

EXPERIENCES OF WOMEN WITH BREAST CANCER:
A CRITICAL INCIDENT STUDY

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A THESIS SUBMITTED IN PARTIAL FULFILMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

THE FACULTY OF GRADUATE STUDIES

(Department of Educational and Counselling Psychology, and Special Education,
Counselling Psychology Program)

We accept this thesis as conforming
To the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

May 2000

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Date 6 June 2000

ABSTRACT

Breast cancer is a disease that affects many thousands of Canadian women every year. Battling such a disease often involves an arduous and highly invasive regime of eradicated medical treatment, including perhaps surgery, chemotherapy, radiation and/or hormonal therapy. A growing body of literature is available which aims at illuminating the various experiences women undergo while receiving such medical treatment. While the majority of the available literature focuses on studies of a quantitative nature, a few are in existence which report on qualitative studies, studies where women undergoing the process of treatment for breast cancer are viewed as the "experts" of this process. The aim of this study was to explore the experiences of twelve women, aged from 41 to 70 years ($M = 55$ years old) who underwent eradicated medical treatment for breast cancer, from their own perspectives. To this end, the critical incident technique was used (Flannagan, 1954), through which women were asked to identify, during audiotaped interviews, experiences which both helped and hindered their treatment processes. Each of the twelve participants, or co-researchers, were interviewed twice; from these interviews, a total of 453 critical incidents were identified, and used to develop 15 thematic categories of experience for the participants involved: (a) relations with the medical team and any support staff (helpful vs. hindering), (b) medical treatment and services (helpful vs. hindering), (c) personal support (helpful vs. hindering), (d) activities/things which aid in treatment and recovery (or which did not help), (e) locus of control (helped vs. hindered), (f) availability and presentation of appropriate educational information (helpful vs. hindering), (g) attitude towards life and the human community (helpful), (h) support/psychoeducational agencies/groups/centres (helpful vs. hindering),

(i) maternal/caregiving role/behavior (helpful vs. hindering), (j) career as a medical professional (helpful vs. hindering), (k) spiritual beliefs (helpful), (l) career (helpful vs. hindering), (m) personal involvement in decision making (helpful), (n) physical appearance (helpful vs. hindering), and (o) alternative treatments (helpful). Category validity was tested through four procedures: (a) cross-checking by the co-researchers, of the incidents (and their appropriate category placement) during the second interviews, (b) exhaustiveness of the categories, where two complete interviews were put aside, and their incidents later placed in the already existing 15 formed categories, (c) the services of an external rater, who independently placed 100 of the 453 critical incidents into the already existing categories, and (d) linking the categories to some of the existing literature on theories related to counselling psychology, particularly those involving crisis, transition and resiliency. Implications for counselling research and practice are briefly discussed.

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ACKNOWLEDGEMENTS

I wish to thank my thesis supervisor, Dr. F. Ishu Ishiyama, for his ongoing dedication, support, and guidance during the various stages of this thesis research.

I also wish to thank Dr. William Borgen and Dr. Karen Meyer, my committee members, for their consistent involvement, support, and contributions to my process.

A special thanks to Ms. Elizabeth Dohan, MSW, of the British Columbia Cancer Agency: Vancouver Clinic, for her warmth, her humour, her valuable feedback, and for helping me make connections with my twelve co-researchers.

To my various friends, for their ongoing love and patience. You know who you are.

Finally, I wish to thank the twelve women who participated in this study- my co-researchers- for your involvement, your warmth, your compassion, your candor, your honesty and, above all, your amazing courage. Without you, this is nothing.

DEDICATION

This research thesis is dedicated to

CYNTHIA LEROSE

“CINDY”

WITH LOVE

CHAPTER I: INTRODUCTION

Breast Cancer in Canada

In its 1995 report, the National Cancer Institute of Canada (NCIC) states that approximately 17,700 new cases of breast cancer in women would be diagnosed that year. Of those 17,700, approximately 5,400 would die of breast cancer. While these figures are horrific, one must regard an important aspect of this tragedy: roughly 70% of Canadian women living with breast cancer survive. To be more precise: the NCIC presents in this report a "Deaths to Cases" ratio of breast cancer to be 0.31 or 31% (number of deaths divided by the number of new cases).

More importantly are the published relative survival rates for 1995. For certain years, in context of a "Special Topic" (1998, p.7), the NCIC provides survival rates from a different provincial registry; 1995 rates are provided by the Quebec Tumor Registry. It is the NCIC's view that results tend to be generally similar per capita across the provinces. The relative survival rate (which is the observed, or actual, survival rate adjusted according to general life expectancy per age group across the country) for women suffering from breast cancer (all ages) is 73%. Survival is generally seen as having lived for five years or more from the time of the cancer diagnosis (Mullan, 1984; NCIC, 1995), not necessarily from the time of cure. Thus, in terms of figures, according to the NCIC report for 1995, approximately 73% of women (all ages) who have received a diagnosis of breast cancer survive, thus placing breast cancer, in terms of NCIC

categorization, as allowing for a very good prognosis (66% or more chance of survival: uterus, breast, cervix, bladder, prostate, testis, Hodgkin's Disease).

The 1998 report, as published by the NCIC, presents a higher figure for new cases of breast cancer as diagnosed in Canadian women for that year (19,300), as well as a slightly lower death rate (5,300), than those figures published in the 1995 report. Thus, the NCIC presents in this report a "Death to Cases" ratio of breast cancer as 27% for 1998, as opposed to 31% for 1995. While these figures may be statistically encouraging, insofar as a slightly lowered death rate as presented over a three year span, they are still horrific: An estimated 19,300 Canadian women were to face new diagnoses of breast cancer in 1998 alone. This figure presents 31% of the total number of Canadian women presented with a cancer diagnosis (the NCIC estimation of new diagnoses of cancer, any type, in Canadian women for that year is 62,700); indeed, cancer of the breast is the most commonly diagnosed cancer for women in Canada. Almost one-third of Canadian women facing cancer diagnoses are being told they have cancer of the breast, totaling, again, an estimated figure of 19,300 Canadians that year alone: one out of nine Canadian women, as is currently believed and reported by the NCIC, will develop breast cancer at some point in their lives; women who are individuals, mothers, daughters, spouses, lovers, friends, and members of our society.

An attempt at imagining the number of Canadian lives who are deeply affected by this disease cannot be accurately represented statistically. An indication may be the circulation figure, in British Columbia and the Yukon Territory, of *Abreast in the Nineties*, a quarterly newsletter offering current information about breast cancer, as published by the B.C. and Yukon Breast Cancer Information Project (BCIF): current

distribution is estimated at 10,000 homes in B.C. and the Yukon. (The title *Abreast in the Nineties* has subsequently been changed to *Abreast in the West* at the turn of the year and century).

Statement of the Problem: Experiences During Treatment

These figures are important as they allow for an initial conceptualization of both the enormity of the problem of breast cancer, as it is faced by Canadian women, and of the hopefulness of a "very good prognosis". A staggering number of women are faced with the diagnosis of breast cancer; of those diagnosed, more than two-thirds of these women survive the disease, insofar as the general yardstick of survival, according to the NCIC, is concerned. Yet how do these women survive? Often they undergo surgery, radiation and or chemotherapy (occasionally referred to as the "Slash/ Burn/ Poison Trilogy") (Langellier & Sullivan, 1998, p.76), with the target nucleus at the onset of treatment being one or both of their breasts. What has been their process, their experience? Their bodies are invaded and counter-invaded; they are subject to tremendous fear, worry and grief. They may find themselves in positions where they face their own mortality. Many have spouses and children, many careers. What helped them through an often elongated period of daily crisis, to treatment completion? What internal mechanisms, what external supports, were valuable to these women who have indeed faced an ongoing nightmare, with the ideal conclusion being survival? Did they see themselves as victims or champions? What aided or prevented the establishment of such identities? Have they been validated, supported, or treated as diseased subjects, through the biomedical treatment regimes? What helped in the process of such treatment? In

short, what helped, and what hindered, these women in their experiences of dealing with the disease? What are their stories, their experiences? Are these experiences ever addressed, or even regarded, by the myriad of helping professionals who aim their efforts at eradicating the cancer- of curing the patient- without destroying her in the process? What do these women experience as they struggle through such treatment, treatment which may not only be highly invasive at multiple levels, but immediately invasive of an area which may be identified as a focus for both individual sexuality, and parenthood; an area which has probably been sexually objectified, on a cultural level, for the individuals facing this disease either at some point, or throughout, their lives?

Thus, this research project explored the experiences of twelve women who have been diagnosed and have been treated for breast cancer, from their own perspectives. Their stories were witnessed, by the co-investigator, as they told them, through the structure of a critical incident study: a study of incidents, or actual events in the women's lives, which were critical, or which affected their individual experiences of breast cancer to an important degree (Woolsey, 1986). The initial interview questions were: "What helped you in your experience of breast cancer? What hindered you through this experience?" Any probing that occurred took place in discussion around the incident presented, insofar as its structure (i.e., what led to the incident; what was the experience; what was the result). Also, at the beginning of the first interview, time was given to presenting a thorough introduction to the study; while reviewing the letter of introduction with the co-researcher, some time was spent in "setting the stage" for the interview (in a further elaboration of the type of study). Such interviews answered, or presented a

combined explanatory framework for, the research question: What do women identify as helping and hindering experiences during the process of breast cancer?

With such a study the often highly traumatic experiences of its participants were given voice, through which they and their experiences were validated. Such validation may be an unusual, even an unique, experience: when one considers the various procedures they may have been subject to over the previous weeks or months- the possible surgery, chemotherapy, radiation, numerous examinations by numerous doctors and specialists- they may have indeed felt like their bodies and psyches had been invaded or were under invasion, that they had been besieged.

Such a history they brought with them to the interviews, during which, through the construction of the interview and the interview questions, they became the experts in the process of breast cancer (with all that implied). Again, they were the experts, not the subjects nor the patients. They had fought a debilitating disease and had come out victorious in the process. Their stories were important, were valued, and needed to be heard. Such voice not only helped those being interviewed but was facilitative of the accumulation of information which resulted in a map of categories, categories comprised of incidents with thematic similarities which were created from the numbers of critical incidents examined (Alfonso, 1997). Such a map should prove useful, not only as a representation of testimonies, from women who have had breast cancer to women who are being told they have it, but as a report of vital information for the development of counselling interventions, for others facing this disease and perhaps some other forms of cancer. Thus, the participants of this study ideally experienced a sense of self-empowerment, as they told their stories; these stories in turn resulted further in a map of

categories which offer a series of testimonies and strategies for others as they experience the process of diagnosis and treatment for breast cancer.

Experiences Versus Questionnaires

Thus was a presentation of the more philosophical and vocational rationale for this study. Also, such a study would be in keeping with not only the client-centred theoretical basis, but also the humanistic stance which the co-investigator prefers in working with clients, such a preference here extended to co-researchers, as opposed to subjects. Of perhaps more pragmatic importance is the need for such a study, in terms of the available literature.

Of the number of research articles examined, at the time of writing this report, only a few presented studies were conducted- with women who have faced breast cancer- from a more qualitative perspective; thus there is a dearth of literature examining such a process from this paradigm. The vast majority of these same articles present reports on data compiled from various quantitative measures- mainly questionnaires- which were administered to women. While most of such data must be of value, insofar as the understanding of the various emotional, spiritual and physical challenges faced by women with breast cancer- and thus contributing knowledge which will ideally lead to enhanced understanding and therapeutic interventions- such procedures alone may inadvertently keep women in the roles of subjects: subjects of treatment, subjects of surgery, subjects of examinations, subjects of questionnaires. They may feel they are being tested, in terms of their experiences with breast cancer, and also in terms of anything from their emotional resilience to their ability (or inability) to maintain spousal intimacy, through such a crisis.

Such research procedures may not enable women to feel like experts in the process, nor like champions. Also, they are adhering to specific constructions of questions worded in particular ways; through the experience of such a procedure they may not feel like they were being heard, that their experiences, as unique individuals who have survived such a nightmare, were given voice. Rather, they themselves were adhering, again one more time, to a set of preconceived constructs, from which they were to follow, in answering the questionnaires. Again, such information is valuable in the accumulation of knowledge, which in turn will hopefully lead to better understanding and interventions, but such a procedure may not necessarily be validating for the "subject". While quantitative measurements tend to be reductionist and hypothesis proving, a study such as this one was designed to be constructionist- in that one begins with the source, the individual who has been through a process around the disease of breast cancer, and constructs a map based on their experiences as they tell them- and, potentially, hypothesis generating. A goal of this research project is, thus, to not only refer to the participants as co-researchers, as opposed to subjects, but to facilitate their believing they are co-researchers, as they endeavor through a joint effort at understanding their experiences of the disease and the treatment process from their perspectives; such an experience would help the participants directly, as well as others in the future.

Definitions

The following six key terms are defined here, under: (a) breast cancer, (b) treatment, (c) experiences, (d) survival, (e) co-researcher, and (f) coping.

“Breast cancer” refers to carcinoma originating in the female breast. While it is feasible for men to develop breast cancer, they will not be included in this study, as less than 1% of all reported cases of breast cancer are diagnosed in men (Abeygunawardena, Dickson, Godel, Kelly, Parry, & Sullivan, 1996). Oncologic terminology tends to refer to any carcinoma from its place of origin, the place where the neoplasm initially developed (i.e., cancer of the breast which has metastasized into a lymph node, or into the blood stream, continues to be, in lay terms, referred to as breast cancer, despite the location of subsequent metastases). Like most carcinomas, breast cancer is rated in terms of severity, or extent, of the cancer at the time it was diagnosed in stages, ranging from Stage I to Stage IV, with Stage I being the least severe and Stage IV the most severe.

“Treatment” refers to anything which is fundamentally involved in the eradication of the cancer. Treatment usually involves surgery, and often chemotherapy and/or radiation.

“Experiences” comprise the heart of the research, and refers to any events that the co-researcher deems applicable, in terms of her treatment for breast cancer as a disease and as a life altering reality (within the parameters of a critical incident study). The experience for some may begin at the time of diagnosis, for others at the time of personal breast lump detection, for others at a time when they began experiencing anxiety over the possibility of developing a breast neoplasm (i.e., the person’s mother may have developed such a neoplasm at a certain age, and that person is reaching that age). Each individual will come with a personal history relative to the experience of the disease; it is these histories, these perspectives, which will be flushed out. Technically, the experience, in terms of this study, ends when the eradication treatment ends. Realistically, however, this

is seldom the experience of women whose treatment has ended; the “experience” of the disease may continue. Thus, during the interviews this parameter will be left fairly open; indeed the “experience” may entail, for example, original diagnosis to the present day.

“Survival” refers to surviving the disease of breast cancer. In terms of the NCIC, the yardstick of survival remains, arguably, the standard five years post-diagnosis. Survival, in terms of the context of the co-researcher, has obviously much greater meaning. In fact, survival could carry different meanings for different individuals, other than the more obvious remaining alive (i.e., victory, living in fear, depression). While all the participants of this study will, indeed, be “surviving” the disease, thus requiring a brief exploration here, the word “survival” will be avoided during the interviews, as it denotes images of “battle” or “war”, as well as images of finality, as opposed to what is considered to be images which these interview processes would ideally include, images of a “process”, or a “journey”, through treatment for breast cancer.

“Co-researcher” refers to the participants of this study. In keeping with the aim of and atmosphere for empowerment of the women being interviewed, they will be referred to as co-researchers; in so doing, the labels of subject, patient, and participant, are avoided.

Finally: while the word “coping” is avoided in the context of the questions proposed for this critical incident study (as it would further limit potential arenas of exploration on the part of the co-researchers while they are examining and discussing their critical incidents), the word and what it implies often emerges in the existing literature on studies conducted with women facing treatment. How these individuals “have coped”, or “are coping” is a popular angle for exploration in the literature.

Data Analysis

The analysis of the data collected (i.e., the critical incidents) has been regarded as the most time consuming, and often the most difficult, stage of a critical incident study (Woolsey, 1986). Presented in the literature on critical incident studies is a procedure involving three stages: selecting a frame of reference; choosing thematic categories; and establishing a level of generality for the categories developed (Flannagan, 1954; Woolsey, 1986). Firstly, the frame of reference was established based on what the investigator and co-investigator wanted the results of the study to be used for. For this study, it is planned that the results will be used as a reference for both women who have been diagnosed with breast cancer, and helping professionals who both care for these women throughout diagnosis and treatment, and who develop, or wish to develop, counselling models for further support. Secondly, the development of thematic categories is presented as the most time consuming of the three stages. This procedure was a highly subjective one, as the co-investigator sorted the incidents into specific "clusters that seem to group together" (Woolsey, p. 249); this part of the analysis was performed with care over time. Finally, the level of generality was established, and was used when reporting the incidents. The key to this lay in the deciding as to how specific the investigators believed they needed to be, insofar as the number of separate categories deemed necessary for effective representation of the incidents presented (Flannagan, 1954). In other words, would, for example, twelve more general categories best represent the research findings, or would 40 more specific categories prove more valuable? The development of this step ran concurrent with category formulation, as was deemed appropriate at the time of

formulation. Further examination of the data analysis will be found in Chapter 3 of this thesis.

CHAPTER II: LITERATURE REVIEW

Literature Involving Gender Differences

It is difficult to imagine what someone being treated for breast cancer with surgery, radiation and or chemotherapy, as well as alternative therapies, experiences. An abundance of literature on quantitative research exists, however, which focuses primarily on the reactions and coping mechanisms exhibited by people with breast cancer specifically, and cancer generally. Some research focuses on the differences between genders on adjustment to cancer treatments. As breast cancer is usually diagnosed in women, a brief examination of some of this literature may be noteworthy, in terms of attempting to flush out possible behavioral mechanisms which may be linked to issues of gender that women bring into the diagnosis and treatment arenas.

Fife, Kennedy, and Robinson (1994) conducted a study of 206 women and 125 men, in an effort to determine if there were any differences between the two genders regarding general psychosocial adjustment to cancer diagnosis and treatment. All subjects had been diagnosed with some form of cancer, predominately: lung, breast, colon, testicular, and lymphoma. Briefly, subjects responded to various scales measuring adjustment to illness, perceived social and professional support, methods of coping, emotional and cognitive responses, and indications of denial. Analysis of their research indicated that women tend to make a more positive adjustment than men, and that emotion based coping strategies generally employed by women tend to help them cope better than the general problem solving strategies employed by men (Fife et al., 1994). Also, women's adjustment was more dependent on family support, while men's tended to

be more dependent on professional support (a type of support not as readily available as family support). The authors also note that men's socialization may work against them in adjusting to the reality of having cancer: for men, the traditional role of provider and hero can induce problems in seeking emotional support from others in the family. The other side to this result is that women's socialization may thus work for them in adjusting to the disease, in terms of their, albeit stereotypical, ability to seek emotional support from family and friends.

These findings are similar to those found in a study conducted by Leigh, Percarpio, Opsahl, and Ungerer (1987). In their study, the authors administered a questionnaire to 101 outpatients reporting for radiation therapy. The questionnaire included sections on demographics, as well as on anxiety, depression, level of awareness towards severity of the cancer, and subjects' feelings regarding their visits for radiation. The authors do not give a clear breakdown of subjects' gender in numbers, but state that breast and prostate cancer were the most common forms being treated, in women and men respectively. Their results indicate that men generally tend to maintain greater levels of denial about their conditions than women, which may not be conducive to adaptation. Thus, relatively lower levels of denial as a process may indeed prove a perhaps gender based strength which women take into the cancer arena. Leigh et al. Also suggest that realistic anxiety may be adaptive in coping with treatment and fears about the future.

Literature Involving Questionnaires

Moving from a very brief look at two articles which studied adaptation to cancer as being influenced by gender, the following is a brief look at some of the quantitative

literature which focuses solely on the experience of breast cancer. Like the articles referred to above, much of the quantitative literature restricts the presentation of women's experiences with breast cancer to their experiences in terms of how they coped with having the disease.

A study of 133 women, all under 55 years of age, who had been diagnosed with breast cancer, was conducted by Waxler-Morrison, Hislop, Mears, and Kan (1991). The subjects responded to questionnaires, soon after diagnosis, which included questions regarding demographics, education, social and family networks, including levels of support available as well as individual responsibility in relationships. These reports were analyzed and matched with the medical records of each patient's condition.

