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THE FIRST RECURRENCE OF CANCER:
REBUILDING THE HOPEFUL VENEER

by

LINDA READ PAUL ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of MASTER OF NURSING.

FACULTY OF NURSING

Edmonton, Alberta
Fall, 1994

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE FIRST RECURRENCE OF CANCER: REBUILDING THE HOPEFUL VENEER submitted by LINDA READ PAUL in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

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Date: Sept. 26, 1994

Dedication

To all the men and women who face a first recurrence of cancer.
May you be successful in rebuilding the hopeful veneer.

Abstract

The benefits of hope for individuals with cancer are well-documented. Lacking, however, is an understanding of hope in what may be the most discouraging phase of the cancer experience -- first recurrence. The purpose of this qualitative, exploratory study was to enhance understanding of the nature and significance of hope and the factors that influence hope in individuals experiencing a first recurrence of cancer. The purposeful sample was comprised of three men and three women, aged 37-64, who had varied cancer diagnoses. At the time of entering the study, each informant had experienced a first recurrence within the past one to two months and was receiving treatment aimed at achieving a second remission. Data were collected via repeat, unstructured, audiotaped interviews and were analyzed using content analysis and axial coding methods. Hope was inductively conceptualized as a protective, energizing veneer that varied in strength and stability throughout the cancer experience and, when intact, enabled informants to actively engage in life. The diagnosis of first recurrence caused this *hopeful veneer* to erode. As a result, informants were overwhelmed by suffering and disengaged from life. In order to re-engage in life and improve quality of life, they proceeded through a basic psychosocial process entitled *Rebuilding the Hopeful Veneer* wherein their hope was renewed and transformed. Through the phases of *appraising* and *reframing*, informants found grounds for hope, dealt with the negative implications of the recurrence, reframed their visions of self and future both realistically and positively, and redefined their objects of hope. Rebuilding was part of a larger cyclical process of *Maintaining the Hopeful Veneer* throughout the cancer experience. Once rebuilding was complete, informants *reinforced* the veneer by using conscious denial, re-establishing normalcy, and living differently. They also regularly *monitored* the integrity of the veneer. Movement through the process of *Maintaining the Hopeful Veneer* was influenced by hopeful and ominous signs, hoping resources and inhibitors, and facilitating and inhibiting hoping contexts. Based on study findings, assumptions regarding unrealistic hope and denial are challenged and implications for nursing practice and research are presented.

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CHAPTER 1

INTRODUCTION

The purpose of this research study was to enhance understanding of the nature and significance of hope and the factors that influence hope for individuals experiencing a first recurrence of cancer. The idea for this study originated during my clinical nursing practice. Given these origins, I have devoted this first chapter to a description of the genesis of the research and the rationale for conducting the study from the perspective of nursing practice. In Chapter 2, I substantiate the need for the study on theoretical and empirical grounds.

Hearing the Story and Sharing the Pain

The idea for this research study originated during my relationship with Joan, a woman with recurrent, metastatic breast cancer. Joan eloquently and openly shared her cancer experience with me. She invited me into her world and allowed me to help her in her struggle. As a result, I was able to view the experience through her eyes, feel the impact of the many assaults on her body and spirit, and share in her pain.

I met Joan in the context of a clinical practicum in my Master of Nursing program. Our initial encounter was during an out-patient visit where the oncologist coldly informed her that the cancer had spread to her liver and bones. I sat with her for several hours thereafter, helping her recover from this first of many assaults. Subsequently, I accompanied Joan during chemotherapy treatments and out-patient clinic appointments and visited her at home. From our initial encounter through to the end of our two month relationship, it was obvious that Joan's hope was fragile and that its sustenance was central to her continued existence. She described how she was working very hard at being positive and how she believed this kind of attitude would facilitate her recovery. Positive thinking, imagery, and humor were a few of the strategies she used. She told me she was fully cognizant of her prognosis and not afraid to die, but had made a conscious decision to focus on living rather than dying. She felt that if she stopped hoping and thinking positively, she would quickly succumb to her disease.

Many factors threatened to hinder or destroy Joan's hope. Some of these threats to hope were related to declining health status, while others were the result of the words or actions of the various health care professionals with whom she was in contact. After a clinic visit with a physician, she made the comment, "He's given up on me. He doesn't have any hope for me at all. I know he just thinks I'm going to die." This impression was gleaned entirely from nonverbal cues and behaviours. When a nurse told her she had end-stage liver disease, Joan said, "When she used that word 'end-stage,' she took all my hope away." She described how the impact of the word left her "catatonic" for several hours. Following that episode, I witnessed a decline in Joan's hope and a fading of her spirit. She died a few weeks later.

Amongst the health care professionals involved in Joan's care, I sensed a pervasive perception that Joan was "in denial" and a concern that she was not responding "appropriately" to her situation. She was far too positive for someone so gravely ill. On more than one occasion, I was asked whether or not Joan knew she was dying, the assumption being that her attitude and behaviour could only be explained by a lack of awareness of her prognosis. The health care professionals seemed to believe that Joan's determination to be hopeful and not focus on dying was to her detriment when, in fact, it provided her with the strength and the desire to continue living.

Sensing Problems and Raising Questions

This rich experience was intensely thought provoking and disturbing. I became acutely aware that nurses and other health professionals didn't seem to understand the nature and significance of hope for this woman with recurrent cancer, nor did they realize the impact of their attitudes, actions, and words on her hope. This experience led to my desire to talk to other people with recurrent cancer about their hope. I questioned: Is hope equally vital to other individuals with recurrent cancer? Do others experience the same struggle to maintain hope? How can health care professionals best foster their hope? What other factors might influence hope for this population? I also wondered if answers to such questions had already been explored by other researchers and this knowledge had not yet been integrated into practice, or if a gap in knowledge in this area existed. Hence, I next conducted a review of the literature on hope in the contexts of cancer, cancer recurrence, and nursing practice, the results of which are included in Chapter 2. This review substantiated the need for the study and led me to narrow my focus to those individuals experiencing a first recurrence of cancer.

Explicating the Value of the Study

By conducting this study, I hope to enhance my own and others' understanding of the nature and significance of hope and the factors that influence hope for individuals experiencing a first recurrence of cancer. This understanding may lead to improvements in the nursing care of these individuals and, thereby, may improve the quality of their lives. In addition, propositions and ideas for future research developed from this study may lead to further advancements in knowledge and provide more definitive recommendations for nursing care. It is my sincere hope that the knowledge gained from informants in this study will result in a reduction in assaults to hope and an enhancement of hope for patients like Joan who are faced with a recurrence of cancer.

CHAPTER 2

REVIEWING THE LITERATURE

Prior to commencing this research study, I reviewed the literature on the topic of hope in the contexts of cancer, cancer recurrence, and nursing practice. The purposes of this review were to enhance my understanding of the present state of knowledge development in this area, identify where gaps in knowledge existed, and determine the need for this study. The results of this preliminary review are summarized in this chapter. In Chapter 9, literature found during this review as well as during a secondary review is discussed in more detail in relation to the findings from this study.

Hope in the Context of Cancer

Hope in the context of cancer has been a topic of qualitative and quantitative research in several disciplines, including nursing, medicine, psychology, psychiatry, sociology, and theology. Researchers studying hope in this context have selected samples on the basis of several factors, including type of cancer, such as breast (Silberfarb, Maurer, & Crouthamel, 1980), gynecological (Mishel, Hostetter, King, & Graham, 1984) or leukemia (Perakyla, 1991); developmental stage, such as elderly (Dufault, 1981/1982) or adolescent (Hinds & Martin, 1988); treatment regimen, such as chemotherapy (Brandt, 1987) or radiation (Christman, 1990); setting, such as inpatient, out-patient, or home (Herth, 1989); and phase of the cancer experience, such as initial diagnosis (Mishel et al., 1984) or terminal (Hall, 1990; Hendon & Epting, 1989; Herth, 1990). Samples in all studies reviewed were comprised of individuals with cancer, with the exception of one wherein the perspective of oncology nurse specialists was studied (Owen, 1989). The results of this portion of the literature review are summarized below under two headings: (a) hope definitions, descriptions, and models; and (b) hope instruments and correlates.

Hope Definitions, Descriptions, and Models

Researchers studying hope in the cancer population using qualitative methods, such as open-ended interviews and participant observation, have contributed greatly to our understanding of this concept. The findings from these studies include definitions of hope (Dufault, 1981/1982; Herth, 1990; Hinds & Martin, 1988; Owen, 1989); conceptual models of hope (Dufault, 1981/1982; Owen, 1989); descriptions of hope objects, sources, and threats (Dufault, 1981/1982); strategies to foster hope (Dufault, 1981/1982; Herth, 1990); and changes in hope over time (Dufault, 1981/1982; Herth, 1990; Perakyla, 1991). There are both similarities and differences in these findings. No universal definition of hope has emerged. Hope has been defined as an inner power (Herth, 1990), a process of responding to changing life events (Owen, 1989), a life force (Dufault, 1981/1982), and the degree to which one believes a positive future exists (Hinds & Martin, 1988). Descriptions and models of hope all reflect its dynamic, multidimensional nature. They also include an element of anticipation of a meaningful, future good and a perception that hope is vital to maintenance of a satisfactory quality of life. Findings suggest that hope objects, sources, and dimensions change over time in response to changing life circumstances, particularly changes in health status, and that some aspect of hope is always operative. Descriptions of the sources of hope and hope fostering and hindering strategies reveal a broad range of influential factors both internal and external to the hoping person, including attitudes, verbal and nonverbal behaviours, and well-being of self and others; memories; and relationships with other people, pets, objects, or with God.

While the majority of qualitative researchers used general exploratory methods or ethnographic methods, researchers in two studies used grounded theory methods. Neither of these latter two, however, developed a theory of the hoping process. Hinds and Martin (1988) set out to determine the process through which adolescents experiencing cancer achieve a hopeful state but discovered this process was one part of a larger process, that is, the process through which adolescents comfort themselves during health-threatening periods (Self-Sustaining process). Owen (1989) inducted a model of hope that included six critical attributes, one of them being a core attribute, but did not describe a process.

Hope Instruments and Correlates

Various conceptualizations of hope have provided the basis for the development of instruments that quantify hope and measure hope level. Early instruments, based on Stotland's (1969) narrow, unidimensional definition of hope, measured only the importance and probability of attaining future-oriented goals (Erickson, Post, & Paige, 1975; Stoner & Keampfer, 1985). More recently developed instruments, including the Miller Hope Scale (Miller & Powers, 1988), the Nowotny Hope Scale (Nowotny, 1989), the Herth Hope Scale (Herth, 1991), and the Herth Hope Index (Herth, 1992), more comprehensively reflect the multidimensional nature of hope.

Some authors have conceptualized hope as the polar opposite of hopelessness (Gottschalk, 1974; McGee, 1984; Stotland, 1969). Hope level has thus been indirectly measured in individuals with cancer using scales and structured interviews that measure level of hopelessness (Brandt, 1987; Christman, 1990; Greer, Morris, & Pettingale, 1979; Grossarth-Maticek, Bastiaans, & Kanazir, 1985; Mishel et al., 1984). The most common and most psychometrically sound instrument used in these studies is the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974).

Levels of hope or hopelessness in individuals with cancer have been measured in a variety of recent correlational studies. A high hope level (or low hopelessness level) has been associated with better health outcomes for individuals with cancer and has been significantly related to coping and adjustment (Christman, 1990; Greer et al., 1979; Grossarth-Maticek et al., 1985; Herth, 1989; Mishel et al., 1984). Thus, the positive impact of hope on the physical and emotional well-being of the individual with cancer is apparent. Furthermore, a high hope level in individuals with cancer has been positively related to increased strength or helpfulness of religious beliefs (Brandt, 1987; Herth, 1989), personal control (Brandt, 1987), internal locus of control (Brockopp, Hayko, Davenport, & Winscott, 1989), and preference for active involvement in treatment decisions and detailed information (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Hope level has been negatively correlated with recalled information about life expectancy (Stoner & Keampfer, 1985), uncertainty (Christman, 1990; Mishel et al., 1984), interference with family role responsibilities (Herth, 1989), and fatigue level (Herth, 1992). Activity level, ability to perform job responsibilities, length of time since diagnosis, phase of illness, and demographic variables such as age, gender, marital status, education level, ethnic origin, and family income have generally not been significantly correlated with hope level (Brandt, 1987; Cassileth et al., 1980; Herth, 1989, 1990; Mishel et al., 1984; Stoner & Keampfer, 1985).

Although hope scales have potential relevance and usefulness in measuring and comparing individuals' hope levels in various populations and under varying circumstances, their reliability and validity has not been well-established, particularly in the oncology population. Furthermore, the assumption that the dynamic, complex, abstract phenomenon of hope may be captured and comprehended by a score is questionable.

Hope in the Context of Cancer Recurrence

In this review of the literature, I found no qualitative or quantitative study with a focus on hope in the context of cancer recurrence. Researchers have primarily studied hope in individuals who are newly diagnosed (Mishel et al., 1984) or in the terminal phase of the cancer experience (Herth, 1990). A few studies were found wherein hope levels of individuals at different phases of illness were compared, but the phase of recurrence was not specifically isolated and definitions of phases of illness varied greatly. For example, hope levels have been compared in individuals with local or advanced disease (Brandt, 1987; Herth, 1989), and in those individuals who have no evidence of disease, are undergoing treatment, or are receiving terminal care (Stoner & Keampfer, 1985). No significant differences were revealed in hope level across any of these phases.

The need for studying hope in the phase of recurrence is apparent in findings from studies of the psychosocial phases of the cancer experience and the experience of cancer recurrence. Weisman (1979b) identified four psychosocial phases in cancer: existential plight (first 100 days following diagnosis), accommodation and mitigation (from day 100 to time of first recurrence), recurrence and relapse (from first recurrence to commencement of palliative care), and deterioration and decline (from commencement of palliative care to death). In discussing the third phase, recurrence and relapse, he states, "Strangely, little psychosocial investigation into this phase has been done, although it may be the most discouraging and difficult period that a patient has to face" (p. 192). Indeed, fear of recurrence has been consistently identified as a universal, ever-present emotional concern for individuals in cancer remission, regardless of prognosis (Canadian Cancer Society, 1992; Northouse, 1981). It is also of note that this fear may be greater in individuals with fewer significant others (Northouse, 1981).

Researchers studying the meaning, impact, and/or experience of cancer recurrence have suggested that this phase is fraught with existential and physical health concerns and may necessitate the revision of the long term hope for a cure (Chekryn, 1981; Mahon, Cella, & Donovan, 1990; Schmale, 1976; Weisman & Worden, 1986). In comparing the experience of initial diagnosis to that of recurrence, Weisman and Worden (1986) found that the average level of emotional distress in recurrence patients was not significantly higher or lower than in newly diagnosed patients. In contrast, Mahon and colleagues (1990) reported that individuals in their study found the recurrence of cancer "much more upsetting than the initial diagnosis, and they were far less hopeful and more discouraged" (p. 52). Several factors have been identified as potential influences on the level of distress experienced on recurrence, including the nature of the experience at initial diagnosis, amount of perceived support, extent of physical sickness and disability, and degree of surprise upon being diagnosed with a recurrence (Mahon et al., 1990; Schmale, 1976; Weisman & Worden, 1986); whereas the type of cancer and length of remission have not been shown to significantly influence the level of distress experienced on recurrence (Weisman & Worden, 1986). In addition, hope has been identified as a factor that facilitates effective coping with a cancer recurrence (Chekryn, 1981).

In studying nurse-patient interactions during the phase of recurrence, researchers have found that nurses may have the most difficulty communicating effectively with patients at this point in their disease trajectories (Mahon, 1991; Wilkinson, 1991), they may underestimate the devastating impact of recurrence (Mahon et al., 1990; Silberfarb, Maurer, & Crouthamel, 1980), and, hence, they may inadequately meet patients' psychosocial needs during this time. It has also been suggested that nurses need to develop strategies for enhancing patients' hope during this phase of the cancer experience (Mahon et al., 1990). Clearly, in studying hope in the oncology population, the phase of recurrence is deserving of further exploration.

Researchers studying the experience of cancer recurrence have commonly included participants with varying numbers of recurrences (Chekryn, 1984; Mahon, Cella, & Donovan, 1990). Findings suggest, however, that the experience of first recurrence may differ from the experience of subsequent recurrences. For example, Silberfarb, Maurer, and Crouthamel (1980) found that the most emotionally disturbing time for women with breast cancer was the time of first recurrence. Given these differences, it has been recommended that the number of recurrences be controlled in future research studies (Given, 1990). Hence, the value of isolating the phase of first recurrence in this research study is apparent.

Hope in the Context of Nursing Practice

Theoretical and empirical nursing literature clearly indicates that nurses play a significant role in enhancing, maintaining, supporting, and restoring hope in patients (Dufault, 1981/1982; Hickey, 1986; Lange, 1978; Miller, 1983, 1985; Travelbee, 1971; Vaillot, 1970; Watson, 1979). These roles are clearly reflected in the headings of nursing journal articles, such as "Enabling hope" (Hickey, 1986) and "Hope doesn't necessarily spring eternal -- sometimes it has to be carefully mined and channelled" (Miller, 1985). Inspiring or fostering hope has been described as integral to the primary aim of nursing, that is, "to help the patient reach out for a plenitude of being that is always possible, in spite of biological limitations against which medicine is helpless" (Vaillot, 1970, p. 272). Furthermore, "hope work" has been identified as an essential nursing skill (Perakyla, 1991).

Descriptions of hope within the nurse-patient relationship emphasize the relational or affiliative characteristic of hope. The nursing literature suggests that nurses can foster hope in patients and significant others by demonstrating hope for patients and conveying a hopeful attitude in the context of the nurse-patient relationship (Brown, 1989; Miller, 1983; Vaillot, 1970). Implicit in this statement is the assumption that hope is somehow contagious or transferable from one person to the other, an assumption that is widely supported in the hope literature (Lynch, 1965; Menninger, 1959; Pruyser, 1963). As Pruyser (1963) stated, "One little ray of hope in a world of darkness may be enough to invigorate [another person]" (p. 94). The following excerpt from an article entitled, "When the patient gives up," further illustrates this characteristic of hope:

> Hope is something that patients can't always find on their own. Relationship expert Helen Perlman (1983) says it well: "Hope is caught from the helper, like a lifeline. It buoys the spirit and restores energy" (p. 87)....[The nurse] could be the one to throw... that lifeline....[and] pull a patient out of the sea of hopelessness. Sometimes they just need to be shown that hope does exist -- before they can experience it on their own. (Stephany, 1992, p. 26)

The significance of enhancing and maintaining patients' hope is well documented in the nursing literature. Hope has been described as a healer (Laney, 1969), as a factor influencing crisis resolution (McGee, 1984), and as the restoration of being (Vaillot, 1970). Authors also emphasize that nurses need to maintain their own hope in order to be able to communicate this hope to patients (Brown, 1989; Lange, 1978).

Summary

Research findings have unequivocally demonstrated the benefits of hope for individuals with cancer and the central role of nurses in fostering their hope. Lacking, however, is an understanding of hope in the phase of first recurrence. This phase of the cancer experience may be the most discouraging and difficult and, hence, the one wherein hope may be needed most. Thus, there is a need for systematic exploration and advancement of knowledge of hope in the phase of first recurrence. Such an exploration will be undertaken in this study.

Refining the Research Questions

Based on a culmination of insights gained from practice, theory, and research, I refined my original questions and developed the following two research questions to guide this study:

For individuals experiencing a first recurrence of cancer:

(a) What is the nature and significance of hope?

(b) What are the factors that influence hope?

CHAPTER 3
CONDUCTING THE RESEARCH

In this chapter, I describe the process of conducting the research. Included are descriptions of the methods I used to accrue the sample, collect and analyze the data, enhance the trustworthiness of the data and analysis, and protect human rights. In addition, characteristics of the sample are described.

Selecting the Research Design

A qualitative, exploratory research method was selected for this investigation. Given the nature of the research questions and the questionable feasibility and relevance of measuring levels of hope, a quantitative method was clearly inappropriate. As Dufault (1981/1982) stated:

> Nurses' concern [should] not be directed at trying to measure whether or not a person has hope or how much one has as though hope were static but rather be directed toward detecting ways in which persons are or could be participating in hoping processes and how they can be supported in that participation. (p. 478)

A qualitative method was best suited to answer the research questions posed in this study for several reasons. First, the intent was to explore a phenomenon in depth from the emic perspective. Second, there was a paucity of previous research on the topics being investigated. Third, the utilization of this approach provided a means to study hope within a context, that is, within the context of a first recurrence of cancer, and thereby develop a more complete understanding of the informants' experiences (Brink, 1989; Field & Morse, 1985).

In the exploratory design used in this study, data were collected via repeat unstructured interviews and were analyzed using content analysis methods. Morse (1991a) has identified that this is a "legitimate [type of] qualitative research for which, as yet, there is no name" (p. 18). The design resembles that of ethnography but, due to the absence of participant observation, it cannot legitimately be labelled as such. Participant observation was not considered appropriate to answer the research questions given that hope is an internal, subjective experience. Grounded theory methods were also considered inappropriate given the lack of a process component in the research questions and the difficulty experienced by other researchers when they tried to isolate a hoping process in the cancer experience (Hinds & Martin, 1988; Owen, 1989). By selecting an exploratory design, the flexibility of the research approach was enhanced and I was able to be open to multiple ways in which the findings could emerge from the data, be they in the form of process or rich description of content.

Accruing the Sample

A nonprobability, purposeful sample was selected for this study. In other words, informants were sought who were best able to meet the informational needs of the study and who were considered to be "good informants" (Morse, 1991b). Potential informants included all adults who were in-patients or out-patients at a major Canadian cancer center during the time of the study and met the following criteria: (a) first recurrence of cancer within the previous one to two months, (b) receiving treatment aimed at achieving a second remission (i.e., not considered to be in the palliative or terminal phase of the cancer experience), (c) able to speak and understand English, (d) aware of diagnosis, and (e) home address within one hour of Edmonton. The time frame of one to two months since recurrence was chosen so the experience was recent enough to be readily recalled and yet distant enough to enable some reflection. Informants receiving palliative care were excluded so that the experience of recurrence rather than terminality could be captured and so informants were not yet facing the loss of hope for cure. Men and women of various ages and with varied types of cancer were sought so the common experience of first recurrence, irrespective of gender, age, and site of cancer, could be captured. In addition to meeting the above criteria, "good informants" were considered those who were able and willing to reflect on their experiences and verbalize their thoughts and feelings relative to the research topic (Morse, 1991b).

Purposeful selection of informants was ongoing throughout the course of the study, occurring concurrently with data collection and analysis, and Morse's (1991b) recommendations were used to guide the accrual process. As recommended by Morse (1991b), I initially interviewed three informants who met the inclusion criteria, analyzed the data, developed preliminary hypotheses, and attempted to identify gaps in the description. Next, I tried to identify informants with particular knowledge or experience to fill those gaps and/or confirm hunches, thus increasing the depth of the description. Finally, I tried to select informants who had atypical experiences and could provide variation in the research so the breadth of the description would be increased.

While attempts were made to follow Morse's (1991b) sampling recommendations, the ability to do so was limited by the paucity of potential informants from which to select. The identification of potential informants proved to be an onerous task for several reasons. First, while there are specific lists of individuals who are newly diagnosed and particular clinics for those who have a metastatic disease or terminal condition, there is neither a list nor a specific clinic for individuals who are experiencing a recurrence of cancer. They may be seen in any number of out-patient clinics, depending on the extent of the disease and the type of treatment required. Second, there is often a prolonged waiting period before the diagnosis of recurrence and the aims of treatment (i.e., second remission or palliation) are determined. Third, the prevalence of first recurrence in the absence of palliation varies greatly across cancer types. For example, it was relatively easy to identify potential informants with breast cancer but much more difficult to identify individuals with prostate or lung cancer who met the inclusion criteria. Hence, the accrual of a heterogeneous sample with respect to cancer type was a time-consuming, difficult process.

To overcome these constraints, it was essential that I develop close connections with the staff at the cancer agency. After obtaining formal ethical clearance, I met with the nursing staff and with several of the medical and radiation oncologists to explain the study and solicit support and assistance in the informant accrual process.

According to the policy of the cancer agency, it was necessary to obtain verbal approval from primary physicians prior to approaching potential informants about study participation. Several physicians provided blanket approval at these introductory meetings. For others, I sought and received approval as each potential informant was identified.

Through information gathered at these introductory meetings, I learned that individuals who would meet the inclusion criteria would rarely be found in the in-patient units. Hence, I focused my accrual efforts on the out-patient clinics. In this setting, I identified potential informants through review of medical records and regular consultation with clinic coordinators. Reviewing medical records proved to be a rather fruitless procedure. Not only were there very few individuals with a first recurrence overall, but it was also very difficult to identify whether the inclusion criteria were met. After identifying a potential informant through medical record review, I would often arrive at the clinic to discover the individual was considered palliative or did not yet have a confirmed diagnosis of recurrence. After reviewing several hundred medical records and identifying less than 10 potential informants, this method was abandoned and I relied solely on regular consultation with clinic coordinators. I kept the coordinators informed about the progress and informational needs of the study both verbally and in writing. They, in turn, provided me with names of potential informants, either by telling me in person or calling me at home. Their assistance was invaluable.

The accrual of informants was terminated after I analyzed the first interview with the sixth informant as saturation of categories was evident at that time. That is, no new information was obtained and the description appeared to be rich and complete. As Morse (1991b) stated, in a study of this nature, it is the number of instances of information, rather than the number of informants, that is critical in determining the adequacy of the sample.

Over the course of the study, eight potential informants were identified, two through review of medical records, five through consultation with clinic coordinators, and one through contact with a colleague. I personally approached all potential informants while they were at the cancer agency, explained the study, provided written information, and established a mutually convenient time to follow up regarding decisions to participate. Some potential informants made their decisions during the initial contact, while others waited until the prearranged follow-up phone call or meeting. Although allowance was made in the initial research proposal for contacting potential informants by mail if I had difficulty contacting them in person, this option felt too impersonal and hence was not utilized. During the accrual process, potential informants were told the study was about living with recurrent cancer, without emphasizing any specific focus on hope. This was done to reduce the likelihood that only those persons who were hopeful would agree to participate in the study, thereby potentially biasing the results. This potential source of bias has been identified as a limitation of other hope research (Ersek, 1992b; Herth, 1993).

Of the eight individuals approached about participation in the study, six agreed and two declined to participate. One individual who declined to participate said he was too ill and did not have sufficient energy, while the other felt she did not have anything to tell me. Hence, it is unlikely that either of these individuals would have been "good informants."

Description of the Sample

Informants were purposefully selected to include heterogeneity in diagnosis, age, and gender. Consideration was given to purposeful selection in regards to other influential variables, such as positive or negative attitude or extent of social support, but the paucity of potential informants from which to select made this an impossibility. Characteristics of the informants in this study are delineated in Tables 1 and 2, with respect to demographics and cancer histories. As can be seen, a wide variation was included in terms of cancer type, extent of disease, duration of treatment, and time from initial diagnosis to recurrence, with little variation in marital and employment status. The time from receiving the diagnosis of recurrence to the time of the first interview ranged from 3 to 10 weeks, with an average of 6 weeks. Of the six informants, five achieved a second remission prior to the second interview. The one who did not achieve a second remission died six months after the second interview (Informant #03). Of the five informants who achieved a second remission, two were diagnosed with a second recurrence, one prior to the second interview (#06) and one following completion of interviewing (#01). Of these two, one achieved a third remission (#06) and the other died six months after receiving this diagnosis (#01).

Table 1 Characteristics of the Sample: Demographics (n=6)

Variable	Statistic
[a]Age	Range: 37-64 Mean: 47
Gender	
• Male	3
• Female	3
Marital Status	
• Married	5
• Separated or Divorced	1
Children	
• Number	Range: 0-6
• [a]Ages	Range: 1-36
Religion	
• Catholic	1
• Protestant	3
• United	1
• Jehovah's Witness	1
Education (Highest Level)	
• Junior High School	1
• High School	1
• Vocational/Technical School	1
• College	1
• University	2
[b]Employment	
• Full Time	5
• Part Time	1

[a] At time of first interview [b] Prior to recurrence

Table 2 Characteristics of the Sample: Cancer Histories (n = 6)

Variable	Statistic
Cancer Type:	
• Breast	2
• Ovarian	1
• Testicular	1
• Colon	1
• Lymphoma	1
Initial Diagnosis:	
[a]Extent of Disease	
• Local	2
• Regional	3
• Metastatic	0
Treatment	
• Rx, Cx, & Surgery	2
• Rx & Surgery	1
• Cx & Surgery	2
• Surgery only	1
Duration of Treatment (Months)	Range: 0.2-11 Mean: 5.5
Time from First Diagnosis to First Recurrence (Months)	Range: 6-95 Mean: 39
First Recurrence:	
[a]Extent of Disease	
• Local	2
• Regional	1
• Metastatic	2
Treatment	
• Rx, Cx, & Surgery	2
• Rx, Cx, & Hormonal	1
• Surgery only	2
• None	1
[b]Duration of Treatment (Months)	Range: 0.5-9 Mean: 4
Second Remission Achieved	5
Second Recurrence	2

Note. Rx = Radiotherapy, Cx = Chemotherapy

[a] For solid tumours

[b] Informant with no treatment excluded

Collecting the Data

Unstructured, in-depth, face-to-face interviews were the primary method of data collection used in this study. Guiding questions were developed prior to commencement of the interview process (see Appendix A), but the foci of the interviews and the nature of the questions posed were directed by the informants' responses. The first interview with each informant commenced with a broad, open-ended question regarding the experience of living with cancer, from initial diagnosis to recurrence. By using this approach, I was able to hear informants' stories from their own unique perspectives, establish a context within which to interpret subsequent responses, and begin to understand the role of hope within this context. Questions posed in second interviews were more specific than those in the first, as they were guided by the ongoing analysis of the data. The purpose of second interviews was to clarify, elaborate, and/or confirm data, interpretations, and conclusions (Field & Morse, 1985).

Each informant was interviewed twice over the course of the study at a time and place that was mutually convenient. The time between first and second interviews ranged from two to six months. Six of the interviews were conducted in informants' homes, two at informants' places of work, one in my home, two at the cancer agency, and one at the out-patient residence. All interviews were audiotaped and transcribed verbatim and ranged from one to two hours in length.

To supplement interview data, an addendum was recorded onto the interview tape immediately after each interview, field notes were entered into the computer within approximately 24 hours after completion of each interview, and a background data form was completed for each informant. The purpose of recording the addendum was to capture on tape any significant verbal interactions that took place before or after the audiotaped portion of the interview, and to record any significant observations before they were lost to memory. The purpose of the field notes was to record in detail the objective data pertaining to the setting and context of the interview and the nonverbal behaviour and appearance of the informant. Field notes were also used to summarize the content of the interview; identify hypotheses, hunches, questions for further exploration, and emerging patterns and trends; and to record subjective data regarding my general impressions, feelings, thoughts, reactions, reflections, and personal biases and assumptions. The computer form used for recording field notes is included in Appendix B. The background data form was used to record demographic and illness-related information for each informant (see Appendix C). This information was obtained from the informants themselves as well as from their medical records and was used to describe the characteristics of the sample (see Tables 1 and 2). The potential influence of these variables was also considered when analyzing the variation in the findings.

To provide an additional source of data, each informant was provided with a blank notebook at the end of the first interview and asked to record any pertinent thoughts, ideas, or experiences that might arise before the second interview. This was presented as an optional task, rather than a requirement for participation in the study. None of the informants in the study chose to contribute additional data via this method.

Analyzing the Data

Data analysis was conducted concurrently with sample selection and data collection. This approach facilitated the development of a richer, more comprehensive, and more accurate description through validation, clarification, and expansion of early hypotheses and findings in subsequent interviews. Interview data formed the primary data source for analysis, but data from field notes and background data forms were also included. Data were compared across interviews with the same informant and between informants and were analyzed using the content analysis methods described by Miles and Huberman (1984), including first-level coding, pattern coding, and memoing. When a process emerged from the data, axial coding procedures described by Strauss and Corbin (1990) were also used to more fully delineate the relationships among categories and concepts.

In the first step of data analysis, first-level coding, all interview transcripts were analyzed line by line and descriptive code names were written in the right hand margins. These code names applied to phrases, sentences, or groups of sentences within the data that represented common ideas, concepts, or themes. Themes relating to hope were of particular interest. The second step of data analysis, pattern coding, began almost concurrently with first-level coding, but extended well beyond the first-level stage. In pattern coding, first-level codes were grouped into a smaller number of overarching themes, constructs, or categories and assigned pattern codes. Pattern codes were explanatory or inferential codes that identified emergent themes, patterns, or explanations; they were more meaningful and parsimonious than first-level codes. For example, the first-level codes of *determination* and *self-reliance* were subsumed under the pattern code of *personal characteristics*. The identification of pattern codes was facilitated by writing all first-level codes on post-it® notes, attaching them to large pieces of paper, and sorting them into like categories. First-level and pattern code names were derived from the words of informants as much as possible.

As pattern codes emerged and data collection and analysis continued, I started to see linkages between these codes. I also perceived a sense of movement amongst the various themes that I thought might provide a unifying conceptual framework for the data. During the second interview with the second informant (fifth interview conducted in the study), this sense of movement was crystallized through this informant's description of two levels of reality and her movement from one to the other. This was a significant turning point in analysis. From this point forward, the emphasis of analysis shifted from content to process. For further direction regarding the induction of a process from the data, I consulted the work of Strauss and Corbin (1990).

In subsequent interviews, the concept of the two levels of reality was shared with other informants and they were asked whether it fit with their experiences. They enthusiastically supported its relevance and validity, making comments such as: "I recognize it perfectly. You betcha I do" and "That's a useful way of appreciating it." Informants were also able to describe what life was like on each level, how one may move upward, and the kinds of factors that may push one downward. All first-level and pattern codes were subsequently subsumed within this larger organizing framework. For example, the pattern code of *personal characteristics* became one of the factors that influenced upward or downward movement.

When I analyzed the transcript of the first interview with the sixth informant (11th interview conducted in the study), the role of hope in relation to the two levels of reality was clarified. This informant described a "hopeful veneer" that varies in thickness over time and is "melted" when one is diagnosed with a recurrence. This hopeful veneer was conceptualized as the barrier that protects one from falling from the upper to the lower level of reality and the hope-related process for individuals experiencing a first recurrence of cancer was labelled "Rebuilding the Hopeful Veneer." After recoding the data within this larger conceptual framework, saturation of categories was evident and no additional informants were accrued into the study. Subsequent analysis then focused on further delineation of stages and phases in the process, description of the influential factors that may account for variation amongst informants, and explanation of negative cases. The preliminary stages in the process were validated with the sixth informant during our second interview and with another informant after analysis was more complete ("member checking").

Throughout the analytic processes just described, particularly in the latter stages, I used the strategies of "memoing" and "diagramming." Memos were written notes that captured my ideas, thoughts, and insights. They were used to refine and expand codes, develop key categories and their interrelationships, generate propositions that were confirmed or denied by returning to the data or the informants, and further elucidate processes in the data (Miles & Huberman, 1984; Strauss & Corbin, 1990). Diagrams were visual representations of the relationships between concepts and of movement through the process (Strauss & Corbin, 1990). They were particularly useful in examining the emerging process as a whole.

Although I anticipated using the Ethnograph computer program as a tool for data labelling and retrieval, I found the process of entering codes by line number to be too removed from the data itself and too labor-intensive to be of value. In the end, the Ethnograph program was used only for numbering and printing the transcripts. Instead of using a computer program, data were sorted by highlighting different stages with different colors and, as described earlier, by using post-it® notes on large pieces of paper. This proved to be a satisfactory method of data sorting for the purposes of analysis but did not readily facilitate the retrieval of excerpts for inclusion in the findings chapter of the thesis. Hence, data retrieval at that point in the project became a very labor-intensive process.

Enhancing Trustworthiness

In the qualitative paradigm, the term "trustworthiness" is used to refer to the reliability and validity of the data and analyses (Guba, 1981; Krefting, 1991). In conducting this type of research, the researcher may be viewed as the primary instrument or measurement tool (Krefting, 1991). Hence, the trustworthiness of this study relies first and foremost on my own abilities and qualifications. Miles and Huberman (1984) identified four criteria for assessing the trustworthiness of the human instrument: (a) familiarity with the phenomenon and the setting under study; (b) a strong interest in conceptual or theoretical knowledge; (c) the ability to take a multidisciplinary approach; and (d) good investigative skills, which are developed through literature review, course work, and experience in qualitative research methods. My educational preparation, research experience, and clinical experience in the oncology setting suggest that these criteria have been met.

To further enhance the trustworthiness of the "researcher as instrument" in this study, several actions were taken. First, to improve my interviewing skills, both thesis co-supervisors listened to the first audiotaped interview and provided valuable suggestions. Second, in order to receive feedback, gain new insights, clarify my own thoughts, and detect biased interpretations, I regularly discussed my thoughts, ideas, hypotheses, and emerging findings with others. These "others" included my thesis co-supervisors, fellow students, and members of two research groups, one related to oncology research and one to hope research. Third, to further expand my awareness of preconceptions, assumptions, beliefs, values, and potential biases that may influence the qualitative research process, I participated in a bracketing interview prior to commencing data collection and recorded my subjective thoughts and feelings in field notes throughout the research process. In the bracketing interview, a colleague interviewed me about my personal views and experiences in relation to the research topic. The interview was audiotaped and transcribed verbatim. The transcript of the bracketing interview and the field notes were regularly reviewed throughout the study to detect possible influences on the research process (Krefting, 1991).

As an additional means of detecting biased interpretations and to improve the dependability (reliability) of analysis procedures, a double-code procedure was used at two separate points in analysis. In this procedure, the thesis co-supervisors independently assigned code names to interview transcripts and their codes were compared to my own (Krefting, 1991). Strong agreement was noted in both instances.

Several other strategies were used to enhance the trustworthiness of this study. Many strategies for enhancing credibility (validity) were incorporated into the study design, including (a) purposeful selection of informants; (b) exclusion of information about hope during the accrual process (decreases likelihood of social desirability influence); (c) audiotaping and transcribing of interviews; (d) triangulation of data collection methods (i.e., interviews, field notes, and background data form); (e) prolonged engagement (helps develop trust and rapport and reduces influence of social desirability); and (f) validation and clarification of data, interpretations, and conclusions with informants during the interview process and at the conclusion of the study (member checks) (Brink, 1991; Field & Morse, 1985; Guba, 1981; Krefting, 1991). In addition, to enhance the accuracy of the data, I carefully compared the transcripts to the audiorecordings and made necessary corrections. Furthermore, I offered to provide each informant with a copy of the first interview transcript for his or her review prior to our second interview. Five of the six informants participated in this verification and clarification process.

Strategies for enhancing the dependability (reliability) of the data and analyses included (a) using guiding interview questions; (b) conducting all interviews myself; (c) conducting more than one interview with each informant (means of checking for consistency in responses); and (d) maintaining a Methods Log wherein the daily schedule and logistics of the study, the methods of data collection and analysis, and the decisions made throughout the study were recorded (Brink, 1991; Krefting, 1991). The latter strategy was also a means to enhance auditability of the findings.

As an additional means of enhancing the trustworthiness of findings and establishing their applicability or fittingness, I presented preliminary research results to fellow oncology nurses and nurse researchers at three conferences during the final stages of data analysis. Feedback revealed that the process made intuitive sense and seemed to fit well with the experience of others. Fittingness and trustworthiness were also enhanced through the identification of strong congruence between the findings from this study and those of from other studies (see Chapter 9).

Protecting Human Rights

To ensure that adequate measures for the protection of human rights were incorporated into the design of this study, ethical clearance was obtained from the Ethics Review Committee of the University of Alberta Faculty of Nursing and the ethics committee at the cancer agency (host institution) prior to the commencement of the research. Permission to access human subjects and facilities (including medical records) at the cancer agency was also obtained. Measures taken for the protection of human rights are described below in relation to informed consent, risks versus benefits, confidentiality, and anonymity.

Informed Consent

When I approached potential informants about participation in the study, I explained the nature of the study verbally, provided written information (i.e., copy of consent form), and ensured they had ample time to consider their decision to participate. If they chose to participate, written consent was obtained prior to the first interview. Three copies of the consent form were signed (see Appendix D); one copy was given to the informant, one placed on the medical record, and one retained for my own records (as per agency protocol). Informants were not coerced or pressured in any way to participate in the study. They were assured they could freely choose not to participate, refuse to answer any questions, withdraw at any time, and request that any information not be included in research reports, without jeopardizing their care. All persons approached about the study were provided with my phone number and those of my co-supervisors so they could have questions or concerns addressed at any point in the study. The process of obtaining consent with each informant was described in the field notes.

Risks versus Benefits

Although there were no direct risks to the informants associated with participation in this study, there was a possibility the informants might become upset or distressed by thoughts or feelings arising from interview discussions. Informants were provided with the name and phone number of a psychologist at the cancer agency whom they could call to discuss their feelings. The benefits of this study may be viewed in terms of advancement of knowledge about the nature and significance of hope and the factors that influence hope for individuals with recurrent cancer and subsequent use of this knowledge to improve nursing care for these individuals.

Confidentiality

A number of measures have been taken to maintain the confidentiality of the data obtained in this study. Only those persons directly involved in the research process (researcher and thesis committee members) and the transcriptionist had access to any of the raw data (audiotapes, transcripts, field notes, background data forms) and they all maintained this information in strict confidence. A statement regarding responsibility for maintenance of confidentiality was included at the bottom of the written contract signed by the transcriptionist (see Appendix E).

Furthermore, I stored the data and consent forms in separate locked files throughout the study and will continue to do so for as long as I retain the data (at least seven years). I will also continue to be the sole possessor of the keys to these files. If secondary analysis is undertaken at a future time, ethical clearance will first be obtained.

Anonymity

Although the informants were not anonymous to me, several measures were taken to ensure their identity was unknown to others. Names and other identifiers did not appear on any of the collected data. Instead, they were removed and code numbers or letters were assigned. Master lists linking numbers and letters to names; identification cards with informants' names, phone numbers, and addresses; and signed consent forms were stored in locked files separate from the data. At the conclusion of the study, the master lists and identification cards were destroyed. In this research report, care was taken to conceal identities by providing a generalized description of the entire group of informants rather than individual informants and by changing names and other identifiers in data excerpts where necessary. Similar safeguards will be taken in future publications.

CHAPTER 4

OVERVIEW OF FINDINGS: MAINTAINING THE HOPEFUL VENEER

As I analyzed the data from this study, emerging findings revealed the need to expand the original research focus to include the nature of hope-related processes in addition to the nature of hope itself. In telling their stories, informants did not emphasize and had difficulty articulating the essence and meaning of hope. Instead, they emphasized and clearly articulated the role and significance of hope, transformations in their grounds for and objects of hope, processes used to rebuild and maintain hope, and factors that influenced these processes, all within the context of their experiences with recurrent cancer. Using an inductive approach, hope was conceptualized as a protective, energizing veneer that informants strove to maintain throughout the cancer experience and rebuild after experiencing a first recurrence.

