THE IMPACT OF MEANING-MAKING COPING ON PSYCHOLOGICAL ADJUSTMENT TO CANCER

Virginia Lee

Faculty of Medicine, School of Nursing

McGill University, Montreal

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Abstract

The diagnosis and management of cancer evokes profound questions about one's understanding of the self, the world, and one's purpose in life. The stress and coping literature suggest that the process of meaning-making provides a suitable framework to study such existential questions, as well as an ideal method of intervention. Through a series of manuscripts, this thesis examines the construct of meaning-making within the specific domain of cancer, describes the development of a meaning-making intervention, and assesses the impact of meaning-making coping on psychological adjustment to cancer.

The recent proliferation of studies on the concept of meaning that includes the adult cancer experience has been conceptualized and operationalized in a variety of ways. To better understand and use the meaning-making concept within the cancer experience, a systematic review of the literature was conducted to synthesize the current level of knowledge and determine where research should be directed. This review of the empirical and qualitative findings suggested that the successful ability to construct a sense of meaning in illness may lead to positive psychological outcomes. Thus a novel meaning-making intervention (MMI) for cancer patients was developed, and its applicability as well as its effects on psychological adjustment to cancer were explored in a pilot study with a heterogeneous group of patients. Significant improvements in self-esteem and self-efficacy were reported in a small, uncontrolled sample and encouraged the need for further confirmatory testing.

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Guided by the pilot study results, a randomized controlled trial tested the effect of the MMI on levels of self-esteem, optimism, and self-efficacy in a homogeneous sample of newly diagnosed breast or colorectal cancer patients. After controlling for baseline differences on each outcome variable, participants in the experimental group (n=35) who received the MMI were found to have significantly improved perceptions of self-esteem, optimism, and self-efficacy immediately following receipt of the MMI compared to the control group (n=39) who received usual care. Although the generalizability of the results warrants further examination, the MMI is proposed as a feasible and beneficial approach to address the existential concerns of patients during the cancer experience.

Résumé

Le diagnostic du cancer et la gestion de cette maladie suscitent des interrogations profondes sur soi, la vie et le sens de sa propre vie. La littérature sur les sujets du stress et de l'adaptation à cette situation suggère que le processus du « faire-sens » (*meaningmaking*) fournit à la fois un cadre pertinent à l'étude des questions existentielles liées à cette expérience ainsi qu'une méthode idéale d'intervention. À travers une série de textes sur le sujet, cette thèse examine le construit du « faire-sens » à l'intérieur du domaine spécifique du cancer, décrit le développement d'une intervention basée sur le processus du «faire-sens» et évalue l'impact du mécanisme d'adaptation du «faire-sens» sur l'ajustement psychologique au cancer.

La récente prolifération d'études sur le concept de « sens » chez l'adulte atteint d'un cancer a conceptualisé et mesuré le «faire-sens» de diverses façons. Afin de mieux comprendre et de mieux utiliser le concept du « faire-sens » dans le cadre d'un cancer, une revue systématique de la littérature a été effectuée pour faire la synthèse du niveau actuel des connaissances et pour déterminer dans quelle direction la recherche devrait être dirigée. Cette revue des résultats qualitatifs et empiriques suggéraient que la faculté de réussir à trouver un sens à la suite d'un diagnostic de cancer peut conduire à des résultats psychologiques positifs. Une intervention originale de « faire-sens » chez des patients atteints d'un cancer a été développée et sa possible application à la population cancéreuse ainsi que ses effets sur l'ajustement psychologique au cancer ont été explorés dans une étude pilote. Des améliorations significatives de l'estime de soi et de la confiance en ses propres capacités à gérer la situation ont été rapportées dans un petit échantillon non

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contrôlé, résultats qui encourageaient la poursuite de recherches ultérieures pour en confirmer les résultats.

À la lumière des résultats de l'étude pilote, un essai contrôlé randomisé a été conçu pour examiner l'effet de l'intervention de « faire-sens » sur les niveaux d'estime de soi, d'optimisme et de la confiance en leurs propres capacités chez un échantillon homogène de patients qui avaient été récemment diagnostiqués avec un cancer du sein ou colorectal. Après un contrôle des différences de base, on a découvert chez les participants du groupe expérimental (n=35) qui ont bénéficié d'une intervention de « faire-sens » que ces patients avaient une meilleure perception de l'estime de soi, de l'optimisme et de la confiance en leurs propres capacités à gérer la situation tout de suite après l'intervention comparés au groupe témoin (n=39) qui a bénéficié des soins habituels. Bien qu'un examen plus approfondi de la généralisabilité des résultats soit souhaitable, l'intervention de « faire-sens » constitue une approche faisable, bénéfique pour traiter les préoccupations existentielles des patients durant leur cancer.

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Preface

The earliest studies exploring the psychological aftermath of the treatment and management of a cancer diagnosis have almost exclusively focused on the negative sequelae of the illness (Hughes, 1982; Waligora-Serafin, McMahon, Pruitt, & Davcenport, 1992; Weisman & Worden, 1976-77). Over the last 2 decades, there has been a pivotal and innovative shift in research to also examine the possible positive outcomes that can be derived from one's experience with cancer. Meaning-making coping is one process that is implicated in the development of such positive outcomes.

The adaptational significance of meaning-making coping was initially recognized during my early clinical interactions with oncology patients, and further shaped in a qualitative study conducted for my Master's degree that explored the beliefs and coping strategies used by patients undergoing bone marrow transplantation. Although theoretical and empirical work on meaning in cancer has grown rapidly in recent years, the knowledge has remained largely at a descriptive and correlational level. Despite recognition that the ability to find meaning in one's situation with cancer may confer psychological benefits, clinical interventions specifically aimed at facilitating this type of coping are only just beginning to be developed and tested by a few clinical researchers. It is believed that this particular area of psychosocial oncology research has been slow to develop because of the conceptual complexity of this relatively new construct. Through a collection of manuscripts, this doctoral thesis was designed to address the conceptual confusion related to meaning, and test the hypothesis that meaning-making coping strategies result in improved psychological adjustment to cancer. McGill University Regulations for a Manuscript-Based Thesis (The following is a direct excerpt from the Guidelines Concerning Thesis Preparation, Faculty of Graduate Studies and Research, McGill University, and specifies the regulations for submitting a manuscript-based thesis.)

As an alternative to the traditional thesis format, the dissertation can consist of a collection of papers of which the student is an author or co-author. These papers must have a cohesive, unitary character making them a report of a single program of research. The structure for the manuscript-based thesis must conform to the following:

1. Candidates have the option of including, as part of the thesis, the text of one or more papers submitted, or to be submitted, for publication, or the clearly-duplicated text (not the reprints) of one or more published papers. These texts must conform to the "Guidelines for Thesis Preparation" with respect to font size, line spacing and margin sizes and must be bound together as an integral part of the thesis. (Reprints of published papers can be included in the appendices at the end of the thesis.)

2. The thesis must be more than a collection of manuscripts. All components must be integrated into a cohesive unit with a logical progression from one chapter to the next. In order to ensure that the thesis has continuity, connecting texts that provide logical bridges preceding and following each manuscript are mandatory.

3. The thesis must conform to all other requirements of the "Guidelines for Thesis Preparation" in addition to the manuscripts. The thesis must include the following:

• a table of contents;

- a brief abstract in both English and French;
- an introduction which clearly states the rational and objectives of the research;
- a comprehensive review of the literature (in addition to that covered in the introduction to each paper);
- a final conclusion and summary;
- a thorough bibliography;
- appendix containing an ethics certificate in the case of research involving human or animal subjects, microorganisms, living cells, other biohazards and/or radioactive material.

4. As manuscripts for publication are frequently very concise documents, where appropriate, additional material must be provided (e.g., in appendices) in sufficient detail to allow a clear and precise judgment to be made of the importance and originality of the research reported in the thesis.

5. In general, when co-authored papers are included in a thesis the candidate must have made a substantial contribution to all papers included in the thesis. In addition, the candidate is required to make an explicit statement in the thesis as to who contributed to such work and to what extent. This statement should appear in a single section entitled "Contributions of Authors" as a preface to the thesis. The supervisor must attest to the accuracy of this statement at the doctoral oral defense. Since the task of the examiners is made more difficult in these cases, it is in the candidate's interest to clearly specify the responsibilities of all the authors of the co-authored papers. 6. When previously published copyright material is presented in a thesis, the candidate must include signed waivers from the publishers and submit these to the Graduate and Postdoctoral Studies Office with the final deposition, if not submitted previously. The candidate must also include signed waivers from any co-authors of unpublished manuscripts.

7. In no case can a co-author of any component of such a thesis serve as an external examiner for that thesis.

Organization of Thesis

It is recommended that clinical intervention studies in oncology research follow an orderly sequence of 5 phases to determine the impact of an intervention in defined populations prior to the broad, systematic application of the research results to the community at large (Cella, Jacobsen, & Lesko, 1998; Greenwald & Cullen, 1985). *Phase I* studies reflect a hypothesis development phase that seeks to identify and define clinically relevant questions and possible intervention strategies that are testable in later phases. *Phase II* studies are a methods development pilot phase designed to test and assess instruments and procedures that are central to the ability to proceed to the later phases. *Phase III* studies are controlled intervention trials that focus on successful research management. *Phase IV* studies are defined population studies that focus on the implementation of interventions on specific populations. *Phase V* studies are demonstration and implementation studies that apply effective interventions on a public health basis.

This thesis is organized into 6 chapters that include a collection of three manuscripts that can be conceptualized as *Phase I* (Chapter 2), *Phase II* (Chapter 3), and *Phase III* (Chapter 4) studies. Chapter 1 provides a brief introduction to the emerging subspecialty of psychosocial oncology research. This overview includes the prevalence of cancer-related psychological distress and a brief introduction to the psychological treatment approaches currently used with cancer patients.

Chapter 2 includes the first manuscript entitled "Clarifying 'meaning' in the context of cancer research –A systematic literature review". This chapter provides a critical synthesis of the research related to meaning within the specific context of cancer.

The results of this systematic review suggest that the development and testing of clinical interventions with a unique focus on meaning-making coping is an appropriate, timely, and critical area of clinical research.

Chapter 3 includes the second manuscript entitled "Meaning-making and psychological adjustment to cancer: Development of an intervention and pilot results". This chapter describes the development of a novel psychological intervention (i.e. the MMI) as well as the results of a pilot and feasibility study to explore who would most benefit from the intervention and the possible psychological outcomes as a result of the intervention. The results from this preliminary study were central to the design and conduct of the next phase of research.

Chapter Four includes the third manuscript entitled "Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy". This chapter examines the effects of the MMI on self-esteem, optimism, and self-efficacy in a randomized controlled trial (RCT). A brief discussion is also included about the possible relationship among the effects of the MMI, intrusive thoughts and avoidant behaviors, and social support.

Chapter 5 discusses the limitations of the thesis and suggests directions for future research based on the pilot study and RCT of the meaning-making intervention. Finally, Chapter 6 concludes the thesis with a discussion related to the clinical implications of the MMI within the context of comprehensive cancer care.

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Contributions of Co-Authors

Each manuscript included in this thesis is the original work composed by the candidate. However, the candidate's co-supervisors (Dr. S. Robin Cohen and Dr. Linda Edgar) are recognized for their on-going conceptual, methodological, statistical and editorial guidance throughout the entirety of the thesis and particularly within each manuscript. The other thesis committee members (Dr. Andrea M. Laizner and Dr. Anita J. Gagnon) are recognized for their roles as consultants in the design of the studies, the logistics of data collection, the statistical analysis of the findings, and the interpretation and reporting of the final results.

Specifically in the first manuscript, the candidate defined the rationale and scope of the literature review, and was responsible for the conduct, extraction, evaluation, synthesis, and reporting of the findings. Several discussions were held with the supervisory committee to define the inclusion and exclusion criteria for the systematic review, and to help in the organization and reporting of the findings. In the second manuscript, the candidate adapted a psychological intervention that she had helped develop originally for critically-injured trauma patients. The candidate was a major contributor to the design and preliminary testing of the MMI for cancer patients but received ongoing feedback from her supervisory committee. Specifically, the candidate conceptualized the pilot study questions, obtained ethical approval from the McGill University Institutional Review Board as well as from each of the four independent hospital Ethical Review Committees, conducted the participant interviews, transcribed a portion of the audiotaped sessions, and analyzed the entire qualitative data set to modify the MMI for cancer patients into its final form. Ten percent of the data analyses were checked by R.C., L.E., and A.L. using a process and content checklist built into the structure of the intervention that was created by V.L. to monitor the internal validity of the intervention. The statistical analyses and interpretation of the findings were performed with ongoing critique from the co-authors.

For the third manuscript, the candidate designed the RCT with constructive assistance from the thesis committee. The candidate obtained full ethical approval from the McGill University Institutional Review Board and each independent hospital site. She was responsible for the ethical conduct of the randomized controlled trial, as well as the analysis, interpretation and dissemination of the results. Her supervisory committee provided methodological support with regard to the design of the trial, sample size estimation, and data analysis. In summary, although the candidate received ongoing support from her supervisory committee, the candidate assumes primary responsibility for the originality of ideas, the rigor with which the studies were conducted, the accuracy of the data, and the quality of the manuscripts.

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Statement of Originality

Interest in the main concept of meaning-making coping originated from a qualitative study on the coping experiences of individuals with cancer undergoing bone marrow transplantation that formed part of the candidate's Master's of Applied Science degree in Nursing. The present dissertation represents a focused venture to further understand the impact of meaning-making coping on psychological adjustment to cancer. For the purpose of this dissertation, the candidate designed and tested a meaning-making intervention (MMI) specifically for patients following a first diagnosis of cancer (Appendix E; Lee, 2004). While the MMI (Lee, 2004) builds on the work conducted with the critically-injured population that the candidate completed under the supervision of Dr. Mary Grossman during the first four years of the Ph.D. program (Appendix D; Grossman & Lee, 1996), the MMI for cancer patients is the original work of and owned by the candidate.

Parts of this thesis could not have been conducted without the input of an exceptional supervisory committee (Dr. S. Robin Cohen, Dr. Linda Edgar, Dr. Andrea M. Laizner, and Dr. Anita J. Gagnon). However, the final thesis as a whole is the original work of the candidate, and contains several original contributions as described below.

First, the systematic literature review with regard to meaning in the context of cancer is the first review of its kind to be published in the literature. Although a body of literature exists on the construct of meaning, a systematic review that synthesizes and rigorously evaluates both the qualitative and quantitative studies on meaning in the context of cancer had been lacking in the literature. Such an undertaking has the potential to raise awareness about the multidimensionality of meaning-making coping

within the cancer experience, to promote the use of a unified language that can build on the research activities across researchers across disciplines, and inspire the development and testing of innovative clinical interventions. It is believed that a common language will help operationalize each of the components of the meaning-making process, enable a clearer exchange of ideas between researchers and permit comparison of findings across studies.

Second, this thesis describes an original psychological intervention that was developed specifically to assist the process of searching for meaning within the cancer experience. The MMI is one of the first interventions in psychosocial oncology dedicated to meaning-making coping strategies to be tested in a controlled manner. During the conceptualization and piloting phases of the MMI, only one controlled trial of a meaningoriented psychological intervention was published in the literature. While the RCT of the MMI was in progress, the literature described two other meaning-oriented interventions that were also undergoing evaluation, but to date no trials of their efficacy have been completed. Prior to this study, the specific effects of meaning-making coping could not be distilled from published studies because they evaluated interventions with multiple therapeutic modalities. This thesis provides prospective evidence that attests to the psychological benefits of using meaning-making coping strategies. One advantage of the MMI is the collection of concrete strategies that are documented in a detailed manual and can be traced in a process and content audit tool. These aspects of the intervention facilitate the conduct of replication studies, the evaluation of treatment adherence, and promote teaching about meaning-making coping strategies. A second strength of the MMI is the flexible and tailored manner in which the strategies are delivered that has

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been demonstrated to be clinically acceptable from the perspective of ambulatory oncology patients. This aspect of the MMI has implications for facilitating the integration of psychological interventions into comprehensive cancer care.

Finally, the clinical acceptability of the intervention being delivered early in the cancer trajectory provides preliminary evidence that recently diagnosed breast or colorectal cancer patients undergoing active anticancer treatment were not adverse to and appeared to be helped by a strategically structured discussion of the existential issues related to their experience with cancer. This is an important finding because intuitively it is considered intrusive, stressful, or burdensome for individuals to discuss the possibility of death, dying and the implications related to the uncertainty of cancer at this juncture in their lives. However, clinical experience suggests that it is perhaps quite stressful to maintain a positive attitude when confronted with the overwhelming decisions related to the treatment, management, and repercussions of cancer. Recently published findings report that open communication about existential issues such as death and dying are not stressful and in fact can be helpful to terminally ill individuals (Emanuel, Fairclough, Wolfe, & Emanuel, 2004). This thesis contributes empirical evidence that talking about the psychological impact of cancer can be helpful for individuals who are newly diagnosed with cancer. In summary, this thesis advances theoretical understanding in the field of psychosocial oncology and makes important contributions to the clinical care of cancer patients.

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Chapter 1 Introduction

1.1 Historical Perspective

Cancer is the leading cause of premature death in Canada (NCIC, 2004). Approximately 145 500 new cases of cancer were developed, and an estimated 68 300 people died of the disease in 2004. This means that on average, 2 798 Canadians were diagnosed with cancer every week, and just under half this number died of cancer every week.

Prior to the 1950s when a diagnosis of cancer was associated with expectations of high mortality, stigma, shame, and isolation, only the family members and rarely the patient were told of the diagnosis (Holland & Rolland, 1989). In the 1980s, psychosocial oncology emerged as a subspecialty to study, understand, and improve the impact of the cancer diagnosis, treatment and management on the patient and the patient's family (Holland, 1998). Today, a dramatically improved psychological climate exists due partly to the medical advances related to chemotherapy, radiotherapy, and hormonal treatment, as well as in the management of treatment side effects. The public is increasingly educated about disease and healthcare, and there is mounting consumer enthusiasm for a closer interface between psychological support services and the physical aspects of cancer treatment (Holland, 1995). However, despite such advances, half of all people diagnosed with cancer will eventually die from it. Cancer continues to elicit existential concerns and evoke great psychological suffering that is often left underrecognized and untreated (Larouche & Edgar, 2004; Holland, 1995, 1999, 2000).

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1.2 Prevalence of Cancer-Related Psychological Distress

Cancer-related psychological distress is broadly defined as an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with optimum quality of life and the ability to cope with cancer treatment (Holland, 2000). The experience of distress extends along a broad continuum that can arise from normal feelings of vulnerability, sadness, and fear to more severe, disabling states, such as clinical depression, anxiety, panic, feeling isolated or in a spiritual crisis (Holland, 2000). Although the prevalence of a cancer-related psychiatric diagnosis by DSM-IV criteria is consistently reported to approximate one third of newly diagnosed patients (Bleiker, et al., 2000; Derogatis, et al., 1983; Farber et al., 1984; Massie & Holland, 1989; Stefanek et al., 1987; Zabora, et al., 1997, 2001), optimal comprehensive cancer care is based on the premise that every patient at every stage of disease experiences some level of psychological distress (CSCC, 2004; Kirsh & Passik, 2002; NCCN, 1999). The importance of early screening and intervention is highlighted in studies showing that unresolved distress in the early phase of the cancer trajectory has been linked to lateonset anxiety and depression (Maunsell, Brisson, & Deschenes, 1992), and may even predict increased mortality (Brown, Levy, Rosberger, & Edgar, 2003).

1.3 Cancer-Related Existential Distress

Frequently occurring concerns that vary in intensity by individual, by cancer type, and phase of the cancer trajectory are the sense of powerlessness, futility, remorse, and demoralization that often result from a confrontation with one's mortality and the perception of life with little or no meaning (Griffiths, et al, 2002; Kissane, 2000; Klemm, Miller, & Fernsler, 2000; Weisman & Worden, 1976-77). Although existential concerns are recognized as part of a normative process of adjustment to the management and treatment of cancer, the available psychological interventions have not focused on the individual's need to make sense of or find meaning in their situation with cancer.

Existential suffering has been challenging to define and relieve for a number of reasons. First, researchers have conceptualized and operationalized the existential impact of cancer in a variety of ways that have contributed to a lack of focus and difficulties building on previous work in the area (Coward, 1998; 2003; Steeves, 1992; Taylor, 1983; Thompson & Janigian, 1988). Second, the existential aspect of cancer has often been peripherally addressed within existing psychosocial interventions designed to also teach about issues unrelated to the meaning and significance of cancer (Classen et al., 2001; Coward, 1998; 2003; Edelman, Bell, & Kidman, 1999; Moorey & Greer, 1989; Kissane et al., 2003). Third, people vary in terms of whether, when and how long they engage in exploring the existential impact of cancer on their lives. Fourth, healthcare professionals are increasingly providing care in ambulatory cancer settings within compressed time frames. Therefore, psychological interventions that aim to help patients manage the existential impact of cancer would need to be focused, sensitive to each individual's level of readiness, and be realistically feasible to deliver in current treatment settings.

Thus, the existential distress that commonly accompanies a diagnosis of cancer remains one aspect of psychosocial oncology care for which there is a need for practical and effective interventions (Kissane & Clarke, 2001; Puchalski, 1998; Puchalski, Kilpatrick, McCullough, & Larson, 2003). To adequately address and alleviate cancerrelated existential distress, effective interventions that are focused, standardized, and feasible need to be developed.

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1.4 Treatment of Psychological Distress

Psychological interventions are systematic efforts to influence the coping behaviors of the cancer patient and subsequent psychological adjustment through individual or group counseling (Holland, 1998). Since the early 1950s, the number and type of interventions have proliferated and generally fall into 3 main categories: cognitive-behavioral, educational, and psychotherapeutic approaches. Cognitivebehavioral interventions are focused on changing specific thoughts or behaviors or on learning specific coping skills. Educational interventions include the provision of sensory, procedural, or medical information. Psychotherapeutic interventions refer broadly to a range of psychodynamic and supportive-expressive approaches. Current psychological interventions consist of a combination of the above approaches and have often addressed the existential impact of cancer in varying degrees through the inclusion of meaning-making coping strategies. Systematic reviews and meta-analyses have established the global efficacy of these interventions in terms of improving emotional and functional adjustment, and treatment- and disease-related symptoms (Andersen, 1992; Edelman, Craig, & Kidman, 2000; Devine & Westlake, 1995; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Meyer & Mark, 1995; Trijsburg, van Knippenburg, & Rijpma, 1992; Watson, 1983). However, the use of multiple therapeutic strategies in a single intervention for heterogeneous samples does not indicate whether specific types of interventions are more effective or more appropriate for certain concerns (Helgeson, Cohen, Schulz, & Yasko, 2000; Meyer & Mark, 1995). In essence, the singular effect of meaning-making coping strategies is unclear given its usual eclectic combination with other treatment modalities.

1.5 Overall Research Purpose and Objectives

Therefore, the first objective of this thesis was to conduct a systematic review of the oncology literature to assess the relevance of meaning-making coping strategies for the cancer population, and to determine whether a meaning-oriented intervention existed that might be appropriate for use with cancer patients. The second objective was to develop and pilot test a standardized psychological intervention that focused on the use of meaning-making coping strategies to assist the search for meaning during the cancer experience. The results from this pilot, exploratory study were intended to guide the design of a RCT of the intervention; namely, the selection of patients according to type of cancer (e.g. breast or colorectal), phase of cancer trajectory (e.g. newly diagnosed, completed treatment, recurrence of disease), and background patient characteristics (e.g. treatment- and disease- related symptoms, social support, prior life events, concurrent life events, self-esteem, self-efficacy, optimism). In the end, the actual design and conduct of the RCT were also guided by feasibility issues in the lessons learned during the pilot study. The final objective of this thesis was to test a novel meaning-making intervention (MMI) on levels of self-esteem, optimism, and self-efficacy with patients who were newly diagnosed with breast or colorectal cancer.

1.6 Ethical Considerations

Full board approval to conduct the pilot study and the RCT were obtained from the McGill University Faculty of Medicine Institutional Review Board and the independent Ethics Committees from each hospital site (see Appendices F1 and F2). Written informed patient consent was obtained from each participant for the pilot study and the RCT using the approved consent forms (see Appendices F3 and F4). Patient confidentiality was assured throughout the study by using coded identification numbers to refer to study participants in all written documentation and labeled audiotapes. All study materials were locked in a filing cabinet in Dr. S.R. Cohen's locked office and access was limited to the candidate, Dr. Cohen's research manager Carmelita McNeil, and the supervisory committee.

All participants were free to withdraw from the study at any time without prejudice to their health care. At any time, if the patient's distress was considered clinically significant either by the patient or the researcher, a referral to the appropriate health care provider (e.g. clinical nurse specialist, psychiatrist, psychologist, or social worker) at their hospital was offered to the patient for follow-up after the study was completed, or sooner if it was in the best interest of the patient.

In one case, permission was granted from the experimental group participant to inform the clinic nurse about the participant's suicidal plan in the event of disease progression or recurrence. The events were documented in the nursing progress notes, a referral to the social worker was made, and the participant continued his involvement in the study until completion. In a second case, an experimental group participant was using the intervention sessions to vent her dissatisfaction with the treating staff and was unable to focus on the purpose of the study. This participant was withdrawn from the study because the candidate felt that the participant's continued involvement in the study was non-productive and would compromise the relations between the clinic staff and the participant.

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Chapter 2 Hypothesis Development Phase

2.1 Preface

Life-threatening illness was included for the first time among the stressor events for the development of post-traumatic stress disorder in the DSM-IV (APA, 1994). As a result, two related but contrasting research directions have evolved within the cancer literature. The first is the attempt to understand the intrusive thoughts and avoidant behaviors associated with the diagnosis and treatment of cancer as possible indicators of post-traumatic distress (Butler, Koopman, Classen, & Spiegel, 1999; Devine, Parker, Fouladi, & Cohen, 2003; Green et al., 1998; Park & Folkman, 1997; Smith, Redd, Peyser, Vogl, 1999; Tiemsland, Soreide, & Malt, 1998). The second is the attempt to understand the development of post-traumatic growth and the broad role of meaning-making as a mediator of cancer-related distress (Coward, 1990, 1998, 2003; Degner, 2003; Fife, 1994; Reed, 1986, 1991; Taylor, 1993). Both trends have undoubtedly contributed to a paradigm shift in our understanding that psychological adjustment to cancer is often characterized by a distressing but normative state of cognitive processing that can lead to a sense of meaning and positive well-being. Although the study of meaning-making and psychological adjustment following adversity is not new in the trauma literature (Affleck & Tennen, 1996; Horowitz, Adler, & Kegeles, 1988; Jaffe, 1985; Joseph, Williams, & Yule, 1993; Lyons, 1991; Park, 1998; Saakvitne, Tennen, & Affleck, 1998), similar studies within the cancer literature is a recent development.

2.2 Need for Conceptual Clarity

Much of the discourse related to the study of meaning-making within the context of cancer evolved simultaneously within a narrow time frame. Different researchers have used different terminology to describe the complex, multidimensional aspects of the meaning-making process. There has been a lack of clarity regarding the role of meaning in coping with cancer. Not surprisingly, differences in the conceptualization of meaning within cancer were also reflected in the range of ways that meaning had been operationalized. As a result, the association between meaning-making and positive adjustment to cancer, while strongly suggested in the literature, has been mixed. A requisite initial step was therefore to synthesize the body of literature on meaning-making specifically within the context of cancer to more clearly define the relationships between the different aspects of the meaning-making process and psychological adjustment. The theoretical framework proposed by Park and Folkman (1997) was used in the current systematic review because its broad yet parsimonious framework did not replace existing frameworks suggested by other researchers, but instead, integrated the seemingly disparate conceptualizations into distinct aspects of the meaning-making process.

One challenge encountered during the initial stages of the systematic review was the absence of appropriate criteria by which to evaluate a body of literature that was composed of both qualitative and quantitative research findings. The application of evaluative criteria that propose the randomized controlled trial as the "gold standard" will inappropriately lead to the conclusion that qualitative findings are of a lower level of evidence when in fact the two research methods have vastly different paradigms and goals (Evans & Pearson, 2001; Malterud, 2001). Proposed guidelines for the evaluation of qualitative or observational studies (Koop & Burgess-Pinto, 2003; Mulrow & Oxman, 1997) had not yet been established at the time that this systematic review was written. Therefore, the systematic review was conducted based on an *a priori* set of criteria we defined separately for the qualitative and quantitative studies.

The following section presents the first manuscript for the thesis: a systematic review of the meaning literature in the context of cancer. Detailed tables that summarize the study purpose, patient population, method, and findings for each of the qualitative and empirical studies included in the review can be found in Appendices A1 and A2. The findings of the systematic review were deemed critical to justify and direct the subsequent steps of this thesis.

2.3 Manuscript One

Clarifying "Meaning" in the Context of Cancer Research - A Systematic Literature

Review

Virginia Lee, N., PhD (candidate)

School of Nursing, McGill University; Nursing Research Consultant, McGill University Health Center- Montreal General Hospital

S. Robin Cohen, PhD

Assistant Professor, Depts. of Oncology and Medicine, McGill University; Project Director, Lady Davis Institute, Sir Mortimer B. Davis- Jewish General Hospital

Linda Edgar, N., PhD

Assistant Professor, School of Nursing & Dept. of Oncology, McGill University; Research Associate, Dept. of Epidemiology, and Hope and Cope, Sir Mortimer B. Davis- Jewish General Hospital

Andrea M. Laizner, N., PhD

Assistant Professor, School of Nursing, McGill University; Nursing Research Consultant, McGill University Health Center - Royal Victoria Hospital

Anita J. Gagnon, N., PhD

Assistant Professor, School of Nursing & Dept. of Obstetrics and Gynecology, McGill University; Nurse Scientist, McGill University Health Center

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Abstract

This paper synthesized the published literature related to the construct of meaning in the adult cancer population. The databases CancerLit, CINAHL, Medline, PsychINFO, and the Journal of Psychosocial Oncology and PsychoOncology were searched to identify all studies related to meaning. The methodological aspects of all studies were described and the conceptual aspects were summarized only from those studies that met criteria for methodological rigor and validity of findings. The definitions for *global meaning, appraised meaning, search for meaning,* and *meaning as outcome* as proposed by Park and Folkman were used to interpret the findings.

Of 44 studies identified, 26 met the criteria for methodological rigor. There is strong empirical and qualitative evidence of a relationship between meaning as an outcome of and psychosocial adjustment to cancer. The qualitative findings were considered useful for the development of psychosocial interventions aimed at helping cancer patients cope with and even derive positive benefit from their experience. However, variations in the conceptual and operational definitions, frequent reliance on homogeneous and convenience sampling, and the lack of experimental designs were considered to be methodological limitations that need to be addressed to advance the study of meaning in the context of cancer.

Keywords: meaning, cancer, systematic literature review, research

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Introduction

To date, no systematic review has been reported of the published qualitative and empirical studies on meaning within the cancer experience. However, research has increasingly focused on the construct of meaning as a critical factor in the psychosocial adjustment to cancer (Breitbart, 2001; Folkman & Greer, 2000; Folkman & Moskowitz, 2000). A profusion of articles and clinical programs (Cole & Pargament, 1999; Greenstein, 2000; Greenstein & Breitbart, 2000; Ishiyama, 1990) have recently explored the clinical and theoretical significance of meaning in relation to coping with cancer across a wide range of populations, cancer types and phases in the cancer trajectory. A synthesis of this knowledge base would establish what is already known, identify areas requiring further study, and provide direction for clinical practice.

This review selected the broad, integrative framework proposed by Park and Folkman (1997) to understand the current state of knowledge related to the multidimensional construct of meaning in cancer. Although other researchers have proposed models meant to clarify the different conceptualizations of meaning across researchers (Davis, Nolen-Hoeksema, & Larson, 1998; Richer & Ezer, 2000; Sullivan, 1993; Taylor, 1995; Thompson & Janigian, 1988), the framework by Park and Folkman (1997) provided the most complete and parsimonious structure to define the different aspects of meaning. (Readers may refer to Park & Folkman (1997) and Folkman & Greer (2000) for an in-depth review). In this review, we present a summary of the methodologies used to investigate meaning in the context of cancer. Next, the studies were appraised in terms of quality, and only those that met our criteria for methodological rigor and validity of findings were summarized with respect to the major themes for global meaning, appraised meaning, search for meaning, and meaning as outcome. Finally, we conclude with a discussion of two issues that should be considered in future theoretical and clinical research.

Methods

Search strategy.

The term "cancer" was used in combination with the terms: meaning; meaningmaking; search for meaning; finding meaning; existential; sense of coherence; purpose in life; coming to terms; experience; and self-transcendence, to electronically search the databases CancerLit (1975 – Dec 2003), CINAHL (1982-Dec 2003), Medline (1966-Dec 2003), and PsychINFO (1967-Dec 2003). As well, a manual search was conducted from the date of first issue to Dec 2003 of the Journal of Psychosocial Oncology (1982) and PsychoOncology (1992). Other strategies included individual searches of and direct communication with key authors, and the perusal of reference lists and bibliographies from articles. The search was limited to studies in English.

Inclusion criteria.

To capture the broadest use of the concept, this review considered all qualitative, correlational and experimental studies related to meaning in the context of cancer. To ensure that the results of experimental studies could be attributed specifically to the meaning-making process, experimental studies were included only if the therapeutic strategies being tested were exclusively devoted to any or all of the dimensions of meaning (i.e. global meaning, appraisal of meaning, search for meaning, meaning as
outcome). All studies must have been conducted with the adult cancer population, regardless of gender, type of cancer, histological stage, or phase in cancer trajectory.

Exclusion criteria.

Anecdotes, editorials, personal testimonials, clinical case reports, and news stories were excluded due to their specificity and lack of generalizability to other patient experiences. Studies pertaining to the couple, family, or pediatric experience were excluded because this review focused on the individual perspective of meaning-making related to a diagnosis of cancer during adulthood. Dissertation abstracts were also excluded because this format did not allow adequate quality assessments.

Data extraction.

The methodological aspects of all studies were summarized according to research design, methodological rigor, and sampling frame. The conceptual aspects were discussed in terms of conceptual and operational definitions, and the recurring qualitative themes and empirical findings were summarized only for those studies that demonstrated methodological rigor and validity of findings. The definitions for *global meaning*, *appraised meaning*, *search for meaning*, and *meaning as outcome* as proposed by Park and Folkman (1997) were used to organize and interpret the findings.

Qualitative studies were considered methodologically rigorous and valid if the study reported at least one method to ascertain each of the following criteria: the credibility, confirmability, and dependability of the findings. Following Carnevale (2002) and Guba and Lincoln (1981), qualitative studies were deemed *credible* if researchers used methods such as triangulation, peer review (i.e. feedback was sought from expert researchers in the field), comparison of findings to previous observations and research, logs, memos, journals, bracketing (i.e. putting aside what is known about the phenomenon under study), member checking (i.e. acknowledgement of findings was sought from people who understood the experience), and identification of negative cases or alternative explanations. *Confirmability* was defined as reporting a clear decision trail, and *dependability* was judged adequate if there was a detailed account of the process, procedures and analyses specific to the study. *Transferability* was not considered in the assessment of quality in this review because this issue is difficult to support in an emerging area until studies of similar contexts are available for comparison (Carnevale, 2002).

Empirical studies were considered methodologically rigorous and valid if researchers reported measures to decrease selection bias and account for attrition bias. Specifically, the empirical findings were summarized from those studies that reported the following: 1) use of representative sampling procedures, 2) the gender and age of the sample, and 3) at least one explanation of participant loss (i.e. refusal rates, reasons for withdrawal, drop-outs, patient characteristics of those remaining versus those not remaining). The reporting of age and gender were considered important factors as these variables affect psychosocial adjustment differently (Edlund & Sneed, 1989; Murray & McMillan, 1993; Siegel, Gluhoski, & Gorey, 1999). Although a complete description of the study sampling frame is desirable, reporting only the rate of refusal was deemed adequate in this assessment of study quality given that the reasons for refusal are difficult to obtain.

Results

The search identified 44 research studies that addressed some aspect of meaning in the context of cancer. Seventy percent (n=31) of the studies originated from the United States, and 30 % (n=13) were published from other countries [i.e. Sweden (n=5), Canada (n=4), Australia (n=1), New Zealand (n=1), Hong Kong (n=1), Israel (n=1)].

Methodological aspects.

Design. Only 1 experimental study (Linn, Linn, & Harris, 1982) was found in which the clinical intervention being tested was reported to be solely devoted to facilitating a discussion about the meaning of one's life in the context of living with cancer. Twenty studies (46 %) used correlational designs in which participants completed self-report questionnaires. Twenty-three (52%) studies used a variety of qualitative approaches, including grounded theory (n=8) (Bowes, Tamblyn, & Butler, 2002; Fife, 1994; Halstead & Hull, 2001; Landmark, Strandmark, & Wahl, 2001; Ramfelt, Severinsson, & Lutzen, 2002; Richer & Ezer, 2002; Taylor, 2000; Thomas & Retsas, 1999), and phenomenology (n=9) (Albaugh, 2003; Carter, 1993; Coward, 1990; Lam & Fielding, 2003; Nelson, 1996; Olsson, Bergbom, & Bosaeus, 2002; Pelusi, 1997; Steeves, 1992; Thibodeau & MacRae, 1997). Heuristic (Utley, 1999) and ethnographic inquiry (Ferrell, Smith, Juarez, & Melancon, 2003) were less frequently used approaches. Three qualitative studies did not describe using a specific theoretical approach (Bolmsjo, 2000; Mahon & Casperson, 1997; Matthews, Lannin, & Mitchell; 1994) and one conducted a secondary analysis of data from a larger study (O'Connor, Wicker, & Germino, 1990). The qualitative data were obtained primarily through semi-structured or unstructured interviews, although written narratives (Coward, 1990), emails, letters, cards (Ferrell et al., 2003), and photographs (Nelson, 1996) were also used.

Methodological rigor and validity of findings. Of the 44 studies that explored meaning in the context of cancer, 26 studies (59%) met our criteria for a minimum acceptable standard of research quality. This subset included 1 randomized controlled trial (Linn, et al., 1982), 3/20 correlational studies (Degner, et al., 2003; Smith, et al., 1993; Tomich & Helgeson, 2002), and 22/23 qualitative studies. Seventeen correlational studies were excluded mainly due to the use of non-representative sampling procedures or to age not being reported (Luker, et al., 1996). One qualitative study (Bolmsjo, 2000) was excluded because there was insufficient information to permit an adequate evaluation of its methodology.