A follow-up was conducted four years after the original data was collected: 105 of the original subjects had survived. The authors compared the data of the survivors with the non-survivors, in order to ascertain any relationships between individual scores and survivorship. Briefly, the authors discovered two medical factors which predicted survival: the stage, or severity, of the disease at diagnosis, and the states of the diseased modules (or masses of tissue) at time of diagnosis (Waxler-Morrison et al., 1991). The authors also discovered a significant relationship between the indicators of social context and survival, particularly regarding friendships and employment outside the home. They discovered that the greater the number of friends perceived by the woman as being supportive, the greater the likelihood of survival. Also, the fact the individual was employed seemed to increase her likelihood of survival. The authors suggest, thus, that a highly positive impact is made by friends who not only offer support, but help in practical ways as well (child-care, shopping, cooking, transportation), as opposed to support

received from family members, which in many cases was perceived by the women in the study as being complex, ambivalent, and sometimes stressful (Waxler-Morrison et al.). Many women reported in fact they were often the ones being supportive of the family during the crisis, particularly if they had young adult children (an issue which also emerges in the research findings reported in this thesis).

Similar to the study of Waxler-Morrison et al. is one which was conducted in Germany and Switzerland, by Beddeberg, Sieber, Wolf, Landolt-Ritter, Richter, and Steiner (1996). For this study, 107 women (ranging in age from 29 to 70 years, with a mean age of 52 1/2 years), who had six months before the study's onset endured surgery for breast cancer, were assessed through the use of two questionnaires- the *Freiburg Questionnaire of Coping with Illness* (FQCI)(Muthny, 1989, as cited in Beddeberg et al., 1996), and the *Zurich Questionnaire of Coping with Illness* (ZQCI)(Sieber, Beddeberg, & Wolf, 1991, as cited in Beddeberg et al., 1996), (both regarding levels of coping)- several times over a period of three years. At the end of those three years, 66 of the original 107 women had remained involved: 27 had dropped out of the study; 14 had died. The authors hoped to discover some relationship between strategies of coping and outcome of disease.

After a process of statistical analyses, the authors reported finding "no significant relationships between coping strategies and survival" (p.259). They do report, however, a statistically significant relationship between survival, post-surgical tumor size and lymphatic node status. Beddeberg et al. (1996) concluded the relationship between the psychosocial dynamics of the person with breast cancer and survival remains unclear, but

state their results as indicative of physiological aspects of the disease's effect as being more important than psychological variables, in terms of survival.

In contrast to the results of the Beddeberg et al. study are those presented by Ora Gilbar (1996). In 1984, the author began a study of 40 women (with a mean age of 50.06 years) who had all undergone mastectomies for breast cancer. These women were interviewed using two assessment scales, the *Brief Symptom Inventory* (BSI)(Derogatis, 1975, as cited in Gilbar, 1996) and the *Psychosocial Adjustment to Physical Illness* Scale (PAIS)(Derogatis, 1976, as cited in Gilbar, 1996). The BSI was used in an effort to measure psychological distress, and contains 53 items, to be answered on a Likert scale format; the PAIS attempts to measure level of adjustment to illness, and contains 46 items, to be answered on a Likert scale format. A follow up was conducted eight years later, in 1992, of the 40 women who had participated in the study. Of those 40, eight had died and seven had had a reoccurrence of cancer. The mean age of those who had survived and were cancer free was 51 1/2 years. The questionnaire scores of those who had survived and were cancer free were then compared, through data analysis, with those who had died. The results indicated that, at the time of original diagnosis and treatment (1984), the level of psychological distress, according to the two questionnaires, was more severe for those who had subsequently died than those who had survived the disease and were cancer free in 1992, at the time of the follow-up. Thus, Gilbar (1996) confirmed "that better coping leads to longer survival"(p.269), and recommended the development of a treatment program which is specifically oriented to those undergoing initial breast cancer surgery who are experience "severe negative feelings immediately after diagnosis" (p.269).

Similar to the findings reported by Gilbar are those presented in a cross-sectional study report conducted by Classen, Koopman, Angell, and Spiegel (1996). The authors here wished "to determine whether psychological adjustment of advanced breast cancer was positively associated with expressing emotion and adopting a fighting spirit and negatively associated with denial and fatalism" (p.434). The authors administered three questionnaires to a group of 101 women who had all been diagnosed with various forms of breast cancer. The three scales used in this study were: The *Mental Adjustment to Cancer Scale* (MAC)(Watson, Greer, & Bliss, 1989, as cited in Classen et al., 1996) which attempts to measure denial, fatalism and the extent to which the examinee has a "fighting spirit"; the *Courtauld Emotional Control Scale* (CECS) (Watson, & Greer, 1983, as cited in Classen et al., 1996), which attempts to measure emotional control; and the *Profile of Mood States* (POMS) (McNair, Lorr, & Droppleman, 1971, as cited in Classen et al., 1996) which attempts to measure mood disturbance and thus psychological adjustment. Through a series of multiple regression analyses, the authors were able to confirm their hypothesis that emotional distress associated positively with emotional control (or controlling the expression of feelings such as anger or fear by, for example, repression), and negatively with fighting spirit. The authors were, however, unable to find any significant association between denial or fatalism and emotional distress. Thus, they purport that a negative association may exist between the overt controlling of ones emotions during the crisis of breast cancer and the psychological adjustment of those in that crisis.

A study more specific to the coping of women undergoing chemotherapy for breast cancer was conducted by Manne, Sabbioni, Bovbjerg, Jacobsen, Taylor, and Redd

(1994). The authors administered three assessments to 43 women who were in the process of receiving chemotherapy treatment. The three measures used were: The *Physical Symptoms Questionnaire* (PSQ)(Manne et al., 1994), an assessment of physical symptoms experienced three days previous to the taking of the questionnaire (which was taken two weeks after the most previous chemotherapy treatment); the *Ways of Coping Questionnaire* (WOC)(Folkman, Lazarus, Gruen, & DeLongis, 1986, as cited in Manne et al., 1994), which attempts to assess "cognitive and behavioral strategies people use to manage internal and/or external demands" (p.46); and, again the POMS (McNair, Lorr, & Droppleman, 1971, as cited in Manne et al., 1994). Manne et al. (1994) purported a significantly positive relationship, as the result of their data analyses, between physical symptoms and level of negative affect. Also, there was no reported relationship between physical symptoms and positive affect. In regards to the relationship between positive affect, negative affect, and coping, the authors concluded that participants who reported greater levels of negative affect over positive affect tended to engage to a greater degree in coping which was, in reference to the sub-scales on the WOC, more "escape-avoidance" and "confrontive". Those who reported greater levels of positive affect tended to score higher in the WOC subscales of "positive reappraisal", "distancing", and "self-controlling". The authors thus proposed "that coping and physical symptoms have different patterns of relationships with positive and negative affect"(p.53), and recommended consideration of this finding during the development of treatment/counselling plans.

In her article, entitled *Functional status of long-term breast cancer survivors: Demonstrating chronicity*, Margaret L. Polinsky (1994) presented a report of a study she

conducted which aimed at discovering and disclosing certain long-term effects of a breast cancer diagnosis as experienced by survivors of this disease. The author presents results of three assessment measurements which she administered to a select group of 223 survivors of breast cancer. She wished to assess the states of long-term (16 months to 32 years post surgery) survivors of breast cancer in the contexts of physical, social and psychological functioning, in an attempt at revealing any long-term effects of the disease, as experienced by the survivors surveyed, in terms of the above three mentioned functional arenas. The three surveys used were as follows: the POMS (McNair, Lorr, & Droppleman, 1971, as cited in Polinsky, 1996), which again aims at accessing mood, disturbance, and psychological functioning; the *Short-Form Health Survey* (SFHS)(Stewart, Hays, & Ware, 1988, as cited in Polinsky, 1996), a 20 item questionnaire derived from the *Medical Outcomes Study* (MOS)(RAND Corporation, no date offered, as cited in Polinsky, 1996). The aim of these two questionnaires is to access the respondent's general well-being, through an assessment of social, physical, and role functioning, perceptions of physical health, mental health, and pain. The third measure, the *Breast Cancer Specific Measure* (BCSM)(Polinsky, 1996), was designed by the author herself, and was adapted from the *Cancer Rehabilitation Evaluation System* (CARES)(Schag, & Heinrich, 1988, as cited in Polinsky, 1996), to become more breast cancer specific. The questionnaire attempts to assess any problems or concerns which are either socially, physically and/or psychologically based, and which are directly relative to the breast cancer.

The results present some noteworthy findings, too numerous to be reported here. In relation to the first two measures, which are both reported as having been tested for

reliability and validity- the SFHS and POMS-levels of functioning of this sample group was high, indicating general health and well-being. However, in reference to results from the BCSM, the measure which has not been thoroughly tested for reliability and validity, various concerns are raised by the author, concerns and problems as indicated by the participants, in all the three ascribed functioning arenas, including: long-term physical effects such as clothing being uncomfortable, the arm involved in surgery being weak; long-term treatment related effects such as vomiting and nausea (from chemotherapy), breast tenderness (from radiation), numbness (from surgery); long-term psychological effects such as anger over having had breast cancer, and anxiety over a possible reoccurrence; long-term social functioning effects (for a smaller percentage of respondents) such as having no one to talk to regarding concerns about the disease, problems with employment income, and problems with health insurance (again, this is an American study). The author reports these findings and concludes with recommendations for the need to provide ongoing accurate information regarding “psychosocial stresses generated by survivorship” (p. 172).

Another study involving questionnaires is reported by Cordova, Andrykowski, Kenady, McGrath, Sloan, and Redd (1995); this study examines the likelihood and degree to which women who have been treated with breast cancer will, as they have faced a life-threatening disease, develop symptoms of posttraumatic stress disorder (PTSD) as detailed in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM IV, American Psychiatric Association, 1994). The DSM IV allows for diagnosis “with a life threatening illness” (1994, p.424), as meeting their criteria for “an extreme traumatic stressor” (1994, p.424). Through the use of three measurements- the *PTSD Checklist-*

Civilian Version (PCL-C)(Cordova et al., 1995), the *Impact of Events Scale* (Cordova et al., 1995), and the *Medical Outcomes Study* (Cordova et al., 1995)- the authors conclude that PTSD like symptoms may be both quite common and may exceed the “base rate of these symptoms in the general population” (Cordova et al., 1994, p. 981). The authors further report that between 5% and 10%, of the 55 women who participated in the study, would probably meet the criteria for PTSD as presented in the DSM IV.

An interesting study, perhaps more pertinent to the research proposed here, was conducted by Boman, Andersson, and Bjorvell (1997), and which involved an open ended question disguised in a 66 item questionnaire, administered to 132 women who were in hospital recuperating from some form of surgery aimed at eradicating breast cancer. The questionnaire was administered to each participant 10 days post-surgery. The questionnaire addressed the patients’ feelings and ideas regarding the care received in the hospital before and after surgery. The particular question of interest in this study was worded: “Is there anything that you wish for or would like to change, when you think about your stay in the hospital and the time that followed it? Write down whatever occurs to you” (1997, p. 26). Of the 132 participants, 97 answered the particular question; the mean age of all respondents was 58 years. Using a type of analysis, as described, which consistently compares statements to each other, the authors present a results of the 97 answers in terms of five categories of needs developed from such clustering work: emotional support, personal treatment, practical assistance, information, and trust (all five needs are represented to some degree in the results of this thesis). Each category is further explored and explained, and a model is presented which illustrates these five categories as being mutually related to each other. Thus, within the disguise of

a questionnaire, the women involved may be viewed as having been given “voice” around what their needs were, and how those needs were met, in a particular scenario they were involved in as the result of their treatment process. Such a study could feasibly be reformulated into one using the critical incident design. Of potential interest cross-culturally is the fact this study took place in Sweden.

This has been a brief look at samples of the literature presenting studies of women who have or have had breast cancer. These studies have maintained a variety of relative purposes for exploration, including: How social relationships may affect women’s chances of survival from breast cancer; how various coping strategies may affect chances of survival; how levels of chronic psychological distress may affect chances of survival; how emotional expression may affect psychological adjustment to this disease; the possible relationship between emotional affect and coping during treatment; possible challenges in daily functioning as experienced by long-term survivors of the disease; possible PTSD symptoms as presented by women who have completed treatment. These are, again, samples of the existing literature: while some of them may be referable in terms of research outcomes discovered through the research reported here, none of them addresses, to an equivalent degree, what helped women through this process, from their perspectives. The articles closest to this aim would be, with the exception of the Boman et al. study, those which aim at addressing the various styles and levels of coping as presented by women who have, or who are, undergoing treatment.

Literature Involving an Experiment

The following study is an experimental study conducted by Jacobsen, Bovbjerg, Schwartz, Hudis, Gilewski, and Norton (1995) in which the authors wished to determine whether subjects undergoing chemotherapy treatment for breast cancer could develop distress responses which were classically conditioned. A total of 80 women undergoing such treatment were randomly assigned to a control group (n=39), or an experimental group (n=41). Before each infusion, patients in the experimental group were given a "distinctive beverage" (i.e., lemon-lime *Kool-Aid*) to drink; the control group were given no such beverage. As the result of extensive procedures involving ratings of emotional distress while drinking the beverage before chemotherapy infusion, ratings of distress when being exposed to the same beverage at home, for the experimental group, as well as general ratings of distress for the control group, the authors were able to confirm their hypothesis "that the pairing of a distinctive stimulus with chemotherapy administration results in the development of conditioned emotional distress" (1995, p.112). The authors justify such an experiment in terms of its contribution to the understanding of and treatment for anticipated distress on the part of individuals undergoing chemotherapy treatment. While this point may be valid, it is questionable whether such a recommendation was worth the perhaps additional distress experienced by those in the experimental group who after all, were already living through the highly stressful situation of undergoing chemotherapy for breast cancer.

Literature Involving Qualitative Research

The following is a review of some of the few purely qualitative reports so far uncovered in the literature. In her report entitled "Struggling to gain meaning: Living with the uncertainty of breast cancer", Jenenne Nelson (1996), presents the results of a phenomenological study, through the use of both hermeneutics and what the author describes as photographic hermeneutics. The study focussed on the construct of uncertainty as experienced by nine co-researchers, between two and six years after the conclusion of their treatment for breast cancer. Through the use of interviews and photograph interpretations, the author collected data and, from the data, developed five themes of uncertainty for these co-researchers. These five themes are, in the order presented by the author: the vicissitude of emotions; the relying on support through relationships; transitions, or discovering new ways of being (in the world); reflections of oneself (in the world); gaining understanding, and in that understanding the incorporation of uncertainty into the perspective of life. The author goes into great detail in her descriptions of each theme. The development of such a study, which focuses on the experiences of women- who have experienced the process of breast cancer- from their own perspectives and, in so doing, validating such perspectives as vital contributions to research and the available literature, is encouraging. The women in Nelson's study truly seemed to have been co-researchers, and not subjects, or patients.

A report of a narrative study, conducted with 17 women who had completed treatment for breast cancer, was presented, by Langellier and Sullivan, in *Qualitative Health Research*. The study explores- by attending to references made to the participants' breasts and breast cancer- issues of sexuality, femininity and body image as

experienced by the participants, through the use of open-ended interviews. The authors refer briefly to the use of phenomenological analysis, where they isolate, through the examination of transcripts and audio recordings, any references made to the breasts unto themselves and also to the breasts as the original cancer sites. As the result of such analysis, four thematic categories, interrelated with each other, are presented: the sexualized breast, involving issues around sexual desire and desirability; the gendered breast, involving issues around body image and femininity; the functional breast, involving issues around motherhood and breast feeding; the medicalized breast, involving issues around the breast as a body part where disease has developed, and which must be treated bio-medically. The authors affirm the importance of such research, in the potential empowerment for the participants, and offer results suggesting both “greater and fewer problems with body image than presumed by such psychosocial research”(1998, p.90). Here, Langellier and Sullivan are referring to the abundance of quantitative research available on how women experience breast cancer.

Perhaps the most poignant article found in the literature, and one which appears closest to the aim of this research project, is one where the author purposefully suspends “the rules of scholarly authorship” (Becvar, 1996, p.83), and speaks to the reader in the first person. The article, written by Dorothy Becvar, is entitled “I am a woman first: A message about breast cancer.” It is based on a culmination of information from professional literature, the author’s experiences as a marriage and family therapist, as well as on her own experience with breast cancer. The article is intended both as a presentation of emotional reactions as experienced by those with breast cancer (such as: fear, anger, mourning, and challenges to female identities), and as a message to friends,

family members, and helping professionals regarding what the needs of such individuals may be during treatment. One of the more poignant messages offered here, for consideration of all who read this article, is the need of the author (and of others in similar positions), "to be treated as a living, breathing person, as a woman who *has* breast cancer, and not as either a statistic or as a disease"(Becvar, 1996, p.84). This quote on its own is affirming of the research study this thesis reports on. In speaking for herself and others, the author goes further to say: "I worry about imposing, so it would help me if you would offer to go with me to the doctor, to be there when the test results come back, to stay with me in the hospital, to talk to me or hold my hand through chemotherapy..."(Becvar, 1996, p.84). Such needs, such actions that potentially help, have indeed been flushed out in critical incidents as described later in this study. Indeed, just as the abundance of literature which present studies of women with breast cancer from more quantitative orientations helps to prove the need for such a study as this, so too does the publication of this researched message.

CHAPTER III: METHODOLOGY

Questions

As presented earlier, the leading interview questions for this study were “What helped you in your experience of breast cancer”. “What hindered you through this experience?” From this question, a number of incidents were gleaned. These questions led to the probing, of responses, when necessary, and of their context (i.e., if a co-researcher began describing her relationship with her spouse as helping her during treatment, specific incidents of support were elicited through the use of probes such as: “Can you recall a specific situation where your spouse was helpful?”). Such questions were, again, aimed at exploring answers to the fundamental research question of: “What do women identify as helping and hindering experiences during the process of breast cancer?”.

Such an explorative design was generally experienced as beneficial for the co-researcher, as some power was given back to her through the validation of her experience. Also, she was perceived as the authority, and was given voice in presenting her experiences of treatment from her own perspective. This study also augments the again seemingly tremendous lack of qualitative research in the literature available on this area.

Method, Design, Data Collection and Procedures

The critical incident design involves a phenomenological approach, through which an experience exists primarily through the co-researcher’s perception of that experience. While conducting the interviews, the co-investigator acted as the measuring tool, the lens, with which and through which the experiences of the co-researchers were

given voice. Overlaying such a perspective is the critical incident structure, which allows some parameters around the exploration through the use of leading questions aimed at eliciting experiences from particular perspectives, as seen by the co-researchers: with this structure, focus is given to what helped and what hindered the process of the experience. Thus the experience is not invalidated, but it is given parameters, insofar as information is recalled and presented by the co-researcher in terms of specific incidents which helped and or hindered her in either her experience total and or her experience specific.

From these experiences, critical incidents were illuminated, and developed into representative themes, or categories. In order to do this successfully, incidents were judged to be incidents in terms of a necessary structure which was comprised of three parts: the source, or what led to the particular incident (i.e., a radical mastectomy); the action taken, or what occurred (i.e., recuperation and subsequent temporary inability to oversee maintenance of the family home); the results, or what the outcome was (i.e., the spouse takes on the responsibilities of maintenance, such an outcome greatly helping the co-researcher who was recovering from surgery and anxious over both the disease and her family). In this study I focused primarily on the action component of each critical incident, the actual experience of each co-researcher. Both the source and outcome components were thus viewed in context of the action component. In so doing, proper emphasis was placed on the experiences themselves, which were initially extracted during the data analysis, and then viewed a second time in context of the framework for a critical incident.

The sample for this study, again, were adult women who had been diagnosed with and who had completed eradicated treatment for breast cancer, in terms of surgery,

chemotherapy, radiation and or alternative treatments. Participants were solicited through an advertisement in the Fall 1998 edition of "Abreast in the Nineties" (now "Abreast in the West"), a quarterly newsletter as published by the BC and Yukon Breast Cancer Information Project and circulated to approximately 10,000 homes in BC and the Yukon Territory. Solicitation of further participants occurred, through visits to certain support groups, as per the invitations of a counsellor from the Patient and Family Counselling Department at the Vancouver clinic of the British Columbia Cancer Control Agency, and of facilitators of these groups. These co-researchers did not necessarily have to be classified as "survivors", in terms of the five year hallmark; again, such reference were avoided during the interviews. They had, however, completed eradicated treatment and were free of cancer reoccurrence, as far as is known at the time of the study.

