a routine basis. Most literature on the subject is based on quantitative methodology, from the health professional's perspective. Such findings present a limited and one-sided perspective.

The finding that women almost never achieved complete freedom from pain, despite using increased levels of painkillers, is consistent with several recent research findings (Arathuzik, 1991; Ferrell and Schneider, 1988; McIntyre, 1988). As well, these findings show that complete relief of cancer pain is possible, as evidenced in the case of one woman.

Consistent with many previous studies, women used a wide variety of cognitive and behavioral approaches to complement their use of medicine and treatments for managing pain. Self-care behaviours were highly individualized

according to each woman's personal style. A new finding, not found in previous studies, indicates that the most common and highly valued self-care behaviour for managing pain was to obtain sufficient rest and sleep. Women did this by taking naps throughout the day, establishing a flexible routine directed towards conserving energy for managing pain, and settling early.

Distraction techniques were also commonly used, and perceived to be effective measures for coping with pain, substantiating previous research (Arathuzik, 1991; McIntyre, 1988). Other consistently used strategies, which have been cited in earlier studies, included using physical aids to enhance mobility, remaining active and busy, positioning, application of heat, relaxation, life review, and maintaining contact with "the outside world".

As "origins" of their fate, women perceived themselves to be coping well when they felt in control. Consistent with other research, loss of control was most often associated with very intense pain, loss of hope, lack of knowledge, and new pain. Acquiring a sense of control was very highly valued, and commonly achieved through these "origin" like attitudes: determination, active participation in care, seeking knowledge, making informed decisions, assertiveness, maintaining hope, and having a positive attitude. Arathuzik's (1991) recent study identified that breast cancer pain frequently caused individuals to feel a sense of determination to get well, achieve life goals, and overcome pain. The importance of hope, optimism, and positive attitude in achieving a sense of control over pain were repeatedly emphasized in the current study.

Current literature on pain management repeatedly emphasizes the importance of patient education as a factor in achieving effective pain control (Bonica, 1990; Ferrell and Schneider, 1988; Marino, 1981; Ziegfeld, 1987). Many previous studies establish that patients, as well as professionals, frequently lack the information needed to successfully manage pain. This study further substantiates earlier research, indicating that women perceived themselves to be lacking the knowledge needed to manage their pain effectively at home. Most of all, women wanted to know enough about treatments and medications to be able to anticipate and manage their side effects at home.

Women found that one of the most useful ways of enhancing personal agency was through the acquisition of knowledge. This included asking questions of health professionals, reading newspaper and magazine articles, and books written by cancer survivors. Nurses were perceived to be the most helpful providers of information. These findings, from the patient perspective, were not found in earlier literature.

Often, women experienced feelings of helplessness and loss of control, in the face of a dreaded, overpowering disease. They described feeling even more impotent in their experiences with the health care system and its members. The challenge of enacting from an "origin" like stance within a system and relationships that were perceived to foster dependence and passive acceptance, were problematic. The goal of eradicating pain with available pain medications seemed to conflict with enhancing personal agency and control, since the primary method of pain relief further undermined the ability to maintain control and live a normal life. By

choosing not to relieve their pain, these women were actually acting from a position of responsibility and choice, toward a life that was normal and livable. This attitude likely put them at odds with health care professionals, as both parties struggled toward conflicting goals. Ultimately, it became quite clear that the co-researchers were the managers of their pain and their lives.

Factors hindering the co-researchers' ability to enhance personal agency were consistent with previous findings, including: feeling constrained by doctors' time limits, not feeling like an equal participant in their care, not knowing what to ask, and being concerned about understanding answers to questions. Although it is cited throughout the literature that knowledge and technology exist to effectively control cancer pain, the current study suggests that pain is not being adequately managed by women managing cancer-related pain at home. This validates previous findings and inferences (Arathuzik, 1991; Bonica, 1990; Ferrell and Schneider, 1988; McIntyre, 1988; Schug, Zech, et al., 1990). Findings indicate, however, that women have acted as "origins" of their own fate and chosen to tolerate inadequate management of pain in order to maintain control of the life they value.

In conclusion, pain is highly subjective and unique to the person experiencing it. It cannot be reduced to a single digit or word. And it is constantly changing. The challenge of describing and managing cancer pain continues to be a serious problem for individuals and professionals alike.

Implications for Theory and Research

The problem of how women are managing breast cancer related pain in the home setting has not been adequately addressed in the literature. Current research is limited in scope and methodology, and is largely confined to unidimensional variables. As well, it is presented primarily from the perspective of the health professional.

This study adds to the current body of knowledge by providing an explicit description of coping with pain in context, but also raises many questions that can only be answered through further research, and from the perspective of the person experiencing cancer pain. Some of the main concerns in need of further study include: the patient's experience of pain killer side effects; relationships between sleep, pain, fatigue, and emotional distress; assessment and measurement of the pain experience; impact of cancer pain on the family of the person with cancer; effectiveness of psychological strategies to deal with pain; the patient's contribution to pain management; effectiveness of current strategies for patient education; and factors contributing to delayed diagnosis of recurrent disease.