The sampling procedures, refusal rates and reasons for subject loss reported in the empirical studies (n=21) are described in Appendix A3. Refusal rates, ranging from 0% to 56%, were reported by 71% (15/21) of the empirical studies. Thirty-eight percent (8/21) of the empirical studies provided reasons for subject loss, such as emotional distress (Lechner, et al., 2003; Moadel, et al., 1999; Vickberg, et al., 2001), fatigue (Post-White, et al., 1996), time restrictions (Ramfelt, et al., 2000; Vickberg, et al., 2001), lack of interest (Lechner, et al., 2003; Post-White, et al., 1996), deteriorating health (Lechner, et al., 2003; Moadel, et al., 1996), deteriorating health (Lechner, et al., 2003; Moadel, et al., 1992). Few studies collected data on the characteristics of participants who remained in the study versus those not remaining in the study. Non-participants were more likely to have been older than 70 years, approached in tertiary care settings (Degner, et al., 2003), less educated or less interested in health issues (Tomich & Helgeson, 2002).

The specific procedures and analyses used by researchers to ensure the trustworthiness of the qualitative findings consisted of member checking (Albaugh, 2003;

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Carter, 1993; Coward, 1990; Ferrell, et al., 2003; Halstead & Hull, 2001; Landmark, et al., 2001; Mahon & Casperson, 1997; Matthews, et al., 1994; Richer & Ezer, 2002; Steeves, 1992; Taylor, 2000; Thibodeau & MacRae, 1997; Thomas & Retsas, 1999), peer review (Albaugh, 2003; Ferrell, et al., 2003; Carter, 1993; Fife, 1994; Halstead & Hull, 2001; Lam & Fielding, 2003; Nelson, 1996; O'Connor et al., 1990; Richer & Ezer, 2002; Steeves, 1992; Taylor, 2000), bracketing (Ferrell, et al., 2003; Pelusi, 1997, Thibodeau & MacRae, 1997), and the use of logs, memos, and journals (Bowes et al., 2002; Halstead & Hull, 2001; Landmark, et al., 2001; Nelson, 1996; Pelusi, 1997; Thibodeau & MacRae, 1997; Thomas & Retsas, 1999; Utley, 1999). Several grounded theory studies did not specify whether theoretical sampling was used and whether data saturation was achieved (Landmark, et al., 2002; Ramfelt, et al., 2002; Thomas & Retsas, 1999).

Sampling frame. Appendices A4 and A5 provide summaries of the demographic data reported by the qualitative (n=23) and empirical (n=21) studies. In spite of the largely incomplete demographic profiles provided by many of the studies, it was apparent that the study of meaning was conducted with a homogeneous population consisting of predominantly married, Caucasian females, at least high school educated and between 50 and 60 years of age. Level of education (45%) and income (73%) were the least often reported in the studies. Twenty-six studies (59%) explored meaning within the context of a specific type of cancer, such as breast, prostate, colorectal, ovarian, leukemia, and malignant melanoma. Of these, 17 (65%) studies included only women with breast cancer. Fourteen studies (32%) included patients with a variety of cancer types (of which breast cancer was also the most common diagnosis in 9 studies), and four studies (9 %) did not specify a cancer type.

Meaning was explored across all phases of the cancer trajectory, although some studies (n=16, 36%) did not report the range of participants' times since diagnosis (Barkwell, 1991; Bolmsjo, 2000; Bowes, et al., 2002; Coward, 1990, 1991; Degner, et al., 2003; Ferrell, et al., 2003; Fife, 1994; Mathews, et al., 1994; Olsson, et al., 2002; Ramfelt, et al., 2000, 2002; Richer & Ezer, 2002; Steeves, 1992; Thomas & Retsas, 1999). Cancer survivors were the most frequently selected sample for study, accounting for 32% (n=14) of the studies (Baider & de Nour, 1986; Carter, 1993; Dirksen 1995; Halstead & Hull, 2001; Lam & Fielding, 2003; Nelson, 1996; Pelusi, 1997; Schnoll, et al., 2002; Smith, et al., 1993; Taylor, 2000; Tomich & Helgeson, 2002; Utley, 1999; Vickberg, 2000, 2001). However, there was great variability in operationalizing the time frame for the "survivor" phase of the trajectory. For example, Nelson (1996) and Pelusi (1996) included cancer "survivors" who were 2 to 6 years and 2 to 15 years postdiagnosis, respectively. In contrast, Utley's (1999) sample included participants who ranged from 5 $\frac{1}{2}$ to 29 years since their diagnosis of cancer. Five (11%) of the studies focused on the experience of patients facing a new diagnosis of cancer, generally defined as the time between 0 to 6 months since diagnosis (Albaugh, 2002; Landmark, et al., 2001, O'Connor, et al., 1990; Olsson, et al., 2002; Ramfelt, et al., 2002). Patients with a recurrence of cancer (Mahon & Casperson, 1997; Taylor, 1993; Thibodeau & MacRae, 1997) or in the advanced stages (Barkwell, 1991; Coward, 1990, 1991; Lewis, 1989; Linn, et al., 1982; Thomas & Retsas, 1999) of cancer were less frequently the subject of study. The remaining studies in this review (n=17, 39%) explored meaning irrespective of time since diagnosis.

Summary of methodological aspects. The study of meaning in the context of cancer remains at the descriptive exploratory level and has focused on a narrow

homogeneous group of patients. Important demographic variables (e.g. time since diagnosis, type of cancer, stage of disease, ethnicity, income level, educational level) that would further understanding about how meaning-making varies across individual, social, cultural, and temporal contexts were not consistently reported.

Conceptual aspects.

Conceptual definition. The major themes and findings from the subset of studies that demonstrated methodological rigor are summarized in Appendix A6. Few studies distinguished between the different aspects of meaning being studied. Instead, the majority of studies have relied on broad conceptual frameworks stemming from the work of several seminal theorists to describe a general concept of meaning. For example, meaning in cancer has been understood in terms of people's cognitive representations of their self and world (Janoff-Bulman, 1992; Thompson & Janigian, 1988), Frankl's (1959) "will to meaning" theory, Antonovsky's (1987) "sense of coherence" theory, Reed's (1991) "self-transcendence" theory, or as one of 8 preset categories of meaning (i.e. challenge, enemy, punishment, weakness, relief, strategy, irreparable loss, and value) (Lipowski, 1970). Of the three studies that specified the particular aspect of meaning under study, there was considerable overlap in conceptual definition. Tomich and Helgeson (2002) and Vickberg (2000, 2001) conceptualized global meaning as the belief that one's life had purpose and order, whereas O'Connor, et al. (1990) defined the search for meaning as "questions about the personal significance of a life circumstance, such as cancer in order to give the experience purpose and to place it in the context of a total life pattern".

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Operational definition. The operationalization of meaning in the context of cancer varied widely across studies. Although some researchers developed their own measures specific for their study's purpose (Dirksen, 1995, Moadel, et al., 1999; Smith, Stefanek, Joseph, Verdieck, Zabora, & Fetting, 1993; Tomich & Helgeson, 2002), the majority used reliable and valid tools to measure meaning. Mullen et al. (1993), Post-White et al. (1996), and Ramfelt et al. (2000) measured meaning with the widely used Sense of Coherence Scale (Antonovsky, 1987). Lewis (1989) and Taylor (1993) used the well-established Purpose in Life Scale (Crumbaugh & Maholick, 1981). Other tools were less frequently used in the cancer context: Coward (1991) and Chin-A-Loy, et al. (1998) used the Self Transcendence Scale (Reed, 1991); Thompson and Pitts (1993) used the Meaningfulness of Life Scale (Thompson et al., 1989), and Vickberg et al. (2000, 2001) used the Personal Meaning Index of the Life Attitudes Profile-Revised (Reker, 1992).

Global Meaning. Three grounded theory studies (Fife, 1994; Halstead & Hull, 2001; Richer & Ezer, 2002) and one correlational study (Tomich & Helgeson, 2002) explored the global beliefs and assumptions about the self and the world related to the diagnosis, management and survival of cancer. Two studies described the need to preserve a sense of continuity between past, present and future within the general context of cancer (Fife, 1994), and specifically, during active treatment with chemotherapy (Richer & Ezer, 2002). Three studies are noted for their exploration of the influence of religious and cultural attitudes on the meaning of cancer (Baider & de Nour, 1986; Lam & Fielding, 2003; Moadel et al., 1999). Other studies identified the changes associated with one's perceptions about the self and world following the experience of cancer (Fife, 1994; Richer & Ezer, 2002; Tomich & Helgeson, 2002), and the struggle to reconcile the paradoxes between previously held beliefs and the present reality of cancer (Halstead &

Hull, 2001; Richer & Ezer, 2002; Utley, 1999). Significant decreases in depression and increases in life satisfaction and self-esteem were reported for patients who received regularly scheduled psychosocial counseling sessions to enhance awareness of the meaning of one's life during cancer as compared to a control group (Linn et al., 1982).

Appraised meaning. All studies alluded to the threat of cancer. This was identified in some studies as a confrontation with the possibility of death and a heightened level of awareness about one's mortality (Carter, 1993; Halstead & Hull, 2001; Landmark et al., 2001; Lam & Fielding, 2003; Mahon & Casperson, 1997; Matthews et al., 1994; Nelson, 1996; Olsson et al., 2002; Pelusi, 1997; Ramfelt et al., 2002). Several studies focused on both the threatening and growth-enhancing aspects of the cancer experience (Coward, 1990; Degner et al., 2003; Ferrell et al., 2003; Mahon & Casperson, 1997; Pelusi, 1997; Ramfelt et al., 2002; Taylor, 2000; Utley, 1999). Degner et al. (2003) found that of 1012 women, 85% chose "challenge" or "value" to describe their experience with breast cancer, with fewer (12%) selecting the meaning of "enemy" or "loss". A three year follow-up study with women who were within 6 months of their diagnosis in the original study indicated that 79% (n=142) maintained this positive view of breast cancer. Although not measured in the initial study, the women who ascribed a positive meaning at follow-up were reported to have significantly less trait anxiety, depression, and better emotional functioning and quality of life compared to women who described a negative meaning at both testing times or had shifted from a positive to negative view 3 years later. Another study characterized patients who viewed their cancer experience as a "challenge" or "relief" as self-confident people who looked forward to the future, whereas patients who perceived the cancer as "the enemy" struggled with their self-value and integrity as a person (Ramfelt, et al., 2002).

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Search for meaning. Eighteen studies addressed the search for meaning. The complexity of this aspect of meaning-making is reflected in the frequency with which it was inextricably linked to the concept of meaning as outcome (Albaugh, 2003; Coward, 1990; Ferrell, et al., 2003; Landmark, et al, 2001; Lam & Fielding, 2003; Mahon & Casperson, 1997; Pelusi, 1997; Taylor, 2000; Thibodeau & MacRae, 1997; Thomas & Retsas, 1999) and global meaning (Halstead & Hull, 2001; Richer & Ezer, 2002). Only 6 studies focused exclusively on the search for meaning (Bowes, et al., 2002; Carter, 1993; Nelson, 1996; O'Connor et al., 1990; Olsson et al., 2002; Steeves, 1992).

Several recurring themes were identified in the search for meaning. First, the diagnosis of cancer often initiated attributions of causality and speculation about its possible impact on the body and future goals (Baider & de Nour, 1986; Bowes, et al., 2002; Carter, 1993; Coward, 1990; Fife, 1994; Halstead & Hull, 2001; Landmark, et al., 2001; Lam & Fielding, 2003; Mahon & Casperson, 1997; Nelson, 1996; O'Connor, et al, 1990; Pelusi, 1997; Steeves, 1992; Taylor, 2000; Thibodeau & MacRae, 1997; Thomas & Retsas, 1999). Second, it was common for studies to report that patients resolved to accept the losses and questions associated with the cancer experience and that uncertainty and a sense of vulnerability now characterize their daily existence (Carter, 1993; Coward, 1990; Halstead & Hull, 2001; Lam & Fielding, 2003; Pelusi, 1997; Richer & Ezer, 2002; Taylor, 2000). Third, reordering, reprioritizing or taking stock of one's life were frequently described activities in the search for meaning (Bowes, et al., 2002; Carter, 1993; Landmark, et al., 2001; Lam & Fielding, 2003; Mahon & Casperson, 1997; Nelson, 1996; O'Connor, et al., 1990; Olsson, et al.. 2002; Pelusi, 1997; Thomas & Retsas, 1990). Lastly, studies reported that patients made deliberate efforts to live life to the fullest and not ruminate over the losses imposed by cancer (Bowes, et al., 2002; Carter, 1993;

Landmark, et al., 2001; Nelson, 1996; O'Connor, et al., 1990; Pelusi, 1997; Ramfelt, et al., 2002; Richer & Ezer, 2002; Thibodeau & MacRae, 1997). Tomich and Helgeson's (2002) study indicated that cancer survivors who previously participated in a support intervention reported searching for meaning less often than either survivors who did not receive the intervention or a group of healthy individuals who were asked to refer to the most stressful event that occurred to them in the last 5 years. Among both cancer survivors and healthy individuals, those who were still searching for meaning had poorer mental functioning, less positive affect, and more negative affect than those who did not report searching for meaning. However, it is not clear whether the lack of meaning search was due to a lack of interest to understand what happened, or was unnecessary because a sense of meaning had already been constructed from their experience.

Meaning as outcome. A total of 12 studies dealt with meaning as an outcome, and were inextricably linked to the concept of searching for meaning (Albaugh, 2003; Coward, 1990; Ferrell et al., 2003; Landmark et al., 2001; Lam & Fielding, 2003; Mahon & Casperson, 1997; Pelusi, 1997; Taylor, 2000; Thibodeau & MacRae, 1997; Thomas & Retsas, 1999; Utley, 1999) or embedded within the exploration of global meaning (Halstead & Hull, 2001; Richer & Ezer, 2002). Discovering a sense of fulfillment despite uncertainty (Halstead & Hull, 2001; Lam & Fielding, 2003; Nelson, 1996; O'Connor et al., 1990; Olsson et al., 2002; Richer & Ezer, 2002), discovering a renewed commitment to oneself (Bowes et al., 2002; Olsson et al., 2002; Pelusi, 1997; Ramfelt et al., 2002: Taylor, 2000; Thomas & Retsas, 1999; Utley, 1999) and becoming more compassionate towards others (Coward, 1990; Landmark et al., 2001; Pelusi, 1997; Steeves, 1992; Taylor, 2000; Thibodeau & MacRae, 1997) were recurring themes reported by patients who had endured the psychological and physical effects of cancer treatment.

Excluded studies.

The findings of the 17 excluded correlational studies demonstrated a trend that was consistent with the findings of the studies that were considered methodologically rigorous. For example, the continued search for meaning was related to higher levels of anxiety (Lewis, 1989), avoidant coping (Schnoll, et al, 2002), greater pain perception (Barkwell, 1991), depression (Barkwell, 1991), dependence on others (Taylor, 1993), irrational beliefs (Thompson & Pitts, 1993), and psychological distress (Mullen, Smith, & Hill,1993; Schnoll, et al., 2002; Taylor, 1993; Tomich & Helgeson, 2002; Vickberg, 2000,2001). In contrast, the ability to find meaning was consistently associated with positive outcomes, such as higher self-esteem (Lewis, 1989), hope (Post-White, 1996), coping (Barkwell, 1991), better physical functioning, and optimism (Thompson & Pitts, 1993). Specifically, the relationship between benefit-finding and distress was proposed as an inverted U-shape: individuals were less likely to perceive a positive outcome from the experience of cancer if the degree of life threat (as measured by stage of disease) was perceived as not serious enough to provoke a re-examination of lifelong beliefs, or so high that the consequences of cancer cannot even be contemplated (Lechner et al, 2003). Three studies also found that younger patients were more likely to have lower levels of meaning (Degner, 2003; Dirksen, 1995; Taylor, 1993; Vickberg, et al., 2001).

Summary of conceptual aspects. Despite substantial variations in the conceptual and operational definitions used across researchers, each of the different aspects of meaning within the context of cancer has been explored. Researchers have tended to focus on some aspects more than others. To date, the cancer patient's search for meaning has received the most attention. As a result, detailed descriptions about the process involved in making sense of the cancer experience has grown consistently and steadily over the years. Although the negative impact and psychological sequelae of a cancer diagnosis have been the subject of much inquiry in the past, current studies reflect a more recent trend that explores the positive appraisal of a cancer diagnosis and the experience of growth or benefit following a cancer experience. In contrast, the aspect of global meaning has received the least research attention, possibly because of the methodological complexity related to the study of how one's assumptions and beliefs about the self and the world develop and change during and following a cancer experience. Although there is preliminary evidence for the psychosocial benefits associated with meaning-making coping, the methodological weaknesses of the correlational studies and the paucity of experimental studies prevent more definitive conclusions.

Discussion

The results of this review suggest that while cancer can profoundly disturb one's sense of global meaning, enough to instigate a search for meaning, a successfully completed search for meaning appears to confer positive effects such as enhanced self-esteem, greater life satisfaction, and less distress despite the uncertain and unpredictable nature of cancer. Interventions that help people find meaning are likely to provide another way in which cancer patients can be helped to cope with and even derive positive benefit from their experience.

The knowledge generated from the qualitative studies reviewed in this paper may inform the development of psychosocial interventions aimed at assisting the cancer patient's meaning-making efforts. Although the majority of the qualitative findings demonstrated a low level of complexity (i.e. findings were presented as a series of labeled data categories and not integrated together into a multifaceted whole) (Albaugh, 2003; Bowes, et al, 2002; Coward, 1990; Ferrell, et al., 2003; Fife, 1994; Landmark, et al., 2001; Mahon & Casperson, 1997; Nelson, 1996; O'Connor, et al., 1990; Olsson, et al., 2002; Pelusi, 1997; Ramfelt, et al., 2002; Steeves, 1992; Thibodeau & MacRae, 1997), this structure was expected when the phenomenon is in the initial stages of study (Kearney, 2001). However, these studies were useful for generating a rich description for each of the various aspects of meaning in the context of cancer. Other studies demonstrated a greater degree of complexity by providing a synthesis of data into processes over time (Carter, 1993; Halstead & Hull, 2001; Matthews et al., 1994; Richer & Ezer, 2002; Taylor, 2000; Thomas & Retsas, 1999; Utley, 1999). This latter group of studies provided insight into how meaning-making was manifested over time and across the phases of the cancer trajectory. Given this body of knowledge, it would be possible to construct a meaning-making intervention and begin exploring its potentially positive effects with people diagnosed with cancer.

Several methodological issues need to be addressed though in order to build on previous knowledge and permit assessments of quality and rigor across studies related to meaning in the context of cancer. First, there is a need for an integrative framework that can provide some consistency in terms of the conceptualization and operationalization of meaning within the context of cancer. While many conceptual frameworks are available to explain meaning in the context of stress and coping, many are too broad to disentangle each of the different aspects involved in the meaning-making process. Many researchers recognize that the multi-faceted and evolving nature of meaning-making makes it necessary to clearly define, theoretically and operationally, the particular aspect(s) of meaning under study (Park & Folkman, 1997; Richer & Ezer, 2000; Thompson & Janigian, 1988). As demonstrated in this review, the four aspects of meaning identified by Park and Folkman (1997) provided a useful and parsimonious framework for categorizing the different aspects of meaning explored within the context of cancer.

The complexity and novelty of the construct also presented challenges to the operationalization of meaning, as reflected in the variety of ways it has been measured. Researchers rarely defined the specific aspect of meaning they were measuring. Many did not use validated instruments to measure outcomes. An increasing number of instruments are available for assessing each of the dimensions of meaning, but further information on their psychometric properties is needed. For example, the Stress Appraisal Measure (Peacock & Wong, 1990) specifically assesses a number of dimensions of primary and secondary appraisal that may be appropriate to explore with the cancer population. Similarly, instruments to measure global beliefs (the Life Evaluation Questionnaire (LEQ): Salmon, Manzi, & Valori, 1996; the World Assumptions Scale: Janoff-Bulman, 1992; the Cross-Cultural Assumptions Scale: Ibrahim & Kahn, 1987; the Just World Scale: Lerner, 1970), and meaning as outcome (the Post-Traumatic Growth Inventory-Revised (PTGI-R): Tedeschi & Calhoun, 1996) exist, but many have not been widely used in general, and few have been specifically used with the cancer population (Salmon, Manzi, & Valori, 1996). The challenge appears to be finding a fit between a reliable and valid measure appropriate for the cancer population and the specific aspect of meaning that is appropriate for each study's purpose.

A second important methodological concern in the study of meaning in the context of cancer is the frequent reliance on correlational designs that were largely based on homogeneous convenience samples. The repeated exploration of meaning among women who were married, Caucasian, newly diagnosed or survivors of breast cancer provided support for the validity of the themes across studies, and as discussed earlier, can be used to develop clinical interventions aimed at assisting cancer patients in their search for meaning. On the other hand, this homogeneity might also hinder the discovery of new perspectives (Kearney, 2001). An even greater degree of qualitative complexity and discovery may be achieved if future studies exploring the experience of meaning were conducted with a more heterogeneous sampling frame.

The use of convenience samples in empirical research may introduce bias and limit the generalizability of findings. How people make sense of their situation with cancer may vary considerably among patients in a different developmental stage of life, a different social context, or a different cancer type with different prognostic factors. Evidence suggests that younger women may experience more distress than older adults following a diagnosis of cancer (Edlund & Sneed, 1989; Reed, 1991; Siegel, et al., 1999). Culturally specific beliefs may influence the meaning of cancer, which in turn may determine treatment decisions (Mathews, et al., 1994). Women reported a preference for emotional or psychosocial terms in discussions related to cancer, whereas men preferred more neutral or biomedical language (Murray & McMillan, 1993). Existential concerns may be more prevalent for people with advancing disease or in the palliative phase of cancer. As well, the lack of information about certain patient characteristics, of nonparticipants, as well as a wide range of reasons for participant refusal or subject loss suggests that the phenomenon of meaning-making in the context of cancer remains unclear for certain patient groups. Thus, caution is indicated in assuming that the findings apply equally to men, ethnic minorities, or people who are very distressed by or not interested in the psychosocial effects of cancer.

Conclusion

Although definitive conclusions cannot be drawn at this time, there is substantial qualitative and empirical evidence to suggest that the ability to reconstruct a sense of meaning following a diagnosis of cancer is related to important psychosocial outcomes such as improved self-esteem, greater optimism, and less psychological distress. Additional research might focus on exploring whether meaning is as relevant or beneficial for patients who do not fall within the narrow sampling frame on which most studies of meaning were based (i.e. married, Caucasian, newly diagnosed or survivors of breast cancer). Given the wealth of information available from the qualitative studies, it is considered timely to begin developing and testing psychosocial interventions that are aimed at assisting the cancer patient's transition through the meaning-making process. Well-designed, controlled studies of novel meaning-making interventions would begin to provide more clarity as to the specific impact of meaning-making coping on some of the psychosocial outcomes suggested by the studies in this review.

Chapter 3 Methods Development Phase

3.1 Preface

This chapter describes the important preliminary work that was necessary to guide the subsequent design and implementation of a RCT of a meaning-making intervention. This preliminary work included the development of a psychological intervention that was aimed at assisting cancer patients in their search for meaning, an evaluation of the feasibility of the MMI, and an exploration of the impact of the MMI on psychological adjustment to cancer.

3.2 Literature Review of Psychological Interventions

There is little research conducted on the efficacy of psychological interventions that use meaning-making strategies alone as a therapeutic technique. However, clinical benefits have been reported from psychological interventions for the cancer population that address the concept of 'meaning' within cognitive-behavioral, educational, or psychotherapeutic interventions. (Please see Appendix B1 for a detailed table describing the psychological oncology interventions that were reviewed in this section.) These are summarized below.

Supportive-expressive group therapy is a psychosocial treatment program that was used for women with metastatic breast cancer that is based on the principles of existential psychotherapy and originally introduced by Spiegel, Bloom, & Yalom (1981). Participants attend weekly 90 minute sessions for at least a year. The group sessions encourage participants to confront existential concerns, as well as learn strategies to express and manage disease-related emotions, increase social support, and enhance relationships with family and physicians. RCTs of this program have reported significant reductions in tension, depression, fatigue, confusion, intrusive thoughts, avoidant behaviors, and overall mood disturbance at 1year post-baseline, and non-significant trends at earlier 4 month interval assessments (Classen et al, 2001; de Vries et al, 1997; Goodwin et al, 2001; Spiegel, Bloom, & Yalom, 1981). This suggests that participation in the group over a 1 year period may be necessary to consolidate measurable changes.

Adjuvant psychological therapy (APT) is brief treatment program that explores each individual's appraised meaning of cancer and also teaches cognitive-behavioral strategies to identify negative thoughts as well as progressive muscle relaxation techniques to cope with impending stressful events (Moorey & Greer, 1989). Quasiexperimental and randomized controlled trials of APT reported significantly less anxiety, depression, helplessness, and greater fighting spirit as early as the 2 month follow-up but only for clinically referred distressed cancer patients (Bottomley et al, 1996; Greer, Moorey, & Baruch, 1991; Greer et al, 1992). However, these benefits were not replicated in a RCT of APT that targeted men who recently completed treatment for testicular cancer (Moynihan et al, 1998). This same study cited a 60% refusal rate and reported that non-participants were more likely to have early stage I, low volume disease, not be receiving further treatment, and not perceive themselves to be in need of psychological support. These trials of APT highlight the critical need to tailor the type of intervention offered to type of disease, phase of treatment course, and perception of need. It is likely that psychological interventions might be more acceptable if such care were perceived as part of the overall cancer treatment plan, not perceived to be targeted to patients with

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"psychological distress", and focused on the normative challenges as well as the mastery of the cancer experience.

Cognitive-existential group therapy (CEGT) was designed to be integrated with adjuvant chemotherapy given as conventional treatment to patients with stage 1 or 2 breast cancer disease (Kissane, Bloch, Miach, Smith, Seddon, & Keks, 1997). With the aim of improving mood and mental attitude during cancer treatment, an RCT was conducted to evaluate 19 groups of CEGT led by a total of 15 therapists (including psychiatrists, psychologists, oncology nurses, social workers, and occupational therapisits) over 3 years with 303 women (Kissane et al, 2003). Each group was typically led by 2 therapists and composed of 6 to 8 women. Women in the treated group (n=154)received 20 weekly group sessions of CEGT that addressed death, recurrence, living with uncertainty, understanding cancer treatment, relationships with health care personnel, friends and family, body and self image, sexuality, and future goals, as well as 3 progressive muscle relaxation classes. Women assigned to the control group (n=149)received only the 3 progressive muscle relaxation classes. Intention-to-treat analyses indicated that the treatment group showed statistically significant improvements in the participants' satisfaction with their overall psychological care 6 months after the baseline assessment, but a diminished fighting spirit 12 months after baseline. Also reported was a non-significant trend towards less anxiety and improved family functioning. Death or the development of metastatic disease in some of the group members might have influenced a sense of demoralization that pervaded the group dynamics and was suggested by the researchers as a possible explanation for the study's weak findings. The lack of sensitive outcome measures was also considered in light of the participants' high ratings of satisfaction with psychological care. This study of a cognitive-existential

intervention highlights the need to consider the importance of offering individual therapies to meet the needs of certain patients who may not be comfortable in group formats. Given the current trend towards ambulatory cancer treatment and the associated constraints related to personnel and time, it is important to note that the Kissane et al. (2003) study also suggests that oncology nurses, social workers, psychiatrists, psychologists, and other allied health care professionals may be valuable resources who can share the provision of effective psychological care.

A 'self-transcendence intervention' was developed and piloted in a program of research that spanned over a decade and included phenomenological (Coward, 1990a), correlational (Coward, 1990b, 1991, 1996) and quasi-experimental studies (Coward, 1998, 2003). This group intervention that was designed to facilitate 'self-transcendence perspectives and behaviors that would enhance emotional and physical well-being' for individuals who are confronted with issues of mortality as a result of aging or a diagnosis of life-threatening illness such as HIV or cancer. Self-transcendence was defined as the developmental capacity of people to reach out beyond personal concerns to take on broader life perspectives and activities (Coward, 1998). The intervention consisted of eight 90-minute weekly group sessions and included a "values clarification" component to assist with the development of a healthy personal meaning of cancer, as well as an educational component about the medical aspects of cancer, relaxation training, assertive communication skills, constructive thinking, problem solving, feelings management, and pleasant activity planning. In a small, uncontrolled pilot study with 16 women who ranged from 3 months to 42 months since being diagnosed with breast cancer, significant improvements in functional performance, mood state, and satisfaction with life were reported by participants immediately following the end of the intervention. However,

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these results were limited by the lack of adherence to the planned activities specified in the treatment protocol. A follow-up study used a partially randomized preference trial design to accommodate patient preferences for participation or nonparticipation in the self-transcendence intervention study (Coward, 2003). Twenty-two women received the intervention and 17 did not. Although the experimental group reported lower levels of positive affect and self-transcendent attitudes at baseline compared to the control group, the experimental group improved to where no difference existed when assessed within a month after the end of the intervention. However, a year later, the experimental group again showed significantly less emotional well-being (e.g. purpose in life, positive affect, mood) compared to the control group. It is likely that those who self-selected themselves into the treatment group perceived the need to discuss their experience and possibly needed ongoing intervention that lasted more than 8 weeks to maintain the gains they showed immediately after the intervention. Data related to the frequency and quality of psychological support that was received outside of the intervention group sessions were not collected.

In summary, the review of the psychological oncology intervention literature indicates 2 gaps in the research. First, the frequent inclusion of meaning-related and existential issues within standardized interventions suggests that such issues are important aspects to explore with cancer patients. However, because this aspect of cancer care has traditionally been combined with other therapeutic modalities, the unique effect of meaning– oriented discussions on psychological adjustment to cancer remains unknown. Second, the literature also suggests that for some individuals, there is a clear need for meaning–oriented discussions and interventions. What is unclear from the available studies are the patient- and disease-related descriptors (e.g. phase of diagnosis, stage of disease, distress level, perceived need and/or expected benefit from psychological interventions) that would help identify who would likely benefit from this type of therapeutic approach.

3.3 Development of a Meaning-Making Intervention for the Cancer Population

To address the research issues identified in the psycho-oncology intervention literature, it became apparent that there was a need to develop a novel intervention that was focused specifically on meaning-making coping that was appropriate for the cancer population. Clinical recommendations specific to meaning-making are available in the literature but have not undergone rigorous testing (Ersek & Ferrel, 1994; Ishiyama, 1990; Folkman & Greer, 2000; O'Connor & Wicker, 1995). Two structured meaning-centered interventions have been described in the literature and are currently being tested in controlled trials (Cole & Pargament, 1997; Greenstein & Breitbart, 2000). Only one completed RCT appeared to focus on the meaning-making process within the context of cancer, but the description of the actual content and procedure does not allow for study replication (Linn, Linn, & Harris, 1982). Thus, the development of a meaning-making intervention described in this thesis represents an original contribution to the subspecialty of psychosocial oncology intervention research.

3.3.1 Appropriateness of Prototype Intervention

The intervention that served as a prototype for the MMI for cancer patients was adapted from a psychological intervention that the candidate helped to design originally for trauma patients with life-threatening injuries and their families (Appendix D; Grossman & Lee, 1996). Coming to terms with the cancer experience shares many of the features of a traumatic life-threatening injury, including persistent re-experiencing of the stressful event in the form of flashbacks or nightmares, engaging in efforts to avoid reminders of the event, and difficulty concentrating (Smith, Redd, Peyser, & Vogl, 1999). However, certain aspects specific to the cancer experience required that the original intervention be adapted to be relevant for the cancer population. First, the distress from cancer does not result from a discrete, short lived event (as opposed to a traumatic injury resulting from a motor vehicle accident), but can extend over months and even years depending on the course of disease progression and treatment. Second, the duration and magnitude of distress experienced depends on the type and phase of treatment for cancer (Clipp, Hollis, & Cohen, 2001; Frost et al., 2000; Lethborg et al., 2000; Sadeh-Tassa et al., 1999). Thus, a novel intervention was developed specifically for the cancer population and it was the MMI for cancer patients that was subsequently tested in this thesis (Appendix E, Lee, 2004).

3.3.2 Rationale for Target Pilot Population

To capture the range of issues that were relevant to the cancer experience and to explore whether the intervention appeared to help certain subgroups more than others, the effects of the intervention were initially explored with a selected sample. Patients diagnosed with breast or colorectal cancer were selected on the basis of their high incidence rates and the documented relevance of existential concerns for these two types of cancer (Barsevick, Pasacreta, & Orsi, 1995; Klemm, Miller, & Fernsler, 2000). According to the Canadian Cancer Statistics (NCIC, 2004), breast cancer is the most frequently diagnosed cancer and the second leading cause of death from cancer in Canadian women. Colorectal cancer is the third most frequently diagnosed and second leading cause of death from cancer in Canada. An estimated 5 200 women and 40 men died of breast cancer, and an estimated 19 100 Canadians (9 800 men; 8 300 women) were diagnosed with colorectal cancer and 8 300 died of colorectal cancer in 2004.

The clinical course of cancer varies greatly across patients and its unpredictability is a great cause of distress to the patients (Cohen, Boston, Mount, & Porterfield, 2001; Holland, 1998; Klemm et al., 2000; Rowland & Holland, 1989). Treatment for an initial cancer diagnosis may result in a complete cure, a long disease-free interval followed by recurrence and progressive disease, or a chronic illness state with rehabilitation to counter dysfunction or illness leading to death (Holland, 1998). Periods of existential crisis are usually associated with major transitional points in the illness course and therefore the initial diagnostic phase, the period immediately following completion of anti-cancer treatment, and the beginning of treatment for a recurrence of cancer were explored for their fit with the MMI.

Other aspects that were considered important to explore in relation to the effects of the MMI were the background features of the individual. These included demographic characteristics such as age, gender, marital status, education level, employment status, family income, religion, and use of other professional psychological support. As well, the patient's sense of self-esteem (Rosenberg Self Esteem Scale, Rosenberg, 1965), optimism (Life Orientation Scale-Revised, Schier & Carver, 1987), purpose in life (Purpose in Life, Crumbaugh & Maholick, 1964), the presence or absence of, and satisfaction with a support network (Short Form Social Support Questionnaire, Sarason, Shearin, Pierce, & Sarason, 1987), and the existence of competing demands arising from current major life events or past life experiences (Life Experiences Survey, Sarason, Johnson, & Spiegel, 1978) were explored. Other aspects were the disease- or treatment-related characteristics which included the extent of distress related to the physical symptoms of the disease or treatment (Symptom Distress Scale, McCorkle & Benoliel, 1983), and the ability to function independently (Karnofsky Performance Scale, Karnofsky & Burchenal, 1949), The rationale for exploring each of these variables are explained in Manuscript Two and will not be repeated here. The demographic and standardized tools that were used to measure these variables in the pilot study can be found in Appendix B2. The psychometric properties of the measurement tools are summarized in Appendix B3.

3.4 Manuscript Two

Meaning-Making and Psychological Adjustment to Cancer:

Development of an Intervention and Pilot Results

Virginia Lee, N., PhD (candidate)

School of Nursing, McGill University; Nursing Research Consultant, McGill University Health Center- Montreal General Hospital

S. Robin Cohen, PhD

Assistant Professor, Depts. of Oncology and Medicine, McGill University; Project Director, Lady Davis Institute, Sir Mortimer B. Davis- Jewish General Hospital

Linda Edgar, N., PhD

Assistant Professor, School of Nursing & Dept. of Oncology, McGill University; Research Associate, Dept. of Epidemiology, and Hope and Cope, Sir Mortimer B. Davis- Jewish General Hospital

Andrea M. Laizner, N., PhD

Assistant Professor, School of Nursing, McGill University; Nursing Research Consultant, McGill University Health Center - Royal Victoria Hospital

Anita J. Gagnon, N., PhD

Assistant Professor, School of Nursing & Dept. of Obstetrics and Gynecology, McGill University; Nurse Scientist, McGill University Health Center

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Abstract

Purpose/Objectives: To develop an intervention that uniquely addresses the existential impact of cancer through meaning-making coping strategies and to explore its impact on psychological adjustment.

Design: Descriptive, qualitative approach to develop the intervention. One group pretest-posttest design to pilot test the intervention.

Setting: Patients' homes or ambulatory oncology clinics affiliated with a university health centre in Eastern Canada.

Sample: A heterogeneous sample was intended, but participants were mainly newly diagnosed with breast (n = 10) or colorectal (n = 8) cancer within the last 3 months.

Methods: Data collected during interviews using a prototype intervention for trauma patients were content analyzed on an ongoing basis to fit the needs of the study population. Pretest and posttest questionnaires were administered to determine its effect.

Main Research Variables: Meaning-making intervention (MMI), background patient variables, disease- or treatment- related symptoms, psychological adjustment.

Findings: The MMI consisted of up to four 2-hour individualized sessions and involved: 1) the acknowledgement of losses and life threat, 2) the examination of critical past challenges, and 3) plans to stay committed to life goals. At post-test, participants significantly improved in self-esteem (p=0.003) and reported a greater sense of security in facing the uncertainty of cancer.

Conclusions: Meaning-making coping can be facilitated and can lead to positive psychological outcomes following a cancer diagnosis. Findings are useful for designing future randomized controlled trials.

Implications for Nursing Practice: The MMI offers a potentially effective and concrete approach to address cancer-related existential issues in routine practice.

Key Points:

- Existential issues are a ubiquitous part of the cancer experience that are challenging to understand, and often left unrecognized and untreated.
- Meaning-making coping is characterized by a distressing but necessary confrontation with loss, which if followed by a plan to fulfill a life purpose, can lead to psychological well-being.
- → A guided approach through the process of meaning-making is a potentially effective method to overcome and possibly grow from the repercussions of cancer.



Introduction

Guidelines for optimal comprehensive cancer care are based on the premise that every patient at every stage of the disease experiences some degree of psychological distress (CSCC, 2004; Holland, 2000; NCCN, 1999). Although only one third of cancer patients experience severe psychological distress (Derogatis et al., 1983; Farber, Weinerman, & Kuypers, 1984; Stefanek, Derogatis, & Shaw, 1987; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001), existential distress related to questions about one's mortality, engagement with and purpose in life appear to be a ubiquitous part of the cancer experience. Meaning-making coping is increasingly recognized as a possible mechanism by which existential concerns can be addressed (Breitbart, 2001; Coward, 1998; 2003; Folkman & Greer, 2000; Lee, Cohen, Edgar, Laizner, & Gagnon, *in press*; Mullen, Smith & Hill, 1993; Taylor, 2000). The purpose of this pilot study was to describe the development of a meaning-making intervention for cancer patients, and to explore its feasibility and efficacy with a small sample of breast and colorectal cancer patients.