The study consisted of two interviews, the initial interview being where the co-investigator and the co-researcher came to know each other somewhat, during which the co-researcher was presented with the various logistics of the study, which involved the review of a letter describing the study. After this began the exploration and illumination of specific events from the co-researcher's experience, in terms of what helped and hindered that person in the process as she viewed it. Questions, as those outlined above, as well as others when appropriate, were used, in order to gain as much information as possible during the time allowed. From the accumulation of these events were created, again, categories which encompassed themes of experience, for the individual co-researcher, and, with certain cases, for the group as a whole. After these categories were developed and analyzed, a second interview was conducted, during which categories appropriate to that interview were reviewed, both for the co-researcher's consideration,

and to facilitate discussion. In so doing the voices of the co-researchers had a greater chance of being heard, and represented, as accurately as possible. It was at this time that critical incidents which had remained unclear to the co-investigator, in terms of the most appropriate category for their placement, were reviewed with the co-researcher who described those incidents, insofar as the choice of best category, in her opinion, for the placement of those same incidents. Such a procedure both took the incidents, again, back to their source- the co-researcher- and further empowered and affirmed the co-researcher as just that, a co-researcher.

As presented by Flanagan (1954), and revisited by Woolsey (1986), the data analysis of a critical incident study can be successfully carried out in a three step process. The first step is referred to as "selecting a frame of reference"(Woolsey, 1986, p.249). Selecting such a frame would be based on the intended use of the results of the study, which in turn would affect category development. In this study, themes- which identified the experiences of the co-researchers- were illuminated throughout the process, for reference and for the possible enhancement of both peer and therapeutic awareness of the more positive and negative components of these experiences. Ideally, knowledge is gained and others experiencing this disease helped, insofar as they may have access to an accumulation of experiences of those in positions similar to themselves, in terms of what really helped these co-researchers through this journey. Also, again, is the belief that heightened awareness on the part of professional helpers may in turn enhance their caregiving of women facing breast cancer in the future.

The second step for data analysis involved the formulation of the actual categories, based on clustering the various incidents extracted in terms of thematic

similarity. Such a step was indeed the most time consuming, as time was required for the categories to become clear, and gel together. Such categories were then checked with the co-researchers during the second interview.

The final step, according to both Flannagan and Woolsey, involves the establishment of a level of generality versus specificity, a level which is most appropriate when reporting the categorical results of the study. In other words: How many categories will best represent the themes developed? This process, again, took time, and ran concurrent with the formulation of categories. It was recommended the co-investigator stay with the category development until a sense of intrinsic "rightness" (Woolsey, p.250) was achieved, a sense of the entire work, again, having gelled. Such categories can be then validated by having them cross-checked by an appointed colleague, and/or perhaps by a professional in the field, or "expert rater" (Alfonso, 1997). This would entail an effort to replicate the categories developed by those independent of the actual interview process. Another method of checking category validity would be one of "exhaustiveness" (Alfonso, 1997; McCormick, 1997), where approximately 10% of the incidents derived from the interviews are left until after categorization is finalized, to see if these incidents indeed fit.

A thorough study of the validity and reliability of this technique was reported by Andersson and Nilsson (1964). The authors reviewed the results of a critical incident study conducted with numerous co-researchers who were all employed in various positions at a grocery store company in Sweden (1,847 incidents collected in total). Andersson and Nilsson (1964) then conducted various reliability and validity checks on the categories and subcategories developed. The first described test in the article is one

of content validity. One aspect of this test may be referred to as exercising exhaustiveness, as referred to above: the final 215 incidents collected were held over until the categories had been developed. The purpose was to then ascertain if these final 215 incidents would fit in the categories already created. All of them were successfully placed in the already existent categories. The authors then went about a procedure of classifying, or re-classifying, the incidents, in differently formed clusters, into the existing categories. After classification of 66% of these critical incidents, 95% of the categories had already emerged. Thus, when the incidents were clustered in a different way, the vast majority of the previously developed categories re-emerged, again supporting the stability of these categories. They also tested the reliability of the critical incident technique, in terms of how it is affected by the manner of collecting critical incidents, or by the person conducting the interviews. Five different people conducted the interviews and gleaned the total number of critical incidents. Through the use of a one-way analysis of variance, they found "no great differences in the number of incidents per interview between the interviewers who interviewed the personnel" (Andersson & Nilsson, 1964, p.400). Also, how well categorization can be controlled was tested with an experiment in which 24 psychology students attempted to ascribe 100 critical incidents in the categories provided. Analysis of their results indicate "that the category system chosen is plausible and not too subjective" (p.401). Thus, the categorization method appears quite stable. With the results of these and other tests of reliability and validity, including a validity test to ascertain if this technique is successful in discovering and categorizing the crucial aspects of a phenomenon, the authors conclude that the critical incident technique is valid and reliable.

Limitations of the Methodology

Generalization: The results of this study cannot be generalized, in reference to a population of women suffering from breast cancer, as this study is completely without experimental controls (Alfonso, 1997; Woolsey, 1986).

Incidents reported not observed: All the critical incidences accumulated were the products of self-reporting on the parts of the participants. Thus, they were highly subjective (which is part of the purpose of this research), yet in such subjectivity there were challenges in terms of accuracy and reliance on memory. This is a limitation in the methodology.

Amount of data: Another methodological limitation may be the large amount of data collected through such an interview process. Alfonso (personal communication) described such a volume of data as seeming “overwhelming” at first.

Possible ambiguity of incidences: Once thematic categories were developed, some critical incidences fit in more than one of these categories. Clarification and or categorization on the part of the co-researcher proved helpful in this regard.

Implications

The four main implications for this work which were considered were: (a) the empowerment of the co-researcher, (b) the development of categories which are applicable as a descriptive reference for both other women facing breast cancer, and for the professionals who care for them, (c) the development of a potentially useful counselling model aimed at this cohort of the population, and (d) the contribution of a qualitative piece to the existing literature. Firstly, such a study was empowering for the

co-researcher, as she was considered the expert in the process of breast cancer, and was thus given voice. The importance of such a facilitation can be seen as vital, in terms of truly helping the client, which the counselling profession sets out to do. Again, the experience of the interview itself acted for most as an experience of empowerment.

Secondly, the development of categories which represent a form of “map” (Alfonso, 1997) in terms of the process of breast cancer as an experience, has strong implications for helpfulness both as a reference for others diagnosed with breast cancer, and for those in the helping professions. A woman facing a diagnosis of breast cancer, with its ensuing prognosis, may find some benefit in the review of a map of categories based on the experiences of some others who have undergone a similar ordeal, from their perspectives. Also, those professionals in positions of care giving would benefit from the insights such a map may offer. Thirdly, future counselling interventions may be developed for people facing breast cancer; such development might be enhanced by the consideration of these categories, as the categories themselves could be considered as possible goalposts for facilitation in effective counselling programs aimed at helping women through this process. As an example, a category which emerged from this research was “personal support”. While this may seem obvious, its consideration when examining existing counselling models, and when designing counselling interventions for women with breast cancer, may result in the formation of a support group for spouses, and significant others, of those undergoing treatment. Such a group would ideally facilitate the “wellness,” of significant others, which may in turn enhance “personal support” as a proactive and vital component of what “helps” women through this process.

Finally, this study contributes to what is not only an absence in the literature of this method of research addressing the crisis of breast cancer, but a lack of qualitative literature, in comparison to quantitative, available on this subject.

Completed Validation Procedures

Cross-Checking by the Co-Researchers During the Second Interview

The primary purpose of the second, or follow-up, interviews was for myself to return to the co-researchers -the sources of all the data collected- - with the intent of both cross-checking, with them, the thematic categories which I had developed, and for general discussion around the degree of success I may (or may not) have attained in his attempts at “capturing” the experiences of the co-researchers, from their perspectives. This was exactly what took place. I began each interview with a review of the reasons for the second meeting; I then followed such review with the presentation, for the co-researcher, of a list of the categories, with their sub-categories, that were relevant to that co-researcher’s interview, and were, thus, representative of the incidents extracted from her story. The co-researcher and I only examined the categories which were relevant to her experiences, as opposed to the entire list of 15 categories. Each category review included a brief look at all the sub-categories associated with that category, not just the sub-categories pertinent to the co-researcher’s experiences, as I did not wish the categories to become too fragmented between co-researchers. We then reviewed, together, all the incidents extracted from that story, both unto themselves (with the defining points to what comprises a critical incident kept in mind, being: source; action; outcome) and in context

of the categories they were placed into. Discussion ensued from such review; some incidents were added at the wish of the co-researcher, some were removed. Any incidents about which I had experienced some uncertainty, were reviewed at this time, and categorized appropriately. Time was given for any debriefing and/or review as was wished for or needed by the co-researcher. The second interviews varied in length, ranging from approximately one hour in length to over three hours, depending on the following factors: the situation, the complexity of the primary interview, the degree to which clarification of incidents was required, and the need for debriefing or further discussion as presented by the co-researcher. The second interviews comprised a highly valuable and necessary process, as the thematic categories, as developed, were not only highly endorsed by the co-researchers, but any necessary clarifications were attended to, which in turn further solidified the categories for myself. Most importantly, however, was the validation that the follow-up interviews ideally offered the co-researchers, whose voices were again being sought and heard, in confirmation and clarification of the categories and incidents offered.

Exhaustiveness of the Categories

In consultation with the thesis supervisor, it was decided that two complete interviews (or 16.67% of the total interviews) would be put aside and analyzed after all the thematic categories had been formed, with the intent on discovering whether redundancy had been achieved in the category formation. If all the incidents from those two interviews fit into the already developed categories, it was considered that category redundancy had been achieved. The co-investigator proceeded to do this, and put aside

two transcribed interviews (the interview with Beth, and the interview with Jane) for later examination. If the incidents extracted from these two interviews required representation by categories other than those formed, then new categories would have to be considered. This was not the case however, as all the incidents extracted from these two interviews could be, and were, accurately represented by the categories already formed. Thus, redundancy, or category exhaustiveness, was attained.

The External Rater

An external rater was selected by the co-investigator, for the purposes of performing an independent rating of 100 of the critical incidents. These incidents were randomly selected, and presented to the external rater, who reviewed the 100 incidents and placed each incident in one of the 15 thematic categories developed. It had been previously determined that an agreement rate of 80% was the minimum requirement for the co-investigator to continue with the categories as developed.

The co-investigator chose a female colleague (a fellow Masters student in Counselling Psychology, from the Department of Educational and Counselling Psychology and Special Education at the University of British Columbia). The initial meeting with the external rater involved: a review of the critical incident methodology, the study developed (of women with breast cancer), specific aspects of the study (i.e., the number of co-researchers involved, the number of interviews involved, the research question), what would be required of the external rater, and an examination and discussion of the 15 thematic categories developed. Finally, the external rater reviewed and classified approximately ten incidents, as chosen by the co-investigator. Discussion

of the ten incidents, with the external rater's reasons for her choices of classification into the existing categories, ensued. When the external rater was satisfied with her understanding of the methodology and classification system, she then independently rated 100 incidents, which the co-investigator had randomly selected from a pool of the 453 critical incidents. Those critical incidents which had been used in the review that the co-investigator conducted with the external rater, were excluded from possible choice.

The 100 incidents were thus independently rated, and later reviewed with the co-investigator, in two lots of 50 incidents each. The first group of 50 incidents were returned by the external rater one week after her initial meeting with the co-investigator. The independent rating of these 50 incidents were later reviewed by the co-investigator, and a category agreement of 94% was achieved, that is, 47 of the 50 incidents were placed by the external rater in the same categories as by the co-investigator. The second group of 50 incidents was presented to the external rater at the same time the first group of 50 incidents was returned. The first group of independently rated incidents was not reviewed by the co-investigator until after he had left the external rater with the second set of 50. The second group of 50 incidents were then returned by the external rater one week later (or two weeks after the initial meeting). The independent rating of this second group of 50 incidents was later reviewed by the co-investigator, and a category agreement of 88% was achieved (i.e., 44 of the 50 incidents were placed in the same categories as by the co-investigator). The overall category agreement, for all 100 incidents, was 91%. As an agreement of more than 80% was thus attained, it was considered that the categories have achieved an acceptable level of validity.

The Categories in Context of Existing Literature

The final validation method involves the linking of the categories to some of the existing literature on theories related to counselling psychology, particularly theories involving crisis, transition, and resiliency. Such a review of the existing literature will be discussed in Chapter V, the Discussion section of this report.

CHAPTER IV: RESULTS

Each of the 12 adult women participated in two interviews; from these interviews a final total of 453 critical incidents were identified. Incidents were considered relevant when experiences helped or hindered these 12 co-researchers coping with the process of treatment for breast cancer. From these 453 incidents, 15 thematic categories were developed. Eleven of the 15 categories subsumed both helpful and hindering incidents. Four of the 15 categories had only helpful incidents. No hindering incidents were found in these four categories. In this chapter, the identified categories will be presented in order of frequency: that is, the first category presented has the highest number of identified critical incidents associated with it. Included in the presentation of each category will be descriptions of the corresponding thematic sub-categories, as well as examples of incidents for each category, which are taken from the interview transcripts verbatim. Each of the co-researchers is identified by her pseudonym only.

Following are three tables. Table 1 presents a list of the 15 categories with their respective frequencies (of incidents) and participation rates. Table 2 presents a breakdown of the critical incidents into those which were found helpful and those which proved hindering. Table 3 presents the list of the categories with their respective sub-categories.

Table 1

List of categories with their frequencies and Participation Rates

| <u>Category</u> | <u>Frequency of Incidents</u> | <u>Participation Rate*</u> |
|---|-------------------------------|----------------------------|
| 1. Relations with the Medical Team and any Support Staff(helpful vs. hindering) | 94 (20.75%) | 12/12 |
| 2. Medical Treatment and Services (helpful vs. hindering) | 85 (18.76%) | 12/12 |
| 3. Personal Support (helpful vs. hindering) | 77 (17.00%) | 12/12 |
| 4. Activities/Things Which Aid in Treatment and Recovery (or which did not help) | 45 (9.93%) | 11/12 |
| 5. Locus of Control (helped vs. hindered) | 39 (8.61%) | 11/12 |
| 6. Availability and Presentation of Appropriate Educational Information (helpful vs. hindering) | 24 (5.30%) | 10/12 |
| 7. Attitude Towards Life and the Human Community (helpful) | 16 (3.53%) | 7/12 |
| 8. Support/Psychoeducational Agencies/Groups/Centres (helpful vs. hindering) | 13 (2.87%) | 7/12 |
| 9. Maternal/Caregiving Role/Behavior (helpful vs. hindering) | 12 (2.65%) | 8/12 |
| 10. Career as a Medical Professional (helpful vs. hindering) | 11 (2.43%) | 4/12 |
| 11. Spiritual Beliefs (helpful) | 10 (2.21%) | 6/12 |
| 12. Career (helpful vs. hindering) | 9 (1.99%) | 5/12 |
| 13. Personal Involvement in Decision Making (helpful) | 8 (1.77%) | 5/12 |
| 14. Physical Appearance (helpful vs. hindering) | 7 (1.55%) | 4/12 |
| 15. Alternative Treatments (helpful) | 3 (0.66%) | 2/12 |
| Total | 453 (100.01%)** | |

* Participation Rate refers to the number of co-researchers (out of a total of 12) who presented an incident or incidents related to each category.

** Actual total is 100.01%, due to the effects of rounding off percentages to 2 decimal points.

Table 2

Breakdown of Incidents By Their Action

| <u>Category</u> | <u>Helpful</u> | <u>Hindering</u> | <u>Totals</u> |
|---|------------------|------------------|---------------|
| 1. Relations with the Medical Team and any Support Staff (helpful vs. hindering) | 72 (20.45%) | 22 (21.78%) | 94 (12/12) |
| 2. Medical Treatment and Services (helpful vs. hindering) | 41 (11.65%) | 44 (43.56%) | 85 (12/12) |
| 3. Personal Support (helpful vs. hindering) | 68 (19.32%) | 9 (8.91%) | 77 (12/12) |
| 4. Activities/Things Which Aid in Treatment and Recovery (or which did not help) | 44 (12.50%) | 1 (0.99%) | 45 (11/12) |
| 5. Locus of Control (helped vs. hindered) | 35 (9.94%) | 4 (3.96%) | 39 (11/12) |
| 6. Availability and Presentation of Appropriate Educational Information (helpful vs. hindering) | 16 (4.55%) | 8 (7.92%) | 24 (10/12) |
| 7. Attitude Towards Life and the Human Community (helpful) | 16 (4.55%) | - | 16 (7/12) |
| 8. Support/Psychoeducational Agencies/Groups/Centres (helpful vs. hindering) | 11 (3.13%) | 2 (1.98%) | 13 (7/12) |
| 9. Maternal/Caregiving Role/Behavior (helpful vs. hindering) | 5 (1.42%) | 7 (6.93%) | 12 (8/12) |
| 10. Career as a Medical Professional (helpful vs. hindering) | 9 (2.56%) | 2 (1.98%) | 11 (4/12) |
| 11. Spiritual Beliefs (helpful) | 10 (2.84%) | - | 10 (6/12) |
| 12. Career (helpful vs. hindering) | 8 (2.27%) | 1 (0.99%) | 9 (5/12) |
| 13. Personal Involvement in Decision Making (helpful) | 8 (2.27%) | - | 8 (5/12) |
| 14. Physical Appearance (helpful vs. hindering) | 6 (1.70%) | 1 (0.99%) | 7 (4/12) |
| 15. Alternative Treatments (helpful) | 3 (0.85%) | - | 3 (2/12) |
| Totals | 352 (100.00%) | 101 (99.99%*) | 453 |

*Actual total is 99.99%, due to the effects of rounding off percentages to 2 decimal points

Table 3**List of Categories And Sub-Categories****1. Relations with the Medical Team and any Support Staff (helpful vs. hindering):**

- 1-1. Faith in the GP/Surgeon/Oncologist(s)/Support Staff
- 1-2. Supportive attitude/empathy/willingness to inform, as displayed by medical personnel and support staff (Including: GP/Surgeon/Oncologist(s)/Nurses/Hospital support staff/Pharmacists/Nutritionists/Naturopaths/Herbalists/Physiotherapists/Social Workers/Massage Therapists/Wig Makers/Hair Stylists)
- 1-3. Sense of rapport and/or respect, as developed by medical personnel and support staff

2. Medical Treatment and Services (helpful vs. hindering):

- 2-1. Timeliness/Efficiency of appropriate medical and rehabilitative treatment
- 2-2. Timeliness/Accuracy/Effectiveness of diagnosis and treatment, given individual needs
- 2-3. Competency of medical personnel
- 2-4. Consistent involvement of primary doctors and nurses (i.e., involvement of the same chemotherapy oncologist throughout treatment)
- 2-5. Medical team working in concordance with rehabilitative team (i.e., physiotherapy)
- 2-6. Involvement in a medical trial/study
- 2-7. Follow-up services

3. Personal Support (helpful vs. hindering):

- 3- 1. By partners/spouses
- 3- 2. By adult children
- 3- 3. By parents
- 3- 4. By other relatives, including siblings
- 3- 5. By friends
- 3- 6. By colleagues/business associates
- 3- 7. By assigned "buddies", and others who have, or have had, cancer
- 3- 8. By spiritualists and/or members of the clergy
- 3- 9. By members of the same spiritual group (i.e.: fellow parishioners)
- 3-10. By co-members of support groups

Table 3 Cont.

4. Activities/Things which Aid in Treatment and Recovery (or which did not help):

- 4- 1. Exercise
- 4- 2. Physiotherapy
- 4- 3. Dragon boat racing
- 4- 4. Massage therapy
- 4- 5. Aromatherapy
- 4- 6. Qigong (Chikung)
- 4- 7. Meditation
- 4- 8. Creative imagery
- 4- 9. Journal writing
- 4-10. Prayer
- 4-11. "Look Good Feel Better" program
- 4-12. "Fit for Recovery" program
- 4-13. Therapeutic Touch
- 4-14. Comedy videos
- 4-15. Relaxation groups
- 4-16. Travel/holidays
- 4-17. Diet
- 4-18. Reading
- 4-19. Hot/warm Baths
- 4-20. End-of-treatment celebrations
- 4-21. Acupuncture
- 4-22. Helping others
- 4-23. Taking more time for relaxation
- 4-24. Effective aids in dealing with side effects from medical treatment (i.e.: anti-nauseates).

5. Locus of Control (helped vs. hindered):

- 5-1. Belief in one's ability to help oneself
- 5-2. Desire to help oneself
- 5-3. Belief that one can be proactive in some ways, which will enhance treatment/recovery
- 5-4. Belief that one maintains some element of control over treatment, and/or the outcome of the disease
- 5-5. Sense of confidence in one's ability to champion crises, based often on previous experience (having the experience of a previous crisis as precedent)
- 5-6. Time to prepare for what lay ahead
- 5-7. Choosing to manage the disease, and ensuing treatment, "one day at a time", or "step by step"
- 5-8. Desire to-and attempts made to- maintain regular routines during treatment.
- 5-9. Determination to champion the disease.