In this chapter, I provide a brief overview of the process of Maintaining the Hopeful Veneer and, in Chapters 5, 6, and 7, I describe each component of the process in more detail. Finally, in Chapter 8, I delineate the factors that facilitated or inhibited movement through the process and describe the significance of the hopeful veneer for the informants in this study. Included throughout the findings chapters are illustrative excerpts from interview transcripts. These excerpts have been judiciously edited to conceal informants' identities, remove extraneous data, improve grammar, and clarify meanings or contexts. Clarifying information added to the excerpts is enclosed in square brackets and informant code numbers are included in round brackets at the end of each excerpt.

Levels of Reality

Informants in this study described how they moved between two different levels of reality throughout their experiences with cancer -- a lower level where they were disengaging and an upper level where they were actively engaging in life. While on the lower level, informants focused on the cancer and its negative implications, viewed life through a jaundiced or darkened lens, and were overwhelmed with suffering. While on the upper level, they focused on health and living, viewed life through a clearer or brighter lens, and enjoyed a good quality of life. On the upper level, the cancer was at the back of their minds, while on the lower level, the cancer was at the front of their minds and dominated existence.

> There's a couple levels of reality. You've got your day to day, try and make it as good as possible. That's where your optimism is. And then you've got what's really going on....Deep down....the sadness and the pain [are] there and the nightmare [is] always there....but I think you just decide that you're not gonna indulge in it....[You] fall into that...morass of darkness....occasionally ...but then are able to get [yourself] back out of it. (02)

The Hopeful Veneer

As informants described what helped them stay on the upper level of reality, the role of hope in their cancer experiences became apparent. Informants' hope was conceptualized as a barrier or shield that protected them from falling to the lower level of reality and also energized them to actively engage in life. One informant described this barrier as the hopeful veneer. He explained:

> When I say there's a thin veneer,....I guess that's sort of the amount of space between scenarios, between situations, or probability and outcome....You're ready for the next knock down. I mean, you've had two or three, so you're ready for it....Underneath that [hopeful] veneer would be the reality. (06)

A veneer is defined as a thin layer of a superior substance laid over an inferior substance (Webster, 1990). The metaphor of hope as a veneer conveys both its protective function and its fragility in the context of recurrent cancer. It also conveys the high degree of uncertainty inherent in the lives of those who live with a diagnosis of cancer. As one informant stated:

> It leaves a guy with a little bit of a question,....it lingers....And so you just wonder how thick the hopeful veneer is....There will always be that little shadow of doubt until I'm through whatever it is, five years now they say....That's part of the veneer is the time lines,...that whole doubtfulness in terms of getting through, like the one day at a time scenario. (06)

The hopeful veneer was further conceptualized as comprising two layers: a foundation made of grounds for hope and a second layer made of objects of hope.

Hence, the hopeful veneer symbolized informants' hopes for self and future, as well as the evidence or understanding upon which those hopes were based. The hopeful veneer varied in strength and stability over time. If the grounds for hope became stronger, then visions of the future became more certain, objects of hope seemed more attainable, and the veneer was reinforced or became more stable. If grounds for hope became weaker, then visions of the future became more uncertain, objects of hope seemed less attainable, and the veneer became less stable. If the veneer became unstable enough, it was in danger of erosion.

> If I was...to feel pain in my lower kidney area, that veneer would melt pretty quickly because that's a pretty HEAVY indicator. But on the same return, if things go along and I'm, you know, fine for five months, the veneer will build. (06)

The hopeful veneer was akin to the layer of ice on the surface of a lake. The ice varies in thickness and strength over the winter months just as the hopeful veneer varies in strength and stability throughout the cancer experience. When the ice is thick and strong, one can safely skate across the lake. When it becomes thinner and weaker, however, there is the potential for one to fall through the ice and sink into the cold, dark depths of the lake. When informants received the diagnosis of recurrence, it was if they fell through the ice. The hopeful veneer was eroded and they fell to the lower level of reality where they disengaged from life. In order to successfully re-engage in life, informants proceeded through a basic psychosocial process entitled Rebuilding the Hopeful Veneer wherein their hope was renewed and transformed. The process of Rebuilding the Hopeful Veneer was set in the context of a larger cyclical process of maintaining hope throughout the cancer experience entitled Maintaining the Hopeful Veneer (see Figure 1).

The Process of Maintaining the Hopeful Veneer

Informants emphasized that the key to successfully living with cancer was to maintain the hopeful veneer so they could keep the cancer at the back of their minds and actively engage in life. They established the hopeful veneer after the initial diagnosis of cancer and subsequently maintained it via three strategies:

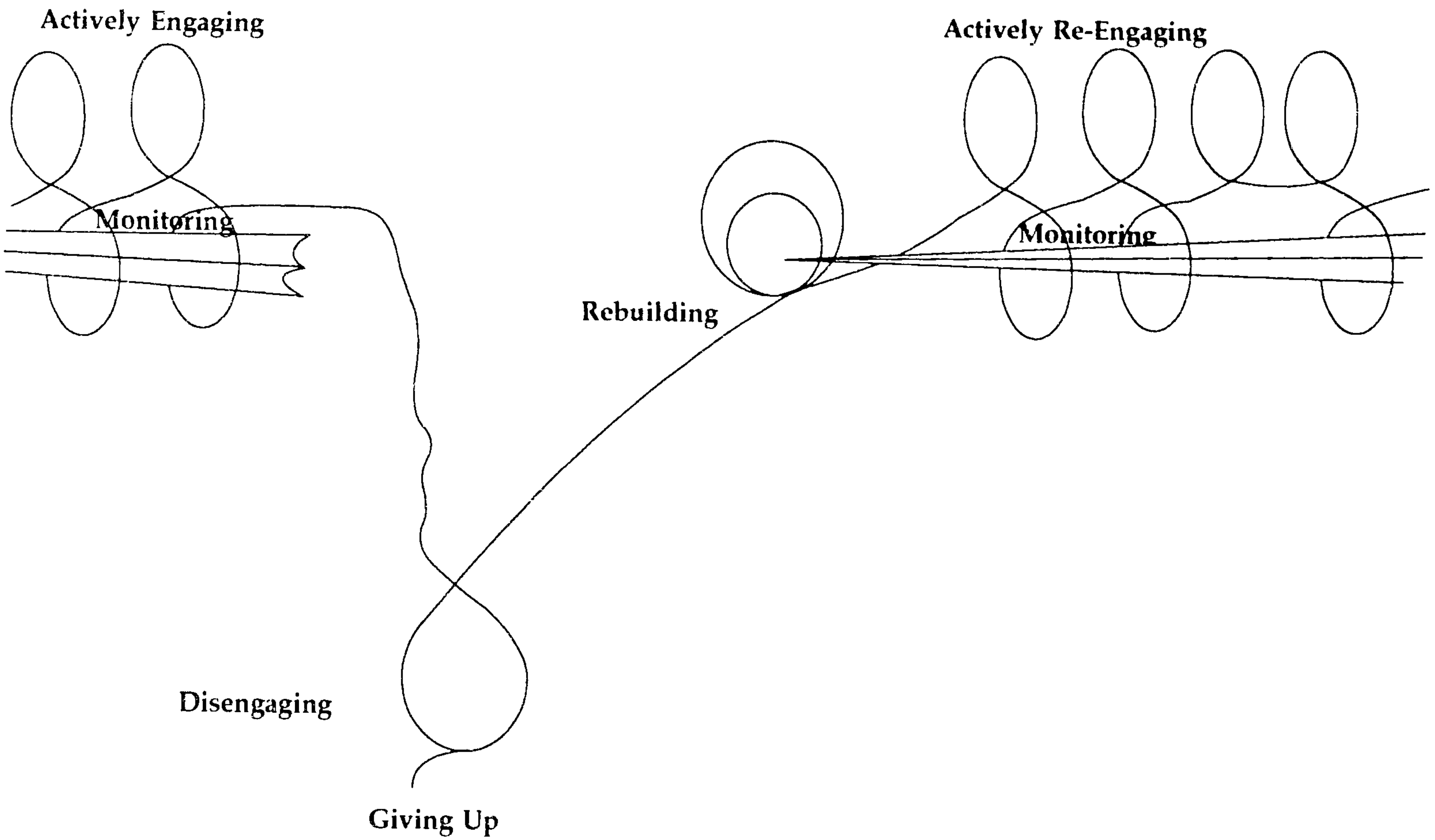

Figure 1. The process of maintaining the hopeful veneer

reinforcing, monitoring, and rebuilding. The first two strategies were employed from above the veneer during times of relative wellness. The latter strategy, rebuilding, was employed from below the veneer after a recurrence or another serious setback had caused the veneer to erode.

When informants received the initial diagnosis of cancer, they fell to the lower level of reality. To get back to actively engaging, they established the hopeful veneer. Although initially tenuous and unstable, the veneer was strengthened upon entering remission and became thicker with the return to normalcy and the continuation of good health. As a result, informants spent more and more time actively engaging on the upper level of reality and this, in turn, further reinforced or strengthened the veneer. Despite the growing strength of the veneer, the fear of recurrence forever lingered in the back of the informants' minds. Cognizant that the veneer may be eroded at any time, they regularly monitored its thickness and integrity. This was akin to measuring the thickness of the ice periodically as you journey across a frozen lake.

When informants noticed signs of a recurrence, it was as if they noticed a crack in the hopeful veneer. When they received a diagnosis of recurrence, this crack widened to a gaping crevasse. The hopeful veneer was eroded, much like the ice on a lake would crack under heavy pressure. Informants fell through the veneer to the lower level of reality and landed in the stage of disengaging. It was as though they had fallen to the bottom of the lake and were afraid of drowning. They were surrounded by darkness, had trouble seeing clearly, and lost their bearings. The depth of the fall and the impact of the landing varied but, if they fell far enough, they lost sight of the hope.

In order to make their way back to the upper level of reality, informants rebuilt the hopeful veneer. This was akin to getting their bearings, swimming up to the surface of the water where they could see clearly again, and refreezing the ice surface. The stage of rebuilding included the phases of appraising and reframing. During appraising, informants developed a realistic understanding of their circumstances, took an inventory of hopeful and ominous signs, and tried to find new grounds for hope to use in rebuilding the foundation of the hopeful veneer. At this point in rebuilding, informants viewed their situations through a microscope and focused primarily on the present.

In the second phase of rebuilding, reframing, informants came to terms with the implications of the appraisal and reframed visions of self and future. In so doing, they redefined their objects of hope, or what they hoped for, in accordance with the new reality. Visions of self and future were the blueprints used in rebuilding the hopeful veneer and objects of hope were the materials used to rebuild the second level upon the foundation. At this point, informants viewed their situations through both telescopic and wide angle lenses and focused primarily on the future.

Once the hopeful veneer was rebuilt, informants were galvanized by hope and were able to re-engage in life. They were once again able to skate on the surface of the lake, although somewhat more cautiously than before the fall. To try to prevent another mishap, they engaged in behaviours that reinforced the hopeful veneer and regularly monitored the thickness or integrity of the veneer, more aware than ever of the potential for erosion.

Movement through the process of Maintaining the Hopeful Veneer was not necessarily linear. Informants revisited stages at various points in the cancer experience and, although they were primarily in one stage at a given point in time, they were sometimes functioning in more than one stage at a time. The pace and pattern of movement varied among informants and was influenced by a number of factors. For ease of presentation, the most common pathway through the stages in the process is described in the next three chapters, commencing with the establishment of the hopeful veneer after the initial diagnosis of cancer (see Table 3 for a synopsis of elements in the process). As the focus of this thesis is on the experience of first recurrence, the rebuilding component of the larger process of maintaining is emphasized and the other components are described in less detail. In essence, the stages preceding rebuilding may be viewed as its antecedents, and those following rebuilding may be viewed as consequences of the rebuilding process.

Descriptions of the stages preceding rebuilding are deliberately brief because, given the cyclical nature of this process, similar stages are experienced after the recurrence and are described in more detail in a subsequent chapter.

Table 3 Elements in the Process of Maintaining the Hopeful Veneer

	The Process of Maintaining the Hopeful Veneer:
Chapter 5	Establishing the Hopeful Veneer
	Actively Engaging: Reinforcing the Hopeful Veneer
	Monitoring: Measuring the Thickness of the Hopeful Veneer
	Reinforcement
	Erosion
	Disengaging: Being Overwhelmed by the Fall
	Reeling
	Wallowing
	Withdrawing
	Deciding
Chapter 6	Rebuilding the Hopeful Veneer: Transforming Hope and Being Galvanized
	Appraising: Finding Grounds for Hope
	Gathering information
	Taking inventory
	Reframing: Redefining Objects of Hope
	Reframing self
	Reframing the future
	Reframing realistically
	Reframing positively
	Being galvanized by hope
Chapter 7	Actively Re-Engaging: Reinforcing the Hopeful Veneer
	Re-Establishing Normalcy
	Living Differently
	Monitoring: Measuring the Thickness of the Hopeful Veneer
	Gathering Information
	Taking Inventory
	Reinforcement
	Erosion
	Giving Up: Losing Sight of the Hope

CHAPTER 5

EROSION OF THE HOPEFUL VENEER AND THE FALL TO DISENGAGING

Establishing the Hopeful Veneer

When initially diagnosed with cancer, informants' visions of self and future were forever altered and their grounds for hope were shaken. After a time, they found new grounds for hope and redefined objects of hope, thereby establishing a hopeful veneer. Although all informants were successful in achieving a remission, their perceptions of their circumstances, selves, and futures differed. Hence, the materials used to establish this veneer, that is, the grounds for and objects of hope, also differed.

At one end of the spectrum, some informants perceived grounds for hope to be so strong that hopes for a cure would almost certainly be attained. One informant recalled the words of his physician when he was first diagnosed with cancer:

> [The physician] told me, "This is not gonna get you....Like believe me. This is not gonna kill you. This is a cancer that is routinely beaten. It's very predictable. We're gonna go through the hoops and we're gonna knock it down....It's a very high success rate." He talked about in the 90% range and up so he was very reassuring. (06)

Subsequent information further strengthened this informant's grounds for hope and confirmed the likelihood of cure.

> I was always under the impression that I was one of the lucky ones, although these hoops were very difficult to go through,...that once I was finished I was gonna be cured, done, because all the stories I was getting from doctors, friends, everybody, colleagues, were all the same. "Oh yeah. Somebody so and so had that and they're fine now. They're great."..."The technology is there so once you're finished you'll be all fixed." So I mean never did I think that I was in the same boat as people who were dying....After I finished chemo I figured I'm done. I'm cured. Everything's good. My CAT scan is clean. The cancer doctor...and his nurse were very happy with the results and almost dancing around the room when they showed me the final CAT scan. And so I thought, O.K., I'm done and off I went. (06)

Another informant described a similar experience:

> The first time...I wasn't worried about it at all. I was actually kinda

> smug....When they said that the lymph nodes were clear, we thought that's good, then we're okay now....They kept saying it was nothing, it was nothing, not to worry. (03)

Most other informants fell in the middle of the spectrum. They hoped for a cure but were less confident of its attainment. One informant was at the opposite end of the spectrum. Having experienced extensive disease and a long, complicated treatment course, she perceived the grounds for hope to be so weak that she could not hope for a cure. Instead, she fully expected to die from cancer and hoped to "get...through this as easily as possible."

Once the veneer was established, informants were able to push the cancer to the back of their minds, move above the hopeful veneer, and actively engage in life.

Actively Engaging: Reinforcing the Hopeful Veneer

Actively engaging included two elements: re-establishing normalcy and living differently. Re-establishing normalcy is reflected in the following informant's description of the remission period:

> When the treatment was over and my hair started to grow back in,...life started getting more normal again, you know, and we talked less and less of the cancer because you're not going for these treatments anymore so naturally you start talking about other things in life. And it was good, it was really good because it's like you can forget about that now and just go on with living, eh. But always in the back of your mind... (01)

In living differently, informants attempted to make changes in their lives in order to prepare for the future, maximize their quality of life, and improve their chances of living longer lives.

As time progressed, the likelihood of recurrence diminished, life became more normal, and the possibility of cure became stronger. The hopeful veneer was reinforced and became thicker. One informant said:

> Then, after awhile, I guess you enter into a state, well, I must be cured....You're much more into the every day bit again. (04)

Monitoring: Measuring the Thickness of the Hopeful Veneer

Despite the growing thickness of the veneer, informants were cognizant of the potential for future erosions, the most dreaded type of erosion being that caused by a recurrence of cancer. With the fear of recurrence forever lingering in the back of their minds, informants regularly measured the thickness of the hopeful veneer and monitored factors that could affect its thickness or integrity. Monitoring resulted in two possible consequences for the hopeful veneer: reinforcement or erosion. If the veneer was reinforced, informants remained in actively engaging. If it was eroded, they fell below the veneer to disengaging.

Reinforcement

If monitoring revealed that the grounds for hope were stable, then visions of the future were confirmed and objects of hope were still perceived as attainable. As a consequence, the veneer was reinforced or thickened.

> They told me that everything was good and stuff and then I went for my two month tests thereafter for the next six months and my tumour markers, which is a blood test, were constantly flat. Zero. Negative. And so I thought this is great. I'm clear because [the oncologist] said, "We're gonna start scaling back the number of tests." (06)

Erosion

If monitoring revealed that the grounds for hope had destabilized, then visions of the future and objects of hope had to be modified accordingly. If the grounds for hope became unstable enough, the veneer eroded and had to be rebuilt. For the informant who established the veneer with the expectation of dying, monitoring revealed that this vision of the future was no longer tenable. In effect, her unexpected survival led to an erosion of the veneer and she had to rebuild it with different visions of and hopes for the future.

> I ALWAYS thought that I was not gonna recover from this. I always thought I was gonna die....The month before every year's CT scan it's like, yeah, they're gonna find something, I'm going in the hospital, I'm gonna die now. NEVER did anything like an RRSP or a retirement anything because, don't be silly, I'm never going to retire. I'm never going to live that long. But then

> gradually, gradually I discovered I was gonna live maybe. So, that was fine. I started doing RRSP things -- just in the last two years though...I took up some interesting things like hiking and stuff. It all made me feel better....I'm just totally convinced now, I'm cured. I don't have to have CT scans anymore, they tell me I'm cured, everything's great....So I'd been about a year of, oh, finally it's gonna be fine. (02)

For all informants, the most significant cause of an erosion of the veneer was a first recurrence of cancer. Finding out the cancer had recurred typically involved four phases: noticing, minimizing, suspecting, and confirming. Informants described how they noticed certain changes in their bodies, including back pain, fullness in the abdomen, changes in stools, and lumps. They tended to minimize these changes at first and attributed them to causes other than a recurrence of cancer: "Surely it must just be something innocent." In doing so, they were trying to prevent the erosion of the hopeful veneer that had been built up during remission.

> Two weeks before I went for my six month CAT scan I started to experience back pain and I never related it at all. As a matter of fact, I went to my family doctor and said, "Jeeze, you know, I think I've strained my back. I've been playing a lot of golf and working in the garden." (06).

> When we first saw [the lump on my shin],...you hope first it was just fatty tissue. Then you hoped it was just skin cancer. The worst scenario really was that it was a God-damn, it was a repeat of the same [strain of lymphoma]....We thought they had it all. See I had an appointment for March and if I had been cleared in March, I wouldn't have had to go back. That's how close I came. (05)

When informants sought medical attention for their problems, physicians frequently concurred with informants' perceptions, minimized the symptoms, and provided false reassurance prior to receiving results from the full diagnostic workup. Like the informants, they tried to keep the hopeful veneer intact.

> So I went in to see [my oncologist] the day of the CAT scan. I told him what was going on. He said, "Forget it. You strained your back golfing." Sort of like that Seinfeld episode where George Castanza thinks that he has cancer because he's got a white mark on his lip....He goes in to see the doctor and he says, "The guy is supposed to say, 'GET OUTTA HERE! Cancer? Get outta here!'" And he doesn't say, "Get outta here," so George says, "What? Don't they teach them that? They're supposed to say that right off the bat. I didn't get a get outta here." So I got a "get outta here" from [my oncologist]: "GET

> OUTTA HERE. Cancer? Get outta here." So that buoyed me. (06)
>
> When I first had the second lump removed, he said to me that night at the hospital, "It's not cancerous. I've seen lots of it and I'm almost 100% guaranteed that this is not cancerous." (01)

Despite concerted efforts to avoid entertaining the possibility, most informants suspected the signs they had noticed may be indicative of a recurrence of the cancer. Family members also suspected this was the case. Thoughts of the cancer were starting to creep towards the front of their minds and the veneer was starting to thin.

> I started to think, "Oh-oh. What have we got goin' here?" And I talked to [my wife] and she was just deathly afraid. (06)
>
> I 'member I was washing dishes that night and I was thinking to myself, now what if I do go there and he tells me that it's cancer again. So you kind of prepare yourself, eh. (01)

After the results of biopsies and scans were back, the recurrence was confirmed, and neither informants nor physicians could prevent erosion of the hopeful veneer. Hopes for a cure with initial treatment were shattered and the dreaded recurrence became a reality.

> When you first experience cancer, it's very scary but you're still naïve, always thinking, well, I'm different....We like to think we're that 1% or whatever it is....And so you go along with it and you think, oh well, this is gonna take care of the cancer and I'm gonna be all right and then everything seems fine for a few months and you come back and they tell you well, your cancer has started acting up again and...you realize suddenly that you're no different than the rest, than so many others who have...cancer and you're facing maybe a limited time too. Everyone likes to think they're a little bit special and that you're going to be maybe that special person that doesn't have to face death, that cancer isn't gonna get you in the end....When you're told that your cancer's reoccurred again well then...suddenly...it hits home, it becomes reality. (01)

Informants fell through the eroded veneer and thoughts of the cancer shifted squarely to the front of their minds. They entered the stage of disengaging.

Disengaging: Being Overwhelmed by the Fall

Disengaging was a time when informants were overwhelmed by the fall through the hopeful veneer and "deal[t] with things in an emotional way." They reacted to the diagnosis of recurrence and grieved the loss of hope for a sustained remission. The focus of their thoughts shifted from health and living to cancer and suffering. They viewed their circumstances through a jaundiced or darkened lens and framed their circumstances negatively. Descriptions of this level of functioning included "morass of darkness" and "periods of misery." Although the stage of disengaging was generally described as an undesirable place to be, spending time in this stage was viewed as somewhat of a necessary evil. One informant said, "You have to go through it," while another said:

> Maybe to develop the positive you need the odd slip out of it. Gee, it's really much better over there. I can hardly wait to get back in there. (04)

The depth of the fall below the eroded veneer varied amongst informants. The further they fell, the more difficult it was for them to see the hope, the more negatively they viewed the world, and the more time and effort it took to move up. If they fell far enough or remained in disengaging for long enough, they lost sight of the hope and exhibited signs of giving up. The stage of giving up is described in Chapter 7 and the factors that influenced the depth of the fall and the length of time spent in disengaging are described in Chapter 8.

The stage of disengaging included three interrelated aspects: reeling, wallowing, and withdrawing. Although reeling was usually experienced first, these three aspects were not necessarily sequential nor distinct. Rather, they were typically experienced concurrently and were highly interconnected. One informant described how she bounced back and forth between the different aspects of disengaging:

> One day you're mad....and then another day you're feeling sorry for yourself and then the next day you say, 'Oh, to hell with it. I'm gonna beat it.' You bounce back and forth. And then once a week you fall apart. (03).

A transitional phase, deciding, marked a turning point wherein informants left disengaging and began to move up toward actively re-engaging.

Reeling

When informants received the news of recurrence and landed in disengaging, it was as if they had been physically struck. Receiving the news was described as a "real blow to your system" that "hit[s you] like a ton of bricks" and "really knocks you for a loop." "It's like somebody put a knife through your heart" or "kick[ed you] in the head." Reacting to the news of recurrence was like reeling from the blow or the impact of the fall. The further informants fell below the veneer, the more severe the reaction and the more extensive the reeling.

Reactions to the recurrence varied from irritation to disappointment to utter devastation. On the first extreme, one informant felt very little impact from the recurrence. In fact, he fell so short a distance below the veneer that he didn't seem to experience reeling at all. He acknowledged a sense of disappointment but described his reaction primarily in terms of irritation about the interference the recurrence would cause in his life. This informant "never really lost sight of...the hopeful...side of things."

> I'm very, very glad that I haven't lost hope....It seems to me I have exactly as much hope as last time, which is maybe quite unusual....When the subject is on, of course, it does irritate me a bit that it has come back but ONLY when the subject comes up. I don't lose any sleep over it....[The recurrence] was a disappointment. But it didn't change my hope at all. Not at all....It was disappointment from the point of view because I knew I'd have some months ahead where I wouldn't have as much fun in life. That's what it is, you know. I knew it was gonna interfere a lot with my pleasure (05)

At the opposite end of the spectrum, three informants were devastated by the recurrence, were quite certain they would die soon, and lost sight of the hope.

> I was brave and I never complained and I was hopeful the first time around but this is different. I've been cheated out of...being...one of the successful ones, having to be lumped off into this smaller percentile group....I guess I'm just gonna be one of those small percentile that don't make it, that, you know, that I'm gonna die....So now I'm not gonna be hopeful. So I pushed the hope out of the picture and denied myself the hope....There wasn't a helluva lot of room for hope. (06)

> I was just devastated, I was ABSOLUTELY devastated for a few weeks there, after I learned that there was the tumour, and I was sure I was gonna die and I was sure I was gonna die fast....I'm not very hopeful. (02)

The third informant also described being "absolutely devastated" and felt a sense of "hopelessness." All three of these informants exhibited some signs of giving up during the initial period following the diagnosis of the recurrence.

In the middle of the spectrum were two informants who reacted to the recurrence with disappointment, considered death a possibility rather than a certainty, and saw their hope become blurry rather than fade completely from sight.

> [When] they tell you, "Well, your cancer has started acting up again,"...it's really, really disappointing....You realize suddenly that you're...facing maybe a limited time. (01)
>
> [There's] the original grand disappointment of finding out it's back again..., disappointments about not having necessarily the length of time that we all assume is there....[I was] disappointed because I think the last time I was in the 85 to 90% [range] and obviously I won on the 10% side. (04)

Although both these informants expressed disappointment, they were determined to get out of disengaging as quickly as possible and not lose sight of the hope. Statements indicating this resolve included: "I can't see sitting back and getting the blues on about it" and "I'm not gonna let it get me down."

Reeling typically began with a period of numbness or surrealness. It was like "walkin' around in a fog" or being "in a haze." "Time seem[ed] to move very slowly and there [was] an unrealness, a not hereness to it." Informants were reacting to the recurrence with shock and disbelief. The reality of the recurrence had not yet sunk in.

> There is the initial sense, there's an unrealness to it. "What do you mean this is happening to me? This is something that happens to other people. I read about it. I hear about it but it doesn't happen to me."....[I was] even occasionally waking up and for an instant thinking the whole thing was a dream and then realizing no, it ain't a dream. And so there was that period and I think about a week....I guess a sort of a denial [is] what it might be called -- the earlier step of: "This can't be happening to me. Maybe there's an error. I wonder if they made mistakes in those labs. How many pathologists are 100% right all the time?" (04)
>
> No, no, seven years later. No, no, no. I was told it can't happen. It just can't happen. It was really a surprise. (02)

This hazy period was followed by a period of mental and spiritual suffering, characterized by "huge swirls of different kinds of emotions," the most predominant being fear, sadness, and anger. One informant talked about being morbid during this period and described this as "a combination...of the anger and the fear...and the denial of hope" (06). Another informant identified her feelings as stages of grief:

"You kinda sit back and you go through the stages of grief basically. You're numb. And then you're terrified and then you're angry." (03)

Feelings of fear and sadness were more pronounced at night and when alone. Nights were "rougher" because "that's when you have more time to think about it and all of the consequences." As a result, several informants had difficulty sleeping during the initial period following recurrence.

> The fear was just sort of one night actually. One night I was kind of rattled. It just kind of grabbed me and it lasted for a few hours and that was it. (06)
>
> Once a week you fall apart. And I try to do that when I'm alone or just with my husband late at night. (03)
>
> Three, four days afterwards,...I was maybe sleeping at two, two and a half hour stretches....I was getting up in a bit of funk, bit of a lassitude, not much enthusiasm. (04)

Most informants were angry the cancer had recurred. For some, the anger was "sort of all-encompassing," while, for others, it was directed at specific targets and took the form of blaming.

> This is where my anger comes in....If he'd of put me through some tests..., then they could have seen that it was other places because it would have HAD to have been other places. Then I coulda had chemo then and had it all over with and it wouldn't have spread half as much as it has. (03)
>
> I was really angry but I wasn't expressing it in an overt "I'm angry" type of way. I was being mean to people. I was saying things that were just outrageous. I was pissing people off -- family, friends. And sometimes even as I was doing it I was thinking, "What am I doing?" Like I could even get outside of myself and look and go like, this is so bizarre. (06)

Several informants recognized anger as a part of the grieving process and one informant commented on the benefits of "going with the anger."

> I think you have to realize that you're gonna be really angry and you should probably go with the anger because anger can spur you on, anger can...make you not give in. So, don't fight it back....Anger can give you some strength. Like, "Die damn it! Not right now, thank you." (02)

Other emotions experienced during reeling included guilt or regret and shame. Two informants expressed regret or guilt about not taking all the treatments that were offered and not demanding more extensive diagnostic tests on initial diagnosis. They felt that, had they done so, they may have prevented a recurrence. Feelings of shame were expressed by one informant. She said that "an illness is somehow your fault and cancer is something to be ashamed of" (03).

The mental and spiritual suffering characteristic of reeling typically continued throughout the other two aspects of disengaging: wallowing and withdrawing. Like the experience of reeling, these two aspects of disengaging were more extensive if informants fell further below the veneer, that is, if they were more devastated by the recurrence.

Wallowing

Wallowing was characterized by self-absorption and self-pity. "[You] wallow in your own bloody misery." (04) "You...let yourself feel sorry for yourself. You go 'oh, poor me, why me.' That kind of crap" (02). While wallowing, informants' thoughts and conversations focused on the cancer and the suffering it had caused for themselves and others.

> And then I feel sorry for myself....and, you know, then I kinda feel sorry for everybody else....It's just as tough on everybody else....[It] really makes your life a mess....It'd be better just to get hit by a truck and be gone....Be a hell of a lot less pain for everybody....and then everybody could at least get on with their lives. You feel like you're dragging everybody down with you. (03)

The more extensive the mental, spiritual, and/or physical suffering, the more extensive the experience of wallowing, the more difficult it was to leave disengaging, and the more likely one would enter the stage of giving up. One informant clearly described the link between suffering and wallowing.

> I don't think you have to be a psychiatrist to know that you become more self-centered if you are suffering. If you are really well, be it physically or mentally, it's much easier for you to help other people. You know, your train of thought will go that way. (05)

Wallowing was usually experienced concurrently with the third aspect of disengaging: withdrawing.

Withdrawing

In the third aspect of disengaging, informants withdrew from their normal patterns of living and put their lives and plans on hold. They relinquished roles and responsibilities at home and work and withdrew from relationships. It was as though the blow of the recurrence knocked them out of gear. A sense of inertia prevailed. Informants felt displaced, isolated, and/or lost.

> I'm a workaholic and I feel quite lost. No, no place anymore....Many people they find their place with their husband and children. But I don't have THAT place. What I have is my place at work which is very important to me....Well, I sort of lost [that] so I don't have a place. So I'm kind of like a little waif -- no where to go. THAT'S very upsetting. I find going to my office...a bit distressing because somebody's in MY desk doing MY work....So I feel displaced. I mean, I have a nice little place to live but it's not the center of my existence the way many people's homes is. So that's really hard. (02)

> You don't really have a normal life....My husband's...aunt comes over and she cleans 'cause I can't do much house cleaning either and my husband cooks most of the meals. (03)

Informants most commonly entered withdrawing when treatment schedules interfered with their patterns of living and when the effects of the disease and treatments impaired their abilities and/or significantly altered their appearances. Abilities were impaired by such effects as fatigue, weakness, pain, bladder dysfunction, nerve compression, fractures, nausea, sleep disturbances, headaches, peripheral neuropathy, and stomatitis; while appearances were altered by hair loss and changes in weight.

> I have always had long hair and that kind of blew me away too, losin' that....It's just such a demoralizing thing....God that's ugly. Just unbelievable. I mean you get these wads of hair in your hand....To an extent, you know, I...feel like this woman said [on the T.V. talk show about ovarian cancer], "70 years old and ugly" which I probably will until I get some hair. (03)

For two informants, abilities and appearance were further altered by wearing a catheter and a cervical collar.

> I've always been very healthy, very strong, very active....but I can't keep very busy because of my neck. This is the frustrating part....Normally I pick up a vacuum cleaner and vacuum like crazy or go out and run around and go take her [dog] out and this really restricts me....Last week it was worse because...I had that damn collar on and I couldn't do anything and the collar made me feel like a turkey, you know, with your head out like this. [juts chin forward] And after standing up for half an hour with that collar on, you're just dead tired. (03)

These effects of the disease and treatment, and the resultant alterations in abilities and appearances, contributed to suffering and led to disruptions in informants' self-identities. These alterations also led to withdrawal from roles and responsibilities which, in turn, further compounded the disruption in their self-identities through a reduction in sense of self-worth and purpose in life.

For three informants, the alteration in self-identity and the suffering caused by the recurrence led to a deliberate withdrawal from relationships with family and friends. One woman refused to answer the phone, return calls, or leave the house and "pushed people away." Others also avoided contact with people and identified reasons for doing so.

> All of a sudden now you've got a recurrence and you're sort of reluctant to talk to people beyond the people that need to know because you've sort of let them down....You'd told everyone that you'd beat it. (06)

> At the beginning [I] was trying to stay away from my friends...'cause I didn't want them to see me like this, almost like I did it to myself. Like an illness is somehow your fault and cancer is something to be ashamed of. So I kind of avoided everybody. (03)

Informants were often frustrated with the lack of normalcy experienced while withdrawing, particulary when it lasted longer than anticipated.

> I was getting quite impatient by not getting over the effect of the chemo. I was still very tired and...it seemed like I had to lay down three or four times a day and I just had no energy at all. Absolutely sacked.....[You felt] impatient because you didn't feel normal. I can't really explain, it wasn't just fatigue. It's other feelings that comes, miserable feelings that comes with the chemo, the massive doses of chemo....I was [also] getting fed up with being overweight. (05)

Despite the frustration, there were advantages to withdrawing, including having a rest from a stressful work environment, an opportunity to conserve energy for rebuilding, and time to deal with the impact of the recurrence.

Deciding: Transition to Rebuilding

The time spent in disengaging varied amongst informants but they all identified reaching a turning point where they decided to move up toward active engagement and attempt to rebuild the hopeful veneer. They made a decision to kick themselves into gear, get at it, move on, and start to look for signs of hope.

Informants also spoke of deciding to beat it, to fight it, to not give in or give up, and to not allow themselves to get sucked into the sadness. Had they not reached this turning point, they likely would have sunk further into the lower level of reality and given up.

> Initially, for about a week and a half afterwards, you're really down on this thing. You know, here we go again and that, but by the same token you realize that you gain not a damn thing getting yourself in a funk so you start the little games of getting yourself up. (04)

> In November and December things were really awful and the sadness and the pain were there and the nightmare was always there. But I think you just decide that you're not gonna indulge in it and you just know it's there but you....sort of just put it aside....and decide that it's gonna be okay OR it could be something external...that just kick[s] you out of it. (02)

After deciding to leave the stage of disengaging, informants began to rebuild the hopeful veneer. As one informant described: "You go through all the morbid stage and then you start to build hope." The stage of rebuilding is described in Chapter 6.

CHAPTER 6

REBUILDING THE HOPEFUL VENEER: TRANSFORMING HOPE AND BEING GALVANIZED

In contrast to the stage of disengaging, where informants dealt with their circumstances in an emotional way, the stage of rebuilding was a time when circumstances were dealt with in a cognitive or intellectual way. Rebuilding comprised the phases of appraising and reframing (see Figure 2). In appraising, informants developed a realistic understanding of the present and tried to find grounds for hope. In reframing, they came to terms with the implications of this appraisal, reframed visions of self and future both realistically and positively, and, in so doing, redefined their objects of hope. Appraising and reframing were highly interdependent. The understanding reached and the grounds for hope found during appraising were the basis upon which self and future were reframed and objects of hope were redefined. Hence, as the grounds for hope shifted, so too did visions of self and future. One informant eloquently described the essence of rebuilding.

> So it's a process in which you are coming to terms with your reality and having the confidence of that reality. I mean, I know reality now. I've gotten over the why me, the denial....Now I've got to know as much about it as I can to know where I am now and the legitimate inferences that all human beings make about the future and how to gauge their behaviour. And that's, I think, what we're all after in the process. (04)

This informant also captured the fact that Rebuilding the Hopeful Veneer was an active process requiring an investment of "mental energy." He said:

> A part of the hope that we may want to define for somebody like myself is there's gotta be a much more active, even proactive dimension to it....And this is not necessarily just physical activity. It requires mental energy. You just can't sit back, listen for Matavanni and see clouds with bright lights behind them. Gotta get out there. I think it's an intellectual game. It's a physical activity game. You've gotta redefine life in terms of possibilities, enjoyments, these kinds of things, and the fact that you can still do this in view of the news you've heard, maybe this constitutes the hope, a more proactive kind of thing. (04)

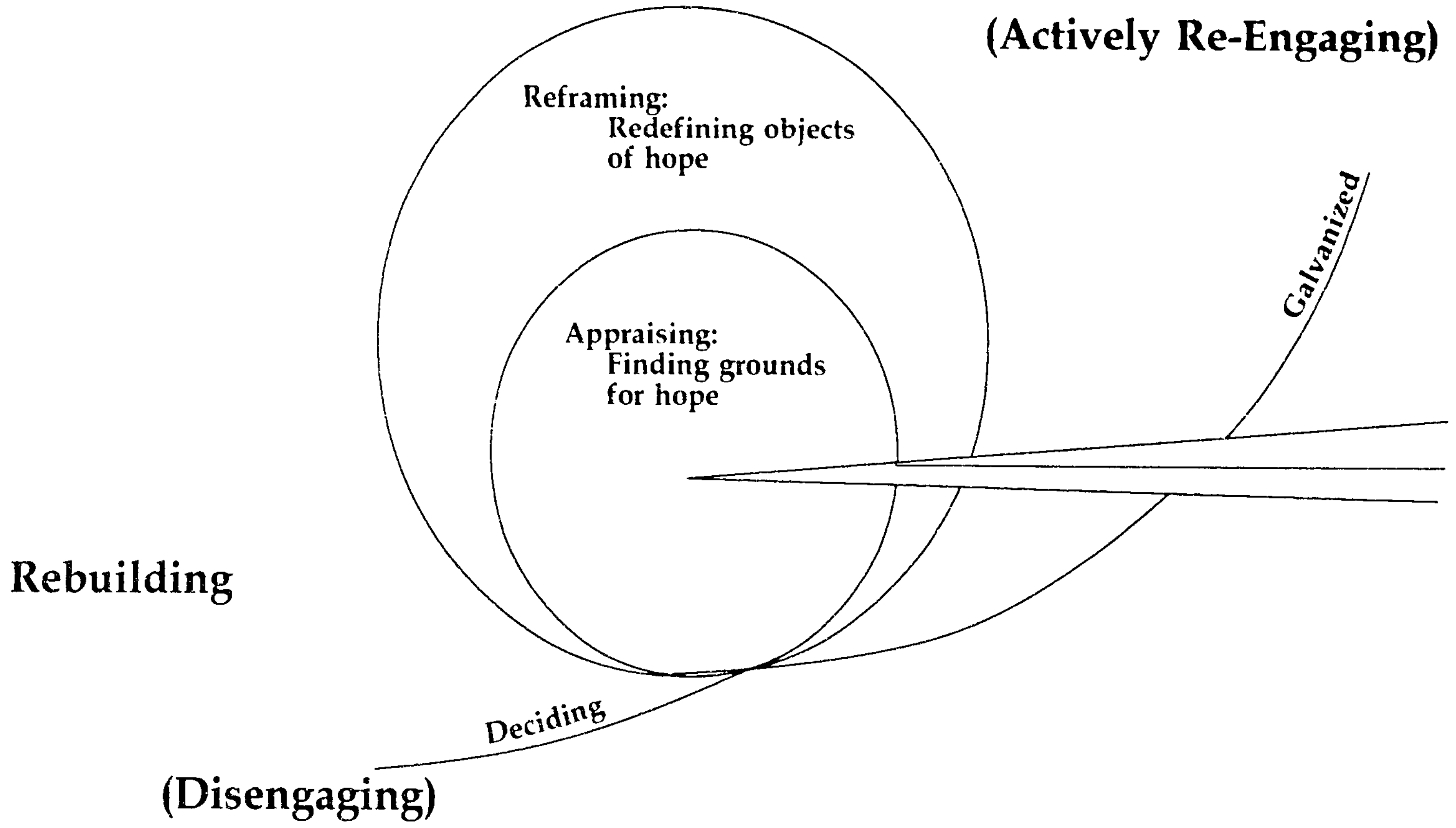

Figure 2. The process of rebuilding the hopeful veneer

As reflected in this informant's comments, the stage of rebuilding resulted in the development of a renewed sense of hope. The materials and blueprints used in rebuilding, however, were different than those used when the veneer was first established. Hence, in rebuilding, hope was transformed. Once the hopeful veneer was rebuilt, informants could move above the veneer and re-engage in life.

Appraising: Finding Grounds for Hope

In the phase of appraising, informants no longer viewed the world through a jaundiced or darkened lens, as they had in the stage of disengaging. Instead, they examined their circumstances through a microscope, focusing primarily on the present. Informants' thoughts still focused on the cancer and its implications but the emphasis shifted from misery and suffering to understanding and hope. The aim of appraising was to develop a realistic understanding of the present, that is, an understanding that one sees as true, and find grounds for hope to use in rebuilding the foundation of the hopeful veneer. In other words, during appraising, informants estimated the damages and repairs to the hopeful veneer, took an inventory of the available building materials, and, if sufficient materials were found, rebuilt the foundation.

Appraising was similar to the stage of monitoring described in Chapter 5. Appraising and monitoring differed, however, in the intensity of focus, point of entry, surrounding circumstances, and purpose. Monitoring was a surveillance activity undertaken from above the veneer, while appraising was an intensified scrutiny from below the veneer. While monitoring was initiated when one suspected a potential or actual threat to the integrity of the veneer, appraising was initiated after the veneer had suffered major damage. The purpose of monitoring was to confirm or disaffirm that previously identified grounds for hope were still stable, while the purpose of appraising was to find new grounds for hope after previous grounds had destabilized. Monitoring was akin to ongoing surveillance of the stability of a dam, these surveillance activities intensifying during inclement weather, while appraising was like assessing the damage to a dam after an earthquake had struck.

Appraising was carried out through use of two strategies: gathering information and taking inventory.

Gathering Information

Information was an essential resource for the rebuilding process. Informants entered the stage of appraising armed with information gained from the experience of initial diagnosis and treatment and some limited information gathered during the monitoring that preceded the erosion of the veneer. Information from the initial experience with cancer was identified as either an asset or a liability. One informant described this information as an asset:

> You're familiar with so many of the things that are happening around you and some of the procedures that are going on whereas before it's new and there's the tenseness that comes with the unknown....I think [the recurrence] was simply easier and there wasn't as much of the unknown. (04)

Two other informants took an opposing view, saying that knowing "about chemotherapy and radiation [and] how bad they were" made the recurrence more difficult to face.