The paucity of psychological research relating to management of cancer pain is glaring. Further research is needed to validate the efficacy of psychological interventions with cancer patients, and explore the role of psychotherapy in supporting individuals through their struggles of daily living.

The need for further exploring the problem of cancer pain management at home, from the perspective of the person experiencing that pain, is evident. It is

this knowledge that will assist professionals in their efforts to help individuals towards effective management of their pain in the home setting.

Implications for Practice

The complexity of concerns experienced by women managing breast cancer-related pain at home are best addressed through a combination of approaches, aimed not only at helping them manage pain, but also to achieve their maximum potential for normal living. Professionals must assist these women to assume an active stance, regain a sense of control, and move positively towards some meaningful end.

All professionals can integrate the following strategies into their practice, in order to enhance the individual's ability to act from a position of responsibility and choice in the management of their cancer pain: assisting individuals to develop their knowledge seeking skills; helping them in their ability to ask for assistance and to mobilize both internal and external resources; and assisting individuals to use varied coping responses, in addition to painkillers.

Because cancer pain is subjective, highly personal, and unique to the person experiencing it, professionals can most effectively attend to the particular needs of each individual by using a person-centred approach. In this study, women identified that adequate time, genuine caring, listening, and unconditional acceptance from professionals most enabled them to manage their pain from a position of choice and responsibility. These qualities are consistent with the mutual respect, trust, and balance of power inherent in the person-centred relationship.

In order to enhance an individual's feeling of empowerment regarding their ability to cope with cancer-related pain, professionals must aim strategies at restoring the individual's sense of control regarding feelings, cognitive and physiological processes, decisions, and surroundings. By encouraging open expression of feelings related to loss of control, a sense of emotional control can be fostered. Within their relationships with professionals, individuals must feel "allowed" to have pain, and permitted to express feelings related to that pain and its impact on their lives.

Providing information and minimizing uncertainty are valuable means of contributing to an individual's sense of cognitive control. In this study, home care nurses were identified as having a pivotal role as providers of information. To maximize their effectiveness with cancer patients, such professionals must have adequate knowledge of cancer and related pain, treatment, and the typical concerns among persons experiencing cancer pain. They must also examine the effect of their own past experiences, personal assumptions, and cancer-related fears, on their ability to provide effective support to persons with cancer.

Women in this study also cited media programs and lay literature as their most commonly utilized knowledge sources regarding the management of life with breast cancer and related pain. Educational brochures and patient teaching hand outs prepared by experts in the field of oncology remained largely unmentioned. It seems that professionals must review the effectiveness of their current patient education practices, and utilize strategies perceived most useful, or accessible, from the patient perspective. Professionals can provide cancer patients with the type of

knowledge and delivery of information they are most likely to find helpful, by familiarizing themselves with books, magazine articles, television shows, radio programs, and movies perceived to be helpful by individuals coping with cancer and related pain. Professionals can also assume a more active role in their contribution to lay publications and media programs.

Women in this study indicated that it was helpful to talk to other women experiencing similar circumstances, but said that structured support/education groups were inaccessible or not their preference. In light of this, it would be helpful for professionals to maintain a list of breast cancer patients willing to make themselves accessible to other women coping with the disease, and for professionals to routinely ask patients if they would like the name of a contact person familiar with the experience of coping with cancer, and from their own perspective.

The challenge of coping with uncertainty can be lessened somewhat for individuals if professionals provide information about what to expect regarding treatment outcomes, drug effects, and disease processes. Women generally expressed a desire for more in depth information than they perceived themselves to have been given by professionals. In particular, they wanted to have more information about potential warning signs of cancer progression. They also wanted to be given accurate explanations for radiation treatment delays, and more information about anticipated length of waiting for treatments.

A sense of decisional control can be enhanced by encouraging and allowing for individuals to become active, informed participants in decisions pertaining to them. Individuals may need assistance developing various coping skills, including: decision making, an ability to communicate more effectively and assertively with medical personnel, and skills necessary for successful negotiation of the health care system. Control over one's surroundings can be promoted by respecting one's privacy in the hospital setting, by ensuring the physical environment does not impose discomfort or immobility, and by minimizing the length of time one is left alone in hospital waiting areas.

Physiological control is achieved through effective management of pain, related physical symptoms, and drug side effects. The fact that individuals often under-report their pain--and possibly other physical symptoms--is compounded by a lack of multidimensional pain assessment tools. This places responsibility with the professional to thoroughly assess the individual's total experience of pain, taking into account the individual, their life, and their environment as a whole.

Women managing breast cancer-related pain in the home setting considered themselves to have important psychosocial needs, physical problems, and knowledge deficits, for which they often received inadequate support from professionals. It is evident that greater multidisciplinary expertise and support must be extended into the home environment. Doctors, psychologists, nurses, social workers, and other professionals must collaborate with each other in an effort to provide individuals with medical and non-medical strategies for managing lives fraught with suffering

and disruption. Further, professionals must present themselves as a unified team, collaborating with individuals and their significant others, in their attempts to manage the problem of cancer pain in the home setting.