Conceptual Framework

Meaning-making coping refers to a multidimensional framework that includes the appraisal of cancer, the process of searching for order and purpose in life, and the outcome of positive adjustment (Lee et al., *in press*; Park & Folkman, 1997). While the search for order and purpose is associated with greater psychological distress (Mullen et al., 1993; Schnoll, Knowles, & Harlow, 2002; Taylor, 1993; Tomich & Helgeson, 2002; Vickberg, Bovberg, Duhamel, Currie, & Redd, 2000; Vickberg et al., 2001), the

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reconstruction of a world and self view that can assimilate or accommodate the repercussions of cancer is associated with an enhanced state of well-being (Bowes, Tamlyn, & Butler, 2002; Carpenter, Brockopp, & Andrykowski, 1999; Coward, 1990; Halstead & Hull, 2001; Lewis, 1989; Pelusi, 1997; Post-White et al., 1996; Richer & Ezer, 2002; Steeves, 1992; Taylor, 2000; Thompson & Pitts, 1993). Thus, meaning-making coping is characterized by a distressing but normative state of cognitive processing that can ultimately lead to positive outcomes.

Meaning-Oriented Clinical Interventions

Components of the meaning-making process are commonly embedded in psychological interventions that also include supportive-expressive, cognitive-behavioral, or educational techniques. Supportive-expressive group therapy is rooted in the principles of existential psychotherapy and includes instruction on coping skills and effective communication with health care providers. Randomized controlled trials of supportive-expressive group therapy have reported improved mood and decreased intrusive and avoidant symptoms in patients with metastatic breast cancer (Classen et al., 2001; de Vries et al., 1997; Goodwin et al., 2001; Spiegel, Bloom, & Yalom, 1981). Similarly, Adjuvant Psychological Therapy (APT) addresses the personal meaning of cancer and focuses on learning cognitive-behavioral coping skills. Self-esteem, life satisfaction, anxiety, depression, fatigue, and confusion improved in samples of highly distressed cancer patients with mixed cancer diagnoses (Bottomley, Hunton, Roberts, Jones, & Bradley, 1996; Greer, Moorey & Baruch, 1991; Greer, et al, 1992; Moorey & Greer, 1989; Moynihan, Bliss, Davidson, Burchell, & Horwich, 1998). Other interventions that combine meaning-making coping strategies with supportive-expressive or cognitive-behavioral approaches significantly improved life satisfaction, functional performance (Coward, 1998), sense of purpose in life (Coward, 2003; Zuehlke & Watkins, 1975), self-esteem (Edelman, Bell, & Kidman, 1999), satisfaction with therapy (Kissane et al, 2003), and resulted in less mood disturbance (Coward, 1998, Edelman et al, 1999).

These interventions clearly demonstrate efficacy for improving emotional, functional, and treatment- or disease- related symptoms (Andersen, 1992; Devine & Westlake, 1995; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Meyer & Mark, 1995; Trijsburg, Van Knippenberg, & Rijpma, 1992). However, because these interventions are often combined with meaning-making strategies, it is difficult to judge which outcomes can be attributed to any one therapeutic approach. The priority of intervention research now is to determine whether certain benefits are associated with specific components of an intervention (Cunningham, 2000; Edgar, Rosberger, & Collet, 2001; Fawzy et al., 1995; Meyer & Mark, 1995).

Despite theoretical (Lee et al., *in press*) and clinical support (Ersek & Ferrell, 1994; Folkman & Greer; 2000; Ishiyama, 1990; O'Connor & Wicker, 1995) for the potential benefits of assisting cancer patients in the search for meaning, interventions that are uniquely dedicated to the use of meaning-making coping strategies are just beginning to be developed and tested (Cole & Pargament, 1999; Greenstein, 2000; Greenstein & Breitbart, 2000). One intervention, though vaguely described, has been empirically tested in a controlled trial (Linn, Linn, & Harris, 1982). It is essential that clinical interventions be specific and clearly defined to permit assessments of treatment integrity and adherence, and future replications (Chambless & Hollon, 1998; Waltz, Addis, Koerner, & Jacobson, 1993). The purpose of this study was to develop and explore the psychological effects of an intervention that focused uniquely on meaning-making coping strategies for individuals with two types of cancer. The specific study questions were: 1) What kind of meaning-making strategies help cancer patients in their search for meaning? 2) Are patients with breast or colorectal cancer, or in a certain phase of the cancer trajectory more likely to benefit from a meaning-making intervention? 3) What outcomes are most sensitive to change due to a meaning- making intervention? 4) Which background patient- or disease-related characteristics are associated with the greatest changes in outcomes following a meaning-making intervention?

Factors Considered in Developing the Intervention

Fit.

Psychological interventions are commonly tested with cancer patients without control for disease- and treatment-related variables, sociodemographic factors, or background individual differences (Bottomley et al., 1996; de Vries et al., 1997; Greer et al., 1992; Linn et al, 1982). The research evidence is mixed regarding the influence of such patient variables on the differential responses to psychological interventions. Gender, marital status, religious orientation, or education level did not influence who benefited from a group psychoeducational program (Cunningham, Lockwood, & Edmonds, 1993). Highly distressed patients appeared to benefit from the effects of APT (Greer et al., 1991,1992; Moynihan et al., 1998). Individuals with low self-esteem or low ego strength were shown to benefit from educational or coping skills interventions (Edgar, Nowlis, & Rosberger, 1992; Helgeson, Cohen, Schulz, & Yasko, 2000). While women with low social support benefited from an educational program or peer discussion group, women with high levels of support appeared to be harmed by the peer discussion group (Helgeson et al., 2000). Given the evidence that not all individuals will benefit equally from a specific intervention, it was important to consider the influence of patient variables in the preliminary testing stages of a novel intervention.

Format.

A large proportion of patients seeking psychological support prefer one format over another: either group or individualized sessions (Coward, 2003; Cunningham, 2000; Edgar et al., 2001; Gotay & Lau, 2002). The choice of format may also depend on the nature of the problem for which help is being sought. For example, group sessions may be appropriate and cost-effective for educational content or teaching relaxation skills, whereas existential issues may be more acceptable and readily discussed in a one-to-one format that allows for greater sensitivity, pacing, and privacy (Edelman et al., 1999). Given the sensitivity of the topic and the mixed evidence regarding the efficacy of individualized versus group sessions (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Edgar, et al., 2001; Fawzy, Fawzy, & Wheeler, 1996), it was considered important to first explore the effects of a novel meaning-oriented intervention delivered in individualized sessions prior to exploring its effects in a larger group format.

Feasibility.

Meaning-oriented interventions offered on a one-to-one basis may also provide a practical approach to respond promptly to the needs of cancer patients. Patient schedules may not coincide with open group sessions or patients may need to wait until enough people are interested to begin specific closed group sessions based on a particular patient or illness characteristics (e.g. groups geared only to males, young adults, or people with

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advanced cancer) (Cunningham, 2000; Edgar et al, 2001). The ambulatory outpatient setting in which an increasing number of patients are receiving cancer care also requires a treatment approach that is both acceptable to the patient and realistic to the health care provider in terms of duration and frequency of sessions. In summary, this study was based on a consideration of the fit, format, and feasibility of a novel intervention aimed at assisting the search for meaning following a diagnosis of cancer.

Methods

Study population.

Our intention was to recruit a small convenience sample of patients (N=40) with equal numbers of patients with breast or colorectal cancer at different phases in the disease trajectory from two university-affiliated hospitals in Montreal, Quebec. Patients with breast cancer were included because the meaning-making literature has mainly focused on women with breast cancer (Lee et al., in press), and this population was available for study. Patients with colorectal cancer were included to explore the effect of a meaning-making intervention on a different gender and cancer type than females with breast cancer. Patients who were within 3 months of a new diagnosis, 1 month of completed treatment, or 1 month of a recurrence of cancer and receiving either curative or palliative treatment were sought because these are critical transition points in the disease trajectory that can amplify a sense of existential vulnerability (Frank-Stromberg, Wright, Segalla, & Diekmann, 1984; Frost et al, 2000; Griffiths, Norton, Wagstaff, & Brunas-Wagstaff, 2002; Lethborg, Kissane, Burns, & Snyder, 2000; Mahon, & Casperson, 1997; Sadeh-Tassa, Drory, Ginzburg, & Stadler, 1999; Taylor, 1993; Weisman & Worden, 1976-77, 1985). Additional inclusion criteria included fluency in English, and over 18

years of age. Patients were excluded if cognitive acuity due to psychiatric illness or brain metastases might interfere with informed consent, or if participation was likely to be burdensome due to physical fatigue.

Intervention.

An 8 session meaning-making intervention that was originally developed to help trauma patients and their families come to terms with a life-threatening critical injury (see Appendix D, Grossman & Lee, 1996) served as a prototype for the development of a meaning-making intervention for cancer patients. This intervention was based on a philosophy that patients are motivated to engage in a collaborative process of exploration and self discovery (Gottlieb & Rowat, 1987; Overholser, 1993a,b). To refine the intervention for the cancer population, the initial participants received the intervention as originally intended for trauma patients. As the intervention progressed, the areas of concern that repeatedly surfaced for cancer patients were retained, purposefully explored and validated with each subsequent participant. A process audit and fieldnotes were written immediately following each session to record impressions about which strategies were particularly effective or not effective, and a plan of action for the next session. At the beginning of each subsequent session, participants were encouraged to reflect on whether and how the last session affected them. Suggestions to improve the intervention were welcomed from the participants throughout the study. Consequently, all participants were engaged in discussions related to the process of searching for meaning. The topics and themes relevant to the cancer experience were gradually shaped and confirmed with the initial participants until the content and procedure achieved a consistent pattern.
Procedure.

A one group pre-test post-test design was used to explore the impact of the MMI on psychological adjustment (see Appendix B4). Ethical approval was obtained from each hospital's Research Ethics Boards. The nurse or oncologist distributed a brief recruitment letter to eligible patients asking those who were interested to provide contact information so that a nurse-researcher (V.L.) could explain the study in further detail. Patients who refused to participate were asked to anonymously provide a reason for their refusal and complete a demographic questionnaire.

Following written consent, all participants completed and returned a packet of pre-test baseline questionnaires. Participants then met individually with the nurseresearcher (an experienced oncology nurse and doctoral candidate) in the patient's home or clinic setting to receive the meaning-making intervention. All sessions were audiotaped. Personal insights, participant feedback, contextual, and clinical information were recorded in detailed fieldnotes following each session. Post-test questionnaires were distributed immediately after the last session. Participants completed the post-tests within the next 24 hours, and subsequently returned them to clinic staff in a sealed envelope or by mail to the researcher. All questionnaires were self-administered except for five participants to whom the pre-test baseline questionnaires were read by V.L.

Measures.

The background variables (i.e. optimism-LOT-R, Scheier, Carver, & Bridges, 1994; purpose in life- PIL, Crumbaugh & Maholick, 1964; satisfaction with social network-SSQ6, Sarason, Shearin, Pierce, & Sarason, 1987; physical functioning- KPS, Karnofksy & Burchenal, 1949; symptom distress- McCorkle & Benoliel, 1983, and

previous major life events- LES, Sarason, Johnson, & Siegel, 1978) were selected based on their theoretical role in the meaning-making process. For example, individuals who are not optimistic, unclear about their purpose in life, or perceive their social network to be unsupportive may benefit more from a meaning-making intervention (Mullen et al., 1993; Taylor, 1993; Thompson & Pitts, 1993). The degree to which one's physical functioning is affected by cancer may also influence the degree to which meaningful goals can be attained (Thompson & Janigian, 1988; Thompson & Pitts, 1993). Major life events prior to the cancer diagnosis may be important in terms of how the cancer diagnosis is appraised and whether a person subsequently embarks on a meaning search (Park & Folkman, 1997; Tomich & Helgeson, 2002).

The possibility of both positive and negative outcomes was explored. Depression, anxiety (HADS- Zigmund & Snaith, 1983), sense of purpose in life (PIL- Crumbaugh & Maholick, 1964), and psychological adjustment to illness (PAIS- Derogatis, 1986) were selected based on empirical studies that have shown them to be responsive in other psychosocial oncology interventions (Bottomley et al, 1996; Greer et al, 1992; Taylor, 1993; Zigmund & Snaith, 1983). The impact of the meaning-making intervention on intrusive thoughts and avoidant behaviors (IES- Horowitz, Wilner, & Alvarez, 1979), optimism (LOT-R-Scheier, Carver, & Bridges, 1994) and self-esteem (RSES- Rosenberg, 1965) were explored because these have been implicated in theoretical models of meaning-making coping (Cella, Mahon, & Donovan, 1990; Curbow & Somerfield, 1991; Epping-Jordan et al., 1999; Green et al, 1998; Thompson & Pitts, 1993). Optimism and purpose in life were considered as both background and outcome variables. All instruments have demonstrated adequate reliability and validity (see Appendix B3 for a summary of psychometric properties and description of each instrument.) Information such as age, gender, employment status, family income, number of dependents, education, and use of adjuvant psychological services were provided by the participant. Date of first anti-cancer treatment and physiological stage of disease were obtained by chart review.

Qualitative analysis.

A purposeful selection of half of the audiotaped interviews (e.g. long and short sessions; male and female patients; breast and colorectal cancer; different phase of the illness trajectory) were transcribed verbatim. Transcripts, audit forms, and fieldnotes were content analyzed for recurring themes and then categorized according to the conceptual underpinnings from the meaning theory (Frankl, 1959; Park & Folkman, 1997), transition theory (Bridges, 1980) and cognitive processing theory (Creamer, Burgess, & Patterson, 1992; Horowitz, 1992; Janoff-Bulman, 1989). The remainder of the audiotapes were used to validate the themes and categories that emerged and to ensure that data saturation had been achieved.

Statistical analysis.

To determine which outcome measures (i.e. LOT-R, PIL, HADS, IES, PAIS, RSES) were most sensitive to change as a result of the meaning-making intervention, two-tailed, paired Student t-tests were performed on the pretest to posttest difference scores for each outcome. Pearson correlation coefficients were used to determine which background measures (i.e. LOT-R, PIL, SSQ6, LES, SDS, KPS) were associated with those outcomes showing a significant change. Because of the low power associated with

a small sample size to detect a change in scores, correlations above 0.4 were considered important.

Results

Data collection terminated after 5 months when data saturation regarding the development of the meaning-making intervention was reached but prior to reaching the accrual rate desired for each phase of the disease trajectory. (These practical limitations were imposed because this pilot formed part of V.L.'s doctoral dissertation.) Due to a lack of resources, it was not feasible to maintain a complete account of who was approached and who refused. Some of the reasons cited for not participating included current involvement in support groups or lack of interest. Of the 21 patients enrolled in the study, 18 completed all questionnaires (one patient died, one left the country, and one returned largely incomplete questionnaires).

Sample characteristics.

Appendix B5 describes the sample characteristics at baseline. The participants had a mean age of 57 years (SD = 11.7, range 38 - 76 years), and the majority were female (n=13/18; 72%), married (n=13/18, 72%), living with spouse and children (n=9/18, 50%), employed full time (n=11/18, 61%), and high school (n=5/18, 28%) or university educated (n=6/18, 33%). Eighty-three percent (n=15/18) of participants had not received professional counseling for their situation with cancer. Eight (44%) participants were newly diagnosed with Stage 1 (n=6/18, 33%) or Stage 2 (n=2/18, 11%) breast cancer. Six (33 %) participants were newly diagnosed with Stage 1 (n=1/18, 6%),

Stage 2 (n=4/18, 22 %), or stage 3 (n=1/18, 6%) colorectal cancer. Three patients (17%) had a recurrence of cancer, and one patient (6%) had completed treatment.

Qualitative results:

What kind of meaning-making intervention helps cancer patients in their search for meaning?

The participants received 3 to 8 sessions on a daily, weekly, or monthly basis that lasted from 10 minutes to 3 hours, according to their preference. Based on the median number of sessions, the final intervention for cancer patients was standardized as four 2hour sessions, but sessions can be shortened to accommodate different levels of patient readiness, variability in medical treatment schedules, and physical status. The final meaning-making intervention for cancer patients is documented in a 35 page procedure manual (Appendix E), and includes a rationale for the timing and sequencing of the strategies, an audit tool to monitor the process and themes within each session, and a "Lifeline" exercise to chronologically embed the cancer experience within a familiar context of critical life events and future expectations (Lee, 2004).

By the fifth participant, a consistent pattern emerged that seemed to facilitate the participants' search for meaning within the cancer experience. These topics were organized as a series of 3 tasks, each being requisite to the next (see Appendix B6). These tasks included: 1) acknowledging losses associated with the cancer, 2) examining the mastery of past challenges, and 3) planning to stay committed to life goals or forming new ones. The first task helped participants to acknowledge the reality of the present circumstances, to distinguish between what was and what is, and what can and cannot be changed. Strategies helped patients identify and explore the basis of their appraisal of

cancer. The second task embedded the cancer experience within a familiar framework of significant life events. Strategies helped patients trace the development of automatic thoughts and beliefs they had about themselves and their capabilities, and how these either facilitated or impeded their ability to integrate the experience of cancer. The third task introduced the idea of gaining wisdom, which was defined as the ability to make important life decisions in the face of uncertainty (Kitchener & Brenner, 1990), and highlighted the challenges already mastered since diagnosis. This last task also encouraged participants to identify what gave their lives a sense of purpose, and to initiate a plan that would enable living a fulfilling life with few regrets given the knowledge and changes brought on by cancer. Past "survival tools" were examined for their ability to conquer present fears associated with the uncertainty of cancer.

It was important to maintain the order of these tasks to build a sense of security and preparedness to address the more distressing or fearful aspects of their situation, and to be sensitive to the different levels of readiness to learn or benefit from their situation. Objective facts and symptoms of the disease were distinguished and clarified prior to exploring the fearful thoughts and beliefs they had about the future or themselves. Whenever possible, the patient's words, metaphors, or analogies were used to strengthen a sense of connectedness and understanding.

Participant feedback

There was general consensus among the participants that they valued the opportunity to talk freely about the emotional toll and social impact of cancer on their lives. Only one participant remained guarded to share his personal experience, preferring to speak in abstract philosophical terms, and described the intervention as "entertaining, a way to pass the time during chemo". Interestingly, this individual improved across all outcomes but showed a dramatic 10 point increase in self-esteem (which corresponds to a 32% change on the scale range of 31) as well as an 8 point increase in purpose in life (or a 7% change on the scale range of 121).

The importance of allowing sufficient time to grieve the losses associated with cancer prior to focusing on the possibility of learning from the cancer experience was highlighted in discussions with the second participant - the only participant to show a consistent (though slight decline) across all outcomes and the only participant to show a decrease in self-esteem. Focusing too early on the positive outcomes of a search for meaning may unintentionally invalidate the normal reactions and emotions associated with learning about a serious threat to life. Once the sequence of tasks and issues to address was defined (by the time the fifth participant completed the study), a greater sense of "security to face the future with less fear" became a prominent and recurring theme offered in the feedback from several participants. This was interpreted by the authors as an improved sense of self-efficacy, which was defined as the belief in one's own ability to respond to novel or difficult situations and to deal with any associated setbacks (Schwarzer, 1992).

Statistical results

Are patients with breast or colorectal cancer, or in a certain phase of the cancer trajectory more likely to benefit from a meaning-making intervention?

Insufficient data prevented subgroup analyses for cancer site or phase of cancer trajectory.

What outcomes are most sensitive to change following the meaning intervention?

Appendix B7 presents the means and standard deviations of the main outcome measures. (Analyses for the PAIS were not done due to the incomplete questionnaires returned by 2/3 of the participants because some of the items were deemed irrelevant or the length of the questionnaire was considered burdensome). At post-test, self-esteem significantly improved by 2.4 points (paired t-test = 3.53, p = 0.003), which corresponds to an 8% change on a 30 point scale range for the RSES, and well over half the standard deviation considered clinically meaningful in the absence of other validity data (Norman et al., 2003). Though non-significant, there was a trend towards greater sense of purpose in life following completion of the MMI. No significant differences were found between the pre-post scores for anxiety, depression, optimism, or intrusiveness and avoidance behaviors on the HADS, LOT-R or IES.

What background patient and disease-related characteristics are associated with the changes in outcomes?

Appendix B8 presents the correlations between the background variables and the pre-post test difference scores. Two background variables were related to changes in self-esteem, the only outcome to show a significant change. Participants with a smaller support system (r = -0.45) or who reported greater symptom distress at baseline appeared to show greater improvements in self-esteem (r = -0.55).

Important correlations with some of the outcomes whose pre-post change in score did not obtain significance suggest that some background characteristics might be associated with changes due to the MMI. Having fewer major life events in the past year (r = -0.42), greater symptom distress (r = 0.58), less satisfaction with the social support

(r = -0.48), and less initial clarity about purpose in life (r = -0.41) was correlated with greater pre-post test differences for anxiety and depression following the intervention. Worse physical status at baseline was correlated with a greater increase in sense of purpose in life (r = -0.49) following the intervention.

Discussion

This paper described the development of a meaning-making intervention that used both an inductive approach based on the insights of patients currently experiencing cancer and its treatment, and a deductive approach based on several theoretical and clinical models of coping with major life events. Although the pilot nature of the present study was intended only to suggest trends in variables and there was a further lack of power that resulted from the early end to recruitment, the study found significant results indicating that levels of self-esteem and self-efficacy improved for newly diagnosed breast or colorectal cancer patients who participated in the MMI. The finding that selfesteem improved for participants receiving chemotherapy who were as early as 3 months post-diagnosis is particularly important because this suggests that meaning-making coping strategies may be a potentially effective approach to buffer the impact of cancer on self-esteem. Self esteem has been shown to decline following a diagnosis of cancer (Revenson, Wollman, & Felton, 1983), and particularly during active chemotherapy treatments (Carpenter and Brockopp, 1994; Ward et al, 1991). However, in view of this study's non-controlled design, further examination is warranted to determine whether the rise in self-esteem was due to the intervention, a function of time, or another mediating variable.

A greater sense of security to cope with an uncertain future emerged as a recurring theme that was interpreted as an improved sense of self-efficacy. It is possible that the second task that highlighted the mastery of past challenges and encouraged reflection about the potential transferability of past coping strategies to the present situation may have improved the belief that one can manage the uncertain and unforeseen events related to cancer. Future studies might explore in further depth which components of the MMI are related to perceptions of self-efficacy.

It is possible that coping processes that promote positive meaning may be key to balancing the inevitable losses and negatives that result from a compromised physical condition (Cohen & Mount, 2000; Folkman, 1997; Folkman & Greer, 2000; Kagawa-Singer, 1993). In this study, worse physical status was associated with a greater increase in purpose in life. The three participants being treated for a recurrence of cancer were noted to increase dramatically by 4 or 5 points on the optimism scale (representing 12%-15% of the scale range), while the other 15 participants had a mean increase of 1 point (3% of the scale range). Past research shows that optimism is mediated by adaptive coping strategies such as meaning-making coping (Epping-Jordan et al, 1999; Taylor, 1993) and is a psychosocial correlate of adjustment (Carver et al, 1993; Lauver & Tak, 1995; Schnoll et al., 2002). Talking to patients about death, dying and other existential concerns has been shown not to be harmful and but frequently helpful (Emanuel, Fairclough, Wolfe, & Emanuel, 2004). Further studies might consider whether and how the realistic examination of existential concerns inherent in the MMI can improve a sense of optimism and potentially mitigate some of the negative repercussions associated with cancer and its treatment.

Clinical Implications

The tailored approach of the MMI enhances the fit, format and feasibility of its utilization within clinical practice. Patients with little difficulty or who have no need to engage in the search for meaning may require a single session to reinforce or highlight the strategies used and the wisdom gained during their experience. For patients who require more time to integrate the experience, follow-up sessions can be scheduled to coincide with the patient's next treatment appointments. Our study found psychological improvements even in a sample that was considered relatively high functioning and not clinically distressed at baseline which suggests that the MMI may offer an effective approach to address existential concerns as part of routine comprehensive cancer care. Alternatively, in this day of cost-containment, the present findings also suggest that people who report greater physical distress, lack a strong support network, or are unclear about their purpose in life may potentially be targeted as a group to receive the MMI because they may be considered at 'higher risk' for distress and subsequent health outcomes. Further testing is clearly warranted to confirm these hypotheses.

Limitations

The present findings need to be interpreted within the context of some study limitations. The small convenience sample composed mainly of newly diagnosed participants suggests that the MMI still needs to be validated for patients in other phases of the illness trajectory. A control group that does not receive the intervention would be necessary to determine with more certainty whether the changes in self-esteem, optimism, and self-efficacy were due to the MMI or maturational processes over time. Positive outcomes can also be derived from the effects of the attention received simply by participating in a research study (Hutchinson, Wilson, & Wilson, 1994; MacCormack et al., 2001). Thus, a second control group would be necessary to determine whether there is a significant difference between receiving a structured, theory-based, meaning-making psychosocial intervention and non-specific, non-health related conversations with someone who was willing to listen.

Conclusion

Existential therapeutic approaches may confer the greatest psychological benefits but demand a greater willingness on the part of the patient to engage in intense selfexploration (Cunningham & Edmonds, 1996). This study developed a novel approach to explore existential issues in an ambulatory care setting that was well received by a clinically non-distressed sample. Preliminary analyses suggest that the intervention may help mitigate some of the understandable negative reactions and emotions that are associated with the threat to life by a cancer diagnosis. Further testing of the MMI in a randomized controlled trial would provide more definitive answers as to its efficacy and effectiveness.

Chapter 4 Controlled Intervention Trial Phase

4.1 Preface

This chapter includes the last of the three manuscripts submitted for this dissertation. Specifically, the manuscript presents a RCT to examine the effects of the MMI on psychological adjustment defined in terms of self-esteem, optimism, and self-efficacy in patients newly diagnosed with breast or colorectal cancer. This chapter is divided into 3 sections. First, a brief discussion is offered to justify the choice of research design (Section 4.2) and second, the plan of analysis (Section 4.3). Third, the description and results of a RCT to determine the effect of the MMI on psychological adjustment (self-esteem, optimism, self-efficacy) is presented in the form of a manuscript (Section 4.4).

4.2 Rationale for Methodology

4.2.1 Randomized Controlled Trial Design

Recent evidence suggests that the validity of treatment effects from well-designed observational studies may be comparable to the RCT that has been traditionally known as the 'gold standard' in intervention research (Concato, Shah, & Horwitz, 2003). However, the RCT was considered the best design to use to test the effects of the MMI in this thesis because it employed strategies to minimize allocation bias and maximize group comparability that is not possible in observational studies. When compared to other methods of allocation (i.e. alternate assignment), random assignment to the study groups eliminates the possibility of allocation bias, particularly if two willing and eligible patients presented at the same time during recruitment. Randomization is also presumed to equally distribute all known and unknown confounding variables among the study participants so that the groups are expected to be comparable except for the intervention being studied.

Other design aspects of the RCT were considered. First, given the lack of formal psychological care offered to new patients in these settings, the psychological care that the treatment and control groups received were deemed sufficiently different to be able to attribute the observed results to the MMI itself. Second, although co-intervention bias was a concern, it was not ethically possible to limit the participants' use of professional psychological care available in the community; therefore this variable was monitored and analyzed at the beginning and end of the study. Third, a wait-list control group was not offered because of the unknown efficacy of the MMI at the time of the study. Fourth, a strict intention-to-treat analysis was not performed because it was not ethically possible to require that the post-test questionnaires be completed from patients who withdrew from the study. However, all remaining subjects were analyzed according to the group to which they had been randomly allocated. Lastly, only two arms were tested in the present RCT because the inclusion of a third "attention control" arm would have required a significantly larger sample size that would not have enabled the study to be completed within the time frame imposed for the thesis. In summary, the RCT design was selected based on considerations of methodological rigor, ethics, and feasibility.

4.2.2 Sample

Decisions regarding the inclusion criteria for the RCT with regards to type of cancer and phase of cancer trajectory were guided by the final sample recruited in the previous pilot study. Patients with either breast or colorectal cancer were included in the

RCT because participants with either type of cancer appeared to benefit from the intervention and rate of accrual was similar across type of cancer (i.e. breast, n= 12; colorectal, n=10). However, only newly diagnosed patients were included in the RCT because difficulties associated with the recruitment of patients who completed treatment or were receiving treatment for a recurrence of cancer had been found in the pilot study.

Initially, newly-diagnosed patients were defined as individuals who received their diagnosis of cancer in the 3 months previous to their recruitment date. During the early stages of the RCT, concerns about the slow accrual rate prompted a review of the inclusion criteria. Following discussions with the clinical staff, the difficulties experienced during recruitment were believed to be related to the lengthy waiting times wherein many of the newly diagnosed patients had already surpassed the 3 month inclusion cut-off at the time of their first visit to the oncology clinic to begin treatment. Thus, an amendment was requested and granted from the McGill University IRB and each independent hospital site to extend the eligibility criteria to include patients who received their diagnosis within the last 6 months (see Appendix F3). Although this addressed the situation for recruiting patients with breast cancer, the recruitment of patients with colorectal cancer remained slow. Furthermore, due to time constraints, forgetfulness, or concerns about creating unnecessary burden for new patients, it was not feasible for the treating staff to maintain a complete list of people who were eligible but did not receive the letter versus people who received the letter and were either recruited or not recruited. During the 18 month accrual period, it was estimated that 1,570 patients were diagnosed within the last 6 months with breast or colorectal cancer and might have been eligible to enter the study (determined by counting all eligible patients over 3 months from each hospital site and multiplying by 6 months).

4.2.3 Main Outcome Measures

Self-esteem, as measured by the Rosenberg Self-Esteem Scale (Rosenberg, 1965) was selected as the primary outcome for the RCT. This was based on important clinical feedback from patients and the questionnaire's ease of administration, as well as a significant pretest-posttest difference in the pilot study of the MMI described in Section 3.4. The decision to select optimism as a secondary outcome was also based on qualitative feedback and ease of administration in the pilot study, as well as a nonsignificant trend towards greater optimism that warranted further investigation. The third outcome selected was a measure of *self-efficacy*. Although not initially included among the outcomes that were explored in the preliminary study, this concept was a serendipitous but consistent theme that emerged from participant feedback in the pilot study. For example, following completion of the MMI, several participants spontaneously and independently reported feeling a greater 'sense of security' to face a life of uncertainty associated with having had cancer. It was the author's interpretation that sense of security might be captured by the concept of self-efficacy and warranted further investigation in the following RCT (see Appendix C1 for the complete set of demographic, pre- and post-test questionnaires, and follow-up questions for RCT study participants).

4.2.4 Sample Size Calculations

The Rosenberg Self-Esteem Scale (RSES) was selected to be the main outcome measure on which sample size calculations were based because a previous study has shown that the extent to which patients attribute meaning to their situation with cancer was a significant predictor of higher self-esteem (Lewis, 1989). Self-esteem was also the only outcome variable to show a significant treatment effect in the pilot study. All sample size calculations followed the formula suggested by Norman & Streiner (1998):

$$N = 2 \begin{bmatrix} (z_{\alpha} + z_{\beta}) \sigma \\ - - - - \Delta \end{bmatrix}^{2}$$

All sample size calculations were based on a two-tailed, α level of 0.05 or $z_{\alpha} = 1.96$, and a β level of 0.10 or $z_{\beta} = 1.28$.

The total sample size (N=136) was calculated using a standard deviation of 6.1 that was obtained from a large psychosocial oncology intervention study conducted with 58 post-mastectomy patients (Neuling & Winfield, 1988), and a mean pre-post test difference of 2.4 based on the sample of 18 participants from the pilot study:

N = 2
$$\begin{bmatrix} (1.96 + 1.28) (6.1) \\ ----- \\ 2.4 \end{bmatrix}^2 = 2(68) = 136$$

The decision to use a larger standard deviation from the literature rather than that from the pilot study was based on the desire to have a more conservative estimate since the pilot study was conducted with a small number of newly diagnosed participants.

However, since analyses from the group of 18newly diagnosed patients in the pilot study suggested that statistically significant changes may be evident with a smaller sample size (e.g. we found significance with 18 patients, an interim analysis was planned when half the sample calculated from the literature was obtained (n= 68). The RCT was to be stopped if the interim analysis results demonstrated a statistical significance

between the experimental group and control group on any of the outcome(s). Following the interim analysis that was performed on 74 participants (greater than 68 because several were in the study at the same time and we stopped the recruitment only when we had 68 who had completed both pre- and post-test questionnaires), the study was terminated because statistically significant results were obtained.

4.3 Rationale for Plan of Analysis

4.3.1 Justification for Choice of Analysis of Covariance (ANCOVA)

Separate 2-way analyses of covariance (ANCOVAs) were conducted on the posttest difference between the experimental and control groups for each of the three indicators of psychological adjustment: self-esteem, optimism, and self-efficacy. The independent variables consisted of treatment group (experimental and control) and cancer site (breast cancer and colorectal cancer). Site of cancer was included as an independent variable because the differing treatment regimens, medications, and demands of illness have been shown to have a differential psychological impact on individuals (Zabora et al, 2001). The randomization procedure was also stratified by cancer site so that equal numbers of participants with each cancer site could be ensured in each treatment group. The pretest (baseline) score for each outcome variable was treated as a covariate for that outcome variable because it represents a source of variation which had not been controlled for in the experiment and is believed to affect the post-test score (Tabachnick & Fidell, 2001).

A multivariate analysis of covariance (MANCOVA) was not selected as the main statistical technique for several reasons. First, there is no evidence in the literature to justify examining whether a composite variable that is based on a linear combination of self-esteem, optimism and self-efficacy, would vary as a function of a meaning-oriented psychosocial intervention. Second, a further ANCOVA would sometimes be necessary to help interpret the MANCOVA results (i.e. to assess the contribution of each dependent variable to a significant effect) (Tabachnick & Fidell, 2001). Third, MANCOVA is believed to improve the chance of discovering what it is that changes as a result of the different treatments and their interactions. However, our choice of dependent variables was based on the results of the pilot study which was designed to explore which psychological outcomes might be most sensitive to the effects of the meaning-making intervention. Thus we had a sense of what changes were likely. Lastly, a MANCOVA is considered advantageous over a series of ANOVAs when there are several dependent variables because it protects against inflated Type I errors due to multiple testing of dependent variables that are likely to be correlated (Tabachnick & Fidell, 2001). However, we controlled for that in this study using the Bonferroni adjustment for 3 planned comparisons to set the significance level ($\alpha = 0.05/3$, or p = 0.02). Statistical significance was achieved for all outcome measures: self-esteem (p=0.006), self-efficacy (p=0.002), and optimism (p = 0.019).

4.3.2 Post-Test Comparisons Between Groups

It was assumed that the MMI would have different effects on different people, which would result in a greater within-subject variance than a between-subject variance. Therefore, it would have been difficult to detect a pre-post test change within individuals (Norman et al., 1989). We therefore chose to examine differences in the post-test scores between the control and experimental groups to determine if there was an overall treatment effect between groups. The use of ANCOVA for post-test scores only is considered to result in greater statistical power than the equivalent test of pre-post difference scores in this situation (Norman et al., 1989).

4.3.3 Choice of Covariates

The choice of covariate(s) should be limited to a small set of unrelated variables because there is a 'point of diminishing returns' (i.e. the use of many covariates that are correlated with each other would result in a loss of too many degrees of freedom without the commensurate removal of error, and a consequent loss of power) (Tabachnick & Fidell, 2001). The criteria for covariates to be included in the present ANCOVA were based on whether 1) the literature suggested important sources of variability that should be controlled, and/or 2) despite randomization, there was a mean difference greater than ½ standard deviation between the experimental and control groups [this is conventionally considered to be a minimum clinically important difference in the absence of knowledge of a clinically meaningful level (Norman et al., 2003)], and 3) the potential covariate satisfied the ANCOVA assumptions of linearity, homogeneity of variance, and homogeneity of regression.

A series of variables were considered as potential covariates. Stage of cancer was considered due to the assumption that more advanced cancers are associated with greater distress. However, stage of cancer was not included as a potential covariate because there is insufficient evidence to suggest that the effect of psychosocial interventions depends on the stage of disease. *Age* was considered a potential covariate because evidence consistently suggests that younger patients may have more difficulty adjusting to their diagnosis of cancer (Edlund & Sneed, 1989; Dunn & Stegninga, 2000; Siegel, Gluhoski, & Gorrey, 1999). *Social support* was also considered a potential covariate

because it has been identified as a potential mediator between intrusive thoughts/ avoidance and psychological adjustment (Devine, Parker, Fouladi, & Cohen, 2003). However, in the analysis, neither age nor social support were included as covariates because the randomization resulted in equivalence between the experimental and control groups for age and social support (they did not differ by greater than ½ a standard deviation).

An *a priori* decision was made to include the *time between first treatment and pretest (baseline) completion* as a potential covariate because it is unknown whether time from diagnosis is a factor in how people make meaning of their situation. The time from first anti-cancer treatment was used as the closest and most reliable proxy for estimating the time when patients obtained their "diagnosis". However, this time frame was not used as a covariate because the results indicated it was not highly correlated with any of the dependent (post-test) variables. There was no relationship between the time of first treatment to pretest (baseline) completion and any of the posttest measures (Appendix C2b).

Each *pre-test score* was considered as a covariate for the corresponding post-test score because of the likelihood that the pre-test would be correlated with the post-test (Tabachnick & Fidell, 2001). Each pretest score satisfied the assumptions of ANCOVA as described in the following section. In the final analysis, comparisons between the experimental and control groups were conducted with the effect of baseline differences removed (i.e. baseline self esteem for the self-esteem analysis, baseline optimism for the optimism analysis, baseline self-efficacy for the self-efficacy analysis).

4.3.4 Assumptions of ANCOVA

Each pretest score considered as a potential covariate was evaluated for the degree to which the ANCOVA assumptions for independence, linearity and homogeneity of regression were met. The *assumption of independence* requires that the covariate not be correlated with the independent variable (Tabachnick & Fidell, 2001). A correlation table indicates that each pretest score was not correlated with site of cancer or treatment group (all correlations were < .22) and therefore this assumption was satisfied (Appendix C2a.). The *assumption of linearity* requires that the relationship between each covariate and the dependent variable should be linear and have correlations above 0.30. A correlation table shows that each pretest score was highly correlated with each corresponding post-test score (i.e. r > 0.50) (Appendix C2b).

The assumption of homogeneity of regression requires that the direction and strength of the relationship between the covariate and dependent variable be similar in each group (Tabachnick & Fidell, 2001). This meant that the slopes should be equal when the dependent variable (i.e. each posttest score) is regressed on the covariate, i.e. there should not be an interaction between cancer site and treatment group and each covariate (i.e. treatment group X cancer site X RSES pretest; treatment group X cancer site X GSES pretest; and treatment group X cancer site X LOT pretest). This assumption was tested by conducting a 3 way ANOVA for each of the dependent variables (see Appendix C2c). There was no significant 3 way interaction found between cancer site, treatment group, and each of the covariates.