> You do become a little more wise and you understand what's happening and you understand that these medicines that they use are not just treatments but they also can do damage, you know, to other organs. (01)

Informants had gathered some limited information about their present situations during the monitoring that preceded the erosion of the hopeful veneer. As soon as they realized the veneer was eroding, however, their capacity to seek and/or retain information was impaired by the shock of the erosion and the impact of the fall.

> All he [oncologist] said [on the phone], all I allowed him to say was, "There's been some changes in your CAT scan and you should come and visit. You could come and see me at this clinic."...But I didn't ask him like, "Well, what do you mean a change?" He just said "a change" and I [said], "Thank you," and hung up and burst into tears. (02)

> He [oncologist] said, "Yeah. There's something there."...He said basically that the...tumour that had been there at 10 cm was back at 4 cm and that it had to be operated on and the operation was major, that they had to go in the front

> and that. So it was whoa, whoa, whoa, whoa. (06)

The strategy of information gathering was undertaken in earnest after informants had spent a period of time in disengaging, particularly in the phase of reeling, and had decided to attempt rebuilding of the hopeful veneer.

> At first you're in a haze and then I think secondly you grasp at every type of information that you can and every word everybody speaks that has ever been around anyone with cancer. (01)

Informants gathered information via a number of means, including asking questions, observing, listening, and reading. Types of information sought, sources of information, variation in breadth and depth of information sought, and the purposes of information gathering are described below.

Types of Information

At the beginning of the recurrence period, all informants sought information about the extent and nature of recurrent disease, treatment options, and prognoses, including the probable impact of the disease and/or treatment on the length and quality of their lives. While undergoing treatment for the recurrence, informants were focused on obtaining information about treatment effectiveness, with some additional interest in understanding the side effects and complications encountered.

Of somewhat lesser concern, albeit still a focus of investigation for some informants, was information about the causes of recurrence and cancer in general, and common reactions to the diagnosis of recurrence. In terms of the latter, one informant identified that knowing about Kubler-Ross's (1968) stages of death and dying helped him get in touch with his feelings and understand his own behaviour and reactions. Another informant said that watching how "other people react when they find out they've got cancer" helped her know if she "handled it properly."

Sources of Information

Physicians, including family practitioners, surgeons, oncologists, and neurologists, were the primary sources of information for informants. Information received from physicians was deemed most useful when it was accurate or factual, clear, and delivered in a timely fashion.

Informants "didn't wanna be conned" or "talked down to," but wanted to "deal with things face to face." They wanted to feel that physicians were telling them "the way it is as they understand it at the moment" so they could "map...out the present as accurately as [possible]" and be prepared for the "worst case scenario." As one informant said to her oncologist, "I require you to be straight with me." Even though hearing the accurate information or "blunt realities" sometimes prolonged the rebuilding process and/or caused informants to slip back into disengaging for a time, most still felt that it was better in the long run if they knew the "truth" about their present circumstances and possible future consequences.

> So he [oncologist] was very candid and very blunt and that's what I needed to know. I mean, I didn't want any punches pulled. (06)

> I think there were points there where I had a certain image in mind which in retrospect were perhaps a little rosy-hued. And I think occasionally, whether intentionally or not, a health care person has chosen some words that maybe even shattered some of those images and made me reassess and look at the evidence and I think look at it in a more honest and clear cut fashion. So at the time it could be a bit of a start for you in some ways. but I think over the long haul it was better. (04)

Clarity of information was the second criterion of importance to informants. The clearer the information, the easier it was to develop an accurate appraisal of the situation and commence rebuilding. One informant described how her physician provided a very clear explanation of the extent of recurrence.

> She drew a picture...on the board...and this was VERY helpful. She drew a picture of all the insides, you know, "Here's your vagina, here's your bowel, here's your aorta, and this is where we think it's sitting." (02)

Another informant described how an unclear explanation led to an upsetting misinterpretation.

> That was another thing that I was uh, pretty upset about when I first learned I had recurrent cancer....They said it was in my lungs and in my bones and in my liver, but nobody said it's breast cancer....I thought I had bone cancer and lung cancer and liver cancer and I thought I was dead for sure. But it wasn't until a couple of weeks later that...one of the doctors explained to me that it was breast cancer that has spread. (03)

Expediency was the third important criterion for receipt of information from physicians. Some informants experienced significant delays when waiting for information about the diagnosis or extent of recurrence, the plan for treatment, and/or the effectiveness of treatment. Some of these delays were perceived as beyond the physicians' control, while others were perceived as unacceptable and unforgivable. Delays were described as distressing, maddening, and frustrating because they extended the period of uncertainty and the rebuilding process.

> You know that there's something wrong because...they had me come back in five or six times and they kept redoing these X-rays....But they don't tell you. It's too bad that when that happens that they couldn't somehow set up an appointment at that time where you could see the doctor and he could say to you, "Well, listen, this is what's happening," because then you have to go away and for a week or two it's in your mind. "Well, is there something there or is it just that they were having trouble with their film or what?"....It would be nice if they could come right out and tell you...because the mind plays tricks with you...during that time. Is it worse than what it was the first time?...Where is it? Is it still in the breast? Has it moved to the other breast? Has it maybe moved into the stomach? ....I would like to have had them tell me right then that same day. (01)

> The unknown is...a strain. The more I can know, the better I feel, even if maybe knowing is not what you want to know. (04)

Two informants were told about their diagnoses of recurrence over the telephone and were thankful for the expediency this afforded.

> I had made it quite clear that no, I wasn't going to wait around to come in to go to clinic...for results....I wanted it as soon as possible....It did not occur to me to find some comfortable place to have the news or have it some way easier or have somebody there. Just tell me the damn news and get it over with. So that's, for me, that was the best way....I don't know if there's a better way to tell somebody. I don't think so. I think you just have to just tell them. I can't imagine it being anything other than devastating. How can it possibly be? How could it be better? (02)

> I can't really see any other way of handling it. I mean, you could idealize we should have got in there and we should have eyeball to eyeball. But I mean...the pressure's on him. What does he do? I mean, by calling me in for a personal interview, my imagination is gonna take off...and I'm gonna figure it out. It's just gonna be an elaborate ritual to get the same bloody informational point. "You got it again, guy." So, you know, I think it would be very easy to take a shot at how I was informed but I just don't see an alternative that really was significant....How are you ever gonna make it 100% telling somebody that you have reoccurrent cancer? ....It's like shooting the messenger because you don't like the message. (04)

The strain of the unknown weighed heavily on one woman who was undergoing an indefinite period of chemotherapy treatments and was waiting to hear if "it's doin' any good."

> You just kinda hope and wait and it's like you put everything on hold....I don't know how long I'm gonna have to go through this. Two days after the chemo next week, I have to go through all the testing again....If you had gall stones or some kinda surgery or something, you know the time limit you're incapacitated ....Now I'm getting to the angry stage. Shit, you know, get it over with. I'll go through all this bullshit and just get it over with and let's get on with our lives -- for however long that'll be. (03)

Informants' quests for information typically reached far beyond their physicians. They gathered information from a variety of additional people, including family, friends, colleagues, neighbours, nurses, pharmacists, physiotherapists, naturopaths, workers in health food stores, volunteers, and other patients. Much of the information gleaned from these other people took the form of cancer stories, or narrative accounts of others' experiences with cancer. While most informants were interested in virtually any type of cancer story from any source, one informant identified that some stories were particularly unwelcome and unhelpful.

> You get these pain-in-the-ass people who are talking to you all the time about so and so had such and such cancer. Well, if it's not the same cancer or it doesn't have any relationship to what I've got, I don't wanna hear it. I don't want to hear your goofy cancer stories. I really don't. (06)

Informants also gathered information from media sources, including books, newspapers, journals, television and radio programs, and cancer clinic information sheets. As one woman said:

> Your mind is like a sponge. It's trying to absorb everything you hear and then trying to pick out the things that are good and things that you know are silly, the things that might help you. It's like, when you find out you have cancer you just can't get enough information, and especially about the type of cancer you have. You're looking for a solution from anybody or even off the TV or in books. So even if you don't pay that much attention to it, you hear it and it plays on the mind. (01)

These additional sources of information, that is, other people and media sources, were most often consulted regarding the causes of cancer and treatment alternatives, including their effectiveness and side effects. Several informants postulated theories of cancer etiology. These included using a lap top computer (testicular cancer), going through your "change of life really early" (breast cancer), "not using your female organs enough" (breast and ovarian cancer), being excessively competitive and very severe in evaluating yourself in those competitions, stress, "not looking after yourself emotionally," and poor nutritional intake.

Informants also looked inward in their quest for information, recognizing the knowledge they gained from past cancer experiences as a valuable resource. In addition, informants relied on their own self-assessments when appraising the impact of the cancer and its treatment on their well-being.

Breadth and Depth of Information

The breadth of the search for information and the depth or amount of detail required varied amongst informants. In terms of the breadth of the search, some relied almost solely on health care professionals for information, while others sought information from widely varied sources. The search for information broadened, particularly in relation to cancer treatment, as faith and confidence in the health care system decreased. This decrease occurred when health care providers were perceived as incompetent and/or when conventional cancer treatments were perceived as ineffective or unacceptably disruptive. One informant described how she lost faith in the health care system.

> I feel like I fell through the cracks...all the way down the line. If I go back in three months and they say I'm fine, I'm not gonna believe 'em. Because they don't check everything out and they don't see everything....I've had such rotten luck with doctors....I think you need a doctor in the family to really feel that you're getting good care....Well, I know the doctors that finally...diagnosed [the metastases]...were scrambling. They knew they had slipped, eh, that they missed something, that they should have been a little more careful. And I think it happens more and more and more and unless you stand up for yourself and say, "Hey, that's it. It's my body. You don't know everything." Well, in that article for Essiac tea,...this nurse...also doesn't have too much faith in a lot of doctors or the system. (03)

This informant searched for information from a wide variety of sources. Another informant had complete faith in his physicians and in conventional cancer treatments. He described chemotherapy as "a good thing. Maybe a bit brutal, but the stuff that'll do it" (05). This informant did not search for information beyond that provided by the physicians involved in his care.

Informants were commonly frustrated when they felt inadequately informed. As with the breadth of the search, the depth of information or amount of detail they deemed adequate varied. Some were content with a brief overview provided by their physicians, while others thoroughly researched the medical literature. One informant clearly described how he set limits on the extent of detail he needed and how some degree of ignorance was helpful.

> In some ways I pity these guys [physicians] if they ever become ill with one of these illnesses that they know about how they go. It must be a real rough thing for them to have to handle. Much more of a challenge than [for] somebody like ourselves who really want to know, want to have a sense that we're in control but there's also a helpful area of ignorance out there for us too....I do not need slides of cancerous guts....For me now, slides of cancerous guts are not gonna be helpful in developing the truth for me....I do not find myself pursuing certain other aspects of medical information. I would say I don't see it as necessary. I suppose if intellectually I felt it was necessary for my perception of what I'm at, then, even if I think I would find it unpleasant, I would still have to go and take it on. But, as I say, I'm the one that's doing the assessing of what information is relevant. So I suppose the thing is a lot of information becomes available to the patient and then the patient obviously must know enough of how to access it but then gets to choose what is going to be accessed....[And there comes a point where you feel you've] got enough to be functional....And actually shovelling more at me might be counterproductive. (04)

When referring to the potential complications of treatments, a second informant said:

> Ignorance was bliss....Not knowing sometimes was better and then just having to go through it. (06)

A third informant extended the idea of "helpful ignorance" even further, saying it may be better not to know about the cancer at all.

> If I could take that part of my memory...and just block it out because the worst thing is knowing. My husband, he could be sicker than I am 'cause he smokes and he drinks and he doesn't look after himself and he's overweight...but....he doesn't know....Maybe running around trying to find out is not such a good thing because it's hard to find out. (03)

In contrast, a fourth informant said,

> It was also really important to be kept informed. There's nothing worse than not knowing what's going on....I could never understand why people wouldn't want to know what was going on. (02)

As with the breadth of the search, the depth of information sought by informants seemed to increase as faith in the competence of physicians and the effectiveness of treatments decreased. One informant described how, during his initial cancer experience, he had complete trust in his physician and confidence in his treatments and therefore felt he didn't need a lot of detailed information.

> I didn't seek out a lot of knowledge. I didn't seek out a lot of information. I just didn't really want to know....I just knew I was gonna get better and that there wasn't really any need for me to have all this knowledge because what good was it gonna do? I was gonna be better. You know what I mean? It was a waste of my time. (06)

Because recurrence meant that initial cancer treatment had failed, confidence in treatment effectiveness naturally waned, along with confidence in physicians in some cases. Hence, the search for information was typically wider and deeper on recurrence than on initial diagnosis.

Purposes of Gathering Information

Gathering information was a means of developing a realistic understanding of the present, thereby decreasing uncertainty, increasing control, and decreasing fear.

> I wanted to....look into it a little bit, you know, do a little bit of research. Maybe, even it wasn't helpful for anyone else, it'd be helpful for me because I would've felt I've...researched it a little bit and had peace of mind. (01)

> There's a sense of knowledge, a sense of control and it's therefore less fearful as a result. (04)

Information enabled informants to get their bearings and determine which direction to head. The search for information was an ongoing process but decreased in intensity once informants felt they had enough information to understand their present circumstances, reframe their visions of self and future, and have some degree of certainty in those visions. One informant explained:

> All human beings are in many ways future oriented. We're causation types. We have to have explanation. Explanation for the past is simply to give us

> some rules that we can apply to the future. If we have a sense that that is going well, we have confidence. We're sure of ourselves....So I suppose what I'm doing...is trying to get a sense that I have mapped out the present as accurately as it can be and, on the basis of that mapping out, I can "know this," quotation marks, about the future. (04)

In other words, gathering information was of primary concern until informants had enough to accurately estimate the damages to the hopeful veneer and determine if and how it could be rebuilt. It was as if the pieces of information were some of the materials for the rebuilding process. Before assembly could begin, it was first necessary to take an inventory of the materials to determine their quality and sufficiency, that is, to find grounds for hope.

Taking Inventory

As informants gathered information, they simultaneously took a running inventory of the hopeful and ominous signs they perceived in that information. The balance between hopeful and ominous signs constituted the grounds for hope that would be used to rebuild the foundation of the hopeful veneer and determine the manner in which informants would reframe their futures. For some informants, the balance between hopeful and ominous signs was continually shifting, producing instability in the grounds for hope and delaying the rebuilding of the hopeful veneer. When asked if she could comment on the part hope has played in her experience with recurrence, one informant replied:

> Depends on the time of day. I got a letter from [voice cracking, crying, sniffling] my husband's cousin yesterday and then she says that her mother-in-law had thyroid cancer real bad and had chemo and has been in remission for 35 years. So then you get hope. Then you watch Donahue and you...see all the statistics on how high the death rate is and then you lose it again. It's.. [holds hands with palms up in front of chest and moves one up while moving the other down to indicate the fluctuations in her hope]. It never stays the same. Mostly you're scared. (03)

When trying to find grounds for hope, most informants sought hopeful signs they perceived as authentic or real, rather than false or invented. The more authentic the signs were perceived, the stronger were the grounds for hope, the more stable the rebuilt veneer became, and the less likely the veneer would be eroded in the future. Determination of whether signs were real or false was influenced by the information gathered but was largely a matter of individual interpretation.

> You just wonder how thick the hopeful veneer is, but it's not a phony hope. My hope is based on facts. You know, body temperature normal, tumour markers normal, a surgeon who says, "Hey, we had a good operation here," and a cancer doctor who seems happy with all the results he's seen. So that's where my hope comes from....[I needed] to look for the hopeful signs and know that they weren't something that was sort of invented or just thrown out there to give me this sense of hope. (06)

When asked how he knew the signs weren't false or invented, this informant replied:

> You try and get two sources but three is better....I've had at least two sources on all the things. Like the blood tests and [the surgeon] backing up what [the oncologist] is saying and stuff like that. (06)

Informants described hopeful and ominous signs in relation to their cancer, cancer treatment, and their health. These are summarized in Table 4.

Cancer-Related Signs

Although finding out they had recurrent cancer was universally viewed as an ominous sign, all informants were able to find some hopeful signs regarding the characteristics of their cancer. A few examples follow.

> I thought I had bone cancer and lung cancer and liver cancer....But it wasn't until a couple of weeks later that the doctor, one of the doctors explained to me that it was breast cancer that has spread. But it's still considered breast cancer. So I don't know if that's good or bad. I think it's good....They said it's quite a common variety. There's 18 varieties of breast cancer and it's one of the common ones. (03)

> Although the tumour was mostly benign, there was a small segment of what they called immature teratoma, in other words, cancerous-type cells. So they feel that that was encased within the tumour itself and that there was no spread at all and the tumour markers are very supportive of that....That's why this is such a curable cancer because it's very predictable. And so there's nothing in my liver, nothing in my lungs and...the tumour that grew again was the same one that grew in the first place. (06)

Table 4 Hopeful and Ominous Signs

	Hopeful Signs	Ominous signs
Cancer	• Small tumour size • Localized, no spread, early stage • Low grade, borderline, slow growing • Predictable, extensively researched • Easily removed or treated • Common variety • [a]Same as/Different than initial diagnosis	• Large tumour size • Spread to other organs, widely disseminated, advanced stage • Virile, aggressive • Little known • Difficult to remove or treat • Rare variety • [a]Same as/Different than initial diagnosis
Treatment	• High cure rate • Mild or temporary side effects • Short treatment course • New developments • Accessible, Available • [b]Signs of effectiveness • [c]HCP optimistic about effectiveness	• Low cure rate • Severe or permanent side effects • Long treatment course • No advancement • Inaccessible, Unavailable • [b]Signs of ineffectiveness • [c]HCP pessimistic about effectiveness
Health	• [b]Few/minor symptoms or complications • [b]Minimal suffering and life interference • [b]Normalcy	• [b]Multiple/major symptoms or complications • [b]Considerable suffering and life interference • [b]Lacking normalcy

[a] Divergence of opinion amongst informants regarding whether it was a hopeful or ominous sign when the same type of cancer recurred.
[b] Sign in self or others with cancer
[c] HCP = Health Care Professional, typically physician

While the latter two informants implied that a recurrence of the same cancer was a hopeful sign, another man identified it as an ominous sign and would have preferred to have had a different type of cancer on recurrence, providing it had a high cure rate.

> The biggest disappointment was probably, and that's related again to hope. ...was that it also was the same strain of lymphoma. It wasn't just a skin cancer....Like if it had been a skin cancer down here, these lumps, I'm sure that wouldn't have been [as serious], unless it had been melanoma. That, of course, would be very, very serious....Any other kind of skin cancer would have been a lot less serious than a repeat of lymphoma. (05)

Another informant talked about how the ominous signs she had noted at the beginning of the recurrence were "erased" by hopeful cancer-related signs found later in the experience.

> Nobody was being optimistic with me at all. I mean [my friend] is talking about help to let go when I decide it's time. The doctors are talking about not being able to do anything, bad prognosis, always bad when it comes back. I can't even remember the stuff 'cause now that's sort of been erased by the fact that it is low grade and that's good because even if they can't get after it, because it's slow growing, it could give them time. I mean every year they're making....HUGE leaps [in cancer research]. So the fact that it's low grade means that even if they can't cure it now, I could be around for awhile and then they'll find something to cure it. So that seemed good, rather than it just taking over. (02)

Treatment-Related Signs

All informants were offered conventional cancer treatments by their physicians on recurrence. The availability of treatment was, in itself, seen as a hopeful sign. All informants were told, however, that the probability of achieving a cure with treatment was lower on recurrence than on initial diagnosis and this change in odds was seen as an ominous sign.

> Coming back you're not an 85-90% player anymore, you know, your odds are changing rather dramatically rather quickly. And so those old concerns about, well, not concerns, disappointments about not having necessarily the length of time that we all assume is there, they're back. (04)

> I said to him,..."O.K., I was in the 90th percentile for cure. Now we're obviously in a different percentile because...this is a recurrence. Where does that drop me too?" And he said, "Well, maybe in the 60s." And that was a real bone shaker....I wanted the candid comment but when he said I dropped to the 60s, I thought well, what happens if this doesn't work? Do I drop to the 30s? You know what I mean? And so that was part of the reason for my morbid comments and that sort of thing. When you're in the 90s you're feeling pretty plucky but boy, 60, you know....It's not like you can have another turn. (06)

Another informant noted that physicians did not even speak in terms of chances of a cure on recurrence.

> Six years ago or seven, when you talked about what's your chance they would put it into percentage and they would talk percentage in terms of chances of being cured....Now they don't talk percentage of cure....They talk percentage of remission....That is a bit disappointing. (05)

While informants carefully noted the words used by physicians when they were relaying information about treatment effectiveness and prognosis on recurrence, they were also closely attuned to physicians' attitudes and nonverbal behaviours. If physicians were perceived as positive or optimistic about treatment effectiveness, this was a powerful sign of hope, sometimes more so than the actual words used.

> You look for things you trust, the truth you know, and the reactions of people who are helping in your treatments. And when I get a doctor who is like excited on the phone and saying things like, "This is great. This is really good,"....that's undeniable. I mean, you've got it to work with. (06)

> They were pleased with the results of the operation, a little tentative until they got the results back from the pathologist. When those results came back two days later, I thought the surgeon was gonna do handstands....He was obviously very pleased with how things were going, very pleased with how the healing was going. (04)

Conversely, if physicians displayed a pessimistic attitude about the treatment, this usually negated any positive words spoken.

> [The oncologist] was quite upbeat and he said, "Hey, it doesn't matter where it is, we're gonna go with chemo now and that'll clear it up." That was his attitude. And the next time when I went back to see him, it wasn't him I saw, it was this other doctor. And he totally devastated me. You know, he made me feel like I was gonna die next week....I asked him what my chances were and he gave me this look like [demonstrates an indifferent, apathetic look]. Not very good, you know....Kind of a shrug....Like he wasn't prepared to give me any odds. But that devastated me. Then I totally fell apart. (03)

> [The oncologist] is more or less up front. She said chemo will maybe prolong your life a year or two. And...like what this doctor said, this Canadian doctor on the television, for recurring cancer they don't bother. You're history and you can see it in their eyes. You can see it in their faces. (03)

> Nobody was being optimistic with me at all....The doctors are talking about not being able to do anything, bad prognosis, always bad when it comes back....My family doctor even said, "You might have to make the choice of not

> having any treatment of any kind. That might be worse than just going quietly." (02)

While undergoing treatment for recurrence, informants carefully watched for signs of treatment effectiveness. These signs were discovered through interactions with physicians and self-assessment. For some, the hopeful signs were clearly evident.

> I'll swear that within five days after the first chemo treatment, the two other tumours that was on my leg was starting to shrink. And within two weeks, they were gone, which was really positive....It gave you a lift at the time. (05)

For others, the mixture of hopeful and ominous signs resulted in unstable grounds for hope.

> I did go for those tests and they said that the tumour appeared to be shrinking on the liver and the lungs were clear. But, well, it's on my bones..., like my chest cavity. I can feel it's really sore on the bones. And I went for more tests with a neurologist..., for a bone scan, and they found more hot spots. So maybe they're keeping it out of my organs....but from what I could tell it's not doing anything to get it out of the bones. And then the other treatment they said as a last resort..., a new treatment where they can...take bone marrow out and give you the chemo in the bone marrow and put your own bone marrow back, they haven't suggested that to me anymore. (03)

The inventory of hopeful and ominous treatment-related signs extended far beyond the information gleaned through interactions with physicians, particularly in relation to treatment effectiveness and availability. As noted in the section on gathering information, informants were more likely to seek information from sources beyond their physicians when they lost faith and confidence in the conventional health care system. In other words, if substantial grounds for hope were not found during interactions with physicians, the search for hopeful signs was more likely to be extended to other sources. Even if some grounds for hope were found during these interactions, most informants sought additional signs from alternate sources. The more hopeful signs were found, the more stable the grounds for hope became.

Others' stories of successful cancer treatment served as significant signs of hope for all informants.

> They had known someone around my age, a younger fellow who had the same

> cancer and even gone through the lymph dissection, in other words, the extra surgery, and five years later he's fine and doing great with no sign of any recurrence. And so hearing that was very helpful and...you sort of look almost for signs, eh. (06)

> You always take hope if you happen to talk to somebody whose been through it before....You know, they've had it for 5 years and they're just coming back in there for a regular check-up and their cancer is either dormant or cannot be detected and you can take hope. "Gee, that sounds like my cancer. That sounds like that could happen to me." (01)

On the contrary, others' stories of failed treatments were seen as ominous signs and weakened the grounds for hope.

> I've had a lot of cancer in...my immediate family and I've seen different types of treatments and it wasn't for them. I mean, it didn't help them....Here 30 years later, the treatments haven't changed that much. If it didn't work then, it's not gonna work now. (01)

> I heard on the CBC news that a young guy, 20-year-old guy in Quebec has the same type of cancer and they didn't get into exactly what treatments he's been through but I had taken it that he had gone through quite a few treatments. And so I heard it was a cancer story and I'm sort of semi-interested but if it's not the cancer that I wanna hear then I'll just tune it out. So they're talking about him going down to Texas to take an experimental chemotherapy which is not paid for by Medicare so his parents had to put up $100,000 for the treatments. And then at that point the...reporter rather said that it was testicular cancer he had and I'm going, "Hey, wait a minute. This story doesn't jive with all the other stories I've heard. They've all been good news stories." (06)

Information about alternate cancer therapies and/or new developments in conventional treatments was eagerly sought by most informants as grounds for hope. As one man explained:

> If I wasn't hopeful, what would it take to get hopeful? How do you get a dose of hope? And maybe that's the answer for some people is to get a hold of some books or some reference material [on holistic healing]...or, you know, maybe for some people it's to take that trip to Texas for the experimental chemo or to Mexico for whatever they are offering down there....You get a ton of people who go to Mexico and seek out certain treatments that aren't available here or are too expensive here, things like that. I'm sure that people hang on every word that's written in a newspaper or a medical journal when they see there's been some new sign of hope. (06)

Indeed, most informants viewed this type of information as "new signs of hope" that would serve to strengthen the grounds for hope and facilitate rebuilding of the hopeful veneer.

> The lady in the health food store in Stony Plain, she gave me a bottle of stuff that she took. She had cervical cancer too and she went to a clinic in Texas and she got all these different kinds of pills and stuff and she's cured. Yet she said her dad passed away from cancer but he passed away in peace and no pain. (03)

> I pointed out to them [oncologists] that if they get into this immunology don't forget about me because I think that's probably where the answers are gonna lie so keep us posted and they said they would. (04)

Some informants, however, were hesitant to use this type of information as grounds for hope. Instead, they thought it created false or unrealistic hope, especially if the treatments were inaccessible or unavailable or if the information came from an unreliable source.

> The worst of all is the secondhand information. My brother-in-law who is a big, gregarious kind of bullshitter...comes in at Christmas time and starts talking about how he had read that there was this new thing and it was a cure for all cancers and I thought, "No, that's horseshit." I mean, that would have been on the news, top item. You know, who are you kidding? ....Obviously he had either misread the information or had it misconveyed to him but he comes in and he thinks that that's helpful. It's not....It really isn't because then you're creating false hopes. And sometimes I wonder about these newspaper articles if they should mention in paragraph one that there's no way that you as a patient are gonna get your hands on this for at least two years and if you have cancer now, you're gonna be dead as a doornail. You know what I mean? So maybe that's the way the article should start off instead of having you try and get on the phone long distance to Virginia where the clinic is that has developed this new whatever...and to be told, "No. It's in research stage here. It wouldn't be to Canada for years. (06)

> [A colleague] sent me a book on this Indian drink which is a magic cure for cancer. That was not helpful. And other people want me to be on macrobiotic diets, or do other things. I haven't even read the book on the miracle....But people do that sort of thing. NOT HELPFUL. Not at all. (02)

In addition to the effectiveness and availability of treatments, the side effects, complications, and duration of treatments were also considered in the inventory of hopeful and ominous signs. The lower the likelihood of severe and/or permanent side effects and complications and the shorter the treatment course, the stronger were the grounds for hope. The sources of information for these treatment-related signs included physicians, self, and other patients.

> [On recurrence], you're not naïve and you know what it's all about....You've gone through some of the treatments and now you're looking at more treatments on a more severe level, you know, maybe stronger chemotherapy. Well, what's it gonna do? The first time I lost my hair. If I take a stronger chemotherapy and maybe a little bit longer what's gonna happen to me then? You know, is my skin color gonna change? Is it gonna affect something else in my system....You do become a little more wiser and you understand what's happening and you understand that these medicines that they use are not just treatments but they also can do damage, you know, to other organs. (01)

Health-Related Signs

In addition to the signs relating to the cancer and its treatment, informants also found grounds for hope in signs of their own health and well-being. The more healthy informants felt and the more they were able to maintain normal roles and responsibilities, the stronger were the grounds for hope. Health-related signs were most commonly discovered through self-assessment and through comparison with others who were "worse off."

> I have cancer but I'm still, two and a half years, three years later, I have all my hair, I feel very physically capable, I'm out building a house, and I mean physically building this house -- my husband, myself, and my 15 year old son. And we work hard, long hours, and I'm still maintaining a home of 5 children. (01)

> He was on exactly the same [treatment] schedule and I could see that....he was suffering far more than I was....I was certainly way further ahead than he was....so that kind of gave me a lift. (05)

Transition to Reframing

All informants were successful in finding sufficient hopeful signs to establish grounds for hope and rebuild the foundation of the hopeful veneer, despite the ominous reality of the recurrence. Informants did identify, however, that it was more difficult to see the hopeful signs or "connect them" if they were overwhelmed by emotions, such as fear, anxiety, anger, or sadness, and/or did not have a good understanding of their circumstances. Hence, dealing with emotions and gathering information were conditions that facilitated finding grounds for hope. Informants were now ready to move on to the next phase of rebuilding, reframing, wherein they selected the best blueprint and rebuilt the second level.

If informants had been unsuccessful in finding sufficient hopeful signs, they would have been unable to rebuild the foundation of the hopeful veneer. Hence, instead of moving forward to reframing, they likely would have remained in the phase of appraising, searching for additional information that might provide them with more hopeful signs. If the search seemed fruitless, they likely would have fallen back down to disengaging and perhaps further to the stage of giving up.

Reframing: Redefining Objects of Hope

In the second phase of rebuilding, reframing, thoughts of the cancer and its implications remained at the forefront of informants' minds. The emphasis of those thoughts, however, shifted from the present to the future. The microscope used to view the world in the stage of appraising was traded for a telescope and a wide angle lens. During reframing, informants came to terms with the implications of the appraisal and reframed visions of self and future. In so doing, they redefined their objects of hope, or what they hoped for, in accordance with the new reality. These visions of self and future were the blueprints used in rebuilding the hopeful veneer. Whereas the grounds for hope found during appraising were used to build the foundation of the veneer, the objects of hope delineated during reframing were used to build the next level upon this foundation. Once the second level was built, informants could re-engage in life.

The phase of reframing comprised two components: reframing self and reframing the future. Informants reframed visions of self in two domains: self as person and self as cancer patient. They also reframed along two dimensions: reframing realistically and reframing positively.

Reframing Self

A first recurrence of cancer disrupted informants' self-identities on both the physical/functional and existential planes. Before they could re-engage in life, they had to come to terms with the changes to self that resulted from the recurrence experience and integrate these changes into their new identities. Changes to self occurred in two domains: self as person and self as cancer patient.

Self as Person

As described in the section on withdrawing in Chapter 5, effects of the recurrent disease and treatments led to alterations in informants' abilities and appearances which, in turn, impaired their ability to perform usual roles and fulfil responsibilities. The net effect of these alterations and impairments was a disruption in the identity of self as a person. These disruptions in identity varied in duration and extent. Disruptions perceived as temporary required only short term accommodation, while those perceived as permanent and extensive required long term integration into a new vision of self.

When disruptions were viewed as temporary, the inherent belief in restoration of normalcy made accommodation a relatively simple process, particularly when there was some certainty regarding the duration and extent of disruption.

> If...the chemo is finished at the end of December, then I can start building up my resistance, fighting other things, and growing some hair. (03)

> When whatever side effect might come up,...I would occasionally take out...the green information sheets that I have on the different...chemo drugs I was on. And I could certainly rationalize much better why I was having these problems. It really did help....You can better deal with it....You knew you were having it because of the chemo so therefore, if it was because of the chemo, then it would just be a matter of time and it would be finished with. (05)

When disruptions were of uncertain duration, informants differed in the extent to which they integrated them into new visions of self. One informant described how he maintained hope for a return to normalcy, hence engaging in short term accommodation, while another described how he chose to move on to long term integration and reframing of self as person.

> One of the major side effects, is that you, at least temporarily, but there's a very strong possibility you permanently become sterile....Because they cut into a certain part of the nervous system in the abdomen, ...[the sperm] recirculates and sort of goes into the bladder....I've since had a consult with [surgeon] and he tells me that they didn't cut into the right side as much as they had to on

> the left, that that may allow for some regeneration and within a year to 18 months things may reconnect....If not, there is a drug therapy they can try. So there's some possibilities being held out and that's hopeful. (06)

> Impotency is, for a mid-fifties male, if you haven't had your mid-life crisis yet, by God, it's gonna bring things to you. And very conscious, of course, of how your wife is gonna feel about this and having to talk it through. And do you talk it through or do you try and ignore it or do you get rosy-hued and say, you know, the electrical wiring will probably come together in eight month's time or something like that? No. Get down and get on with it. It's interesting how much less a factor it turns out to be than you thought it would be from before but you just have to get on with that. (04)

When disruptions to self-identities were perceived as permanent, long term integration was necessary. Under these circumstances, informants developed new patterns of normalcy and visions of self.

> Occasionally, in the very early stage with the [colostomy] irrigation, you know, technical little thing, but it wasn't working quite right and jeeze, it was just so frustrating and angering and that....[Now] irrigation has taken pretty good. I think maybe the fact that it isn't 100% perfect is a little bit my habits. Sometimes I overeat a little bit, sometimes a little too much roughage, I think. I'm gonna have to learn I can't eat corn on the cob anymore and a few things like that. And sometimes, you know, possibly a couple beer too many kind of throw it off schedule. But I'm working on, I think, a satisfactory routine as far as I'm concerned and so the whole drill with the bags and everything else [is]...getting down to a second nature. I've worked out a backup system now so when the little surprises occur we can react effectively to them. (04)

> Although I feel well and am so-called back to normal, I do not have the same energy level that I had a year ago for work....Right now, the thought of harvest which in many ways is sort of an exciting time somewhat, mentally to me that's a lot to handle right now...because I know I cannot handle the work that I could...a year ago....I think that I'm back to as normalcy as I will ever get and if that's what it is, that's fine....I'm not complaining one bit. (05)

Ramifications of the recurrence for visions of self extended beyond the physical/functional plane. Informants also experienced disruptions to their self-identities on an existential plane. Whereas achieving the first remission kindled hopes for a cure and a long life, the recurrence of cancer made dying "a bloody real possibility" and forced informants to come to terms with their mortality.

> It kinda brings your mortality into focus....I always thought I had another 20 years. Now I'm not so sure. (03)

> It's coming to terms [with] your own mortality, and the death of your parents

> is part of the process of doing this, but then when you encounter a major illness, you also perhaps push further along that path. And I would think people with reoccurrent cancer probably come to terms with it much more than most people have. (04)

In addition to reframing self as a person, the recurrence also necessitated reframing self as a cancer patient.

Self as Cancer Patient

Experiencing a first recurrence of cancer led to disruptions in informants' identities as cancer patients. Prior to the recurrence, they viewed themselves as the "lucky" or "special" ones who are cured after initial treatment. They now had to integrate a new identity as a patient with recurrent cancer, that is, one of the "unfortunate" ones who is "no different" than the rest. Rather than epitomizing successful cancer stories, they now represented failures.

> It's a real blow to your system because you realize suddenly that you're no different than the rest, than so many others who have...cancer and you're facing, maybe a limited time too. Like everyone likes to think they're a little bit special and...that you're going to be maybe that special person that doesn't have to face death, that cancer isn't gonna get you in the end. When you're told that your cancer's reoccurred again well then you suddenly get, it hits home, it becomes reality....You're just one of the very unfortunate people. (01)

> I was always under the impression that I was one of the lucky ones, although these hoops were very difficult to go through, that I was meeting the test because I was strong and I was able to do it and that once I was finished I was gonna be cured, done....So I mean never did I think that I was in the same boat as people who were dying....I now feel like a full blown cancer patient....I feel like, yeah, I've been to the max and I'm not as LUCKY as I suggested at first. (06)

Reframing the Future

In the next component of reframing, informants used their new visions of self and the grounds for hope found during appraising as the basis for reframing the future. They had "come to terms with [the new] reality" and, on the basis of that reality, made "legitimate inferences...about the future." In reframing the future, objects of hope were redefined and used to build the second level of the veneer.

Building of this next level of the hopeful veneer was contingent upon the strength and stability of the foundation, that is, the grounds for hope. The stronger and more stable the foundation, the sooner building of this next level commenced and the higher it was built. The more certain informants felt about their circumstances and outcomes, that is, the more stable the grounds for hope, the sooner they reframed their futures and redefined objects of hope. The more positive those outcomes were perceived, that is, the stronger the grounds for hope, the longer the anticipated future and the more distant the objects of hope. One informant, who was 64 at the time of recurrence, perceived the grounds for hope to be stable and strong and anticipated a very positive outcome of treatment. He described one of his long term objects of hope.

> [My grandson] won't graduate from grade 12 till I'm 79 or 80 and, by God, I hope I'm there when he graduates when I'm 80. And I think I have an excellent chance....It just seems like automatic I'm gonna be here at 85. So the hope must be there. If I didn't have a hope, I wouldn't have that feeling. (05)

In contrast, another informant perceived the grounds for hope to be unstable and weak, anticipated a shorter future, and defined objects of hope that were less distant.

> I'm hoping that at least this chemo will give me one more year or something, two more years maybe. 'Cause we just bought a place in B.C. and we were going to start to think about semi-retiring there. Start up a little business there with a bed and breakfast and my craft stuff. (03)

For the latter informant, the blow of the recurrence led to such instability in her grounds for hope that she was afraid to adopt a positive attitude and envision a positive future for fear that she would be "kicked in the head even harder."

> I don't have a positive attitude....I find it very difficult because when I had a positive attitude at the beginning of all this, it seemed like somebody was saying, "Uh-uh. Sorry. You lose."...I said, "Ah, it's nothing. Not to worry about it. I'll have a little surgery. I'll get through this. Next week I'll be fine," and then [I got] kicked in the head even harder. And every time it seemed that happened. Like they said only 15% of those tumours are malignant so I thought, "Fine, what are the odds? Mine won't be."...So... sometimes I even feel I'm afraid to have [a positive attitude] because I figure then I'll get kicked even harder. (03)

The stability and strength of the grounds for hope changed throughout the experience of first recurrence, each change necessitating additional reframing of the future and redefining of objects of hope. From the time they received the diagnosis of recurrence until they knew the outcomes of treatment, most informants perceived the grounds for hope to be too unstable to look very far into the future.

> I guess after they go in and do more pathology, they'll have a clearer idea. But it's just such an uncertain future. (02)

Descriptions of living life "one day at a time" or "one week at a time" were common. Informants focused on mapping out the schedule of treatments and check-ups and identified short term objects of hope, such as having enough energy to go for a walk or getting through the treatments.

> You're always hoping to get through it as quickly as possible. There's no doubt that say the middle of January this year I was really looking forward to the 10th of March, two months later because I'd be finished chemo. I was taking it, not one day, I was taking it one week at a time. I remember [my daughter] coming in and she says, "Well just remember, Dad, you've got one chemo behind you now. There's only so many left." And after five she said, "Dad, you've got five chemos behind you. There's only two or three left." That's a method I suppose...I used to get through...the effect of the chemo. (05)

Two informants were atypical in being quite certain of the more distant future before treatment had even commenced. One informant was certain the treatment would fail in inducing a second remission and she would die, while the other was certain it would succeed and he would live a long life. As would be expected, these informants also fell on the extremes of the continuum in terms of their reaction to the news of recurrence, the first being utterly devastated and the second viewing the recurrence as an irritation. For both these informants, the grounds for hope were perceived to be stable at a relatively early point in the experience and, hence, they reframed their futures, were more confident of those futures, and rebuilt the hopeful veneer sooner than the other informants.

The informant who was certain treatment would fail said:

> After I learned that there was the tumour, I was sure I was gonna die and I was sure I was gonna die fast. (02)

Perceiving that ominous signs outweighed hopeful signs, she envisioned a shortened future and redefined objects of hope accordingly. She hoped to bring a good conclusion to her life, prepare well for death, enjoy the short time she had remaining, and have a quick, painless dying process. These objects of hope were not new for this informant. As described in the section on monitoring in Chapter 5, they were the materials this informant used to establish the original hopeful veneer after initial diagnosis. As the length of remission had increased, these materials were replaced with hopes for a long life but were not completely discarded. It seems they were only temporarily kept in storage and were at the ready to rebuild the hopeful veneer on recurrence, therefore making rebuilding a relatively quick process.

> From the first time I was diagnosed I think that I knew that I was going to die soon. And maybe it's been a little longer than I thought, but it was gonna come. And now it has. And so I'm not certain that I've had very much hope. I mean I go through these things on sort of a day-to-day basis, but I don't think I have much for the long term. The only HOPE I have is of getting through this as easily as possible. I DON'T have any hope for the long term and I don't think I have had for a long time. Like it was just a matter of when was it going to come. And it did. And it sorta surprised me on one level, but not....I had accepted that I was going to live on one level, but deep down you always know you're not going to. So, I don't have much hope, except for just the next little while and things will sort of be okay, but they won't be in the long run. (02)

The informant who was certain treatment would be effective said:

> In the back of my mind, all along, it was automatic I was gonna get better. (05)

Rather than investing a lot of time and energy in finding specific grounds for hope, this informant seemed to take it for granted that he would have a long, positive future. When asked how he was able to be so certain of this positive future, he described himself as having "the general hope." His long term objects of hope were virtually unchanged by the recurrence. The hopeful veneer he had established after initial diagnosis seemed to have required only minor repairs rather than complete rebuilding.

> I'm very, very glad that I haven't lost hope....It seems to me, I have exactly as much hope as last time, which is maybe quite unusual....[The recurrence] was a disappointment but it didn't change my hope at all. Not at all. It was a disappointment because I knew...I'd have some months ahead where I wouldn't have as much fun in life. I knew it was gonna interfere a lot with my pleasure.... It did not seem to change what I knew automatically I [was] gonna

> do in August [or]...seven, eight months down the road [or] the next years....[In] the general feeling of hope ahead,...the daily thinking of what you are going to do ahead, both pertaining to work and many other things, I find...there's no darn difference from last time. (05)

For the other informants, uncertainty did not dissipate and futures were not confidently reframed until they received information about the ext nt of recurrent disease and, more importantly, treatment effectiveness. If the hopeful signs in this information outweighed ominous signs, the grounds for hope became stronger and future visions became longer and more positive. After a CT scan revealed that his tumour had been eradicated by chemotherapy, one informant described his new vision of the future and his distant objects of hope.