Conclusion

This study leaves little doubt that the impact of breast cancer pain is potentially devastating to a life. Current literature on the subject fails to capture the enormity of suffering inflicted by cancer-related pain. By engaging in dialogue with women who have endured cancer pain in their own lives, this study provides a first hand description of what it really means to be coping with such pain in day to day life.

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Appendix A

MANAGEMENT OF BREAST CANCER PAIN IN THE HOME SETTING A PATIENT PERSPECTIVE

PATIENT INFORMATION AND CONSENT FORM

My name is Kathy Bartlett, and I am a graduate student at the University of British Columbia (Master of Arts, Counselling Psychology). I am conducting a research study under the supervision of UBC professor Dr Larry Cochran, with Dr Ivo Olivotto overseeing my study at [the cancer treatment centre].

I am interested in knowing what it is like for women who experience pain associated with breast cancer to manage their care at home. You have been recommended as someone who could make a valuable contribution to this study. I invite your participation, and hope that knowledge gained will contribute to the future care of patients.

If you would like to take part, it will involve two or three one hour interviews, in your home. You will be asked to describe how you have managed your pain on a day to day basis (how you make decisions about controlling your pain, what things you do to relieve your pain, what you find helpful or unhelpful, what you think and feel about your pain, how well you are able to relieve your pain). You may refuse to answer any particular question.

Interviews will be tape recorded to assist in writing reports. All information will remain confidential. Audiotapes and written records will contain no names, and audiotapes will be destroyed once they have been transcribed. No one will have access to this material other than myself and Dr Larry Cochran.

There are no direct risks or benefits to you for participating, although some people find it helpful to talk about their experiences with a professional. Your participation in this study is entirely voluntary. If you decide not to participate, or if at any time in the future you decide to withdraw from the study, your present and future care at the [cancer treatment centre] will not be affected.

If you have any questions now or at any time during the study, please call myself or Dr Olivotto at the numbers provided.

Appendix C

THE LIFELINE EXERCISE

The lifeline is an exploration exercise that focuses on your life as an evolving whole. It is simply a line drawn on paper, with the left edge representing your birth, and the right edge your death. Between them is the present. Draw your life line as follows: write in important life events (changes, transitions, crises, moves, illnesses) on the line between your birth and today. Write the positive events toward the upper part of the chart and the negative events on toward the bottom edge, recording the highs and lows in your life so far. Now draw a line connecting the events, to reflect the emotional climate and course of your life. Continue your lifeline, projecting into the future. All lifelines are unique, shaped by different events and actions or decisions.

Reference: Jaffe and Scott (1989).

Appendix D

MANAGEMENT OF BREAST CANCER PAIN IN THE HOME SETTINGA PATIENT PERSPECTIVE

SAMPLE INTERVIEW QUESTIONS

Participant Description of Pain and its Impact in Daily Living

We have used the lifeline to outline the period of your life I am interested in learning about, the time in which you have coped with pain related to your cancer. I am interested in developing an overall perspective of what it has been like for you since you first had pain. What has your life been like from the time you first experienced pain up until the present?

I would like to know about the pain you have had in the last day (week, month...). Can you describe it to me?

In what ways does pain interfere in your life, if at all?

When you are experiencing pain, what makes the pain better? or worse?

What do you think causes your pain?

What feelings do you associate with your pain?

When you are having pain, what do you think about?

Management of Pain by the Participant (cognitive, behavioral, affective strategies)

Tell me about managing your pain at home. What is it like?

What do you do that makes the pain better? disappear? worse?

Describe the physical (psychological, medicinal, spiritual, religious, other) things do you do to relieve your pain.

What things (medicine, herbs, foods, beverages, other substances) do you take to manage your pain?

How do you decide how often, and how much medicine (or other substances) to take?

I am interested in what leads people to try different things to manage their pain, while ignoring others. What led you to try the methods you are using to control pain?

Tell me about the things you do other than take medicine to relieve your pain.

What activities are helpful for you in controlling your pain?

What people help you to manage your pain at home? What has been the most helpful for you? the least helpful?

What suggestions do you have for other people who are trying to manage their pain at home? for professionals you are helping people to manage their pain at home?

Is there anything else you would like to tell me about your experience of managing pain at home?

Effectiveness of Pain Management, from Participant's Perspective

What does it feel like for you to have relief of your pain?

How effectively are you able to control your pain?

Appendix E

Letter Accompanying Case Studies for Validation

_____, 1991

Dear _____,

Enclosed you will find a draft of the case study I've written, based on our taped interviews and transcripts. Please review it and take note of errors, omissions, or areas where I have inaccurately perceived the meaning of your experience. Feel free to write on this copy however you choose. You will notice that I have used pseudonyms in order to protect your confidentiality.

The intent of the case study is to provide an explicit description of what it was like for you to be coping with pain at the time of our interviews. Please keep in mind that things may have changed since then, and the paper will only serve to reflect that earlier moment in time. I have structured the paper according to the subjects that were common to all six women interviewed.

I look forward to meeting with you briefly to discuss the case study and necessary revisions. Again, thank you for your commitment of time and effort. I will see you soon.

Yours truly,

Kathy Bartlett