Additional assumptions for ANCOVA existed but were not performed because they were not applicable. For example, the requirement that the relationship between pairs of covariates should be linear was not relevant because there are no pairs of covariates to test since there is only one covariate per ANCOVA. Similarly, the requirement that the covariates should not be highly correlated with each other to avoid multicollinearity was also not relevant because there is only one covariate for each ANCOVA.

4.3.5 Outliers

Using a box and whisker plot, extreme cases were identified for each outcome variable. The extreme cases were double-checked to see if the data were correctly entered, and all data was found to be correctly entered. Such cases were retained unchanged in the analyses because they represent the range of scores in the target population.

4.3.6 Missing Values

The pretest and posttest questionnaires that were returned by mail were screened by a research assistant upon receipt, and participants were telephoned within a week of completing the questionnaire after the missing value was discovered to provide a response. Missing values were screened again prior to the main statistical analyses. Missing values constituted < 10% of the data within each scale. Less than 2 missing values were from the same person and less than 3 missing values were from the same variable. There did not appear to be any systematic pattern in the missing values. Because the missing values were scattered throughout the cases and variables, the deletion of cases would have meant a substantial loss of subjects. Therefore the method of mean substitution was the procedure used to handle the missing data. The means were calculated from the available data for each variable and used to replace missing values prior to analysis. Although this is considered a conservative procedure since the mean for the distribution as a whole does not change, the variance for each variable is reduced because the mean is closer to itself than to the missing value it replaced (Tabachnick & Fidell, 2001).

4.4 Manuscript Three

Meaning-Making Intervention During Breast or Colorectal Cancer Treatment

Improves Self-Esteem, Optimism, and Self-Efficacy

Short title: Meaning-making improves psychological adjustment

Virginia Lee, N., MScA, PhD (candidate)

School of Nursing, McGill University; Nursing Research Consultant, McGill University Health Centre- Montreal General Hospital

S. Robin Cohen, PhD

Assistant Professor, Depts. of Oncology and Medicine, McGill University; Project Director, Lady Davis Institute, SMBD- Jewish General Hospital

Linda Edgar, N., PhD

Assistant Professor, School of Nursing & Dept. of Oncology, McGill University; Research Associate, Dept. of Epidemiology, and Hope and Cope, SMBD- Jewish General Hospital

Andrea M. Laizner, N., PhD

Assistant Professor, School of Nursing, McGill University; Nursing Research Consultant, McGill University Health Centre - Royal Victoria Hospital

Anita J. Gagnon, N., PhD

Assistant Professor, School of Nursing & Dept. of Obstetrics and Gynecology, McGill University; Nurse Scientist, McGill University Health Centre

Please address correspondence concerning this manuscript to:

Virginia Lee c/o Nursing Research Department McGill University Health Centre – Montreal General Hospital 1650 Cedar Avenue, Room D6-156 Montreal, Quebec, Canada H3G 1A4 Tel.: (514) 934-1934 ext. 44371 Fax. : (514) 934-8357 Email : <u>virginia.lee@mail.mcgill.ca</u> An original manuscript submitted to the journal Social Science and Medicine.

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Abstract

The existential issues that often accompany a diagnosis of cancer remain one aspect of psychosocial oncology care for which there is a need for focused, effective, and empirically-tested interventions. This study examined the effect of a novel psychological intervention specifically designed to address existential issues through the use of meaning-making coping strategies on psychological adjustment to cancer. The meaningmaking intervention (MMI) assisted patients to understand their cognitive and emotional responses to cancer from an existential perspective within the context of past life events and future goals. A randomized controlled trial assigned 82 patients recently diagnosed with breast or colorectal cancer to receive up to 4 two-hour sessions of the MMI (the majority received 2 or 3 sessions) plus usual care (experimental group) or usual care alone (control group). Self-esteem, optimism, and self-efficacy were measured at baseline and then post- intervention. After controlling for baseline scores, the experimental group participants demonstrated significant improvements in their levels of self-esteem, optimism, and self-efficacy. The results are discussed in light of the theoretical and clinical implications of meaning-making coping in the context of stress and illness.

Keywords: Meaning, coping, psychological adjustment, randomized controlled trial, existential

Existential distress is the experience of life with little or no meaning (Kissane, 2000). It can lead to a sense of demoralization, futility, and powerlessness that can interfere with psychological adjustment and the ability to cope with cancer treatment (Holland, 2000; Kissane, 2000). Despite modern technology and medical advances, cancer continues to evoke difficult existential questions that are challenging to understand and relieve, and are often left unrecognized and untreated (Cunningham, 1995; Holland, 2000; Kissane, 2000; Taylor, 2003).

The existential plight of cancer is commonly addressed in psychosocial interventions that incorporate the role of meaning into psychological adjustment, but are also designed to teach about the medical effects of cancer treatment (Coward, 1998; 2003), coping skills training (Edelman, Bell, & Kidman, 1999; Moorey & Greer, 1989), and communication with family and health providers (Classen et al., 2001; Coward, 1998; 2003; Kissane et al., 2003). Although such interventions are beneficial in terms of improving physical symptomatology, and emotional and functional adjustment (Goodwin, Leszcz, Ennis, et al., 2001; Meyer & Mark, 1995), it is unclear what the effects of meaning are on psychological adjustment. To more adequately address cancerrelated existential issues, more focused and standardized interventions need to be developed and tested. The purpose of this randomized controlled trial was to determine the effect of a novel meaning-making intervention on self-esteem, optimism and selfefficacy in patients newly diagnosed with breast or colorectal cancer.

Meaning-making coping.

The concept of meaning is highly relevant to the process of coping with cancer because it refers to the beliefs and goals used to appraise and manage stressful life experiences (Park & Folkman, 1997). The appraisal of a negative life event such as a cancer diagnosis occurs in light of a set of basic assumptions about the self and the world (Janoff-Bulman, 1989). These fundamental assumptions include beliefs about a) the extent to which people perceive themselves to be good, moral, worthy individuals, b) the controllability and justifiability of how good versus bad outcomes are distributed in the world, and c) the extent to which good versus bad outcomes generally occur in the world (Janoff-Bulman, 1989). A cancer diagnosis that severely challenges any of these assumptions would likely evoke an existential crisis (Halstead & Hull, 2001; Klemm, Miller, & Fernsler, 2000; Lechner, 2003; Taylor, 1983, 2000; Weisman & Worden, 1976-77).

The ensuing struggle to understand the paradoxes and reconcile dilemmas imposed by a new diagnosis of cancer may include a search to attribute causality (e.g. why cancer occurs in general, how prevalent cancer is in general, whether there is a reason for having cancer) and responsibility (e.g. why cancer happened to oneself in particular, whether one deserved or could have prevented cancer) (Gotay, 1985; O'Connor, et al., 1990; Taylor, 1983, 1995; 2000). Such questioning is considered a hallmark of a normative process of searching for meaning following traumatic lifethreatening events (Creamer, Burgess, & Pattison, 1992; Frankl, 1959; Lee et al., 2004a; Park & Folkman, 1997; Thompson & Janigian, 1988).

The continued process of searching for meaning is consistently shown to have a negative impact on quality of life (Tomich & Helgeson, 2002; Vickberg et al., 2001) and psychological adjustment (Mullen et al., 1993; Schnoll et al., 2002; Taylor, 1993;

Thompson & Pitts, 1993) including anxiety (Lewis, 1989), depression (Barkwell, 1991), and avoidant coping (Schnoll et al., 2002). In contrast, the ability to successfully place the experience of cancer within a more global perspective of life has been positively associated with improved quality of life (Tomich & Helgeson, 2002; Vickberg et al., 2001), as well as overall adjustment to illness (Taylor, 1993), greater optimism (Thompson & Pitts, 1993), hope (Post-White et al., 1996), improved coping abilities (Barkwell, 1991), and greater self–esteem (Carpenter, Brockopp, & Andrykowski, 1999; Lewis, 1989). The global reconstruction of a belief system often includes a satisfactory explanation for the occurrence of cancer and preserves the integrity of the self.

Meaning-oriented psychosocial interventions.

Cognitive strategies to assist in the search for meaning during the cancer experience have often been suggested as a potentially effective approach to alleviate existential distress (Ersek & Ferell, 1994; Folkman & Greer, 2000; Ishiyama, 1990; O'Connor & Wicker, 1995). Discussions about the personal significance of cancer are often combined with other therapeutic approaches (e.g. cognitive-behavioral, educational) in many existing psychosocial oncology interventions (Bottomley, et al., 1996; Classen et al., 2001; Coward, 1998, 2003; de Vries et al., 1997; Goodwin et al., 2001; Greer, Moorey, & Baruch, 1991; Greer, et al., 1992; Kissane, et al., 1997, 2003; Moorey & Greer, 1989; Moynihan et al., 1998; Spiegel, Bloom, & Yalom ,1981). One trial (Linn, Linn & Harris, 1982) randomly assigned 120 men with end-stage cancer to receive counseling sessions that focused on reminiscence and meaningful life activities (n = 62) or to a usual care control group (n = 58). Subject attrition due to death was consistent throughout the length of the study. By 12 months, 9 subjects remained in the experimental group and 14 in the control group. Quality of life indicators were compared only for those patients who were still alive at each assessment point. Significantly greater life satisfaction, improved self-esteem, and a decreased sense of alienation were apparent at 3, 6, 9, and 12 months for the experimental group. Depression was significantly decreased only at 3 months, and a greater sense of control was observed at 9 and 12 months for the experimental group. Limitations of the study were that details about the treatment protocol were vague as was therapist adherence to the treatment protocol. Although the meaning-making approach is a frequently embedded component in established and efficacious psychosocial interventions (Meyer & Mark, 1995), the specific effect of the meaning-making approach on psychological adjustment remains unclear. Despite the clinical importance of meaning-centered interventions, only a few interventions that are dedicated to meaning-making coping strategies have been developed, and are currently undergoing prospective trials (Cole & Pargament, 1999; Greenstein, 2000; Greenstein & Breitbart , 2000).

A meaning-making intervention.

A novel approach to facilitate reflection about the existential impact of cancer was recently developed (Lee, et al., 2004b) based on how people appraise and cope with severely stressful life events (Park & Folkman, 1997; Janoff-Bulman, 1989). The meaning-making intervention (MMI) (Lee et al., 2004b) consists of an ordered series of cognitive strategies to guide patients through a review of the cancer experience and the broader life context. The influence of old and new assumptions related to patients' perceptions of self-worth, controllability of events, and distribution of good and bad outcomes in the world are key underpinnings of the cognitive strategies. Initial testing of the MMI in a small pilot study found statistically significant gains in self-esteem, a trend towards greater optimism, and patients reported a greater sense of self-efficacy (Lee et al., 2004b). It was therefore the objective of this study to examine the effect of the MMI in a larger sample of patients currently receiving anticancer treatment for a recent diagnosis of breast or colorectal cancer. It was hypothesized that compared to participants who received usual psychological care, participants who completed the MMI would report a greater sense of self-esteem, a greater sense of self-efficacy and a greater sense of optimism, presumably as a result of having successfully integrated the experience of cancer within a reconstructed set of assumptions about one's self-worth, controllability of events, and distribution of good and bad outcomes in the world.

Methods

Design.

A randomized controlled trial design stratified by cancer site was used to ensure equal numbers of participants with breast and colorectal cancer in each treatment group. Patients with these two types of cancer were selected based on the past accrual rate of the pilot study (Lee et al., 2004b), to permit comparison of our results with other intervention studies which have mainly focused on women with breast cancer, and to explore the impact of the MMI with participants who have diagnoses other than breast cancer and who are male. Because there may be important differences in the experience of breast and colorectal cancer (Zabora et al., 2001), the influence of cancer site was controlled by its inclusion as an additional independent variable (Munro, 2000). The treatment arm consisted of the MMI plus usual care, and the control arm consisted of usual care.

Study population and recruitment.

Patients from four university teaching hospitals were eligible if they were: 18 years or older; diagnosed with breast or colorectal cancer within the last 6 months; receiving anti-cancer treatment; fluent in written and spoken English; alert, oriented and capable of giving informed consent. Patients with a suspected or confirmed diagnosis of brain metastases or psychiatric history were excluded.

Ethical approval was obtained from McGill University and each hospital's Institutional Review Board. The first author (V.L.) was regularly available to assist a staff member to identify eligible subjects from the medical oncology or breast cancer clinics between January 2001 and June 2002. Eligible patients were given a brief recruitment letter by the treating staff member to whom they returned their response in sealed envelopes (see Appendix C3). Patients who refused were asked to anonymously provide a reason and complete the demographic questionnaire on the reverse side of the letter. Interested patients provided a telephone number for the first author (V.L.) to call and inform them of the study procedures, obtain permission to audiotape the intervention sessions, and the offer of a single two hour session following completion and return of the post-test questionnaires for those who would eventually be assigned to the control group. Written informed consent was obtained prior to enrolling the patient in the study.

Data collection procedure.

All participants were asked to complete self-administered pre-test questionnaires within 48 hours of receipt and return them by mail to R.C. Participants who did not return their questionnaires within a week received a reminder telephone call on the 7th, 10th and 14th day from the time of distribution (Appendix C4). Twelve participants

required one reminder, five required two reminders, and two required three reminders. Five participants were considered to have withdrawn from the study because the pretest was not received 1 week after the last reminder call. Participants were informed of their group assignment after the pre-test questionnaires were returned (Appendix C5).

Participants in the experimental group were asked to complete their post-test measures within 24 hours of terminating their last session. Both experimental and control groups were asked to report whether other kinds of psychological support were used during the time of their participation in the study. The experimental group questionnaire included 3 additional open-ended questions asking a) what were the reasons to recommend and b) not recommend the intervention to others in similar situations, and c) what was of most value to them during the intervention (Appendix C1). To match the time between pre- and post- test completion between groups, control group participants were asked to complete the post-test questionnaires at the same time interval as the last experimental group subject. Participants who did not return their post-test questionnaires within one week of their receipt received 2 reminder telephone calls one week apart before they were considered uninterested and to have withdrawn from the study.

Randomization.

Participants were assigned to the experimental group or the control group on the basis of a computer-generated sequence of random blocks of 4, 6, or 8. Participants were not stratified by hospital where recruited because the type and quality of care received by oncology patients was considered to be similar across hospital sites, i.e. the community of healthcare professionals for oncology crossed over sites, and some patients received

treatment from more than one hospital. Only R.C. was aware of the computer-generated sequence, on the basis of which she prepared consecutively numbered, sealed, opaque envelopes containing the group assignment, which were then given to V.L. Once R.C. confirmed that the pretest questionnaires were received and correctly completed, V.L. broke the seal to the next envelope containing the treatment allocation for the participant's type of cancer and notified the participant of his or her treatment assignment.

Meaning-making intervention.

The MMI for patients with cancer was adapted from an original intervention that was initially developed to assist trauma patients cope with the post-traumatic distress symptoms experienced in the wake of a life-threatening critical injury (Grossman & Lee, 1998; Lee et al., 2004b). Although the cancer experience shares many of the features of a traumatic injury (e.g. persistent re-experiencing of the stressful event in the form of flashbacks or nightmares, engagement in efforts to avoid reminders of the event, difficulty concentrating), other distinguishing aspects specific to the cancer experience (e.g. the distress from cancer does not result from a discrete, short lived event but can extend over months and even years; the duration and magnitude of distress experienced depends on the type, stage, and treatment for cancer) required that the original intervention be adapted to be relevant for the cancer population.

Participants received up to 4 individualized sessions (of up to two hours duration) in the patient's home or clinic setting (determined by patient preference). A "Lifeline" exercise chronologically embedded the cancer experience in the historical context of other important life events (see Appendix E). A narrative, story-telling approach characterized the sessions that included 3 tasks (see Appendix B6): 1) an appraisal of their emotional and cognitive responses to the cancer diagnosis, 2) an exploration of past significant life events and the influence of past coping strategies on the present cancer experience, and 3) the development of a realistic plan that would facilitate a commitment to new or previous life goals within the context of an acknowledged mortality. In general, participants engaged in collaborative, thought-provoking discussions that followed the basic tenets of a therapeutic relationship as described in the McGill Model of Nursing (Gottlieb & Rowat, 1987). Discussions encouraged participants to view their situation from different perspectives, and examined the validity of their beliefs about their own self-worth, the degree of justice or randomness in the world, and the sustainability of their goals and life purpose.

Though the discussions may at times be disturbing or emotional, the process is considered a normal and requisite passage in the search for meaning during the cancer experience (Taylor, 2000). Because the content of these discussions is intended to generate more individual reflection that may cause feelings of uncertainty or unease, it was important to provide participants at the first session with an overview of the rationale for each of the objectives (Appendix C6), and end each session with a reminder that the work begun in the session may continue afterwards on their own. All strategies within the MMI are documented in a manual (available from the first author).

Usual care control group.

Participants in the usual care group were not offered formal psychological assistance as it is not usual practice in this setting. However, they were free to participate
in various hospital- or community-based support groups, or receive psychological assistance if they sought it or it was offered to them.

Treatment fidelity and integrity.

All MMI sessions were conducted by V.L., a doctoral candidate with 10 years of oncology nursing experience who was involved in the development of the MMI. A procedure manual describes the theoretical basis, purpose, timing, and sequence of strategies, and includes sample situations. Each session with each participant was monitored with a process and content audit tool. Adherence to treatment protocol was verified by three raters (R.C., L.E. and A.L.) who reviewed a purposeful selection of completed audiotaped sessions and audit forms. The selection consisted of 10% of the experimental group participants based on sex (male, female), cancer site (breast, colorectal), and intervention session length (short, long). The intervention was delivered according to protocol in all cases reviewed.

Masking.

Neither V.L., the participants, nor the treating staff were blinded to group allocation due to the nature of the intervention. To minimize co-intervention bias, the clinic staff and study participants were asked not to discuss the intervention with each other. To minimize contamination bias, participants were asked not to discuss their participation with other patients. To minimize researcher bias, all the questionnaires were self-administered and mailed to R.C. to prevent V.L. from being influenced by participants' baseline scores. The blocked randomization sequence prevented V.L. from predicting to which group the next recruited participant would be assigned. The Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1989) is a widely used measure of self-esteem in the cancer literature (Carpenter, 1997; Curbow & Somerfield, 1991). Ten items are scored on a 4-point scale, ranging from 1 "strongly agree" to 4 "strongly disagree". Half the items are reverse scored, and all responses are summed to obtain a total score ranging from 10 to 40. Low scores indicate high self-esteem. The RSES has demonstrated adequate internal consistency (Carpenter, 1997; Vinokur et al, 1989), test-retest reliability (Silber & Tippett, 1965), and concurrent validity (Crandall, 1973) in individuals with cancer.

The Life Orientation Test-Revised (LOT-R) (Scheier & Carver, 1987; Scheier, Carver & Bridges, 1994) was used to measure optimism. This 12 item measure is composed of four positively phrased items scored on a 5-point scale ranging from 0 "I agree a lot" to 4 "I disagree a lot", four negatively phrased items which are subsequently reverse scored, and four filler items designed to disguise the purpose of the test. The filler items are not included in the total score, which ranges from 0 to 32. High scores indicate a greater sense of optimism. It has demonstrated adequate internal consistency with the cancer population (Carver et al., 1993; Epping-Jordan et al., 1999; Scheier & Carver, 1987; Thompson & Pitts, 1993), and construct, convergent and divergent validity (Scheier & Carver, 1987; Scheier, et al., 1994).

The Generalized Self-Efficacy Scale (GSES) (Schwarzer, 1992) assesses the strength of an individual's belief in his or her own ability to respond to novel or difficult situations and to deal with any associated obstacles or setbacks. On a scale of 1 "not at all true" to 4 "exactly true", the scores of ten items are added to give a total that ranges

from 10 to 40. High scores indicate a high sense of self-efficacy. It has demonstrated high internal consistency as well as adequate concurrent and predictive validity with healthy adults (Schwarzer, 1992) and people with arthritis (Barlow, Williams, & Wright, 1996).

Demographic data.

Age, sex, diagnosis, marital status, education level, employment status, family income, religion, and use of other professional psychological support were collected on a separate form. Stage of disease and date of first anti-cancer treatment (e.g. surgery, radiation therapy, chemotherapy) were obtained from a medical chart review. The dates on which the pre-test and post-test questionnaires were completed (or when unavailable, the date that the questionnaire was received) were also noted.

Sample size.

Based on pilot study results (Lee et al, 2004b), the RSES (Rosenberg, 1965) was used as the main outcome measure for this trial. In the absence of an *a priori* definition of how large a change on the RSES was necessary to declare that a clinically important shift has occurred, sample size was based on a mean pre-post test difference of 2.4 reported in the pilot study. Since the pilot study was too small to provide a reasonable estimate, a standard deviation of 6.1 was obtained from a prospective study of a counseling program with 58 post-mastectomy patients that was evaluated using the RSES (Neuling &Winfield, 1988). The required total sample size for a power of 0.80 and alpha of 0.05 was calculated to be 136 participants for the RCT.

Since the results from the pilot study suggested statistically significant changes may be evident with a smaller sample size, an interim analysis was planned halfway through recruitment (i.e. total n = 68). The study was to be stopped if the interim analysis results demonstrated statistical significance between the experimental group and control group on any outcome(s).

Statistical analysis.

Three separate 2 way analyses of covariance (ANCOVA) were conducted using the SPSS Version 11.0 statistical software package. The independent variables were treatment group (experimental vs control) and cancer site (breast vs colorectal). The three separate dependent variables were: the post test scores of the RSES, LOT-R, and GSES. The selection of potential covariates was based on 1) knowledge of the literature regarding the important sources of variability that might affect the outcome, and/or 2) whether despite randomization, there was a mean difference greater than $\frac{1}{2}$ standard deviation between the experimental and control groups [this is conventionally considered to be a minimum clinically important difference in the absence of knowledge of a clinically meaningful level (Norman et al., 2003)], and 3) whether the potential covariate satisfied the assumptions for ANCOVA. From an initial list that included the baseline scores, age and number of days from first treatment to pre-test completion, only the baseline score for each corresponding outcome measure (i.e. baseline self-esteem for RSES, baseline optimism for LOT, and baseline self-efficacy for GSES) were selected (Munro, 2000; Myers & Well, 2003; Tabachnick & Fidell, 2001).

Results

Participant flow.

Maintaining an accurate list of potentially eligible patients who did not return recruitment letters was not feasible given the resources available for this study. During the 18 month accrual period, 129 patients out of an estimated 1570 eligible patients were known to have received and returned completed recruitment letters (Appendix C7). Of these, 26 refused participation, 21 were ineligible or unreachable prior to randomization, and 82 participants were randomized. Of 41 participants assigned to the experimental group, 4 did not complete the post-test questionnaires (2 were lost to follow-up, 1 died, and 1 was withdrawn because of the participant's inability to focus on the purpose of the study due to conflicts with the treating team). Of the 41 in the usual care group, 1 withdrew to care for an ill family member. Two experimental group participants and 1 control group participant were excluded from the analysis as their post-test questionnaires were returned after the analysis was completed. This paper reports the final analysis from 74 patients (35 experimental; 39 control) for whom complete outcome data was available at the time of the planned interim analysis. This subsequently became the final analysis as our stopping criterion was met.

Sample characteristics.

Appendix C8 presents the frequencies, means and standard deviations of the demographic, disease, and baseline variables for the experimental and control groups. The majority of participants were female (n = 60/74, 81%), had a mean age of 57 years (SD =10.0), and were married or living with a partner (n = 48/74, 65%). Over two thirds of the sample had breast cancer (n = 52/74, 70%). Seventy-eight percent of participants (n = 58/74) were in the early stage 0-2 of either type of cancer (Breast cancer: Exp, n = 20, Ctrl, n = 25; Colorectal cancer: Exp, n = 9, Ctrl, n = 4). Twenty-two percent (n = 58/74) the same state of the same state cancer (n = 52/74, n = 9, Ctrl, n = 4).

16/74) had stage 3-4 cancer (Breast cancer: Exp, n = 3, Ctrl, n =4; Colorectal cancer: Exp, n = 3, Ctrl, n =6).

The demographic data available from patients known to have refused participation (n=24/26) or who withdrew after they were randomized (n=5) were compared to the participants. Twenty-nine percent of non-participants were already receiving professional psychosocial support compared to 11% of participants. Non-participants were also older (29% were over 70 years versus 7% of participants), less educated (63% reported high-school as their highest level of education versus 37% of participants), and of lower socio-economic status (66% reported family incomes below \$40,000 versus 36% of participants). Four of the five participants who voluntarily withdrew from the study had been assigned to the experimental group and had reported higher family incomes (80% above \$40,000) than participants (42% above \$40,000).

Comparability of groups.

Slight differences existed between the experimental and control groups in terms of education, family income, and religion (Appendix C8). There was less than a 10% difference at each level of the variable between groups with regards to sex, marital status, employment, and stage of cancer. The treatment groups were similarly distributed in terms of having received surgery or chemotherapy less than 3 months earlier [Exp, n = 22 (63%); Ctrl, n = 21 (54%)] and between 3 and 6 months earlier [Exp, n = 12 (34%), Ctrl, n = 17 (44%)]. One control group patient (3%) was 10 days, and one experimental group patient (3%) was 20 days past the study's eligibility criteria of a recent diagnosis within the last 6 months. Both patients were retained in the study as group allocation was

already assigned when this was discovered from the chart review, and was not believed to have an important impact on the findings.

The median time between pre-test and post-test completion was shorter for the control group (46 days, range 14 to 192 days) compared to the experimental group (61 days, range 11 to 166 days). This was due to the allocation sequence. Participants were randomly allocated to either group in blocks of 4, 6, and 8, and control group participants were matched to the time that the last experimental group participant completed their post-test questionnaires. However, when the last experimental group participant had not yet completed the intervention, the control group participant was asked to complete the post-test questionnaires in the same amount of time as the previous experimental group participant, which on several occasions happened to follow a short intervention time. This matching did not result in greater than half a standard deviation difference between groups.

Use of external psychological support.

The frequency of using external psychological support services prior to entering the study was similar for the treatment and control groups (ie. Exp: 10%; Ctrl: 11%). By the end of the study, the use of such services doubled in the control group (20%) and tripled in the experimental group (34%).

Intervention characteristics.

The time between pretest completion to beginning the intervention ranged from 3 to 94 days (median = 20 days). Participants required 1 to 89 days (median = 25 days) to complete the intervention. Two (6%) experimental group participants received 1 session, 11 (31%) received 2 sessions, 16 (46%) received 3 sessions, and 6 (17%)

received 4 sessions to complete the intervention. Thus, 77% had 2 or 3 sessions. The time between completing the intervention to post-test completion ranged from 1 to 46 days (median = 8 days).

Effect of the MMI on between-group differences.

The post-test means and standard deviations for the baseline score for each outcome measure are presented in Appendix C9. Comparison of the post-test means using each pre-treatment baseline score as the covariate for each outcome indicated that there was no significant interaction effect between group and diagnosis for each of the outcomes (self-esteem; optimism; self-efficacy). There was no significant effect for type of cancer diagnosis for each of the outcomes. A statistically significant effect was found for treatment group. Participants who received the MMI (experimental group) significantly improved on each outcome variable compared to the participants who received usual care (control group). A post-test difference between groups of 1.66 points was observed on the RSES, which corresponds to a change of approximately 5.4% on the scale range of 31, or an effect size of 0.26. A post-test difference of 3.08 points on the LOT showed a 9.3% change on the 33-point optimism scale, or an effect size of 0.24. A post-test difference of 2.41 points on the GSES demonstrated a 7.7 % change on the 31 point self-efficacy scale, or an effect size of 0.22.

Clinical significance.

Responses to the open-ended questions that were returned with the post-test questionnaires after the study was terminated supported the clinical significance of the intervention. All participants supported the value of the intervention for themselves and all recommended the intervention for others in similar situations. The opportunity to openly and freely talk about one's situation with cancer without fear of being judged or misunderstood, and to discuss issues that otherwise might not have been raised with family members or friends were the two main reasons that participants cited for recommending this intervention to others. The opportunity to learn that one's reactions and emotions to cancer were 'normal', to identify and begin tending to those areas in one's life that had been 'neglected', and to begin seeing a 'wider field of responses' were some of the more valued elements within the intervention highlighted by the participants. The following is a quote from a 40 year old woman with stage 2 colorectal cancer:

"I was actually able to realize my ability to cope and I was able to reflect back on my behavior and discover certain innate strengths which I may not have realized I possessed. I now believe that everyone should experience this opportunity, especially people such as myself who didn't believe that it would be helpful or useful... even one session would be helpful...I would not have seeked "professional /counseling" voluntarily. I was never interested in that type of help. However, these 2 sessions allowed me the chance to realize that I have excellent coping mechanisms and was able to handle this major crisis with relative ease, considering ...and I will probably be able to cope with any other crisis I may experience in the future. I was able to completely reinforce my positive outlook- general self confidence has generally increased. My outlook regarding the future is even more positive."

Discussion

This randomized controlled trial investigated the impact of a psychological intervention that was designed to help patients derive a sense of meaning from their recent experience with cancer. Statistically significant improvements in self-esteem, optimism, and self-efficacy were found for the experimental group as compared to the control group, although the effect size is small. This empirically supports the growing body of literature suggesting that positive outcomes can follow from negative events through the ability to derive a sense of meaning from the situation (Folkman, 1997; Park, 1998; Saakvitne, Tennen, & Affleck, 1998).

Self-esteem and meaning.

Although the negative impact of cancer on self-esteem has been the focus of much past research (Bertero, 2002; Curbow & Somerfield, 1991) and specifically during treatment with chemotherapy (Carpenter & Brockopp, 1994), our finding that self-esteem increased despite the participants' ongoing chemotherapy treatments was particularly important. Being provided with the opportunity to engage in directed discussions about the significance of cancer on one's life may provide a buffer for the adverse effects associated with the arduous treatment and management of cancer. Overall, our results are consistent with other studies suggesting that baseline self-esteem levels of cancer patients did not significantly differ from the general population, and may even improve as people learn to adjust and live with cancer (Carpenter, 1997). Future research could begin to identify the factors that might influence the positive or negative impact of cancer on selfesteem, and the mechanisms responsible for the coexistence of both types of outcomes. Future studies that include a direct measure of the process of constructing meaning would be able to examine with more certainty the positive relationship between self-esteem and the ability to derive meaning from a life changed by cancer (Carpenter, et al., 1999; Lee et al., 2004b; Lewis, 1989; Linn et al., 1982).

Optimism and meaning.

Researchers have shown that the use of problem-focused engagement coping strategies (e.g. cognitive restructuring, problem solving) can mediate the effect of dispositional optimism on distress as early as 3 and 6 months after diagnosis (Carver et al, 1993; Epping-Jordan et al., 1999). Our finding demonstrates that a sense of optimism can be improved as a result of participating in an intervention that examines the fearful aspects of cancer following a review of each individual's inherent strengths and capacities. It remains to be shown in future prospective studies whether interventions such as the MMI might reduce the psychological distress associated with cancer through strengthening or developing a sense of optimism.

Self-efficacy and meaning.

The experimental group participants demonstrated a significant increase in selfefficacy compared to the usual care control group. The MMI sessions were deliberately structured to establish a supportive, collaborative therapeutic relationship prior to the progressive, sensitive introduction of fearful and emotional issues. Moreover, the MMI asked participants to vividly recount relevant past accomplishments in order to identify personal strengths that could transfer to the present situation. According to Bandura's self-efficacy theory (1977, 1986) high physiological arousal is proposed as a deterrent to enhancing self-efficacy whereas past performance accomplishments can be a powerful source of influence to promote a person's conviction that he or she can execute a related behavior to achieve a desired outcome. Edgar et al. (1992) found that increased emotional upset associated with a cancer diagnosis decreased a person's confidence in the ability to carry out specific behaviors, and suggested grief work may need to take place before one is able to cope. The benefits of further studying an effective perceived efficacy-enhancing intervention such as the MMI in the context of coping with cancer treatment include the potential to improve psychological adjustment, overall quality of life, and influence on actual health practices (Lev, 1997). Further research could examine the extent to which different components of the MMI are responsible for improving sense of self-efficacy, and whether a greater sense of self-efficacy influences actual behavior over the course of the cancer trajectory.

Meaning-making coping and world assumptions.

This study demonstrated that one's beliefs about one's self-worth, one's likelihood of encountering future good, and one's ability to master unforeseen events, can be improved when given the opportunity to examine long-held assumptions about cancer and one's own strengths. In a recent study by Tomich and Helgeson (2002), breast cancer survivors five years past completion of cancer treatment who received a psychological intervention reported the world as less controllable and more random, but felt more in control of their own lives when compared to a healthy age-matched control group that responded with respect to the most stressful event that occurred to them approximately five years ago. Our study findings suggest that important shifts in world and self assumptions may occur early in the cancer trajectory and may lead to short-term psychological benefits. Finding a sense of meaning in the cancer experience may be an important coping strategy that if started as early as possible near the time of diagnosis, may mitigate the development of adverse psychological effects later on during the recovery and survivor phases of the disease trajectory. Whether and how the MMI affects these variables over the longer term and course of the disease trajectory is

unknown and may be studied using longitudinal designs that explore the relationship between meaning-making coping and world and self assumptions.

Use of psychological support services.

It needs to be acknowledged that the positive effects found in this study might in part be due to the greater proportion of individuals in the experimental group over the control group who sought additional psychological support. However, it is also possible that the experimental group participants who accessed additional support may have felt more prepared to assess their own needs, seek out the appropriate resources, and have more confidence in their ability to deal with difficult issues (Edgar et al., 2000). This "positive/confronting" coping style has been consistently associated with better psychological adjustment as compared to the "hopeless/helpless" coping style that is characterized by distancing, escape-avoidance types of coping strategies and typically associated with greater psychological distress (Burgess, Morris, & Pettingale, 1988; Stanton, Danoff-Burg, & Huggins, 2002; Zabalegui, 1999). For some, the positive/confronting coping style may have existed prior to entry into the study, but the further increase may be due in part to the MMI. Thus, this trial suggests that positive coping strategies, such as meaning-making coping, may be developed or altered through intervention.

Limitations and Future Directions

Generalizability.

Due to the under-representation of participants with colorectal cancer and the early end to the study following the interim analysis, the sample on which the final analyses was conducted consisted mainly of women with breast cancer. Subgroup

analyses about the effect of meaning-making coping for patients with breast or colorectal cancer would have been possible had we reached the full sample size on which the power analysis was performed.

Further consideration should also be given to understanding whether everyone should be offered the intervention or a specific population should be targeted. Our data demonstrated benefits even for participants who were psychologically healthy. Nonparticipants tended to be older, less educated, and had lower family incomes, while individuals who later withdrew from the study reported higher family incomes. It is likely that other contextual factors (e.g. competing life demands, developmental stage) may provide more information as to who would most benefit from the MMI. A content analysis of the audiotaped intervention sessions is underway to determine if other important clinical variables that could not be gleaned from quantitative measures might yield some more information about the generalizabilty of the MMI.

Effect of 'attention'.

Despite the methods to increase the internal validity of our study (e.g. randomization to treatment groups, monitoring use of other psychological services, availability of a detailed treatment manual, monitoring treatment adherence, controlling for baseline differences), we did not include a second 'attention" control group that received non-specific, non-cancer related discussion of the same frequency as the MMI. It is possible that the experimental group experienced improved outcomes that were due to the extra attention of being in a study, and not due to the specific content provided in the intervention (Hutchinson, Wilson, & Wilson, 1994; MacCormack, Simonian, Lim, Remond, Roets, Dunn, et al., 2001). This is an important limitation to control for in future studies.

Single intervener.

It is unclear whether the observed benefits were attributed to the process and content of the intervention or to the therapeutic relationship that developed between the experimental group patients and the single intervener. Future studies should consider the use of multiple interveners to deliver the intervention.

Single end-point assessment.

A single follow-up measure did not allow assessment of the long-term effects of the MMI. Future studies should consider collecting data on multiple occasions (e.g. at least 6 and 12 months later).

Efficacy vs. effectiveness.

The MMI was tested under conditions that permitted a nurse researcher to provide participants with a choice of home or clinic session, and devote up to two hours per session with each participant. It is unknown whether the effects of the MMI can be replicated given the time and resource constraints in routine ambulatory practice. However, several aspects support the feasibility of testing the MMI in routine practice. First, the MMI provides a theoretical and clinical frame of reference that nurses and other health providers may become skilled at using to understand, assess, and manage the existential issues associated with cancer. Second, the MMI can be tailored to follow the variations in cognitive processing across and within patients, and parts of it are concrete enough to be of potential use within the clinical setting (e.g. the lifeline exercise). Third, although the majority of participants received 2- 3 sessions in the present trial, the variability of the length of sessions suggests that the intervention may be readily adapted to individual needs. For example, patients with less difficulty or interest in the search for meaning would required fewer and shorter sessions. Lastly, the MMI has been demonstrated to be a helpful approach to address existential issues even by many participants who considered themselves to be managing well with their situation.

Conclusion

This randomized clinical trial is the first prospective study to show that an intervention based on meaning-making coping strategies can enhance percepts of self-esteem, self-efficacy, and optimism in patients with cancer. The MMI offers a concrete, theoretically-based, and empirically-tested approach for health care providers to strategically address the existential issues that are associated with the challenges of living with cancer. The results of this study make an important contribution to the area of psycho-oncology intervention research and can begin to meet the challenge of overcoming attitudinal biases regarding psychological care, managing the complexity of understanding and treating existential distress, and integrating psychological care into total cancer care.

Chapter 5 Limitations and Directions for Future Research

The completion of the studies for this thesis was complex due to the need to simultaneously consider the scientific integrity of the study, the ethical treatment of the participants who varied in terms of their physical and emotional states, and the reality of the clinical resources. For example, the burden of completing 10 questionnaires in the pilot study prompted many of the participants to omit the lengthiest measurement tool which resulted in a loss of information about the global adjustment to illness. Patients who voluntarily withdrew or were withdrawn from the RCT by the researcher did not, nor were they obliged to, complete post-test questionnaires. This precluded an intentionto-treat analysis. An additional constraint was the time limitation imposed for the completion of the thesis. The early end to recruitment in the RCT limited the generalizability of the study results to those patients who have the same characteristics as the sample recruited, and did not allow for subgroup analyses. The inability of the treating staff to gather complete information about the study population also limited the generalizability of the study results. The results of the RCT make important contributions to the field of psycho-oncology, however questions remain unanswered. Some of these questions have been addressed in Section 4.4, and include 1) the need for a second control group to rule out the possibility that the effects of the MMI were due to the attention received, 2) the need to have different healthcare professionals deliver the MMI to rule out that the effects of the MMI were due to the characteristics of the thesis candidate, and 3) the need to consider longer follow-up assessments to determine whether and for how long the immediate effects of the MMI persist. This chapter discusses how

future research might begin to address the questions that were suggested in the pilot study but either were not addressed in the RCT or were not answerable in the RCT.