> It's now to the point where I'm just full of hope, brimming with hope and realize that hey, I'm gonna get better and I'm gonna get old. I'm gonna have my retirement, use up some of my retirement money and all that kind of thing. (06)

If the ominous signs in this information outweighed hopeful signs, the grounds for hope became weaker, future visions became shorter, and objects of hope became less distant. After chemotherapy treatments failed to slow the progression of her metastatic bone disease, one informant described her reframed future and redefined objects of hope.

> I'm not looking too far ahead. Not at all....I'm not looking any farther ahead than this summer. Actually, Christmas, next Christmas. I plan on going to Kamloops as soon as these tests are done this week and then...in March for a couple of weeks, go[ing] down to New Mexico, Arizona, and hopefully Texas. We're gonna buy a camper if I can travel....And this summer, well, in May, we're gonna go to B.C....and at Christmas I'm going to Florida to visit my family. And I'm not looking any farther ahead than that. (03)

The more certain informants were about their future visions, regardless of the nature of those visions, the more stable was the rebuilt veneer, the further they looked into the future, and the easier it was to re-engage in life. For some informants, considerable uncertainty persisted even after they achieved a second remission and life continued to be lived "one day at a time."

> That's part of the veneer is the time lines, okay, that whole doubtfulness in terms of getting through, like the one day at a time scenario. Well, the one day at a time, for me, [will continue until] I get through to the point where

> [the oncologist] starts saying, "Okay, we can slack off on the CAT scans with you....We can slack off and start doing them once a year instead of once every six months or once every three months." (06)

Because the first treatment for cancer had not succeeded in achieving a cure, informants tended to be more uncertain or doubtful about a positive future after entering the second remission than they had been on entering the first. This uncertainty or doubtfulness was reflected in one informant's description of his reluctance to celebrate achievement of a second remission in case he "jinxed it."

> After I was all done chemo and got the clear CAT scan, I betcha I bought $150 worth of champagne and it was yah, yah, yay, yay, happy, happy. [Waves arms in the air in a celebratory motion] And [I] went to Vancouver and did a lot of things. I'm less inclined to do that now....We've had a half bottle of champagne in the fridge upstairs since I had the surgery...a month [ago]....I'm just a little reluctant to open that bottle of champagne because you think to yourself, "Maybe it'll jinx it."...So I'm not really doin' a lot of hootin' and hollerin' this time around. I'm more sort of just kind of gauging the situation a little more carefully. Like the last time it was all through and then a big....Whoop-dee-doo. Whoop-dee-doo. This time I have at least as many hopeful signs as I did last time but there's no whoop-dee-doo. (06)

In reframing self and future and redefining objects of hope, informants endeavoured to be both realistic and positive.

Reframing Realistically

Just as informants sought hopeful signs they perceived as real or authentic to use in building the foundation of the veneer, they also sought objects of hope they perceived as realistic to use in building the second level. By developing a realistic view of the present and the future, that is, by using realistic grounds and objects of hope, they felt the veneer was less likely to be eroded in the future and, if an erosion did occur, rebuilding would be a quicker and easier process. Being realistic enabled them to envision the future, make plans, and re-engage in life with more certainty and confidence. In addition, by pursuing realistic objects of hope, they felt there was a higher probability of realizing them and, hence, of experiencing success rather than failure, disappointment, and discouragement in the future.

> I think hope is always best when it's blended with realism because I suppose if you had hoped for a certain situation and to do certain things and it didn't

> come about and you were just really set on it, then that hope could almost create a negative situation, particularly if it's not realistic hope. Then you could become discouraged because it didn't happen....The hope itself is good. I can see that. But I'm not so sure the idea that goes with that hope would necessarily be beneficial in the long run. (05)

> I guess it could be discouraging if you are very hopeful to the point where you sort of build up your expectations perhaps too much. [You] hope that maybe this disease somehow has been put dormant for good, and then it comes back on you. If you're that kind of a person that you put too much faith and hope in whatever you want to happen and it doesn't happen for you, you become so discouraged that you just throw up your hands and give up. And that would be even worse because then it would be just not willing to even try anymore to help yourself. (01)

Making the distinction between realistic and unrealistic objects of hope was similar to making the distinction between real and false grounds for hope. This judgement was influenced by the information used to form the grounds for hope but was also influenced by individual perceptions and interpretations of the strength and stability of those grounds. One informant explained how having too much information may be detrimental in that it forces one to come to the realization that desired objects of hope are unrealistic. When asked if there was realistic and unrealistic hope, he replied:

> You're probably never gonna know for sure in drawing that line. Perhaps a more experienced health professional in observing my case would say, "Gee, that's great but, you know, two and a half years down the line, da-da-da-da-da." I remember overhearing a couple of doctors in a social circumstance basically commenting that way on a third party. It was obvious they knew the etiology of the disease and they knew what the consequence was going to be. Now that's something somebody who was not a health professional like myself doesn't know. So from the perspective of that kind of an individual there might almost be a falseness, a belief in Santa Clausism or something like that. So be it. That's the way it has to be. In some ways I pity these guys if they ever become ill with one of these illnesses that they know about. It must be a real rough thing for them to have to handle. Much more of a challenge than somebody like ourselves who really want to know, want to have a sense that we're in control but there's also a helpful area of ignorance out there for us too....I guess what we're getting at, Linda, is getting right down to this process of getting an understanding that one sees as "true," quotation marks. (04)

Receiving information about the recurrence shattered "rosy-hued" future images that informants had strived to maintain during remission. When asked about these images, one informant described:

> It probably reflects Hollywoodisms in terms of being sick but you're not going to be the one that gets it. Almost immature, childish, but they couldn't help but go around, particularly the first time through. (04)

Realistic reframing of self and future typically entailed envisioning a shortened life, a second recurrence, a cancer-related death, and a shift in objects of hope from quantity to quality of life.

Shortened Life

In attempting to reframe realistically, five of the six informants envisioned a life that was shorter than that anticipated prior to the recurrence. Given this change, some previously held objects of hope came to be viewed as unrealistic and images of self in the future were reframed.

> Well, I think the future is not so distant anymore. It's a foreshortened kind of thing....Dad made it to 85. I'll back off trying to make it that far but I'd certainly like to beat the five years. We'll cut it short. We'll go for the five years counting the first one and then we'll go for the five years after that one....The kind of a future as a happy dottering old man with grandkids and all of that kind of thing, it would be nice to have it, but it's not there because that's a LONGER period in the future. (04)

Second Recurrence

Although all informants hoped they didn't have a second recurrence, they acknowledged that is was now highly probable.

> It's almost like you've cheated it a little bit because you've gotten away a second time with it not being so bad. But your luck doesn't hold out forever....You know that perhaps that time is gonna come when cancer will start up again. Like mine seems to be almost...laying dormant for awhile but it's going to apparently act up again....[The oncologist] said that I do have reoccurring cancer. My cancer's gonna reoccur....I'm not being silly, naïve. I know that that's probably gonna happen, and if it does, well, I'm prepared for it. (01)

> I may well battle in that again in another year or two, or not another year, but two or three, which is not a pleasant thought...but it's realistic. (05)

Confidence in the ability to beat cancer for a third time varied amongst informants, as evidenced by comments ranging from "It'll get me" to "I'll take care of it again."

Most informants identified that a recurrence of cancer was now less fearful than it had been during the first remission.

> I hope that I don't have another reoccurrence but, for some reason, I accept that it could happen down the road and that's okay, they'll take care of it....It's a long term fight. It's not finished. But it's finished in the sense that it happened again and we've fought it and successfully and so it happening again is not as frightening because, you know, hell, that was okay. That worked out....I faced the monster down and beat it and I can do it again. Whereas before I wasn't sure. I always thought...if I got sick again, that was the end. And it didn't turn out that way. (02)

> I'm not scared anymore about cancer. It doesn't scare me anymore. I've just realized the day is gonna come when perhaps I have to do something more about it. (01)

Regardless of the degree of confidence or fear, informants dreaded the prospect of a second recurrence.

> If something returned, if my tumour markers ever spiked and suggested that I had to return for more chemotherapy, I would be devastated....Jesus, what a nightmare. It would be like being told if you were a Jewish prisoner of war that you were going to have to go back to Buchenwald for another three months. (06)

<u>Cancer-Related Death</u>

Dying of cancer was another scenario commonly incorporated into visions of the future. The perceived probability of dying from cancer was usually greater on recurrence than on initial diagnosis and, hence, informants spent more time and energy envisioning their deaths.

> [My aunt] passed away. She had breast cancer. She had had both breasts removed but it had gone into the brain....I didn't go to her funeral....It bothers you because you imagine that that's what maybe you're gonna be like a few years down the road or a few months down the road. (01)

> My wife and I both have talked...a lot about dying, about my not being there and things that we'd like to do. (06)

If cancer recurred for a second time, as was the case for two informants, this probability increased even further and informants felt like they were running out of chances. While in his second remission, one man explained:

> Being told that it had spread from my testicle into my lymph system [on initial

> diagnosis] was a strike, sort of strike one. And when it recurred, that was strike two. And so, if it did come back again I'd feel that, if it wasn't strike three, that perhaps I was facing a pitcher that I knew I wasn't gonna get a hit off of and the best I could do was maybe get a draw and walk based on balls sort of thing. So that scares me. (06)

When his cancer recurred for a second time, he described how dying of cancer became more of a reality.

> It's the level of morbidity I think that you had to deal with between the second time and the third time where you're saying to yourself, "Okay, well, there is a chance I may die," and...we talked about strikes and stuff like that and the baseball analogy in the first go around, but now it's...VERY real. (06)

In envisioning their own deaths, informants explored their hopes, fears, and beliefs related to death and dying. They feared being a drain on those close to them, falling apart in front of their families, lingering, being incapacitated, and being in lot of pain and, consequently, hoped for a dying process that was quick and painless. To avoid the suffering anticipated with a cancer-related death, one informant hoped to "have a heart attack and drop dead right on the golf course" when he was 84.

Leaving children behind was another fear identified by informants.

> My children are still young. I have a little 10-year-old and I have a 13-year-old daughter and a 16-year-old son....I fear leaving them behind and depriving them of...a mother helping them to maintain their full maturity. That's my biggest fear is leaving my children behind and maybe not helping them on the road to life a little bit more. (01)

This fear was so great for one informant that, although he envisioned the possibility of dying, he set limits on the detail of this vision and did not allow himself to think about leaving his children.

> I could never ever dwell on the idea of leaving my kids. It's too much. There's certain bridges you have to cross. Yes, I may die and leave family and stuff like that and you do it in sort of a general way but if you start thinking about, "I'm going to leave these two lovely children," I think you're going to bind yourself up so badly. Maybe for somebody that is dying they have to do that but I've never really dwelled on that. On the brief periods I have, you just wanna reach out and hug them and stuff like that. So there's certain things I won't allow myself to do and that's one of them. (06)

Fears of death and dying were also related to the unknown. Information about the dying process, gathered through observation or by asking direct questions, helped reduce the unknown, facilitated revisioning of this aspect of the future, and made dying less fearful.

> If it's dying that is in the cards and I'm gonna do that and the one side of that that I don't really like is the fact that because you can't pull Jack Kevorkian's little number and get your insurance pay outs, you have to be brave enough or strong enough or whatever to go through what it takes to die. And I've actually had to think about that too. I mean,...if you stop all treatments, this cancer works fairly quickly so it would be a matter of months. What's that gonna be like?....I've seen people around me here who were dying and they get treated pretty well, especially in terms of the painkillers....I think that's what you need is you need to know that nobody's gonna get too stingy with the painkillers and that you're gonna be made comfortable and that hopefully it goes quickly. (06)

> [The oncologist] and I actually sat and talked about how I was going to die because it was a great concern to me. I had watched the breast patients die from bone cancer. You know their bones fall apart. And that seemed to me the most miserable of [deaths]. But, no, [the oncologist] assured me that with this kind of cancer, what would happen to me is I would have an obstruction in my bowel and I would die quickly. This was a CONSIDERABLE comfort to me....That was just great. If we hadn't had that conversation I would have been much worse off than I was....I wanted to know, "How am I gonna die?" And he told me, "This is how you're gonna die. You're gonna die fast and you might have a little bit of pain but don't worry we'll take care of that for you." (02)

Information about what happens after death, as derived through religious faith, made death less fearful.

> I'll regret leaving the world because I'll regret leaving my family behind but I'm not fearful of death itself and that's because I have a strong faith and a faith that offers me a hope for the future beyond death. So I think if you're not living in fear of, you know, what's it like after death or what's death like or what happens then, you know, when you have a knowledge of what's... there for you after death, then you don't feel afraid....I believe that death comes naturally [and]....death isn't necessarily the end of all life....I don't feel that death is something that you have to be afraid of. (01)

Although only this one informant identified herself as having a strong religious faith, others agreed that religious faith would reduce fear of death.

> My girlfriend...she's very religious and she says, "We're only here for a short period, for a testing period." She says, "The best is yet to come." And I think if you can believe that, it's not so scary. You know, if somebody could come

> back and say, "Hey, it's great over there. You don't just disappear or disintegrate or" -- that's what's scary. (03)
>
> I think for a person who has a religious frame of reference, I think what it does is it gives them a statement about themselves in the present and from the present to the future and it holds out the statement, of course, that you do not disappear into nothing, that there is a validity to your existence, a legitimacy and that will continue even after your death. And a belief in that [is], you know, obviously very meaningful to people. I wouldn't see myself as having faith in that kind of a religious sense. (04)

Of those who did not have a strong religious faith, two likened death to falling asleep and were comforted by this belief. One said:

> Every night you go to bed and you figure, "I go to sleep and where am I when I'm sleeping?" So maybe it's like that. I don't know. (03)

Shifting from Quantity to Quality

In a final element of reframing realistically and in recognition of the increased likelihood of a second recurrence and a cancer-related death, informants began to shift the object of their hopes from cure or quantity of life to quality of life.

All informants hoped for both a long life and a good quality of life. When faced with a recurrence of cancer, attainment of these hopes was jeopardized. The extent to which these hopes were maintained was largely influenced by the expected impact of the available cancer treatments. Cancer treatments, conventional and alternate, afforded a chance for remission or cure, thereby fuelling hopes for a long life. They also afforded a chance for reducing disease-induced suffering, thereby fueling hopes for a good quality of life. However, these treatments also had the potential for impairing quality of life through life interference, treatment-induced suffering, and/or financial burden. As chances for having a long life and a good quality of life changed, so did treatment choices and objects of hope. Four possible combinations of chances for realizing hopes for quantity and quality of life, as afforded by cancer treatments, are depicted in Figure 3.

Quantity of Life

		↑	↓
Quality of Life	↑	Ideal A	Shift to focus on quality B
	↓	C Focus on quantity Compromise quality	D Not worth it

Figure 3. Impact of treatments on objects of hope

In the ideal scenario (Cell A), available treatments afford a high chance for prolonging life and for improving or, at least, not impairing quality of life. In this scenario, the treatment is usually selected with little deliberation and one can confidently maintain hopes for both quantity and quality of life. In a second scenario (Cell C), treatments still afford a high chance for prolonging life but now afford a low chance for improving or a high chance of impairing quality of life on a short or long term basis. If treatments in cell A are unavailable, the treatments in Cell C are usually viewed as the next best choice. If they are selected, one can maintain hopes for a long life, even though quality of life is compromised on a short or long term basis. In this scenario, quantity of life is the primary focus of one's hopes. A third scenario (Cell B), is the mirror image of Cell C. Treatments in this cell afford a low chance of prolonging life but a high chance of improving quality of life. If these are the only treatments available, they are usually selected and one begins to shift the focus of hopes from quantity to quality of life. In the final scenario (Cell D), chances for prolonging life and improving quality of life are both low, while chances for impairing quality of life may be high. Treatments of this nature are typically "not worth it" and are not selected. If these are the only treatments available, one focuses on hope for a good quality of remaining life and, when that becomes unattainable, shifts hope to a good death.

When first diagnosed with a recurrence, five of the six informants perceived that conventional cancer treatments (surgery, chemotherapy, or radiation) fell into category C. That is, they afforded a reasonably high chance of cure or remission but would also impair quality of life on a temporary basis. These informants opted to undergo the recommended treatments, willing to pursue quantity of life at the expense of quality.

> In my particular case I was told that if they just went with radiation, then remission chances were only in the 10% category whereas if I went to chemotherapy, that raised it to 90% and that's a pretty simple choice to make....I knew I was gonna get sick this time but it NEVER struck my mind to say, "Oh, well, I'm not gonna do it." It was just a given. (05)

The sixth informant (01) was unwilling to compromise her quality of life in pursuit of quantity and perceived that the recommended conventional cancer treatment (mastectomy) fell more into category D than C. That is, she perceived the treatment afforded a low chance of prolonging life and a high chance of impairing her quality of life, these perceptions being largely derived from experiences with family members who died of cancer.

> They [family members] tell you about all these horror stories -- ...how sick they would get and how they wished they had never taken it and the treatment was worse than the cure. (01)

Hence, she decided not to undergo the recommended treatment and chose to shift her hopes from quantity of life to quality.

> I just don't seem to think that operations are the answer. [Maybe] there's...a different type of cure that's not quite so dramatic or -- I don't even know if I'm lookin' for a cure....To me quality of life is better than quantity. If I only have 2 or 5 years left to live, I don't wanna live that in a hospital bed like my mom did...under all this pain and this stress and, oh sure, she knew who we were when we'd come to visit her and stuff but she couldn't go home with us....She just wasted away in the hospital there. They were constantly giving her treatments and stuff like that. It didn't seem to help her....[and] she didn't feel good about herself. Maybe my cancer will advance to that point too, you know, but right now I'm not willing to give up my quality of life for that....I wanna continue to live at home with my family while they're growing up....I

> would rather just maybe have a little bit shorter time [than]....be in some hospital bed somewhere having treatments....The less amount that these treatments can affect me physically, the better I feel about myself....I don't want my life interfered with to the point where my medical treatments have to come before everything else, you know. To me, that's not living. (01)

One informant failed to achieve a second remission (03) and two others experienced a second recurrence (01 and 06) during the course of the study. Under these circumstances, chances of prolonging life via conventional cancer treatment decreased considerably, these treatment options began to fall more into categories B and D, and the focus of hopes and of treatments began to shift from quantity to quality of life.

The informant who didn't achieve a second remission (03) continued with chemotherapy treatments for awhile, but soon perceived they were impairing her quality of life, while offering little, if any, hope for prolonging her life (Cell D). She explained:

> It would be easier if they were just up front with you. You know, kind of, "Well, we'll give you chemo just to kinda pacify you and keep you sick and weak so you don't bother us but it's not gonna fix you." That's the way I feel. (03)

Consequently, she decided chemotherapy was "not worth it," discontinued treatments, and pursued alternate or experimental cancer treatments. She perceived these treatments fell into categories A or B, offering hope for a better quality of life with or without an increase in length of life. She died six months after our second interview.

> I had four treatments of chemo and I thought that would be it. I went to the doctor and we discussed it and I literally broke down. I says, "I can't take this anymore." I've got to lie there for five, six hours....and then I'd come home and I'm sick for a week and I'm weak and it takes two weeks to finally start feeling half human. And then I get to look forward to going back again....[And] maybe hair loss doesn't mean anything to other people but I used to have waist-long hair. That means a hell of a lot to me....I had thought after the four weeks he'd say, "Fine, you know, go home. That's it." But, uh, then they started playing around with switching drugs....So I thought, well no, I'll at least try something that at least is gonna make me feel better. If I do die then at least I'll feel better before I do rather than wasting away and starving to death because I'm not a big person and once I got onto chemo I was losing five pounds every treatment and I had a hell of a fight trying to get that back

> in between treatments. And you know, I mean, it would be really stupid to starve to death....Not that I'm giving up because otherwise I wouldn't be bothering. I'm gonna go to Kamloops first for a week or so and then if that doesn't work out then I may even go to Texas. There's clinics down there. But I'm not gonna go the traditional, make-me-as-sick-as-you-can route that I wanna die. (03)

> What bothers me is falling apart in front of my family and being in a lot of pain and depending on them for everything. That was another reason why I think I don't want chemo because what's the point of saving my organs if my bones are falling apart? Like if my backbone is disintegrating and I'm gonna be a quadriplegic, what's the point? And people who I've heard have been on these nutritional plans and Essiac tea, they don't have pain. Even if they do pass away, they don't have pain. (03)

One informant who experienced a second recurrence (01) followed a similar course in treatment decision-making to that of the latter informant. She did not achieve a third remission and subsequently died. The situation for the other informant with a second recurrence (06) was considerably different. He perceived that the recommended conventional cancer treatment fell into category C, affording a reasonably high chance of cure, while also significantly impairing quality of life on a temporary basis. He underwent the treatment and achieved a third remission.

Informants hypothesized about how they would choose treatments and when they would shift objects of hope if faced with another recurrence in the future. In so doing, they were able to come to terms with various possibilities, weave them into the rebuilding blueprint, redefine their objects of hope accordingly, and reduce some of the uncertainty surrounding the future.

Hypotheses about future shifts from quantity to quality of life were most extensively described by one of the informants undergoing treatment for a second recurrence. He acknowledged that making this shift in his objects of hope was now "within the realm of consideration."

> Who knows? Down the road if after we go through ALL of this, if I have a recurrence then we have to start talking about: Do you wanna continue treatment or do you wanna basically live out the rest of your short life with some kind of dignity and travel with your family and do a few things? So that's certainly now something that is within the realm of consideration. You're sorta one step away from that....I knew last time if things didn't work out that there would be more treatment and that that was always there. Now

> I know that really there isn't more treatment, that if this doesn't work that I can seek more treatment and they will offer it, but at the same time they will be more than willing to sit down with me and talk about quality of life and that's already been sort of discussed in that, "If you don't wanna take any treatments, we understand sort of thing."...If you try and take some more treatments you might delay the inevitable but you also might make yourself a lot sicker and just weaker and stuff and not really have...any quality of life in the last few months. (06)

He also described how he would look for changes in hopeful signs to know when to make this shift in focus of hope and how, after noting these changes in signs, he would begin to pursue quality of life in earnest.

> I went through the processes and looked for the [hopeful] signs and they were there and so far so good but at the same time I guess maybe the same things that I'm talking to you about now would all come into play if things don't work out in the future. And that's how I would go through the processes to shut down the treatment....If I didn't have people jumping up and down and saying, "No, you HAVE to try this. No, no. This is not a step to be missed." But if they were saying, "Well, we could TRY this," and that sort of thing, then I would, I would give them the easy out too in that, "Okay, listen, you're off the hook. It's my decision. Here's what I'm gonna do. I'm going to Phoenix. I'll send you a postcard and that's the end of it. And, you know, when I'm sick enough that I have to come back here and die, I guess then that's what I'll do."...[I'd go to Phoenix to] start my vacation, taking my serious vacation....There's vacation and then there's SERIOUS vacation when you collapse your RSP and....get that money into your pocket and start spending it on fine wines and good suppers and things like that and time with your family....and make sure that you're not leaving out any things you might want to do. (06)

When hypothesizing about the quantity to quality shift, informants contemplated whether they would pursue alternate or experimental cancer treatment in the future, particularly if conventional treatment failed. If they perceived these treatments would afford a high chance for improving quality of life, with or without a chance for prolonging life (Cells A or B), they considered pursuing them. If they thought these treatments or the pursuit of them would significantly impair quality of life (Cells C or D), either through suffering, life interference, or financial burden, they were less likely to consider them, even if they may offer some chance of prolonging life.

> I don't wanna get ripped off...by con artists saying they can cure you and just

> take all your money and do nothing for you. I don't want that kind of hope. (03)

> And so you sort of say to yourself, "Boy,...if I wasn't hopeful, what would it take to get hopeful? How do you get a dose of hope?" And maybe that's the answer...is to take that trip to Texas for the experimental chemo or to Mexico for whatever they are offering down there. But, on the flip side, I sorta look at that and I think, oh boy, I mean, does that really give you any hope....or do you just wake up in a Mexican hospital and go, "Oh, what the hell am I doing far away from friends and family spending the last of my resources, instead of on the dream vacation, on some goofy, money-grabbing health care procedure that doesn't really offer much more than a way of emptying your resources." ...I don't really wanna get caught up in the quackery. If this doesn't work out, I'd rather just die [than]....run down to Mexico and try and take experimental treatments or something. Enough is enough. (06)

Informants also envisioned future scenarios wherein the grounds for hope would be altered to the extent that hope for quality of life would not be attainable and they would shift their focus to a hope for an end to suffering through a quick, painless death. In these scenarios, treatments were perceived to be "not worth it" (Cell D), as was continued existence.

> It's really hard to put it in words but if I ever had to...be dependent on morphine or some type of oxygen tank or something to keep me alive, I would rather die I think because that's not living. (01)

> It's there [the possibility of death]. And if it comes to be, fair enough. I'd regret it. I'm quite willing to cooperate in anything to put it off providing one is a coherent participant in what's going on. Once that's lost then I see no benefit whatsoever in hanging around. And again, the same thing with pain. I think I have a better tolerance than a lot of people but there's a point at which pain becomes so debilitating you're not functioning effectively either and I don't see any profitability in encountering life with a constant biting the bullet thing dominating your thinking and your feeling....[There's also] the problem of....being a drain on those that are close to you....[And] obviously, with our medical plans, if we have to back off and families have to contribute much more..., then costs become a concern and there's a point there where you're not doing them any darn good....If there is a terminal point at which I'm not particularly functional, I would want it to come to an end fairly quickly. (04)

Reframing Positively

At the same time as being realistic, informants tried to reframe their current circumstances and their visions of self and future as positively as possible and thereby strengthen the rebuilt veneer. This process of balancing realism with positiveness is reminiscent of balancing hopeful and ominous signs during appraising and is described by one informant.

> Somewhere in [my]...story I. .get to identify what I think are the positive elements of it and at the same time by virtue of the nature of your way of life and how you earn your dollar you have to be realistic so you keep kind of balancing the two of them together and making the best case for how you're going. (04)

Reframing positively at this point in the experience was in direct contrast to the negative framing that dominated the stage of disengaging. In reframing positively, informants tried to be as hopeful as possible despite the ominous reality of the recurrence of cancer.

> I think you've gotta redefine life in terms of possibilities, enjoyments, these kinds of things. And the fact that you can still do this in view of the news you've heard, that maybe constitutes the hope. (04)

After acknowledging the reality of their circumstances, they now tried to "look on the bright side," "put a bright picture on it," or see that "a lot of the clouds have silver linings." One man explained:

> It's examining the data and when you examine the data, you come to the conclusions. There are different ways you can phrase the conclusions and they're all true in terms of the data. I probably choose the adjectives and adverbs that constitutes as positive as one can get in the face of the evidence. So calling that hope is probably as good a term as any. (04).

By reframing positively, informants were able to emphasize the hopeful signs and minimize the ominous signs, thereby strengthening the grounds for hope and improving the perceived attainability of objects of hope. Reframing positively also helped informants endure the suffering, come to terms with the recurrence and its implications, and move towards actively re-engaging in life. Even if their attainability was uncertain, developing positive future visions gave informants "something to look forward to" and helped "spur some recovery."

Reframing positively encompassed three interrelated strategies: normalizing, comparing, and identifying positive outcomes.

Normalizing

Normalizing was the strategy whereby negative aspects of the recurrence experience were viewed as normal, common, and/or inevitable, thereby making them less negative and easier to accept. When coming to terms with changes to self experienced after chemotherapy treatments, one informant normalized these changes by viewing them as inevitable sequelae of the aging process.

> I do not have the same energy level that I had a year ago for work. Maybe that has to do with my age too. It could well be....Lots and lots of people are completely retired by the time they're my age....At my age, in that year,...many people would change like that. I'm 65 in November so I don't know how much can I expect....It's even on pure speculation as to whether I would really have been much better off physically with or without the [recurrence] because, after all, you do reach an age where you slow down a bit. (05)

Normalizing was also evident when informants were coming to terms with the possibility of death. They were able to put death into perspective and make it less fearful by realizing that they were not alone in facing this possibility and that dying was inevitable.

> To know that everybody's gonna die kinda makes you feel better....You know, so it kinda makes you feel like at least you're not alone in that aspect....I'm not accepting the disease. I don't think I ever will. I'm still damn ticked off....But [I'm] accepting that I'm gonna die....I probably would have gone through this in 20 or 30 years down the road I figure....I just figure now I'm doing this sooner than I would have, that's all. Like it's inevitable anyway. (03)

> I think there's an element...of...moving into where you see yourself in the light of the whole human process and the human existence and the fact that it does come to an end. (04)

Informants also normalized the cancer recurrence by identifying that they were not the only "unfortunate" ones and that others had also been "dealt a [similar] hand." One informant stated, "I'm certainly not being the only one pooped on by the process," while another quoted the Bible in stating, "Time and unforseen occur[rences]...befall us all."

Comparing

The strategy of comparing included comparing to others and comparing to alternatives. Comparing to others was a strategy used extensively by all informants when coming to terms with the implications of the recurrence and positively reframing self and future. By comparing to others who were "worse off," they were able to consider themselves lucky or fortunate, rather than unlucky or unfortunate. By comparing to others with more severe physical or functional impairments, informants were more readily able to accept changes to self and reframe their visions of self more positively. The most common comparisons of this nature were those made with other cancer patients.

> When you just go in there [to the cancer clinic] and you look around at the people and you maybe see somebody who they bring down from upstairs in a wheelchair or something and they're hooked up to all kinds of gadgets, you look at them and you feel, oh gee, am I ever lucky. I'm not that bad. You feel bad for them but you're glad that he's there and you're here....[You're] always constantly looking around at the next person to see how bad they are and how much better you're doing than them....When I talk to people who have cancer and they seem to be worse off than I am, I guess I feel hopeful then that mine hasn't progressed to the stage that theirs has or my cancer doesn't seem to be the type that they have and so there's hope for me that perhaps my cancer can be beaten. (01)

Informants also reframed visions of self more positively by comparing their physical and functional impairments to those with other illnesses.

> I have cancer but, two and a half years, three years later, I have all my hair, I feel very physically capable, I'm out building a house,....and I'm still maintaining a home of 5 children. Then I look at people who....have multiple sclerosis or they've got some other type of crippling disease. And 3 years time can take them from being a healthy person to being completely bedridden and I think I'm very fortunate....There are other diseases out there that should be feared just as much as cancer and cancer shouldn't be looked upon as being the only dreaded disease because maybe you die quickly from cancer but maybe that's a blessing too. I mean I wouldn't wanna live ten years in a bed [if] I couldn't even feed myself or care for myself and be a burden to my family. So, be positive. There's always somebody out there that's a lot worse off than you are. (01)

Comparing to others who were "worse off" was also used to reframe the possibility of death more positively. In this case, comparisons were made with other cancer patients who were facing death at a younger age. Informants acknowledged that "there's a lot of people out there that didn't get where [they] got."

> I'm 43 years old. That's not a long life but there's little children who have cancer and die from it too....It's a shame that life is cut so short for them. (01)

> There's a lot of people out there that didn't get where you got....[My wife's friend developed] cancer...very shortly after the birth of her daughter....She was 38, 39, [when she died, with] a daughter 7 years of age who'd probably just vaguely remember her. That's a heck of a lot rougher one to face than myself and, I mean, I can cite endless examples of people who have been dealt that kind of a hand. So hey, it all depends on who you compare yourself with. There's Methusala on one side and there's these other people who've had various experiences on the other. (04)

While not as extensive as comparisons to others who were "worse off," informants also compared themselves to others who were doing well. These individuals served as positive role models that inspired informants to move forward and helped them develop a more positive vision of the future.

> Seeing her the way she is kind of makes me feel like well, yeah, if she can do it, so can I. (03)

> You always take hope if you happen to talk to somebody whose been through it before....You know, they've had it for 5 years and they're just coming back in there for a regular check-up and their cancer is either dormant or cannot be detected and you can take hope. "Gee, that sounds like my cancer. That sounds like that could happen to me." (01)

The second type of comparing used by informants was comparing to alternatives. To positively reframe physical and functional changes to self, informants compared living with these changes to the alternative, that is, not living at all.

> Occasionally, in the very early stage with the [colostomy] irrigation..., it wasn't working quite right and jeeze, it was just so frustrating and angering. And then what you would tend to do is look ahead and, you know, "I'm gonna be doing this for the next 20 years of my life." And then [it would] occur to you, you better thank God if you're doing it 20 years from now. What a lucky person you're going to be. (04)

Identifying Positive Outcomes

Identifying positive outcomes was the third strategy used to reframe the experience of recurrence and visions of self and future more positively. The negative implications and consequences of the first recurrence of cancer were readily apparent. Positive outcomes, however, were also identified by most informants in this study, and fell into five categories.

First, informants identified positive changes in their physical selves as a result of the recurrence or its treatment. This facilitated coming to terms with the recurrence and helped to create a more positive vision of self.

> I always try and look on the bright side of things and I've always lived by the credo that everything happens for the best as bizarre as that can seem at times. It's funny because at my age I find losing weight very difficult and I'll tell you it was almost worth it to go through this last surgery to lose those 15 pounds. Fifteen pounds! LOOK at that scale!....So that's what I was always telling people. I'd say, "This is my weight loss program," and they'd look at me like, "What are you, nuts? Are you absolutely crazy?" And yeah, even when I lost the 35 pounds, I was secretly happy, going, "Hey, look at this I can fit into a size 34 or 32 pant." I'm pulling stuff out of my closet that I haven't worn since my mid-20s. (06)

> Now I'm gonna get beautiful small curly hair back in a short while....We were told last time that your hair may not necessarily come back exactly the way it was before and it so happened six years ago it came back in the curly head I had when I was three or four years old....And they really looked nice too. (05)

Second, negative future possibilities were reframed in terms of the benefits they might offer. The most extreme example of this type of reframing was one informant's description of the "up side to dying." By identifying these positive outcomes related to dying, death became less fearful and the future appeared less ominous.

> It's gonna sound weird but...there's sort of an up side to dying. If I live, I have to go through some things in my life that everyone has to go through that are really unsettling to me and I'm a feeling type person. Like, my mom's 70, for instance. She's gonna die one of these days. So your MOM's gonna die, right, and I'm really close to my mom and stuff like that and I don't necessarily want to be around for that, you know what I mean? So if I could take the chicken gate I would. And then brothers and sisters who are older than you, I'm sure at some point maybe one of them might DIE, you know what I mean? Friends. Uncles. I'm close to a lot of uncles too and some of

> them are 80 years old and they're gonna die. And so all this stuff's gonna happen and then my kid's gonna break his arm some day and I'm gonna be an emotional basket case or something. So I think to myself, "Well, jeeze, if I died, I wouldn't have to go through any of that."...I don't know if that's the weirdest thing you've ever heard but the bottom line is that I think to myself, "Yeah, everything happens for the best." (06)

Third, the recurrence was positively reframed as having provided an opportunity for rest and leisure.

> I've always been able to see the hopeful signs in a situation. As a matter of fact, I was telling my wife the other day that I've turned a life-threatening surgery into an extra month off work....I'm going to be going hunting and things like that....I've got all this time off work now and I'm enjoying myself. (06)

> There's some sort of relief, like, hey, I get a rest now....I'm very tired. I've worked in a very high stress job for almost four years. Good job. But I'm tired....It will give me a rest from work. I'll go back to work not as tired, more focused. (02)

The fourth positive outcome was a decreased fear of recurrence. This was identified by several informants and was described earlier in the reframing section. When asked if she could identify any positive outcomes of the recurrence experience, one informant replied:

> Personally and psychologically it's not been very good for me....Well, now, what about the fact that you faced the monster down. I mean, maybe that's useful. Maybe then I won't be as afraid. So yeah, I guess that's positive. Yeah, I think that's quite a big thing actually. (02)

The final category of positive outcomes of the recurrence experience was the development and/or reaffirmation of insights into the meaning and value of one's existence, the competence of others, ways to help others who are facing adversity, and the important priorities for living.

One informant developed insight into the meaning and value of his existence by viewing his life as an integral component of a larger human process.

> You see yourself in the light of the whole human process and the human existence and the fact that it does come to an end....Remembering me as a specific entity ain't gonna last too far into the future, like with the whole vast bulk of mankind. Very few of us get to do Jesus Christ or Napoleon. So, it's just the way the cards get dealt, but by the same token maybe that's the strength. You are a part of this larger thing....It goes on and you've been a

> part of it....You...have by definition some kind of connection with the rest of the species....The big thing is, you'd like to come back a little later and just see how the heck things have gone on since you left...and that's the one regret I suppose one might have about going out. But hey, you've been there for a time. You've got certain insights that you feel get you to the heart of the processes involved and you feel right about them and what the heck? It's been an enjoyable relationship. (04)

The meaning and value of one's existence were also recognized through a review of accomplishments and enjoyments. As one informant said, "There's been some very good times so let's acknowledge the account."

The development of insight into the competence of others and ways to help others were also positive outcomes of the recurrence experience. An example of the former type of insight is included below:

> I've got the idea my wife is awfully damn competent. She may not make the decisions I would make but she's gonna make the decisions that are gonna take care of her and the kids....They're gonna survive. They're gonna do all right. (04)

Insights into ways to help others covered a broad range. Informants described how they were able to be more sensitive and empathetic to others' crises and were better able to provide practical, helpful information regarding such things as how to reduce hair loss or types of juice to avoid while on chemotherapy.

The final and most prevalent insight developed and/or reaffirmed as a result of the recurrence experience was related to a reassessment of the important priorities for living. As one informant described:

> [The possibility of dying] sets you back and you do a reassessment. Now just really what is important here....You begin re-evaluating...and I think quite profitably so. You turn things around, take a less jaundiced view. Quite frankly, my relationship with my son improved tremendously. Not that he improved anything but I sure began re-evaluating certain things that were important and not so important. (04)

As a consequence of this reassessment, informants developed a renewed appreciation of others, self, life, and living.

> What's a positive outcome of the first case of cancer and that's maybe even stronger this time, is how you appreciate life every day....I'm pretty sure that, for instance, if I'd done exactly the same thing one year ago that I've done the last two months, I know I would have enjoyed doing [it]...but I'm enjoying it

> even more this year....Life is for the living and you enjoy it as MUCH as you possibly can....I also probably feel myself even more fortunate to be well again than last time. I think often of the feeling of well-being which you are liable to...take for granted....I've certainly thought of that often through the years but even more so this summer [now] that I survived it twice. (05)

They also made and/or reaffirmed resolves to live life differently. The experience of recurrence prompted them to refocus their plans and priorities in order that quality of life and the chances of living a long life could be improved.

> The illness, sort of the time out, has made me see some things that I want to change my life. It's a little hard to articulate and I'm not quite sure how I'm gonna change it but I seem to have a lot of friends who are friends because I do stuff for them....I seem to be lacking in people who are just friends for the sake of friends. So those ones who expect stuff are sort of gonna get turfed. And there's a few things like the camp that are gonna become more important ....I'm gonna take it a little easier...and kinda get things a little more organized. Work a little harder. Be a little more focused in my work. Training somebody else to do my job made me see the most important parts of it. And it's sort of been good for me to have a break. It's good for me and for my job that I've been out of it for awhile because it's been refocused and so I'll go into it with a new focus. I'm more determined to do things more for myself than, like I'm always doing...too much work outside of work. I'm gonna do a lot less of that. (02)

> I hope to use this as a catalyst really, this whole situation, not to take your health for granted....If you try and stay healthy, maybe you'll have a better chance of staying out of the hospital in the future. (06)

Several informants identified they had made similar resolves to live differently after the initial experience with cancer but that, over time, these resolves had faded. Experiencing a recurrence, however, brought these issues abruptly into focus for a second time. As one informant said, "You have to go back and readdress these things all over again....Sort of a reaffirmation maybe is what you would call it."

Positive outcomes extending beyond the sphere of self were identified by one informant. She described how her cancer experience "opened up a lot of people's eyes" and spurred them to reassess priorities and live their lives differently.

> Actually, my cancer has opened up a lot of people's eyes, like all our friends and stuff. It's made a positive impact. A lot of people, they kind of realize they should try and get along better, like couple-wise, and that they should go take their holiday now rather than waiting and all that kind of stuff....I have one girlfriend, I've got her going to church now every week,....whereas I think

> she'd have not gone as often....And my other girlfriend [and her husband], ...they did a few things financially plus they went on a holiday....and then they appreciate each other a little more. (03)

It is of note that one informant was unable to identify any positive outcomes of the recurrence experience. She described positive outcomes of the initial experience with cancer but saw "nothing positive about reoccurring cancer."

> Just cancer in general makes you appreciate how short life can be and I think you do that when they first tell you you've got cancer. Boy, then you really start appreciating maybe your family a little bit more....[But] I see nothing positive about reoccurring cancer. To me, that's very negative. I've learned nothing from it except that it's just maybe a longer fight. I don't get any strength from it. That's for sure....It was just a low point. (01)

Being Galvanized by Hope: Transition to Actively Re-Engaging

All informants were successful in reframing meaningful visions of self and future and finding worthwhile objects of hope, despite the shift in grounds for hope caused by the recurrence. Hence, they completed rebuilding of the hopeful veneer and, in the process, experienced a renewal and a transformation of their hope. As a consequence of this transformation, uncertainty and fear were reduced, control was regained, and informants were galvanized by hope. One informant said:

> Hope...galvanizes a person into taking those human energies, applying them to the situation and coming up with as positive a course of action as one can take. (04)

The word galvanize means to energize or stimulate into activity and to coat metal with a protective layer of zinc. Once hope was renewed and transformed, informants were energized and stimulated into moving forward and upward to the upper level of reality where they actively re-engaged in life. Once actively re-engaged, the hope that formed the fabric of the veneer protected them from falling back down to the lower level of reality and enabled them to keep thoughts of cancer and its implications at the back of their minds. This was in contrast to the experience below the veneer, where thoughts of the cancer and its implications were persistently at the front of informants' minds. One informant clearly described how rebuilding the hopeful veneer, that is, gaining an understanding of the present and reframing the future, enabled him to move from the lower level to the upper level of reality.

> I guess what we're getting at, Linda, is getting right down to this process of getting an understanding that one sees as "true," quotation marks, and on the basis of understanding that truth about now and the future, one then can undertake these courses of action in a responsible sense and not only a responsible sense but in a hopeful sense....As a result of that [process] then one can spend one's time in this reality. You don't have to go to the other one. (04)

If informants had been unable to reframe meaningful visions of self and future and find worthwhile objects of hope, they would have been unable to complete the rebuilding process and re-engage in life. Hence, they would have remained in the lower level of reality. At first, they would have likely been caught in the perpetual cycle of appraising and reframing, making repeated attempts at finding more hopeful signs to strengthen the grounds for hope, and using those grounds to reframe visions of self and future more positively. If experiencing repeated failure in this process, however, they likely would have fallen back to the stage of disengaging and sunk further to the stage of giving up.

In Chapter 7, the stages of actively engaging and monitoring are described. Also included is an overview of the stage of giving up.

CHAPTER 7

ACTIVELY RE-ENGAGING, MONITORING, AND GIVING UP

Actively Re-Engaging: Reinforcing the Hopeful Veneer

In the stage of actively re-engaging, informants functioned above the hopeful veneer in the upper level of reality and viewed the world through a clearer, brighter lens. By dealing with the cancer and its implications in an emotional way during disengaging and in a cognitive or intellectual way during rebuilding, informants "acknowledge[d] what [their] circumstances [were] and what the consequences may be" and were now able to "put cancer in its place," that place being at the back of their minds. The focus of their existence shifted from cancer and suffering to health and living. As one woman said, "You try to not let cancer...deal every card in your life. You...forget about that now and just go on with living."