Table 3 Cont.**6. Availability and Presentation of Appropriate Educational Information (helpful vs. hindering):**

- 6-1. Helpful information/literature, offered in a timely manner, by medical teams, information networks, and or support groups, on treatment (including: surgery, radiation, chemotherapy, hormonal therapy)
- 6-2. Helpful information/literature, offered by medical teams, information networks, and or support groups, on possible side effects of treatment (including: severe nausea, hyper-activity, tethering (cording), lymphedema, hair loss, burns and rashes, immune suppression, treatment induced menopause), and appropriate ways to manage/alleviate those side effects
- 6-3. Ready availability of helpful literature (i.e., the British Columbia Cancer Agency library)

7. Attitude Towards Life and the Human Community (helpful):

- 7-1. A sense of optimism over recovery from disease
- 7-2. A belief that it is not "my time to die"
- 7-3. A belief that one can contribute more to others both as the result of what is "learned" through such a crisis (learned about breast cancer; learned about managing crises), and sometimes through personal involvement in treatment studies
- 7-4. Re-examination of one's view on what is important in life (as the result of having had breast cancer), and on the temporary nature of life
- 7-5. Seeing oneself as fortunate, in terms of the severity of one's diagnosis, in comparison to others with the disease

8. Support/Psychoeducational Agencies/Groups/Centres (helpful vs. hindering):

- 8-1. Patient and Family Counselling at the British Columbia Cancer Agency
- 8-2. Treasure Chests (a support group for women with breast cancer)
- 8-3. Abreast in a Boat (a group of dragon boat racing teams)
- 8-4. Hope House (as operated by the Hope Cancer Health Society)

9. Maternal/Caregiving Role/Behavior (helpful vs. hindering):

- 9-1. Sense of personal responsibility to children (including adult children), and/or concern for their welfare
- 9-2. Sense of personal responsibility to elderly parents (and other relatives), and/or concern for their welfare

Table 3 cont.**10. Career as a medical professional (or a professional related to the medical fields)(helpful vs. hindering):**

- 10-1. Professional knowledge of breast cancer as a disease, and of the various treatments for it
- 10-2. General medical knowledge (as a professional), including general knowledge of patient treatment and care
- 10-3. Ways in which one's career as a medical professional is altered by the experience of breast cancer
- 10-4. Professional connections through one's career

11. Spiritual Beliefs (helpful):

- 11-1. Faith in God/Higher Power/Spiritual Entities
- 11-2. Faith in the potential involvement of such, in one's life
- 11-3. Faith Healing/Miracles
- 11-4. Belief in the power of prayer

12. Career (helpful vs. hindering):

- 12-1. Support/flexibility of employers/job supervisors
- 12-2. Ability to stay connected with career
- 12-3. Ensuing financial security
- 12-4. The workplace as representative of a segment of one's life separate from breast cancer (the "normalization" experience of one's life through involvement in the workplace)

13. Personal Involvement in Decision Making (helpful):

- 13-1. Being treated as- and believing that one is- an integral member of the decision making team, with regards to one's medical treatment
- 13-2. Respect by the team for the co-researcher's decisions regarding treatment

14. Physical Appearance (helpful vs. hindering):

- 14-1. Use of wigs and or scarves
- 14-2. Experiences related to baldness and hair

15) Alternative Treatments (helpful):

- 15-1. Herbal Medicines
- 15-2. Naturopathy

Category 1: Relations With The Medical Team and Any Support Staff (Helpful vs. Hindering)

A total of 94 incidents, or almost 21% of the incidents identified, had to do with the relationships which the co-researchers developed (or were unable to develop) with the medical professionals and support staff involved in their treatment and care: see Table 1 (p.41). Of those 94 incidents, 72 were deemed helpful by the co-researchers, or 77% of the total for this category, while 22 were considered hindering (23%): see Table 2 (p.42). All twelve co-researchers presented incidents applicable to this category.

This category represents a broad range of experiences on the part of the co-researchers- including some considered quite detrimental to their well being, and can be further explored through examination of the thematic sub-categories: (a) faith in the general practitioner(GP) /surgeon /oncologist(s) /support Staff (a sense of trust and/or confidence felt towards the professional offering treatment or care); (b) supportive attitude/empathy/willingness to inform, as displayed by medical personnel and any support staff (as perceived by the co-researcher; medical personnel and support staff may include: GPs, surgeons, oncologists, nurses, hospital support staff, pharmacists, nutritionists, naturopaths, herbalists, physiotherapists, social workers/counsellors, massage therapists, wig makers, hair stylists); and (c) a sense of rapport (of lack of rapport) as developed by medical personnel and/or support staff.

Example 1: Elizabeth (43 years old); Sub-Category 1-1 (helpful)

I had to go back to my doctor's office because I know him and trust him, and I had to consult with him a lot even though the surgeon had told me what I would need. I would have a choice of a mastectomy or a lumpectomy. I ended up going to my doctor because he's the one that I trusted. I had been through my pregnancy with him, and all of my son's little problems and that so I do feel confident....I had to go back to my GP and see him and talk with him, and he phoned the surgeon and that comforted me...

Example 2: Beverley (49 years old); Sub-Category 1-2 (helpful)

My surgeon...had no hesitation asking or answering any of my questions; it didn't matter how stupid they appeared to be she had no problem with that. I need information; for me I need to know, I need to understand...

Example 3: Rene (61 years old); Sub-Category 1-2 (helpful)

So I went back to the surgeon with my husband, and he and I went through all the questions; it must have been the end of the day because he sure took time with me...I really appreciated that...he was willing to listen and to answer them, so I felt really good...

Example 4: Beth (52 years old); Sub-Category 1-2 (helpful)

When I did have the surgery he (the surgeon) was also very kind when he told me that it was cancer. It seems like it wouldn't be the ideal situation since I was in a recovery room, but this was a very small hospital and there's nobody else in there and there was a couple of nurses who I think he knew. And he knew that they were very warm people; I think he

probably told them what the situation was already. He just told me very briefly that it was cancer which was quite a shock...I was quite shocked that it was cancer, but he stood there, he held my hand, I cried. He didn't you know turn away at all. He was very present and caring, and then he just said we'll talk more about this a little later. So the nurses were right there, and they realized what the situation was; more warm blankets you know whatever you know Kleenex...

Example 5: Bridget (58 years old); Sub-category 1-2 (helpful)

I had my GP who was a female GP, and she was wonderful. She would phone me about once every three weeks... She's been my GP for almost 10-15 years, so I thought that was quite remarkable that she would take the time to phone and find out how I was.

Example 6: Allyson (41 years old); Sub-Category 1-2 (helpful)

My experience with this person... he wasn't an oncologist, he wasn't my GP... He wasn't somebody who was in the position, I guess, properly to enlighten me of the situation. He was more...doing his job, doing aspirations... He re-iterated and said do you have any questions, and I said yeah...what do you think...is it cancerous...? It was the way he looked at me...with such tenderness and such concern and such sincerity...he paused...deliberating whether he should say something or not. He went ahead and he said I don't like what I see, and I would like to see you in surgery as soon as possible. I think I stopped breathing for about ten minutes, but at the same time I experienced relief... I knew deep down

indeed it was cancerous... I just couldn't have imagined anyone else having told me, and in the manner that he told me. It was just quite lovely actually... The way he looked at me...it set up...the manner in which I was going to find courage to negotiate this. He set the precedent up: okay, now this is how it's going to be all the way through this...is this kind of humanness, this kind of courage, because he did have courage to... He could have said: you know this isn't appropriate for me to tell you... He just said all the right things...

Example 7: Meagan (42 years old); Sub-Category 1-2 (hindering)

There were some negative things, and I found sometimes health care professionals, and this will include the nurses, would assume that because I had this diagnosis it would be overwhelming for me, and that I wouldn't be able to take in any information and.... The thing that I found annoying for people was when I, when I wanted information and I needed data; sometimes people oh well you know don't worry...about that. I know it's very overwhelming and there's so much stuff so don't worry about getting that kind of information. And in fact all that did was annoy me, actually, because one of the ways for me to cope was to have information, and to be knowledgeable about my disease...

Example 8: Isabella (55 years old); Sub-Category 1-2 (hindering)

As soon as I made this decision, I called the cancer agency and I said...I have made the decision that I'm not going to take radiation, so I'm giving you time to, you know, fill someone in my spot, because I'm not going to

take it. And left my name and phone number... I had never met this radiation specialist...this guy calls me back. He's never met me, he doesn't know what kind of person I am... He says to me you can't not take radiation treatment; you must take it, and I said no I don't. I'm not doing it; I'm not taking the treatment; I don't feel that I can deal, my body can deal with anything more. He says well I can tell you right now that if you don't you will be dead within a year. He told me that on the phone. He didn't know me; he didn't know how I'd react; he didn't even bother to think that maybe I'd go out and kill myself or something. There was no safety, no caring, no compassion involved. It was you get in here and take this radiation treatment, like you're told, or else. That was his attitude and I was just furious, completely infuriated, but not feeling good enough to... start a big curfufal and fight about this whole thing... I was very ill at that point: I had quit chemo...because I couldn't take any more. I was very very ill, mentally, and physically, and I thought it was despicable...

Example 9: Lee (61 years old); Sub-category 1-3 (hindering)

I had one very brief incident where they had asked me to go into a room, for some sort of an examination, or check up. And this particular nurse went flipping by the door, and called to the lady down at the end, I'll take this one, and pointed in the door, And I thought: oh yes. She came in and immediately said I am very sorry, I did not mean that, I apologize, and it was forgotten instantly... If she hadn't I would have taken her to task for it; I would have said my name is "Lee" and I am not this one; I am a

patient, but I didn't have to, she knew...When you are in somebody else's hands, and you're traumatized...it's very easy to be offended... I just wanted her to acknowledge that I was not an anonymous white gown; I was a person underneath that and if I had wanted to be called this one, I would be pretty bad off. I would have given up all my personality.

Example 10: Killie (61 years old); Sub-Category 1-3 (hindering)

The next chemo, I think it was my third chemo, I had another oncologist... I went, and my friend was with me, and this oncologist for some reason decided she had to tell me how serious my case was... I don't know what triggered this, but she decided to go through and tell me all the statistics, all over again, about you know what my chances of survival were... I guess I asked her and said: well how do you know if the chemo's working; you know how do you know if it's gone or not? And she said: well you don't, and if it comes back it's incurable. Well that one word did me in. We went out of the room and I was just... really upset and this friend who was with me said: dear God, you know, if it was a man it'd like being kicked in the balls... This woman set me back... I actually went (back) to the cancer agency to see her, because I was going to tell her the effect of her communication... I was going to go to her and say: look, I'm a pretty strong individual; now that really affected me. I'm not sure what it would do to somebody who was a lot more fragile than I was... So I said: don't use the word incurable; chronic, you have a chronic disease, I understand that, don't tell me I'm incurable... You have to pay attention to your

communication skills, because this is what it did to me... The next time I saw Dr....I said: I don't want to see that doctor again... This is what happened, I said, and I was really upset. So that's my really negative part of all this...

Category 2: Medical Treatment and Services (Helpful vs. Hinderling)

Distinct from the first category, (which focuses again on relations as developed with helping personnel) "medical treatment and services" comprises a representation of approximately 19% of the extracted incidents, and refers to any incidents that are concerned with the actual medical and rehabilitative treatment, as experienced by the co-researchers: see Table 1 (p.41). Of the 85 incidents applicable to this category, 41, or 48% of the total for "medical treatment and services", were deemed helpful by the co-researchers, while 44, or 52% of the total, were considered hinderling: see Table 2 (p.42). There were actually more hinderling incidents for this category than helping ones (which will be discussed in the following chapter of this report). All twelve co-researchers presented incidents applicable to this category.

Thematic sub-categories for "medical treatment and services" are as follows: (a) timeliness/efficiency of appropriate medical and rehabilitative treatment; (b) timeliness/accuracy/effectiveness of diagnosis and treatment, given individual needs; (c) competency of medical personnel; (d) consistent involvement of primary doctors and nurses (i.e.: involvement of the same chemotherapy- or medical- oncologist throughout treatment; (e) medical team working in concordance with rehabilitative team (i.e., radiation technicians working in concordance with physiotherapists, in helping the co-

researcher with the side-effects of radiation therapy); (f) involvement in a medical trial or study; and (g) follow-up services. Again, 85 of the incidents deemed helpful or hindering by the co-researchers involves some aspect of the eradivative and/or rehabilitative treatment itself.

Example 1: Isabella (55 years old); Sub-Category 2-3 (hindering)

I got to BC, and started working here, and I got a doctor who was, you know, keeping an eye on the ulcer treatment. She said: well I'd like to send for your records, from your doctor in Alberta... So she sent for it, and that's when she found out that I had... from the mammogram report, breast cancer, when I was in Alberta the prior year. Nobody had informed me of this. So anyway, this was a year later, and I go for a mammogram and, of course, then it was quite clear that this was the situation... I was freaked out and upset... I'd had all this health care the year before, right. I'd thought everything was fine with my ulcer... I had a totally incompetent doctor in Alberta, obviously, who didn't read the report on the mammogram, didn't even make an attempt to get in touch with me, which was quite pathetic, because where I worked I had left my forwarding address. He could certainly have contacted me, had he made any effort to...

Example 2: Elizabeth (43 years old); Sub-Category 2-3 (hindering)

The nurses are being trained for chemo. They were working at different jobs, like bone marrow at VGH, and they've transferred out here. The IV nurses...were really nervous, and that just totally added to my anxiety... She (the nurse) was very anxious starting my IV, and then she had to get somebody else to start it. And I know the danger of chemotherapy going into your tissue, and what could happen, and that was my first experience and that...my first treatment I think that's why I had an anxiety attack... She seemed unsure, and so she made me feel more unsure. I would have liked a nurse that had been doing this for like ten years...

Example 3: Beth (52 years old); Sub-Category 2-3 (helpful)

My GP I am extremely grateful to, because she did screening mammography. I was 46 at the time, and I was doing breast self-examination, and there was nothing to find whatsoever. I wasn't living in Vancouver. I was in a smaller town, and there was a mammography van coming around. So I just happened to go to her, for something totally unrelated, and she said that the mammogram was in town, it's time, you're due for a mammogram, and gave me the requisition...

Example 4: Beverley (49 years old); Sub-Category 2-2 (helpful)

I got to my doctor. She investigated; decided she didn't like it. She immediately made an appointment for me with a surgeon, I believe, right at that point, even before I had gone for the ultrasound. So the speed with which I was able to get in to see the surgeon, I was probably in to see her

within two to three weeks. She, based on the x-rays, had already booked a surgery date for me... She specializes in breast cancer, she has a block of dates; I guess she has one day a week... and she slots people in. So I was slotted in before she even saw me; if I hadn't needed it there is always somebody else she could put in. So, again, within a matter of a couple of weeks I was in surgery. So for me that helped, because I had this feeling of urgency. I got to get this thing taken care of...

Example 5: Meagan (42 years old); Sub-Category 2-3 (hindering)

Most of the nurses, actually, were very good about changing the catheter (as used in certain forms of chemotherapy treatment). It had to be changed once a week, and to use sterile technique, because if the catheter goes straight in through a major vein, right actually into sort of the top part of your heart. If you get an infection it can be very bad.. One of the nurses really didn't know what she was doing and....she wasn't using sterile technique. So she does this thing on me, and I'm...looking at her and thinking oh my God she's doing it wrong. So stupid me, I actually let her finish, but then I went to the nurse, and I said: all the other nurses have done the dressing change in such and such a way. This nurse did it in this way, and I said it wasn't sterile. And the other nurse, of course, agreed, and said: oh I'm really sorry we'll re-do it. So they re-did the whole thing. But then again I thought: gee you know...because I knew what sterile

technique was, I could see the error, but what if I... had the average education...

Example 6: Hilary (68 years old); Sub-Category 2-6 (helpful)

Something I found really helpful, or I do feel helpful, is that I still go to the cancer clinic every four months. And Dr.... still sees me every four months, and that's because I'm on this study. My friend, I mentioned, who had the incident when she left hospital, and her drain wasn't looked after properly...she saw her oncologist a great deal, and was followed through all her chemo, and her radiation. And when it is all finished, she went and had an appointment with her oncologist, and the oncologist said: okay that's fine, that's the end of everything for you, go and be followed up by your GP or your surgeon, goodbye. And she found that was absolutely dreadful... You like the support... I find it very helpful to have... To me this is one of the advantages of being on the study, and would probably be quite happy, when the five years is up, if something else comes up, so that I can be on the study again...

Example 7: Lee (61 years old); Sub-Category 2-2 (hindering)

I went back in ten days, I guess. He still didn't have the results from the lab, as to whether the wound was clean or whether I had lymph node involvement. I know the labs are busy, but you sit for another ten days, after two surgeries in five weeks, not knowing whether it's spread into

your lymph nodes, and it's pretty scary... A week to ten days, just to find out the results. Do you know what that can do to your head? It doesn't matter, by the time you find out if you've got something or not, you've psyched yourself up for it. You know it's just running 'em up through your body. Nobody's helping you. Nobody's doing anything. I mean it's terrible; ten days after surgery is not good enough, and yet this is quite normal...

Example 8: Killie (61 years old); Sub-Category 2-3 (hindering)

Then I have this history of mammograms and ultrasounds, and they all look great except... there was a hell of a lot of cancer there before. That's the part that makes me angry... and I decided I couldn't stay with the anger... I had had mammograms every year, and I'd had these ultrasounds. I'd had the needle. What the hell was wrong with the technology, or the competence of the doctors, that they didn't pick this stuff up... How could they miss all this? When I finally discovered how much actually I had...and then I felt well I can't spend my life being angry. That's a waste, it's over, its done with-. Can't do anything about that; need to put that on the side...

Example 9: Allyson (41 years old); Sub-Category 2-3 (hindering)

My GP shares a practice with another doctor; they're both wonderful physicians but not infallible. And my GP was unavailable at the time that

I discovered the lump... It worked out that I would go and see this partner so I went... She checked the lump, and she determined she was pretty sure it wasn't anything of concern... But she said... just to be sure we'll send you for...an ultrasound. And I almost...postponed this (the ultrasound), because I generally have lumpy boobs, so I thought oh this is just another thing... The doctor... she's pretty sure she knows her stuff and... At the last minute I thought oh no I'll go... So then I had the ultrasound done, and then a woman said it's actually a combination of fluid and solid, and so then the next step...to have a needle biopsy... I was feeling like oh it's probably nothing... I was really contemplating canceling the appointment, which would have been really not a good idea...my canceling my ultrasound... With that GP I don't know what made her think...she said...where she had been checking wasn't the same spot that they found a lump... So there was a bit of a conflict in that whole thing there... That was unsettling, and so I had to work through that with my GP, and this other doctor.

Category 3: Personal Support (Helpful vs. Hindering)

This category represents those incidents, as presented by the co-researchers, which involve support received in their personal lives, during their treatment processes (as opposed to any support received by the professional helpers involved in treatment). A total of 77 incidents, or 17% of the total number of 453 incidents, had to do with the personal support received and identified, by the co-researchers during treatment: see

Table 1 (p.41). Of those 77 incidents, 68 were deemed helpful by the co-researchers, or 88% of the total for this category, while 9 were considered hindering (12%): see Table 2 (p.42). Hindering incidents usually involved support expected but either not received, or received in a manner deemed unhelpful by the individual undergoing treatment. All twelve co-researchers presented incidents applicable to this category.

Sub-categories here act more as descriptors of the types of relationships held with the individuals involved; incidents of personal support include that received by: (a) partners/spouses; (b) adult children; (c) parents; (d) other relatives, including siblings; (e) friends (f) colleagues/business associates; (g) assigned “buddies”, and others who have, or have had, cancer; (h) spiritualists and/or members of the clergy; (i) members of the same spiritual group (i.e.: fellow parishioners); and (j) co-members of support groups.

Example 1: Rene (61 years old); Sub-Category 3-1 (helpful)

My husband was great...he just was extremely supportive through the whole thing and... He got to the internet, and this was before I got all the information from the doctor initially... So I imagine he was pretty scared too, but he wasn't... showing that side. And again, maybe because I was getting information, and maybe that was also assisting him, you know, in looking at what my scenario was. He was certainly there throughout all that...so that was big, that was great...