5.1 Meaning-Making and the Disease Trajectory

The pilot study provided sufficient information to understand the procedure of the MMI and suggest potential outcome variables for patients in the early diagnostic phase. However, the premature end to the recruitment of patients who had completed treatment for cancer or who were receiving treatment for a recurrence of cancer meant that further work is needed to validate the MMI for patients in these other phases. The absence of records describing the eligible patients who were approached and refused participation made it impossible to determine whether this was due to a lack of access or a lack of interest on the part of the individuals in these phases of the cancer trajectory. It is important to remember that the MMI was developed and pilot tested on patients who were newly diagnosed with cancer. Further validation of the MMI is needed to assess its relevance and usefulness for patients in other transition phases. For example, a notable (though non-significant) increase in optimism was found in the pilot study for the only three patients recruited with a recurrence of cancer. Future research might initially focus on patients with recurrent cancer to understand the relationship between optimism and meaning-making coping. Later studies involving larger sample sizes might be able to determine if patients in certain transition phases of the disease trajectory would receive more benefit from the MMI than others.

5.2 Meaning-Making and Colorectal Cancer

The pilot study supported the feasibility of recruiting patients with either breast or colorectal cancer for a larger trial. However, for unknown reasons for the RCT, patients

newly diagnosed with breast cancer were recruited at a much faster rate to reach the required number of participants for the interim analysis. Recruitment was ended following the significant results found in the interim analysis, and patients newly diagnosed with colorectal cancer were greatly underrepresented in the final RCT. The decision to end the study before we reached the final sample that would have provided equal numbers of breast and colorectal cancer patients was made because the RCT was *not* set up to estimate treatment effects in each cancer group separately but rather, as a whole.

Questions remain as to whether the low accrual rate of colorectal cancer patients was due to accessibility issues or lack of interest on the part of the patients. Although clinical feedback suggests that patients with colorectal cancer have issues that are unique to the management of their disease, research indicates that the distress levels are similar to patients with other types of cancer (Zabora et al., 2001). Future study is needed to determine if the MMI needs to be adapted to the unique, if any, issues of patients with colorectal cancer.

5.3 Meaning-Making and Purpose in Life

Purpose in life was not measured in the RCT because of the need to be parsimonious in the number of tools selected for this population. Baseline PIL scores in our pilot sample were slightly higher compared to other studies (Coward, 1998; de Vries et al., 1997). At baseline, 11 participants reported having a clear sense of purpose in life, seven reported being uncertain, but none indicated that they were lacking a sense of purpose in life as measured by the PIL (Crumbaugh & Maholick, 1964). After the intervention, the scores for 12/18 patients increased by 2-12 points with a mean pre-posttest change score of 4 points following the MMI. Six patients showed a decrease in their sense of purpose in life but none fell below the critical score of 91 which indicates a lack of purpose. Future studies should aim to measure purpose in life as a main outcome of the MMI because purpose in life increased in the desired direction. Although the increase was not statistically significant (p=0.14), the trend suggests that the MMI may be beneficial even for those patients who considered themselves to be managing well given their situation.

Insufficient power due to the small sample size (n=18) in the pilot study may account for the lack of statistical significance since the same magnitude of change was found to be significant (p=0.04) in a study that measured purpose in life following experiential-existential counseling with 96 cancer patients (de Vries et al., 1997). Alternatively, the development of newer instruments that can detect clinically important changes in patient status during the meaning-making process may also provide more meaningful results related to changes in one's perception of purpose in life. Future studies that employ larger samples and more sensitive tools are needed to directly measure how the MMI affects one's purpose in life following a cancer diagnosis.

5.4 Effect of the Meaning-Making Intervention on Cognitive Processing and Emotional Social Support

Intrusive thoughts and avoidant behaviors are indicators of normative cognitive processing following severe adverse events (Horowitz, 1986; Janoff-Bulman, 1992). However, persistent intrusive thoughts and avoidant behaviors are indicative of underlying pathology (Horowitz, 1986; Silver, Boon, & Stones, 1983). The MMI sessions systematically enquired about and provided opportunities for participants to review aspects of their cancer experience. In particular, the presence of recurring thoughts related to the cancer situation or efforts to suppress them were deliberately explored. If present, these were explained as normative and necessary pathways in the search for meaning following a traumatic event. Participants were then encouraged to explore the possible assumptions or beliefs associated with the intrusive thoughts related to cancer.

The baseline scores for intrusive thoughts, avoidant behaviors and satisfaction with social support did not differ significantly between groups in the RCT. An ANOVA indicated that there was no significant main effect for either group or cancer site. Both the control and experimental groups showed a decrease in total level of cognitive processing (F $_{(1,73)} = 0.723$, p = 0.40; effect size 0.07) as well as the subscales for intrusiveness (F $_{(1,73)} = 0.348$, p = 0.56) and avoidance (F $_{(1,73)} = 0.925$, p = 0.340). The decline in level of cognitive processing symptoms for both groups might reflect the natural integration of the cancer experience over time. Multiple follow-up assessments would have been helpful to determine if the decrease in cognitive processing symptoms would have been greater in magnitude or occurred sooner for the experimental group compared to the control group. It also remains to be explored whether the MMI would increase the frequency of intrusive thoughts because the intervention encourages fearful or distressing issues to be processed, or decrease the frequency of occurrence because the intervention facilitates the discussion and resolution of disturbing thoughts and feelings related to the cancer experience. It is possible that psychological distress associated with the cognitive processing might be greater early in the intervention, but decline as cognitive processing comes to completion at the end of the intervention, as the person learns the skills to master living with the uncertainty of cancer.

The relationship between the MMI and social support also requires further consideration. How the expression of these post-traumatic symptoms are received socially may influence an individuals' willingness to face the traumatic stimuli and integrate the event (Devine, Parker, Fouladi, & Cohen, 2003). Social support may promote psychological adjustment by facilitating the cognitive processing of stressful events. Unsupportive or negative social responses to disclosure can lead to the suppression of the responses that promote cognitive integration of the traumatic event and has been shown to be associated with adverse psychological and physical health outcomes (Butler, Koopman, Classen, & Spiegel, 1999; Gross and Levenson, 1993; 1997; Pennebaker, 19851; Petrie et al., 1998; Wegner et al, 1987). In contrast, a supportive environment that encourages recall and reflection of the trauma memories and possibly the construction of more positive appraisals of the event is likely to facilitate healthy psychological adjustment and recovery (Foa, Steketee, & Rothbaum, 1989; Horowitz, 1986, Janoff-Bulman & Frieze, 1983; Pennebaker, 1990).

The pilot study suggested that participants with a smaller support system appeared to show greater improvements in self-esteem following receipt of the MMI (r = -0.45). Recent evidence suggests that the size of the social network was related to greater emotional support since individuals with few social ties (regardless of their quality) have less emotional support available to them (Bloom, Stewart, Johnston, Banks, & Fobair, 2001). It is possible that the MMI may have benefited those participants with smaller support networks by providing them with an additional source from which to receive emotional support. That is, the MMI may not have been as beneficial for those individuals who can readily draw from a larger network of friends, family, or health professionals with whom to discuss their experience of cancer. Future research should

explore whether the MMI should target individuals who continue to try to integrate the experience but lack an available social network for these discussions to happen.

Chapter 6 Conclusion

In the preceding chapters, a systematic literature review identified that the concept of meaning might be a key element to the psychological adjustment to cancer. This hypothesis was later supported in a RCT that demonstrated improved levels of selfesteem, optimism, and self-efficacy in a group of newly diagnosed breast or colorectal cancer patients who participated in a novel meaning-making intervention when compared to a control group who received usual care. Although the effect size was small for all three outcomes (ranging from 0.22 to 0.26), these results are similar to the magnitude of effect reported for emotional adjustment (0.24) in a meta-analysis of 62 psychosocial interventions with adult cancer patients (Meyer & Mark, 1995). Thus, this thesis provides additional evidence that psychosocial interventions have positive effects on one's adjustment to cancer. More importantly, our results specifically highlight the unique and significant contribution of meaning-making coping strategies, which to date have not been clearly elucidated because of its frequent association with other therapeutic modalities in psychosocial interventions.

The improved sense of self-esteem, optimism, and self-efficacy are thought to be related to the concept of meaning in that they reflect the three fundamental assumptions about the self and the world that are implicated in the meaning-making process following a diagnosis of cancer. Namely, these are the beliefs about the self as a good, moral, worthy individual; beliefs about the occurrence of good and bad events in the world and particularly for the self; and beliefs about the extent to which good and bad events can be controlled or distributed in the world (Janoff-Bulman, 1989). The direct measurement of meaning must wait until the development of a valid and reliable tool that can assess both

the content and processes involved in meaning-making coping. This chapter closes with a perspective of how the MMI would fit within current ambulatory oncology practice.

6.1 The Challenge of Integrating Psychosocial Care into Total Cancer Care

Despite increasing recognition that psychosocial services are essential to a comprehensive, holistic approach to cancer care, several challenges exist that have hindered the integration of such services into routine care. The pilot study indicated that participants with smaller support networks or who reported greater symptom distress at baseline appeared to show greater improvements in their self-esteem. These background factors may provide important sources of information when nurses assess patients at diagnosis for distress. However, the underrecognition and undertreatment of psychological distress among patients across the disease continuum is a well known fact in the psychosocial oncology field (Holland, 2000; Zabora et al., 1997). There are at present only a few screening tools that can be easily used in practice to identify patients who would benefit from intervention (Holland, 2000; Larouche et al., 2004). The unwillingness of some patients to share their distress for fear of being stigmatized as having psychological or psychiatric problems is a frequently cited reason for the underrecognition of distress (Holland, 2000; Zabora et al., 1997). Psychological distress usually does not overtly manifest itself until it reaches an observable crisis (Holland, 2000). Thus, the potential for distress to mount if left unaddressed is great. Paradoxically, the anxiety and distress experienced during crisis may also lead to brief periods of enhanced openness to outside counsel and motivation for relief (Localszo & Brintzenhofeszoc, 1989; Viederman, 1983). It is believed that if psychological screening, that includes an assessment of the patients' social support network and level of distress associated with physical symptomatology, can be routinely incorporated into the early assessment of cancer care, this would convey the message that the psychological concerns and distress associated with the impact of cancer are normal, and may lessen the stigma attached to receiving psychological assistance.

The present RCT demonstrated an openness and willingness to participate in a psychological intervention on the part of the participants who were as early as 1 day to 6 months from initial diagnosis. It is believed that the intervention was received well because it was offered early in the patient's treatment plan, an effort was made to reach and offer it to all newly diagnosed patients, and it was tailored to address the differing levels of need for each patient. Future studies that incorporate longitudinal designs will be able to determine whether early intervention would indeed avert later psychological morbidity.

Another common barrier that is frequently cited for the undertreatment of psychological distress among cancer patients is the shortage of time to adequately address psychological concerns (Holland, 2000). It is believed that the format, if not the time requirements, of the MMI would provide a practical approach that can be realistically integrated into the routine care of the patient with cancer. This is a very interesting point because the individualized format of the MMI addresses a feasibility factor that is not entirely obvious: there is a general assumption that group interventions require much less clinician time than individualized ones. The group interventions that have demonstrated effectiveness in the literature have typically described the need for multiple sessions over time, a factor that in turn results in a high number of clinician hours per patient, or requires multiple clinicians to be available on rotation to deliver the intervention. In contrast, the MMI for cancer patients was found to require far less time than the 8 sessions originally anticipated from the original intervention for trauma patients, i.e. up to 4 sessions was found to be adequate for most patients on average to have an effect when the MMI was adapted for cancer patients. It may be that the content addressed within the MMI is more appropriate and therefore more effective when delivered in individualized sessions. Research (Kissane et al, 2003) and clinical observations suggest that the social comparisons that occur in group sessions may lead some participants to feel demoralized or inadequate as they listen to other patients who have either more or less difficulties coping with their situations. In contrast, the individualized sessions offered in the MMI may allow participants to use their own past life experiences as a baseline from which to realistically assess their present situation. Given the current health care system with its financial constraints, future work could examine whether there is a group format to the MMI that might also provide the benefits of the present study, and what is the costbenefit ratio between the two formats.

Several other implications for practice are highlighted. First, the MMI was based on the McGill Model of Nursing (Gottlieb & Rowat, 1987) that has been shown to be both applicable and appropriate to caring for the needs of patients with cancer (Laizner, 2002). The individualized sessions of the MMI are consistent with how nurses are currently providing care in an ambulatory setting. For example, the MMI uses a nonthreatening, conversational approach that can be used by skilled nurses for screening, intervention, or ongoing evaluation of existential issues while performing other clinical procedures, such as infusion of chemotherapy or doing a wound dressing change. Second, as it is not realistic for ambulatory oncology patients to be treated consistently by the same nurse at each treatment session, detailed documentation using the progress and content audit forms would allow different nurses at different treatment sessions to follow each patient's progress. Although some clinicians believe that the crisis nature of the situation prepares the patient to be more receptive to psychological intervention (Localszo & Brintzenhofeszoc, 1998), the influence of an *a priori* therapeutic relationship between the nurse and the patient on the effectiveness of the MMI needs to be further explored. Third, the MMI was also based on theories from other disciplines (e.g. psychology) that would allow health care providers other than nurses to be trained to use the MMI manual for screening or follow-up at times other than the actual treatment procedure, i.e. while patients wait for their oncologist appointment or prior to being called for treatment. Multi-hospital effectiveness trials (i.e. *Phase IV* and *V* trials) would be required to determine the feasibility and effectiveness of the MMI applied in the 'real world' of oncology care. The effect of combining meaning-making strategies within the broader scope of psychosocial coping interventions also needs to be explored.

6.2 Summary

In summary, this thesis contains important new theoretical and clinical information that has the potential to improve the quality of care for people diagnosed with cancer. Some of the key points to emerge from this thesis are that:

- Participation in the MMI has shown improved levels of self-esteem, optimism, and self-efficacy.
- 2. It is possible to facilitate the process of meaning-making within a supportive therapeutic relationship as outlined in the MMI.
- For people whose lives are affected by a new cancer diagnosis, the process of meaning-making is a useful coping strategy for the integration of the cancer event.

4. The meaning-making process involves a potentially distressing period of reflection that arises from those existential issues that relate to questions about one's self-worth, how good and bad outcomes are distributed in the world, and how successful one is able to manage future events.

The results from this single RCT begs the design and conduct of further studies to determine who would most benefit from the MMI, how enduring are the positive outcomes, how easily can the MMI be applied in the ambulatory oncology setting by nurses or other allied health professionals, and whether the MMI is a cost-effective mechanism to pave the way towards comprehensive cancer care. In closing, this thesis provides a departure point to further examine the theoretical importance of meaning-making coping in psychological adjustment to cancer, as well as to further explore the potential benefits of meaning-making coping as a viable clinical intervention towards comprehensive cancer care.

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Author	Study	Patient	Method	Outcomes	
Country	purpose	population		·	
Steeves (1992) United States	To describe the role that the quest for meaning plays in easing the suffering from cancer	N=6 males with leukemia undergoing their first bone marrow transplantation Age : Range:20 -46 yrs Mean not reported Two men were married Not reported: Time since diagnosis, ethnicity, income and education	Hermeneutic analysis Unstructured interviews (researcher spent 1-2 hours /day with each patient, engaging in conversation, observing surroundings, activities, and social interactions)	The search for meaning involved Negotiating a new social position as a patient. Patients a) learned who held power in the healthcare system, b) compared themselves with others who were worse off, c) maintained or formed close relationships with others, d) normalized their situation. Understanding the experience as a whole. Patients a)relied on superstition and luck, b) saw their situation in terms of fate or odds, and sought a higher order of meaning through altruistic, religious, or transcendent experiences.	
Carter (1993) United States	To describe the daily lived experience of long- term breast cancer survivors	N= 25 women survivors of breast cancer Age: Range: 40-78 yrs Mean : 56 yrs Time since diagnosis: 5-26 yrs Majority of patients were married (72%), Caucasian (96%), had 13 – 16 yrs of education (56%), and with household income between \$15000 – \$50 000 (68%)	Semi-structured interview including questions about the events at time of diagnosis, beliefs about causality, personal and other people's responses to cancer, changes in activities, goals, behaviour, philosophy, relationships, personal characteristics, meaning of cancer, and reason for participating in study	 Patients described the process of "Going Through" - six conceptually distinct phases across time (past, present, future) as a way of giving meaning to their experience with cancer. 1) Interpreting the diagnosis: Patients considered how cancer and its treatment have affected others and might affect their own lives 2) Confronting mortality: Patients became aware of and discussed the possibility of their own death 3) Reprioritizing: Patients made changes to their lifestyle and life goals 4) Coming to terms: Patients learned to accept and then integrate their experience with cancer (although some people have not resolved this phase yet) 5) Moving on: Patients placed the cancer experience in the background in order to live the present 6) Flashing back: Patients revisited and relived the cancer experience as a way to tie the past, present and future together in a meaningful context 	

Appendix A1. Qualitative studies of meaning-making in cancer populations

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Fife (1994) United States	To develop a conceptualization of meaning within the context of serious illness	N= 38 patients N=16 men N=22 women Age: Range: 31-74 yrs Mean: 54 yrs All patients were married, Caucasian, and the majority were blue or white collar workers, with at least a high school education Not reported: Types of cancer,	Symbolic interactionist Open-ended questions focusing on the individual's response to the cancer, the impact of the illness on the individual 's self- perception, relationship with his or her social world, and the potential impact on future plans.	 The meaning of illness was comprised of two inextricably related dimensions 1) self meaning (the perceived effect of the illness on one's identity) and 2) contextual meaning (the perceived characteristics of the cancer and its implications regarding one's life, the future and social relationships. Patients described experiencing a series of changes that ultimately reformulated their identity, how they conceptualized the world, and perceived the future. Self meaning was described in terms of losses (personal control,
		time since diagnosis		 predictability sense of power) as they became increasingly dependent on medical personnel and family and friends. self-esteem and self-worth were threatened by changes to one's roles, social status and interpersonal relationships, and body image. The challenge was to maintain a perspective that did not denigrate the self so that a sense of mastery and control could be regained. Contextual meaning was discussed in terms of its impact on career, personal relationships, extended family and friendships.
Luker et al (1996) England	To assess the meaning of breast cancer for women at diagnosis and follow-up	N= 105 women with breast cancer Time since diagnosis: 2.5 weeks, then a mean of 21 months after diagnosis Not reported: Age, marital status, education and income	Women were asked to select from among 8 meanings of illness (i.e. challenge, enemy, value, loss, punishment, weakness, strategy, relief) that best described their experience with cancer	 62% of women at diagnosis and 63% of women at follow-up chose "challenge" to describe their illness. Similarly, 14% at diagnosis and 20% at follow-up chose "value". This suggests that the meaning of breast cancer remained stable over time. Fewer women chose the meanings "enemy" and "loss" at follow-up than at diagnosis, suggesting that the negative meanings of cancer may diminish over time

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Coward (1990) United States	To describe the essential features of self- transcendence in women with advanced breast cancer	N= 5 women diagnosed with stage IV breast cancer Age : Range: 48-72 yrs Mean: 62.6 yrs Married (n=2), widowed (n=2), single (n=1) Time since diagnosis: 2-7 yrs	Phenomenology Participants were asked to provide written descriptions of their thoughts, feelings, and perceptions related to a self- transcendent experience, defined as a sense of well- being, purpose in life, and interconnectedness with others	 Self-transcendence was considered a necessary component to finding meaning in one's life. Self-transcendence was characterized by an increased understanding of self moving beyond the crisis situation a feeling of lightness, relief of burden a closeness to others, environment, God a commitment to purpose acceptance of inescapable circumstances Self-transcendence was obtained through acceptance of inescapable circumstances helping others permitting others to help oneself reminiscence of past self-transcendent experiences
O'Connor, Wicker & Germino (1990) United States	To describe the search for meaning in recently diagnosed patients with cancer	N= 30 patients n= 20 women n= 10 men Types of cancer n= 18 breast n= 10 lung n= 2 colorectal Time since diagnosis: 2 weeks - 6 months Age : Range: 36-67 yrs Mean: 55 yrs Ethnicity: 83% Caucasian Education range: 5- 22 years Income range: < \$10 000 to > \$50 000	Content analysis of secondary data derived from a larger study of the concerns of newly diagnosed patients and their families Patients initially identified issues of concern, and then were asked specifically about physical symptoms, feelings, dependency on others, work and finances, professional care, information about cancer and its treatment, religion and faith, relationships with others, the future and meaning of life	 6 dimensions in the search for meaning were identified 1) Seeking an understanding of the personal significance of the cancer diagnosis by acknowledging its reality or searching for a cause 2) Looking at the impact and consequences of the cancer diagnosis on everyday activities and future plans 3) Reviewing and "taking stock" of their life 4) Changes in outlook toward the self, life and relationships with others 5) Acknowledging actions, beliefs, attitudes that helped them to live with the cancer 6) Acknowledging sources of hope for a positive outcome

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Country Mahon, & Casperson . (1997) United States	To describe the meaning of a cancer recurrence, and to explore whether the recurrence is perceived differently from the initial diagnosis	N=20 patients informed of recurrence within past 30 days N=7 men N=13 women Time since diagnosis:15 – 134 months Time since recurrence: 8 – 94 months Age: Range: 26-72 yrs Mean: 52 yrs Types of cancer n= 6 breast n= 4 leukemia n= 10 other Ethnicity: 75% Caucasian 25% African American Not reported: Income, education	Content analysis of narrative data Semi-structured first interview included questions about reactions to recurrence, fears, support systems. Unstructured second interview included 11 questions about changes occurring since recurrence, interventions from healthcare professionals, communication with family and friends.	 Patients most frequently attributed a landmark event (eg. career advancement, children entering high school, birth of a first grandchild) or a stressor (eg. death in the family, relocation for a job, or marital, family problems) as a possible cause or reason for the recurrence Existential concerns about death, meaning, and purpose in life were discussed extensively with minimal probing. All subjects were able to identify some positive aspect as a result of the recurrence, such as a greater awareness, shifting of, or reordering of priorities. Some patients expressed a sense of urgency to reorder priorities or accomplish some task. The major difference perceived from the initial diagnosis was the realization of the extent of their own vulnerability and how uncontrollable and difficult it was to treat cancer.
Thomas & Retsas (1999) Australia	To describe the development of spiritual meaning for people with terminal cancer	N= 19 patients with terminal diagnosis of cancer n = 12 women n= 7 men Age : Range: 30-90 yrs Mean: 55 yrs Not reported: Time since diagnosis, types of cancer, ethnicity; income, education	Grounded theory Patients were interviewed about their attitudes and behaviours surrounding the diagnosis	Patients made sense of and came to terms with their diagnosis through the process of "Transacting Self-Preservation". This process was dependent on three interconnected behaviours : 1)Taking it all in: Patients initially responded emotionally to the cancer diagnosis, and questioned the possible causes of cancer 2)Getting on with things: Patients actively participated in decisions, mobilized resources and connected with family, friends, other support systems despite thoughts about cancer permeating all aspects of their lives 3)Putting it all together:Patients created meaning and discovered their self by taking stock of and changing their outlook on life, for example by reconciling family matters, and achieving a deeper spirituality

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Utley (1999) Unites States	To discover the different meanings of cancer for older women who are long-term survivors of breast cancer	N=8 women with breast cancer Age: Range: 65-76 yrs Mean not reported Time since completion of treatment: 5. 5 –29 yrs Majority were widowed (75%), all were second or third generation immigrants, all had completed at least high school Not reported : Income	Heuristic inquiry Three life history interviews including questions about the meaning of cancer, defined as how the women perceived the cancer, what kind of event it was for them, and how they characterized the nature of their cancer experience.	 The meaning of cancer evolved over time: Before diagnosis and during the early phases of treatment, cancer represented "sickness and death". Many expressed shock and disbelief because they "did not feel sick". During treatment, cancer represented an "obstacle" or intrusion in their lives. Many expressed surprise at their own strength and abilities. Once completed treatment, the cancer experience was perceived as "transforming". Many were motivated to make positive changes in their lives.
Taylor, E.J. (2000) United States	To describe the process of how women with breast cancer attribute positive meaning to their illness	N= 24 women with breast cancer Age: Range: 39-70 yrs Mean:52 yrs Time since diagnosis: 2–27 months Ethnicity: African American (n=10), Caucasian (n=14) Education: Range: 9-20 yrs Not reported: Marital status, income	Grounded Theory Interview questions included asking patients for their definition of "searching for meaning" and specifically "what does having breast caner mean to you?" followed by their beliefs about causality, selective incidence, blame or responsibility	The basic social psychological process (BSP) of "Transforming personal tragedy" was observed in the data and involved 4 overlapping, cyclical phases: 1) Encountering darkness: In order for the process to begin, patients necessarily asked themselves psychologically and spiritually difficult questions about how and why cancer happened to them 2) Converting darkness: Patients came to accept that some questions remained unanswerable, and some aspects of their lives remained uncontrollable 3) Encountering light: Patients were able to see the significance in or the benefits inherent in their illness 4) Reflecting light: Patients acted more compassionately which reflected an internal transformation

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Nelson (1996) United States	To describe the experience of uncertainty in breast cancer survivors	N=9 women previously treated for localized breast cancer Time since diagnosis: 2-6 yrs Age: Range: 38-69 yrs Median: 50 yrs Ethnicity: 78% Caucasian Income: Range: \$20 000 – \$60 000 Education : 2-6 yrs post- secondary	Phenomenology Unstructured interview format and use of symbolic photographs	 An uncertain future was found to be the impetus for identifying, and prioritizing what was meaningful in life. The struggle to gain meaning involved: -confronting the thoughts and emotions associated with one's mortality -reliance on supportive relationships -learning new ways of living and coping with feelings of insecurity and uncertainty -an exploration and incorporation of what was meaningful in their lives -putting uncertainty into life's perspective which included a consideration of multiple possible outcomes in their uncertain future
Pelusi (1997) United States	To explore women's perspectives of the experience of surviving breast cancer	N=8 women post- treatment for breast cancer Age: Range: 34-70 yrs Mean: 54.6 yrs Time since diagnosis: 2-15 yrs Majority were married (75%), and Caucasian (75%) Not reported: Education, income,	Phenomenology Open-ended interviews in which patients were asked to talk about their experiences of surviving after being diagnosed and treated for breast cancer	 The search for meaning in the experience of surviving breast cancer was characterized by : 1)The realization of one's own mortality and a future that is uncertain and uncontrollable 2)The feeling of abandonment by healthcare professionals and of life prior to the cancer 3)Mediating the expectations of healthcare providers and of family, friends and society 4)Finding resolution to the financial cost of cancer 5)Finding sanctuaries or comfort along the way: in the treatment, healthcare providers, follow-up appointments, and celebrating personal and cancer anniversaries 6)The experience of self-transcendence: Setting life priorities, finding purpose in the illness event, and looking within self 7)Finding lifelines (eg. helping others, finding resources for self and increasing personal health awareness practices 8)Being aware of one's influence on others 9)Being able to tell the stories of their journey Growth came as a result of deriving meaning from this experience

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Landmark, Strandmark . & Wahl (2001) Norway	To describe the existential issues faced by women newly diagnosed with breast cancer	N=10 women with breast cancer Age: Range: 39-69 yrs Mean: 50.7 yrs Time since diagnosis: 4-19 months Majority were married (70%), all were Caucasian Not reported: Income, education	Grounded theory Patients were interviewed about their thoughts, experiences and reactions prior to the diagnosis, while living with breast cancer, and regarding the future	 The acknowledgment of death as a reality and the intense fight for life characterized the central issues faced by women in this study. The core category, "the will to live" included the following core aspects: "Different levels of life expectation" describes the reminders of the threat of death that activates the will to live "The fight against death" describes the concerns related to a threatened future "Life related to the future" describes the beliefs in a meaningful future that counterbalances the fear of death "Religious beliefs and doubts" describes the influence or non- influence of religion and faith "Increased awareness of values in life " describes the changes in attitude towards valued relationships and things when the future appears insecure
Halstead, M.T. & Hull, M. (2001) United States	To describe the process of spiritual development in women diagnosed with cancer	N=10 women Age: Range: 45-70 yrs Mean not reported Types of cancer: n= 8 breast n= 1 nonHodgkin's lymphoma n= 1 ovarian Time since diagnosis: 3 months to 5 years Majority were married (60%), all were high school graduates, and Caucasian Not reported: Income	Grounded theory Semi-structured interview questions including "What does spirituality mean to you?", "what are some experiences that shaped your spirituality?"	 -The basic social psychological process (BSP) of "Struggling With Paradoxes" emerged from the data. Women were challenged to make sense of a variety of contradictory feelings that were not all necessarily resolved, but simply accepted over time. 1)Deciphering the meaning of cancer for me: Initially patients questioned their own and the healthcare system's roles in causing and controlling the illness. 2) Realizing human limitations: As patients faced treatment options, questions of altered physical strength, appearance, emotional. lability and spirituality emerged. Patients needed to ask difficult questions about their faith and let go of aspects of their life they could not control 3)Learning to live with uncertainty: As the physical effects faded, patients struggled with questions about their vulnerability and survival in the future. Patients redefined meaning in their experience, identified spiritual growth, shifted priorities, and faced the possibility of recurrence

Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Ramfelt, Severinsson, & Lutzen (2002) Sweden	To explore the meaning of illness for patients with colorectal cancer at diagnosis, 3 months, and 1 year after.	N=52 patients with colorectal cancer N= 27 women N= 25 men Age : Range: 34-83 yrs Mean: 68 yrs Majority had high school education (77%), married (63%) Not reported: Time since diagnosis, ethnicity	Symbolic interactionist Patients chose from among 8 meanings of illness prior to being interviewed 3 separate times to gain an in-depth understanding of their perceived meaning of illness	 The main theme "attempting to find meaning in illness in order to achieve emotional coherence" consisted of 2 further dimensions: Unified embodiment: Patients who chose to perceive the cancer experience as a "challenge", or "relief" often expressed Gratefulness for one's achievements Confidence in oneself and others to regain health Looking forward to creating a new future Dichotomized embodiment: Patients who perceived the cancer as "the enemy" An altered self-value and struggled against "the enemy" A loss of temporality An infringement of body integrity
Bowes, Tamblyn, & Butler (2002) Canada	To explore the psychological experience of living with ovarian cancer	N=9 women with ovarian cancer Age : Range: 36-70 yrs Mean: 56 yrs Time since diagnosis: At least 6 months after chemotherapy treatment Majority were married (89%), and all were Caucasian Not reported: Income, education	Grounded theory Semi-structured interview	 The basic social concern was dealing with an early or impending death. The core variable of finding meaning in life involved : self reflection, reappraisal of life, and development of new short-term goals. Necessary conditions for the women to find meaning in life included: -hope -physical wellness -action strategies (sharing experiences with other women diagnosed with ovarian cancer, relying on family support, searching for meaningful information, seeking solace in religion, and rationalizing) -interactional strategies (crying, use of humour, being angry) Consequence of finding meaning was a sense of despair and unhappiness or dissatiefaction



Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Olsson, Bergbom, & Bosaeus (2002) Sweden	To describe the experience of the recovery period 3 months after surgery for colorectal cancer	N= 10 patients N= 6 men (52-84 yrs) N= 4 women (57- 75 ys) Not reported: Time since diagnosis, marital status, ethnicity; education ; income level	Hermeneutic inquiry Patients interviewed 3 months after surgery for 45- 60 min. about their thoughts and feelings at the time of diagnosis and during the 3 month recovery period	 Almost all patients waited 3 to 6 weeks after their diagnosis until their surgery 5 main categories of themes emerged: "Down in the depths": loss of normal life, loss of freedom, physical symptoms dominated "Loneliness, disappointment, abandonment": loss of friends, not listened to by professionals "Sharing": reaching out for confirmation of self "Regaining strength and energy as signs of recovery and "finding myself" again": Change and revaluation of life, freedom from physical discomforts "Reaching the turning point and returning to life with some hesitation": Disease coming to an end, life becoming normal again, fragile feelings of recovery
Richer & Ezer, 2002 Canada	To explore the meanings assigned to the experience of receiving chemotherapy	N= 10 women with breast cancer Age : Range: 44-69 yrs Mean: 56 yrs Majority were married (80%), and Caucasian (90%) Not reported: Time since diagnosis:, income, education	Grounded theory Semi-structured interviews were conducted with patients selected at different points in time while undergoing their first course of chemotherapy	 Women used two types of coping strategies ("put it aside" and life lines") to move between three major dimensions of receiving chemotherapy: "Living in it": reflected the intrapersonal dimension of the experience, and included the categories "side effects make the cancer real, my body: friend or foe?, applying things learned in the past". "Living with it": reflected the interpersonal dimension of the experience, and included "sparing the family, unwanted sympathies, my life around the clinic" "Moving on": reflected the reconciliation with one's life in light of the entire cancer experience, and included "seeking a new balance, making plans, back to normal" Existential meaning was ever present throughout the experience in varying degrees Situational meanings were salient initially and became less important as the treatment processed



Author	Study	Patient	Method	Outcomes
Country	purpose	population		
Bolmsjo (2000) Sweden	To describe the existential concerns of very ill cancer patients	N= 10 N= 7 women N= 3 men Age: Range: 47-84 yrs Mean: 62 yrs Mixed types of advanced cancers Not reported: Time since diagnosis, marital status, education, ethnicity, income	Content analysis In-patients were interviewed on 7 issues including the present situation, the future, meaning, remorse, respect, information, and confidence.	 Six categories were identified as being important to patients in terminal stages of advanced cancer Dignity: to be treated like a person not a patient Autonomy: to be able to maintain self- control, be independent, and make informed decisions Meaning: to not give up, to have something worth striving for, getting satisfaction from small, ordinary things, believing in God Guilt: distinguishing between rational and irrational guilt Relations: the need to conclude unresolved conflicts, concerns about close relatives left behind, feelings of isolation Communication: the need for truth with tenderness

Author Country	Study Purpose	Patient Population	Method	Outcome Measures	Results
Lewis (1989) United States	To examine the effects of attributed control over one's health and experienced meaning of one's situation on anxiety and self-esteem in adults with advanced cancer	N= 57 patients with advanced cancer N= 21 men N= 35 women Time since diagnosis: Approx. 2/3 within 12 mths of the study Age: Range: 21-79 yrs Mean: 54 yrs Types of cancer: Mixed with majority breast (25 %) and lung (23%) Majority of patients were married . Not reported : Education, income ethnicity	Cross-sectional, correlational Convenience sample recruited from hospital or private practice. Refusal rate not reported. Entire method not reported	Self-esteem (RSES); Anxiety ; Control (HLOC); Derived meaning (PIL)	 Patients with higher levels of derived meaning had higher self-esteem and less anxiety Time since diagnosis did not affect patients' self-esteem, anxiety, or ability to derive meaning in their situation Attributions of control did not affect patients' levels of anxiety or self- esteem
Coward (1991) United States	To investigate the relationships among self- transendence, emotional well-being, and illness- related distress in women with advanced breast cancer.	N= 107 women with Stage III and IV breast cancer. Time since diagnosis: within last 6 years Age : Range: 29-86 yrs Mean: 61yrs Ethnicity: 92% Caucasian Education Range: 0- 22 yrs Mean: 14 yrs Income range: Range: <\$10 000 to > \$^0 000 Mean: \$20 000 - \$29 000	Cross-sectional, correlational Convenience sample recruited from private practice, cancer center and community hospitals Questionnaires completed in one interview	Self- transcendence (STS); Emotional Well-being (ABS); Illness distress (SDS)	 Self-transcendence directly and positively affected emotional well-being Self-transcendence, through its effect on emotional well-being, decreased illness – related distress No significant correlations between age, length of time since diagnosis, and self- transcendence,

Appendix A2. Quantitative studies related to meaning-making

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Author Country	Study Purpose	Patient Population	Method	Outcome Measures	Results
Barkwell (1991) Canada	To examine the relationships among the variables depression, coping strategies, ascribed meaning to cancer , and level of pain intensity reported by patients with advanced cancer	N= 100 patients with palliative cancer pain N=19 women N=12 men Age: Range: 26-81 yrs Mean: 61.3 yrs Not reported : Time since diagnosis, marital status, ethnicity, education, income	Cross-sectional Correlational Convenience sample drawn from caseload of the visiting nurses program of the VON. Refusal rate not reported. Face to face interviews asking patients to rank order the categories from the one that most described the meaning they ascribed to their pain to the category that least described their pain	Pain (MPQ); Depression (CES-D); Coping strategies (CSQ);	- Patients who attributed a meaning of "challenge" to their pain reported significantly higher coping scores, and lower depression scores than those patients who attributed a meaning of "enemy" or "punishment".
Thompson & Pitts (1993) United States	To examine what factors in the "life - scheme model" (eg. optimism, irrational beliefs, internal / external goals) are related to the ability o find meaning subsequent to a diagnosis of cancer	N= 79 patients recruited through a tumor registry, and screened by their physician N=26 men N=53 women Age: Range: 31-82 yrs Mean: 56.1 yrs Types of cancer n= 42% breast n= 17% colorectal n= 13% prostate n= 28% other Median time since diagnosis:18 mths All patients were married, majority were lower to middle class, and Caucasian (percentages not reported)	Cross-sectional, correlational Pts recruited through local tumour registry ; 16% refusal rate . Questionnaires were mailed, then patients were interviewed by telephone	Optimism (LOT); Irrational beliefs; Internal or non- materialistic goals; External, or materialistic goals; Meaningfulness of life; Depression (CES-D); Physical functioning (Karnofsky Performance Status)	- The ability to find meaning was related to high physical functioning, optimism, low endorsement of irrational beliefs, and the pursuit of internal, non- materialistic goals (eg. time with family, enjoying each day,) - Pre-diagnosis beliefs and goals were not related to the ability to find meaning after the diagnosis of cancer - Patients with higher levels of physical functioning were more likely to have current external, materialistic goals

Author	Study	Patient	Method	Outcome	Results
Country	purpose	population		measures	
Taylor (1993) United States	To identify what illness- related factors (eg. symptom distress, dependency, cancer site, time since diagnosis, length of disease-free interval) were associated with the sense of meaning in life for people with recurrent cancer	N= 74 patients N=29 men N=45 women Age: Range: 20-89 yrs Types of cancer 42 % breast 19% non-solid tumors 39 % other Time since diagnosis of recurrent cancer: 11% <2 mths, 28% 2-4 mths 22% 5-8 mths 7 % 9-12 mths Majority of patients were Caucasian (60%), married (54%), of fairly high SES	Cross-sectional, correlational Convenience sample recruited from two outpatient departments. Refusal rate not reported. Power = 0.96 Medium effect size= 0.40 Instruments were completed by mail, telephone, in hospital, or in clinic setting	Meaning in life (PIL); Adjustment to illness (PAIS); symptom distress (SDS); dependency with ADLs (ESDS); Search for Meaning Survey, demographic tool	 A greater sense of meaning in life was related to positive psychosocial adjustment to illness, low symptom distress, and decreased dependency on others Purpose in life was significantly higher for married and middle-aged patients The longer the length of time since diagnosis of recurrence, the more unclear the sense of meaning
Mullen, Smith, & Hill (1993) United States	To examine the influence of an accumulation of demands on the perceived levels of psychological stress of cancer patients and spouses, and to examine the intervening role of spiritual resources, family strengths, and sense of coherence (Only the results of the patients are presented here)	N= 42 patients N= 18 men N= 24 women Age: Range: 31-75 yrs Mean: 57 yrs Types of cancer 60 % breast 20% prostate 19% other Time since diagnosis: n= 9 (3 - 6 mths) n=16 (6-12 mths) n=17 (>1 yr) Mean family income \$20 000 - \$30 000 All patients were married, majority were Caucasian (75%) Education: not reported	Cross-sectional, correlational Convenience sample recruited from hospital inpatient and outpatient departments by patients' nurse or physician. Only 1 patient who was approached refused. Instruments completed in hospital, outpatient clinic, or by mail	Accumulated demands(FILE); Spiritual resources (ROS); Family strengths (FSI); Sense of coherence (Orientation to life questionnaire); Psychological stress (Occupational stress inventory)	- Sense of coherence was the only direct predictor of psychological stress - Neither family strengths nor spiritual resources directly reduced psychological stress, but both were associated with less psychological stress when mediated by a sense of coherence
Author	Study	Patient	Method	Outcome	Results
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Country	purpose	population		measures	
Dirksen (1995) United States	To explore the prevalence of the search for meaning, and the relationship between this search and attributions of self-blame and well-being in long term survivors of malignant melanoma	N= 31 survivors of malignant melanoma N=19 women N=12 men Age: Range: 25-83 yrs Mean: 55 yrs Time since diagnosis: Range: 5-20 yrs Mean=9 yrs Majority of patients were married (68%), college educated (45%). All were Caucasian. Not reported : income	Cross-sectional, correlational Convenience sample drawn from 2 oncology clinics. Refusal rate not reported. Instruments administered in patients' homes, followed by informal discussion of patients' thoughts and feelings related to living with cancer.	Search for meaning defined as the individual's understanding of why an event occurred and what has been the impact of that event on their life. Search for meaning (SMS); self blame; well- being (IWB)	 52% searched for meaning 90% reported experiencing positive life changes such as increased self-awareness, re- ordering of priorities, and living in the present younger patients searched for meaning more often than older subjects survivors who blamed themselves for their cancer expressed a greater meaning search than the group who did not blame self no difference in well- being scores between survivors who searched for meaning and those who did not
Post-White et al (1996) United States	To explore how individuals with cancer define hope, to determine if spiritual or religious beliefs and relationships with others influence that hope, if sense of coherence and hope are parallel concepts, and if hope influences perceived quality of life	N= 32 patients n= 13 women n= 19 men Types of cancer 53% leukemia 34% solid tumours 9% lymphoma 3% multiple myeloma Time since diagnosis: < 6 to 108 months Age : Range: 29-74 yrs Mean: 47 yrs Majority of patients were Caucasian, college-educated, and middle income	Cross-sectional, Correlational Convenience sample of patients admitted to oncology unit ; 39% refusal rate	Hope (HHS); Spirituality; Sense of coherence (SOC); Quality of life ; 20 item semi-structured interview	 Hope was highly correlated with sense of coherence but not with spirituality or quality of life 5 themes influence hope: finding meaning through spirituality, faith, connectedness, belief in an eternal life relying on inner resources having affirming relationships living in the present anticipating survival

Author	Study	Patient	Method	Outcome	Results
Country	purpose	population		measures	
Chin-A-Loy & Fernsler (1998) United States	To examine self- transcendence in older men with prostate cancer	N= 23 men with prostate cancer attending a prostate cancer support group Age: Range: 61-84 yrs ; Mean: 69 yrs Time since diagnosis: Range: 2 mths – 11 yrs ; Mean: 7.4 yrs Majority of patients were Caucasian (83%); married (78%), at least college educated (65%), Income not reported.	Cross-sectional Correlational Convenience sample; 33% refusal rate	Self- transcendence (STS);	 Overall, the men scored high on the STS Items related to involvement and interest in life as opposed to issues about accepting death as a part of life were most important to this group of men No significant correlations between age, educational level, length of time since diagnosis, and self-transcendence
Moadel et al (1999) United States	To identify the nature, prevalence, and correlates of spiritual / existential needs among an ethnically diverse sample of cancer patients	N= 248 patients with cancer N=145 women N=96 men Age: Range: 18-85 yrs Mean: 56 yrs Time since diagnosis: Range: 1 mth -22 yrs Mean=3 yrs Majority of patients were Caucasian (48%); married (54%), high school educated (39%), Income not reported	Cross-sectional survey Convenience sample of outpatients from oncology clinic; 30% refusal rate Questionnaires completed in clinic waiting room	34 item self- report needs assessment developed by researcher, including 7 items specifically related to spiritual / existential needs	 In order of prevalence, patients reported wanting help overcoming fears, finding hope, talking about peace of mind, finding meaning in life, Least highly endorsed item was the need to have someone to talk to about dying and death Greatest need for spiritual/existential support was among patients who were within 2 years of diagnosis, Hispanic, not college educated, and lacking a significant partner.