In the stage of rebuilding, informants had developed a realistic understanding of their circumstances and had reframed visions of self and future realistically. By finding hopeful signs and reframing positively, however, they were also able to develop a "positive view of themselves,...their current circumstances,...[and] what the future holds for them." As a consequence, they were now ready to re-engage in life "in a responsible sense and not only a responsible sense but in a hopeful sense." The manner in which informants re-engaged in life and the courses of action they undertook were largely determined by the materials and blueprints they used in rebuilding the hopeful veneer, that is, their grounds for hope, objects of hope, and visions of self and future.

The stage of actively re-engaging comprised two elements, re-establishing normalcy and living differently, the aim of both elements being to reinforce or thicken the hopeful veneer.

Re-Establishing Normalcy

Re-establishing "some semblance of normality" was of paramount importance to informants. One informant described re-establishing normalcy as follows:

> You just sort of chug along and put into the world....Just keep on going. Just do the things you're supposed to do and sort of don't let yourself get caught up in feeling sorry for yourself. You try and make things normal. (02)

The extent and timing of the re-establishment of normalcy were greatly influenced by the extent of physical or functional impairment and life interference incurred by the disease and/or treatment. The more severe and prolonged the impairment or interference, the more difficult it was to re-establish normalcy.

> One particular stage where there was certainly a sharp change was somewhere in late May. By late May, I was no longer so-called 'fed up' with the fatigue from chemo. It had dissipated to a large extent. So therefore your train of thought went to other things. You didn't spend as much time on that....You no longer dwelt on....self pity....By the first of June..., my life was much more back to normal than it was in the first of May. (05)

To facilitate a re-establishment of normalcy, some informants refused recommended treatments or did not follow advice that they perceived would result in an unacceptable degree of life interference or functional impairment, even if the recommendations could enhance the chances of prolonging their lives. (This was a reflection of the shift in focus of hope from quantity to quality of life that was described in the section on reframing realistically in Chapter 6.)

> I don't feel that...my cancer...ever in any way interfered in any of those aspects of my life -- like...perform[ing] in my job or...cop[ing] with my natural life at home here -- ....because I won't let it interfere in that....I don't want my life interfered with to the point where my medical treatments have to come before everything else. To me, that's not living. (01)

To hasten the re-establishment of normalcy, two informants stopped cancer treatments earlier than recommended and one quit wearing her cervical collar against medical advice.

> I've stopped wearing the friggin' collar because that was causing more problems than it was helping. You know, all my muscles in my arms...are kinda shot...and it was all painful....With that neck brace I couldn't even hug anybody which was worse 'cause you need lots of hugs....My husband...[is] terrified of me doing more damage but I said, "Hey, listen, I walked around for a month...[before] they slapped this neck brace on me. And at least before I slept good." (03)

Informants emphasized that the key to re-establishing normalcy and, thereby, successfully re-engaging in life, was to NOT dwell on the cancer. Once they rebuilt the hopeful veneer, they shifted the focus of their thoughts, conversations, and patterns of living away from the cancer to "all the little normal everyday things." The nature of the experience in this part of the process was in direct contrast to the wallowing and withdrawing experienced while in the stage of disengaging. One informant described:

> I've seen it through, back at it. It's there. It's like an Alberta winter. It's out there but it doesn't have to preoccupy your existence. There are points where it's gonna insert its reality and you bump up against it, crawl around it. But then don't dwell on it. On you go from there. There's no moving to Hawaii with this one. (04)

To shift their "thinking away from [cancer and] misery," all informants used a strategy called conscious or purposeful denial. While fully cognizant of the realities and implications of the cancer recurrence, they consciously and purposefully pushed these thoughts to the back of their minds and kept "living each day as though [they were] in good health." The nature of this strategy is reflected in the following comments.

> I indulge in self-deception a lot, denial, but I knew that's what was happening. Like, oh yeah, I suppose I should be sad but no, I'm not gonna bother to be today. I'm sad deep down but no, sorry, not gonna indulge today....and maybe I'll be sad tomorrow....But I mean you know it's there....And you know there's lots of pain but you don't bother to, you sort of just put it aside....
>
> I went into sort of a what I called catatonic denial and I figured that was okay because I wasn't neglecting to do anything. I was doing all my appointments -- sort of doo-do-do-do-do-doo, [humming] probably a little nuts, but I thought, well, why should I sit around and sulk....I was sort of doing cheerful....When I said I was in a state of catatonic denial there for a while, I'm not sure that's really true because I knew what I was doing. I knew what I was trying to deny. So I'm not sure that if it's deliberately done that it could be called denial. (02)

> The odd time when it [cancer and its negative implications] comes into mind, as quickly as I can I simply force myself to think of the so-called upper level. I feel there is NO use to dwell on the other side even if I'm very realistic on the realities of what that other side might be....I simply make myself think of something else -- ....everyday things, both pleasant things and things that have to be dealt with. (05)

Informants were more successful in using conscious denial when they kept "cancer talk" to a minimum and kept busy and active with everyday activities.

When they were trying to re-establish normalcy, informants advised others they did not want to talk about their cancer any longer and actively shifted the focus of conversations away from their cancer to other, more normal, topics.

> Don't sit around talking about cancer all the time with your friends and your relatives. That's what they feel they have to do. It's like a death in the family. People feel they have to talk to you about it....And at first maybe you really do wanna talk to your friends and stuff about it, especially your husband or your wife....But, after a while then you don't wanna talk about it anymore ....I have it, I'll deal with it, and let's just go on with living. (01)

> I've had a lot of close friends and some of my husband's family come over and they try and make meals and stuff like that, which is okay as long as the topic stays off me. It's like at a funeral or a wake. It's the idea that life goes on and there's other things happening rather than talkin' about yourself. (03)

During his initial experience with cancer, one informant even shifted conversations away from the cancer when he was attending out-patient appointments in the cancer clinic. He described use of this strategy as evidence that he was "hope to the extreme." When the hopeful veneer was eroded on recurrence, he was less able to employ this strategy.

> [The nurse and oncologist] used to just chuckle to themselves because I would spend my time talking about hunting and ski trips and stuff like that. She [nurse] said, "You know, he doesn't even...acknowledge that he has cancer." And I wasn't acknowledging I had cancer in a bad way. I was not acknowledging I had cancer because as far as I was concerned it was just something we were doing....I was sort of hope to the extreme in the first go around....I just never liked to talk about it. When I came to the clinic, they would do their thing and I would look for some acknowledgment [that]...this is going well or whatever, but I used to talk to [the oncologist] mostly about hunting and anything but....My personality is I never dwell on anything negative and I've always been that way....Once...all of this negative aspect of my life....[is] done, I will forget it. I mean completely....So, as far as the cancer went, when I first got it I just thought well, there's no point in even really acknowledging this because it's gonna be just erased from the memory banks as soon as I come out of here, as soon as I'm done this treatment. (06)

Re-establishing normalcy also entailed getting lives back in gear and attempting to return to normal patterns of living. These patterns of living encompassed routines, roles, responsibilities, activities, and relationships. In attempting to return to normal patterns of living, informants kept themselves busy and active with everyday activities and this facilitated their use of conscious denial.

> We are very active people....I'm really a very busy person. I just don't have time to be saddled down with anxieties with cancer....If you fill your life with other more important activities, then you won't let these anxieties of life come in on you and you won't let this disease get to you to the point where you can't enjoy this day. [Don't] wake up in the morning and say, "Oh, I've got cancer. This is gonna be a terrible day," or "What am I in for today?" Don't think that way. Just get up and realize well, today is another day....Get on with living. (01)

> This is very much a process in terms of getting active, getting involved in things....Don't wallow in your own bloody misery. There's gotta be that point where you acknowledge what your circumstances are and what the consequences may be. Fine. Acknowledged. Let's get on with the other aspects of cutting the lawn, war on those weeds,....finding little projects to do around the house,....all of these kind of things....Get at it and get on with it. (04)

Informants placed great value on the return to everyday activities and routines, especially when they anticipated their lives may be shortened as a result of the recurrence of cancer. This was in direct contrast to how they predicted they would react if faced with this circumstance.

> Once you know that you may not be around all that long,...you always think...[you'd] want to travel the world, eh? It's just the opposite....You wanna do all the normal little everyday things. You want your family around, your friends. You don't wanna travel that much anymore or do those kinds of things. (03)

> The good things in life aren't the major events anymore. They're the little daily things. So get on with them and take your time to enjoy them. (04)

Re-establishing normalcy held many benefits for informants. By returning to previous roles and responsibilities, they regained a sense of self-worth and purpose in life, and by re-engaging in pleasurable activities and relationships, they realized that life could be good again.

> [Returning to work] went really well. [It's]...important to get back on your feet and show that you can play the game again. (06)

> Taking part in community affairs, good conversation with neighbours and friends, I think it's very beneficial to get your mind off your problems....My thinking was away from my misery and that's very beneficial. I'm sure it makes you more positive because you know then that you can have periods of time where you are not feeling quite as rotten. (05)

In addition, by putting cancer in its place and using conscious denial, they believed their health and their quality of life could be improved.

> I think the best thing is just try not to dwell on it as much as the mind wants to. If you can control your mind and not let yourself dwell on these things and become so negative about it, then you have a better chance because if you're feeling good emotionally, then I think you do better health-wise too. The body's more able to fight. (01)

As a consequence of re-establishing normalcy, informants' positive visions of self and future were confirmed, hope was reinforced, and the hopeful veneer became stronger or thicker and more stable.

Re-establishing normalcy did not necessarily mean that life was identical to that before the recurrence. To the contrary, informants typically lived differently and established a "new normalcy" after experiencing a first recurrence of cancer.

Living Differently

Informants described many ways in which they altered their lives after experiencing a first recurrence of cancer. The ways in which informants lived differently were largely determined by the grounds for hope, objects of hope, and the visions of self and future used in rebuilding the hopeful veneer. In the words of one informant, they had made "legitimate inferences...about the future" and were now "gaug[ing] their behaviour" accordingly. The greater the difference between the fabric of the rebuilt hopeful veneer and the original veneer established after the initial diagnosis of cancer, the more extensive were the changes to informants' lives.

For some informants, the extent of physical or functional impairments or life interference incurred by the recurrent disease or treatments precluded a return to previous patterns of living. Hence, these informants re-engaged in life by establishing new routines and regained a sense of self-worth and purpose in life by adopting different roles and responsibilities.

> I'm a workaholic and I feel quite lost. No place anymore....My place at work is very important to me and then all the things I do: the labor council and the inner city community development work. Well, I sort of lost those so I don't have a place. So I'm kind of like a little waif -- no where to go....So that's really hard....which is probably why I like to go to Santa's Anonymous so much because I have a place there. They have a function. I'm considered sort of part of the staff. They're always happy to see me and I can do useful

> stuff....It's sort of like this refuge....Hey, you could stay at home and cry or you can get out and do somethin' for someone else and that's really therapeutic. (02)

While realistically reframing self and future, most informants envisioned a shortened life, a second recurrence, and a cancer-related death. These visions led informants to alter their lives in two respects. First, to ensure they were adequately prepared should these visions become reality, informants put their affairs in order. Second, to maximize the quality of remaining life and to reduce the possibility of these visions becoming reality, they made lifestyle changes. Making these lifestyle changes was a means of putting into action the resolves they had made while reframing positively.

Putting affairs in order entailed such activities as "checking out pensions and life insurance," inquiring about health benefits, "getting that mortgage paid off," making wills, saying good-byes, and ensuring adequate provisions and arrangements were made for family members. The more likely an early death was perceived, the more extensive were the efforts to put affairs in order.

> I seem to be doing things to bring conclusion to a lot of things. I seem to be reconciled to...finishing my life. For example, my very best friend in the whole world...is coming in this weekend because we were concerned that if he didn't come this weekend, it might be too late for him to come -- anytime....I made...sure the right people had a key to my apartment, [set up] the joint account with [my friend] so he could manage my financial affairs....I made sure that everything was set up..., thinking, well, I may not be able to handle my affairs so I'll just make sure everybody is organized. (02)

> My mother is 90....We've had her interviewed to move into a lodge and gone through that whole process....At one time I would have just assumed...she was gonna go before me. Now, we just can't be sure about that so that means all of a sudden a whole number of things have to be taken a look at. And so this is the kind of future one tends to envisage. (04)

As described in the section on reframing positively in Chapter 6, the recurrence experience led informants to develop and/or reaffirm insights into the important priorities for living. Based on these insights, they resolved to live life differently so the quality of remaining life could be maximized and the chances of living a long life improved. Once they entered the stage of actively re-engaging, they put these resolves into action and thereby reinforced or thickened the hopeful veneer. Some informants had put similar resolves into action after the initial cancer experience but, with the passage of time, had slipped back into previous patterns of living. After experiencing a recurrence, they thought they would be more cognizant of this "slip" and more able to prevent it from happening.

> You get back into the harness, the social, the occupational, whatever kind of harness, and you tend to lapse back into some of the old behaviours. And you have to catch yourself up sometimes....So I think this slipping back into the old patterns is there, but I think being able to pull yourself out of some of these old patterns is also there as a result of having it. And perhaps this time, the second time around, I still see the same thing going on but I'm perhaps more conscious of the slip than I was the first time...so that's probably the "benefit," quotation marks, that comes out of a second time in there. (04)

In living differently to maximize the quality of their lives, informants focused on "liv[ing] each day as though it were [their] last," trying to "get the most out of every day," and "enjoying...life to the fullest." They shifted focus from work to leisure; reconnected with others; took more time to appreciate others, life, and nature; and made more of an effort to treat themselves well.

> I'm somewhat more set on now to retire from farming than I probably even was in the spring....I don't mean retire from life....This fall, with my other activities, I don't know how the heck I'm gonna find time to get the harvest off. And if you understand what I mean by that, that's not negative at all. It's very positive. It's just that the things that I find very pleasant in life, I feel I must pursue them. And I feel that I don't really want to work any more 15, 18 hour days. And I also know that I really don't need to do it either. (05)

> Reach out to friends and family....Treat yourself well....Treat...yourself pretty special....Do some things that make you feel good. (06)

Informants also shifted attention away from cancer treatment to the correction of other health problems. By correcting these other problems, their ability to enjoy life to the fullest was enhanced.

> As a matter of fact, for reoccurrent cancer it couldn't have come together any better than it did....This is where now I start paying attention to other things. I've got a little problem with one knee here so I think I'll be going to see the doctor. I'd hate to sorta beat cancer and then find out I can't do too much mobility because the knee's gone on me so I've got to take a little care of these other things now. Before you weren't too concerned. If the car isn't gonna last the year, you're not gonna fix the seating and the upholstery, but since we might go a little longer I think we'll take a look at those things now. (04)

Informants also made lifestyle changes they hoped would improve their odds of living a longer life through prevention of another recurrence or an ailment of another nature. These types of lifestyle changes included quitting smoking, getting more exercise, changing diets, getting more rest, reducing stress, taking vitamins, finding religion, drinking bottled water, reducing alcohol intake, and using visual imagery and positive thinking. By making such changes, informants felt like they were taking an active role in improving their health and stacking the odds of "beating cancer." They felt like they were "doing something about it." Hence, they regained more of a sense of control over their lives and reinforced the hopeful veneer.

> If they suggest cutting fats out of your diet or maybe getting more exercise or something, why not try that because, I mean, you've nothing to lose....[It makes you feel] like you're doing something about it. Like you're not just sitting there waiting for the doom day. (01)

> Maybe what the cancer did was it scared a little behaviour out of me in terms of my eating habits. All of a sudden I get serious about knocking off the nuts and things like that, cutting back on the Coke, and I've usually liked two or three drinks a day and I've knocked that off. I don't know if it's the old Puritan streak and getting in a better relationship with the Divinity or whether, hey, if they're gonna go this route let's do our little bit to pitch in....So, these kind of things are giving you mini senses of achievement, a sense of being in control or MORE control, than just sitting back and watching the whole damn thing fly by you. Whether they'll produce the kind of results one always hopes for, that's another thing. But I think, like a lot of things, it's process rather than end result that's the important thing now....There is an orientation towards some kind of action that is acceptable and makes sense. No passivity on my part at the moment. (04)

As the latter informant stated, making these lifestyle changes also afforded the possibility of "getting in a better relationship with the Divinity." By adopting a healthier lifestyle and taking better care of their bodies, informants hoped that God would look more favourably upon them, prevent another recurrence, and grant them a longer life. One informant described this process as "making bargains with God."

> I quit smoking in October....That's another part of the grief process I think, you make bargains with God. I made a bargain that....if I got healthy, if I got better, I'd stay off of cigarettes. (03)

> I'm now prone to go towards a healthier lifestyle although this cancer, I'm told, is not a lifestyle related disease....I can only sort of...speak an analogy related to [when] the oil boom went bust back at the end of the 1980s and you saw those bumper stickers "Please Lord, let there be another oil boom and I promise not to piss it all away this time." (06)

It is of note that one informant did not make any lifestyle changes to improve her odds of living a longer life. Being quite certain she would not achieve another remission and would die soon, she thought, "What's the point?" At one point in the experience she even made lifestyle changes that would reduce rather than improve her chances of living a longer life.

> I've never really dieted much but I'm conscious of things. Like never in my life do I eat potato chips or ice cream or any of those things....But since I've been sick, I eat ice cream. I had potato chips for the first time in about five years the other day, and dip. I never eat dip. At first I was doing it 'cause it didn't matter....I'm gonna die so what the Hell, I may as well get cholesterol problems....What difference does this make? Who cares?....And the sort of making the most of each day, I haven't been very good at that and I don't know why. Like you'd think that when you have cancer the first time, you'd become a broccoli buff, right? Sulphureous vegetables, right? No, no not me. And I don't seem to have done anything to change any environmental conditions that might have [an effect]. Maybe I'm self destructive, I sort of feel that way. (02)

Transition to Monitoring

By re-establishing normalcy and living differently, informants aimed to reinforce or thicken the hopeful veneer. The thicker the veneer became, the more protection it afforded from falling back down into the lower level of reality and the easier it was for informants to keep thoughts of the cancer at the back of their minds. To determine how thick or stable the veneer was becoming, informants engaged in monitoring activities, much as they had done during the first remission.

Monitoring: Measuring the Thickness of the Hopeful Veneer

As in the first remission period, the stage of monitoring entailed measuring the thickness of the hopeful veneer and monitoring the signs that could affect its thickness or integrity. Because the hopeful veneer had already been eroded once, informants were less confident in the protection it afforded during the second remission than they had been during the first remission. As one informant stated:

> I'm just not sure how thick the veneer of hopefulness is....It leaves a guy with a little bit of a question. (06)

Informants were cognizant of the increased potential for future erosions and hence were "very guarded" and "gaug[ed] the situation a little more carefully" than they had during the first remission. When gauging or monitoring the situation, thoughts of the cancer and its implications temporarily moved toward the front of informants' minds, although not as far forward as when functioning below the veneer.

The thickness of the veneer was primarily determined by the strength and stability of the foundation or grounds for hope which, in turn, determined the height of the second level or objects of hope. The stronger and more stable the foundation, the higher the second level. In other words, when the grounds for hope were more positive or certain, informants defined more distant objects of hope and perceived their objects of hope to be more attainable. If monitoring revealed that the grounds for hope had remained stable or shifted in a direction that made objects of hope more attainable, the veneer was thickened or reinforced and thoughts of the cancer returned to the back of the mind. If objects of hope were now perceived as unattainable, the veneer was eroded, and thoughts of the cancer moved squarely to the front of the mind.

Like the phase of appraising, monitoring entailed the use of two strategies: gathering information and taking inventory.

Gathering Information

In monitoring, gathering information about health status was of paramount significance. Self-assessment and medical check-ups were the two means by which this information was gathered.

Informants had "a tendency to look for...changes in [their] bod[ies]." Hopeful changes were those that indicated progress and improvement in health status. Seeing these hopeful changes sometimes required an adjustment in the time frames of self-assessment.

> I thought I'd try, instead of tak[ing] it one DAY at a time, tak[ing] it one WEEK at a time because I couldn't gauge any difference from one day to the next but I could probably gauge at that stage a slight difference from one week to the next....And that turned out to be the way to do it because...over three or four weeks you could feel a difference and by the first of June, certainly my general energy level...[was] a lot different from what it was on the 20th of April. (05)

Ominous changes were those that might indicate a decline in health or, at worst, another recurrence. Fearing that their cancer "will start up again," informants felt like they were "kinda on egg shells" or "pins and needles" and closely monitored their signs and symptoms.

> You have a tendency to look for things, changes in your system, in your body....About a month ago, when I started getting these burning sensations, I thought, "Oh, here we go again." This is something new and I'm wondering, "Is it bone cancer? Is it cancer in the muscles? Is it skin cancer? What is it?"....You know that perhaps that time is gonna come when cancer will start up again. Like mine seems to be almost...laying dormant for awhile but it's going to apparently act up again and so I look for signs. And at that time, you're going to feel a little down. And it diminishes your hope because you had hoped that this wouldn't happen but it has happened. (01)

Through self-assessment, informants also gathered information regarding the extent to which they were able attain their objects of hope, including hopes to re-establish normalcy and enact resolves to live differently. Attainment of objects of hope led to an enhanced sense of accomplishment and success which contributed to overall health and well-being. Defining, monitoring, and attaining objects of hope was a cyclical and hierarchical process. As monitoring revealed that objects of hope were attained, new objects of hope were defined and the extent of their attainment was monitored.

Medical check-ups were the other means of gathering information about health status. At these check-ups, physicians provided informants with the results of diagnostic tests and physical examination, thereby enhancing their ability to monitor progress.

> That's the ones I'll be watching for is where the tumour markers are at....Two months from now I have tumour markers again and then four months from now I'll have another CAT scan. So then probably...six months from now if I

> have, say, three sets of tumour markers and a CAT scan all negative, I'll be going, "Okay, yeah, here we go." (06)

There were two types of medical check-ups: worried checking and routine checking. When informants sought medical attention after noticing changes in their bodies and suspecting that something was wrong, this was "worried checking." When they were symptom-free and attended a regularly scheduled follow-up appointment at the cancer clinic, this was "routine checking." Medical check-ups were viewed with both positive anticipation and dread. On the one hand, they offered the potential for reaffirmation of remission, dispelling of fears and doubts, and reinforcement of the hopeful veneer; whereas, on the other hand, they offered the potential for discovery of a recurrence, confirmation of fears, and erosion of the veneer. "Routine checking" was particularly discomforting for informants because thoughts of the cancer were forced to the front of their minds even though they were symptom-free. When a check-up of this nature loomed in the near future, going "through the day-to-day routine" became more difficult.

> I guess I'm gonna have to keep busy from now for a long time before you start forgettin' about it. And if you've got a three month appointment every time to get checked, it's gonna come back every three months. (03)

Some informants even chose not to attend their routine check-ups in order to maintain normalcy and facilitate use of conscious denial.

While not as significant as information about health status, information about advances in and effectiveness of cancer treatments was also sought by informants when they were monitoring their situations. As described in the section on appraising in Chapter 6, this type of information was gathered from a wide variety of sources, including health care professionals, friends, family, colleagues, other cancer patients, and the media.

Taking Inventory

As in the phase of appraising, monitoring was completed by taking an inventory of the hopeful and ominous signs in the information that had been gathered. As described above, signs related to health and treatment were of most significance during monitoring. The same health-related and treatment-related signs appraised from below the veneer during rebuilding were now monitored from above the veneer (see Table 4 in Chapter 6). In addition, informants monitored the frequency and intensity of medical check-ups, length of remission, and extent of enactment of resolves to live differently. Informants readily identified particular signs that would significantly impact the integrity of the hopeful veneer. It was as though some signs were "heavier" than others.

> [The hopeful veneer] builds over time....Now that I've had some time, and especially with the latest CAT scan result, the veneer builds. If I was...to feel pain in my lower kidney area that veneer would melt pretty quickly because that's a pretty heavy indicator. But on the same return, if things go along and I'm, you know, fine for five months, the veneer will build. (06)

As the latter informant described, monitoring hopeful and ominous signs resulted in two possible consequences for the hopeful veneer: reinforcement or erosion.

Consequence: Reinforcement

If, during monitoring, the balance between hopeful and ominous signs remained the same or shifted in a direction that made objects of hope more attainable, the hopeful veneer was thickened or reinforced. Consequently, informants experienced a decrease in fear and uncertainty and an increase in hope, returned to actively re-engaging, reduced the frequency and intensity of monitoring activities, moved the cancer further to the back of their minds, and were more successful in using conscious denial. One of the most substantial reinforcements of the hopeful veneer occurred when informants' hopes for a cure and a long life were fuelled by receipt of a "clean bill of health" during medical check-ups, particularly if they had been engaged in "worried checking."

Because the first treatment for cancer had failed in achieving a cure, the hopeful veneer was typically not as easily reinforced during the second remission as it had been during the first remission. It seemed that most informants needed to see more hopeful signs and/or see these signs over a longer period of time before they felt the veneer becoming stronger or more stable.

Consequence: Erosion

If the balance between hopeful and ominous signs shifted in a direction that made objects of hope less attainable, the hopeful veneer destabilized and was eroded. Consequently, informants were overcome by fear, uncertainty, and loss of control and they could no longer remain in actively re-engaging nor successfully use conscious denial. They fell to the lower level of reality, thoughts of the cancer moved squarely to the front of their minds, and they had to rebuild the hopeful veneer for a third time. The further the shift in the balance of signs and the more radically the attainability of objects of hope was altered, the further informants fell. The shortest fall was to the stage of rebuilding, while the furthest was to the stage of giving up.

Most informants had rebuilt the hopeful veneer using hopes for a cure and a long life, although these were viewed as less attainable than on first diagnosis, and hopes for a good quality of life. When attainment of these hopes was seriously threatened, the veneer eroded. Hopes for a cure and a long life were most seriously jeopardized when informants' suspicions of a second recurrence were confirmed during medical check-ups. Such was the case for two informants in the study. Attainment of hopes for normalcy and quality of life were threatened by setbacks, including prolonged complications, severe symptoms, and job loss. After achieving a second remission, one informant described how a surgical complication reduced his quality of life, prevented him from re-engaging in life, and caused him to temporarily return to disengaging.

> I went home [from the hospital] and I guess after about seven days..., the bladder muscles weren't really functioning that well and so I got blocked up. Three days later I had to go back into emergency and...they still couldn't get it moving so they gave me a catheter to wear for a month at home. And I must say, muscle spasms travelling along a plastic catheter really do reverberate and get your attention quite quickly. And that was probably the bluest part there. Not so much the operation or anything else but this damn piece of plastic that we're carting around day and night. And then it just seemed to get increasingly painful all the way through and it cuts down on your physical activity and that begins to influence how you look at things. So, anyway, I got a little funky by the end of May. Came out and the muscles worked so that was obviously a very positive lift and so it's essentially been coming back

> from there. (04)

As described in the section on reframing the future in Chapter 6, one informant was atypical in that she was certain she would die soon after being diagnosed with the recurrence and she had held the same vision of the future after receiving the initial diagnosis of cancer. In rebuilding the hopeful veneer after the recurrence, she had used hopes for bringing a good conclusion to her life, preparing well for death, enjoying the short time she had remaining, and having a quick, painless death. While waiting for surgery, she was able to travel above this veneer and re-engage in life in pursuit of these objects of hope. When the results of tumour pathology revealed some unexpected hopeful signs, the grounds for hope shifted, the veneer was destabilized, and she re-entered the stage of rebuilding. Here, she made some minor alterations to her visions of the future and objects of hope.

> So the fact that it's low grade means that even if they can't cure it now, I could be around for awhile and then they'll find something to cure it. So that seemed good, rather than it just taking over. Because I mean I had myself dead by Christmas. Honest to God. I was reconciled to being dead REAL soon. And it's obvious from talking that I've changed my attitude about that....Now I have a feeling that I have some more time. I'm not optimistic in the long run. I mean sure, maybe we'll fight it and maybe I'll go back to work and then, oh, it'll happen again. It'll get me. But, I'm not quite as gloomy as I was at first. (02)

When the tumour was completely removed at the time of surgery and no follow-up treatments were necessary, the balance between hopeful and ominous signs shifted dramatically in favour of hopeful signs, previously identified objects of hope were now unattainable, even irrelevant, and the veneer was completely eroded. This informant then fell to disengaging where she engaged in wallowing and withdrawing for a considerable period of time. It was as though she didn't know how to get back into gear after being prepared to die.

> I've had, for the last month, a totally faded out time of it. I haven't really been able to function very well. I've just been a little hermit in my house....I won't go out. Like there's been lots of weeks where I haven't gone anywhere near out....The phone rings and rings and rings. All these nice people phoning, wanting to do stuff. I don't answer the phone. Just terrible. I don't phone people back. I don't talk to anyone. Terrible, terrible, terrible. Makes me

> feel just awful....I'm sleeping 12 hours a night. I think I'm really depressed. Well, not going to work is horrible. Especially now that this is not ongoing. This is finished. I really feel like I brought closure to it and I'm not worried about the next possibility, the next possible recurrence. It is complete. And so it's time to get on with it but I'm not very good at it, getting on with it. I just feel like I've been a brat. I just can't get going...., just can't be bothered...., just sulking around....I just can't seem to get myself to go out. Sort of have nowhere to go. I can do it tomorrow....Since the surgery I've been really, not pessimistic about health, but just pessimistic....It's been really horrible. So there's quite a contrast between the way I behaved before and the way I behaved afterwards. I've gotta get my act together. (02)

Eventually, this informant did move up from disengaging into rebuilding. Given the shift in grounds for hope, she rebuilt the veneer using hopes for a long life and altered her visions of the future.

> So when I talked to you before it was sort of like ongoing life threatening. Now it's sort of behind me. It's not ongoing. It may happen again in five years but I've bounced back to where I was before assuming a long life. When I talked to you last time that's not where I was. So it's quite, quite different....I hope that I don't have another reoccurrence but, for some reason I accept that it could happen down the road and that's okay. They'll take care of it....It's a long term fight....I faced the monster down and beat it and I can do it again. Whereas before I wasn't sure. I always thought...if I got sick again, that was the end. And it didn't turn out that way. (02)

Giving Up: Losing Sight of the Hope

After experiencing an erosion of the hopeful veneer, there is the potential that one may be unable to initiate or successfully complete the rebuilding process. Under these circumstances, one sinks below the stage of disengaging, completely loses sight of the hope, and enters the stage of giving up. "Giving up" is a time of hopelessness and helplessness. It is akin to perpetual wallowing and withdrawing and is more intense and/or of longer duration than the typical experience of disengaging. One informant clearly identified the difference between periodic disengaging and giving up. When asked whether she ever felt like giving up, she replied:

> No. I'm not like that....That's not to say that I didn't get gloomy sometimes but I think there's a difference between having a cry and then going out or something and sort of immersing yourself in sadness. So I don't want you to

> think that I was not sad. I just didn't give in to [it]. I cried lots. I talked to people and I expressed the sadness but then I moved on. I didn't lose function or anything because of it....I never allowed myself to get sucked into it. (02)

Other descriptions of giving up included "letting yourself be beaten," being "not willing to even try anymore to help yourself," not "bothering," and "crash[ing] and burn[ing]." Spending any length of time in this stage was described by one informant as a "waste of human experience."

> To go on and have any duration in a funk is just such a waste of human experience. To me, it approaches suicide in terms of human wastage and lack of fulfilment. So that's what I think the cost is involved here. It's a very, very large cost....I can't think of almost a more horrible term to apply to human life than waste. It's the antithesis of life. And that's what's involved I think when you can't develop this positive kind of thing. (04)

During the process of Maintaining the Hopeful Veneer, one may enter the stage of giving up from various points and under certain conditions. These points and conditions were described throughout Chapters 5-7 and are listed in Table 5. Typically, from each of these points of entry, one would fall to disengaging first and, if there for an extended period, one would fall further to giving up.

Table 5 Points of Entry and Conditions for Giving Up

Points of Entry	Conditions
Erosion after recurrence	• knocked far below the veneer (i.e., devastated) • completely overwhelmed with suffering • unable to reach turning point of deciding
Appraising	• unable to find sufficient hopeful signs to rebuild foundation of veneer (i.e., too weak or unstable)
Reframing	• rebuilt foundation too weak or unstable to rebuild second level (i.e., to support worthwhile objects of hope or meaningful vision of self and future) • unable to reframe positively
Monitoring	• grounds of hope weakened or destabilized (e.g., no progress, setbacks) • objects of hope unattainable (especially hope to re-establish normalcy)

All six informants in this study were successful in rebuilding the hopeful veneer and actively re-engaging in life. Some of them did, however, exhibit some signs of giving up at two points in the experience: after being diagnosed with the recurrence (three informants) and when unable to find sufficient hopeful signs to reframe a meaningful future (one informant). The latter informant was successful in leaving the stage of giving up when she stopped attending chemotherapy treatments and pursued alternate cancer treatments, thereby being able to reframe a more meaningful future and re-engage in life.

Informants recognized that, even though they had been successful in rebuilding the hopeful veneer and re-engaging in life during this experience, there are others who may be unable to do so.

> I'm sure for some people there is no hope....I often wonder where those people find their hope. Like I wonder about my colleague in Calgary. I don't really want to press the button down there and say, "Are you getting hope and where are you getting it from?" (06)

Informants also recognized that there may come a time in the future when they too would be unable to rebuild the veneer and may give up.

> I recognize that at some point I might have to [give up] but not yet....There may be some time when I['m]...just gonna crash and burn but [I'm not] gonna do that till I ha[ve] to. (02)

While not specifically stated by informants, the situations when they would choose to give up would likely be those described in the section on shifting from quantity to quality in Chapter 6, wherein hopes for quality of life would not be attainable and they would choose death over continued existence.

CHAPTER 8

MAINTAINING THE HOPEFUL VENEER: INFLUENTIAL FACTORS AND SIGNIFICANCE

Findings presented in the last four chapters have addressed the research question: "What is the nature of hope for individuals experiencing a first recurrence of cancer?" This question was expanded to include the nature of hope-related processes and was answered through descriptions of the hopeful veneer and the process whereby it was rebuilt and maintained. Included in this chapter are findings pertaining to the remaining research questions: "What are the factors that influence hope?" and "What is the significance of hope?" for individuals experiencing a first recurrence of cancer. Given the findings regarding the nature of hope and hope-related processes, the questions became: "What are the factors that influence movement through the process of Maintaining the Hopeful Veneer?" and "What is the significance of the hopeful veneer?"

Maintaining the Hopeful Veneer: Influential Factors

A variety of factors facilitated or inhibited informants' movement through the process of Maintaining the Hopeful Veneer and thereby accounted for the majority of the variation in their experiences. Some of these factors have been mentioned at specific points within the preceding chapters, particularly if they only influenced movement at one point in the process. The majority of factors, however, influenced the process at more than one point and in multiple ways. These points and ways of influence are summarized in Table 6. For ease of reference, an overview of all influential factors is included in this section, with cross-references to sections in preceding chapters as appropriate.

Three relatively distinct categories of factors were elicited from the informants' stories: signs, resources, and contexts. Within each category were facilitators and inhibitors in the process of Maintaining the Hopeful Veneer. As one would expect, facilitating factors supported upward and forward movement, while inhibiting factors thwarted this movement and/or initiated downward or backward movement. Given the focus on recurrence in this thesis, the influence of factors on the stage of rebuilding is emphasized in this section.

Table 6 Influence of Factors in the Process of Maintaining the Hopeful Veneer

Stage/Phase in Process	Potential Influence of Factor
Disengaging & Giving Up	Depth of fall Duration of time spent in stage Ability to make decision to move up
Appraising & Monitoring	Ability to gather information Ability to see and/or connect hopeful signs Ability to find grounds for hope Strength and stability of grounds for hope
Reframing	Ability to reframe positively Ability to redefine objects of hope Perceived likelihood of positive future or attainability of objects of hope Distance of hope objects in future
Actively Re-Engaging	Ability to re-establish normalcy Ability to pursue and/or attain objects of hope

Hopeful and Ominous Signs

Signs provided the evidence or basis for rebuilding or maintaining hope. As described previously, signs were categorized as hopeful or ominous (see Table 4 in Chapter 6) and the balance between hopeful and ominous signs constituted the grounds for hope. The more the balance favoured the hopeful signs, the stronger and more stable were the grounds for hope and, hence, the more distant were objects of hope and the more attainable they were perceived to be. In addition, hopeful signs were conceptualized as the materials used in rebuilding the foundation of the hopeful veneer. Hence, hopeful signs facilitated the rebuilding process and served to reinforce the veneer, while ominous signs inhibited rebuilding and served to destabilize or erode the veneer.

Hoping Resources and Inhibitors

Hoping resources were like the assets or laborers in the process of Maintaining the Hopeful Veneer. Resources were those factors that helped informants move up from disengaging, rebuild the hopeful veneer, and move forward to actively re-engage in life, while absence of these resources inhibited this movement. In addition, the presence of a factor directly opposite to a hoping resource served as a liability or inhibitor in the process of Maintaining the Hopeful Veneer. Hoping resources and inhibitors included factors both internal and external to the person. Internal factors were those pertaining to self, while external factors included other people, God or a Higher Being, pets, and treatments.

Internal Resources and Inhibitors

Internal factors that served as resources or inhibitors in the process of Maintaining the Hopeful Veneer are listed in Table 7. These factors were highly interdependent, each building on the other.

Positiveness/Negativity.

The degree of positiveness or negativity inherent within the self profoundly impacted informants' abilities to rebuild the hopeful veneer on recurrence and maintain it throughout the cancer experience. It seemed as though some informants had a tremendous capacity to see the hopeful signs and envision a positive future, while, for others, this capacity was limited. Strong undercurrents of hopelessness, negativity, and defeat ran through interviews with some informants, while for others, there were undercurrents of hope, positiveness, and certain victory. Two contrasting statements are included below to illustrate these two extremes.

> I ALWAYS thought that I was not gonna recover from this. I always thought I was gonna die....I had accepted that I was going to live on one level, but deep down you always know you're not going to. (02)

> Even when I was really sick,....I'd say to [my wife], "....I feel rotten but there's nothing wrong with my spirit. This WILL pass, there will be a good day tomorrow."...In the back of my mind, there was not the slightest doubt that I would be on the golf course in July. As it turned out, I was there already in late April....It was automatic I was gonna get better. (05)

Table 7 Internal Factors: Hoping Resources and Inhibitors

Internal Factors (Self)	
Resources	Inhibitors
Positiveness: • Hope, Hopeful • Positive attitude • Positive view of self & life • Optimism	Negativity: • Little or no hope, Hopeless • Negative attitude • Negative view of self & life • Pessimism
Inner Strength: • Courage • Determination • Assertiveness • Self-confidence, Personal control • Independence, Self-reliance	Inner Weakness: • Fear, Anxiety • Giving in • Introversion, Passivity • Lacking confidence & personal control • Dependence, Co-dependency, Self-pity
Comforting spiritual beliefs	Lacking comforting spiritual beliefs
Health: • Energy, Physical strength • Comfort	Illness: • Fatigue, Weakness • Pain, Suffering
Knowledge & understanding	Lack of knowledge
Insight/Self-Awareness	Lacking insight/self-awareness

In the preceding excerpts, both informants referred to something deep within themselves that exuded either a negative or a positive glow over their experiences. This may be viewed as their inner capacity for hoping or inner core of hopefulness. One informant identified that this capacity may not be fully known until one is facing a personal crisis.

> I lost a brother from cancer ten years ago....and I remember...telling [my wife]...."Boy, if this happened to me I'm gonna be a crying wimp." As it turned out, I wasn't. That's something you don't know till it happens. You don't. I have hope. It was just there. I think either you have it or you haven't. There might be some degree,....[but] I think you have to have that in you. (05)

As delineated in Table 7, positiveness was reflected in several ways, including having hope or being hopeful, having a positive attitude or a positive view of self and life, and/or being optimistic. Informants seemed to use these terms interchangeably. When asked to identify differences between these terms, most informants stated they all had the same meaning. All of the informants considered hope and a positive attitude to be synonymous. Some differences between hope and optimism, however, were identified by three of the informants.

> Well, I think [optimism, positive mental attitude, and hope] are basically saying the same except maybe when people speak of hope perhaps they speak of that in a spiritual sense more than they do optimism. (01)
>
> I'd almost say if you use the term, "I'm hopeful it's good," that hopeful is not as positive a word as if you said you are optimistic that it is good. You could hope it is even if you don't think so. (05)
>
> Hope and optimism are definitely different. Optimism is dealing with the best part of what's real whereas hope is something that deals not necessarily with reality....I think, as well as having hope, it's really important to have optimism, to know that the bad things are gonna really happen but you will make them as good as they can be when they're bad. (02)

The latter two comments both suggest that optimism may be more reality based than hope. Interestingly, all informants in this study said they tried to ground their hopes in reality. This then leads one to question whether their realistic hope could be described as optimism.

Informants described being hopeful or having a positive attitude as having a "plucky...spirit," "never dwell[ing] on anything negative," having a "feeling....that things will get better," and look[ing] on the bright side of things." Negative individuals were described as "gloomy," "morbid," in a "funk," or "cynical." They were also described as needing help to see or connect the hopeful signs.

> I guess it depends on your personality. If you have a really gloomy personality, you could say to yourself, "Well, that's not enough." Maybe people like that need somebody to, you know, go over it very slowly, connect the dots for them and stuff like that, but I don't. I mean, I see it. (06)

Informants' inherent positiveness or negativity colored their views of self and life in the past, present, and future, and these views greatly influenced their ability to rebuild and/or maintain the hopeful veneer.

> I think it's a self-feeding process. I think people who have tended to have a

> very negative view of themselves and their circumstances and get something like cancer, it just confirms all their cynical views of what life's been all about. How do these people ever develop hope? It's not been a major part of their world all their life and so again we start spinning downwards. On the other hand, I think people who have had very positive views about themselves or how they function, their circumstances -- it doesn't mean they haven't had their little traumas through life -- ....how [they]'re putting it together, obviously, when something like this comes along, [they] get on with dealing with it like [they]'ve done. (04)

One informant clearly described how his positive view of self, or self-image, kicked him into gear and helped him start to put hope in place.

> I think you have your own image of yourself and your background. It goes all the way to self, to male, to this kind of thing, so it puts certain demands on you -- you've gotta behave this way...in this kind of a circumstance....I come from a background, [an] ethnic and social class that emphasized certain kinds of...euphemisms...."You play the hand you're dealt," you know, "No crying over spilled milk,"...."Nobody likes a crybaby."....There's a certain message that goes with them. "A MAN does this and does not do this." "You're not dead. Get up and take care of your responsibilities."....If any of that image of yourself still remains,....you begin drawing on them [and they]....become helpful because they do maybe get you that initial boot up the first stair....Some of those things programmed into you do have a benefit, not just load you down with impossible guilt and impossible standards. They do have a benefit of kicking you into gear too....Maybe they're the foundation step necessary for this active hope to be put in place. But they certainly work for me and yet it's not something you have to call upon all the time. It's just when that funky bit gets there. (04)

A positive view of life was reflected in an enthusiasm or zest for living. Individuals who held this type of view were described as "ebullient," "full of piss and vinegar," "gung ho," "curious," "willing...to engage everything that they encounter," and "looking forward to [life]." The connection between zest for living and hope was evident by informants' descriptions of actively engaging in life once they had rebuilt the hopeful veneer. One informant made specific reference to a "gung ho" attitude as a component of hope.