Example 2: Elizabeth (43 years old); Sub-Category 3-6 (helpful)

There's a period of time before long term disability... and the girls at work they gave me money, hundreds of dollars. They just cared and they took up a collection... Yes my co-workers, because I worked casual at the hospital for ten years. People knew me all over the hospital, and my friend from work... I told her not to do it but she did it anyway. She went and she just said: you know, Elizabeth's a single mom and she's going through breast cancer chemotherapy. And they gave me hundreds of dollars... I just cried ... I've just never experienced that. I've never been in a position to have to just really learn to receive, and that was another positive thing out of this, is just learning to receive...

Example 3: Jane (70 years old); Sub-Category 3-5 (helpful)

Believe it or not college friends, the group that I knew very well, they're still on the east coast, started phoning and writing... Boston, New York, Washington, knew that I was ill so that was kind of nice... And my friends here... bring you a dinner a lunch or something, while you're under treatment, so you don't have to cook...

Example 4: Killie (61 years old); Sub-Category 3-5 (helpful)

I had a friend who came with me (to her first chemotherapy treatment) and then we went home... This friend, who had been with me all day, she left and another friend came... and was going to stay overnight, because we did not know what was going to happen... I woke up the next morning, she had

gone and my other friend had come back, because we knew that the first 24 to 48 hours were critical, and nobody knew what I was going to be like... My friend left at the end of the day, because she was exhausted. I was still going a million miles an hour... The other friend, who was spelling off, came over that night, and I said let's go out for dinner. We went out; we had a marvelous dinner... I had everybody phoning me... that first night... The friend, who was spelling me off for that night, she came in and she said my God there you are, I thought you'd have your head in the basin... at this point... So a lot of people were very supportive and phoning me, I knew I was very well loved and cared for and that came through just in spades. It was just remarkable...

Example 5: Lee (61 years old); Sub-Category 3-2 (helpful)

She (Lee's adult daughter) sent me information from friends, dietary stuff, vitamin regimens to follow... She would help by sending information... Every day in the mail more pamphlets, more info... I mean it was very sweet and we read all of it. Some of it fit, but the dietary stuff was very helpful. This was her way of saying oh my God. She flooded me with information... She said something about oh my God you have no idea how scared I was when you told me, but she didn't say that at the time. She just flooded me with information... I don't think she knew how to say God I'm terrified without maybe scaring me, so she just handled it the way she could, which was trying to give me anything that would help me, and it was very

much appreciated. We sort of laugh; everyday here's this other envelope in the mail. But it was sweet, and I appreciated the input...

Example 6: Hilary (68 years old); Sub-Category 3-10 (helpful)

I like to go on Tuesday and Thursday, because I meet with them, and we have coffee afterwards, and it's another sort of support group...it's a more personal support group... I have made a definite support group from the Fit for Recovery group... When I had my hysterectomy... they were all right there for me and brought me suppers... That's the one definite positive...

Example 7: Meagan (42 years old); Sub-Category 3-3 (helpful)

My parents were phenomenal. My mother was like a saint. She was amazing... They were really there for me a hundred percent, and she really took care of all my laundry and cooking. I didn't have to do anything, it was so great...

Example 8: Beverley (49 years old); Sub-Category 3-5 (helpful)

We don't (Beverley and a close friend) necessarily see each other that often, but when we do we just start right off from where we left off. And she was very helpful to me, and we like to talk about all kinds of stuff. And she's had various health problems as well, so she can sort of appreciate the same kind of thing. So yeah, that was very useful...

Example 9: Beth (52 years old); Sub-Category 3-5 (helpful)

Another thing that was really important was a close friend of mine who lived in Vancouver, and when I told her what was happening...we were on the phone... there was a long pause, and you could tell she was shocked, and then she said: what are we going to do? It was just like right now she was right there... She picked me up at the airport when I flew down, it was in the middle of a blizzard, picked me up... and took me to the appointment, took me to lunch, took me back to the plane afterwards, offered to have me stay at her house if I wanted to do that, and took the day off work. She could only do that once a year, but she took that day, and so she was just tremendously supportive through the whole thing...

Category 4: Activities/Things Which Aid in Treatment and Recovery (or Which Did Not Help)

This category denotes any and all activities (such as exercise) and things (such as comedy videos) cited by the co-researchers, which acted as helping aids during treatment and recovery, including (not in order of frequency): (a) exercise; (b) physiotherapy; (c) dragon boat racing; (d) massage therapy; (e) aromatherapy; (f) Qigong; (g) meditation; (h) creative imagery; (i) journal writing; (j) prayer; (k) "Look Good Feel Better" program; (l) "Fit for Recovery" program; (m) therapeutic touch; (n) comedy videos; (o) relaxation groups; (p) travel/holidays; (q) diet; (r) reading; (s) hot/warm baths; (t) end of treatment celebrations; (u) acupuncture; (v) helping others; (w) taking more time for relaxation; and (x) effective aids in dealing with side effects from medical treatment (i.e., anti-nauseates): see Table 3 (p.43).

A total of 45 incidents, or approximately 10% of the total number of incidents, were applicable to this category: see Table 1 (p.41). Of those 45 incidents, 44 were deemed helpful by the co-researchers, or 98% of the total for this category, while only one incident was presented as hindering (2%): see Table 2 (p.42). The single hindering incident had to do with an event which took place, which was not helpful, during an activity which was deemed very helpful by the co-researcher involved. Eleven of the twelve co-researchers presented incidents applicable to this category.

Example 1: Killie (61 years old); Sub-Category 4-16 (helpful)

I had planned a vacation to Italy a week after I was diagnosed, and to Scotland for a college reunion, and I asked the doctor whether you know there was any reason I shouldn't go. That (the trip) for me was one of the best things I could ever have done... A week after I came back I went into surgery, but a change of culture, a change of language, a change of place totally shifted my head space, so that I came back and I was a totally different person...

Example 2: Bridget (58 years old); Sub-Categories 4-18 and 4-19 (helpful)

Usually my partner would take me to the chemo and then bring me home, and then I'd do the bath and then read and then have a sleep, usually, and then I'd get up for dinner... It (the reading) calmed me... Reading this book calmed me; you know that was what I was doing when I was taking the

bath, to calm me down, to make me very without stress, very stress free so I wouldn't think too much about what was happening...

Example 3: Jane (70 years old); Sub-Category 4-3 (helpful)

I kind of sat back and took it easy until April of the following year, when I heard about the dragon boating. And I was a dragon boat lady for two years, and I must say that that was really helpful. I don't know whether you've had any other dragon boat ladies here, but I'm sure you'll find them all saying it's very positive...

Example 4: Isabella (55years old); Sub-Category 4-7 (helpful)

The most beneficial thing for me in my whole experience with cancer was meditation, because it was through meditation that I was able to get clarity, that I was able to see myself: what I was doing, observe where I was going, observe my fears, you know...

Example 5: Meagan (42 years old); Sub-Category 4-17 (helpful)

I changed my diet actually it's like I...have a low fat high fiber diet; it's very low fat in fact... I've found to me that's very helpful... I've actually become a vegetarian. I switched my eating habits quite a bit since before my diagnosis. That's been very positive and I continue to do that...

Example 6: Hilary (68 years old); Sub-Category 4-12 (helpful)

I had heard about this group called Fit for Recovery, and it's run out of the Jewish Community Centre, and I would willingly boost that to anybody, and I wish we could get more people... The instructors are excellent, and they're very knowledgeable. At the Fit for Recovery they take you through all sorts of different: weight training, yoga, aquasize, step classes, power walking, everything... That's one of the major positive things that's come out of all this is that I continue... I joined the Jewish Community Centre...

Example 7: Rene (61 years old); Sub-Category 4-8 (helpful)

I was doing some of the imagery you know. I did that during the radiation actually, or at least I tried to in my own, not very sophisticated way I guess... It gives you something else to think about or try to imagine... I felt maybe it's positive...

Example 8: Allyson (41 years old); Sub-Category 4-9 (helpful)

I actually started journaling. I really didn't realize...what I was sensing or feeling... Sometimes I just didn't even think or I suppose have the energy to journal, and I know there were times where I'd think oh I should write this in there, just because this is just a revelation or something. But I did capture some of them so I'm glad about that...

Category 5: Locus of Control (or Personal Agency)(Helped vs. Hindered)

This category denotes incidents as described which represent a desire for a sense of personal agency and/or an internal locus of control, as experienced and often acted upon (through specific behaviors) by the co-researchers during treatment. Many discuss the importance of exercising agency and/or control, whenever possible, during an often highly stressful and frightening period in their lives, a period during which they are bombarded by an highly invasive treatment regime (one over which they have little control). A total of 39 incidents, or almost 9% of the total 453, where incidents applicable to this category: see Table 1 (p.41). Those 39 incidents can be broken down into 35 which were deemed helpful (90% of the total 39), and four, or 10%, deemed hindering: see Table 2 (p. 42). Eleven of the twelve co-researcher presented incidents applicable to this category.

Thematic sub-categories, which further illuminate such feelings, are as follows: (a) belief in one's ability to help oneself; (b) a desire to help oneself; (c) belief that one can be proactive in some ways, which will enhance treatment/recovery; (d) belief that one maintains some element of control over treatment, and/or the outcome of the disease; (e) sense of confidence in one's ability to champion crises, based often on previous experience (having the experience of a previous crisis as precedent); (f) time to prepare for what lay ahead; (g) choosing to manage the disease, and ensuing treatment, "one day at a time", or "step by step"; (h) desire to- and attempts made to- maintain regular routines during treatment; and (i) determination to champion the disease: see Table 3 (p.43).

Example 1: Rene (61 years old); Sub-Category 5-5 (helped)

In my early thirties I had a growth on my thyroid, and at that time that's a fairly common time for malignancies in the thyroid in women. And I had myself dead and buried... And it was benign; I swore that I would never do that to myself again. And so I think that, in retrospect, that was one of the main things that helped me through this early. I thought... this time, that I wouldn't destroy myself in this process...

Example 2: Elizabeth (43 years old); Sub-Category 5-4 (helped)

I went right down and had them (her surgical stitches) taken out... I went to the (Boundary) Health Unit, and I thought well there's gotta be somebody there. I want these things out now. My drainage is low, and I knew that, and they just did it there. I didn't want to wait an extra two days... So it put me in control...

Example 3: Meagan (42 years old); Sub-Category 5-3 (helped)

I truly felt that in order for me to get the very best care, that I had to be knowledgeable about my disease. I would get the standard routine care that... everybody got, but being knowledgeable I actually got more things done. Like I got this oophorectomy done, which isn't standard care, but everyone supported me once I sort of presented the data to them. And so that was important for me to be knowledgeable about that...

Example 4: Lee (61 years old); Sub-Category 5-7 (helped)

From the very beginning we never let ourselves get too far ahead; we used to talk about it after and say that we were the masters of the short term goal, because you can't project what's going to happen with your illness number one. You can't project that the machine could break down, and you can't go in for your surgery, your treatment, whatever for four days... You just don't know, there are too many variables, so you never allow yourself, not because you think you're going to die, but you never allow yourself to think too far ahead, because there are too many things that can come in and alter the picture totally. So we never looked farther than the next step... We only read as far as we had to for what was coming up... When I was reading, initially, I was reading way ahead of where I should have been, and I got to one chapter about if you have too much chemotherapy your veins break down, and I thought oh my God you'd better quit this, this is not helping you. You know you don't even know if you're going to have chemo, so why are you reading this? And you've got to pull back and deal with what you've got to know... We just sort of drew back from everything but the immediate, and we found that was the way we got through it...

Example 5: Killie (61 years old); Sub-Category 5-9 (helped)

I discovered I had a pattern because I got bad news, and I discovered that what I tended to do was I would cry and I would get upset, and I would process it for about two and a half to three days, and then I could move on

and decide okay now what am I going to do? And I decided that I was going to do everything that I could do to give myself the best chance of coming out of all of this, because I was determined I was going to be a survivor, and whatever I needed to do or learn or find out I was going to do... So I went to the cancer agency... I tend to be proactive; I deal better when I know what I'm dealing with... I went to the cancer agency, and figured what do you have to offer me, what can I do... from soup to nuts I'm ready to go...

Example 6: Bridget (58 years old); Sub-Category 5-8 (helped)

I didn't want to get too programmed. As my sister calls it the cancer culture... get too drawn into the cancer culture....because I really tried to maintain a relatively normal life, in the sense that I would still go to concerts, I'd still go to parties. I'd do what I could do... I'd still go out, etc.... So I didn't do anything at the cancer agency (in terms of group involvement during treatment)... was my sanity I guess... I was actually president of the (a large community oriented social club)...for God's sake...so I was there every week... It... was important to keep doing that...

Category 6: Availability and Presentation of Appropriate Educational (Helpful vs. Hindering)

Many of the co-researchers referred to the benefits of having appropriate educational information offered them, in a timely manner, by medical staff and/or support personnel; information on the disease, and on the treatments and side effects pertinent to

that individual's case, when offered by such personnel, was usually helpful and well received by the co-researchers. Just so, a lack of forthcoming information was at times referred to, by the co-researchers involved, as a real hindrance in their process, as appropriate knowledge was usually considered beneficial. A total of 24 incidents, or approximately 5% of the total 453, were placed in this category: see Table 1: (p.41). Of those 24, 16 were presented as helpful incidents (approximately 67%), while eight were considered hindering (33%): see Table 2 (p. 42). Ten of the twelve co-researchers presented incidents applicable to this category.

The explanatory sub-categories offered here are as follows: (a) helpful information/literature, offered in a timely manner, by medical teams, information networks, and or support groups, on treatment (which may include: surgery, radiation, chemotherapy, hormonal therapy); (b) helpful information/literature, offered by medical teams, information networks, and or support groups, on possible side effects of treatment (which may include: severe nausea, hyper-activity, tethering [cording], lymphedema, hair loss, burns and rashes, immune suppression, treatment induced menopause); and (c) ready availability of helpful literature (i.e.: the BC Cancer Agency library): see Table 3 (p.43).

Example 1: Rene (61 years old); Sub-Category 6-1 (helpful)

I... had the appointment with the surgeon, and he gave me a number of articles and this neat book, I forget what it's called right now, but a lot of reading material, which I found extremely helpful. And I'm not sure that all doctors, or all surgeons, are giving those to women, but that was incredibly important...

Example 2: Lee (61 years old); Sub-Category 6-1 (hindering)

From my point of view it was more of a self-help than anything else. The doctor's office has the usual rack, with pamphlets... if you have, if you have, if you have. It's very broad range, there's nothing very specific, there's nothing detailed, there was nothing for my family's position, there was nothing from my surgeon... Nobody ever sat me down and said now this is what you can expect through your treatment. It was do it yourself, and as a layman that's very difficult. You don't know what you should be studying... You don't always know how to get the information, and mostly people do not have the capability, even if they do have the information, of actually understanding all of it to the extent where they can make an informed decision. So technically you're facing a very big milestone in your life, and you're totally unprepared to deal with it personally, and the medical community is not exactly forthcoming with any help... You're facing something that's very difficult to deal with, very hard to come to terms with, and yet you've got to get out and start beating the bushes to get the information for yourself, and then learn what you should be reading and what you can gloss over as not being relevant...

Example 3: Hilary (68 years old); Sub-Categories 6-1 and 6-3 (helpful)

It was my GP principally who offered me the first book... It's called "The Intelligent Patient's Guide to Breast Cancer"... The Cancer Clinic was very helpful. When I saw the radiation oncologist she recommended that

we go and watch a video on radiation, and they had that up in the Cancer Clinic library... I wanted to read more, and certainly the Cancer Clinic library is definitely a very good resource place, and they were very helpful...

Example 4: Killie (61 years old); Sub-Category 6-2 (helpful)

He was a young Chinese doctor; he had this sort of low key style, and he sort of said well you know one of these drugs... some women when they get them, he said, they want to clean house at 3 o'clock in the morning. And I said to him, not much chance of that happening to me, first of all I don't clean, and secondly... I sleep pretty well... He was right, because I got home and I kept waiting for the nausea to hit, because you've even got a basin for God's sake, in case I ended up throwing up... We had dinner and there's no signs of anything, so I was fine. I took the pills, you wake up in the middle of the night and you've got to take all these pills, etcetera, and so I woke up the next morning... The next day I got up, and it was like motor mouth, I did not stop talking the whole day, the energy level, it was these pills...I was...going a million miles an hour...

Example 5: Beverley (49 years old); Sub-Category 6-1 (helpful)

My surgeon gave me a whole package of information, which I believe comes through the Cancer Agency. She's...one of the authors of the book that's been included, which again gave me a good sort of solid feeling...

Example 6: Isabella (55 years old); Sub-Category 6-2 (hindering)

I got really sick, really disoriented, I couldn't function very well at all mentally or physically. I was in a lot of pain, from my bones and muscles; it was from the chemo. Once again, I was never given the true picture about what chemotherapy is. I was not given that treatment: you might have this, you might have that, you might have that, But no, they didn't tell me; what happened to me was not on any of the sheets I got. It was disgusting..

Category 7: Attitude Towards Life and the Human Community (Helpful)

This category denotes incidents extracted which reflect certain of the co-researchers' views on life itself, and how those views at times face scrutiny during the process of treatment for, and recovery from, a disease which challenges one's mortality. Separate from "locus of control", "attitude towards life" represents more the co-researcher's personal philosophy of her life, and may also include incidents which illuminate how she sees herself as a member of the human community, one who may have more to contribute to that community, as the result of what she has learned in championing breast cancer. A total of 16 incidents, or almost 4% of the total 453, were presented which were placed in this category: see Table 1 (p.41). All 16 incidents were identified as helpful by the co-researchers during their processes: see Table 2 (p.42).

Seven of the twelve co-researchers presented incidents which were placed in “attitude toward life and the human community”.

Thematic subcategories here include the following: (a) a sense of optimism over recovery from disease; (b) a belief that it is not “my time to die”; (c) a belief that one can contribute more to others both as the result of what is “learned” through such a crisis (i.e., learned about breast cancer; learned about managing crises), and sometimes through personal involvement in treatment studies; (d) a re-examination of one’s view of what is important in life (as the result of having had breast cancer), and on the temporary nature of life; and (e) seeing oneself as fortunate, in terms of the severity of one’s diagnosis, in comparison to others with the disease: see Table 3 (p.43).

Example 1: Hilary (68 years old); Sub-Category 7-3 (helpful)

I’m on a drug study for something with the Tamoxifen....I’m on it for five years. But, as I say, I’m happy... if I can help out. I was also on another study that they have going; one of the dietitians at the Cancer Clinic set it up for soy products... Soy products are supposed to be what they call fighter estrogen, plant estrogens, and the breast cancer doesn’t mind them. It takes no notice of it, so to have plant estrogens gives you some estrogen... I enjoy doing that sort of thing and I feel I’ve been given this road; as I say, there are some people who say: I don’t want to hear that word again, I don’t want to hear anything about it... I don’t feel that way at all, and I think somehow we’ve all got to help each other, to find some way...to fight...

Example 2: Bridget (58); Sub-Category 7-3 (helpful)

There's another woman, a friend of a friend, who got breast cancer, and this friend said: oh would you phone her. And I said: well sure I will. So I would phone her about once every three or four weeks, and she went through about the same regime that I did. And she said: oh it's really nice that you called; she said: things must be awful for you just to talk about it, to remember it...(This incident was endorsed by Bridget, during the 2nd interview, as one which accurately represents her desire to use her knowledge of treatment, for breast cancer, as a contribution to another undergoing treatment).

Example 3: Killie (61 years old); Sub-Category 7-2 (helpful)

To me it's a process that's ongoing. You don't have answers because you don't know when it's (the cancer) going to side swipe you again. You just have to try and deal with what comes along. I don't think I ever thought about dying before, and I figured that I wasn't really ready to die, I was too young to die and there was a lot of things I wanted to do. But I think I got to a point where I thought okay I'm going to give this my best shot... I can do all the things, I would do all that I can do that's positive... If I'm meant to survive I'll survive...

Example 4: Allyson (41 years old); Sub-Category 7-4 (helpful)

I remember, in the early days after diagnosis, I'd lay on the floor in my living room and I'd just feel like I would just open wide up... I was just wanting to be still, and just feel this emotion, and I just think this is so bizarre, if anyone saw me now... it's just the bizarrest thing to lay here, and know I have breast cancer and... Just feeling so at peace with things...I'm okay with everything and anything and it was just the strangest thing... To feel that and it came in a form of joy... Because had I not had the breast cancer, not that I necessarily think you have to have that to reach this...but it was like my being on the edge of losing my life, I guess... where with some people, I see them, where they have these moments of am I gonna die, where I had this moment of... being ...on that edge, but instead feeling like no matter what happens I'm okay...(This event required further clarification during the second interview).