Author	Study	Patient	Method	Outcome	Results
Country	purpose	population		measures	
Vickberg et al. (2000)	To examine the role of global meaning as a potential moderating factor between intrusive	N= 61 survivors of breast cancer Age: Range: 30-81 yrs ; Mean: 59 yrs	Cross-sectional, Correlational Convenience sample recruited from physicians' records. 17% refusal rate.	Psychological distress (BSI- GSI); intrusive thoughts (IES); global meaning (PMI of the LAP-R); physical	 Psychological distress was higher for patients who were divorced, widowed, or separated, had lower incomes, or were less physically healthy Younger patients
	thoughts and psychological distress	lime since diagnosis: Range: 2 – 15 yrs ; Mean: 7.4 yrs Majority of patients were Caucasian (81%), married (50%), at least college educated (70%), and had annual incomes between \$20 000 and \$60 000 (55%)	Conducted as past of larger research investigating quality of life and psychological adjustment among adult breast cancer survivors. Telephone interviews	(MOS-SF36)	 reported more intrusive thoughts A strong sense of global meaning was associated with lower distress – More frequent intrusive thoughts was related to greater psychological distress, especially among individuals with lower global meaning However, no relationship was found between intrusiveness and distress among those with a strong sense of global meaning
Ramfelt, Langius, Bjorvell & Nordstrom (2000) Sweden	To examine the relationships among treatment decision- making, sense of coherence, and meaning of illness in patients with colorectal cancer.	N= 86 patients newly diagnosed with colorectal cancer N= 45 women N= 41 men Age: Range: 34-84 yrs Mean: 70 yrs Time since diagnosis: Range: 1 mth -22 yrs Mean=3 yrs All patients were Swedish (100%) and majority were married (64%),	Cross-sectional Correlational Convenience sample of patients scheduled for surgery within 3 weeks; 9 % refusal rate Questionnaires were completed the day before surgery.	Preferred and actual treatment decision-making (CPS); Meaning of the disease (Lipowski); Sense of coherence (SOC)	 71% of patients chose an optimistic meaning (challenge, relief, strategy or value) to describe their cancer. No significant correlations were found among sense of coherence, perceived meaning of the disease, demographic variables, and patients' preferences for decision-making
		high school educated (50%), Income not reported			

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Study	Patient	Method	Outcome	Results
purpose	population		measures	
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To examine global meaning (ie the belief that life has purpose and	N= 85 patients who underwent BMT for the treatment of acute or chronic leukemia	Cross-sectional, correlational Convenience sample recruited from list of all	Global meaning (Personal Meaning Index of the LAP-R); Global psychological	- Global meaning was inversely related to global and BMT-related psychological distress, depression, anxiety, numbing/ avoidance and
coherence) and psychological adjustment in survivors of bone marrow transplant (BMT)	N= 42 men N= 43 women Age: Range: 17-59 yrs ; Mean: 40 yrs Types of cancer 60 % breast 20% prostate 19% other Time since BMT: Range: 6 mths – 11 yrs ; Mean: 4 yrs Education: 67% with college degree Majority of patients were Caucasian (75%), married (77%), and high SES (46% with annual household income over \$50 000)	BMT survivors (1984-1994) at a major cancer center; 27% refusal rate. Conducted as part of a larger study investigating psychological adjustment and quality of life in BMT survivors Telephone interviews	distress (BSI- GSI); BMT- related psychological distress (PTSD- civilian checklist); quality of life (MOS-SF-36); physical functioning (MOS-SF-36); number of days hospitalized; number of rehospitalizations after discharge	hyper arousal - Global meaning was positively related to mental health dimension of quality of life and vitality - Having a partner or significant other was associated with an increased sense of global meaning - The longer the time since BMT, the less one has a sense of global meaning
To test a brief measure of meaning in illness and to link the ascription of meaning to psychosocial	Cross-sectional N= 1012 patients with breast cancer Mean age: 58 yrs Majority of patients were	Cross-sectional survey Consecutive sample scheduled for annual visits at tertiary and	Meaning of illness; Depression (BDI); Anxiety – State/trait (Speilberger) quality of life	 Most frequently chosen meanings at diagnosis: challenge 57% and value 28% Women who were younger or with late stage disease or of a different cultural group than
a follow-up study three years later	had at least high school education (57%), and Caucasian Not reported : income Follow-up study N=205 patients (20% of original sample) Mean age: 60 yrs Majority of patients were married (69%), had at least high school education (64%)	oncology clinics 15.4 % refusal rate (cross- sectional sample) ; 12.4% of the 278 eligible women refused to participate in follow-up study. Women were asked to select from Lipowski's 8 meanings of illness that best described how they currently felt about their breast cancer		likely to ascribe negative meanings - Majority of women maintained a positive view at follow-up 3 years later (79%) - Women who rated cancer positively at diagnosis had less anxiety at follow-up than women who initially gave negative ratings
	Study purpose To examine global meaning (ie the belief that life has purpose and coherence) and psychological adjustment in survivors of bone marrow transplant (BMT) To test a brief measure of meaning in illness and to link the ascription of psychosocial functioning in a follow-up study three years later	Study purposePatient populationTo examine global meaning (ie the belief that life has aud ocherence) and adjustment in survivors of bone marrow transplant (BMT)N= 85 patients who underwent BMT for the treatment of acute or chronic leukemiaN= 42 men N= 43 women adjustment in survivors of bone marrow transplant (BMT)N= 42 men N= 43 women adge: Range: 17-59 yrs ; Mean: 40 yrsTypes of cancer 60 % breast 20% prostate 19% otherTime since BMT: Range: 6 mths - 11 yrs ; Mean: 4 yrsEducation: 67% with college degree Majority of patients were Caucasian (75%), married (77%), and high SES (46% with annual household income over \$50 000)To test a brief meaning in illness and to link the ascription of meaning to ysudy three years laterCross-sectional N= 1012 patients were Caucasian Not reported : incomeTo test a brief meaning to psychosocial functioning in a follow-up study three years laterCross-sectional N= 1012 patients were follow-up study N=205 patients (20% of original sample)Majority of patients were married (67%), had at least high school education (64%)	Study purposePatient populationMethodTo examine global meaning (ie the belief that life has purpose and coherence) and mswivors of bone marow transplant (BMT)N= 85 patients who underwent leukemiaCross-sectional, correlationalN= 42 men sychological adjustment in survivors of bone marow transplant (BMT)N= 42 men N= 43 women Age: Types of cancer 60% breast 20% prostate 19% otherConducted as part of a larger study investigating psychological adjustment and quality of life in BMT survivorsTo test a brief meaning in illness and to link the ascription of reasing to sychosocial in a follow-up study three years laterCross-sectional N= 1012 patients with breast cancer or \$50 000)Cross-sectional surveyTo test a brief meaning in a follow-up study three years laterCross-sectional Najority of patients were Caucasian (75%), married (77%), and high SES (46% with annual household income over \$50 000)Cross-sectional surveyTo test a brief meaning in a follow-up study three years laterCross-sectional Najority of patients were married (67%), and Caucasian (57%), and Caucasian (57%), and Caucasian (64%)Cross-sectional sample)N=205 patients (64%)N=205 patients eligible women refused to patients were married (69%), had at least high school education (64%)Neen age: 60 yrs Had at least high school education (64%)	Study purposePatient populationMethodOutcome measuresTo examine global meaning (ic the belief that life has purpose and coherence)N= 85 patients who underwent BMT for the treatment of acute or chronic leukemiaCross-sectional, correlationalGlobal meaning (Personal Meaning Index of the LAP-R); Globaland psychological adjustment in survivors of transplant (BMT)N= 42 men N= 43 womenConvenience sample recruited from list of all BMT survivors (1984-1994) at a ajostment and adjustment and global married (19%) other transplant (BMT)Global meaning (Personal Meaning Index to the LAP-R); Global married (17%), and high SES (46% with annual household income over \$50 000)Cross-sectional adjustment and adjustment and adjustment and adjustment and adjustment and hospitalized; number of days hospitalized; number of fays hospitalized; number of fays hospitalized; numa



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Author	Study	Patient	Methoa	Outcome	Results
Country	purpose	population		measures	
Schnoll, Knowles & Harlow (2002) United States	To examine the demographic, clinical, and psychosocial correlates of adjustment among cancer survivors	N=109 cancer survivors defined as "currently free of disease and not receiving any treatment" N= 26 men N= 83 women Mean age: 60.3 yrs Types of cancer 60 % breast 20% prostate 19% other Mean time since diagnosis: 61 mths Majority of patients were Caucasian (99%), and married (71%), mean of 13 yrs education	Cross-sectional, correlational Convenience sample from local hospital and American Cancer Society; 56% refusal rate Questionnaires were mailed.	Psychosocial adjustment (PAIS); Meaning in life (PIL); Optimism (LOT); Coping strategies (COPE); Social support (ISEL)	 A higher meaning in life was correlated with high psychosocial adjustment meaning in life was inversely correlated with avoidant coping However, meaning in life was not a significant predictor of adjustment in the prediction model Time since diagnosis was unrelated to psychosocial adjustment

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Study**	Sampling Procedure Random Convenience Or Consecutive		Refusal Reasons Rate Reported fo Reported (%) Subject Loss		
*Linn et al. (1982)	X		x	x	
Baider & de Nour (1986)		x	x		
Lewis (1989)		x			
Coward (1991)		x			
Barkwell (1991)		x			
Thompson & Pitts (1993)		x	x	x	
Taylor (1993)		x			
Mullen, Smith & Hill (1993)		x	x		
Dirksen (1995)		x			
Post-White et al. (1996)		x	x	x	
Luker et al.(1996)	x				
Chin-A-Loy & Fernsler (1998)		x	x		
Moadel et al.(1999)		x	x	x	
Vickberg et al. (2000)		x	x		
Ramfelt, Langius, Bjorvell, & Nordstrom (2000)		x	x	x	
Vickberg et al. (2001)		x	x	x	
*Degner et al. (2003)	x		x		
Schnoll, Knowles, & Harlow (2002)		x	x	x	
*Tomich & Helgeson (2002)	x		x		
Lechner et al. (2003)		x	x	x	
*Smith et al. (1993)	x		x		
TOTAL (out of 21) (% of studies)	5 (24%)	16 (76%)	15 (71%)	8 (38%)	

Appendix A3. Assessment of selection and attrition bias in quantitative studies (n=21)



Study	Commla	1 ~~~	Tumo of	Time	Marital	Ethnicity	Educatio
Study	Sample	Age	I ype of	line	Status		Educatio
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					(2)		
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(1990)	10 male						(N-1)
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Steeves	6 male	20 -46,	Leukemia		Married	NK	NK
(1992)		NK			(2)	а -	
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Carter (1002)	25	40-78,	Breast	5-26 yrs	(19)	90	13 - 10
(1993)	iemale	50			(18)		yrs of
							Iormal
							r (56%)
Tife	22	21.74	ND	ND	A 11	100	"(10%)
(1004)	22 formala	51-74,	INK		All	100	high
(1994)		54					mgn
	10 male						school
							n"
Mathews	26	30_83	Breast	NR	NR	Black	"Lower
et al	female	NP	Dicast			Women	educated
(1004)	Temate	INIX				from	"
(1994)						North	
						Fast	
						Californi	
						a	
Nelson	9	38-69.	Breast	2-6 yrs	NR	78	2-6 vrs
(1996)	female	Median					post-
(1))))	Terrare	=50					secondar
							y
Thibode	45	29 - 75.	Breast	3-31 yrs	NR	NR	NR
au &	female	NR		,			
MacRae							
(1997)							
Pelusi	8	34-70,	Breast	2-15 yrs	Married	75	NR
(1997)	female	55			(6)		
Mahon	13	26-72,	Breast (6)	15-134	NR	75	NR
&	female	54	Leukemia	months		African	
Casperso	7 male		(4)			American	
n (1997)			Other (10)			(25)	
Thomas	12	30-90,	NR	NR	NR	NR	NR
& Retsas	female	55					
ce recebus							
(1999)	7 male						

Appendix A4. Summary of demographics provided in qualitative studies (n=23)

Utley	8	65-76,	Breast	5.5–29	Widowed	100	High
(1999)	female	NR		yrs	(6)		school
Taylor	24	39-70,	Breast	2–27	NR	58	9-20 yrs
(2000)	female	52		months		African	
						American	
						(42)	
Bolmsjo	7	47-84,	Mixed	NR	NR	NR	NR
(2000)	female	NR					
	3 male						
Landmar	10	39-69,	Breast	4-19	Married	100	NR
k, et al.	female	51		months	(7)		
(2001)							
Halstead	10	45-70,	Breast (8)	3 months	Married	100	High
& Hull	female	NR	NonHodgki	to 5 years	(6)		school
(2001)			(1) Ovarian				(100%)
			(1) (1)				
Ramfelt,	27	34-83,	Colorectal	NR	Married	NR	High
et al.	female	68			(33)		school
(2002)	25 male						(77%)
Bowes,	9	36-70,	Ovarian	NR	Married	100	NR
et al.	female	56			(8)		
(2002)							
Olsson,	4	52-84,	Colorectal	NR	NR	NR	NR
et al.	female	NR					
Richer &	o maie	44-69	Breast	NR	Married	90	NR
Ezer	female	56	Dicust		(8)	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	
(2002)							
Ferrell,	All	NR	Ovarian	NR	NR	NR	NR
(2003)	N = NR						
Albaugh	5	44-74,	Breast (2)	"At least 1	NR	NR	NR
(2003)	female	61	Colorectal	month			
	2 male		(1)	prior "			
			Prostate (1) Other (3)				
Lam &	17	30-65,	Breast	6-8	Married	Chinese	NR
Fielding	female	46		months	(15)	(100)	
(2003)							

NR: Not reported



Mppc	<i>nam 115.</i> D	unning c	i ucinogi upi	ics provide	a m quamu	ante staat	05 (11 21)
Study	Sample Size and Gender	Age (yrs) (Range, Mean, SD)	Type of cancer (n)	Time since diagnosis	Marital Status (n)	Ethnicity (%) Caucasian unless otherwise noted	Educatio n
Linn, et al. (1982)	120 male	45-77 (58, 8)	Lung cancer (65) Colon, stomach, pancreas, other (55)	NR	"Over half were married"	88	NR
Baider & de Nour (1986)	30 female	Range NR Moslem (47, 5) Jewish (48, 6)	Breast	Moslem: M= 29months Jewish : M= 19 months	Married (5)	100	Moslem: M=6 yrs, SD=5yrs Jewish: M=13 yrs, SD=4
Lewis (1989)	35 female 21 male	21-79 (54, 13)	Breast (14), lung (13), ovarian (6), other (19)	"2/3 of patients were diagnosed within a year of study"	"Majority were married"	NR	NR
Barkwell (1991)	100 female	26-81 (61, 12)	NR	NR	NR	NR	NR
Coward (1991)	107 female	29-86 (61, 14)	Breast	NR	Married (71)	98	14 years
Smith et al (1993)	59 female 57 male	18-83 (53; 15)	Breast (21) Colon (21) Leukemia (14) Other (47)	Range: 1 mth to 15 yrs	Married (75)	82	NR
Taylor (1993)	45 female 29 male	20-89 (NR)	Breast (31) colorectal (12) non-solid tumors (14) other (17)	<2 -21 months since recurrence	Married (40)	60	16 years (84%)
Mullen, et al. (1993)	24 female 18 male	31- 75 (57,NR)	NR	<6 mths (9) 6-12 mths (16) > 1 yr (17)	Married (42)	NR	NR
Thompson & Pitts (1993)	53 female 26 male	31– 82 (56,NR)	Breast (33), colorectal (13), prostate (10), other (23)	Median = 18 months	Married (79)	100	M= 1-2 years college
Dirksen (1995)	19 female 12 male	25-83 (55,NR)	Malignant melanoma	9 years (5- 20 years)	Married (19)	100	College (45%)

Appendix A5. Summary of demographics provided in quantitative studies (n=21)

Luker et	105	NR	Breast	M=2.5	NR	NR	NR
al. (1996)	female			weeks			
Post- White et al. (1996)	13 female 19 male	29-74 (47,NR)	Leukemia (17) Solid tumors (11) Other (4)	0-108 months M=22 months	NR	90	At least college (97%)
Chin-A- Loy & Fernsler (1998)	23 male	61-84 (69, 6)	Prostate	2 mths- 11 yrs M= 3 years	Married (18)	83	At least college (65%)
Moadel et al. (1999)	145 female 98 male	18-85 (56, 14)	Breast (47) Solid tumors (33), Hematologic (78)	1 month – 22 years M=3 years	Married (131)	48	At least high school (39%)
Ramfelt et al. (2000)	45 female 41 male	34-84 (70, 10)	Colon (58) Rectal (28)	NR	Married (55)	100	At least high school (50%)
Vickberg et al. (2000)	61 female	30- 81 (59, 11)	Breast	2 – 15 years M=7.4, SD=3.6yrs	Married (31)	80	At least college (70%)
Vickberg et al. (2001)	43 female	17 – 59 (40,NR)	Leukemia	4.6 – 11 years since BMT	Married (33)	75	At least college (82%)
Schnoll, et al. (2002)	83 female 26 male	NR (60, 11)	Breast (65), prostate (22) other (31)	M= 61 months, SD=69 months	Married (77)	99	M =13 yrs
Tomich, & Helgeson (2002)	164 female	33-81 (54,NR)	Breast	5 ½ yrs	NR	95	At least college (63%)
Degner, et al. (2003)	1012 female	NR (58,NR)	Breast	NR	Married (68)	100	At least high school (57%)
Lechner et al. (2003)	59 female 24 male	34 - 85 (63, NR)	Breast (28), colorectal (16), lung (7), other (32)	0-172 months M=39mth s, SD=41	Married (55)	90	College training (68%)

NR: Not reported

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Appendix A6. Major findings extracted from studies in conceptual review

Global Meaning

Definition: Existential beliefs that provide an orderly framework to a) understand cancer against the backdrop of life experiences and future expectations, and b) create a sense of purpose in life.

Appraised Meaning

Definition: The perception of threat or challenge associated with the experience of cancer based on the extent to which valued life goals are affected.

Heightened awareness of one's mortality Potential growth-enhancing aspects of cancer

Search for Meaning

Definition: Cognitive coping strategies aimed at reducing the discrepancy between the appraised meaning and previously held global meaning.

Speculation about	Decis
etiology and	loss, v
impact of cancer	and

Decision to accept loss, vulnerability and uncertainty Reprioritization of values

Decision to focus on life, not cancer

Meaning as Outcome

Definition: The product of a successful search for meaning. May include philosophical changes, perception of personal growth, positive outcomes, enhanced social resources.

Discovering a sense of	Discovering a (re)newed	Becoming more
fulfillment despite life's	commitment to oneself	compassionate towards
uncertainty		others

Appendix B. Information to Accompany Pilot Study

Author Country Grade	Study Purpose	Patient Population	Method	Outcome Measures	Results
Bottomley et al, 1996 United States	To evaluate the degree of benefit of a cognitive – behavioural group (CBT) intervention versus a social support (SS) control group 1 and a standard –care non- intervention (NI) control group 2 for distressed cancer patients	N=31 patients with high psychological distress (HADS, MAC) I: Female 100%; Mean age 50 yrs; Married 56%; Breast cancer 67% C1: Female 63%; Mean age52 yrs; Married 63%; Breast cancer 50% C2: Female 71%; Mean age 57 yrs; Married 71%; Breast cancer 28%	Pretest posttest Nonequivalent Groups; distressed patients consecutively allocated to groups CBT (n=9) : Eight 90 min sessions focusing on the personal meaning of cancer SS (n=8): 8 Eight sessions; discussions guided by an agenda NI (n= 14): no psychological intervention Assessments: Baseline,post- therapy,3 month follow-up	Anxiety, Depression (HADS); coping style (MAC); Bottomley Social Support Cancer Scale	 Significantly less anxiety and greater fighting spirit demonstrated for CBT group immediately after, but effects did not persist after 3 months Control group significantly increased in fatalism, helplessness, anxiety and depression immediately after
De vries et al, 1997 The Netherland s	To investigate the effects of an experiential -existential psychosocial counselling program on the progression of advanced cancer	N= 35 cancer patients who were no longer eligible for curative medical treatment 54% female, mean age 55 years (range 27 - 73 years), various cancer types	One group pretest- posttest; 11% refusal rate All patients received individual psychosocial counseling (1.5 – 2 hours per week for 12 weeks) in addition to fortnightly group meetings. Individual sessions encouraged patients to become aware of and restore incongruities between internal schemata and actual feelings, as well as discovering and living a meanineful life	Purpose in life (PIL); depression (Zung); loneliness Inventory, control (CLOC); natural killer cell activity (NKCA); semi- structured interviews assesses level of autonomy, social relationships, apprehension of / outlook on, and purpose in life. Assessment : Baseline, follow-up after 6 and 12 sessions	 46% attrition due to withdrawal, physical deterioration or early death Tumor progression occurred in 86% of patients After the 12th session, there was a small significant increase in purpose in life There was no relationship between NKCA and psychosocial variables Depression was positively related to loneliness and negatively to purpose in life The more patients saw a purpose in life, the less they saw God as determining their illness

Appendix B1. Review of psychological interventions with a meaning-oriented component for cancer patients

Author Country Grade	Study Purpose	Patient Population	Method	Outcome Measures	Results
Moynihan et al. (1998) UK	To determine the efficacy of APT in patients with testicular cancer	N= 73 patients post-surgery for testicular cancer I: 85% between 18-39 yrs, 63% married, 48% stage I disease C: 73% between 18-39 yrs, 65% married, 71% stage I disease	RCT, convenience sample recruited from 193 eligible patients between 1988-1990. 16% refusal rate I (n= 73): patients received APT (see Greer, S., Moorey, S., & Baruch, J. (1991) C (n=81): patients received standard medical care	Anxiety and depression (HADS); adjustment to cancer (MAC); psychological adjustment (PAIS); symptom (Rotterdam checklist); emotional concealment subscale of the Brannon masculinity scale; sexual adjustment (Rieker)	 60 % of eligible men refused to participate, of which 44% provided assessments non-participants had less psychological and physical morbidity (eg. stage 1 disease, not receiving further treatment) participants had more psychosocial dysfunction at baseline no significant differences in psychosocial variables between experimental and control group
				Assessment: Baseline, follow-up at 2, 4, and 12 months	
Classen et al, 2001 United States	To test the efficacy of supportive- expressive group therapy on reducing mood disturbance, and traumatic symptoms in women with metastatic breast cancer	N= 125 women with metastatic or recurrent breast cancer I: mean age 53 yrs (range 33 – 73 yrs); 91% Caucasian ; 62% married C: mean age 54 yrs (range 33 – 80 yrs); 80% Caucasian ; 52% married	RCT; adaptive randomization biased coin-design method to ensure comparability of medical status in both groups; 7 % refusal rate I (n=58): In addition to educational materials, patients received 1 year of a weekly (90 min session) existentially based group therapy.	Mood disturbance (POMS); Trauma symptoms (avoidance and intrusion) (IES)	- Women in the treatment group showed significantly greater declines in both mood disturbance and trauma symptoms than those in the control group when follow up assessments undertaken within a year of the patient's death were excluded from the analysis
			C (n=44) patients received only educational materials		

Author	Study Purpose	Patient	Method	Outcome	Results
Grade		Population		Measures	
Spiegel, Bloom, & Yalom, 1981 Speigel et al, 1989 United States	To evaluate the efficacy of a psychological support group for women with metastatic breast cancer	N= 86 women I: Mean age 54 yrs; Married (57%); Mean time since diagnosis 54 months C: Mean age 55 yrs; Married (70%); Mean time since diagnosis 68 months Treatment group was of a significantly higher social status than control group	RCT; convenience sample referred by oncologists; 17% of 109 eligible patients refused I (n=34): Group met weekly for 90 min. over 1 year. Informal discussions focused on death and dying, communication with doctors, family, friends, living as richly as possible in the face of a terminal illness, how to extract meaning from tragedy by helping others. C (n=24): did not receive group meetings Assessments at 4 month intervals for l year	Perceived control over one's health (HLC); Affective response (POMS); self- esteem (Janis- Field Scale); Maladaptive coping response; Phobias; denial Only 52% of sample completed all 4 administrations of the measures.	 Intervention group reported less tension, depression, fatigue, confusion, fewer maladaptive coping responses and phobias, and more vigor. Survival time for intervention group was significantly longer compared with controls
Linn, M.W., Linn, B.S. & Harris, R. (1982) United States	To assess the impact of psychosocial counseling for late stage cancer patients	N=120 men with Stage IV cancer expected to live more than 3 months but less than a year I: 53% lung cancer C: 55% lung cancer "No significant differences between groups on personal characteristics, diagnosis, treatment, or degree of impairment" Mean age 58yrs (Range 45 – 77 yrs)	RCT; convenience sample of patients hospitalized from 1976-79 in a Veteran's Administration hospital 15% refusal rate . I (n= 62):received routine medical care and individual counseling comprised of unstructured open discussions aimed at reducing denial, maintaining hope, encouragement to continue meaningful activities. Duration and frequency of meetings not reported. C (n=58) received only routine medical care. Follow-up at 1, 3, 6, 9, and 12 months	Depression (POMS); Self- esteem (Sherwood), Life satisfaction (Cantril); Alienation(Sro le);Locus of control (Rotter); Functional status(Rapid Disability Rating Scale); Survival (# days from entry into study until death, and from time of diagnosis until death)	 Intervention group improved in depression (3 mths) life satisfaction (3,6,9,12 mths) self-esteem (3,6,9,12 mths) alienation (3,6,9,12 mths) locus of control (9, 12 mths) no significant differences at 1 month no significant differences in functional status or survival

Appendix B2- Questi	onnaire packet for pilot stud	y participants
Date :	Sub	ject #:
PERSC	NAL INFORMATION SHEET	
PLEASE DO NO	TWRITE YOUR NAME ON THIS	FORM
Yes, I have decided to partition	cipate in this study	
□ No, I have decided not to p	articipate in this study becau	se
Age :		
Sex :		
Diagnosis :		
Marital Status:	Divorced	Single
Married	Divorced	Single Widowed
Number of dependents :		
Who do you live with?		
Highest Level of Education Comp	leted.	
Elementary	High School	Graduate
CEGEP / Vocational	Baccalaureate	
Before this illness, I was :	Studening full times	Hamamaltan
Employed full-time Employed part time*	Studying null-time	Homemaker
Employed part-time	Studying part-time	Kellieu Unemployed
* If employed, what type of wo	rk were you doing?	
Yearly income:		
Less than \$20 000		
□ Between \$20 000 - \$40 000		
Between \$40 000 - \$80 000		
Between \$80 000 - \$ 100 000		
More than \$100 000		
What religion do you practice?		
	~ · · · · · ·	C 1. 1
lave you received counseling from	n a protessional to deal with	your feelings about y
	_ 1E5	INU ORI

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and the second second

DEMOGRAPHIC DATA FORM

Da	te :/	_/
Ag	ge:	Sex :
	arital Status: Married Common-law Divorced Separated Single Widowed	
Nu	mber of dependents : _	Who do you live with?
	vel of education: Elementary School CEGEP / Vocational High School Baccalaureate Graduate	
	fore this illness, I was : Employed full-time Employed part-time Unemployed Housewife/husband Studying full-time Studying part-time Retired	If employed, what type of work were you doing?
Ye □ □ □	early income: Less than \$20 000 \$20 000 - \$40 000 \$40 000 - \$80 000 \$80 000 - \$ 100 000 More than \$100 000	
W	hat religion do you prac	etice?

Have you received counseling from a professional to deal with your feelings about cancer?

• YES

į.

• NO

Chart Review

Diagnosis :

Stage :

Phase in illness trajectory :

Past Medical Hx and Tx:

Family Hx:

Medications :

DATE:

Hospital Anxiety and Depression Scale

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item and circle the reply which comes closest to how you have been feeling *in the past week*.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. I feel tense or "wound up":

Most of the time A lot of the time From time to time, occasionally Not at all

2. I still enjoy the things I used to enjoy:

Definitely as much Not quite as much Only a little Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all

DATE: _____

I can laugh and see the funny side of things:

As much as I always could Not quite so much now Definitely not so much now Not at all

4. Worrying thoughts go through my mind:

A great deal of the time A lot of the time From time to time but not too often Only occasionally

5. I feel cheerful:

- Not at all Not often Sometimes Most of the time
- 6. I can sit at ease and feel relaxed:
 - Definitely Usually Not often Not at all

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DATE: _____

7. I feel as if I am slowed down:

Nearly all the time Very often Sometimes Not at all

- 8. I get a sort of frightened feeling like "butterflies" in the stomach:
 - Not at all Occasionally Quite often Very often
- 9. I have lost interest in my appearance:

Definitely I don't take as much care as I should I may not take quite as much care I take just as much care as ever

10. I feel restless as if I have to be on the move:

Very much indeed Quite a lot Not very much Not at all



DATE: _____

11. I look forward with enjoyment to things:

As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all

12. I get sudden feelings of panic:

Very often indeed Quite often Not very often Not at all

13. I can enjoy a good book or radio or TV programme:

Often Sometimes Not often Very seldom

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS. Thank you.

4

DATE: _____

Psychosocial Adjustment to Illness Scale

INSTRUCTIONS:

The present form contains a set of questions concerning the effects that your recent illness has had on your personal relationships. In answering each question, please put a mark (X) in the bracket alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience you have had.

The time we would like you to refer to is the past 7 days, including today. Answer each question in terms of what your experience has been like during this time.

Section I : Health Care Orientation

- 1. Which of the following statements best describes your usual attitude about taking care of your health?
 - () I am very concerned and pay close attention to my personal health.
 - () Most of the time I pay attention to my health care needs.
 - () Usually, I try to take care of health matters but sometimes I just don't get around to it.
 - () Health care is something that I just don't worry to much about.
- 2. Your present illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.
 - () I do things pretty much the way I always have done them and I don't worry or take any special considerations for my illness.
 - () I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
 - () I do a pretty good job taking care of my present illness.
 - () I play close attention to all the needs of my present illness and do everything I can to take care of myself.

- 3. In general, how do you feel about the quality of medical care available and the doctors who provide it?
 - () Medical care has never been better, and the doctors who give it are doing an excellent job.
 - () The quality of medical care available is very good, but there are some areas that could stand improvement.
 - () Medical care and doctors are just not of the same quality they once were.
 - () I don't have much faith in doctors and medical care today.
- 4. During your present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?
 - () I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.
 - () I have not been impressed with the treatment I have received, but think it is probably the best they can do.
 - () The treatment have been pretty good on the whole, although there have been a few problems.
 - () The treatment and the treatment staff have been excellent.
- 5. When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.
 - () I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
 - () My illness has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
 - () My illness has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
 - () I feel worn out and very weak from my illness and there are times when I don't know if I am really ever going to be able to overcome it.



- 6. Being ill can be a confusing experience, and some patients feel that they do not receive enough information and detail from their doctors and the medical staff about their illnesses. Please select a statement below which best describes your feeling about this matter.
 - () My doctor and the medical staff have told me very little about my illness even though I have asked more than once.
 - () I do have some information about my illness but I feel I would like to know more.
 - () I have a pretty fair understanding about my illness and feel that if I want to know more I can always get the information.
 - () I have been given a very complete picture of my illness and my doctor and the medical staff have given me all the details I wish to have.
- 7. In an illness such as yours, people have different ideas about their treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your treatment.
 - () I believe my doctors and medical staff are quite able to direct my treatment and feel it is the best treatment I could receive.
 - () I have trust in my doctor's direction of my treatment; however, sometimes I have doubts about it.
 - () I don't like certain parts of my treatment which are very unpleasant, but my doctors tell me I should go through it anyway.
 - () In many ways I think my treatment is worse than the illness, and I am not sure it is worth going through it.
- 8. In an illness such as yours patients are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.
 - () I have been told almost nothing about my treatments and feel left out about it.
 - () I have some information about my treatments but not as much as I would like to have.
 - () My information concerning treatment is pretty complete , but there are one or two things I still want to know.
 - () I feel my information concerning treatment is very complete and up-to-date.

Section 2: Vocational Environment

- 9. Has your illness interfered with your ability to do your job (schoolwork)?
 - () No problems with my job.
 -) Some problems, but only minor ones.
 - () Some serious problems.
 -) Illness has totally prevented my from doing my job.

10. How well do you physically perform your job (studies) now?

- () Poorly.
-) Not too well.
- () Adequately.
- () Very well.

11. During the past 30 days, have you lost any time at work (school) due to your illness?

- () 3 days or less.
-) 1 week.
-) 2 week.
-) More than 2 weeks.

12. Is your job (school) as important to you now as it was before your illness?

- () Little or no importance to me now.
- () A lot less important.
- () Slightly less important.
- () Equal or greater importance than before.
- 13. Have you had to change your goals concerning your job (education) as a result of your illness?
 - () My goals are unchanged.
 - () There has been a slight change in my goals.
 - () My goals have changed quite a bit.
 - () I have changed my goals completely.
- 14. Have you noticed any increase in problems with your co-workers (students, neighbors) since your illness?
 - () A great increase in problems.
 - () A moderate increase in problems.
 - () A slight increase in problems.
 - () None.

Section 3: Domestic Environment

15. How would you describe your relationship with your wife / husband since your illness?

- () Good.
- () Fair.
- () Poor.
- () Very poor.