> If you're gung ho....[and] saying, "Let's get the show on the road. We want to get on it,"...that's part of the hope. You've got to get at it to have hope, you've got to get at it. That's an automatic. (05)

A second informant reflected this element when I asked him how he would know if a person has hope.

> I suppose, a little bit facetiously, it's why I like terriers. There's just this perkiness and positive[ness] -- and why I like pit bulls. They have an assertiveness and a positive sort of willingness to engage everything that they encounter. Now in their case they can overdo it a few times....There are various social styles but...you get a sense of some people engaging life, looking forward to it, coming in contact with it, wanting to handle it, wanting to be creative with it....The person who engages life...has a very positive view of themselves, has a very positive view of their current circumstances, has a very positive view of what the future holds for them. And...I've found...that people with a serious illness...can do that. (04)

A positive view of life was also reflected in a sense of humor. The benefit of humor in facilitating the use of conscious denial was articulated by one informant.

> Go and talk to people and get as much humor going as you can. You find some humor in lots of little things. I suppose the reason I feel that way is because basically what you're going over there [to the patient lounge]...for is to get your thoughts away from your situation, be that the cancer or chemotherapy, whatever. And, of course, if there's humor and you laugh, that gets you even further away from it. And I'm sure that's positive. (05)

Inner strength/Inner weakness.

Inner strength was a resource that facilitated forward movement through the process of Maintaining the Hopeful Veneer, while inner weakness inhibited or reversed movement through the process. Inner strength was described in terms of having a "strong personality," being "mentally very strong," and being "a strong individual." One informant said his friend described him as a "tough bugger," while another said: "I'm a STRONG personality and a strong individual. I can take it" (06). Informants clearly pointed out that inner strength was unrelated to physical strength or size. One man explained:

> You could have the biggest, strongest man who might be a wimp. You could have a little tiny lady that may have not much strength be very strong. So that has nothing to do with that at all. (05)

In providing advice for others with recurrent cancer, two informants mentioned the importance of finding inner strength:

> I feel very, very bad for anyone who comes down with it but I would say that the only thing you can do is deal with it on your own terms and try and be strong. (01)

> I don't know how I would explain [it] to somebody. I think it's something you'd have to go through to find your own strength. (02)

As delineated in Table 7, inner strength was characterized by a combination of personal qualities, including courage, determination, assertiveness, self-confidence, personal control, independence, and/or self-reliance. One informant identified that two of these qualities, control and assertiveness, were characteristics of a hopeful person. Excerpts exemplifying these qualities and/or demonstrating their importance in the process of Maintaining the Hopeful Veneer are included below.

Courage:

> I was very lucky that I wasn't scared of it. I always had hope. There's a connection there. (05)

Determination:

> I was just goin' through the hoops and kept my head down to cut the wind. You just plowed through it and that's the kind of person I am. I mean I'm a Taurus....I've always been a bit of a scrambler, a survivor. (06)

Assertiveness:

> You can't let other people manoeuvre you or push you into doing something....If you don't feel good about that kind of treatment, don't go ahead with it. Even if ten people are telling you you should have it, you look into it first and you feel good about it and make sure that that's what you want and not what other people want because you're the one that's to deal with it in the end....You have to stand up for yourself. (01)

Self-Confidence, Personal control:

> The extent that you think you are handling this in a professional context, ...you feel you're in control. You're handling it. It may BEAT you in the end but it ain't gonna now. You're getting your shots in at it....I think the idea of hope is a sense of being in control....like anticipation but with some substance to it. (04)

Independence, Self-Reliance:

> I just feel that, eventually, when it comes down to it, YOU are the one with the disease and YOU make the final decision on it....It's YOU that has to deal with it. You're the one who has the cancer. They can all talk about it and they can all support you but, in the end, when it comes down to it, you're the one who has it and it's up to you how you're gonna deal with it. (01)

In contrast to inner strength, inner weakness was characterized by the qualities of fear, anxiety, giving in, introversion, passivity, lack of confidence and personal control, dependence, co-dependency, and/or self-pity. Included below are a few excerpts exemplifying these qualities and/or their negative impact on the process of

Maintaining the Hopeful Veneer.

Fear:

> It's much more difficult to have hope if you are really scared of it....Was he [other cancer patient] scared of it even though his prognosis was fairly good. And I think his hope was out the window because he was so scared of it. (05)

Giving in, Introversion:

> I'm a giver inner. I do anything for peace and I hate fighting....I'm a very quiet, introverted person who hates fights. (03)

Dependency:

> There seems to be two kinds of people in the world. There seems to be people, and it's not me, who go, "Oh, my goodness, what I'm going through. Poor me....I can't function because I'm going through this."...It's like everything in their life is a crisis....The world seems to be divided into those two kinds of people. Maybe they're victims....People who are inclined to be victims are gonna fall into that morass....And the rest of us don't do that. We only do it occasionally but then are able to get ourselves back out of it....You can't let yourself be a victim and you can't let yourself feel sorry for yourself....And I think that's just strength of personality or personality type. (02)

Self-Pity:

> And then I feel sorry for myself....and, you know, then I kinda feel sorry for everybody else....It's just as tough on everybody else....[It] really makes your life a mess....It'd be better just to get hit by a truck and be gone....Be a hell of a lot less pain for everybody....and then everybody could at least get on with their lives. You feel like you're dragging everybody down with you. (03)

Spiritual beliefs.

Spiritual beliefs comprised a third category of internal resources that influenced movement through the process of Maintaining the Hopeful Veneer. There were two primary ways in which this type of resource was facilitative. First, as described in the section on reframing realistically in Chapter 6, religious beliefs or faith made death less fearful by offering informants "a hope for the future beyond death." Informants distinguished between hope and faith by identifying that the term "faith" was usually used in a religious context. One informant made a further distinction as follows:

> I guess hope is you're hoping that things will get better. It's more of a feeling. Faith is your innermost being. For me, my faith is my whole life and it's the

center of my whole life. (01)

Second, some spiritual beliefs or explanations about how the world works and why things happen helped informants come to terms with the recurrence, make sense of it, and reframe their circumstances positively. Even though informants viewed personal control as a positive resource, a belief that some events in life were beyond their control and that their destinies were somehow predetermined seemed to facilitate forward movement through the process of Maintaining the Hopeful Veneer. Informants who held this belief attributed their recurrence to fate, luck, or the will of a Higher Being. This belief was reflected in comments such as "these things happen," "you've been dealt a particular hand," "your luck doesn't hold out forever," and "life is not fair." It was also reflected in one informant's view of his life as a "part of the [whole] process of human experience," that is, as one element of the master plan. Additional examples of this type of belief or explanation included:

> Time and unforseen occur[rences]...befall us all, that's what the Bible says.... Accept this fact and don't expect miracles because miracles don't happen anymore. Just try and take some refuge in your faith and understand why these things happen. The best way that you can deal with it is to accept it and to just cope with it. (01)
>
> I've always lived my life looking at things in trends. Your Karma's up or your Karma's down. I'm not a person who lives and breathes by Karma but some days you're just running with the luck. It just works out that way. (06)

The latter informant also held the belief that, while some events in life were beyond his control, everything happened for a reason and happened for the best.

> I've always lived by the credo that everything happens for the best as bizarre as that can seem at times. (06)

This explanation was particularly comforting and made reframing positively a relatively easy process.

Health/Illness: Energy, physical strength, comfort.

While indicators of health were viewed as hopeful or ominous signs, certain elements of health, namely, energy, physical strength, and comfort, were also viewed as internal resources that facilitated forward movement through the process of Maintaining the Hopeful Veneer. Fatigue, weakness, and pain were the most significant inhibitors in the process and were described as compromising one's ability to move from the lower level of reality to the upper level and to remain on that upper level.

> He was sick enough and painful enough that it would be impossible for him to bring himself to the higher level....His quality of life was just terrible because of the pain level he was in. He didn't have the physical ability no doubt to bring himself up to the so-called higher level. (05)
>
> I really go into that world [lower level of reality] very, very infrequently. There are literally days, if not longer, that simply are not there for me in that world....But occasionally one does go down there. Something can trigger it off. I find sometimes you get overly tired. So I try to make a point of, "Hey, you need a power nap? Take a power nap." (04)

One informant also emphasized the importance of entering cancer treatments feeling "rested and relaxed" rather than "full of angst and kinda tired" in order to speed recovery and re-engage in life more quickly.

Knowledge and understanding.

Knowledge and understanding were key resources in the process of Maintaining the Hopeful Veneer, particularly in the stages of rebuilding and monitoring. As described in the section on appraising, however, there was also a "helpful area of ignorance out there" that may facilitate the development of a more positive vision of the future. For a detailed discussion of the purpose and importance of knowledge and information, the reader is referred to the section on appraising in Chapter 6.

Insight, self-awareness.

The importance of insight or self-awareness in the process of rebuilding hope was identified by one informant. He described how he needed to get in touch with his feelings before he could see or connect the hopeful signs.

> Sometimes getting in touch with your own feelings in terms of where you're at in this cycle [Kubler-Ross's (1968) stages of death and dying]....It took a long time to see those signs that were fairly obvious....I think it was after vacation. It was after I was able to go through some of the processes and get in touch with my feelings a little bit and sort of let the air clear. So I think that some of my rational judgements were clouded by anger more than anything....The anger and not being able to get in touch with the hope. (06)

External Resources and Inhibitors

External resources and inhibitors fell into three categories: health care professionals; family, friends, and colleagues; and others, including God or a Higher Being, pets, and treatments.

Health care professionals.

Health care professionals had the potential to be either hoping resources or inhibitors. Informants identified that the characteristics or qualities, attitudes or styles, and actions of health care professionals influenced whether or not they were resources or inhibitors, assets or liabilities, in the process of Maintaining the Hopeful Veneer (see Table 8). Of all the elements listed, the most important resources were health care professionals who were competent and upbeat. In addition, frankness in physicians and compassion in nurses were qualities of great importance.

Table 8 Health Care Professionals: Hoping Resources and Inhibitors

Health Care Professionals		
Category	Resources	Inhibitors
Characteristics or Qualities	Competent, Confident	Incompetent, Negligent
	Honest, Frank	Hiding the truth, Snowing, Talking down, Being cute
	Compassionate, Empathetic, Warm	Lacking compassion, Unconcerned, Cold
	Patient	Impatient, Rushed
Attitude or Style	Positive, Upbeat, Optimistic, Ebullient	Negative, Morbid, Pessimistic, Lacklustre
	Respectful	Disrespectful
Actions	Making connections	Detaching, Distancing
	Sharing information and control	Lack of explanation or patient involvement

Health care professionals influenced movement through the process of Maintaining the Hopeful Veneer in several ways. First, by providing information and explanations, and being frank and honest in doing so, health care professionals helped informants accurately appraise and monitor their circumstances and thereby reframe their visions of self and future realistically. Physicians were most frequently mentioned in this regard. It is significant to note, however, that informants felt it was their prerogative to determine the amount and type of information accessed from health care professionals and that there was a "helpful area of ignorance out there" that could facilitate their abilities to reframe positively. Hence, it is apparent that health care professionals who assessed informants' preferences regarding information provision and provided accurate information according to informants' requests and preferences, were effective resources in both reframing realistically and reframing positively. Those who provided information with no regard for informant preferences were potential inhibitors in the processes of rebuilding and maintaining the hopeful veneer.

Second, by being positive and upbeat, health care professionals helped informants develop a more positive attitude or outlook. It was almost as if the "positive vibes" were somehow contagious.

> That nursing team at the [hospital] after the operation last time, I was extremely positive about the way they handled everything there....I had very positive vibes there....I call it professionalism, professionalism with style. You see that kind of thing going on around you, that's another positive reinforcement, at least for myself it was. It not only suggests knowledge and competence but there's also a kind of joie de vivre about it. You're upbeat, you're at it -- hey, it rubs off on other people. So I think style and attitude perhaps as much as the words sometimes...rub off positively. (04)

Health care professionals who were frank and honest, while also being upbeat, were particularly influential resources in the stage of rebuilding. In terms of the components of rebuilding, health care professionals who were positive and upbeat helped informants see or connect the hopeful signs and reframe positively.

> A woman came in and joined us half way through the time I was there [for my biopsy] and she was having chemotherapy....I think they [nurses] did this on purpose....They put her in there, she had the same drugs I had [on initial diagnosis], she got up, she walked out, she was a little bit tired and probably

> her tummy didn't feel very well particularly, but she walked out on her own steam and she was going to work the next day. Holy mackerel, that was so good. And the nurses were making remarks about, "Aren't those new anti-nausea drugs good?"...."Yeah, right, you're talking to me aren't you?" So...they showed me that maybe it wouldn't be so bad and that was very good. (02)

> She [medical intern] had sat in on the surgery She was the one who observed and told me about my surgeon being very surprised and pleased. To hear that story was kinda nice. (02)

Some informants noticed a change in the attitude of health care professionals between initial diagnosis and recurrence, perceiving them as less positive and upbeat on recurrence.

> It occurred to me it wasn't quite the same....I perceive the first time as much more positive and sunnier. The second time, absolutely competent and absolutely pleasant, but not quite perhaps as ebullient as previously. (04)

Third, by making connections and being compassionate, empathetic, and respectful in those connections, health care professionals were better able to identify where informants were at in the process of Maintaining the Hopeful Veneer, acknowledge their suffering, help them work through a particular phase, and help them move forward. This connection also served as a conduit for the transference of the "positive vibes" mentioned earlier. One informant identified that patients may be helped to become more hopeful if psychiatrists or counsellors are able to "get the right connection" with them.

> Your general hope and optimism, I think you have to have that in you, and if you don't have it in you, then I think the only damn way you're gonna get it is if you get counselling of some kind. You need psychiatric help for that....Certainly counselling...can influence that....Hope...can come quite fast when you get the right connection. (05)

Examples of positive connections with health care professionals and their influence on informants' experiences are included below.

> She's a nurse who does the preparations for the [CT scan]. She's always been wonderful. I've seen her every year since '85....She knows me really well. She was wonderful this time because she knew that this wasn't just an ordinary [test]. This was bad....And she took me by the hand and she's so good to me. She's just a wonderful, wonderful nurse. I love her a lot. This was different. She knew that. This was something bad. (02)

> I think [being close to my oncologist and nurse] was helpful in that [the

> oncologist] was quick to identify me being angry and [the nurse] was able to talk to me over the phone about the [side effect of the surgery] in a case where she would [maybe] have said to another patient, "Well, you're gonna have to sit and talk with the doctor because I'm not gonna break this to you over the phone because I don't know you." But I'd spent a lot of time with her talking while I was waiting for [the oncologist] to finish with a patient or whatever and so, I mean, it's nice to be able to sorta touch a few stones with your doctor. (06)

One informant felt that physicians deliberately avoided developing connections with her in order to protect themselves from getting hurt.

> It's kind of like a blocking mechanism so they don't get involved or attached so you don't get hurt....You have to develop some kind of mechanism to not get attached. And this is what I find these doctors are doing because even when I see the neurologist, there's five or six of them and I've never seen the same one twice. And they don't know who you are from Adam. I was watching them and they bring out a file and they clip up these x-rays of you and five or six of them all talk about it and they kind of read the first few pages. Then one comes in and talks to you. (03)

Health care professionals who were respectful honored informants' choices and rights, considered their feelings and beliefs, listened to them and believed what they said, and treated them as individuals.

> It was nice to be able to go to the [cancer clinic] and talk to somebody and let them listen to how you feel and not just be another medical chart to them. (01)

In contrast, those who were disrespectful were described as treating a patient like "a piece of meat," "a piece of coal," "just another face in the crowd," or "a machine."

Some informants noted a difference in the degree of compassion or empathy displayed by health care professionals in different institutions and at different points in the cancer experience. Nurses at the cancer clinic were described as more compassionate and empathetic than those at other hospitals and as being more able to develop connections with patients. Informants described oncology nurses as "universally caring," "very gentle and very kind," and "hand picked."

> The nurses at the [acute care] hospital didn't seem to know what was wrong with me. There didn't seem to be any recognition of reoccurrence of cancer or even cancer. They were treating an incision, a nose tube.....They were NOT treating a reoccurring cancer patient who was concerned....And that was much different than...in the [cancer clinic]....THEY were treating the cancer and the

> fear of it....[Also], in the [cancer clinic],...there's this universal gesture: knee patting. Everybody in the entire place has it mastered including the janitors. It is so wonderful. It's such a simple little thing but at the [acute care] hospital they don't know about knee patting. (02)

> The nurses in the [cancer clinic] are quite wonderful....They're a certain combination of compassionate and...matter of fact like, "Yeah, this is bad but it's gonna pass." So they acknowledge both those things, "Yeah it's horrible," but they make you feel like you're gonna go back to being normal....Very very important. I mean, you can't negate the experience, but it's important to understand that it comes to a conclusion. (02)

The latter comment emphasizes the importance of acknowledging the suffering, while also fostering hope for a more positive future. Two informants noted that health care professionals seemed less compassionate, concerned, or willing to develop connections on recurrence as compared to initial diagnosis.

> The first time you're going in there everybody seems very sympathetic and wants to help you and comfort you and the nurses all come up and they say, "Well I had cervical cancer, is there anything you want to discuss? I got through it, you will too." The second time you go in you get none of that. None of it....They seemed to be trained for your first shock....When I was told the second time, I was told in the emergency with no preparation, nothing to buffer it. It's like somebody put a knife through your heart....When you're going through the second time around, it's the NOT treatment you get that scares you, that makes you feel alone and frightened....Nobody pays any attention. It's like, "Well you've been through the routine before. You should know where to go and what to do," and you don't get any compassion or any consoling or nothing. (03)

> I think initially I got a sense I was much more the focus of the health care activity and consideration. The second time I would have a sense that this was not as extensive. (04)

Fourth, by displaying competence and confidence, health care professionals earned informants' trust, faith, and confidence in their ability to help them. Consequently, informants' grounds for hope were strengthened, they were more readily able to reframe their futures positively, and they were more certain that objects of hope would be attained.

> I think they've all handled it beaut[ifully]. I think [the oncologist] maybe has a little more experience in this and therefore there's a sureness with him. (04)

In addition, as described in the section on appraising in Chapter 6, they felt less of a need to seek additional information elsewhere. In contrast, informants lost trust, faith, and confidence in health care professionals who were perceived as incompetent or negligent. Consequently, connections with these individuals inhibited rather than facilitated forward movement through the process of Maintaining the Hopeful Veneer.

> I think he failed me in every way....I'm still pretty bitter, pretty angry with him. I mean the bottom line is if he had just done his job I feel we might have caught it earlier because at this point I've gone through a lot of hoops and I think maybe I might have not had to go through quite as many hoops. (06)

> From what I've seen of doctors this last year, I'm not impressed....I don't know whether it's the funding or there's too many people who have it, but I sure wasn't checked out properly....I feel like I fell through the cracks all the way down the line. If I go back in three months and they say I'm fine, I'm not gonna believe 'em because they don't check everything out and they don't see everything. If it can jump to my spine from my breast, I mean it can go anywhere. (03)

Fifth, by sharing control and being patient, health care professionals helped informants chart their own courses through the process of Maintaining the Hopeful Veneer and fostered their internal resources such as personal control and assertiveness.

> I think that they have a tendency to make you feel like it's a life and death matter. Right now you've gotta make that decision. Right now. Today is good but yesterday would have been better....I think that they have to just sit back and give people time to think about their treatments and like I said before, to get a treatment that you are happy with, that you are satisfied with too. That you understand what's happening to you. Don't rush into something that maybe isn't for you. Take the time to look into it. There's always more than one treatment....To a doctor maybe it's better but maybe that treatment isn't necessarily the best way for you....If they would just not press it so, don't make you feel as though you have to make that decision today because...you have to have time to think about it....In some ways you want the doctors to make the decisions for you but only to a point. You still wanna have a say in your treatment, and you want all these different avenues opened up to you. (01)

> They're so busy, but at the same time they're so caring...[and] they're very patient with you. You don't know what's all going on and maybe you ask a question that they've probably heard a thousand times in a week but they take the time, they answer it as best they can. (01)

Family, friends, colleagues.

Family, friends, and colleagues were often described as influencing informants' movement through the process of Maintaining the Hopeful Veneer. Colleagues included co-workers and fellow cancer patients. One informant described fellow cancer patients as "colleagues-in-arms." As with health care professionals, these people had the potential to be either resources or inhibitors in the process. Individual characteristics or actions that determined whether an individual was considered a resource or inhibitor are listed in Table 9. Being supportive was by far the most frequently cited and most important characteristics of these other resources. It is interesting to note that several informants considered themselves to be hoping resources for other individuals who were facing cancer or other forms of adversity. Being a resource to others helped increase their sense of meaning and purpose in life.

Table 9 Family, Friends, and Colleagues: Hoping Resources and Inhibitors

Family, Friends, Colleagues	
Resources	Inhibitors
Being supportive Being there	Being neglectful Abandoning, avoiding, blaming
Being empathetic, concerned Listening	Being oversympathetic
Being positive or optimistic	Being negative or pessimistic
Focusing on normalcy	Dwelling on the cancer
Allowing normalcy and independence	Being overprotective
Sharing similar experiences	Limiting self-disclosure
Gathering helpful information	Providing unsolicited advice
Letting you go at your own pace	Imposing own expectations

As can be seen in the Table 9, there was sometimes a rather gray line between those characteristics and actions that made individuals resources and those that made them inhibitors. To be effective resources, family, friends, and colleagues needed to be there for informants in ways that were sensitive and responsive to their needs for both independence and support, and for both dealing with the cancer and being normal. This was similar to the ways in which health care professionals needed to be there for informants, except that, in connections with health care professionals, there was more of an emphasis on professional help and competence rather than support, and on cancer rather than normalcy. Despite these differences, the ways in which connections with these other human resources influenced the process of Maintaining the Hopeful Veneer were much the same as those described for connections with health care professionals.

The importance of support from friends and family members was frequently emphasized by informants. One man said his wife "should get a medal" and described her as "very supportive," "a real trooper," and "more than anyone could ask for." Another man said that support from his family was "fabulous as far as giving hope" and that it may have more effect on his hope than he gives it credit for. Additional comments included:

> I was able to sit there and deal point blank and if I wanted to sit down and have a cry I could....If I wanted to sit with my wife -- she was always there -- and just have her hold my hand for a while and sometimes just lie with me and stuff when I was feeling the nausea from the chemo, that was always available to me. Friends. I was always able to go with them or have them visit and get buoyed by that whole thing. (06)

> You always need support, always. My husband was very supportive because he didn't know any more than I did about the cancer or the treatments and yet when I had decided that I didn't want this mastectomy, he didn't fight me or he didn't say to me, "Well, the doctors know what's best for you." He just let me make my own choice and I was really really glad of that. And not only did he let me make my own choice but he worked at it with me, he did research with me, and he tried to help me, encouraged me along this line of thinking. That really helps. Your family, your friends, they're all very supportive. (01)

When informants perceived that family members or friends abandoned them, were neglectful, or blamed them for having cancer, these people inhibited forward movement through the process of Maintaining the Hopeful Veneer.

When I first got cancer, she [my daughter] got very angry.....She's 15....My son

> kind of denied it -- pretended it didn't exist. He's 16. And my daughter just got very angry with me because I wasn't fit. I wasn't the strong one in the family anymore. (03)

> Christmas Eve, they [husband and kids] went to my husband's aunt's and I stayed home by myself and cried a lot that night. (03)

> [My brother] open[ed] up this whole discussion about how pathetic I was, and that was the word he used. And then he sort of blamed me for having a recurrence of cancer. (06)

Most informants described support in global terms or referred to an emotional type of support. A few others emphasized the importance of instrumental types of support, or "the practical help things." These types of support included making meals, looking after a vehicle, and paying bills. Instrumental support was provided by family, friends, and also by colleagues.

> My co-worker in Ottawa...has taken it upon herself to be absolutely rabid about money for me. So she's taken it upon herself to make sure I got sick leave....[She is] walking my long term disability through the system. Like this is HER responsibility. That's what SHE'S gonna do for me is make sure that everything gets done financially. (02)

As mentioned above, other cancer patients were also viewed as colleagues and were potential resources in the process of Maintaining the Hopeful Veneer. The benefits of making connections with other cancer patients were often described in terms of mutual support.

> So we [informant and friend with cancer] go and we visit there [at Bingo] and have a good time and kind of forget tomorrow....Support groups like that is great because we kind of boost each other up. We know we're both not well and when we first met we both were reasonably well....Seeing her, the way she is, kind of makes me feel like well, if she can do it, so can I. And I guess it's the same for her. (03)

> You talk to different patients and...you have that common bond between you that you don't have with anyone else because they know what you're going through. Your husband doesn't really know, your kids, your family, they don't.....So...even if you just say a few words to one another, sometimes that has more meaning than talking to a family member for half the day. (01)

Family, friends, or colleagues who helped informants gather information and/or provided information from their own experiences with illness, were usually viewed as valuable resources. Several informants identified friends, such as research scientists, librarians, or journalists, who were particularly instrumental in facilitating their processes of gathering information. Informants also emphasized the benefits of hearing about the illness experiences of others.

> Another colleague had a triple bypass about two years ago and they thought they were going to have to do another one.....[He had] a sense of being cut off before one should have to be....He had a sensitivity as to what I was going at, different than what other people who haven't quite looked down the old barrel have had on it....It's useful to have these people's comments and, in some ways, they've been the important ones. I appreciate, of course, other people's efforts but it's been the people who have been there that you appreciate [most]....I guess it's the sense that you're not alone or isolated in doing this kind of thing. (04)

There were some situations, however, where individuals were viewed as unhelpful in their attempts to share information. These situations were described in the section on appraising in Chapter 6 and include: a stranger providing unsolicited advice, a family member providing information from an unreliable source, and a cancer patient describing an experience unrelated to that of the informant.

In terms of emotional support, others who were empathetic and good listeners were seen as resources, while those who were oversympathetic inhibited forward movement through the process of Maintaining the Hopeful Veneer.

> My wife has been very good. Obviously concerned but not overly frothy or frilly which would probably have a very negative reaction on me, that kind of behaviour. And there's a few people who've meant well who have attempted that a little bit and I've had to discourage it quite quickly. (04)

> The hardest thing for me is when I first see friends that I haven't seen, I've maybe talked to them on the phone or something but I haven't seen [them]. The look in their eyes, the sympathy and the pity, it just kind of blows me away. I can't take it. (03)

One informant described how others who were good listeners helped him identify the hopeful signs or "positive elements" in his story.

> [When] people ask how [I am], they're getting a half an hour discourse. Obviously, it's probably good therapy for me -- articulating it and making it conscious and mapping it out. And I suppose somewhere in that story I also get to identify what I think are the positive elements of it. (04)

As with health care professionals, family, friends, and colleagues who demonstrated a positive, optimistic attitude were assets in the process of rebuilding hope. They helped informants see or connect the hopeful signs, redefine objects of hope, and envision a positive future.

> When I was diagnosed and during the very bad time before the surgery, Jason still continued to get the hiking books, look at the maps, talk about all the same stuff we always had, make me look at mountains and ways up mountains and that kind of thing and Tom continued to do the, "So what are we gonna do at our summer camp that we direct together?" (02)

Those individuals who focused on and allowed normalcy, as opposed to those who dwelled on the cancer and were overprotective, were seen as resources, particulary in terms of facilitating successful re-engagement in life.

> Normality is more what I would look for. Normalness in routine....People try and make me into an invalid. I hate that. My Mother didn't want me to wash dishes. Well excuse me, but I like washing dishes. Don't make me be an invalid before I have to be one. Don't make me fight for everything I have to do because then I not only have to do it, which might be a little harder than usual, but I also have to FIGHT to GET to do it and that's very very hard....People worry always about you're doing too much. I'm sorry, I don't believe people die from overwork....Let ME ask if I need help but don't try and force me. So I find people who were trying to force me not to do my regular things are annoying and very unhelpful. And LOTS of ordinarily helpful people fall into that trap....People who are allowing me to be normal are VERY very helpful, allowing me to go about my business. I'm really annoyed they had an executive meeting...at a different time than usual and they didn't tell me. And so I didn't go....How dare they? I'm the Vice President. I chair the meetings. And yet their way of being helpful was just to leave me alone -- not helpful. Not helpful at all. It would have been much better if I had been there chairing the meeting. That would have been the place to be, the place where I belong. (02)

> If you are trying to not let cancer just deal every card in your life, if you are trying to put cancer in its place,...and go on with life, it's very hard when your family thinks that you should be taking it more seriously. It's not that I don't take it seriously. It's just that I don't want it just to be my every thought. (01)

In a similar vein, other people, particularly family and friends, who allowed informants to progress through the process of Maintaining the Hopeful Veneer at their own pace rather than imposing their own expectations were also seen as resources.

> My mother [was] perturbed that I wasn't upset....She kept accusing me of hiding it from her....And then...people expected me to get better faster than I

> did and I found that fairly annoying. People just need to kind of let you take your own time. I don't really know how they do that. They just kind of accept the way you are, let you talk when you want to and not talk when you don't want to....I think they need to pick up their cues from what you say....Just let me do what I want to do and don't worry about it if it's right or not....Let me run on my own speed. Take my own time. (02)

Other external resources.

Other external resources in the process of Maintaining the Hopeful Veneer included God or a Higher Being, pets, and treatments. The importance of God or a Higher Being as a resource was alluded to in the section on spiritual beliefs and was described further by the following informant.

> Family and friends, they're supportive, but they can only be to a point. And, at that point, it's you and your Creator and you're on your own. I really feel very bad for people who don't believe in a Superior Being because I wouldn't want to only have the medical minds of the world today to rely on for help because try as they do, there is so much to deal with, there's so many questions unanswered, so many things that they can't do. I'm glad that I have a faith, that I can see that there is someone superior to the people who are all the medical minds of the world who one day MIGHT help us. (02)

One informant described and demonstrated close connections with her pets and identified them as a source of support and a positive influence. This was the same informant who evidenced a lack of support from her family.

> Even the dog senses somethin's weird. She seems a lot more, I don't know, gentle and loving. When I took off my neck brace, right away when I bent down, she snuggled her head in here [points to side of neck] 'cause I mean with that neck brace I couldn't even hug anybody which was worse. 'Cause you need lots of hugs and you're strapped in that thing. (03)

> She [cockateel] chirps and chatters....[She] lifted our spirits at Christmas time. That's for sure. She was crazy. You know, funny little characteristics and mannerisms. (03)

Cancer treatments were another external resource of importance in the process of rebuilding hope. While aspects of treatments were described as hopeful signs in Chapter 6, the treatments themselves were also viewed as resources, particularly when informants had confidence and faith in their effectiveness. When informants did not have confidence in the effectiveness of treatments and/or experienced disruptive side effects, treatments were sometimes viewed as inhibitors in the process of Maintaining the Hopeful Veneer. The two informants below viewed surgical treatment as an inhibitor rather than a resource.

> They've proven that...[when] they open you up, and maybe a lot of it is just the air getting at you, but I've heard from different people that having surgery spreads it faster. (03)

> Like I remember my aunt[s] saying to me, [both of whom had bilateral mastectomies for breast cancer], "Oh, we wish we never had been operated on. It seems like after you're operated on it just spread so wildly." Now maybe that's just an old wive's tale, we don't know. But, you know, these things flash through your mind. (01)

Facilitating and Inhibiting Hoping Contexts

Contexts also facilitated or inhibited movement through the process of Maintaining the Hopeful Veneer. If one considers the metaphor of rebuilding, the context is like the environment for rebuilding. When one sets out to rebuild, a level, firm surface upon which to build and fair weather would facilitate the process, while uneven or soft terrain and inclement weather may inhibit it. Similarly, once the veneer is rebuilt, environmental conditions such as storms or earthquakes would destabilize the structure, while fair weather would make reinforcement an easier process. The contextual factors that facilitated or inhibited movement through the process of Maintaining the Hopeful Veneer are listed in Table 10.

Table 10 Hoping Contexts: Facilitators and Inhibitors

Hoping Contexts	
Facilitators	Inhibitors
Few concurrent stressors	Multiple concurrent stressors
Minimal uncertainty, Control	Extensive uncertainty, Lack of control
Purposeful, meaningful existence	Lacking purpose or meaning in life
Future plans and goals	No future plans or goals
Positive past experience, Success	Negative past experience, Failure
Positive atmosphere	Negative atmosphere

Concurrent stressors

Informants who were dealing with multiple stressors in their lives had greater difficulty rebuilding the hopeful veneer when faced with recurrent cancer than did those who had fewer concurrent stressors. The presence of multiple stressors seemed to drain the informants' time and energy, thereby decreasing the time and energy available for dealing with the recurrence and moving forward in the rebuilding process. Concurrent stressors included financial concerns, household chores, "personal problems," conflict, caring for a disabled child, and the death or serious illness of a family member or friend. The informants below described their perceptions of the number of concurrent stressors in their lives.

> I've had my share of [stress] over the last 10, 15 years with my daughter and stuff. And with my husband's profession, you never know if he's gonna get a pay cheque or if the bills are gonna be paid in the next three months. You're always kinda livin' on the edge that way....Financially this year it's tough because my husband hasn't been workin'....We went through all my savings this year.....And my daughter has not made life easy. She's mentally disabled. More behavioral-wise rather than physical....and she's got a very very powerful dominant personality. And I don't. I'm a giver inner. I'd do anything for peace and I hate fighting....And we've had a lot of fights in this house. The kids have more than anything. It breaks my heart that they can't get along. (03)

> I have a sort of pleasant, easy kind of life. I don't have a whole lot of major problems. I don't have children and I don't have any problems with drinking or drugs or violence. My mental health is reasonable. So, you know, I have a sort of a straightforward, pleasant life. (02)

Another informant described how he was fortunate enough to have all his "encumbrances" removed so that he could "deal with things every step of the way."

> I've been fortunate enough to be able to sort of deal with things every step of the way where all of my encumbrances were removed. I didn't have to work. I got the full cheque. I didn't have any household responsibilities. They were immediately lifted from me because of friends, family, wife, everybody else. So I was basically in a really enviable position and I see other people who have cancer and I know that they are still goin' through these day-to-day routines. "Oh, gotta get the garbage out. Look we've gotta shovel."...I think some people are not in necessarily as enviable a position.....It was all lifted off my back and I was able to sit there and deal point blank. (06)

The latter informant also described the importance of taking a vacation before entering cancer treatments, if at all possible. He firmly believed that, in so doing, one is able to reduce the number of concurrent stressors in one's environment and, hence, more readily rebuild "inner strength," "go through all the morbid stage, and...start to build hope."

> I couldn't start this whole process at a better time -- coming off three weeks vacation as opposed to coming off a busy period at work....I knew that the vacation would be a hope-building process....It's the vacation time that you need to go and clear your head, rebuild your strength, physical and mental, and prepare....You use it to prepare yourself and to get through a certain stage. You go through all the morbid stage and then you start to build hope and then people and family help you with the process....It was good timing....It's funny. They talk about real estate being location, location, location. Well, maybe cancer treatment is timing, timing, timing. So I mean it helped that I was feeling good and not too stressed out. (06)

Uncertainty and Control

Contexts wherein informants perceived a great deal of uncertainty and, hence, a lack of control, were those that inhibited forward movement through the process of rebuilding hope. As described in the section on reframing in Chapter 6, when informants perceived their situations and their futures to be very uncertain, the grounds for hope were unstable and informants were less able to reframe visions of self and future or redefine objects of hope. Hence, they were also less able to move forward and re-engage in life. When uncertainty was decreased and control regained, informants were able to move forward.

Purposeful Existence, Future Plans and Goals

If informants experienced a recurrence of cancer in the context of a purposeful, meaningful life with established plans and goals for the future, they were better able to rebuild the hopeful veneer and re-engage in life than if they lacked meaning, purpose, plans, and/or goals. Having a sense of purpose and future plans and goals gave informants reasons to rebuild the hopeful veneer, get back to actively engaging in life, and stay out of the lower level of reality. They were needed, they had things to accomplish, and they had something to look forward to. "There was life on the other side." When asked what helped him stay on the upper level of reality, one informant explained:

> Well, I think the nature of my work tends to be longer term. It isn't a bunch of little things that are done in a day. It's longer term, requires a little planning, a little scheduling. There's a variety at work, I do as much golf as I can, [I have] a social life which isn't onerous but it's still active. And so I think there's things that automatically extend you into future horizons by the very nature of the activities and there's a variety of them without at the same time being demanding....I can see people if they just have, for lack of a better term, mundane activities of a very immediate nature, very little tie in to future events, then maybe they're going to spend a little more time in the other reality. Maybe the nature of my work, the nature of my other activities and my social activities, maybe they tend to keep me pulled out of that reality and just automatically orient me in this other direction....I can see maybe if a person was retired and had a very limited field of action and interest, then this kind of circumstance would maybe be more trying on them. (04)

Another informant described a marked improvement in this type of context on first recurrence as compared to initial diagnosis.

> [The recurrence] was easier because my personal situation was MUCH different. I didn't have to worry as much about money. I had much more personal support. I had a place, job to go back to, so there was sort of something to look forward to to spur some recovery whereas before there was nothing, NOTHING to get better for, except maybe rebuilding a life which had sort of collapsed....But this time I had a good life. And it didn't collapse, it continued. And there were some things to look forward [to]....So there was life on the other side. I wasn't sure I was gonna get there but there was something to get to. (02)

Past Experience, Success

Informants' past life experiences were particularly influential contexts in the process of Maintaining the Hopeful Veneer, particularly in the stage of rebuilding. If informants had a history of positive, successful experiences, as opposed to negative experiences characterized by failure and defeat, they were better able to rebuild the hopeful veneer and redefine objects of hope. In addition, they had more confidence in their ability to re-engage in life and attain these objects of hope. These experiences seemed to directly influence the capacity of informants' internal resources, particularly inner strength and positiveness.

Influential past experiences included general life experiences and those specifically related to cancer. In discussing the influence of general life experiences, one informant stated:

> The process of creating hope -- ....I suppose how people do it is a function of...their life to this point and how they've handled their life and then this comes along and you're gonna get some people, I think, handling it...very effectively. They make it through the early stages very, very quickly and get on with it. There are gonna be other people that wallow in the attention getting and everything else there and I think even when they get on to the next stage, some of them may never get beyond it, and even if they get to the next stage, they're just not going to be able to create the same kind of hopeful process for themselves. (04)
>
> For people who haven't had those kinds of positive experiences I can see it being a real bummer for them. (04)

In terms of past experiences with cancer, informants' experiences of initial diagnosis and treatment were of particular influence.

> It's the same fear that...I had before. It's just come back. But unfortunately the feelings that have come back with it are the nightmare things -- the being alone and isolated and trapped, the nightmare of the being so sick and alone. So what I'm having is waves of those things just sweeping over me. And I don't know how to deal with that. Anger -- that it was so bad. I remember the chemotherapy. I mean I can feel it. I can FEEL when they were taking blood. That whole nightmare seems back. It's like this purgatory revisited. Is it gonna be like this again?....Boy..., your previous experience impacts so much. I just can't get over all that crap. That's what haunts me. (02)
>
> There's a connection between having that hope this time because I had such a good outcome last time. (05)

Whether the initial cancer experience was characterized as positive or negative, a success or failure and, hence, how it influenced the ability to rebuild the hopeful veneer on recurrence, depended to a large extent on informants' interpretations, that is, their ability to see or connect the hopeful signs. When reflecting on her past experience with cancer, one informant explained the importance of looking for hopeful signs or signs of success:

> [Hope is] entirely internal. It comes from fighting the battle and winning. And I don't really think there's anything external that can help you with that. I think you have to face, some demons you just have to face on your own. People could be comforting but I don't think you can get hope from anywhere except inside. And you just do that by being successful in whatever way that

> might manifest itself. For example, last time I might say that I wasn't successful as fast as this time but maybe [getting] through the chemotherapy is successful and so that's a victory, and then you move on to the next....step. [You get] through radiation and then you get through the six month CAT scan. (02)

Also of influence were past experiences with others who had cancer, particularly close family members. The more negative and unsuccessful these experiences were, the more difficult it was for informants to envision a positive future for themselves.

> Cancer isn't something that's strange to me because it's been very prevalent in my family. I've had three aunts die from it, a mother die from it, and just recently, I had a fourth aunt that's come down with brain tumour. It started as breast cancer. In all cases except my mother's it was all started as breast cancer and they advanced to other stages. (01)

Atmosphere

The final category of contexts is atmosphere. Those atmospheres perceived as positive in some way were facilitators and those perceived as negative were inhibitors in the process of Maintaining the Hopeful Veneer. Two informants commented on the influence of the brightness or warmth of an atmosphere or environment.

> But hope, no you go through hope. It depends on the time of day. In the morning if it's sunny, I have hope. At night if I'm alone and everybody's out, I don't....I think a lot of it is this time of year you're house bound. The nights are long [and]....it's cold and dark all the time....It was easier to go through this in the summer. (03)

> It could be something external....that kicks you out of it [lower level of reality]....It's sunny out so I just won't be sad. (02)

One informant commented on the atmosphere at the cancer clinic and the positive impact this had on patients.

> It's the atmosphere. It pervades the [cancer clinic] and I wish I could package it and ship it out. I don't know what it is, but I've had a LOT of experience with the [cancer clinic], a lot of nursing units, a lot of out-patient. I've been in every department in that place. I've been in nuclear medicine....They're all the same. Where do they get it from? What, what is that? It's not at the [acute care hospitals],...it's not anywhere else I've ever been. Where does it come from? If anybody could figure that out, they could make lot of people awfully happy. (02)

The Significance of the Hopeful Veneer: Being Galvanized

Presented in this section are findings relating to the research question: "What is the significance of hope for the individual with a first recurrence of cancer?" Given that informants' hope was conceptualized as a hopeful veneer that required rebuilding after experiencing a cancer recurrence, the question became: "What is the significance of the hopeful veneer?" or "Why rebuild?"

The answer to this question lies in the informants' descriptions of the two levels of reality. As the reader will recall, informants described upper and lower levels. While functioning in the lower level, one's mind is overwhelmingly flooded with thoughts and feelings regarding the cancer and its negative implications. As a result, one is unable to actively engage in life and disengages from normal patterns of living, roles, and/or relationships. A sense of inertia and suffering prevails. While functioning in the upper level, one is able to keep thoughts of cancer at the back of one's mind and actively engage in life, thereby focusing on health and living and leading a meaningful, purposeful life despite having cancer. A sense of activity and purpose prevails. Separating these two levels of reality is a veneer of hopefulness. Staying in the upper level is dependent on successfully maintaining the integrity of this veneer, including rebuilding it after an erosion. From this conceptualization, the significance of the hopeful veneer is readily apparent and may be summarized in terms of being protected and energized or, in a word, galvanized.