Example 5: Beth (52 years old); Sub-Category 7-3 (helpful)

I wanted to connect...there was another woman at work who was diagnosed around the same time, and we became quite close, all of a sudden, through that, but you know there weren't very many other women. I wanted to get more involved, and also to do something myself to be able to help other women. So that's what I'm doing, volunteering in a lot of different things.

Category 8: Support/Psychoeducational Agencies/Groups/Centres (Helpful vs. Hindering)

A portion of the extracted incidents present direct references to co-researcher involvement with one (or more) of four agencies or groups which operate in the Vancouver area, being: (a) BC Cancer Agency Patient and Family Counselling department; (b) Treasure Chests (a psychoeducational and support group for women with breast cancer; (c) Abreast in a Boat (the social/activity group which organizes and sponsors dragon boat racing teams; such teams are comprised of women who have, or have had, breast cancer); and (d) Hope House (a centre operated by the Hope Cancer Health Society, a non-profit society which focuses on support and psychoeducational programming for both people living with cancer and their loved ones): see Table 3 (p.43). Such involvement has provided, as presented through the incidents extracted, varying degrees of: support, awareness of issues surrounding breast cancer, and a sense of community.

A total of thirteen incidents, or almost 3% of the total 453, were applicable to this category: see Table 1 (p. 41). Of those thirteen, eleven were presented as helpful, which is 85% of the total for the category. Two incidents were described by the co-researchers as hindering (15% of the total): see Table 2 (p. 42). Seven of the twelve co-researchers presented incidents applicable here.

Example 1: Isabella (55 years old); Sub-Category 8-4 (helpful)

Hope House... this place I went to is amazing; it was where you saw survivors. You weren't besieged by death and statistics. You saw people who survived. You sat together and talked about mutual feelings and problems you were dealing with; the sharing... I grabbed onto this like a lifeline...

Example 2: Beverley (49 years old); Sub-Category 8-1 (hindering)

I went down to counselling once at the Cancer Agency, I found for me it wasn't that useful for a variety of reasons: one was that I had a fairly good network anyway. I had two friends: one is a professional counsellor, and one is in sort of the counselling area, and so having both of them as very close friends, that I could talk to any time, and spend time with any time, I didn't really feel I needed counselling persay. So that was part of it. Another part of it was that I started out, at one point in my working life, doing counselling, and I've done a fair amount of training and reading in counselling, and I felt a little bit like I was in a session where it was now we're on to page 26, ah, how did that work? Or how did that make you feel? So a little bit of the: you're no more skilled than I am. What am I doing here kind of feeling, because I already had people I could talk to. So I wasn't sure what I was there for. And it so I only went once, and I had a chat with them, and that was the end of it...

Example 3: Allyson (41 years old); Sub-Category 8-2 (helpful)

I would like to say, about the Treasure Chests, is that the first meeting I went to there were there must have been 35, 40 women there... Usually what they do is, they have a speaker, who speaks on a special topic, and then after that I was into the group discussion, and if there's any new diagnoses then you're asked to speak if you'd like and tell...your background. And I think I was the only one who was newly diagnosed, and so I told a bit of my story. I wasn't nervous or scared being around these people... I felt really comfortable; they help make it that way, but what happened was that and I've never seen this at another one of their meetings...one of the...senior breast cancer people said: maybe what we should do is have a round where everybody tells a snippet about their history for Allyson. So this is what happened, and as each person went around...I was so moved by the dynamics of the ages, the experiences...I completely forgot that I even had it, because I was just so in awe of these people and all their, you know, different colours and ages and sizes...and the courage... When the last person finished, I felt like I had had every single person just reach out to me with their arms. I just felt so nurtured... I tell you it just so made the difference for me...

Example 4: Killie (61 years old); Sub-Category 8-2 (helpful)

I found the support group, Treasure Chest... I went there and I will remember that first night...I came out of there and I was flying, the most incredible group of women, they were upbeat, they were dynamic... A

number of them were survivors, and some of them were still going through the cancer. They were bright, they were smart. I thought: this is my kind of group, this is fantastic... I thought: it was the best thing that's happened to me... I'd just arrived the first night, and you had to spill out your story, and stuff, and they just glommed on. And I guess I'm not particularly shy... part of that was, you know, in me. And then there were people there that you could ask questions of, and they had been fantastic, just in terms of information and support and you can phone people etcetera... I went every time, didn't miss, still haven't missed. I try not to miss. That was a huge plus, huge plus and... you meet different people... who deal with all this differently...

Category 9: Maternal/Caregiving Role/Behavior (Helpful vs. Hindering)

Six of the 12 women interviewed for this study discussed with the co-investigator- at some point during the primary interview- their children's roles and involvement in their treatment processes. Of these same six, five of the women are mothers of adult children; this fact is not surprising, as the mean age of the co-researchers in this study is 55 years. What may be surprising, and what warrants categorical representation here, is the roles these women as mothers continued to play in the lives of their adult children, during their own crises of breast cancer. Of the five women with adult children, four referred to incidents which may be understood as situations where the mother continued to maintain the role of maternal support for the child, to some degree, during the mother's own crisis,

that crisis forming the source of fear, despair, and anxiety for the adult child. Such ongoing support is referred to here as the maternal role.

Just as such behavior is represented, through certain critical incidents, as extending from mother to adult child, so do a portion of the co-researchers refer to such behavior as extending from themselves to elderly parents and other relatives, individuals closely related to the co-researchers, for whom the co-researchers have tended to adopt a caregiving role (as is often the case with middle-aged adult children and their elderly parents). In fact, four of the women in this study refer to such care-giving inclinations and behavior, as extended to elderly parents, or other closely related individuals of advanced years. Thus, the two thematic sub-categories offered here are as follows: (a) sense of personal responsibility to children (including adult children), and/or concern for their welfare; and (b) sense of personal responsibility to elderly parents (and other relatives), and/or concern for their welfare: see Table 3 (p. 43).

A total of 12 incidents were described which were applicable to this category: This comprises close to 3% of the total number of 453 incidents: see Table 1 (p.41). Of those twelve, five incidents were considered helpful (42%), while seven were considered hindering to the treatment process (58%): see Table 2 (p.42). Eight of the twelve co-researchers described incidents which were placed in this category.

Example 1: Lee (61 years old) Sub-Category 9-1 (hindering)

My daughter was...out of work and sick. She was freaking. She was writing exams, and I kept saying: you don't bother with me, you do your

own thing... you have to get your life on track, your dad's here for me, we'll manage... She was off work for a long time, and finally got her foot in the door with a training program, and was taking exams at the time that I was sick, and kept saying: oh I can't, I can't get out to see you. This is when I said to her: I am not your first priority, your first priority is your exam and your job, and you get that off your hands and then we'll visit, and Dad will look after me in the meantime. All you have to do is get your studying done and pass your exams. I'm fine. The input was wonderful, and I know you'd be here, but at this point in time if you don't get this exam finished and pass and get into the work force, we've lost all the time and money that's been put into it...

Example 2: Isabella (55 years old); Sub-Category 9-1 (hindering)

I had my daughter and my son and his girlfriend wife whatever...and the baby... They were young and they were both struggling with their lives, and they were more afraid of me dying than I was afraid of dying... I still felt I had to be strong and I had to be...good for them... That was very hard... There were times when they were...certainly were supportive... they didn't know how to reach out, kind of thing, or what to do in a way that people (who) aren't able to speak openly, when they are afraid...

Example 3: Rene (61 years old); Sub-Category 9-2 (hindering)

My mother...is 90, 91... Oh that's a couple of years ago now... That was difficult for me, because my mother had broken her arm and was in hospital, and she was in intermediate care. She wouldn't be going back to where she lived, she was waiting for (an) intermediate care facility. That was a hard time in a way because I was going through all this. I knew it was too much for her... to be aware of at this point, and I let the nursing staff know there. She had a different doctor... it was all strange people, and I let them know what was going on with me... 'cause I'm an only child. So that seemed important that they knew that. I did have all that to deal with while this was going on... They felt that... when I'm in the hospital I wasn't going to be going to visit her... it was better for her to know, and that she had the support... which I agree with, and so I told her. She's been having more difficulty with her memory and what not too... One of my daughters was listening when I told her... I thought that was important, because how one of the daughters responded would probably help my Mom to recognize maybe that things were okay... I guess... she was a bit shocked...

Example 4: Meagan (42 years old); Sub-Category 9-2 (helpful)

I actually took her (Meagan's mother) along with me when I was getting my chemo treatments. I actually did that mostly for her because she was quite devastated when...she heard of my diagnosis... Your kid isn't supposed to die before you are. So when I went for my treatment I thought

it was really important to bring her along, so that she could see the Cancer Agency, 'cause otherwise you think of cancer and it's like this big black hole this awful black thing right... I took her along...so she could meet the nurses and the doctors and the social worker, and so she was there when I had my treatment, so that she could see what I was going through, 'cause I think that was important for her...

Category 10: Career as a Medical Professional (or a Professional Related to the Medical Fields) (Helpful vs. Hindering)

Five of the 12 women interviewed are registered nurses; of the five, two are currently practicing as nurses, while two are retired, and one works in the pharmaceutical industry. Of those five, four presented incidents which were specifically related to this category. Thus, for one-third of the co-researchers involved, the process of treatment for breast cancer was influenced by their professional medical knowledge and training. Not surprisingly, a thematic category representing incidents related to such knowledge is essential. A total of eleven incidents were identified (approximately 2% of the total 453), which are applicable to this category: see Table 1 (p. 41). Of those eleven, nine were considered helpful to the treatment process (82% of the total for this category), while only two were considered hindering (18%): see Table 2 (p.42).

Sub-categories here include: (a) professional knowledge of breast cancer as a disease, and of the various treatments for it; (b) general medical knowledge (as a professional), including general knowledge of patient treatment and care; (c) ways in

which one's career as a medical professional is altered by the experience of breast cancer; and (d) professional connections through one's career: see Table 3 (p.43).

Example 1: Elizabeth (43 years old); Sub-Category 10-4 (helpful)

I worked here at this hospital and when I was in emerg. (due to the intensity of her reaction to chemotherapy) I knew the nurses; they got me right in. I was sitting there... very sick, throwing up, and they (said) Elizabeth... we'll get you in. I've worked here for a long time and... I knew them on the ward... Elizabeth, we did a real re-arrangement here for you. I just needed a private room... I couldn't lift my head off the pillow. I just needed to lie there without a whole lot of interaction and noise going on around me, so that was good...

Example 2: Beth (52 years old); Sub-Category 10-2 (hindering)

There was one nurse, when I first woke up (from surgery), who came immediately to take my blood pressure on the operative side, which you're not supposed to do because of lymphedema. I knew that, so I said could you take it on the other side, and she said well if you insist, and I thought, good grief, totally unnecessary and if I had been a little more awake I could have been quite furious, because it's one thing for her to not know that she shouldn't take it there, but another thing for her to react like that... A lot of the nurses were in my same age group, and they knew what was wrong, and they sort of didn't want to talk about it and kind of backed off,

did the routine checks or whatever, vital signs and...that was it... Being a nurse myself you expected... you sort of wish the standard (of care) was a bit higher...

Example 3: Meagan (42 years old); Sub-Category 10-4 (helpful)

When I got sick... I'm in the pharmaceutical industry and I have friends that work in the area of oncology, I asked around right away to let me know who the best people were in their estimation, because you get a really good sense when you're in the industry and working with these guys, get a really good sense of who's really good. So I got the best people sort of on my team...

Category 11: Spiritual Beliefs (Helpful)

Six of the 12 co-researchers present an incident or incidents which illuminate the involvement of some form of spiritual faith in their treatment journeys. A total of ten incidents, of just more than 2% of the total 453, were applicable to this category: see Table 1 (p. 41). All ten incidents were deemed helpful to the co-researchers: see Table 2 (p. 42).

The degree of importance placed on the presence of some form of faith varies with the co-researchers, and may be better represented through the following sub-categories: (a) faith in God and or a higher power and or spiritual entities; (b) faith in the potential involvement of such, in one's life; (c) faith healing and or miracles; and (d) belief in the potentially real power of prayer and the effects such an activity may have on

one's life: see Table 3 (p.43). This category may be seen as different than prayer as an activity which aids in treatment and recovery (Category 4), as it focuses more on the spiritual faith or beliefs which uphold the potential for prayer as a helpful activity.

Example 1: Elizabeth (43 years old); Sub-Category 11-3 (helpful)

The day that that woman (the mother of a friend) prayed for me, I was never sick again a day from the chemo. You can get the flu or you can get a cold, but you know this chemo sick, there's nothing like it. I was never sick again... I'll never forget that because... I've never experienced anything quite like that. To me it was just like a miracle, because it ended one day and it never came back. It wasn't like back and forth it was very clear: she prayed I was never sick again... Prayer did work. You have to be able to back these statements up; can't just say well yeah... I had a miracle... But to me, that was a miracle, and I waited it out; I didn't assume immediately I've had this supernatural thing happen. I was just never sick again...

Example 2: Isabella (55 years old); Sub-Category 11-1 (helpful)

What was the motivation behind all this freaking out that I was doing? What was I really afraid of, which was death, and how did I want to deal with that? How did I want to get my spirituality intact to a degree where this was finally acceptable, which is inevitable, but acceptable...? And to me that's the basis of all our fears (death); not only when we have to deal

with cancer but with other things in life. We're always living on the...edge so to speak... We have to accomplish all this; we have to be so good; we have to do all things; we have to live this way. Somehow we think we won't be punished with death if we do or something, I don't know. It's some weird western phenomenon... I started going intensely to...eastern philosophical ideology and mediation after that, which deals a lot with death; so that was another way that...I was able to that was positive in my dealing with cancer..

Example 3: Jane (70 years old); Sub-Category 11-1 (helpful)

I've been Roman Catholic all my life... I suppose it does help, yeah. I'd try to get to daily mass, and that was something I could do. I could burn the candles... I don't live far from the church and I still go to daily mass. I...think (it) is very important but I think... maybe from the spiritual you get your positive attitude... But you still have to cope with the day... You still have to eat the right stuff, get out there and walk... I'm just trying to think of this old saying: you pray as if everything depended upon God and you work as if everything depends on you. There is that interdependence, yeah...

Example 4: Hilary (68 years old); Sub-Category 11-1 (helpful)

I'm a participant (in a church parish). I enjoy singing in the choir and I enjoy the music. I'm not a deeply religious person, I don't think, but I

guess I do have some convictions... I've maintained the Anglican Church... I was on the prayer list... They asked me if I would like to (be) and I said yes, if you would like to pray for me then I would be very happy... We've got to do the surgery to get rid of the cancer; the cancer that could have spread to the breast, so you're going to get radiation to make sure that that's gone. You're going to take tamoxifen for (it) and that's the end of that... It would take a lot to take me away from the western medicine, which I guess I've been brought up with... The church is definitely a part... If I actually had to say how much faith do I have, I don't know, but I think there must be something up there that's guiding us in the right direction and something to hang on to... I suppose if I really think about it there is; I do think there's somebody somewhere that's guiding us along, but whether it's (what) you've learned, or what you believe, I don't know...

Category 12: Career (Helpful vs. Hindering)

This category denotes the critical incidents associated with the careers of the co-researchers; it is a separate category from Category 10 (career as a medical professional) as, rather than representing extracted incidents which focus on how certain co-researchers' treatment processes were influenced and affected by professional medical knowledge, this category illuminates incidents associated with the co-researchers' careers in general, as they were affected during treatment. Thematic sub-categories for Category 12 are as follows: (a) support/flexibility of employers/job supervisors; (b) ability to stay

connected with career; (c) ensuing financial security; and (d) the workplace as representative of a segment of one's life separate from breast cancer (the "normalization" experience of one's life through involvement in the workplace): see Table 3 (p.43).

Five of the twelve co-researchers described a total of nine incidents which were placed in this category (approximately 2% of the total 453): see Table 1 (p. 41). Eight of those nine incidents, or 89% of the total for this category, were valued as helpful by the co-researchers. Only one incident, which itself comprises 11% of the total for this category, was presented as hindering: see Table 2 (p.42).

Example 1: Beverley (49 years old); Sub-Category 12-1 (helpful)

My director, the woman whose mother had had breast cancer and whose sister has been diagnosed with breast cancer, she was very understanding. As I say I'm not dead sure that she knew sometimes how short a day I was actually working, but basically she was sort of saying: you do what you need to do. I am an independent worker anyway. Nobody else depends on me; I do my own work totally independently... so she was sort of basically leaving me to do what I felt was the right thing to do, and necessary to do, and I was able to shorten my day, which certainly helped. Not every day; there were days when I did work a full day, but there were certainly days when... I'd sort of get to the office when I got there...

Example 2: Elizabeth (43 years old); Sub-Category 12-4 (helpful)

After I was diagnosed I wanted to keep it a total secret. I didn't want anyone to know. I went back to work and I didn't tell anybody. I was hoping I could just slip away, have my surgery, come back, and nobody would ever have to know. I guess I'm a private person in some ways... but then when I was gonna have to be off for chemo too I had to tell people. But I just needed to go to work, during the interval between diagnosis and surgery... it was it was wonderful to be able to go to work. It took my mind off things. It was my routine in my life... I just didn't tell anybody. And I needed to not tell anybody during that time, except my close friends and family... I didn't want any involvement with this and the work situation... For me, that's what I needed to do, and it helped. I just didn't want to talk about it anymore, didn't want to have to think about it. I just wanted to go there and do my job...

Example 3: Meagan (42 years old); Sub-Category 12-1 (helpful)

Work was also really great. I worked as a sales rep... I actually took about six months off. I took three months off, short term disability, and then my boss...was phenomenal too. I had so many good people that were just so great; it just made the...whole thing so much easier. Rather than putting me on long term disability, because he said if you go on long term disability it's actually gonna show up on...any future jobs that you want..., I worked very little like hardly any at all..., just as much as I wanted to, which was just a little bit to sort of keep in touch with what I...was doing...

He just put me down...that I was working, but he never actually made me claim long term disability, which was actually very helpful because now that I've left the company and moved on to a new company that made a big difference... There hasn't been any problems with me getting coverage, even though I had cancer. So anyway he was fabulous...

Category 13: Personal Involvement in Decision Making (Helpful)

Five of the co-researchers made reference, through certain incidents described, of their desire for personal involvement in the decision making process, regarding their treatment for breast cancer. It was important to them that their wishes and desires be considered by the medical team when deciding the treatment regime. A total of eight incidents were presented which are applicable here, all of them of a nature deemed helpful by the co-researchers: see Table 1: (p. 41). The eight incidents comprise just under 2% of the total 453.

The two thematic sub-categories for Category 13 are as follows: (a) being treated as- and believing that one is- an integral member of the decision making team, with regards to one's medical treatment; and (b) respect, by the medical team, for one's decisions regarding treatment: see Table 3 (p.43).

Example 1: Beth (52 years old); Sub-Category 13-1 (helpful)

So when I did go there (to a consultation with a second surgeon, with the purpose of obtaining a second opinion on the best type of surgery to pursue for her diagnosis), that was a very helpful thing to do, because it

was a totally different reason but the same result: that I needed a mastectomy (as opposed to a lumpectomy), because of the type of tissues... She (the second surgeon) also pointed out that with those type of cells, the chemotherapy and radiation weren't as effective... So... with the two of them (the two surgeons)... it felt like it was my decision; that it wasn't just any one person. But I felt much more comfortable doing it, and it was my decision, and I felt comfortable ever since. I think it was because of that process, and not... sort of somebody telling me... making the decision for me...

Example 2: Rene (61 years old); Sub-Category 13-1 (helpful)

Once I saw the surgeon, I had... a number of questions, he said well you have a decision to make: either a mastectomy, full mastectomy, or just a partial. Well what's the advantage of having the full? So, according to him, you have very little breast tissue, again, to develop further cancer, although you can; and there's a real move for women to be part of the decision making, and I think that's incredibly important. But you need to understand. So I went away with this big quandary about what was the best thing... I was wondering...what are the stats. for either way, you know, based on my scenario? Then there was the Cancer Information Service... I phoned, and this woman I talked to was absolutely wonderful. And I explained my scenario... This woman said that she would be in touch with an oncologist at the Cancer Clinic, and either he or she would

call me back... She called me back, and said that he had said that, based on my scenario, he thought a partial mastectomy would be appropriate, that I probably wouldn't need tamoxifen..., but that I'd need some radiation. So I went back to the surgeon... I went through all the questions... He reinforced me making this decision (for a partial mastectomy), and that was fine...