- 16. How would you describe your general relationships with the other people you live with (e.g. children, parents, aunts, etc.)?
 - () Very poor.
 -) Poor.
 - () Fair.
 - () Good.

17. How much has your illness interfered with your work and duties around the house?

- () Not at all.
- () Slight problems, easily overcome.
- () Moderate problems, not all of which can be overcome.
-) Severe difficulties with household duties.
- 18. In those areas your illness has caused problems with your household work, how has the family shifted duties to help you out?
 - () The family has not been able to help out at all.
 -) The family has tried to help but many things are left undone.
 - () The family has done well except for a few minor things.
 - () No problems.
- 19. Has your illness resulted in a decrease in communication between you and members of your family?
 - () No decrease in communication.
 - () A slight decrease in communication.
 - () Communication has decreased, and I feel somewhat withdrawn from them.
 - () Communication has decreased a lot, and I feel very alone.
- 20. Some people with an illness like yours feel they need help from other people (friends, neighbors, family, etc) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?
 - () I really need help but seldom is anyone around to help.
 - () I get some help, but I can't count on it all the time.
 - () I don't get all the help I need all of the time, but most of the time help is there when I need it.
 - () I don't feel I need such help, or the help I need is available from my family or friends.



- 21. Have you experienced any physical disability with your illness?
 - () No physical disability.
 - () A slight physical disability.
 - () A moderate physical disability.
 - () A severe physical disability.
- 22. An illness such as yours can sometimes cause a drain on the family's finances. Are you having any difficulties meeting the financial demands of your illness?
 - () Severe financial hardship.
 - () Moderate financial problems.
 - () A slight financial drain.
 - () No money problems.

Section 4: Personal Relationships

- 23. Sometimes having an illness can cause problems in a relationship. Has your illness led to any problems with your wife/ husband?
 - () There has been no change in our relationship.
 - () We are a little less close since my illness.
 - () We are definitely less close since my illness.
 -) We have had serious problems or a break in our relationship since my illness.
- 24. Sometimes when people are ill, they report a loss of interest in sexual activities. Have you experienced less sexual interest since your illness?
 - () Absolutely no sexual interest since illness.
 -) A marked loss of sexual interest.
 -) A slight loss of sexual interest.
 -) No loss of sexual interest.

(

(

- 25. Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?
 - () No decrease in sexual activities.
 - () Slight decrease in sexual activities.
 - () Marked decrease in sexual activities.
 - () Sexual activities have stopped.

- 26. Has there been any change in the pleasure or satisfaction you normally experience from sex?
 - () Sexual pleasure and satisfaction have stopped.
 - () A marked loss of sexual pleasure or satisfaction.
 - () A slight loss of sexual pleasure or satisfaction.
 - () No change in sexual satisfaction.
- 27. Sometimes an illness will cause an interference in a person's ability to perform sexual activities even though they are still interested in sex. Has this happened to you, and if so, to what degree?
 - () No change in my ability to have sex.
 - () Slight problems with my sexual performance.
 - () Constant sexual performance problems.
 - () Totally unable to perform sexually.
- 28. Sometimes an illness will interfere with a couples' normal sexual relationship and cause arguments between them. Have you and your partner had any arguments like this, and if so, to what degree?
 - () Constant arguments.
 - () Frequent arguments.
 - () Some arguments.
 - () No arguments.

Section 5: Extended Family Relationships

- 29. Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your illness?
 - () Contact is the same or greater since illness.
 - () Contact is slightly less.
 - () Contact is markedly less.
 - () No contact since illness.
- 30. Have you remained as interested in getting together with these members of your family since your illness?
 - () Little or no interest in getting together with them.
 - () Interest is a lot less than before.
 - () Interest is slightly less.
 - () Interest is the same or greater since illness.



- 31. Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
 -) I need no help, or they give me all the help I need. (
 -) Their help is enough, except for some minor things. (
 - () They give me some help but not enough.
 - They give me little or no help even though I need a great deal.)
- 32. Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your illness reduced such socializing?
 - Socializing with them has been pretty much eliminated. ()
 -) Socializing with them has been reduced significantly. (
 -) Socializing with them has been reduced somewhat. (
 - Little or no change socializing, or slight or no effect of illness.)
- 33. In general, how have you been getting along with these members of your family recently?
 -) Good.

 -) Fair.) Poor.) Very poor.

Section 6: Social Environment

- 34. Are you still as interested in your leisure time activities and hobbies are you were prior to your illness?
 -) Same level of interest as previously.

 -) Slightly less interest than before.
) Significantly less interest than before.
) Little or no interest remaining. (
- 35. How about actual participation? Are you still actively involved in doing those activities?
 -) Little or no participation at present.
 -) Participation reduced significantly. (
 - (
 -) Participation reduced slightly.) Participation remains unchanged.



- 36. Are you as interested in leisure time activities with your family (i.e. playing cards and games, taking trips, going swimming, etc) as you were prior to your illness?
 - Same level of interest as previously. (
 - Slightly less interest than before. ()
 - Significantly less interest than before. ()
 - Little or no interest remaining.)

37. Do you still participate in those activities to the same degree you once did?

-) Little or no participation at present. (
-) Participation reduced significantly.
) Participation reduced slightly.
) Participation remains unchanged. (
- (
- 38. Have you maintained your interest in social activities since your illness (e.g. social clubs, church groups, going to the movies, etc)?
 - Same level of interest as previously.)
 -) Slightly less interest than before. (
 -) Significantly less interest than before. (
 - Little or no interest remaining.)

39. How about participation? Do you still go out with your friends and do those things?

-) Little or no participation at present. (
-) Participation reduced significantly.
-) Participation reduced slightly.
-) Participation remains unchanged.

Section 7: Psychological Distress

40. During the past 7 days, have you felt afraid, tense, nervous, or anxious?

-) Not at all.
-) A little bit.
-) Quite a bit.
- Extremely.
- 41. During the past 7 days, have you felt sad, depressed, lost interest in things, or felt hopeless?
 -) Extremely.
 -) Quite a bit.
 -) A little bit.
 -) Not at all.

- 42. During the past 7 days, have you felt angry, irritable, or had difficulty controlling your temper?
 - () Not at all.
 - () A little bit.
 - () Quite a bit.
 - () Extremely.
- 43. During the past 7 days, have you blamed yourself for things, felt guilty, or felt like you have let people down?
 - () Extremely.
 - () Quite a bit.
 - () A little bit.
 - () Not at all.
- 44. During the past 7 days, have you worried much about your illness or other matters?
 - () Not at all.
 - () A little bit.
 - () Quite a bit.
 - () Extremely.
- 45. During the past 7 days, have you been feeling down on yourself or less valuable as a person?
 - () Extremely.
 - () Quite a bit.
 - () A little bit.
 - () Not at all.
- 46. During the past 7 days, have you been concerned that your illness has caused changes in the way you look that make you less attractive?
 - () Not at all.
 - () A little bit.
 - () Quite a bit.
 - () Extremely.



DATE: _____

Life Orientation Test

Using the scale below, write the appropriate letter in the box beside each statement. Please be as honest and accurate as you can be throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

I	A agree a lot	B I agree a little	C I neither agree or disagree	D I disagree a little	E I disagree a lot	
1.	In uncertain ti	mes, I usually expe	ect the best.		1.	
2.	It's easy for m	ne to relax.			2.	
3.	If something o	can go wrong for m	e, it will.		3.	
4.	I always look	on the bright side.			4.	
5.	. I'm always optimistic about my future.					
6.	. I enjoy my friends a lot.					
7.	It's important		7.			
8.	I hardly ever e	expect things to go	my way.		8.	
9.	Things never	work out the way I	want them to.		9.	
10.	I don't get up	set easily.			10	
11.	I'm a believe	r in the idea that "e	very cloud has a silver	lining".	11	
12.	I rarely count	on good things hap	opening to me.		12	

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS. Thank you. ÷

Subject	#:
DATE:	

Purpose in Life

For each of the following statements, circle the number that would be most nearly true for you. Note that the numbers always extend from one extreme feeling to its opposite kind of feeling. "Neutral" implies no judgment either way; try to use this rating as little as possible.

1. I am usually:

1 Completely bored	2	3	4 (neutral)	5	6	7 Exuberant; enthusiastic
2. Life	to me seen	ns:				
7	6	5	4	3	2	1
<i>Always</i> routine		(neu	tral)			Completely exciting
3. In li	fe I have:					
1 No goals or aims at all	2	3	4 (neutral)	5	6 Ver	7 Ty clear goals and aims
4. My	personal ex	sistence is:				
1 Utterly mea without pur	2 mingless pose	3	4 (neutral)	5	6 Ve and	7 ry purposeful 1 meaningful
5. Eve	ry day is :					
7	6	5	4	3	2	1
<i>Constantly</i> new			(neutral)			Exactly the same

6. If I could choose, I would:

1 2 Prefer never to have been born	3	4 (neutral)	5		6 7 Like nine more lives just like this one
7. After retiring	, I would:				
7 6 Do some of the exciting things I always wanted to de	5	4 (neutral)	3		2 1 Loaf completely the rest of my life
8. In achieving l	life goals, I have	:			
1 2 Made no progress whatever	3	4 (neutral)	5		6 7 Progressed to complete fulfillment
9. My life is:					
1 2 Empty, filled only with despair	3	4 (neutral)	5	e	6 7 Running over with exciting good things
10. If I should di	e today, I would	feel that my life h	as been:		
7 6 Very worthwhile	5	4 (neutral)	3	□2	1 Completely worthless
11. In thinking c	of my life, I :				
1 2 Often wonder why I exist	3	4 (neutral)	5		6 7 Always see a reason for my being here
12. As I view th	e world in relation	on to my life, the	world:		
1 2 Completely confuses me	3	4 (neutral) 2	5		6 7 Fits meaningfully with my life

13. I am a :

1 Very perso	2 irresponsible n	3	4 (neutral)	5	6 Very p	7 v responsible erson
14.	Concerning man's	s freedom	to make his own ch	oices, I belie	eve man is:	
7 Absol make	6 utely free to all life choices	5	4 (neutral)	3	2 Comp by 2	1 letely bound limitations of heredity and environment
15.	With regard to dea	th, I am:				
7 Prepa unafra	6 red and aid	5	4 (neutral)	3	2 Unp	1 repared and frightened
16.	With regard to suid	cide, I have	e:			
1 Thoug seriou	2 ght of it sly as a way out	3	4 (neutral)	5	6 New sec	7 ver given it a ond thought
17.	I regard my ability	to find a r	neaning, purpose, o	r mission in	life as:	
7 Very	6 great	5 (r	4 neutral)	3	2 Pr	1 actically none
18.	My life is:					
7 In my am in	6 hands and I control of it	5	4 (neutral)	3	2 Out o an	1 of my hands d controlled by external factors


19. Facing my daily tasks is:

7	6	5	4	3	2	1
A sou and s	arce of pleasure atisfaction	(ne	eutral)		bor	A painful and ing experience
20.	I have discovered:					
1 No m purpo	2 hission or ose in life	3	4 (neutral)	5	6 Cl and	7 ear cut goals l a satisfying life purpose

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS.

Thank you

Subject #: _____ Date: _____

Rosenberg Self-Esteem Scale

Here is a list of statements dealing with your general feelings about yourself. If you agree with the statement, circle A. If you strongly agree, circle SA. If you disagree, circle D. If you strongly disagree, circle SD.

		1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree	
1.	On the whole, I am satisfied with myself	f. SA	А	D	SD	
2.	At times, I think I am no good at all.	SA	A	D	SD	
3.	I feel that I have a number of good qualities.	SA	А	D	SD	
4.	I am able to do things as well as most other people.	SA	А	D	SD	
5.	I feel I do not have much to be proud of.	SA	А	D	SD	
6.	I certainly feel useless at times.	SA	A	D	SD	
7.	I feel that I am a person of worth, at least on an equal plane with others.	SA	А	D	SD	
8.	I wish I could have more respect for myself.	SA	А	D	SD	
9.	All in all, I am inclined to feel that I am a failure.	SA	Α	D	SD	
10.	I take a positive attitude toward myself.	SA	А	D	SD	

PLEASE CHECK THAT ALL QUESTIONS ARE ANSWERED. Thank you.

Karnoj	fsky Performance Status	s Scale
Condition	Performance status Per cent	Comments
A:	100	Normal. No complaints. No evidence of isease
ABLE TO CARRY ON NORMAL ACTIVITY AND TO WORK NO SPECIAL CARE IS NEEDED	90	Able to carry on normal activity. Minor signs or symptoms of disease.
	80	Normal activity with effort. Some signs or symptoms of disease.
B: unable to work.	70	Cares for self. Unable to carry on normal activity or to do active work.
ABLE TO LIVE AT HOME AND CARE FOR MOST PERSONAL NEEDS.	60	Requires occasional assistance, but is able to care for most of his needs
A VARYING DEGREE OF ASSISTANCE IS NEEDED.	50	Requires considerable assistance and frequent medical care.
C: UNABLE TO CARE FOR SELF.	40	Disabled. Requires special care and assistance.
REQUIRES EQUIVALENT OF INSTITUTIONAL OR HOSPITAL CARE. DISEASE MAY BE	30	Severely disabled. Hospitalization indicated, although death not imminent
PROGRESSING RAPIDLY.	20	Hospitalization necessary. Very sick, active supportive treatment necessary.
	10	Moribund. Fatal processes progressing rapidly.
	0	Dead.

Subject #: _____ Date: _____

Symptom Distress Scale

Instructions:

Below are 5 different numbered statements. Think about what each statement says, then place a circle around the one statement that most clearly indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number 1 indicates no problems and number 5 indicates the maximum amount of problems. Numbers 2 through 4 indicate you feel somewhere in between these two extremes. Please circle only one number for each statement.

Nausea (1)

1	2	3	4	5
I seldom feel any nausea at all	I am nauseous once in a while	I am often nauseous	I am usually nauseous	I suffer from nausea almost continually
Nausea (2)				
1	2	3	4	5
When I do have nausea, it is very mild	When I do have nausea, it is mildly distressing	When I have nausea, I feel n pretty sick	When I have ausea, I feel very sick	When I have nausea, I am as sick as I could possibly be
Appetite				P
1	2	3	4	5
I have my normal appetite	My appetite is usually, but not always, pretty good	I don't really enjoy my food like I used to	I have to force myself to eat my food	I cannot stand the thought of food
Insomnia				
1	2	3	4	5
I sleep as well as I always have	I have occasional spells of sleeplessness	I frequently have trouble getting to sleep and staying asleep	I have difficulty sleeping almost every night	It is almost impossible for me to get a decent night's sleep

Pain (1)

1 I almost never have pain	2 I have pain once in a while	3 I frequently have pain –several times a week	4 I am usually in some degree of pain	5 I am in some degree of pain almost constantly
Pain (2)				
1 When I do have pain, it is very mild	2 When I do have pain, it is mildly distressing	3 The pain I do have is usually fairly intense	4 The pain I have is usually very intense	5 The pain I have is almost unbearable
Fatigue				
l I am usually not at all	2 I am occasionally rather tired	3 There are frequently periods when I am quite tired	4 I am usually very tired	5 Most of the tired time, I feel exhausted
Bowel				
1 I have my normal bowel pattern	2 My bowel pattern occasionally causes me some discomfort	3 I frequently have discomfort from my present bowel pattern	4 I am usually in discomfort because of my present bowel pattern	5 My present bowel pattern has changed from what was normal for me

Concentration

	1	2	3	4	5
-	I have my normal ability to concentrate	I occasionally have trouble concentrating	I often have trouble concentrating	I usually have at least some difficulty concentrating	I just can't seem to concentrate at all
	Appearance				
	1 My appearance has basically not changed	2 My appearance has gotten a a little worse	3 My appearance is definitely worse than it used to be, but I am not greatly concerned about it	4 My appearance is definitely worse than it used to be, and I am a little concerned about it	5 My appearance has change drastically rom what it was
	Breathing				
	1	2	3	4	5
	I usually breathe normally	I occasionally have trouble breathing	I often have trouble breathing	I can hardly ever breathe as easily as I want	I almost always have severe trouble with my breathing
	Outlook				
	1 I am not fearful or worried	2 I am a little worried about things	3 I am quite worried, but unafraid	4 I am worried and a little frightened about things	5 I am worried and scared about things
	Cough				
	l I seldom cough	2 I have an occasional cough	3 I often cough	4 I often cough, and occasionally have severe coughing spells	5 I often have persistent and severe coughing spells

Subject #:	
DATE:	

The Life Experiences Schedule

Listed below are a number of events which sometimes bring about change in the lives of those who experience them and which necessitates social readjustment. Please check those events which you have experienced in the recent past and indicate the time period during which you have experienced each event.

Also, for each item checked below, please indicate the extent to which you viewed the event as having a positive or negative impact on your life at the time the event occurred. For example, a rating of -3 would indicate an extremely negative impact. A rating of 0 suggests no impact either positive or negative. A rating of +3 would indicate an extremely positive impact. Be sure that all check marks are directly across from the items they correspond to.

		0 to	7 mo to			
		бто	1 yr	-3-2-1	0	+1+2+3
1.	Marriage	бто	1 yr	-3-2-1	0	+1+2+3
2.	Detention in jail or comparable institution	6то	1 yr	-3-2-1	0	+1 +2+3
3.	Death of a spouse	бто	1 yr	-3-2-1	0	+1+2+3
4.	Major change in sleeping habits (much more or much less sleep)	бто	1 yr	-3-2-1	0	+1+2+3
5.	Death of close family member:					
	a. mother	6mo	1 yr	-3-2-1	0	+1+2+3
	b. father	6mo	1 yr	-3-2-1	0	+1+2+3
	c. brother	6mo	l yr	-3-2-1	0	+1+2+3
	d. sister	6mo	lyr	-3-2-1	0	+1+2+3
	e. grandmother	6mo	l yr	-3-2-1	. 0	+1+2+3
	I. grandiather	omo	1 yr	-3-2-1	0	+1+2+3
	g. other (specify)	01110	I yr	-3-2-1	U	T1T2T3



				Sub DA	ject #: TE:
	0 to 6mo	7 mo to 1 yr	-3-2-1	0	+1 +2 +3
 Major change in eating habits (much more or much less food intake) 	бто	1 yr	-3-2-1	0	+1+2 +3
7. Foreclosure on mortgage or loan	бто	1 yr	-3-2-1	0	+1+2 +3
8. Death of close friend	бто	1 yr	-3-2-1	0	+1 +2 +3
9. Outstanding personal achieveme	ent 6mo	1 yr	-3-2-1	0	+1 +2 +3
10. Minor law violations (traffic tio disturbing the peace, etc)	ckets,	1 vr	-3-2-1	0	+1 +2 +3
11. <i>Male</i> : wife / girlfriend's pregna	ancy 6mo	1 yr	-3-2-1	0	+1 +2 +3
12. Female: Pregnancy	6то	1 yr	-3-2-1	0	+1 +2 +3
 Changed work situation (differ work responsibility, major chain working conditions, workin etc.) 	ent ange g hours бто	, 1yr	-3-2-1	0	+1 +2 +3
14. New job	6mo	1 yr	-3-2-1	0	+1+2 +3

					Sub DA	ject #: TE:
		0 to 6mo	7 mo to 1yr	-3-2-1	0	+1 +2 +3
15.	Serious illness or injury of close family member:					
	 a. father b. mother c. sister d. brother e. grandfather f. grandmother g. spouse h. other (specify) 	6mo 6mo 6mo 6mo 6mo 6mo 6mo	lyr lyr lyr lyr lyr lyr lyr lyr	-3-2-1 -3-2-1 -3-2-1 -3-2-1 -3-2-1 -3-2-1 -3-2-1 -3-2-1	0 0 0 0 0 0 0 0	$\begin{array}{rrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrrr$
16.	Sexual difficulties	6mo	1 yr	-3-2-1	0	+1 +2 +3
17.	Trouble with employer (in danger of losing job, being suspended, demoted, etc)	бто	l yr	-3-2-1	0	+1 +2+3
18.	Trouble with in-laws	6mo	1 yr	-3-2-1	0	+1 +2+3
19.	Major change in financial status (a lot better off or a lot worse off)	6то	1yr	-3-2-1	0	+1 +2+3
20.	Major change in closeness of family members (increased or decreased closeness)	6то	1yr	-3-2-1	0	+1 +2 +3

					Subje DAT	ect #:
					DI	D
		0 to 6mo	7 mo to 1yr	-3-2-1	0	+1 +2 +3
	-					
21.	Gaining a new family member (through birth, adoption, family member moving in, etc)					
		6mo	1 yr	-3-2-1	0	+1 +2+3
22.	Change of residence	6mo	1yr	-3-2-1	0	+1 +2 +3
23.	Marital separation from mate (due to conflict)	6то	1yr	-3-2-1	0	+1+2+3
24.	Major change in church activities (increased or decreased attendance)	6mo	1 yr	-3-2-1	0	+1+2+3
25.	Marital reconciliation with mate	6mo	1 yr	-3-2-1	0	+1+2+3
26.	Major change in number of arguments with spouse (a lot more or a lot less arguments)	6mo	1 yr	-3-2-1	0	+1 +2+3
27.	Married male: Change in wife	s				
	work outside the home (beginn work, ceasing work, changing a new job, etc)	ing to 6mo	1yr	-3-2-1	0	+1 +2+3
28.	<i>Married female</i> : Change in husband's work (loss of job, beginning new job, retirement,	etc.)				
		6mo	1 yr	-3-2-1	0	+1+2+3

				Subj	ect #:
				DA	ГЕ:
	0 to 6mo	7 mo to 1 yr	-3-2-1	0	+1 +2 +3
29. Major change in usual t and / or amount of recr	type reation 6mo	1 yr	-3-2-1	0	+1 +2 +3
30. Borrowing more than \$ (buying home, business	10 000 s, etc.) 6mo	1 yr	-3-2-1	0	+1 +2 +3
31. Borrowing less than \$10 (buying car, TV, getting loan, etc)	000 g school 6mo	1 yr	-3-2-1	0	+1 +2 +3
32. Being fired from job	бто	1 yr	-3-2-1	0	+1 +2 +3
33. <i>Male</i> : Wife / girlfriend abortion	having 6mo	1 yr	-3-2-1	0.	+1 +2 +3
34. <i>Female</i> : Having aborti	on 6mo	1 yr	-3-2-1	0	+1 +2 +3
35. Major personal illness of	or injury				
	6mo	1yr	-3-2-1	0	+1 +2 +3
36. Major change in social a eg. parties, movies, vis (increased or decreased participation)	activities iting 6mo	l yr	-3-2-1	0	+1 +2 +3
 Major change in living c of family (building new remodeling, deterioration neighborhood, etc.) 	onditions v home, on of home, 6mo	1 yr	-3-2-1	0	+1+2 +3
38. Divorce	бто	1 yr	-3-2-1	0	+1 +2 +3

				Subje	ect #:
				DAT	`E:
	0 to 6mo	7 mo to 1yr	-3-2-1	0	+1 +2 +3
39. Serious injury or illness of close friend	6то	lyr	-3-2-1	0	+1+2 +3
40. Retirement from work	6mo	1yr	-3-2-1	0	+1 +2 +3
41. Son or daughter leaving home (due to marriage, college, etc.)	бто	1 yr	-3-2-1	0	+1 +2+3
42. Ending of formal schooling	6mo	1yr	-3-2-1	0	+1 +2+3
43. Separation from spouse (due to work, travel, etc)	6mo	1yr	-3-2-1	0	+1 +2+3
44. Engagement	6то	1 yr	-3-2-1	0	+1 +2+3
45. Breaking up with boyfriend/girlfriend	бто	1yr	-3-2-1	0	+1 +2 +3
46. Leaving home for the first time	6mo	1yr	-3-2-1	0	+1 +2+3
47. Reconciliation with boyfriend / girlfriend	6mo	lyr	-3-2-1	0	+1 +2+3

				Sub DA	ject #: TE:	
Other recent experiences						
which have had an impact on your life. List and rate.	0 to	7 mo				
48	6mo	1yr	-3-2-1	0	+1 +2 +3	
49	6mo	l yr	-3-2-1	0	+1 +2 +3	
50	6то	1 yr	-3-2-1	0	+1 +2 +3	

PLEASE CHECK THAT ALL QUESTIONS WERE ANSWERED.

Thank You

Subject #: _____ Date: _____

Short Form Social Support Questionnaire

INSTRUCTIONS:

The following 6 questions ask about people in your environment who provide you with help or support. Each question has two parts. The example below has been completed to help you. All your responses will be kept confidential.

Part one:

List all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Describe their relationship to you (see example).

Part two:

Using the scale below, circle how satisfied you are with the overall support you have.

If you have no support for a question, tick the words "No one", but still rate your level of satisfaction.

Example:

Who do you know whom you can trust with information that could get you in trouble?

Part 1:

No One

1)T.N. (Brother)	4)A.S. (friend)	7)
2)L.M. (friend)	5)S.F. (father)	8)
3)R.S. (employer)	6)	9)

Part 2:

6	5	$\begin{pmatrix} 4 \end{pmatrix}$	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 1. Whom can you really count on to be dependable when you need help?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 2.

Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 3.

Who accepts you totally, including both your worst and your best points?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 4.

Whom can you really count on to care about you, regardless of what is happening to you?

No One

1)	4)	7)		
2)	5)	8)		
3)	6)	9)		

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 5.

Whom can you really count on to help you feel better when you are feeling generally down-inthe-dumps?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 6.

Whom can you count on to console you when you are very upset?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS. *Thank you.*



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Appendix B3- Summary of psychometric properties of background and outcome variables

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Perceived	Short Form	Internal	Concurrent:	Information
support	Social Support	Consistency:	Moderate correlation with	not
Definition:	Questionnaire	Cronbach's $\alpha = .90$	long form SSQ, $r=.37$ -	available
Number and	(SSQ6, Sarason,	to .93	.58	
level of	Shearin &	(Sarason et	(Sarason et al., 1987)	
satisfaction	Pierce, 1987)	al.,1987)		
with support			Convergent:	
	6 item, 6 point	Test-retest (4	High correlations with	
	scale	weeks): r= .90	Beck	
1	Part A: number	(Sarason, Shearin	Depression Inventory,	
	of supports; Part	& Pierce, 1987)	other social support	
	B: scores level		measures	
	of satisfaction		(Sarason et al., 1987)	
Physical	Karnofsky	Interrater	Construct:	Sensitivity
functioning	Performance	Reliability	Correlated with physician	to change:
	Status Scale	Pearson Product	ratings (r = $.16$ to $.51$, p<	Significant
Definition:	(KPS;	Moment r= .89	.05)	changes in
Measure of	Karnofsky &	Kappa statistic: .53	(Schag et al., 1984)	scale
overall	Burchenal,	% complete		descriptors
functional	1949)	agreement= .59		as patients'
status		(Schag, Heinrich &		self-rated
	l item	Ganz, 1984)		severity of
	100 point scale,			their
	scored 0 dead			physical
	to 100 no			anu
	disease"			1 difficulties
	Dated by			(P < 05) (N =
	investigator			293 cancer
	linvestigutor			natients)
				(Schag et
				al., 1984)
Symptom	Symptom	Internal	Content:	Sensitivity
distress	Distress Scale	Consistency:	Expert panel consensus,	to change:
Definition:	(SDS;	Cronbach's $\alpha =$	field testing with cancer	Significant
Degree of	McCorkle,	.83	patients	difference
illness	Cooley & Shea,	Patients with lung	(McKorkle & Young,	in SDS
related to	1989)	cancer	1978)	between
cancer or		(McCorkle &	Construct:	home
treatment	13 items	Benoliel, 1981)	Significant differences	nursing care
	5 point scale,	Cronbach's $\alpha = .$	between known groups (intervention
	scored 1-5	72 to .92 in 47	lung cancer vs MI	group vs
	5 min to	studies	patients) (McKorkle &	routine care
	>25 = moderate	Challithe counting	Concurrent:	166
	distress	Stability over time:	Initial high SDS score for	advanced
	>33=severe	month): r 78	newly diagnosed cancer	lung cancer
	distress	Lung cancer and	patients predicted shorter	patients)
		MI natients	survival time	(McCorkle
		(McCorkle &	(Kukall et al, 1986)	et al. 1989)
		Benoliel, 1983)		,,





Previous	Life	Internal	Construct:	Information
major life	Experiences	Consistency:	Significant between group	not
events	Survey	Stability over time:	means for negative change	available
Definition:	(LES; Sarason,	Test-retest (6 wks	scores, $t(34) = 2.89$, p<.01	
Assesses the	Johnson &): $r = .63$ and $r =$	(N=36 students treated at	
presence or	Siegel, 1978)	.64 for total change	university counseling	
absence of		scores	center)	
positive and	47 life event	On 2 samples of	(Sarason et al.,1978)	
negative	items + 3 blank	undergraduate	Convergent:	
major life	spaces	students(N=34,	Significantly correlated in	
events and	7 point scale,	N=58 students)	expected directions with	
the quality of	scored –3	(Sarason et	anxiety, personal	
that	"extremely	al.,1978)	maladjustment, and	
experience	negative" to +3		depression	
	"extremely		(N = 64 - 100 students)	
	positive"		(Sarason et al.,1978)	
Anxiety and	Hospital	Internal	Construct:	Sensitivity
depression	Anxiety and	consistency	Principal components	to change:
	Depression	Anxiety :	analysis	Statistically
Definition:	Scale	Cronbach's $\alpha = .93$	confirmed 2 factors,	significant
Assesses	(HADS;	Depression:	N=568 cancer patients	differences
degree of	Zigmund &	Cronbach's $\alpha = .90$	(Moorey et al., 1991)	between
anxiety and	Snaith, 1983)	N= 575 cancer	Concurrent :	cognitive
depression		patients (Moorey et	Correlated significantly	behavioural
	7 items each for	al., 1991)	with psychiatric rating	intervention
	anxiety and		scales Anxiety: r=.054	group and
	depression		Depression: $r = .79$	non-
	subscales		(Zigmund and Snaith,	interventior
	4 point scale,		1983)	groups
	scored 0-3			(N=31
				newly
	Scores $> 10 =$			diagnosed
	severe			cancer
	depression			patients,
	Scores $> 8 =$			Bottomley
	Severe anxiety			et al., 1996
				N = 73 - 174
				cancer
				patients,
				Greer, et al.
				1991, 1992
				et al 1009
Psychosocial	Psychosocial	Internal	Construct :	Sensitivity
adjustment	Adjustment to	Consistency:	Factor analysis confirmed	to change:
to illness	Illness Scale –	Cronbach's $\alpha = .61$	7 factors	Significant
	Self Report	to .92	(Merluzzi & Sanchez,	changes
Definition:	(PAIS-SR:	(N=502 mixed	1997)	observed in
Assesses	Derogatis 1986)	cancer patients)	Low inter-correlations	group mean
global		(Merluzzi &	among domain scores (r =	differences
adjustment to	46 items	Sanchez, 1997)	.28 to .61)	between
illness	Grouped by 7		(N=148 renal dialysis	cancer
	domains · health	Cropbach's $\alpha = 47$	patients)	patients

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	care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, psychological	to .85 N= 69 cardiac bypass patients (Derogatis & Lopez, 1983)	(Derogatis, 1986) Concurrent: Significant correlations in expected directions with Karnofsky Performance Status, social support, coping (Merluzzi & Sanchez, 1997) Moderate correlation with Stait Trait Anxiety Inventory, r=.51, N= 272 chronic dialysis patients	receiving psychiatric or psychosocia l intervention s (Cain et al, 1986; Fawzy et al, 1990)
	distress 4 point scale; scored 0 to 3 Low scores = high adjustment		(Kaplan & de Nour, 1982)	
Intrusive thoughts and Avoidant behaviors Definition: Measure of cognitive processing	Impact of Events Scale (IES; Horowitz, Wilner & Alvarez, 1979) 15 items 4 point scale, scored 0-3 High distress cut off score: > 8.5	Internal consistency: Intrusion : Cronbach's α = .78 Avoidance: Cronbach's α = .84 Total IES : Cronbach's α = .92 N=51 critically injured patients (Grossman et al., 1998) Split-half: Tested with 66 subjects, r=.86 Stability over time: Test-retest (1 wk): Intrusion : r=.79 Avoidance: r= .89 Total IES : r=.87 N=25 students exposed to cadaver dissection (Horowitz et al., 1979)	Construct: Subscales confirmed by cluster analysis (Horowitz, Wilner & Alvarez, 1979) Factor analyses confirm item assignment to subscales (Zilberg, Weiss and Horowtiz, 1982)	Significant indicator of change in clinical status for patients treated with psychothera py vs no therapy (N=66 stress response patients) (Horowitz et al.,1979; Zilberg et al., 1982)

Self-esteem	Rosenberg Self	Internal	Concurrent:	Information
	Esteem Scale	Consistency:	r=.60 with Coopersmith's	not
Definition:	(RSES;	Cronbach's $\alpha = .77$	Self-Esteem Inventory	available
Measures	Rosenberg,	N=349 breast	(Crandall, 1973)	
degree of	1965, 1989)	cancer patients		
perceived		(Vinokur et al.,		
self-worth	10 items	1988)		
	4 point scale,	Cronbach's $\alpha = .87$		
	scored 1-4	N=128 breast		
		cancer patients		
	High scores =	(Carpenter, 1997)		
	Negative self-			
	esteem	Stability over time:		
		Test-retest (2 wks):		
		r=.85		
		(Silber & Tippett,		
		1965)		



Varia	ble	n (%)
Site		
Dite		10 (50)
	Breast	10 (56)
_	Colorectal	8 (44)
Stage		
	I	7 (39)
	II	8 (44)
	III	3 (17)
Phase	of trajectory	
	Newly diagnosed	14 (78)
	Completed treatment	1(5)
	Recurrence	3(17)
	(with curative or palliative treatment)	5 (17)
Receiv	ving counseling prior to study	
	Ves	3 (17)
	No	15(83)
	NO	15 (85)
Back	ground Variables	Mean (SD)
SDS ¹		22.6 (6.8)
KPS ²		84.3 (14.5)
SSQ6	3	
	Satisfaction	33.4 (4.2)
	Number of supports	3.6 (1.8)
LES^4		-1.2 (6.5)
		1.2 (0.0)

Appendix B5- Baseline characteristics of sample (N=18)

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*SDS (Symptom Distress Scale): Range 13 to 65, Higher scores indicate greater symptom distress

*KPS (Karnofsky Performance Status): Range 0 to 100, Higher score indicates greater functional ability *SSQ6 (Social Support Questionnaire): Level of Satisfaction : Range 6 to 36, Higher scores indicate

greater satisfaction; Number of supports: Range 0 to 9

*LES (Life Experiences Survey): Range -141 to +141, Positive scores indicate desirable changes, negative scores indicate undesirable changes

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Appendix B6 - Tasks of the Meaning-Making Intervention for cancer patients

Objective: T	o provid	e a secure context to revisit events since the cancer diagnosis
Rationale:	1.	Telling one's story allows the patient to slowly accommodate and assimilate new and possibly threatening material
	2.	Telling one's story allows the patient to selectively revisit disturbing aspects in a controlled rather than random manner
	3.	Understanding what happened to the self reestablishes a sense of order in the present
	4.	Grieving one's losses initiates the process of acceptance and growth
		Task II : Contemplate the Past
Objective: T challenges	o embec	I the new cancer experience within a familiar framework of past
Rationale:	1.	Reflection upon one's life acknowledges what was previously perceived as improbable and incompatible with one's understanding of the self and the world
	2.	Intrusive thoughts and avoidant behaviors reflect the mind's way of challenging the natural tendency to resist change and maintain a sense of stability
	3.	Reflecting on how past challenges were overcome may allow one to realize similarities and strengths that can be applied to the present challenge of living with the cancer
		Task III : Commit to the Present. For the Future

Rationale:

1.

Acknowledging one's mortality often serves as an impetus towards living or maintaining a meaningful life in the present

- 2. Acknowledging one's mortality helps rearrange life priorities
- 3. Acknowledging one's mortality allows personal decisions to be made with more clarity

Measure	Pre-test Mean (SD) n=18	Post-test Mean (SD) n=18	Paired t test (d.f. 17)	p value
RSES ¹	16.39 (3.34)	14.00 (3.40)	3.53	0.003
HADS ² total	7.94 (4.71)	7.11 (5.27)	0.34	0.74
PIL ³	114.90 (11.98)	118.83 (14.51)	-1.55	0.14
IES ⁴ total	28.39 (10.61)	29.06 (12.82)	-0.49	0.63
LOT-R ⁵	25.17 (3.87)	26.28 (3.61)	-1.71	0.11

Appendix B7. Means and standard deviations of main outcome measures

at baseline and post-intervention

¹ RSES: Rosenberg Self –Esteem Scale (Range 10 to 40; Lower scores indicate greater self-esteem) ² HADS: Hospital Anxiety and Depression Scale (Range 0 to 42; Higher scores indicate greater anxiety or depression)

³ PIL: Purpose in Life Scale (Scores < 92 indicate lack of clear p \Box rpose in life, 93 to112 indicate an uncertain purpose in life, > 113 indicate definite purpose in life)

⁴ IES: Impact of Events Scale (Total scale: Range 15 to 60; Higher scores indi□ate greater impact) ⁵ LOT-R: Life Optimism Test- Revised (Range 0 to 32; Higher scores indicate greater optimism)

	Pre-post test difference scores for outcome variables					
	RSES ⁷	LOT-R	HADS ⁸	IES ⁹	PIL	
Baseline Background Variable						
LES ¹	0.06	-0.20	-0.42	0.39	-0.36	
LOT-R ²	-0.15		0.02	-0.11	0.05	
SDS ³	-0.55	0.19	0.58	0.06	-0.26	
KPS ⁴	-0.33	0.29	0.27	0.35	-0.49	
SSQ⁵num	-0.45	0.10	-0.23	-0.26	-0.11	
SSQ ⁵ sat	-0.03	-0.15	-0.48	0.32	0.17	
PIL ⁶	0.39	0.05	-0.41	-0.01		

Appendix B8. Correlations among baseline background variables and pre-post test difference scores

¹ LES: Life Experiences Survey
² LOT-R: Life Optimism Test-Revised
³ SDS: Symptom Distress Scale
⁴ KPS: Karnofsky Performance Status

⁶ KPS: Karnotsky Performance Status
⁵ SSQ6: Social Support Questionnaire (num- number; sat- satisfaction)
⁶ PIL: Purpose in Life Scale
⁷ RSES: Rosenberg Self –Esteem Scale
⁸ HADS: Hospital Anxiety and Depression Scale
⁹ IES: Impact of Events Scale

Appendix C. Information to Accompany Randomized Controlled Trial

Appendix C1. Questionnaire packet for RCT participants

Date :

Subject #: _____

PERSONAL INFORMATION SHEET Please do not write your name on this form

a check and a second

Yes, I have decided to participate in this study

No, I have decided <u>not</u> to participate in this study because

Age :		
Sex :		
Diagnosis :		
Marital Status:		
Married	Divorced	Single
Common-law	Separated	Widowed
Number of dependents :		
Who do you live with?		
Highest Level of Education Com	bleted:	
Elementary	High School	Graduate
CEGEP / Vocational	Baccalaureate	
Before this illness, I was :		
Employed full-time*	Studying full-time	Homemaker
Employed part-time*	Studying part-time	Retired
Unemployed		
*If employed, what type of work	were you doing?	
Yearly family income:		
Less than \$20 000		
Between \$20,001 - \$40,000		
Between \$40,001 - \$80,000		
Between \$80,001 - \$ 100,000		
More than \$100 001		
What religion do you practice? _		
Have you received counseling fro	m a professional to deal with	n your feelings about y
experience with cancer?	YES	NO

DEMOGRAPHIC DATA FORM

Date : ____/ ____/

Age : _____ Sex : _____

Marital Status:

- □ Married
- □ Common-law
- □ Divorced
- □ Separated
- □ Single
- □ Widowed

Number of dependents : Who do you live with?