In terms of protection, the hopeful veneer prevents one from falling down to a lower level of reality where one is engulfed in suffering, disengages from life, and may give up. The veneer protects one from continually confronting the frightening possibilities inherent in a cancer diagnosis and, even more so in a diagnosis of cancer recurrence. As an alternate conceptualization, the hopeful veneer may be viewed as the barrier that holds thoughts of the cancer and its implications at the back of the mind. In terms of the energizing function, maintaining the integrity of the veneer provides one with the energy to move forward and actively engage in life.

As a consequence of being galvanized, informants were able go on with living and enjoy a good quality of life. They also believed that, by being protected and energized, they would be better able to deal with their cancer and their prognoses may improve. One woman described hope as "a cushion to help you deal with your disease." Others described the significance of hope as follows:

> Hope and a good mental attitude can help you to perhaps contain the disease a little while longer so that it doesn't catch up with you....If you can control your mind and not let yourself...become so negative about it then you have a better chance because if you're feeling good emotionally, then I think you do better health-wise too. The body's more able to fight....If I have a good mental attitude I think that's really half the battle in dealing with cancer....Maybe with a better mental attitude you can delay that death sentence just a little bit longer....And even if it doesn't,...if I have a good attitude at least I'm enjoying my life to the fullest right now. (01)

> A lot of people talked about how plucky my spirit was the first time....I can't tell you how many people said, "Well, you've got the right attitude and it's that kind of attitude that'll beat this thing." (06)

> I think it's imperative to have hope....I guess even scientists have proved that there's a correlation between that and the immune system. The people who...are either very scared of it or very pessimistic about it...do NOT have [as high a] survival rate as the ones who are gung ho and very optimistic....I'm sure that the positive attitude and a gung ho attitude helps the treatment. (05)

In addition, informants identified that, if they rebuilt the hopeful veneer and functioned in the upper level of reality, it would be easier for health care professionals, family members, and friends to support them.

> I also think that if you're hopeful and optimistic, not only does the person who happens to be the patient have a lot easier time, but it's one heck of a lot easier for family members and other people to be around you, to support you. (05)

> I'm a fairly social person, a fairly astute observer of the social scene. People are interested, people are curious, but there's a point at which they have limits to it. And so if you become self indulgent. . . Even the health care workers that had to work with them. You see the difference in the x-ray technicians in handling the blue funk kind of person.... -- it was a drain on them -- as opposed to the person who can take a more positive aspect. So, it's just one of these things you see and you observe and make your choices of which side you're comin' down on. (04)

Summary of Findings

In this thesis, the nature and significance of hope for individuals experiencing a first recurrence of cancer has been described in terms of a hopeful veneer that is protective and energizing and varies in strength or thickness and stability over time. This veneer provides one with the energy to stay in an upper level of reality, actively engage in life, and use conscious denial to push thoughts of cancer to the back of one's mind. It also protects one from falling to a lower level of reality where one is overwhelmed by suffering, disengages from life, and may give up.

When one experiences a first recurrence of cancer, one falls to the lower level of reality and must engage in a process of Rebuilding the Hopeful Veneer in order to return to the upper level. This is a dynamic process involving the identification of grounds for hope, the redefinition of objects of hope, and the reframing of self and future both realistically and positively. Once the veneer is rebuilt, one is protected and re-energized to actively re-engage in life. While functioning on the upper level, one re-establishes normalcy and lives differently in an attempt to reinforce the veneer. In addition, one regularly monitors the thickness and stability of the veneer, the results of which determine whether the veneer is further reinforced or in danger of subsequent erosion. The combination of rebuilding, reinforcing, and monitoring activities comprises the process of Maintaining the Hopeful Veneer throughout the cancer experience.

Movement through the process of Maintaining the Hopeful Veneer is influenced by several factors, including signs, resources, and contexts. Signs are viewed as hopeful or ominous and are related to cancer, treatment, and health. Resources are internal and external to the individual. Internal factors that facilitate Maintaining the Hopeful Veneer include positiveness, inner strength (courage, determination, assertiveness, self-confidence, self-reliance), spiritual beliefs, health (energy, physical strength, comfort), knowledge, and self-awareness. External resources include health care professionals who make connections and share control, and are competent, frank, compassionate, patient, positive, and respectful; family, friends, and colleagues who listen, focus on and allow normalcy, share experiences, gather information, and allow one to go at one's own pace, and who are supportive, empathetic, and positive; God or a Higher Being; pets; and treatments. Maintaining the Hopeful Veneer is facilitated if it takes place in the context of few concurrent stressors; minimal uncertainty; a positive atmosphere; past success; a purposeful, meaningful present; and a planned future.

Through the process of Rebuilding the Hopeful Veneer, informants were able to deal with the negative implications of the recurrence, reframe their circumstances and futures positively, keep thoughts of the cancer at the back of their minds, re-engage in their lives, and thereby improve the quality of their lives.

CHAPTER 9

DISCUSSION, IMPLICATIONS, AND REFLECTIONS

In this final chapter, I compare the findings from this study to those in the literature, identify implications for nursing practice and research, and share my personal reflections on the research experience.

Discussion of Findings

The purpose of this study was to explore the nature and significance of hope and the factors that influence hope in individuals experiencing a first recurrence of cancer. As described in Chapters 3 and 4, emerging findings revealed the need to expand the original research focus to include the nature of processes to rebuild and maintain hope, in addition to the nature of hope itself. Using an inductive approach, hope was conceptualized as a protective, energizing veneer that varied in strength and stability throughout the cancer experience and was eroded by the news of first recurrence. By rebuilding and maintaining the hopeful veneer, informants were able to actively engage in life, keep thoughts of the cancer at the back of their minds, and avoid being overwhelmed by suffering. An exploration of hope and/or the processes of rebuilding or maintaining hope in the context of recurrent cancer has not previously been reported in the literature. Therefore, these findings represent a unique contribution to the body of literature on hope, the processes of rebuilding or maintaining hope, the cancer experience, and the experience of recurrence.

Given the paucity of research on hope-related processes in the oncology population, I conducted a secondary review of a wide range of theoretical and empirical hope literature once I finished analyzing the data. This literature supplemented that found during the initial literature review conducted at the beginning of this study. In this section, I compare the findings from the present study to the reviewed literature regarding the factors that influence hope or hope-related processes; the nature of hope-related processes, particularly processes for maintaining or re-establishing hope; and the significance of hope. In addition, I compare findings in this study regarding realistic and unrealistic hope, and hope and denial, to perspectives in the literature.

Factors that Influence Hope or Hope-Related Processes

In the present study, factors that influenced movement through the process of Maintaining the Hopeful Veneer were conceptualized as hopeful and ominous signs, hoping resources and inhibitors, and facilitating and inhibiting hoping contexts. The identification of factors that influence hope has been a predominant focus of both quantitative and qualitative hope research. Hence, hope has primarily been conceptualized as a dependent variable.

In quantitative research, instruments that purport to measure the level of hope or hopelessness have been used to demonstrate relationships between hope levels and other variables in individuals with cancer. The direction of these relationships is not always clear. Variables found to positively correlate with a high level of hope (or low level of hopelessness) that are congruent with facilitating factors in the present study include spiritual well-being (Mickley, Soeken, & Belcher, 1992); strength or helpfulness of religious beliefs (Brandt, 1987; Herth, 1989), personal control or internal locus of control (Brandt, 1987; Brockopp et al., 1989), preference for active involvement in treatment decisions and detailed information (Cassileth et al., 1980), and performance status or degree of normalcy (Cassileth et al., 1980). In addition, hope level has been negatively correlated with uncertainty (Christman, 1990; Mishel et al., 1984), interference with family role responsibilities (Herth, 1989), and fatigue level (Herth, 1992, 1993).

Using qualitative methods, several researchers have explored the factors that influence hope or hoping in individuals who are terminally (Herth, 1990), critically (Miller, 1989), or chronically (Nekolaichuk, 1990; Raleigh, 1992) ill, as well as in individuals with cancer (Dufault, 1981/1982; Owen, 1989) and caregivers of individuals who are terminally ill (Herth, 1993). Substantial overlap exists between findings in these studies and those in the present study. For example, in Herth's

(1990) study of hope-fostering categories for the terminally ill, points of congruence were noted in terms of internal resources (courage, determination, lightheartedness, spiritual base), internal inhibitors (uncontrollable pain and discomfort), external resources (interpersonal connectedness, affirmation of worth), external inhibitors (abandonment and isolation, devaluation of personhood), and hoping contexts (attainable aims). It is interesting to note the wide variation in terminology used to label these influential factors. For example, factors labelled as internal hoping resources in the present study has been variously labelled as parts of the hoping self (Nekolaichuk, 1990), hope sources (Dufault, 1981/1982), or hope-fostering or inspiring categories (Herth, 1990; Miller, 1989). It is also evident that many of the factors I have presented as influencing one's ability to maintain hope have been defined by others as critical attributes, elements, or dimensions of hope itself. For example, Miller and Powers (1988) identified interpersonal relationships as one critical element of hope, whereas, in the present study, these relationships were viewed as potential resources or inhibitors in the process of maintaining hope. Also, Dufault's (1981/1982) description of a contextual dimension of hope includes many of the facilitating or inhibiting contextual factors identified in the present study.

The contributions of the present study in the realm of influences on hope and hope-related processes are twofold. First, the categorization of factors is more extensive than that presently in the literature. A schema distinguishing hopeful and ominous signs, internal and external resources and inhibitors, and facilitating and inhibiting contexts has not previously been reported. Second, only two other studies were found where influential factors have been placed within a larger coherent framework of the process of hoping or maintaining hope, neither of which as extensively as in the present study (Dufault, 1981/1982; Nekolaichuk, 1990). These contributions enhance the potential for more effective facilitation of the processes of maintaining and/or re-establishing hope.

The Nature of Hope-Related Processes

Informants in this study described a dynamic process whereby they maintained the hopeful veneer throughout the cancer experience. In times of relative wellness, the veneer was maintained through reinforcing and monitoring strategies. When faced with a recurrence or another serious setback, the veneer was eroded and the strategies of appraising and reframing were used to rebuild it. During the process of rebuilding, informants found new grounds for hope and redefined objects of hope. Hence, the process of rebuilding included not only the re-establishment of hope, but also its transformation.

The process of maintaining or re-establishing hope in individuals with cancer has not been a major focus of research in nursing or other allied health disciplines. Only six studies were found wherein the researchers specifically examined the processes of hoping, maintaining hope, or re-establishing hope, three in individuals with cancer and three with other populations. All of the studies used inductive, qualitative methods. Populations in these studies included adults undergoing bone marrow transplantation for leukemia (Ersek, 1992b); elderly individuals with cancer (Dufault, 1981/1982); adolescents with cancer (Hinds & Martin, 1988); men with human immunodeficiency virus (HIV) disease (Hall, 1990); individuals with chronic illness, including cancer (Nekolaichuk, 1990); and children with disabilities and their parents, teachers, and therapists (Wright & Shontz, 1968). Striking similarities were found between findings from these studies and those from the present study.

Findings from the study by Ersek (1992b) are highly consistent with those from the present study. Ersek delineated a Dialectic of Maintaining Hope that comprises a synthesis of the two antithetical strategies of Dealing With It and Keeping It in Its Place. In this dialectic, hope is maintained by limiting the threat, while also acknowledging it. While not presented as a dialectic per se, this view of maintaining hope is congruent with findings from the present study. In order to rebuild hope, informants had to deal with the recurrence and its implications both emotionally (during disengaging) and intellectually (during appraising and reframing). During appraising and reframing realistically, they acknowledged the threat of the recurrence and, through finding hopeful signs and reframing positively, they minimized the threat. By dealing with the cancer in these ways, they could push the cancer to the back of their minds or put it in its place. Keeping it in its place, or maintaining hope, was further facilitated through the ongoing strategies of monitoring and reinforcing, whereby potential threats continued to be acknowledged, monitored, and further minimized.

Although components within Ersek's (1992b) process are not entirely consistent with those in the present study, there is considerable overlap. The process of Dealing With It is comprised of four components: appraising the illness experience as a threat and monitoring reality, allowing the emotional response, working through it, and moving on. These roughly correspond to the following components in the process of Maintaining the Hopeful Veneer: appraising or monitoring, reeling, reframing, and actively engaging. Interestingly, the order of the first two components is reversed in the two processes. Given that both processes are intended to be nonlinear, however, this may be an insignificant difference.

Ersek (1992b) depicted the process of Keeping It in Its Place as an expansion of the third component in the process of Dealing With It (working through it). Strategies identified as part of Keeping It in Its Place are comparable to many of those described in the present study as part of reframing positively, re-establishing normalcy, and living differently. For example, Ersek's (1992b) list of strategies includes: seeing the disease or treatment as a positive influence, making downward comparisons, not dwelling on it, keeping distracted, and restraining the disease through exercise, diet, or stress management.

One aspect of the process of Maintaining the Hopeful Veneer that does not appear to be reflected in the Dialectic of Maintaining Hope is that of the transformation of hope. In the present study, informants found new grounds for hope and redefined their objects of hope during the rebuilding process. Although she did note that informants in her study perceived the illness and treatment to have "the potential to result in loss, including death" (p. 885), Ersek (1992b) did not comment specifically on how this perception altered the nature of their hope.

Given that Ersek's informants included both those in remission and relapse, it is possible there was less consistency in this aspect of her findings than in the findings from the present study.

The process of Maintaining the Hopeful Veneer also complements parts of the Self-Sustaining process delineated by Hinds and Martin (1988), although not as extensively as the one just described. Hinds and Martin described four phases: cognitive discomfort, distraction (replacing the disruptive thoughts), cognitive comfort, and personal competence, through which adolescents with cancer achieve hopefulness. Elements of disengaging and reframing realistically are evident in the phase of cognitive discomfort, elements of reframing positively and re-establishing normalcy are included in the phase of distraction, and elements of actively engaging are represented in the phase of cognitive comfort. The phase of personal competence is not reflective of the findings from the present study. Interestingly, the strategy of conscious denial used by informants in the present study is reflected in three of the four phases of the Self-Sustaining process, being labelled thought-stopping, cognitive clutter, and forgetting cancer. The Self-Sustaining process differs from the process of Maintaining the Hopeful Veneer in three ways. First, in contrast to the cyclical, ongoing nature of the process found in the present study, the description and diagram of the Self-Sustaining process implies resolution. Second, as in Ersel 's (1992b) study, the transformation of hope was not described as part of the process. Third, Hinds and Martin (1988) referred to the strategies used in the phase of distraction as emotional-focused coping strategies. In the present study, as well as in others (Ersek, 1992b; Herth, 1993), these same strategies were considered strategies to maintain or foster hope.

A third hope-related process comparable to that in the present study was described by Nekolaichuk (1990). She delineated separate, concurrent processes of hoping and coping in the context of the uncertainty associated with chronic illness. The hoping process was entitled Maintaining the Hoping Self and includes three phases: assessing hope, strengthening the hoping self, and maintaining the hoping self. These phases globally correspond to appraising, rebuilding, and actively engaging, respectively. The stage of disengaging found in the present study is not reflected in Nekolaichuk's process, likely because it was viewed as an antecedent rather than an integral component.

For each phase in the process of Maintaining the Hopeful Self, Nekolaichuk (1990) identified potential changes in the hoping self, hoping resources and inhibitors, and objects of hope. Changes in the hoping self reflect some of the findings from the present study regarding living differently. For example, Nekolaichuk stated that, in the third phase of Maintaining the Hopeful Self, "there may be a shift in values and priorities towards the enjoyment of simple pleasures and greater self-care" (p. 145). Descriptions of changes in objects of hope in the face of uncertainty are also consistent with those described as part of reframing in the present study (e.g., setting realistic goals). Another interesting point of congruence was noted regarding the relationship between one's hope perspective and the impact of uncertainty on hope. Nekolaichuk (1990) stated:

> The impact of the uncertainty of a situation upon the hoping self is dependent upon one's hope perspective. For those who view hope on a continuum, their hoping may be inversely related to their level of uncertainty....For those individuals who view hope in terms of two spheres, general and specific, the hoping self is less dependent upon or influenced by external sources, such as uncertainty, hoping resources and hoping inhibitors. (p. 135, 136)

In the present study, the one informant who stated the recurrence did not affect his hope at all was also the one who clearly described having both a general and specific sense of hope. This particular finding is also supported by the work of Dufault (1981/1982).

Although strategies used in each phase of the process of Maintaining the Hoping Self are not extensively described in Nekolaichuk's (1990) research report, some overlap with strategies identified in the present study is evident. For example, comparison with others was identified as a strategy for both strengthening and maintaining hope in Nekolaichuk's study and as a strategy for reframing positively in the present study. It is interesting to note, however, that some of the strategies described by Nekolaichuk as integral to the process of coping, were considered integral to the process of maintaining hope in the present study. For example, reducing uncertainty by searching for a cure, measuring and monitoring, and developing a normal routine, were viewed as coping strategies by Nekolaichuk while, in the present study, they were viewed as strategies to reinforce the hopeful veneer. Thus, the issue of overlapping definitions and descriptions of hope-related processes and coping processes resurfaces.

Although hoping, maintaining hope, and coping are clearly interconnected, the relationship between these processes is a muddy one indeed. A positive correlation has been found between hope and coping or adjustment (Christman, 1990; Herth, 1989; Mishel et al. 1984), but the nature or direction of influence in this relationship is not entirely clear. Nekolaichuk (1990) and Jevne (1993) have described hoping and coping processes as separate, yet concurrent, and have identified hoping as a co-requisite to effective coping. Hinds and Martin (1988) presented coping strategies as a means to achieve hopefulness, and Miller and Powers (1988) identified coping as an element of hope. Hence, these researchers have implied that coping will influence hope. Others have postulated that hope and/or hoping are prerequisites to coping (Herth, 1989; Stotland, 1969; Weisman, 1979a) or are coping strategies or methods of coping (Chekryn, 1981; Craig & Edwards, 1983; Jalowiec & Powers, 1981; Korner, 1970; Miller, 1989) and, hence, have implied that hope and/or hoping will influence coping. As noted previously, it is also quite unclear as to whether certain strategies contribute to hoping, maintaining hope, or coping, and how one is to make these distinctions.

The process of coping was not a focus of the present investigation. Secondary analysis of the data would be required to extricate the process of maintaining hope from that of coping and elucidate the relationships between them. It is postulated, however, that findings from the present study would support the view that the processes of maintaining hope and coping are reciprocal, each reinforcing the other (Nekolaichuk, 1990). Informants stated that maintaining hope helped them to "handle" or "deal with" the disease, and also stated that having a sense of "handling it well" served to enhance their hope. It is also postulated that many of the strategies employed by individuals in a time of crisis serve multiple purposes, two of which are coping and maintaining hope.

A fourth hope-related process for comparison was found in the work of Hall (1990). While not presented as an ordered process per se, Hall's (1990) description of the process used by HIV positive men to re-establish and maintain hope confirms the components of the process of Maintaining the Hopeful Veneer and echoes the sentiments of the informants in the present study. After learning of their diagnoses, informants in Hall's study experienced periods of shock, anger, withdrawal, and giving up hope for the future. These periods are akin to the stages of disengaging and giving up in the present study. Like the informants with recurrent cancer in the present study, the HIV positive men were also successful in re-establishing hope. In contrast, however, they did not use information-seeking as a predominant strategy. Information about their disease resulted in further loss of hope. This mirrors the comment by informants in the present study regarding "a helpful area of ignorance." For the HIV positive men, hope was re-established through use of "affect-control strategies," wherein "they changed their outlooks, their attitudes, and their priorities for living" (p. 182), and thereby established a future vision and a zest for life. This description has obvious congruence with the strategy of reframing positively delineated in the present study. Both groups of informants were also congruent in their use of conscious denial and their focus on actively engaging in life. Hall (1990) stated, "None of these men wanted to deal with dying on a daily basis after his diagnosis any more than he did before his diagnosis" (p. 182).

A fifth hope-related process for comparison is that described by Wright and Shontz (1968) in their study of the hope of disabled children and their parents, teachers, and therapists. These researchers described adult hoping as comprising the cognitive task of reality surveillance and the affective tasks of encouragement, worrying, and mourning. These affective tasks were conceptualized as both products and instigators of attempts at reality surveillance. According to Wright and Shontz (1968), mourning occurs when hopes are given up or seriously modified.

"Forced by the intolerability of mourning forever, [however], the person eventually considers other possibilities on which to construct and nurture hopes" (p. 330). This is akin to falling to disengaging or giving up after an erosion of the hopeful veneer and then deciding to move upward. Reality surveillance is the means by which other hoping possibilities are considered and hopes are grounded in reality in order to enhance the probability of their attainment. This part of the process closely parallels the elements of appraising and reframing realistically in the present study. Encouragement is the affective component that results when grounds for hope are found. When the grounds for hope are uncertain, this results in worrying which, in turn, leads to the continuation of intermittent reality surveillance. The results of this surveillance may then be either encouragement and decreased worrying or mourning. This part of the process is highly similar to the stage of monitoring in the present study, as well as its consequences, that is, reinforcement or erosion of the hopeful veneer.

Wright and Shontz (1968) also described variations in the hoping process that fit with the variation observed in this study. According to these researchers, hoping varies "according to the manner in which the person copes with the problem of uncertainty regarding the realizability of his hopes" (p. 331). If one perceives there to be insufficient grounds for hope in the present reality, one may take several courses of action. First, one may spend additional time in reality surveillance in order to try to glean more support. In the present study, this course of action was reflected in informants' searches for additional hopeful signs to use in rebuilding the hopeful veneer. Second, one may ground hopes "in terms of possibilities that do not have to conform to the laws of nature" (p. 325). In the present study, this was evident in informants' reliance on bargains with God and in their efforts to find grounds for hope in the alternative health care system. Third, one "may rest from the strain of reviewing a troubling reality, temporarily pushing it out of his [*sic*] mind" (p. 325). This third course of action is clearly congruent with the strategy of conscious denial used by informants in the present study. According to Wright and Shontz (1968), reality surveillance may be postponed for a specified period of time or indefinitely. For informants in the present study, monitoring was often postponed until they attended follow-up appointments or until a specified period of time had elapsed (e.g., evaluation of hope for a cure after five years). In terms of an indefinite postponement, Wright and Shontz (1968) stated:

> Instead of timing the review of reality, it may be indefinitely postponed, not because one lacks sufficient information, but, on the contrary, because one knows enough to wish to avoid a fruitless confrontation with a frightening reality....Differentiation [of the future is] avoided. Instead, stress is put on the present. (p. 326)

While reality surveillance is indefinitely postponed, one lives one day at a time and maintains hope by concentrating on the meaning and value of the present. As Wright and Shontz (1968) stated, "Despair does not flourish when the present is bleak and the future is bright, nor when the present is bright and the future is held in abeyance" (p. 329). In the present study, descriptions of living differently to maximize the quality of life and to make the most of each day are congruent with this description of the indefinite postponement of reality surveillance.

The final hope-related process for comparison is that delineated by Dufault (1981/1982) in her study of the hope of elderly persons with cancer. Dufault defined the hoping process as "a dialectic between accepting and going beyond the limits of the present and past reality to future possibilities" (p. 292). This definition suggests a similar process to that identified in the present study and includes elements of both realistic and positive reframing. Dufault described hope as comprising two spheres, general and specific, and six dimensions. Although she stated that all six dimensions contribute to the hoping process, only the cognitive and behavioral dimensions appear to include process elements.

Process components of the cognitive dimension include: reality surveillance, reality grounding, and imaginative use of facts. Dufault's (1981/1982) descriptions of reality surveillance and reality grounding are virtually identical to those delineated by Wright and Shontz (1968). As such, they are also highly congruent with descriptions of appraising and reframing realistically in the present study. The similarity between *reality grounding* in Dufault's study and *taking inventory* in the present study is particularly noteworthy. Dufault described reality grounding as a process of sifting out and weighing the factors that promote and those that inhibit realization of hope objects while, in the present study, taking inventory was described as a process of balancing hopeful and ominous signs. Imaginative use of the facts is the third process component of the cognitive dimension in Dufault's model. According to Dufault (1981/1982), the function of this component is to permit "the belief that the boundaries of favorable possibility are wider than they might seem, and the boundaries of unfavorable possibility are narrower than they seem" (p. 290). This component thus mirrors the strategy of reframing positively in the present study.

In Dufault's (1981/1982) hoping process, components of the behavioral dimension succeed those of the cognitive dimension. These behavioral components are comparable to the stages of actively re-engaging and monitoring in the process of Maintaining the Hopeful Veneer. Dufault stated that informants in her study were "energized by their hope to cope in a positive fashion and continue living" (p. 293). She also described how they took action to achieve hopes and monitored progress toward attainment of hopes, the result of this monitoring being the maintenance, modification, substitution, or abandonment of a hope object. Actions taken to achieve hopes were comparable to those taken by informants in the present study when they were living differently.

Two additional points of congruence among the process delineated in the present study and in the studies by Dufault (1981/1982) and Wright and Shontz (1968) are of note. First, all three processes reflect the transformation of hope that occurs when grounds for hope are significantly altered. Second, in all three studies, reality grounding is described as a subjective, individual process. In other words, reality is defined from the perspective of the hoping person.

As one final comparison, it is interesting to note the similarities between the process of Maintaining the Hopeful Veneer and the Pathways Through Grief model developed by Martin and Elder (1993). These researchers depicted the grieving process as comprising an emotional component, characterized by denying, despairing, and detaching; and an intellectual and relational component, characterized by exploring, hoping, and investing. Entering the emotional component is described as an inward, downward journey and moving to the intellectual/relational component is described as an outward, upward journey. Hence, the diagram of the Pathways Through Grief model is shaped like a figure eight, with the emotional component on the bottom and the intellectual/relational component on the top. Movement up or down takes place through the assignment and redefinition of meanings. As is readily apparent, the emotional component closely parallels the stage of disengaging, exploring typifies the phase of appraising, and hoping and investing are comparable to the stage of actively engaging. In addition, the development of meanings shares similarities with the phase of reframing. Hence, the possibility arises that the process of Rebuilding the Hopeful Veneer after a recurrence of cancer may also be viewed as a process of grieving the losses associated with such a phenomenon. Conversely, the process of grieving may be viewed as comprising a process of rebuilding hope.

The Significance of Hope: Being Galvanized

In this thesis, hope was conceptualized as a galvanizing veneer that protects and energizes the hoping individual. The hopeful veneer acts as a barrier that prevents one from falling down to a lower level of reality where one is disengaged from life and engulfed by suffering. It may also be viewed as the protective barrier that holds thoughts of the cancer and its implications at the back of one's mind. When the hopeful veneer is intact, it provides one with the energy to move forward, go on with living, and actively engage in life. Informants believed that, by rebuilding the hopeful veneer, their quality of life would improve, they would be better able to deal with the recurrence, their prognoses might improve, and it would be easier for health care professionals, family members, and friends to support them.

The informants' beliefs and experiences regarding the benefits of maintaining hope are corroborated by findings in the literature. The energizing nature of hope and hoping has been widely recognized (Haase, Britt, Coward, Leidy, & Penn, 1992; Lange, 1978; Lynch, 1965; Miller & Powers, 1988; Nowotny, 1989; Travelbee, 1971). Hope has been described as an inner readiness and a not-yet-spent activeness (Fromm, 1968). Hence, once hope is experienced, activity becomes possible. This is in contrast to hopelessness or despair where the consequence is stagnation or inaction (Campbell, 1987). Whereas one must invest psychic energy in the hoping process itself, this initial investment results in the mobilization of more energy that is required for action (Jevne, 1991; Owen, 1989; Stotland, 1969). Jevne (1991) stated that "physically, people with hope report a greater sense of energy" (p. 151).

The role of hope in improving psychological well-being and quality of life is readily apparent in the literature (Frank, 1968; Haase et al., 1992; Stotland, 1969). Researchers have described hope as an ingredient necessary for enhancing the quality of each day and as a source of nourishment and enrichment until the time of death (Hall, 1990; Herth, 1990, 1993; Kubler-Ross, 1968). As described previously, hope has also been linked to effective coping as a prerequisite (Herth, 1989; Stotland, 1969; Weisman, 1979a) and co-requisite (Jevne, 1993; Nekolaichuk, 1990), hence substantiating the informants' belief that hope will help them deal better with their circumstances. Furthermore, maintaining hope, having a positive attitude, and hoping for a cure have been identified as keys to effectively coping with a cancer recurrence (Chekryn, 1981; Hanson, 1994).

In terms of prognosis, findings in the literature suggest that the most fundamental consequence of maintaining hope is continued existence. Hall (1990) stated that "hope is so vital to life that its loss is equated with loss of life itself" (p. 179) and Fromm (1968) described hope as "an intrinsic element of the structure of life, of the dynamic of man's [*sic*] spirit" (p. 13). Hope has been described as resulting in revival, renewal, perseverance, survival, and sustainment (Marcel, 1951; Menninger, 1959; Vaillot, 1970). Without hope, one may lose the will to live and give up, resulting in an early death or suicide (Dubree & Vogelpohl, 1980; Engel, 1968; Farber, 1968; Frankl, 1946/1962). Research findings have suggested that a high hope level (or low hopelessness level) may result in a better prognosis for individuals with cancer (Greer et al., 1979; Grossarth-Maticek et al., 1985) and that an affect of hopelessness may predispose one to the development of cancer or other illnesses (Engel, 1968; Gottschalk, 1985; Schmale & Iker, 1966). In relatively recent years, the influence of positive emotions, such as hope, on prognosis has been explained by researchers in the field of psychoneuroimmunology (Cousins, 1989; Kemeny, Solomon, Morley, & Herbert, 1991). Hence, the belief expressed by informants that rebuilding the hopeful veneer may improve their prognoses is substantiated in the literature.

The final benefit of hope identified by informants in this study is related to its impact on the receipt of support from others. Informants believed that, if they were positive and hopeful, it would be easier for family members, friends, and health care professionals to support them. Findings pertaining to this benefit of hope were not prevalent in the literature reviewed. Yates (1993), however, did identify that individuals may choose to appear outwardly hopeful when they inwardly lack hope in order to preserve social relationships (i.e., to avoid making others uncomfortable), to appear to be succeeding in coping well, and to appear to be good patients. Yates defined this type of hope as unrealistic hope or denial.

The issues of realistic and unrealistic hope, and hope and denial, are discussed further in the next two sections. Included in each section are a summary of the findings from the present study in relation to the issue, a comparison of these findings to perspectives in the literature, an exploration of the controversies and assumptions inherent in the literature, and an overview of literature on outcomes in relation to the issue.

Realistic and Unrealistic Hope

In the present study, informants defined grounds for hope and objects of hope as realistic and unrealistic and, in rebuilding the hopeful veneer, attempted to use grounds and objects they perceived to be realistic. In so doing, they thought they could reduce the risk of another erosion of the veneer, reduce the depth of a subsequent fall, and/or decrease the time required to rebuild in the future.

Reframing realistically enabled informants to envision the future, make plans, and re-engage in life with more certainty and confidence. In addition, by pursuing realistic objects of hope, they felt there was a higher probability of realizing them and, hence, of experiencing success rather than failure and discouragement. They were also less likely to give up in the future. This finding is congruent with elements of the hoping processes described by Wright and Shontz (1968) and Dufault (1981/1982), wherein individuals tried to ground their hopes in reality to increase the probability of their attainment and avoid discouragement and mourning.

To determine whether hope was realistic or unrealistic, informants gathered information from a variety of sources. Although this information was useful in coming to know "reality," it was also clear there was a "helpful area of ignorance out there." Informants said that having too much information may be detrimental because it may force them to come to the realization that desired objects of hope are unrealistic. Hence, they recognized their perceptions may differ from those of health care professionals due to discrepancies in knowledge and experience, but also felt it was their prerogative to determine how much information was accessed and how that information was translated into hopes for the future.

While acknowledging reality and reframing realistically, informants in the present study also reframed their present circumstances and their visions of self and the future positively. By reframing positively, they were able to minimize the negative implications of their circumstances, envision a more positive present and future and, thereby, more readily rebuild the hopeful veneer. This strategy was described by informants as "putting a bright picture on it" or "looking on the bright side." Reframing positively was not considered by informants to be unrealistic hope. Rather, it was a strategy for being as positive as they could be in the face of the evidence.

The ability to reframe positively has been described by researchers as integral to the concept of hope. A phrase regarding "a belief in a positive future" was included in several inductively derived definitions of hope (Dufault, 1981/1982;

Hall, 1990; Hinds, 1984; Hinds & Martin, 1988). Reframing positively is also integral to the concept of illusion, as described by Taylor, a social psychologist, and her colleagues (Taylor, 1983; Taylor & Brown, 1988; Taylor, Lichtman, & Wood, 1984; Taylor & Lobel, 1989). Taylor (1983) described illusions as follows:

> By illusions, I do not mean that the beliefs are necessarily opposite to known facts. Rather, their maintenance requires looking at the known facts in a particular light, because a different slant would yield a less positive picture. (p. 1161)

Efforts used by informants to reframe positively parallel Taylor's three major types of illusions regarding an optimistic future, positive self-image, and personal control or efficacy (Taylor, 1983; Taylor & Brown, 1988). Elements of reframing positively are also evident in all six of the hope-related processes described earlier in this chapter and in hope-fostering strategies used by individuals who are critically ill (Miller, 1989) and family caregivers of the terminally ill (Herth, 1993). All of the aforementioned authors viewed the strategy of reframing positively as adaptive and beneficial. Lazarus (1983) concurred with this view, stating that "illusion is necessary to positive mental health" (p. 1). There are others, however, who seem to disagree.

In their extensive review of the literature on illusion and well-being, Taylor and Brown (1988) reported: "The view that psychological health [and effective functioning] depend on accurate perceptions of reality has been widely promulgated and widely shared in the literature" (p. 194). As a reflection of this view, there is evidence in the literature to suggest that individuals who reframe positively and express hopefulness despite negative circumstances may be labelled as "unrealistically hopeful" (McGee, 1984) or having "false hopes" (Hickey, 1986; Proulx, 1972/1974) and, hence, may be subjected to reality orientation. McGee (1984) proposed a continuum of hope ranging from unrealistic hopefulness to unjustifiable hopelessness. Without defining her terms, she claimed that "health care providers can become a...powerful force against unrealistic hopefulness" (p. 34) and that "reality is one antidote for total hopefulness" (p. 40). Similarly, Hickey (1986) stated that "nurses...must be careful not to encourage obviously false hope" (p. 135). She defined realistic hope as practical hope and advised nurses to use their knowledge and experience to help patients distinguish between realistic and false hope.

It seems, then, that some health care professionals may view the strategy of reframing positively as psychologically unhealthy and maladaptive, discourage its use, and label those who use it as unrealistically hopeful. Implicit in these views and actions are four assumptions. First is an assumption that individuals who reframe positively and express hopefulness in the face of negative circumstances have neither acknowledged nor dealt with the implications of those circumstances. This assumption did not hold true for informants in the present study, nor for those in the study by Ersek (1992b). In both these studies, informants dealt with their circumstances emotionally and intellectually and reframed BOTH realistically and positively. The second assumption in the issue of unrealistic hope is that reality is defined from the perspective of the health care professional and hopes that are not grounded in that view of reality ought not to be encouraged. Inherent within this assumption is a third assumption, that is, that health care professionals know the "true" reality and can accurately predict client outcomes (Ersek, 1992a; Hall, 1990; Yates, 1993). This assumption has been refuted by more than one author on the grounds that health care professionals' "truth" or reality is largely defined by statistical probabilities and clinical experience, neither of which can accurately be applied to the individual (Dufault, 1981/1982; Ersek, 1992a; Hall, 1990). In other words, if 90% of women with a first recurrence of breast cancer die within two years of diagnosis, a woman in this circumstance is said to have unrealistic hope if she hopes to be cured or even to live for five more years. In making this type of judgment, one ignores the fact that there will always be those individuals who fall outside the average. What is also not considered is the fact that "such predictions are based almost exclusively on physical findings. They ignore social, contextual, and psychological facets that the literature has inextricably connected with longevity" (Hall, 1990, p. 180). The fourth assumption inherent in the issue of unrealistic hope is that health care professionals are responsible for ensuring patients' hopes are realistic and for deciding what they ought to be hoping for. This assumption was clearly unsupported by findings from the present study, as well as from a study regarding the provision of information about a cancer diagnosis (Peteet, Abrams, Ross, and Stearns, 1991). An informant in the latter study stated:

> You people worry too much about giving false hope; your job is to give me the facts; hope is what I do with the information you give me. (cited in Ross, Peteet, Medeiros, Walsh-Burke, & Reiker, 1992, p. 427)

Furthermore, Pruyser (1963) stated:

> It is presumptuous to judge another man's [*sic*] attitude to reality in such a way as to justify or not justify his [*sic*] hoping...because hoping is always in the sphere of reverence [and]...also because the boundaries of reality are fluid and uncertain. It is precisely because reality as a whole cannot be exhaustively defined that hoping is a most intimate and private prerogative of persons. (p. 90)

Given that unrealistic hope was viewed as detrimental by the informants in this study as well as by some health care professionals, empirical evidence of detrimental effects was sought in the literature. None was found. Studies regarding the effects of hope and hopelessness do not distinguish between realistic and unrealistic hope and there is a paucity of empirical evidence regarding the outcomes of positive illusions (Taylor & Brown, 1988). In terms of theoretical literature, McGee (1984) stated that "persons who experience unrealistically high levels of hope may be immobilized in the face of crises" (p. 39). She provided no evidence to support this claim. The benefits of positive illusions were empirically demonstrated in one study wherein women with breast cancer who maintained illusions of control over their disease adapted better to the illness (Taylor, Lichtman, & Wood, 1984). Based on findings from related research, Taylor and Brown (1988) have suggested that positive illusions may be associated with greater happiness and contentment, increased ability to care for others, and enhanced capacity for creative, productive work. Furthermore, they have hypothesized that positive illusions may have the potential to prompt people to persevere at impossible tasks, resist adopting important health habits, ignore legitimate risks in their environments, interfere with the rights of others, and/or ignore important sources of information. In the present study, there was no evidence to suggest that individuals who had reframed positively were experiencing any of these hypothesized detrimental effects.

Hope and Denial

The strategy of denial was used at two points in the process of Maintaining the Hopeful Veneer. First, when reeling from the blow of recurrence, some informants said they had a feeling that the events weren't really happening to them and that there must have been a mistake. This type of denial lasted a very brief period of time. Second, after having rebuilt the veneer, all informants extensively used another form of denial labelled "conscious denial." Conscious denial was a deliberate process whereby frightening or negative facts and implications were pushed to the back of one's mind and removed from awareness in order that one may re-establish normalcy and actively engage in life. Informants emphasized that this type of denial was a purposeful, conscious process and that they were fully aware of what they were trying to deny. As one man said, "I feel there is NO use to dwell on the other side even if I'm very realistic on the realities of what that other side might be."

Use of the strategy of conscious denial was evident in four of the six hope-related processes described earlier (Ersek, 1992b; Hall, 1990; Hinds & Martin, 1988; Wright & Shontz, 1968). Comparable terms included forgetting cancer, pushing a troubling reality out of the mind, and not dwelling on it. In addition, thought-stopping and thinking about other things have been cited as strategies used by critically ill (Miller, 1989) and chronically ill (Raleigh, 1992) individuals to raise or inspire hope; denying has been viewed as a coping style that maintains hope (Lange, 1978); and oncology nurses and physicians have described denial as a coping mechanism closely akin to hope (Ross et al., 1992). In contrast, Proulx (1972/1974) stated that "fantasy and denial are antithetical to hope and the hoping process" (p.

144). He further stated, "Hope and denial cannot be used at the same time, although false hope and denial are often intermingled" (p. 98). Other authors have equated the terms denial, unrealistic hope, and false hope (Ersek, 1992a).

The concept of denial originated in Freudian psychoanalytic literature where it was described as a primitive, unconscious defense mechanism that preserves psychological equilibrium by protecting an individual against painful stimuli arising in the external world (Freud, 1936/1966). Weisman and Hackett (1961) expanded this definition to include a conscious form of denial that resembles that defined by informants in the present study. They defined denial as "the conscious or unconscious repudiation of all or part of the total available meaning of an event to allay fear, anxiety or other unpleasant effects" (cited in Ross et al., 1992, p. 423). De Hennezel (1989) described a form of denial called "splitting of the ego" that also is comparable to the strategy of conscious denial. She described this as a common type of denial occurring under the influence of psychic trauma wherein "the ego splits into two parts, one of which takes reality into account..., while the other becomes detached from it" (p. 28). The person moves back and forth between denial and recognition, much like the informants in the present study moved thoughts of the cancer from the back to the front of their minds. De Hennezel (1989) also stated:

> It is probably this denial that is the origin of a sort of hope....Denial develops surprising psychic and sometimes physical energy. This fuels the hope, or hoping, without which, clearly, few of our patients would be psychically alive up to the end. (p. 28, 31)

Interestingly, De Hennezel conceptualized denial as the origin and "fueller" of hope, whereas, in the present study, hope was conceptualized as the source of energy that enabled informants to use the strategy of conscious denial. It is apparent, however, that, after the veneer is rebuilt, consciously denying and maintaining hope may be viewed as reciprocal processes, each fuelling the other. That is, consciously denying facilitates maintenance of the hopeful veneer which, in turn, facilitates use of conscious denial.

A prevalent assumption in the literature on denial, particularly that which equates denial with false or unrealistic hope, is that when one chooses to deny a negative reality and focus on health and living rather than on illness and dying, one has neither acknowledged, dealt with, nor accepted what the consequences of that reality may be and, therefore, one will be unable to cope or adapt effectively (Lazarus, 1983). (This parallels the first assumption regarding unrealistic hope stated earlier.) Russell (1993) identified that this assumption regarding denial has been reinforced by inaccurate, linear interpretations of models such as that of Kubler-Ross (1968) wherein the goal of acceptance is viewed as unattainable as long as denial exists. He also identified two other beliefs that have supported this view of denial. First is the "common religious belief that denial blocks acknowledgment, acceptance, and repentance of sin"; and second is that "psychiatric treatment in mental illness has traditionally required the removal of denial as an essential prerequisite to a cure" (p. 938).

As with the assumptions regarding unrealistic hope, the assumption that denial necessarily involves a lack of acknowledgement and/or acceptance of negative facts and implications was clearly refuted by informants in the present study, and those in the study by Ersek (1992b). Others have also questioned this assumption, noting that behaviour labelled as denial may range in degree from complete disavowal to mere avoidance, the latter extreme being characterized by not focusing on, thinking about, or talking about the threatening implications of events (Breznitz, 1983; Druss & Douglas, 1988; Lazarus, 1983). This "less extreme" form of denial parallels the type of denial used by informants in the present study.

Findings from two other studies are noteworthy in relation to refutation of this assumption about denial. First, Ross and colleagues (1992), in a study of nurses' and physicians' approaches to denial in oncology, stated:

> Denial is an interpersonal process; that is, it may vary with one's role, supports, and perhaps the setting. Each patient determines what information can be shared with a particular caregiver....It is an error to assume that the patient underestimates the seriousness of the situation. (p. 426-427)

Second, Hall (1990) vehemently asserted that it is inappropriate for health care professionals to expect individuals to focus on the negative implications of their circumstances, particularly if they have been diagnosed as terminally ill.