Example 3: Meagan (42 years old); Sub-Category 13-2 (helpful)

I could read all this stuff, and then I came actually to my...own conclusion, which in fact was a different conclusion than the cancer agency had drawn up in their draft guidelines. However, when I presented the data to my oncologist...and she was one of the people that drafted the guidelines, she was very supportive of actually going along with what I wanted, which was to have my ovaries removed. Because, (there) actually is some data that shows that it is helpful for certain women, and I had a type of breast cancer that...I felt it would be helpful to have my ovaries removed...

Category 14: Physical Appearance (Helpful vs. Hindering)

Four of the co-researchers presented a total of seven incidents which were associated with the importance that they placed on their physical appearance during treatment: see Table 1 (p. 41). These seven incidents comprise approximately 2% of the total 453. Six of the seven incidents described were deemed helpful by the co-researchers

(86% of the total for this category), while one incident was presented as hindering the individual's process (14%): see Table 2 (p.42).

Particular reference is made in this category to chemotherapy treatment, with it's ensuing common side-effect of hair loss, and how the co-researcher is affected by that hair loss. The two thematic sub-categories for Category 14 are as follows: (a) use of wigs and or scarves; and (b) experiences related to baldness and hair: see Table 3 (p. 43).

Example 1: Killie (61 years old); Sub-Categories 14-1 and 14-2 (helpful)

...Having the wig ahead of time (was helpful), so that was ready, and she (Killie's sister) said well let's go and look at hats. Because I decided... (if) I'm going to lose my hair, then I'm going to look good, and that was my motive throughout this thing... if you look good you feel better. I have no intention of walking around looking like death warmed over. So I thought I was all set... I knew the hair was going to fall out etcetera... But I will never forget the morning in the shower, when it actually started to fall out; ooh, I don't know, despite the fact I thought I was ready for it, we joked about it, something happens to you. I had even talked to my hair dresser, about when it falls out... I'm going to have it shaved... We had the hair taken off and I had the wig and then...we went down to where we got the wig, and we had it trimmed, 'cause if you try on a wig with hair it's different fit from when you have no hair... And that night I went to a party and...(thought) now can I carry this off? Because these were people who knew me. And I walked in, and nobody noticed... and finally the friend

who's party it was who's very observant... it wasn't until the next day and she said it was fantastic. Anyway I was very fortunate...

Example 2: Beverley (49 years old); Sub-Categories 14-1 and 14-2 (helpful)

My hair has always been very important to me, and people have always admired my hair for years and years. Even when I was having sort of a bad hair day, everybody always talked about how beautiful my hair was. So my hair was important. I wanted a wig, like some people say well you know get a blond or get something wild, get something long; I wanted to look just the way I was. I didn't want people to know I was sick. I just wanted to continue on as if everything was okay. So I got a wig which was exactly the same colour; exactly the same style; cut to fit; tailored; the whole thing. Because I wanted to look just the way I did before, because I was okay. I wasn't sick, and that was important to me. It was very important that people couldn't see that I looked any different. So... there was a bit of a panic, because the UPS strike was on, and she (the wig designer) gets her wigs in from the States, and we didn't know whether it was gonna come or it wasn't gonna come. But it did, it arrived. We got it all fixed up, and custom made, and all the rest of it. And I went in, had my hair cut off, when I could start feeling it falling out...

Example 3: Allyson (41 years old); Sub-Categories 14-1 and 14-2 (helpful)

But it was a moment where I took off my wig, and I normally don't except ... (with) a few close friends who come over, when I don't have makeup on or whatever. I normally don't go around without hair on and no makeup... And here I was, in a room full of people, and the second I took off my wig the cameras... were just flashing like crazy. It was really uncomfortable, but at the same time... I knew they said... it's up to you to do this or not. And I felt, right from the beginning... that I needed to do this, because I needed other people to know that it's okay. It's okay not to be freaked, or freaked out, about your hair being lost, or not. It's okay. It's okay to not have hair...

Category 15: Alternative Treatments (Helpful)

Two of the co-researchers referred to alternative treatments which they deemed helpful in conjunction with the more mainstream eradicated treatment as presented at the Cancer Clinic; one of these two co-researchers actually found such alternative treatments more helpful than that prescribed from the mainstream medical treatment arena. A total of three incidents, or approximately 1% of the total 453, were applicable to this category: see Table 1 (p.41). All three incidents were considered helpful by the co-researchers: see Table 2 (p.42).

The two representative sub-categories for this category are as follows: (a) herbal medicines; and (b) naturopathy: see Table 3 (p.43). The components of this category need separation from Category 4 (Activities/Things which Aid in Treatment and

Recovery), as they unto themselves may comprise separate (but usually adjunctive) treatment protocols.

Example 1: Lee (61 years old); Sub-Category 15-1 (helpful)

I'm not a health food nut, but I got to know the people at my local store very well. They all knew the problems I was experiencing. I went in there crying some days. They knew what was wrong. They gave me a homeopathic pill, for the nausea I had initially with the radiation. They suggested this cream for my skin, which was just wonderful. And that's a whole untapped resource. I'm not asking them for a medical opinion. I'm not likely go in and say: I have breast cancer, can you help me? There were things that they can give you to help as your treatment goes along...

Example 2: Isabella (55 years old); Sub-Category 15-1 (helpful)

One of the good things about it (a post-operative breast infection), was I decided that I was going to then go in to some herbal things; into some proper healing... Anyway, I went to this place, this herbal store, and the herbalist there I told him I had an infection in my breast, from breast cancer surgery, and could he give me something that would draw this infection out...? Anyway, he gave me a cream salve to put on my breast, and to cover with a towel because it was going to bring out the infection. And I did that for three nights, and it was gone, gone completely. I won't tell you what it was like, what came out...

CHAPTER V: DISCUSSION

Each of twelve adult women participated in two interviews, during which was discussed, from their perspectives, helping (or facilitative) and/or hindering experiences as occurred during their respective periods of treatment for breast cancer. From these initial and follow-up interviews, a total of 453 incidents were identified, in accordance with the definitive parameters set out in descriptors of the critical incident methodology (Woolsey, 1986). These incidents were successfully represented through the development of 15 thematic categories. They are: (a) relations with the medical team and any support staff, (b) medical treatment and services, (c) personal support, (d) activities and or things which aid in treatment and recovery, (e) locus of control (or personal agency), (f) availability and presentation of appropriate educational information, (g) attitude towards life and the human community, (h) support/psychoeducational agencies/groups/centres, (i) maternal/caregiving role/behavior, (j) career as a medical professional, (k) spiritual beliefs, (l) career, (m) personal involvement in decision making, (n) physical appearance, and (o) alternative treatments.

Successful validation procedures were carried out on the above 15 categories, and included: (a) cross-checking of the relevant incidents by the co-researchers during the second interview, (b) exhaustiveness of the categories, as tested by the placing of two complete interviews aside, for categorization in the already existing 15 categories, (c) the independent classification of 100 of the 453 incidents, into the existing 15 categories, by an external rater, and (d) the linking of the categories to some of the existing literature, on both studies conducted with women with breast cancer, and on counselling theories which focus on issues of transition, validation, and resiliency.

It is important to note that, while all 15 categories are together representative of the experiences as described by the co-researchers, a total of 340 incidents, or 75.05% of the total number, fall within the first five categories. Also, of the twelve co-researchers whose experiences comprise the core of this study, at least eleven or more presented experiences related to each of the first five categories. Indeed, all the co-researchers (12/12) presented experiences which were placed in each of the first three categories, while eleven out of twelve described experiences related to the fourth and fifth categories: see Table 1 (p.41). Thus, the following first five categories warrant closer examination here: a) relations with the medical team and any support staff, b) medical treatment and services, c) personal support, d) activities/things which aid in treatment and recovery, and e) locus of control.

Relations with the Medical Team and Any Support Staff.

All twelve co-researchers presented experiences which in their total comprise this first category. Of the 453 incidents, 94, or 21%, fell within this category: see Table 1 (p.41). This category thus represents more incidents than any other of the 15 categories offered in this report. Of those 94 incidents, 72 proved to be those deemed helpful by the co-researchers, in that they were helpful to them through their treatment processes, while 22 were described as hindering: see Table 2 (p. 42). Hindering incidents varied from a lack of faith in the doctor's or specialist's level of ability to a lack of rapport with or respect for that individual: see Table 3 (p.43).

The importance of the relationships one has with one's medical team, particularly in the context of treatment for a life threatening disease, is strongly represented here: more than one-fifth of all the critical incidents extracted had to do with such relations.

The co-researchers discussed such relationships, in the context of actual experiences, more than any other topic. Such an aspect of one's treatment process corresponds with some existing literature on both certain counselling theories, and in actual studies conducted with women who have or have had breast cancer.

Ishu Ishiyama states that "people are motivated to seek self-validation, that is, the affirmation of one's sense of self and positive valuing of one's unique and meaningful personal existence" (1995, p.135). This forms part of the foundation for his self-validation model, which includes five thematic components of self-validation, with their corresponding themes of self-invalidation: (a) security, comfort and support, (b) self-worth and self-acceptance, (c) competence and autonomy, (d) identity and belonging, and (e) love, fulfillment and meaning in life. The model was developed in order to explore experiences of personal transition, and would be used in this context to illuminate the individual's transition as caused by a major health crisis. Ishiyama purports such transitions may induce shifts in the individual's self-validation sources (Ishiyama, 1995).

The relations one has with one's medical team, during a period of crisis, directly corresponds with at least the first theme of self-validation: security, comfort and support. In this light, each co-researcher's life was threatened by the diagnosis of breast cancer. During the process of treatment for such a disease, the medical team who are treating the individual will become extraordinarily important to her, as they are the ones who will, or will not, cure her medically. Thus, her sense of security, both in daily life and in the context of her surviving the disease, will be closely linked to those who she is relying greatly on for her survival. Not only her security in life, but her comfort during treatment (both emotional and physical), as well as the support from which she may benefit, will all

be closely linked to those caring for her medically. It is not surprising, then, that her relations with her medical team may prove to be highly validating for her during this crisis, as well as highly invalidating potentially, given the roles they now play in this time of her life which involves such a tremendous crisis and transition. Her medical team become very important to her sense of self, and to her very existence.

This category also corresponds with some of the results of a study cited earlier, by Boman et al. (1997). Their study, again, involved an open ended question disguised in a 66 item questionnaire, answered by female patients recuperating from eradicated surgery for breast cancer. The particular question read: "Is there anything that you wish for or would like to change, when you think about your stay in the hospital and the time that followed it? Write down whatever occurs to you" (1997, p.26). For this particular question, the authors conclude with five categories: (a) emotional support, (b) personal treatment, (c) practical assistance, (d) information, and (e) trust. While all five of these categories may be seen as corresponding to more than one of the categories developed in the present study, they all correspond with this first category, in context of the participants of the Boman et al. (1997) study reporting on their experiences while recuperating in hospital. The treatment, information, and practical assistance that these women received in hospital, as well as their perceptions of emotional support and trust, are all components of their relationships with their medical team and support staff, those people caring for them. If the participant does not feel supported, if she does not trust her team, if they do not give her the information or assistance she needs and or desires, her recuperation in hospital will be hindered.

Medical Treatment and Services.

Of the 453 incidents extrapolated from the interviews, 85 of them, or 19%, fell within the category of medical treatment and services: see Table 1 (p.41). This category depicts any incidents related to the actual medical treatment the co-researchers underwent, and may included experiences around chemotherapy, radiation therapy, hormonal therapy, surgery, and any rehabilitative treatment, such as physiotherapy. All twelve co-researchers presented experiences related to this category. Of the 85 incidents presented, 41 of them were deemed helpful, while 44 of them were considered hindering: see Table 2 (p.42). Thus, the women presented a greater number of hindering incidents than helpful ones. Many of the incidents here deemed hindering focused on what the co-researcher viewed as the incompetence of a medical professional, specifically during the performance of an eradicated procedure, thus reducing the level of success of the procedure. Many other hindering incidents focused on a lack of timeliness in having the procedure carried out (i.e., delays in performing the procedure; delays in learning the results of the procedure).

A link may be found between this category and the results of the study by Boman et al (1997) cited earlier. As the results of their study were derived again by women recuperating in hospital from surgery for breast cancer, the category of “personal treatment” can be linked with the category developed here, as the personal treatment received would partly be in context of treatment by the medical professionals caring for the co-researchers as patients.

Through the development of his theory of motivation, Abraham Maslow (1970) discusses what he refers to as the hierarchy of human needs. According to Maslow the primary, or basic, human needs begin with the satisfaction of the physiological needs,

which are then followed by safety needs, belongingness and love needs, esteem needs and, finally, actualization needs. Maslow argues that the earlier level of needs must be gratified before the person may be in a position to focus on the next level of needs. Thus, in order to experience motivation towards self-actualization, one must have the first four levels of needs in the hierarchy satisfied. The first level, the ground level, of this hierarchy are the physiological needs. Maslow writes: "in the human being who is missing everything in life in an extreme fashion, it is most likely that the major motivation would be the physiological needs rather than any others. If all the needs are unsatisfied, then the organism is then dominated by the physiological needs, all other needs may become simply nonexistent or be pushed into the background." (1970, pp. 36-37). Maslow refers primarily here to the need for nutrients the body is lacking, through food, and for homeostasis, or a "constant, normal state of the blood stream." (1970, p.36).

The thorough understanding of the actual medical procedures involved, as well as the examination of the actual competency of the medical professionals performing these procedures, goes well beyond the scope of this study. Maslow's theory is useful here, however, in keeping in context the physical crisis the co-researchers underwent, as they not only developed cancer within their physical beings, but those physical beings were then invaded by the various components of the medical regime utilized to destroy that cancer. The homeostasis of the person undergoing eradication treatment would be severely disrupted, which may, according to Maslow, override the person's motivation towards the fulfillment of higher order needs. This is arguable, as the needs for belongingness and love, for example, are strongly presented through many of the categories offered here, particularly Category 3: personal support. Yet it is important to

remember that the disrupted homeostasis of a person undergoing treatment will certainly play a strong role in the individual's process; such a disruption could indeed override what would otherwise be the pursuit of other needs in the individual's life. However, the pre-existing establishment (before the cancer diagnosis) of the higher order needs, such as safety, belongingness and love, and esteem, would indeed act as strong supports for the individual whose physiological needs have indeed been disrupted by both the development of the cancer and the treatment for it. Without such eradicated treatment coming into play, one could argue that the physiological needs would be disrupted to a much greater extent.

Personal Support.

A total of 77 incidents, or 17% of the whole, were placed in this third category of personal support: see Table 1 (p.41). Within this category are ten sub-categories, which act as descriptors of the sources for personal support as presented by the co-researchers (i.e., by partners, by friends): see Table 3 (p.43). Of the 77 incidents, 68 were described by the women as helpful during their processes, while 9 were presented as hindering: see Table 2 (p.42). The hindering incidents were mainly representative of situations where the individual was expecting or relying on the personal support of someone important in her life, only to experience that support as not forthcoming and or of an ambivalent nature.

The theme of support was offered, to various degrees, in a large portion of the literature previously examined in the literature review. Fife et al. (1994) again sought out to discover what differences existed, if indeed there were any differences, between the two genders regarding general psychosocial adjustment to cancer diagnosis and treatment.

The authors concluded that women's adjustment was more dependent on family support, while men's tended to be more dependent on professional support. Fife et al. (1994) also reported that the socialization which women experience as they mature, tended to work in their favor, as they maintained a greater ability of seeking emotional support from family and friends, than men. Thus, emotional support played a key role in their cancer processes. Waxler-Morrison et al. (1991) in turn present, in the results of their study, a significant relationship between the indicators of social context- as derived from questionnaires administered- and survival, particularly regarding friendships and employment outside the home. Waxler-Morrison et al. (1991) discovered that the greater the number of friends perceived by the woman as being supportive, the greater the likelihood of survival. They go further to suggest that a highly positive impact is made by friends who offer pragmatic help, such as shopping, cooking, and transportation. Such findings correspond to those of the study reported here, that is: not only did all the co-researchers present incidents around personal support, they often discussed the pragmatic ways such personal support manifested. Examples are: transportation, cooking, collecting money, providing information, and ensuring the co-researcher was not alone the night after a chemotherapy treatment. Indeed, such examples of pragmatic support can be found throughout the sample of incidents pertaining to this category.

Some of the thematic components of personal support correspond to the study by Jenenne Nelson (1996), cited earlier. Through her research, Nelson (1996) developed five themes of uncertainty for her co-researchers. They were: (a) the vicissitude of emotions, (b) the relying on support through relationships, (c) transitions, or discovering new ways of being (in the world), (d) reflections of oneself (in the world), and (e) gaining

understanding, and in that understanding the incorporation of uncertainty into the perspective of life. Here there is a clear correspondence between her second theme, the relying on support through relationships, and this category of personal support.

Finally: the desire for personal support is aptly represented, in this context, by a quote by Dorothy Becvar (1996), again cited in her article: I am a woman first: A message about breast cancer: "I worry about imposing, so it would help me if you would offer to go with me to the doctor, to be there when the test results come back, to stay with me in the hospital, to talk to me or hold my hand through chemotherapy." (1996, p.84).

The category of personal support corresponds directly to more than one of the thematic components as again presented by Ishiyama (1995). He writes: "the theme of love, fulfillment, and meaning in life is considered to be central to human existence and to form the core component of self-validation." (1995, p. 135). The theme of love is certainly represented within the sub-categories to be found in this category, as many of the sub-categories (i.e., partner, parents, and friends) identify relationships which involve love. So too would the thematic components of "identity and belonging", as well as "security, comfort, and support", correspond well with the category presented in this study (Ishiyama, 1995). An individual's sense of belonging is often developed and identified through the significant relationships she maintains, ideally with those who will be supportive during such a crisis as breast cancer. While "security, comfort, and support" may correspond with "relations with the medical team and any support staff" the theme would also match well with the category of "personal support", as the co-researcher would both seek and benefit from support in more than one of the interpersonal arenas of her life during treatment.

An interesting theory on social support is presented by Alan Vaux (1988, cited in Kanfer & Goldstein, 1991). Vaux (1988) purports that social support is in fact a combination of three main arenas: networks which offer support to the individual, behavior which is supportive in nature towards the individual, and the individual's personal evaluations of that support. Vaux (1988) presents eight distinct mechanisms through which support manifests: protective direct action, inoculation, primary appraisal guidance, secondary appraisal guidance, reappraisal guidance, diversion, supportive direct action, and palliative emotional support. While all eight mechanisms are important in certain contexts, the last three seem most applicable in context of the personal support which the co-researchers of this study reported on: diversion, supportive direct action, and palliative emotional support.

Diversion is exactly that: attempts made by supportive others to divert the individual from the problem or crisis at hand, if only momentarily. In so doing, the woman undergoing treatment experiences, albeit for probably a short period of time, some form of respite from her crisis. Supportive direct action refers to incidents where the individual is helped through action taken by others, action aimed at problem solving (i.e., child care, ready transportation to and from the cancer clinic). Palliative emotional support refers to ongoing support of an emotional nature, such as the support ideally received by the co-researcher's spouse, parent or close friend, during the crisis. Again, the last three mechanisms of Vaux's (1988) theory on social support appear directly applicable to much of the support presented in this study, by the co-researchers through their direct experiences.

Activities/Things which Aid in Treatment and Recovery.

A total of 45 or 10% of the incidents presented by the co-researchers are applicable to this fourth category: see Table 1 (p.41). Table 3 (p.43) presents a total of 24 sub-categories, all of which depict activities or things which the co-researchers named as helpful during treatment and recovery. Of the 45 incidents, one was presented as hindering, in that a helpful activity was interrupted by a component, of that activity, deemed hindering by the co-researcher: see Table 2 (p.42). Eleven of the twelve co-researchers presented incidents related to this category.

The pursuit of such helpful activities may in itself prove an indication of the co-researcher's resourcefulness in solving the problems associated with treatment for breast cancer. Such resourcefulness can be theoretically connected to some of the literature available on the concept of psychological resiliency (van der Pompe, Antoni, Visser, & Garssen, 1996). In their discussion on psychological resiliency, van der Pompe et al. (1996) state that: "breast cancer patients who are at low risk for emotional morbidity can be described as resourceful problem solvers, who had coped successfully with other life events..." (1996, p.211). Thus, to the authors, effective problem solving proved to be one strong component of psychological resiliency (which will be further explored in the next paragraph).

Locus of Control.

A total of 39 incidents, or 9% of the total, were presented, by eleven of the twelve co-researchers, which relate to this category: see Table 1 (p.41). Of the 39 incidents, 35 were presented as experiences which helped the co-researchers during their processes; as such these were incidents in which they were able to exercise what may be referred to as personal agency, thus relying on an internal locus of control: see Table 2 (p.42). The four

reported incidents that were deemed hindering were associated more with the individual needs for personal control being thwarted, by others and or by events, during treatment.

A comprehensive theory of resilience is presented by Mrazek and Mrazek (1987, as cited in Jew, Green, & Kroger, 1999). In discussing Mrazek et al.'s (1987) theory, Jew et al. (1999) state that: "promotion of resiliency lies in encountering stress at a time and in a way that allows a person to experience mastery and appropriate responsibility, thus increasing his or her sense of self-confidence and competence." (1999, p.76). I believe that one of the skills involved would have to be defined as the maintenance of a sense of personal agency, or of exercising an internal locus of control whenever possible, as exemplified through the sub-categories associated with this category: see Table 3 (p.43). Indeed, behavior which allows one to experience a sense of mastery in life- which would include the maintenance of a sense of appropriate responsibility for one's actions- can directly be linked to the pursuit of a sense of personal agency or internal locus of control in life.

The incidents from this category may also relate, again to one or more of the thematic components for self-validation presented earlier (Ishiyama, 1995). Indeed, one of the five components focuses on "competence and autonomy". This thematic component would subjectively link with such concepts as exercising one's personal agency and internal locus of control. An interesting activity would be the utilization of the validationgram, an activity which Ishiyama developed from the self-validation model (1995); further sources of personal agency would probably become evident- through such an activity- in direct association with some of the incidents discussed with the co-researchers for this report. The use of the validationgram as a component of a

counselling model for women with breast cancer will be explored further, later in this chapter.

General Themes

Both the initial and follow-up interviews, with each of the twelve co-researchers, proved rich in the presentation and clarification of experiences. Indeed, a total of 453 incidents- as representative of the experiences of twelve women- onto themselves entail an abundance of experiential information. While the 15 thematic categories, as developed, are distinct, and thus warrant separation from each other (at least for the purposes of this study), there do exist four general themes, which can be extrapolated from the categories, and which may prove helpful if briefly examined here. They are: (a) community, (b) treatment, (c) personal agency, and (d) information. These four themes onto themselves may indeed present an alternative avenue for representation of the co-researcher's experiences during their processes of treatment for breast cancer. Some of the categories may overlap into more than one theme, as these themes may be viewed across categories, and thus interwoven throughout each woman's experience. An example of this would be an overlapping of Category 4: activities/things which aid in treatment and recovery; some aspects of this category is best represented by community, such as Sub-Category 4-20: end of treatment celebrations. On the other hand, some aspects are best represented by treatment (such as 4-2: physiotherapy), and others may be represented best by personal agency (such as 4-22: helping others). Thus, these themes may indeed present another view of the experiences of these co-researchers- or a different lens through which to examine the experiences- than the categories hitherto referred.

The first general theme can be easily identified as “community”, and represents the community in which the co-researcher lives her life and, through which, lives her process of treatment for breast cancer. One’s community would be comprised of the people in one’s life- from all the varying arenas in one’s life- and the relationships one has, as well as the roles one enacts, with those people. The various levels of interaction, between each co-researcher and those in her life comprises, by virtue of the numbers of incidents and categories in direct association with this general theme, an extremely important aspect of this process. Categories in direct relation to the theme of “community” illuminate each co-researcher in the various relationships she has, and the roles she enacts, in her life, including: (a) patient, client: Category 1: relations with the medical team and any support staff, and Category 8: support/psychoeducational agencies/groups/centres, (b) spouse, lover, friend: Category 3: personal support, (c) daughter: Category 3: personal support, and Category 9:maternal/caregiving role/behavior, (d) co-member: Category 3: personal support, Category 4: activities/things which aid in treatment and recovery, and Category 8: support/psychoeducational agencies/groups/centres, (e) mother: Category 3: personal support, and Category 9: maternal/caregiving role/behavior, and (f) colleague, employee: Category 3: personal support, Category 10: career as a medical professional, and Category 12: career. These relationships, and the interactions which take place within them, were discussed more often, and thus presented within more incidents, than any other of the general themes presented here, if only in terms of the sheer numbers of relatable incidents, from all the categories listed above. Tremendous meaning was thus attributed to these relationships throughout each co-researcher’s taped interview, just as tremendous influence was

attributed, by each co-researcher, on her treatment process, by her relationships with others, and by what took place within them.

The second general theme, "treatment", draws attention to the categories distinct unto themselves as representative of the eradivative and rehabilitative treatment each co-researcher undergoes, as the goal of destroying the cancer within her body is pursued. Thus, both Categories 2 (medical treatment and services) and 15 (alternative treatments) can be represented by this thematic outcome.

The third general theme of "personal agency", represents those categories wherein the co-researcher presents the view of her place within the process of treatment, and her responsibilities within that process. Since the process of treatment for breast cancer can be seen as one arena within the greater arena of the process of each woman's life, this outcome further places her in that process, in terms of what she believes she needs and wants to do for herself, as well as what her responsibilities are to herself and to the others in her community. Thus, the categories which can be represented by this thematic outcome are as follows: Category 4: activities/things which aid in treatment and recovery, Category 5: locus of control, Category 7: attitude towards life and the human community, Category 11: spiritual beliefs, Category 13: personal involvement in decision making, and Category 14: physical appearance.

The fourth general theme can be described simply as "information". This thematic outcome is representative of Category 6: availability and presentation of appropriate educational information, and refers to the needs and the desires of each co-researcher to understand what is happening to her (what the cancer means; what is being done to her medically; what can she do to help herself; what can others do to help her).

As such, "information" as a thematic outcome also overlaps into Categories 3: personal support, Category 4: activities/things which aid in treatment and recovery, Category 5: locus of control, and Category 8: support/psychoeducational agencies/groups/centres.

Implications for Counselling and Research

Empowerment of the Co-Researchers.

The primary implication of this study has been the empowerment of the co-researchers. For many of the women who participated in this study, the act of sitting down and telling of their experiences, in their own words, truly became a cathartic experience during the initial- and for some even the follow up- interviews. The study allowed them an arena in which they could explore their processes, within the context of what helped and what hindered them through these processes. Many shed tears during the initial interview. Many expressed anger, which was primarily aimed at the medical professionals who were treating them (as exemplified by some of the incidents pertinent to Categories 1 and 2). Many saw their involvement in this study as a viable way in which they could help other women facing the disease. A few even referred to their involvement in this study as an extension of their treatment, as the interviews allowed them a chance to review, and even bring a greater sense of closure to this process.

Throughout both interviews, indeed throughout the study, the co-researchers were viewed by myself as the experts of their own processes; such a view was further confirmed and enhanced by the follow-up interviews, which I viewed and presented throughout as being accuracy checks (to make sure I had captured their experiences accurately and completely, from their viewpoints). In so doing, I believe the co-

researchers were empowered by the experience, and were indeed given "voice" in talking about the events which affected their treatment. Through both conference presentations and written articles for publication, a contribution of qualitative research will be made to a field where quantitative research has so far predominated.

Use of Data for Patient Education.

Another implication of this research is the development of the 15 thematic categories that present the helpful and hindering experiences of the twelve co-researchers during treatment. These categories may be used in the development of both explanatory brochures and of counselling models, to be further elaborated on here.

This critical incident study presents a rich resource of experiences as reported by the twelve adult women who participated as co-researchers. These findings cannot be, again, generalized to a population of women experiencing treatment for breast cancer, as this study is without experimental controls (Woolsey, 1986; Alfonso, 1997). They can, however, be used as a resource for the understanding and further exploration of issues which may be relevant to many women beginning this process, within the context of women telling each other of their experiences, through the reporting of the researcher. To this end, I will develop a brochure, which gives a brief report of the study, as well as a brief outline of the thematic categories developed here. The brochure will offer a concise presentation of the study, with an outline (and brief explanation) of the 15 thematic categories. The brochure will be written from an explanatory perspective, maintaining a focus on the experiences of twelve women who have completed treatment for breast cancer, as offered to facilitative ideas for other women facing the disease, in the hopes such ideas will prove helpful to them while on their journeys. The idea for such a

brochure was received in discussion with a member of my thesis committee, and warrants further consideration as a viable tool for helping women in the future who are facing such a diagnosis.

Development of a Short-Term Counselling Skills Training Program.

Further implications for counselling and research may include the development of a short-term counselling skills training program for oncologists- and other helping professionals- who work with women undergoing treatment for breast cancer. Again, of the 453 critical incidents extracted, 94 of them were in direct relation to the first thematic category, "relations with the medical team and any support staff": see Table 1 (p.41). Of those 94 incidents, 72 proved facilitative, while 22 proved hindering: see Table 2 (p.42). While it is reassuring to note, that for the twelve co-researchers involved in this study, a majority of the incidents which involved their interactions with, and their relationships with, helping professionals, were facilitative, almost 25% of the incidents extracted were around relationships which hindered the co-researchers' process of treatment. Given the positions these helping professionals hold in the lives of these women, both during and after treatment, this figure is high and must be addressed, particularly when considering how horrible some of these experiences have proved to be for some of these women, as reported. One way to address these issues, and to further enhance services offered women undergoing treatment, would be through a training model, for oncologists and other helping professionals, as suggested above. Such a model has emerged in discussion with the thesis supervisor of this project, and warrants further attention, as it would have to be a model of counselling training which would prove to be clear, concise, and brief, if

it is to eventually be successfully incorporated into the already rigorous training programs of oncologists and other medical professionals, and or offered to those already in practice.

Development of a Psychoeducational Program.

Another use for the study reported here could be the development of a brief psychoeducational program for women who have recently faced diagnosis, and are about to undergo treatment, for breast cancer. Such a program could be conducted in a workshop format at cancer agencies throughout the country, and could include: a brief presentation of the research, with an explanation of the “map” of the 15 helpful categories (Alfonso, 1997), as well as a review of the counselling departments, support groups, services and avenues of information available to these women through their treatment centres and communities (including avenues for debriefing their experiences with those professional helpers who are treating them).

Development of a Counselling Model, Including the Validationgram.

The results of this study may also contribute to the development of a counselling model for women who have, or have had, breast cancer, as there are issues (such as, again, the ramifications of the relationships one has with one’s caregivers) which could be addressed. The development of this model could include the use of the validationgram (Ishiyama, 1995). Developed from Dr. Ishiyama’s model of self-validation (1989), the validationgram would allow the counsellor to explore, with the client, the effects and ramifications that the crisis of breast cancer- with it’s ensuing process of treatment- has had on the client’s sources of self-validation: on the client’s constructs of values and meanings in life.

The validationgram is comprised of a large circle, which is divided into quarters, each quarter representing a different aspect of the client's sources of personal validation: relationships, things, activities, and places. Each quarter is divided into three regions, with the core, or centre, of the circle representing the self. The client is asked to spend time with this visual activity, and to map out all the aspects of her personal life, in terms of what aspects of the four domains are important to her. The more important that aspect is, the closer it is placed to the core of the circle, the self (i.e., in the arena of relationships, the relationships one has with one's adult children may be placed by writing "children" in the region of that arena closest to the "self"). Both the completion of the activity, by the client, and the discussion of such completion with the counsellor, should prove facilitative for the client, as it will allow her to explore her world of meanings. Also, the validationgram "provides opportunities for exploring threats to their validation network and their loss-and-grief issues associated with a transition or a critical event in life" (Ishiyama, 1995, p.138). Such an activity could prove thus highly facilitative and cathartic for the client who has, or has had, breast cancer; facing such a diagnosis, and undergoing corresponding treatment, would certainly comprise a critical event in one's life, with an ensuing process of intense transition.

Thus, a counselling model for women who have, or have had, breast cancer, may be comprised of a number of components, or stages, and may include individual and group components, which could run concurrently. Through the group component, members could develop relations with each other; the commonality which they all share- breast cancer- may enhance the instigation of rapport building between them. Facilitation of group development would have to include the introduction and discussion of standard

group mores (i.e., confidentiality; equal air time). The group component may be seen as an arena in which, not only would the members ideally develop a community with each other, but one in which they may learn about, and discuss, their treatment and its ramifications on their lives. This part of the model would need to include, thus, psychoeducational aspects. Various aspects of treatment could be explored and reviewed, including: information on treatments, information on alternative treatments, and possible side effects of treatments. Programs, groups, and agencies, for women with breast cancer, could also be introduced and reviewed, including: Hope House, Treasure Chests, Abreast in a boat, the "Look Good Feel Better" program, and the "Fit for Recovery" program. Guest speakers could be invited, and could present information, and facilitate discussion, on various aspects of breast cancer. Of great importance would be the way in which the group component would allow its members to be with each other, to develop a community together, and to, within that community, discuss and debrief whatever aspects of their personal processes they wish, in an arena of safety, confidentiality, and mutual support.

The individual component of this model would include both individual and, if desired, couples and or family counselling. In exploring the crisis of breast cancer with the client, the validationgram could be used (Ishiyama, 1995). If, after some form of counselling relationship has developed, between client and counsellor, the client wishes to bring in others from her world (i.e., her spouse, her partner, her child or children), this service should be available to her, and may involve collaboration with a colleague specializing in marriage and or family counselling.

This has been a very brief review of a counselling model for women with breast cancer. This model would certainly require greater development in the future, yet the introduction of such a design is important here. It is hoped that such a model would address the needs of women with breast cancer, as represented by the 15 thematic categories developed in this thesis.

Limitations

There are a number of factors, in context of the limitations of this study, which require exploration. They are concerned with: (a) generalization, (b) self-reporting of incidents, (c) amount of data collected, and (d) gender differences.

Generalization: First, again, the results of this study cannot be generalized to a population of women with breast cancer, as no experimental controls were used here (Woolsey, 1986; Alfonso, 1997). This reality must be kept in focus and reiterated, when using the results of the study in the development of any articles, counselling models and or teaching models.

Self-reporting of incidents: A second limitation of this study, and possibly one of the critical incident methodology, is that the incidents are self-reported by the co-researchers, as opposed to being observed by trained researchers. Thus, the incidents will be reported from a position of complete subjectivity, which is one of the aims of this methodology. However, with such subjectivity comes challenges in terms of both accuracy of experiences related, and in reliance on memory. This was indeed the case, as was even purported by some of the co-researchers while telling their stories. That is,

some gave expression to their attempts to remember the exact order of events-particularly those events involving medical treatment-during the process.

Amount of data collected: A third limitation has to do with the amount of data collected. The examination of these twelve initial interviews resulted in the extrapolation of a huge amount of data; several months was spent in the examination and review of the 453 incidents referred to here. The amount of data indeed did seem overwhelming (Woolsey, 1986) at first, and the time spent unpacking the interviews proved the greatest aid in working through such a feeling. However, a number of the incidents presented some ambiguity, in that they could be interpreted in more than one way, and thus placed in more than one category. This was one of the reasons why a follow-up interview with each co-researcher proved vital. Any incidents, to which I felt uncertain, were presented to the co-researcher, who in turn made the final decision, based on her view of the experience (again, herself being the source of the data), as to how best to categorize the incident. Every decision made by the co-researchers was adhered to, in the most accurate placing of any incident deemed ambiguous. The careful review of all the incidents, and their category placement, with the co-researchers, resulted in greater clarification of these experiences, as I felt an ongoing concern over the subjective nature of such a data analysis.

Gender differences: A final limitation of this study is the possible effect of any issues which may emerge around gender differences; I am male, and the co-researchers are all female. Not only were the co-researchers all women, but they were women talking to a man whom they had never met before, about their experiences of treatment for a disease as personal and gender based as breast cancer.

Such an issue was first addressed at the onset of the research proposal, and further explored, through my consultation with a counsellor at the Patient and Family Counselling Department of the British Columbia Cancer Control Agency: Vancouver Clinic. This counsellor, who works with many women undergoing treatment for breast cancer, simply stated as follows during the consultation: "It does not matter that you are a man, but what kind of man you are." This statement, and the consultation which ensued, acted for the co-researcher as a green light (through which to proceed), through which I continued my discussions with my thesis supervisor, and eventually proceeded with my proposal.

In order to further create a framework for greater understanding of how gender differences may affect the interviews, I reviewed some published work of Patti Lather. In her book *Getting smart: Feminist research and pedagogy with/in the postmodern* (1997), Lather states that "feminism argues the centrality of gender in the shaping of our consciousness, skills and institutions as well as in the distribution of power and privilege" (p.71). She goes further to add that "the overt ideological goal of feminist research in the human sciences is to correct both the *invisibility* and *distortion* of female experience in ways relevant to ending women's unequal social position" (p. 71). These two quotes became anthems for reference throughout the research, in that (as referred to repeatedly on cue cards), they represented for me some fundamental differences- between genders- which still exist in society and which require adherence, for the purposes of personal conviction, and as a frame of understanding when facilitating the interviews and writing up the data: there are differences in human interaction, based on gender, which I, as a

man, may not consider, or be aware of, which the co-researchers, as women, may have faced throughout their lives.

One of the ways in which I addressed such issues could be found in the methodology itself: the co-researchers were consistently viewed and behaved toward, by myself, as the experts of their processes, and the experts of their breast cancer treatment. Also, I hoped that the respectful and non-interpretive manner which I focused on displaying, when meeting with the co-researchers, further facilitated their sense of both comfort, and of being truly heard, during the interviews (as was the case, as reported by some of the co-researchers). It was also my “keeping in mind” the “centrality of gender...,” as quoted by Lather (1997), throughout the research, which proved important, and which facilitated a hopeful reduction of the effects of gender differences on this study. Indeed, some inferences that were based on gender, were cited by some of the co-researchers during both interviews. It is hoped that this ease in citing such differences was the result of feelings of comfort and safety, on the parts of the co-researchers, during these interviews.

With the above acknowledged, I speculate that gender differences still affected the interviews (which, to some degree, is inevitable), and the disclosing (or not disclosing) of certain experiences by the co-researchers (which indeed further illuminates the “centrality of gender...” in our daily lives). Very few references were made- by the co-researchers- to experiences associated with some probable aspects of breast cancer, specifically in how such a disease affected them as sexual beings (if applicable). Without any data this remains speculative; it would have obviously been inappropriate to attempt a prompting of discussion around this aspect of the co-researchers’ experiences. Indeed, many people

do not discuss their sexual selves, nor their sexual behavior, no matter what the gender is of the person they are addressing; yet it is possible that such an almost complete absence of disclosure may have been the result of gender differences. This issue could be addressed by the conducting of any future qualitative research- on breast cancer- in collaboration with a female colleague and researcher.

Conclusion

Briefly, this study was successful as it met its goals, in the illumination of incidents and the formation of categories. Twelve adult women were interviewed, each on two occasions; from these interviews a total of 453 critical incidents were extracted and examined, and 15 thematic categories were developed. These categories act as representative descriptors of the helpful and hindering experiences of these twelve participants, these twelve co-researchers, as they explored their processes of treatment for breast cancer. The results here reported will contribute to counselling practice, and research, through further development of: (a) educational material for women with breast cancer, (b) a psychoeducational workshop on breast cancer, for women about to undergo treatment, (c) a counselling model, specifically designed for women with breast cancer (which will include use of Ishiyama's (1989) validationgram, and (d) a concise counselling skills training model for oncologists, and other medical professionals. It is hoped that such models for counselling and training, as well as brochures (as previously described), will facilitate both greater knowledge and understanding, on the parts of not only the professional helpers of these women with breast cancer, but of the women themselves. Such facilitation can only be empowering for all, but particularly for the

women undergoing treatment for breast cancer, as their needs will be met to a greater degree. Ideally, the implementation- of both the educational material and the programs- will lead to more helpful incidents, and fewer hindering incidents, for women facing treatment for breast cancer in the future.

EPILOGUE

This project has provided a huge learning experience for me, if only in the avenue it provided for meeting with, and sharing the experiences of, twelve incredibly courageous women. These meetings, aside from comprising a wonderful gift unto themselves, have facilitated for myself a re-examination of what is truly important in life, and of the extraordinary value of life itself. It also provided a true lesson in courage. These women, all of whom had faced their own mortality- the possibility of death- and who had all undergone the tremendous ordeal of cancer treatment, displayed, to me, warmth, humour, gratitude, compassion, and, again, courage. Such individuals are truly inspiring. Also, their gratitude for being "allowed" to share their stories, and for the efforts made by myself in capturing those experiences, was at times almost overwhelming. I feel very grateful to them. Their stories are, again, truly inspiring, not only for myself as an individual, but as a researcher and counsellor as well.

Such experiences will further be represented through both the presentation of the research findings, by myself, at the annual conference of the Canadian Psychological Association (to be held in Ottawa June 29-July 1, 2000), and by the co-authoring of an article for publication, with my thesis supervisor. Thus, I will benefit greatly, professionally, from this research project. What is most important, however, is that I believe I am a better man, for this process.

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