> No one can predict whether he or she will be alive a month from now, but we go around acting as though we can....It is acceptable if the undiagnosed do not deal with dying, but the diagnosed must see this outcome as their fate. If they do not, they are accused of wishful thinking or denial....Although their life could be as full and rich as anyone's life, they are not expected to live a normal life, but to prepare for death. (p. 180, 183)

Based on her personal experience with a terminal illness and that of the HIV positive men in her study, Hall (1990) concluded that, "People who are diagnosed as having a potentially terminal illness, no matter how serious it is, want to live until they die, and a large part of living is having a future orientation" (p. 182). This conclusion mirrors the sentiments of the informants in the present study.

The literature on denial was examined to elucidate possible deleterious effects. Studies regarding the effects of denial, however, do not distinguish between conscious and unconscious denial. As Lazarus (1983) stated: "It may be a much better research strategy to carefully differentiate denial-like processes so that their impact on adaptational outcomes can also be distinguished" (p. 16). In her review of empirical literature on outcomes related to denial, Ersek (1992a) concluded results are scarce or contradictory. In one study of women with breast cancer, denial was associated with lower mood disturbance and was not associated with a delay in seeking treatment (Watson, Greer, Blake, & Shrapnell, 1984). In contrast, two other studies with individuals with cancer indicated that denial may be associated with a delay in seeking treatment or with an increased mortality rate (Ersek, 1992a). Russell (1993), in a review of the role of denial in clinical practice, cited evidence that denial may lower anxiety and aid decision-making. He concluded his review by saying:

> Denial is an important coping mechanism and health care professionals should be aware of its value and tread carefully when it may be operating....Denial

> buffers the individual against what is sometimes a bleak reality....Being unrealistic may help the patient cope. We must be aware, therefore, that whilst trying to promote psychological well-being, we do not ask patients to be unrealistically realistic. (p. 940)

Russell's view of denial as buffering against a bleak reality fits perfectly with the view of conscious denial and the image of the hopeful veneer inducted in the present study.

It is apparent that, if health care professionals see individuals' hope as unrealistic or label it as denial, and dissuade them from retaining this hope, they may force these individuals to move to the lower level of reality and thereby reduce the quality of their lives. Given the findings from the present study and others, it is also conceivable that this may lead to impaired coping, poorer prognoses, and decreased support from others.

Implications

The findings from this research study have several implications for the practice of health care professionals and for continued research in this field. Given my professional affiliations, implications are presented for the practice and research of nurses. The reader is advised, however, that these implications are equally relevant for all health care professionals.

Implications for Nursing Practice

Given that this study is the first to document the process of rebuilding and maintaining hope in individuals experiencing a first recurrence of cancer, and there is a paucity of comparable research, implications for practice drawn from this research must be considered suggestions rather than definitive recommendations. Further research is needed to confirm or disaffirm the findings and provide more direction for nursing practice.

The most global implication of the findings from this study comes from the conceptualization of hope as a protective, energizing veneer, the maintenance of which contributes significantly to quality of life, improves coping, and may improve prognosis. By considering this conceptualization, nurses may be sensitized to the vital significance of hope for people with cancer, particularly those experiencing a first recurrence.

In terms of more specific implications, three areas were identified. First, an understanding of the stages in the process of Maintaining the Hopeful Veneer may help nurses recognize where people are at in the process, support them where they are, allow them to progress at their own pace, and help them move forward when ready. In order to help people in this manner, it is critical that nurses earn their trust, confidence, and respect by demonstrating competence, developing connections, and being honest, empathetic, compassionate, and respectful in those connections.

In terms of progressing through the process of Maintaining the Hopeful Veneer, it was apparent that informants resented being pushed into a stage before they were ready to move there. Hence, nurses must create an environment that freely allows people to deal with the recurrence emotionally and intellectually, as well as to push thoughts of the cancer and its implications to the back of their minds, when they choose to do so. Encouraging them to deal with the recurrence when they would rather be actively engaging would be unhelpful, as would encouraging them to be engaged and hopeful when they prefer and need to be disengaged. As one informant said:

> I don't think anybody could say to you..., "Why don't I just give you all this information...and...get you straight to hope." I don't think that would necessarily be healthy. You might get there on shaky legs. You have to go through it....[And] if you get there on a firm footing, on your own or with help, then you can go, "Hey, this is not bad."

Certain nursing actions may be beneficial in supporting people at each stage of the process and facilitating their forward movement. Some potentially facilitative actions are outlined below:

Disengaging:

- Allow people to experience reeling, wallowing, and withdrawing as needed.
- Acknowledge suffering and grieving and emphasize its normalcy.
- Assist in identification of feelings and emotions.

- Don't underestimate the potential for devastation upon receipt of the diagnosis of recurrence. At the same time, however, don't assume all people will be devastated. Reactions in this study varied greatly.

Rebuilding:

- Identify and respect people's needs and preferences regarding information. Don't bombard people with information if they prefer to maintain a "helpful area of ignorance."
- Be honest, clear, and expedient in the delivery of information.
- Identify that predicted outcomes are based on statistical averages that may or may not apply to an individual.
- Help people find or connect hopeful signs and reframe positively (e.g., identify progress and success, help with normalizing and identifying positive outcomes, share cancer stories, provide information about support groups, identify advances in treatments).
- Recognize and accept that conventional cancer treatments may not be viewed as hopeful signs or resources for all people. Respect individual choices.
- Assist in identifying objects of hope but don't assume responsibility for ensuring they are realistic. Respect people's future visions.
- Support people in their choice to shift their objects of hope from quantity to quality of life.

Actively Engaging:

- If people focus on living and use conscious denial, don't assume they haven't acknowledged, dealt with, or accepted the negative implications of their circumstances.
- Avoid viewing denial as necessarily maladaptive.
- Don't expect or encourage people to continually focus on their cancer and its implications.
- Support efforts to re-establish normalcy, identify and pursue goals, and live differently.

Second, nurses may share their understanding of this process with people experiencing cancer to help them put their experiences in perspective and have a sense of what to expect. The metaphors of the hopeful veneer, the movement of the cancer in the mind, and the two levels of reality were particularly meaningful to the informants in this study and may help others better understand and interpret their experiences.

Third, by considering the many factors that influence movement through the process of Maintaining the Hopeful Veneer, nurses may identify strategies to facilitate forward movement and may more readily identify those people who will likely need more assistance in the process. For example, forward movement may be facilitated by encouraging assertiveness, sharing control, alleviating pain, helping people to see past successes, limiting concurrent stressors, providing an atmosphere of sunshine and warmth, including family and friends in caregiving, and educating significant others about how they can be resources in the process.

Of paramount significance for nurses, however, is that we must be ever conscious of the profound impact our actions, words, and, perhaps even more importantly, our attitudes, have on the hope of others. This is particularly evident at the time of first recurrence when several informants in this study sensed that health care professionals were less hopeful and less compassionate than on initial diagnosis. It is critical that nurses convey a hopeful attitude when with people with cancer, find ways to maintain their own hope, and bolster their own hoping resources.

Implications for Nursing Research

Implications for nursing research have arisen from this study in five areas. First, the process of Maintaining the Hopeful Veneer needs to be validated with other populations, including people at other phases of the cancer experience, such as the initial diagnosis or terminal phase, and those with other chronic illnesses. Given that all informants in this study were middle-aged, adult, and caucasian, differences in the experiences of individuals in different age groups, cultures, and ethnic groups would also be important to examine. Furthermore, because there was little variation in marital and employment status in the present sample and these factors may influence the process of maintaining hope, subsequent validation ought to be conducted with samples that are more heterogeneous with regard to these variables. In addition, given the congruence with Martin and Elder's (1993) model of Pathways Through Grief, it would be interesting to examine the applicability of this process to the experience of grieving.

Second, the process itself needs further clarification and elaboration. Additional research is needed to more clearly distinguish the stage of disengaging from the stage of giving up and to further elucidate strategies used in rebuilding.

Third, ways to facilitate movement through the process must be more closely examined. Questions to be addressed include:

- How does one best identify where people are at in the process?
- How does one know when people are ready to move to another stage?
- How does one best assist a person to move to the next stage?
- How does a person develop the capacity to see hopeful signs or reframe positively? Can this be learned or is it innate?

Fourth, hypotheses may be developed and tested regarding the cumulative and/or individual influences of the identified strategies and factors on one's movement through the process. Seven such hypotheses are included below:

- Until one identifies grounds for and objects of hope, one is unable to fully engage in life following a first recurrence of cancer.
- The fewer internal hoping resources one has, the longer the time spent in disengaging throughout the cancer experience.
- Individuals who reframe positively re-establish normalcy more quickly after a recurrence than those who do not.
- Use of the strategy of conscious denial will improve one's ability to maintain hope and actively engage in life throughout the cancer experience.
- A history of past success is associated with a faster return to actively engaging following a first recurrence of cancer.
- Relationships with health care professionals who are perceived as positive or

optimistic will improve one's ability to maintain hope throughout the cancer experience.

- Overprotection by significant others is associated with more time spent in disengaging throughout the cancer experience.

Fifth, after additional verification and clarification of this process, research may be directed toward the operationalization of the strategies people use to maintain the hopeful veneer and the development of an instrument to measure hope-maintaining strategies. This line of research may have more relevance for practice than current research aimed at measuring levels of hope.

Finally, the relationship between hoping, maintaining hope, and coping requires further study; and outcomes, such as quality of life and prognosis, need to be further researched in relation to the maintenance of hope, particularly when the individual's hope is perceived by health care professionals as unrealistic hope or denial.

Reflections on the Research Experience

This project represents my inauguration into the researcher role. I found the experience both challenging and overwhelming, rewarding and frustrating, exhilarating and exhausting and, in the end, personally meaningful and inspiring. This section is devoted to my reflections on the research experience.

Looking back over the past two years, I can see many parallels between my research experience and the experiences of the informants in this study. In order to actively engage in the research experience, I too had to maintain the hopeful veneer and rebuild it on more than one occasion. When I developed the idea for the study and defended my proposal, I was overflowing with confidence and enthusiasm, charging straight ahead with a well-formulated plan and what I thought was a realistic time frame. The hopeful veneer was intact and I was galvanized. When I encountered delays in receiving ethical clearance and finding potential informants, my enthusiasm began to wane and the veneer became ever so slightly thinner. When I finally started interviewing, this sign of progress thickened the veneer for a time. After reviewing my first few transcripts, however, the veneer was completely eroded by the overwhelming realization of the enormity of the task that lay ahead. I fell to disengaging and felt as though I was drowning in data. I was overcome with fear, doubt, and panic. How could I possibly make sense of all this? Did I really know what I was doing? Was I capable of doing this? I felt as though I had been taken out of gear. The wind was out of my sails.

I moved in and out of this lower level throughout the research experience, both in response to my own setbacks and those of the informants in the study. I'll speak to the latter first. After sharing each informants' intimate story during the first interview, I found myself "walking on eggshells" alongside them. I worried about whether they would achieve another remission and, if so, how long it would last. For the purposes of recording background information and determining the appropriateness of follow-up calls, I reviewed the informants' medical records at the cancer agency three times over the course of the study. Each time, I opened the charts with trepidation, fearing the worst. If I discovered the informants were continuing in good health, I breathed a sigh of relief and the hopeful veneer was reinforced. On two occasions, however, I unexpectedly discovered that one of the informants had either experienced a second recurrence or had recently died. This was devastating news that shattered the hopeful veneer and led to my own process of disengaging.

In terms of my own personal setbacks, it seemed I would just start to feel confident with one aspect of the research process and then have my feet knocked out from under me when I got to the next stage. Just when I started to feel comfortable with interviewing, I became overwhelmed with coding. When I got the knack of coding, I struggled with how best to sort the data. When I developed a system for sorting, I was overwhelmed with the prospect of writing. And so it went. With each knock down, however, I was somehow able to move forward and upward and rebuild the hopeful veneer.

Like the informants in this study, my process of rebuilding the hopeful veneer involved looking for hopeful signs and reframing both realistically and positively.

Reframing realistically was an incredibly difficult endeavour. How could I develop realistic goals and time frames when I had no idea what lay around the next corner? How overwhelming would the next stage be? How many more times would I feel like I was drowning? How long would it take me to pull it all together? When would I get the "a-ha"? I felt like I was trying to estimate how long it would take me to get to a destination with no knowledge of the road conditions or the capabilities of my vehicle or, for that matter, how I would know when I had arrived. There were many many times when I failed to complete a portion of the study within my estimated time frame. This became so discouraging that I suspended long term goal setting for a time and, instead, took the process one day at a time or, better yet, one month at a time. As one informant in this study pointed out, if you review your progress one day at a time, it is unlikely you'll see any. Hence, by taking it one month at a time, I could see progress but not be too overwhelmed or distraught about what lay further ahead.

Seeing this progress, even if incremental, was a key hopeful sign that helped me to reframe positively. I was also able to reframe positively by focusing on the richness of this learning experience. I consider it a great privilege to have been entrusted with the intimate stories of six ordinary, yet extraordinary, individuals. They each openly shared their private hopes and fears, their physical and spiritual suffering, and the ways in which they found inner strength during a time of tragedy. While being a privilege and a great honor, however, it was also a weighty responsibility. I felt a great obligation to these individuals to represent them accurately and convey the messages to others they so wanted to convey. I think this sense of responsibility was one of the primary reasons why I felt so overwhelmed with data analysis. Was I representing them fairly? Would I lose their uniqueness and their individual messages by telling the common story? Validating my hunches in second interviews, sharing the model with one informant at the end of the study, and having oncology nurses comment on the fittingness of the model all helped to assuage these fears.

Another strategy I used to reframe positively was to remind myself of the professional and personal reasons I was doing the study. Throughout this research process, my strong convictions regarding the significance of this study and its potential contribution to nursing practice did not wane. There were also personal reasons why I was deeply interested in the process these informants used to maintain hope after a first recurrence of cancer. My father was diagnosed with colon cancer a few months before I commenced this study. While he continues to be in remission and I hope and pray he does not experience a recurrence, this learning experience will give me insight into how to help him and understand his pain if he does.

By seeing signs of progress and reframing positively, I was able to actively engage in the research process. It was apparent, though, that I was living differently than I had before entering this role. The research project completely overtook my life at several points. When I was immersed in analysis and in writing, it was difficult to think about, talk about, or do much else. The amount of energy, focus, and perseverance required for this type of work was well beyond what I had imagined.

I was also living differently with regard to my relationship with individuals with cancer. I was no longer the helper, supporter, and comforter I had been in my nursing role. I now had to wear the hat of the researcher. This was difficult at first. I felt like I was somehow using these individuals' experiences for my gain and wasn't offering them anything in return. I found myself wanting to offer advice and solve problems. It took a concerted effort to not do so. I learned to accept this new way of being with people by seeing that I was indeed helping them, but in a different way than I had in the past. By listening to their stories as they wanted to tell them, I was able to help them make sense of their experiences. By sharing these stories with others, I will become the vehicle through which their suffering may take on more meaning and purpose by contributing to improvements in care and/or greater understanding for others who face similar circumstances.

There were several factors that facilitated and inhibited my rebuilding process. Support from colleagues, thesis committee members, family, and friends was essential. Being a part of two research groups was invaluable. I firmly believe that qualitative research must not be conducted in isolation. It is far too easy to lose yourself in the complexity and intensity of the process if you don't have others with whom you can discuss ideas, share doubts and fears, receive feedback, and celebrate progress. Comparing to other colleagues was both encouraging and discouraging. It was important to remember that my study, my needs, my standards, and my personal situation were unique. Concurrent stressors were a definite inhibitor in the process. If a significant portion of my concentration and energy were being channelled elsewhere, my progress in the study rapidly declined.

Personal strengths that were essential in this process included perseverance, independence, courage, and, of course, hope. My ability to analyze and conceptualize on an abstract level was also a strength in the process, but my need to obsessively scrutinize and integrate every minute facet of the informants' experiences slowed me down considerably. It was difficult for me to conclude the study knowing there was still so much to be learned from the data. I need to work on accepting the fact that qualitative analysis is a perpetual, never-ending process. Another inhibitor in this process was my lack of patience with and confidence in the inductive analysis process. The ambiguity and uncertainty inherent in qualitative research was frustrating at first. Exactly how will these findings miraculously emerge from the data? And exactly how long is this going to take? Having experienced first hand that this process does indeed work, I anticipate that I will be more patient in future research endeavours.

Lastly, I'd like to reflect on the personal and professional outcomes of this research experience. First, through my interaction with the informants in this study, I now have a heightened awareness of both the resiliency and the fragility of the human spirit and the core of hope that lies therein. I am also more cognizant of how easily this vital essence of being may be nurtured or destroyed by the actions or attitudes of those in the health care field. Second, the process developed through this study has provided me with a new way of viewing the cancer experience and, indeed, all life experiences. I am confident that sharing these findings with others will lead to greater insights for both caregivers and individuals with cancer. Third, my experience in conducting qualitative research has confirmed how well this method of inquiry fits with my personal philosophy, goals, and approach to nursing. The most satisfying aspect of my clinical nursing career has been the opportunity to develop connections with others, hear their stories, learn from their experiences, and, hopefully, make a positive difference in their lives. Qualitative research provides an avenue whereby I may continue to derive these same satisfactions, yet have the potential to make a positive difference on a much larger scale. Finally, the clinical origin of this research study makes the process and the findings particularly meaningful. By hearing Joan's story and sharing in her suffering, I was able to identify a problem from the emic perspective, research it from that same perspective, and derive implications that will hopefully lead to improved care for others like Joan in the future. That is what nursing research is all about.

Conclusion

The findings from this study represent a unique contribution to nursing knowledge regarding the process of maintaining hope throughout the cancer experience and rebuilding hope after a first recurrence. There is still much to be learned. Further knowledge development in this area and its application to nursing practice is vital to the enhancement of quality of life for the individuals who entrust us with their care. Let us continue to hear their stories and share their pain, for they are our best teachers.

References

Beck, A., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The hopelessness scale. Journal of Consulting and Clinical Psychology, 42, 861-865.

Brandt, B.T. (1987). The relationship between hopelessness and selected variables in women receiving chemotherapy for breast cancer. Oncology Nursing Forum, 14(2), 35-39.

Breznitz, S. (1983). The seven kinds of denial. In S. Breznitz (Ed.), The denial of stress (pp. 257-280). New York: International Universities Press.

Brink, P.J. (1989). Exploratory designs. In P.J. Brink & M.J. Wood (Eds.), Advanced design in nursing research (pp. 141-160). Newbury Park, CA: Sage.

Brink, P.J. (1991). Issues of reliability and validity. In J.M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 164-186). Newbury Park, CA: Sage.

Brockopp, D., Hayko, D., Davenport,W., & Winscott, C. (1989). Personal control and the needs for hope and information among adults diagnosed with cancer. Cancer Nursing, 12, 112-116.

Brown, P. (1989). The concept of hope: Implications for care of the critically ill. Critical Care Nurse, 9(5), 97-100, 102, 104-105.

Campbell, L. (1987). Hopelessness: A concept analysis. Journal of Psychosocial Nursing and Mental Health Services, 25(2), 18-22.

Canadian Cancer Society. (1992). Final report on the needs of people living with cancer across Canada. Toronto: Author.

Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., & March, V. (1980). Information and participation preferences among cancer patients. Annals of Internal Medicine, 92, 832-836.

Chekryn, J. (1984). Cancer recurrence: Personal meaning, communication, and marital adjustment. Cancer Nursing, 7, 491-498.

Christman, N.J. (1990). Uncertainty and adjustment during radiotherapy. Nursing Research, 39, 17-20.

Cousins, N. (1989). *Head first: The biology of hope*. New York: Dutton.

Craig, H., & Edwards, J. (1983). Adaptation in chronic illness: An eclectic model for nurses. *Journal of Advanced Nursing*, *8*, 397-404.

De Hennezel, M. (1989). Denial and imminent death. *Journal of Palliative Care*, *5*(3), 27-31.

Druss, R.G., & Douglas, C.J. (1988). Adaptive responses to illness and disability: Healthy denial. *General Hospital Psychiatry*, *10*, 163-168.

Dubree, M., & Vogelpohl, R. (1980). When hope dies -- so might the patient. *American Journal of Nursing*, *80*, 2046-2049.

Dufault, K. (1982). *Hope of elderly persons with cancer* (Doctoral dissertation, Case Western Reserve University, 1981). *Dissertation Abstracts International*, *42*, 1820B-1821B.

Engel, G. (1968). A life setting conducive to illness: The giving-up -- given-up complex. *Annals of Internal Medicine*, *69*, 293-300.

Erickson, R.C., Post, R.D., & Paige, A.B. (1975). Hope as a psychiatric variable. *Journal of Clinical Psychology*, *31*, 324-330.

Ersek, M. (1992a). Examining the process and dilemmas of reality negotiation. *IMAGE: Journal of Nursing Scholarship*, *24*, 19-25.

Ersek, M. (1992b). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. *Oncology Nursing Forum*, *19*, 883-889.

Farber, M. (1968). *Theory of suicide*. New York: Funk & Wagnalls.

Field, P.A., & Morse, J.M. (1985). *Nursing research: The application of qualitative approaches*. Rockville, MD: Aspen.

Frank, J. (1968). The role of hope in psychotherapy. *International Journal of Psychiatry*, *5*, 383-395.

Frankl, V. (1962). *Man's search for meaning: An introduction to logotherapy* (rev. ed.) (I. Lasch, Trans.). Boston: Beacon Press. (Original work published 1946).

Freud, A. (1966). *The ego and the mechanisms of defense* (rev. ed.) (C. Baines, Trans.). New York: New York Universities Press. (Original work published 1936).

Fromm, E. (1968). The revolution of hope: Toward a humanized technology. New York: Harper & Row.

Given, B. (1990). Study critique. Oncology Nursing Forum, 17(3)(Suppl.), 53-54.

Gottschalk, L. (1974). A hope scale applicable to verbal samples. Archives of General Psychiatry, 30, 770-785.

Gottschalk, L. (1985). Hope and other deterrents to illness. American Journal of Psychotherapy, 39, 515-524.

Greer, S., Morris, T., & Pettingale, K. (1979). Psychological response to breast cancer: Effect on outcome. The Lancet, 2, 785-787.

Grossarth-Maticek, R., Bastiaans, J., & Kanazir, D.T. (1985). Psychosocial factors as strong predictors of mortality from cancer, ischaemic heart disease and stroke: The Yugoslav prospective study. Journal of Psychosomatic Research, 29, 167-176.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. Educational Communication and Technology, 29, 75-91.

Haase, J.E., Britt, T., Coward, D.D., Leidy, N.K., & Penn, P.E. (1992). Simultaneous concept analysis of spiritual perspective, hope, acceptance and self-transcendence. IMAGE: Journal of Nursing Scholarship, 24, 141-147.

Hall, B.A. (1990). The struggle of the diagnosed terminally ill person to maintain hope. Nursing Science Quarterly, 3, 177-184.

Hanson, V. (1994, August). The experience of cancer recurrence: What does it mean and how do families cope? Paper presented at the Eighth International Conference on Cancer Nursing, Vancouver, BC.

Hendon, M.K., & Epting, F.R. (1989). A comparison of hospice patients with other recovering and ill patients. Death Studies, 13, 567-578.

Herth, K. (1989). Relationship between level of hope and level of coping and other variables in patients with cancer. Oncology Nursing Forum, 16, 67-72.

Herth, K. (1990). Fostering hope in terminally-ill people. Journal of Advanced Nursing, 15, 1250-1259.

Herth, K. (1991). Development and refinement of an instrument to measure hope. Scholarly Inquiry for Nursing Practice: An International Journal, 5, 39-51.

Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing*, *17*, 1251-1259

Herth, K. (1993). Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing*, *18*, 538-548.

Hickey, S.S. (1986). Enabling hope. *Cancer Nursing*, *9*, 133-137.

Hinds. P.S. (1984). Inducing a definition of "hope" through grounded theory methodology. *Journal of Advanced Nursing*, *9*, 357-362

Hinds, P.S., & Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. *Nursing Research*, *37*, 336-340.

Jalowiec, A., & Powers, M.J. (1981). Stress and coping in hypertensive and emergency room patients. *Nursing Research*, *30*, 10-15.

Jevne, R. (1991). *It all begins with hope: Patients, caregivers & the bereaved speak out*. San Diego, CA: LuraMedia.

Jevne, R. (1993). Enhancing hope in the chronically ill. *Humane Medicine*, *9*, 121-130.

Kemeny, M.E., Solomon, G.F., Morley, J.E., & Herbert, T. (1991). Psychoneuroimmunology. In C.B. Nemeroff (Ed.), *A comprehensive textbook of neuroendocrinology*. Caldwell, NJ: Teleford Press.

Korner, I. (1970). Hope as a method of coping. *Journal of Consulting and Clinical Psychology*, *34*, 134-139.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, *45*, 214-222.

Kubler-Ross, E. (1968). *On death and dying*. New York: MacMillan.

Laney, M. (1969). Hope as healer. *Nursing Outlook*, *17*(1), 45-46.

Lange, S.P. (1978). Hope. In C.E. Carlson & B. Blackwell (Eds.). *Behavioral concepts and nursing intervention* (2nd ed.). Philadelphia: Lippincott.

Lazarus, R.S. (1983). The costs and benefits of denial. In S. Breznitz (Ed.), *The denial of stress* (pp. 1-30). New York: International Universities Press.

Lynch, W.F. (1965). *Images of hope: Imagination as healer of the hopeless*. Baltimore: Helicon.

Mahon, S.M. (1991). Managing the psychosocial consequences of cancer recurrence: Implications for nurses. Oncology Nursing Forum, 18, 577-583.

Mahon, S., Cella, D., & Donovan, M. (1990). Psychosocial adjustment to recurrent cancer. Oncology Nursing Forum, 17(3)(Suppl.), 47-52.

Marcel, G. (1951). Homo viator: Introduction to a metaphysic of hope (E. Craufurd, Trans.). New York: Harper & Row. (Original work published 1951).

Martin, K., & Elder, S. (1993). Pathways through grief: A model of the process. In J.D. Morgan (Ed.), Personal care in an impersonal world: A multidimensional look at bereavement (pp. 73-86). Amityville, NY: Baywood.

McGee, R. (1984). Hope: A factor influencing crisis resolution. Advances in Nursing Science, 6(4), 34-44.

Menninger, K. (1959). The academic lecture: Hope. The American Journal of Psychiatry, 116, 481-491.

Mickley, J.R., Soeken, K., & Belcher, A. (1992). Spiritual well-being, religiousness, and hope among women with breast cancer. IMAGE: Journal of Nursing Scholarship, 24, 267-272.

Miles, M., & Huberman, A. (1984). Qualitative data analysis: A sourcebook of new methods. Beverly Hills, CA: Sage.

Miller, J.F. (1983). Inspiring hope. In J.F. Miller (Ed.), Coping with chronic illness: Overcoming powerlessness (pp. 287-299). Philadelphia: F.A. Davis.

Miller, J.F. (1985). Inspiring hope. American Journal of Nursing, 85, 22-25.

Miller, J.F. (1989). Hope-inspiring strategies of the critically ill. Applied Nursing Research, 2(1), 23-29.

Miller, J.F., & Powers, M.J. (1988). Development of an instrument to measure hope. Nursing Research, 37, 6-10.

Mishel, M., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychosocial adjustment in patients with newly diagnosed gynecological cancer. Cancer Nursing, 7, 291-299.

Morse, J.M. (1991a). Qualitative nursing research: A free-for-all? In J.M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 14-22).

Newbury Park, CA: Sage.

Morse, J.M. (1991b). Strategies for sampling. In J.M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 127-145). Newbury Park, CA: Sage.

Nekolaichuk, C. (1990). Learning to live with uncertainty: The role of hope and medication compliance in chronic illness. Unpublished master's thesis, University of Alberta, Edmonton, Alberta.

Northouse, L.L. (1981). Mastectomy patients and the fear of cancer recurrence. Cancer Nursing, 4, 213-220.

Nowotny, M.L. (1989). Assessment of hope in patients with cancer: Development of an instrument. Oncology Nursing Forum, 16, 57-61.

Owen, D.C. (1989). Nurses' perspectives on the meaning of hope in patients with cancer: A qualitative study. Oncology Nursing Forum, 16, 75-79.

Perakyla, A. (1991). Hope work in the care of seriously ill patients. Qualitative Health Research, 1, 407-433.

Perlman, H. (1983). Relationship: The heart of helping people. Chicago, IL: University of Chicago Press.

Peteet, J.R., Abrams, H.E., Ross, D.M., & Stearns, N.M. (1991). Presenting a diagnosis of cancer: Patients' views. Journal of Family Practice, 32, 577-581.

Proulx, J.R. (1974). Hope and the hoping process in the health-care setting: An introductory study (Doctoral dissertation, Columbia University, 1972). Dissertation Abstracts International, 33, 85A.

Pruyser, P.W. (1963). Phenomenology and dynamics of hoping. Journal for the Scientific Study of Religion, 3, 86-96.

Raleigh, E.D. (1992). Sources of hope in chronic illness. Oncology Nursing Forum, 19, 443-448.

Ross, D.M., Peteet, J.R., Medeiros, C., Walsh-Burke, K., & Rieker, P. (1992). Difference between nurses' and physicians' approach to denial in oncology. Cancer Nursing, 15, 422-428.

Russell, G.C. (1993). The role of denial in clinical practice. Journal of Advanced

Nursing, 18, 938-940.

Schmale, A.H. (1976). Psychological reactions to recurrences, metastases or disseminated cancer. International Journal of Radiation Oncology, Biology, Physics, 1, 515-520.

Schmale, A.H., & Iker, H.P. (1966). The affect of hopelessness and the development of cancer. Psychosomatic Medicine, 27, 714-721.

Silberfarb, P., Maurer, L., & Crouthamel, C. (1980). Psychosocial aspects of neoplastic disease: I. Functional status of breast cancer patients during different treatment regimens. American Journal of Psychiatry, 137, 450-455.

Stephany, K. (1992). When the patient gives up. The Canadian Nurse, 88(10), 25-26.

Stoner, M.H., & Keampfer, S.H. (1985). Recalled life expectancy information, phase of illness, and hope in cancer patients. Research in Nursing and Health, 8, 269-274.

Stotland, E. (1969). The psychology of hope. San Francisco, CA: Jossey-Bass.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park: Sage.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.

Taylor, S.E., & Brown, J. (1988). Illusions and well-being: A social psychological perspective on mental health. Psychological Bulletin, 103, 193-210.

Taylor, S.E., Lichtman, R.R., & Wood, J.V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. Journal of Personality and Social Psychology, 46, 489-502.

Taylor, S.E., & Lobel, M. (1989). Social comparison activity under threat: Downward evaluation and upward contacts. Psychological Review, 96, 569-575.

Travelbee, J. (1971). Interpersonal aspects of nursing. Philadelphia: F.A. Davis.

Vaillot, C. (1970). Hope: The restoration of being. American Journal of Nursing, 70, 268,270-273.

Watson, J. (1979). Nursing: The philosophy and science of caring. Boston: Little, Brown, & Co.

Watson, M., Greer, S., Blake, S., & Shrapnell, K. (1984). Reaction to a diagnosis of breast cancer: Relationship between denial, delay and rates of psychological morbidity. Cancer, 53, 2008-2012.

Webster. (1990). Webster's new dictionary and thesaurus. New York: Russell, Geddes, & Grosset.

Weisman, A.D. (1979a). Coping with cancer. New York: McGraw-Hill.

Weisman, A.D. (1979b). A model for psychosocial phasing in cancer. General Hospital Psychiatry, 1, 187-195.

Weisman, A.D., & Hackett, T.P. (1961). Predilection to death: Death and dying as a psychiatric problem. Psychosomatic Medicine, 23, 232-256.

Weisman, A.D., & Worden, J.W. (1986). The emotional impact of recurrent cancer. Journal of Psychosocial Oncology, 3(4), 5-16.

Wilkinson, S. (1991). Factors which influence how nurses communicate with cancer patients. Journal of Advanced Nursing, 16, 677-688.

Wright, B., & Shontz, F. (1968). Process and tasks in hoping. Rehabilitation Literature, 29, 322-331.

Yates, P. (1993). Towards a reconceptualization of hope for patients with a diagnosis of cancer. Journal of Advanced Nursing, 18, 701-706.

Appendix A

Examples of Guiding Questions

The guiding questions will be used to assist in systematic data collection by seeking similar content from all subjects during the interviews. The questions will not necessarily be asked in the order or form specified, all informants may not be asked all questions, and some questions may be asked in the second or third interviews.

- Tell me about your experience with cancer and what it has been like for you to live with this diagnosis?
  Probes: What was it like before you were diagnosed?
  At the time of diagnosis?
  During treatment?
  During remission?
  When you found out the cancer had recurred?

- Were there times that were more difficult than others? What helped you get through those times?

- Some people say that hope helps them get through the difficult times. What is the importance or purpose of hope for you? Has hope helped you live with cancer? Has it been unhelpful in any way? If so, how?

- Tell me about times when your hope has changed. Tell me about times when you felt very hopeful and times when you felt you had lost hope.

- What sort of things do you hope for? Has this changed? If so, how, why, and when has it changed?

- If you could identify a source of hope for yourself, what would it be?

- What or who helps you maintain your hope or makes you feel hopeful? In what ways do they help?

- What kinds of things do you do to affect your hope or that of others around you?

- What are signs or symbols of hope for you?

- What things cause you to lose hope or become less hopeful?

- What kinds of things have health care workers, such as nurses or doctors, said or done that have affected your hope?

Appendix B

Form for Recording Field Notes

FIELD NOTES*

Informant/Interview Code #:

Interview Date: **Starting Time:** **Ending Time:**

Pre-interview Goals for this interview:

Location of Interview:

People Present:

Significant Timing Parameters: (e.g., day before chemo, day before appointment)

Description of Environment: (including personal belongings, pets)

Description of Informant:

Nonverbal Behaviour: (e.g., tone of voice, posture, facial expressions, eye movement, forcefulness of speech, body movement, hand gestures)

Content of Interview: (e.g., topics, focus, exact words or phrases that stand out, highly pertinent information)

Researcher's Impressions: (e.g., encouragement or discouragement about outcome of interview; discomfort with certain topics; emotional responses to people, events or objects)

Analysis: (e.g., questions, hypotheses, inferences, interpretations, emerging patterns and trends)

Technological Considerations:

* Note: The researcher will complete the Field Notes within 24 hours of each interview based upon memory, recall, and any notes taken or recorded immediately following the interview. Additional information entered into the Field Notes after the 24 hour postinterview period will be dated.

Appendix C

Background Data Form

Code Number:________________ Date: ______________________

PART A: DEMOGRAPHICS

1. **Age (in years):** _____

2. **Gender:**
   (a) Male _____
   (b) Female _____

3. **Marital status:**
   (a) Married (incl. common-law) _____
   (b) Separated or Divorced _____
   (c) Never married _____
   (d) Widowed _____

4. **Number of children:** ________ **Ages:** ________________________

5. **Religion:**
   (a) Catholic _____
   (b) Protestant _____
   (c) Jewish _____
   (d) Islam _____
   (e) Other ________________

6. **Education (highest level completed):**
   (a) No formal education _____
   (b) Grade/Elementary School _____
   (c) Junior High _____
   (d) High School _____
   (e) Vocational/Technical School _____ (# yrs_____)
   (f) College _____ (# yrs_____)
   (g) University _____ (# yrs _____)

7. **Employment:** Occupation: ___________________
   (a) Full Time _____
   (b) Part Time _____
   (c) On Leave _____
   (d) Unemployed _____
   (e) Retired _____
   (f) Other ____________________

PART B: CANCER HISTORY

8. **Initial Diagnosis:**
Date: ________________
Type of Cancer:
(a) Hematologic
Diagnosis ________________
(b) Solid Tumour
Primary Site ________________
Extent of Disease:
(i) Local _____
(ii) Regional _____
(iii) Metastatic _____ Site(s) ______________________
Treatment:
(a) RT _____
(b) CT _____
(c) Surgery _____
(d) Hormones _____
(e) Other ______________________

9. **Remission:**
Date: ______________

10. **First Recurrence:**
Date: ______________
Type of Cancer:
(a) Hematologic
Diagnosis ________________
(b) Solid Tumour
Extent of Disease:
(i) Local _____
(ii) Regional _____
(iii) Metastatic _____ Site(s) ____________________
Treatment:
(a) RT _____
(b) CT _____
(c) Surgery _____
(d) Hormones _____
(e) Other ________________________

Appendix D

Consent Form

Page 1 of 3

LIVING WITH RECURRENT CANCER

CONSENT FORM

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This research study is being conducted by a student in the Master of Nursing Program at the University of Alberta. The purpose of the study is to find out what it is like to live with recurrent cancer. The researcher also wants to know what helps patients with recurrent cancer get through the more difficult times. If you take part in this study, the researcher will interview you two to three times. She will ask you questions about living with cancer and what has helped you get through the more difficult times. You can refuse to answer any question you are asked. Each interview will last about one to two hours and will be taped. You will not need to be in the hospital to take part in this study. Interviews will be set for a time and place that is good for both you and the researcher. You may choose to talk with the researcher in person or over the telephone. These interviews are not a standard part of care for patients with recurrent cancer.

Information gathered in this study will be kept strictly confidential. Numbers will be written on the interview tapes and written records instead of your name. Only the researcher will know your name and which number was given to you. A secretary will listen to the tapes and make typed copies of them. Other people helping with the study may read the typed copies or listen to the tapes. These people will not know who you are and will not share the information with anyone. The researcher will not discuss your problems and concerns with other health care personnel unless you agree.

________________ ________________
Patient Initials Date

Information from this study will be shared with others through reports or articles. Some of your words may be in these reports but your name will not be used. There will be no way of knowing who you are. All information obtained in this study will be stored in locked files for as long as it is kept by the researcher. The consents will be stored separately from the data (tapes and written records). Only the researcher will have keys to the files. The researcher will keep the data and consent forms in separate locked files for at least seven years after the study is over. This data may be used in future studies but only if an ethics committee first gives approval.

Taking part in this study will not result in any health risks or extra costs for you. If you feel upset during or after an interview, you can call Dr. Michael Handman in the Department of Psychology at the [cancer agency] at 492-0896. He will talk with you about your feelings. Taking part in this study may be of no personal benefit to the patients. However, based on the results of this study, it is hoped that, in the long term, patient care can be improved.

Your doctor has consented for you to be approached to take part in this study. The final decision, however, is entirely up to you. You are free to choose not to take part in this study. As well, you can leave the study at any time by telling the researcher of your wishes. You can also ask her to leave any information out of study reports. Your care will not change as a result of any of these actions or choices.

My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to participate as a subject. In no way does this waive my legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I am free to withdraw from the study at any time without jeopardizing my health care. My continued participation will be as informed as my initial consent, so I am free to ask for clarification or new information throughout my participation.

_______________ _______________
Patient Initials Date

I understand that the researcher, Linda Read Paul, or thesis co-supervisors, Dr. Marion Allen and Dr. Karin Olson, will answer any questions that I have about the research project. They can be contacted at the numbers below:

Linda Read Paul, R.N., B.S.N., M.N. (candidate)
  Faculty of Nursing, 3rd Floor Clinical Sciences Building
  University of Alberta, Edmonton, Alberta T6G 2G3
  Telephone: 492-6411 (24 hour answering machine at Faculty of Nursing) or leave a message at 492-8771 after business hours
Marion Allen, R.N., Ph.D.
  Professor, Faculty of Nursing, University of Alberta
  Telephone: 492-6411 (24 hour answering machine)
Karin Olson, R.N., Ph.D.
  Coordinator of Nursing Research, [cancer agency]
  Telephone: 492-7751 (business hours) or leave a message at 492-8771 after business hours

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Patient Advocate at (403) 492-8585.

A copy of this consent form will be given to me to keep for my records and future reference.

____________________ Name of Patient	____________________ Signature of Patient
____________________ Name of Witness	____________________ Signature of Witness
____________________ Name of Investigator	____________________ Signature of Investigator

____
Date

Appendix E

Transcribing Contract

Project: Qualitative research study (Master of Nursing thesis): Hope in the Patient with Recurrent Cancer

Researcher:
Name: Linda Read Paul
Home Address: 10715 132 St. Edmonton T5M 1C8
School Address: Faculty of Nursing, 3rd Floor Clinical Sciences Building
University of Alberta, Edmonton T6G 2G3
Phone Number:

Secretary:
Name:
Address:
Phone Number:

Wages: $13.00 per hour including benefits and GST

File Format: see Transcribing Guidelines attached

Word Processing Format: WordPerfect 5.1

Anticipated Volume of Work: approx. 15-20 audiotaped interviews of 1-2 hrs each (2-3 interviews with 6-10 informants)

Anticipated Duration of Contract: February to June 1993

Oath of Confidentiality:

THIS IS TO CERTIFY THAT I, ______________________________, HEREBY
(print name)
solemnly affirm that I will diligently maintain the confidentiality of all information pertaining to the above project. I will not disclose or make known any matter which comes to my knowledge by reasons of my involvement in this project. I will keep all data (audiotapes, diskettes, and typed transcripts) in a secure location and will discuss the information therein with no one other than the researcher or members of the researcher's thesis committee.

I have received a copy of this contract for my records.

______________	______________________	______________________
(Date)	(Signature of Secretary)	(Signature of Researcher)

Transcribing Guidelines

1. Prepare data files as per Ethnograph guidelines. (40 character line, 10 characters per inch, indent of two spaces after each speaker identifier).

2. Create a new file for each interview. For filenames, use INF followed by the code number for the informant and interview as provided by the researcher. For example, the first interview with the first informant would be labelled INF0101. For file extension, use SEC so I know the file is the version received from you (i.e., INF0101.SEC). Once I check it and make any revisions, I'll rename it with a DOC extension and then convert it to ASCII and label it with an ETH extension.

3. For speaker identifiers, use "R" for researcher and "I" for informant. If a third person joins in the interview, use "O" for other.

4. Type *'s around all names mentioned in the interviews (other than the researcher's name) (e.g., *Dr. White*). This way, I can locate all names easily and replace them with a code letter.

5. Type blanks (i.e., _____) wherever there is a section you cannot understand.

6. Type dots (i.e., ...) wherever there are pauses in the conversation. Use one dot to represent each second of the pause so that the relative length of the pauses is apparent by looking at the number of dots.

7. When a brief comment (e.g., Oh yeah. M-hm. Mmm. Is that right.) is made by one person while the other person is talking and the other person continues talking after the brief comment is made, insert the comment into the text of the first person's transcript using **square brackets** rather than starting a new line with a new speaker identifier each time a brief comment is made. (e.g., I went to the hospital [M-hm] in January. [Oh yeah] Then I had radiation in March.)

8. Type emphasized words in all capital letters. (e.g., I lost ALL my hair that weekend.)

9. Type contextual information in **round brackets** where it is perceptible on the tape. e.g., I'm so upset. (sobbing) or That made me so mad! (voice louder)

10. If the informant continues talking after the tape recorder has been shut off at the end of the interview, I'll record an Addendum to the tape after I leave in which I will describe the conversation that took place after the tape recorder was off. At the beginning of this section, type + ADDENDUM at the left

hand margin, leave one space, and then type the description I've recorded on the tape.

11. Make a back-up copy of the file on a disc and store it in a secure place.

12. Return the audiotape to the researcher along with the disc containing the transcribed interview.

13. When I provide the next tape, I'll also give you a disc containing a copy of the corrected file (i.e., DOC file) so that you can replace the SEC file with the DOC file and thus retain a copy of the final version of each file.