Level of education:

- □ Elementary School
- □ CEGEP / Vocational
- □ High School
- □ Baccalaureate
- □ Graduate

Before this illness, I was :

□ Employed full-time doing?

If employed, what type of work were you

- □ Employed part-time
- □ Unemployed
- □ Housewife/husband
- □ Studying full-time
- □ Studying part-time
- □ Retired

Yearly income:

- □ Less than \$20 000
- **□** \$20 000 \$40 000
- **\$40 000 \$80 000**
- **a** \$80 000 \$ 100 000
- □ More than \$100 000

What religion do you practice?

Have you received counseling from a professional to deal with your feelings about cancer?

- D YES
- D NO

Subject #: _____

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DATE: _____

Life Orientation Test

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Using the scale below, write the appropriate letter in the box beside each statement. Please be as honest and accurate as you can be throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

Α	В	С	D	E
I agree a lot	I agree a little	I neither agree	I disagree	I disagree
		of disagree	a Intic	a lot
13. In uncertain t	imes, I usually expo	ect the best.		1.
14. It's easy for r	ne to relax.			2.
15. If something	can go wrong for m	ne, it will.		3.
16. I always look	on the bright side.			4.
17. I'm always o	ptimistic about my	future.		5.
18. I enjoy my fr	iends a lot.			6.
19. It's important	t for me to keep bus	sy.		7.
20. I hardly ever	expect things to go	my way.		8.
21. Things never	work out the way I	want them to.		9.
22. I don't get u	pset easily.			10.
23. I'm a believe	er in the idea that "e	every cloud has a silver	lining".	11
24. I rarely coun	t on good things ha	ppening to me.		12.
PLEASE CHEC	K THAT YOU HA	VE ANSWERED ALI	THE QUEST	IONS.
			Т	hank you.

Subject #: _____

. . . .

DATE: _____

Rosenberg Self Esteem Scale

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Here is a list of statements dealing with your general feelings about yourself. If you agree with the statement, circle A. If you strongly agree, circle SA. If you disagree, circle D. If you strongly disagree, circle SD.

	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
1) On the whole, I am satisfied with my	vself. SA	A	D	SD
2) At times, I think I am no good at all.	SA	Α	D	SD
3) I feel that I have a number of good qualities.	SA	Α	D	SD
4) I am able to do things as well as mos other people.	t SA	Α	D	SD
5) I feel I do not have much to be proud	of. SA	Α	D	SD
6) I certainly feel useless at times.	SA	Α	D	SD
7) I feel that I am a person of worth, at least on an equal plane with others	. SA	Α	D	SD
8) I wish I could have more respect for myself.	SA	Α	D	SD
9) All in all, I am inclined to feel that I am a failure.	SA	Α	D	SD
10) I take a positive attitude toward myse	elf. SA	Α	D	SD

PLEASE CHECK THAT ALL QUESTIONS ARE ANSWERED. Thank you.

Subject #: _____

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Generalized Self-Efficacy Scale

Here is a list of statements dealing with your general feelings about yourself. If you believe the statement is <u>not at all true</u>, circle 1. If you believe the statement is <u>barely true</u>, circle 2. If you believe the statement is <u>moderately true</u>, circle 3. If you believe the statement is <u>exactly true</u>, circle 4.

	Ν	1 Not at all True	2 Barely True	3 Moderately True	4 Exactly True
1)	I can always manage to solve difficu problems if I try hard enough.	ılt 1	2	3	4
2)	If someone opposed me, I can find the means and ways to get what I want.	he 1	2	3	4
3)	It is easy for me to stick to my aims accomplish goals.	and 1	2	3	4
4)	I am confident that I could deal efficiently with unexpected events.	1	2	3	4
5)	Thanks to my resourcefulness, I kno how to handle unforeseen situations	w . 1	2	3	4
6)	I can solve most problems if I invest necessary effort.	: the 1	2	3	4
7)	I can remain calm when facing diffic because I can rely on my coping abi	culties lities. 1	2	3	4
8)	When I am confronted with a proble I can usually find several solutions.	m, 1	2	3	4
9)	If I am in a bind, I can usually think something to do.	of 1	2	3	4
10) No matter what comes my way, I'm usually able to handle it.	1	2	3	4

Pre- Post Test Date:

Subject #: _____

Short Form Social Support Questionnaire

INSTRUCTIONS:

The following 6 questions ask about people in your environment who provide you with help or support. Each question has two parts. The example below has been completed to help you. All your responses will be kept confidential.

Part one:

List all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Describe their relationship to you (see example).

Part two: Using the scale below, circle how satisfied you are with the overall support you have.

If you have no support for a question, tick the words "No one", but still rate your level of satisfaction.

Example:

Who do you know whom you can trust with information that could get you in trouble?

Part 1:

No One

1) T.N. (Brother)	4)A.S. (friend)	7)
2)L.M. (friend)	5) S.F. (father)	8)
3)R.S. (employer)	6)	9)

Part 2:

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied



Pre- Post Test	t Date:			Subject #:	
Question 1. Whom can you really count on to be dependable when you need help?					
No One					
1) 2) 3)		4) 5) 6)		7) 8) 9)	
How satisfie	How satisfied are you with the overall support you have?				
6	5	4	3	2	1
Very Satisfied	Fairly Satisfied	A little Satisfied	A little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied

Question 2.

Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

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6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied



Pre- Post Tes	t Date:			Subject #:	
Question 3.					
Who accept	s you totally, i	ncluding both	your worst ar	nd yourbest po	pints?
No One					
1) 2) 3)		4) 5) 6)		7) 8) 9)	
How satisfie	d are you with	n the overall s	upport you ha	ve?	
6	5	4	3	2	1
Very Satisfied	Fairly Satisfied	A little Satisfied	A little Dissatisfied	Fairly Dissatisfied	Very Dissatisfied

Question 4.

Whom can you really count on to care about you, regardless of what is happening to you?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

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How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied
Pre- Post Test Date: _____ Subject #: _____ Question 5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps? No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

Question 6.

Whom can you count on to console you when you are very upset?

No One

1)	4)	7)
2)	5)	8)
3)	6)	9)

How satisfied are you with the overall support you have?

6	5	4	3	2	1
Very	Fairly	A little	A little	Fairly	Very
Satisfied	Satisfied	Satisfied	Dissatisfied	Dissatisfied	Dissatisfied

PLEASE CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS. *Thank you.*

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Post-Test Date : _____

Subject #: _____

Follow-up Questions - Experimental group

- Did you receive other kinds of support or counseling in addition to our sessions together (e.g. cancer support groups, psychologist, psychiatrist, social worker, nurse, etc?)
 - Yes, I received support from :

When did you begin? Date _____

How often did you meet?

- □ No, I did not receive another type of support
- 2) What are some reasons for recommending this intervention to people in a similar situation as yourself?

3) What are the reasons for not recommending this intervention to people in a similar situation as yourself?

4) What was of most value to you during this intervention?

Post-Test Date : _____

Subject #: _____

Follow-up Question - Control Group

1) Did you receive other kinds of support or counseling while waiting for our sessions to begin ? (e.g. cancer support groups, psychologist, psychiatrist, social worker, nurse, etc?)

• Yes , I received support from :

When did you begin? Date _____

How often did you meet?

No, I did not receive another type of support

Appendix C2. Evaluations of the assumptions for ANCOVA

C2a. Test of the assumption of independence

Correlations	Self-esteem	Optimism	Self-efficacy	Diagnosis to	Group	Cancer Site
Self-esteem (pretest)	(pretest)	(pretest)	(precest)	pretest	Assignment	
Optimism (pretest)	552					
Self-efficacy (pretest)	518	.531				
Diagnosis to pretest	.228	.032	061			
Group Assignment	.095*	.029*	093*	096		
Cancer Site	.211*	147*	078*	.119	.094	

* Each pretest score was not correlated with site of cancer or treatment group

(all correlations were < .22)

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Correlations							
	Self-esteem (pretest)	Optimism (pretest)	Self- efficacy (pretest)	DiagnosisS to pretest	elf-esteem (posttest)	Optimism (posttest)	-Self efficacy (posttest)
Self-esteem (pretest	ו)						
Optimism (pretest	n552)						
Self-efficacy (pretest	y518)	.531					
Diagnosis to pretes	o .228 t	.032	061				
Self-esteen (posttest	.674*	541	451	.048**			
Optimism (posttest	n299)	.700*	.232	.130**	560		
Self-efficacy (posttest	/294)	.526	.582*	.012**	617	.592	

C2b. Test of the assumption of linearity

* Each pretest score was highly correlated with each corresponding post-test score (i.e. r > 0.50).

** There was no relationship between the time of first treatment to pretest (baseline) completion and any of the posttest measures.

C2c. Evaluation of the assumption of regression of slopes for self-esteem, optimism,

an a Channa

and self-efficacy

Tests of Between-Subjects Effe	cts					
Dependent Variable: SELF-EST	ГЕЕМ (POST-T	EST)			
Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Observed Power
Intercept	186.715	1	186.715	17.155	.000	.983
Group	.002	1	.002	.000	.990	.050
Diagnosis	1.551	1	1.551	.142	.707	.066
Group*Self-esteem(pretest)	9.956	1	9.956	.915	.342	.156
Diagnosis *Self-esteem	2.273	1	2.273	.209	.649	.074
(pretest)						
Group* Diagnosis *Self-	2.047	1	2.047	.188	.666	.071
esteem (pretest)						
Error	729.229	67	10.884			
Total	21352.065	74				

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a Computed using alpha = .05
b R Squared = .525 (Adjusted R Squared = .483)

Tests of Between-Subjects Effect	cts					
Dependent Variable: OPTIMISM	A (POST-TEST	.)				
Source	Type III Sum	df	Mean Square	F	Sig.	Observed
	of Squares					Power
Intercept	683.846	1	683.846	40.630	.000	1.000
Group	105.337	1	105.337	6.259	.015	.693
Diagnosis	182.910	1	182.910	10.867	.002	.901
Group * Optimism (pretest)	44.594	1	44.594	2.650	.108	.361
Diagnosis * Optimism (pretest)	140.366	1	140.366	8.340	.005	.812
Group * Diagnosis *Optimism	.289	1	.289	.017	.896	.052
(pretest)						
Error	1127.677	67	16.831			
Total	46436.300	74				

a Computed using alpha = .05

b R Squared = .624 (Adjusted R Squared = .590)

Tests of Between-Subjects Effe	cts					
Dependent Variable: SELF-EFF	FICACY (POST	-TES	ST)			
Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Observed Power
Intercept	228.355	1	228.355	14.529	.000	.964
Group	238.866	1	238.866	15.198	.000	.970
Diagnosis	4.106	1	4.106	.261	.611	.080
Group * Self-efficacy (pretest)	178.592	1	178.592	11.363	.001	.913
dx * Self-efficacy (pretest)	4.641	1	4.641	.295	.589	.083
Group * dx * Self-efficacy	7.030	1	7.030	.447	.506	.101
(pretest)						
Error	1053.057	67	15.717			
Total	83826.747	74				

a Computed using alpha = .05b R Squared = .516 (Adjusted R Squared = .473)

Appendix C3. Recruitment letter distributed by staff to eligible patients

McGill University – School of Nursing A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

Hello,

I am a nurse and a graduate (PhD) student at McGill University School of Nursing. I am carrying out a research project to find out whether meeting with a nurse 1 to 4 times to review the meaning of the cancer experience would be helpful for patients coping with a diagnosis and treatment of cancer. Your input would be invaluable to this study.

If you are interested in learning more about this study, please write your name and telephone number below and return the sheet to your nurse or physician so that I may contact you to explain the study in further detail.

Your name below does *not* indicate that you have agreed to participate in the study. Your name below only allows me to contact you to explain more about the study.

Thank you for your time and attention Virginia Lee, N., MScA, PhD (Candidate)

Date : _____

Yes, I, (please print name) ______, am willing to give my name and telephone number to Virginia Lee so that she can contact me to explain the study.

My telephone number is : ()_____.

Please circle the best time to reach you by phone:

Mon	Tues	Wed	Thurs	Fri	Sat	Sun

Morning Afternoon Evening

Appendix C4. Standardized script for delayed pre-test questionnaire returns

Phone call #1 - Questionnaires not returned after 7 days.

Hello, Mr/Mrs.____

1. 1. 1.

This is Virginia Lee speaking. We met last week (specify day) when you had expressed an interest to participate in a nursing study. The study was about giving you an opportunity to talk about what your experience with cancer has been like for you and to determine whether these meetings would be helpful for you.

I had sent you the envelope containing the questionnaires but we have not yet received them back. Which is why I am calling - to see how you were doing with the forms. Have you been able to complete them yet? ... Have you any questions about the forms? ... Have the questionnaires been mailed? ... So I can have an idea as to when to expect them, when were they mailed? ... Thank you very much!

Please do not hesitate to call my supervisor Dr. Robin Cohen at 842-1231 ext 5158 if you have any questions. We will be glad to answer any questions you might have.

I thank you for agreeing to participate. I will be in touch with you soon.

Phone call #2 - Questionnaires not returned after 10 days

Hello Mr/Mrs.____,

This is Virginia Lee calling again. How are you doing? ... I am calling to follow-up on the questionnaires for the nursing study...I understand this may be a difficult time for you and your family. I was wondering if you had found some time to complete the questionnaires and whether I should be expecting your questionnaires in the mail soon... I appreciate your considering the study/ agreeing to participate. Thank you very much.

<u>Phone call #3 - To drop patient from study because questionnaires not returned</u> <u>after 14 days</u>

Hello Mr/Mrs .____,

This is Virginia Lee calling again. How are you doing? I am calling to follow-up on the questionnaires for the nursing study...

I get the feeling that you may have other priorities at this time and you are finding it hard to find time to answer the questionnaires. I understand that. As I had mentioned in our first meeting, you have the option to withdraw from the study at any time. Would you like to withdraw your participation from the study ? I appreciate your interest and offer to participate in the study. And I wish you the best in your recovery.

Appendix C5. Standardized script to inform participants about group assignment

Hello Mr. / Mrs. _____. This is Virginia Lee calling. How are you? I am calling to let you know that we received your questionnaires in the mail today. Thank you very much for filling them out.

For experimental group : I'm also calling to let you know that you have been assigned to the experimental group – that's the group that meets with me between 1 and 4 times.... Would you like to schedule a time when we can meet to begin the sessions? As I mentioned before, our meetings can take place at the hospital or at your home? Which location would be more convenient for you?

For control group: I'm also calling to let you know that you have been assigned to the control group- this means that you continue to receive the regular care from your doctors and nurses for now. Then in about <u>2 weeks or matched time</u>, I will be sending you the same set of questions that you had filled out. After I receive those questionnaires, we can schedule a time to meet for 1 session.

Do you have any questions for me at this time?

Thank you again. I will be in touch with you soon.

Appendix C6. Standardized introduction to first session for experimental group

...I thought that today I could begin by telling you a little about what our sessions will be about and what we'll be focusing on.

More and more research is showing that for some people, the diagnosis of cancer can be a very traumatic experience that creates a psychological trauma. And just like a physical trauma that needs to heal, so does a psychological trauma. I am sure you are familiar with the symptoms of physical trauma, but the symptoms of psychological trauma are less well-known. Some examples of psychological trauma are: the inability to concentrate, inability to sleep, intrusive thoughts – thoughts that we just can't seem to get out of our head, ruminations – thoughts that play back over and over again in our mind, just feeling numb, deliberately avoiding the topic that causes great stress . These symptoms actually take up a lot of energy and effort, you may feel exhausted, cry a lot, cry at the drop of a pin, feel depressed, feel sad, feel like you just don't care anymore. People react very differently to a diagnosis so there isn't one right way to feel. There isn't a better way than another. What works for one person may

Our sessions will focus on these symptoms that you may or may not have. Our sessions will address the psychological trauma of being diagnosed with cancer.

We will concentrate a lot on the thoughts and beliefs that you have about cancer and the whole experience. Because it's not the actual situation that you are reacting to, but actually the thoughts that you have about the situation that you are reacting to. Let me explain.

This is one model of how the mind and the body are linked together –actually like the layers of an onion (show card with picture of onion)



The cognitive model of the self

not be appropriate for another.

Our beliefs and internal thoughts influence how we feel, how we act, what physiological symptoms are experienced The actual situation is made up of facts. You can't change these.

The next layer are the physiological symptoms – pain, heart racing, Behviours come next. This is what you do in response to the physical symptoms. For example, you can cry, you can scream, you can hit something, you can curl up in a fetal position.

And how you act on the outside is determined by how you are feeling on the inside. So this is the next layer. If you're sad, you cry, If you're angry, you can scream, or hit something.

But what's underneath those emotions? What's controlling your feelings? It's your thoughts. Your thinking pattern. And this is the most important part of this model, because you can change your thoughts. And by changing your thoughts, you can change how you feel, how you behave and how your body reacts.

The trick is to catch these thoughts when they happen. The hardest thoughts to catch are automatic. They just appear momentarily, and you don't even notice them but they were in your consciousness long enough for you to react to it.

On a deeper level, are the intermediate thoughts which are rules that you live by. For example, if I eat and live a healthy lifestyle, then I should not get sick. Or another one is, if I am a good person, then bad things should not happen to me.

Lastly, are the core beliefs. And these are the hardest things to change and the scariest thing to change because this is how you identify yourself. This is your identity. These are the values and beliefs that you grew up with and define who you are.

Now this model of yourself exists on a timeline (Show card with timeline).



Our current responses to a specific event are influenced by past experiences and have the potential to influence future expectations and goals. Who you are now and how you react to things are influenced by what happened in the past, and in turn what happens today will influence the future. So, we are always in transition. On the move. Nothing ever stands still. So, all transitions begin with endings and end with beginnings. To begin something, we must end something else.

So this is where we are now. in the present. And this is an opportunity for you to talk about what's happening to you now. In the second session, we'll complete this time line by reflecting on where you've been in life and how that is affecting how you are doing now. In the third session, we'll look at where you are heading.

So, let's start with this timeline (give timeline exercise). Where do you see yourself on this timeline if this is your birth and this is the end.





		Experimental (n=35)	Control (n=39)	Difference**
Categorical Variables (n,	%)			%
Sex	Female	28 (80.0)	32 (82.1)	-2.1
	Male	7 (20.0)	7 (17.9)	2.1
Marital	Married/ with partner	22 (62.9)	26 (66.7)	-3.8
Status	Divorced/ Separated	4 (11.4)	6 (15.4)	-4.0
	Single/Widowed	9 (25.7)	7 (17.9)	7.8
Education	Elementary	2 (5.9)	2 (5.4)	0.5
(* Exp n=34; Ctrl n=37)	High School	14 (41.1)	12 (32.4)	8.7
	College	6 (17.6)	6 (16.2)	1.4
Unive	ersity/ Graduate School	12 (35.3)	17 (45.9)	-10.6
Employment	Full time	18 (51.4)	19 (50.0)	1.4
(* Ctrl n=37)	Part time	4 (11.4)	6 (15.8)	-4.4
	Homemaker	2 (5.7)	3 (7.89)	-2.2
	Retired/Other	11 (31.4)	10 (26.3)	-5.1
Family Income	< \$20 000	6 (18.2)	4 (12.1)	6.1
(* Exp n=33; Ctrl n=33)	\$20 001 - \$ 40 000	6 (18.2)	8 (24.2)	-6.0
	\$ 40 001 - \$80 000	16 (48.5)	11 (33.3)	15.2
	>\$ 80 001	5 (15.2)	10 (30.3)	-15.1
Religion	None	4 (11.8)	2 (5.1)	6.7
(* Exp n=34)	Catholic	21 (61.8)	16 (46.1)	15.7
	Protestant	5 (14.7)	6 (15.4)	- 0.7
	Jewish	2 (5.9)	9 (23.1)	-17.2
	Other	2 (5.9)	4 (10.2)	-4.3
Cancer site	Breast	23 (66.0)	29 (74.0)	8.0
	Colorectal	12 (34.0)	10 (26.0)	-8.0
Stage	0-2	29 (82.9)	29 (74.4)	8.5
	3-4	6 (17.1)	10 (25.6)	-8.5
Use of other psychol	ogical support	4 (11.4)	4 (10.2)	1.2
Continuous variables (M,	SD)			М
Age		56.43 (9.79)	56.87 (10.09)	-0.30
Baseline Self-esteen	1	17.60 (6.29)	16.56 (4.65)	1.04
Baseline Self-efficad	су	31.71 (5.49)	32.68 (4.93)	-0.97
Baseline Optimism		22.74 (5.95)	22.36 (7.29)	0.38
# of days from first t	reatment to pretest	77.28 (56.79)	86.90 (44.32)	-9.62
# of days between pr	etest and posttest	66.03 (37.69)	60.33 (42.13)	5.70

Appendix C8. Baseline characteristics for experimental versus control groups

* Sample size varies due to missing data

** Difference calculated by subtracting control group from experimental group using % for ordinal variables and mean for continuous variables

	Experimental (n=35)	Control ($n = 39$)	ANCOVA of posttest means	
Outcome Measure	Posttest, Mean (SD)	Posttest, Mean (SD)	 39) ANCC posttes F 7) 8.01 5) 5.78 	р
Self-esteem* (RSES)	15.49 (4.39)	17.15 (4.67)	8.01	0.006
Optimism [†] (LOT)	25.85 (4.67)	22.77 (7.40)	5.78	0.019
Self efficacy [‡] (GSES)	34.49 (3.80)	32.08 (6.45)	10.76	0.002

Appendix C9. Analysis of covariance: Post-test means and standard deviations (SD) for experimental and control group for each outcome measure

covariate = baseline self-esteem score

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†covariate = baseline optimism score

‡covariate = baseline self-efficacy score

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Appendix D. Meaning Intervention for Trauma Patients and their Families-

Meaning Intervention for Trauma Patients and their Families

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Introduction

This manual provides health professionals with a cognitive- based intervention to help people come to terms with an unexpected lifethreatening event through a process of finding meaning. The ability to find meaning in a traumatic situation has been shown to minimize the potential development of more serious symptomatology in the future. Thus the intervention is given early to work simultaneously with the cognitive processing of the trauma that begins as soon as the event is experienced. Intended for patients and families learning to cope with normal but disturbing reactions to a traumatic event, *it is not intended for persons with known cognitive deficits, or critically-injured due to suicide attempts, sexual assault, or criminal activity.*

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This manual provides an overview of theory and pertinent research findings related to the concepts of coping, meaning, and psychological adjustment. It provides the background to the specific strategies for working with patients and families at each phase of the intervention.

Rationale

Health professionals tend to view post- trauma reactions such as intrusive thoughts and disturbing memories as cognitive attempts to process an unexpected, life-threatening event (Creamer, Burgess & Pattison, 1992). The unexpected and traumatic nature of these images not only challenge the person's cognitive representation (i.e. beliefs and assumptions of how the world works) of a meaningful world, but undermine the patient's sense of personal control (Janoff-Bulman, 1989; Thompson & Janigian, 1988). According to this theory, the traumatic event must be integrated into the person's current or reconstructed cognitive representation of the world and the self in order for a full psychological recovery to occur (Meichenbaum, 1994).

Integrating the traumatic event however is sometimes impeded by the patient and family's beliefs about the self, the world, and their relationship to it. The nurse, the patient and his or her family need to explore family or personal beliefs that may promote and / or interfere with the patient's recovery. In a collaborative process, the positive beliefs about the self and the world are used to help the patient regain his or her sense of self, especially in the planning of future goals and directions. In contrast, those beliefs that impede the patient's progress are analyzed in a series of repeated discussions about how these beliefs function and impact on their understanding of the traumatic event in relation to their past and future experiences.

Finding meaning involves the use of story-telling through a process of Socratic questioning strategies which enables the person to make sense of a seemingly senseless event. These strategies consist of telling the story, getting the facts, reviewing the stressor from different

perspectives, or exploring alternative explanations to account for what happened. In contrast to other cognitive interventions that are directed toward 'changing a stressor' or 'finding a solution to a stressor', this cognitive approach is directed toward controlling and reshaping one's thoughts and feelings about an event or new realities that cannot be undone. These strategies are directed primarily at the inner world of the person in terms of the thoughts, feelings and behaviors experienced as a result of a traumatic event. These strategies are embedded in a review process that centers on the person's previous life, the stressor event, and present and future implications of the event for the person belief.

Definitions

Life scheme refers to the person's cognitive framework or representation of their lives in terms of the events that have happened to them, the goals they have reached, and the goals they wish to attain (Thompson & Janigian, 1988). It is based on an evolving set of values, beliefs and assumptions shaped by personal experiences as well as by family and significant others. The purpose of a life schema is to provide an interpretative context for events that happen. It shapes how we see oneself (i.e. the self-concept), how we 'see' the world (i.e. the world view), and helps create a sense of order and purpose. A sense that the world is orderly reaffirms our desire for stability and predictability. A sense that one's life has purpose allows for the possibility of creating a set of goals that can then be actualized through commitment and work.

Finding meaning is composed of both finding a sense of order and a sense of purpose. Finding a sense of order refers to the ability to make sense of the events in one's life and the world that directly or indirectly influences our life. Making sense of one's life is thought to be inextricably linked to our beliefs in an orderly, predictable, and stable world in which resides the possibility of some personal control. These beliefs allow us to develop a sense of purpose and a set of goals to be pursued and hopefully realized during the course of our lifetime. Thus finding a sense of meaning following a trauma event includes finding three central elements of order, control and purpose in seemingly senseless circumstances. Because meanings are also thought to shape the person's use of cognitive and behavioral coping strategies, they are a key determinant of the patient's healthy recovery.

Beliefs are the automatic thoughts, interpretations, attributions, and / or explanations created by the patient in the process of trying to understand and make sense of traumatic and unexpected events. These beliefs are the windows to the patient and family's core assumptions. These beliefs are thought to shape the perception of an event, the emotional reaction, and the type of coping strategy to be employed. An ability to come to terms with shocking and senseless situations depends on the fit between the person's beliefs and assumptions about the world and the self, the stressful situation, and the social context. Current thinking is

hat there are 'positive', facilitative beliefs that promote the patient's recovery. In contrast, there are 'negative', constraining beliefs that impede the patient's recovery.

Core assumptions are the most fundamental beliefs in one's life scheme. These core assumptions guide the formation of facilitative or constraining beliefs which are generally unquestioned and unchallenged prior to a crisis event.

Post -traumatic stress disorder (PTSD) is a diagnosis characterized by feelings of intense fear, helplessness or horror following direct or indirect exposure to actual or threatened death or serious injury, or threat to the physical integrity of the self. The patient experiences both recurrent and intrusive memories as well as persistent attempts to avoid the traumatic stressor for a period of at least one month. Symptoms may include feelings of intense anxiety or fearfulness to cues resembling the stressor event, flashbacks, nightmares, feelings of detachment from others, inability to recall or avoidance of thoughts and feelings related to event, emotional lability, exaggerated startle response, and difficulties sleeping.

Acute stress disorder (ASD) is a diagnosis similar to that of PTSD but which symptoms of intrusion and avoidance occur in the immediate aftermath of the extreme stressor, i.e. within 4 weeks. Also characteristic is the presence of 3 or moire dissociative symptoms such as a sense of numbing, detachment, of "being in a daze", derealization, depersonalization, and inability to recall important aspects of the trauma. The importance of this diagnosis is the ability to predict which individuals are likely to develop PTSD, and to begin early counselling to prevent loss of control and further worsening of symptoms.

A stressor is any unexpected, threatening event to one's life or physical integrity which may be accompanied by temporary or permanent changes to one's personal life. Two theoretical perspectives explain the significance of the event for the person. First, a stressor is thought to challenge a person's values, beliefs, and assumptions of the world and the self. It challenges beliefs that the world is orderly, controllable, just, and stable; that life has meaning. Because the threatening and unexpected event is totally unrelated to the person's beliefs about the world and the self, it has difficulty being processed, lying outside the cognitive schema. A second, biological explanation is that if an event is unexpected, the stimulus to the perceptual sense cells will not set off a positive neural feedback circuit. Instead the firing is inhibited by other circuits which determined, on the basis of previous experience, that it was not expected. Thus, if the stressor is inconsistent with our mental schema (use of inhibitory neurons) it will not be accepted as an integral part of who we are based on our goals, values and beliefs about ourselves.

Types of reactions to stressors. There are 4 types of reactions that patients and family members may experience in response to a stressor event. 1) *Emotional reactions* include anxiety, shock, disbelief, depression, sadness, guilt, vulnerability, psychic pain, numbness, intense distress. 2) *Cognitive reactions* include difficulty concentrating,

intrusiveness, avoidance, decreased self-esteem, decreased sense of personal control, fear that trauma may re-occur; self- blame. 3) *Behavioral reactions* include difficulties with social relationships, work, social withdrawal. 4) *Biological reactions* include fatigue, hyperarousal, startle response, nightmares, physiological parameters (e.g. increased heart rate, pupil dilation, increased blood flow to muscles, increased respiration, increased release of epinephrine & norepinephrine, increased sympathetic nervous system arousal, hypofunction of the hypothalamic-pituitaryadrenocortical axis, dysregulation of the endogenous opioid system, changes in the physiology of sleep and dreaming (insomnia), cardiac problems, increased blood pressure, changes in immune system functioning, increased urinary catecholamine levels, decreased urinary cortisol levels, increased symptom reporting, general lowering of pain threshold at rest.

Strengths are personal and social resources that the patient draws on to actualize his or her potential. Among the patient's potential personal resources are the values and beliefs that may be viewed as positive meanings in stressful situations.

Philosophical Underpinnings

The meaning intervention is based on a constructivist philosophy which subscribes to the notion of multiple subjective realities. This position believes that "facts" can be understood only through the perspectives of each person's subjective lenses of the world. "Facts" are received, interpreted and translated through a person's set of values, beliefs, and past experiences. Realities are multiple and they exist in people's minds. Thus, there can be many constructions and views of any one event, the ultimate truth or falsity of which cannot be determined.

The process of constructivism is characterized by two aspects: hermeneutics and dialectics. The hermeneutic aspect attempts to capture the individual constructions as accurately as possible. The dialectical aspect consists of comparing and contrasting these individual constructions, including that of the nurse's, with the aim of generating one or a few constructions on which there is substantial consensus.

Theoretical Framework

The meaning intervention for families is based on the theoretical concepts of learning to cope with life-threatening events.

Assumptions

The meaning intervention is based on the following assumptions:

- 1) people are motivated and capable of working towards self-healing and higher levels of health.
- 2) people strive to find meaning in their lives

- 3) the therapeutic relationship between the nurse, and the patient and family is non-hierarchical and is characterized by mutual trust and regard.
- 4) the meaning intervention is tailored to the feelings, thoughts, behaviours and medical status of the patient and family, and progresses at their pace and level of readiness

Overview

The purpose of the meaning intervention is to promote the psychological adjustment of the patient who has sustained an unexpected traumatic event and his or her family. Through the main strategies of Socratic questioning and therapeutic story-telling, the primary goal is to facilitate the ability to create a meaningful context for what happened. A second goal is to strengthen a sense of personal control, order, and purpose during the course of the intervention.

The meaning intervention may be conceptualized in terms of context, process, and intended outcome. *Context* refers to the patient's and the family's experience before, during, and after the traumatic event. It also refers to the elements that compose the external world (i.e. facts and behaviours) and the internal world (i.e. thoughts, explanations, interpretations, attributions and feelings) of the patient and family, which have been influenced by the traumatic event. The traumatic event serves as the central prism through which patient and family perceptions of their past, present, and future are filtered. Thus, the context of the meaning intervention may be conceptualized as taking place along three main axes: the external world, the inner world, and across time. (See Figure1) 250



Figure 1. Three axes of the meaning intervention

The meaning intervention for families is based on an interactive process that is characterized by two main mechanisms: a Socratic approach by the nurse, and repeated storytelling by the patient and family. The Socratic approach includes a series of systematic questions that invite the patient and family to explore their reactions to the traumatic event from alternative perspectives. Repeated storytelling is the act of sharing the rich, detailed narratives in which thoughts, feelings and behaviours serve as the pathways to understanding the inner world of the patient and family. The repetition allows the patietn and family to shape and shift new perspectives to fit their current or altered life scheme. It is via these mechanisms that the facts, behaviors, thoughts, feelings and the inner world of assumptions and beliefs, may be purposefully explored in relation to their past, present, and anticipated future life. By progressively discovering the key dimensions of these understandings, the patient and family can gradually find meaning in the sudden, unexpected traumatic event they had sustained.

The meaning intervention is guided by four main interviewing principles of circularity, hypothesizing, neutrality, and strategizing (Tomm, 1987, 1988). *Circularity* refers to the dialectcal dialogue between the nurse, and the patient/family, which involves a continual back and forth cycle of asking questions, paraphrasing answers, and noting verbal and non-verbal responses. *Hypothesizing* refers to the cognitive processes involved in seeking connections among observations, reported data, personal experience, and prior knowledge in order to formulate explanations of the phenomenon one wishes to understand. *Neutrality* refers to the balancing of the multiple realities that are explored. This involves remaining open and non-judgmental to the multiple perspectives. *Strategizing* refers to the nurse's ongoing cognitive activities in evaluating the effects of past actions, constructing new plans of action, anticipating the possible consequences of various alternatives and deciding how to proceed at any given moment in order to maximize therapeutic utility. Therefore, everything that is said and done by the nurse, or does not say or do, can have potentially therapeutic or non-therapeutic consequences.

Outcomes may be assessed in terms of a indicators of psychological well-being such as a sense of purpose, a sense of personal competence, a sense of personal control, and self-esteem.

In general, the meaning intervention for families is administered in hourly sessions within a 6 to 8 week period. Each session may address one or more of the 6 key dimensions outlined in Table 1. The nurse will begin and continue from where the patient and family are in their own attempts to cognitively process the traumatic event. Although the key dimensions follow a logical progression, in practice, the nurse will move back and forth among the key dimensions in response to the needs and readiness of the patient and family. There is considerable flexibility in the application of the strategies and key dimensions, however, the first and final sessions delineate specific objectives to be fulfilled prior to beginning or terminating the intervention. To facilitate the continuity between sessions, it is suggested that each session begin with a brief overview of the work accomplished in the previous session. For example, one may ask how they have been since the last meeting and whether they have thought further about the issues discussed. Or one may follow up on a concern expressed in the last session. As well, it is suggested that each session end with a summary of the work accomplished during that session with directions for the next session outlined. Specific objectives and strategies accompanying each key dimension are described in the following sections.

Meaning intervention for trauma patients and their families.



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First Session: Creating the conditions for a therapeutic relationship

Rationale: A therapeutic relationship creates a) a sense of trust or disclosing intimate thoughts and feelings, b) creates an emotionally safe atmosphere, which was likely shattered or challenged by the traumatic event, and c) temporarily alleviate feelings of anxiety that may interfere with future work.

Objective: To establish a therapeutic relationship

Suggested Strategies:

- 1.1 Validate the patient and family's experience
 - Allow patient and family to set the pace, the agenda, and identify where to start
 - Encourage and be open to comments or questions as they arise
 - Acknowledge symptoms as evidence they have been through alot
 - Acknowledge the seriousness of the trauma
 - Validate experience by empathizing with the hurt.
 - Be supportive, caring and non-judgmental
 - Be responsive to and acknowledge clinical cues of engagement or disengagement (anxiety level, affect, eye contact, and fatigue)
 - Ensure patient and family are comfortable, that physical needs and other concerns are addressed

1.2 Educate the patient/family

• Explain what the patient can expect in terms of the trauma experience

For example, state that the psychological aftermath of the accident consists of immediate and delayed emotional reactions

State that these reactions may include feeling numb, angry, out of control, and having frightening images, nightmares, or recollections related to the accident. They may also experience palpitations, lack of appetite, problems sleeping

• Explain the significance of signs & symptoms

State that a trauma is like a 'psychic wound' similar to a physical wound that needs to heal

Normalize these negative symptoms as normal responses to an abnormal situation

Reframe these negative symptoms as coping strategies used by the brain as a part of the recovery process

a sense of losing control indicates there are important things to work on

intrusive memories, thoughts, and feelings are the brain's attempt to make sense of what happened

feelings of denial, numbing, or a sense of disconnectedness is the mind's way of saying 'time out'

feelings of behavioural self-blame will help them figure out what they can change and control in future behavior

• Help anticipate the expected recovery trajectory

Indicate that the situation may feel like it is getting worse before they get better

State that there is no one way to cope, but they will be exploring several possible ways to help get through this experience with a sense of hope and purpose. 255

- 1.3 Provide a sense of personal control
 - Help patient recognize, name, and monitor symptoms

For example, increased heart rate, rapid shallow breathing, inability to concentrate can indicate the existence of negative thoughts or emotions

- Offer coping strategies that help patient manage unwelcomed symptoms -egs. deep breathing, imagery, medication
- Educate about the use of drinking and drugs as a way of coping
- 1.4 Invite the patient and family to share what they would hope to get from these sessions together
 - Ask the question: If you could have just one question answered in our work together, what would it be?

Meaning intervention for trauma patients and their families.

Key Dimension I: Telling the story

Rationale: There are as many perceptions of one event as there are people who experienced it. Encouraging the retelling of stories over many times helps to cognitively process what happened and begins to piece together the fragments of the story to reestablish a sense of reconnectedness. Telling and listening to a story from different perspectives allows the mind to slowly assimilate the unwanted material and process it. Storytelling also allows the patient and family to retain greater control when revisiting the disturbing aspects of the trauma. In general, the Socratic method of asking 'what' questions is utilized to thoroughly draw out the distinct parts of the stories.

Objective 1. To encourage the patient and family member to each share their story **Objective 2.** To examine how their life was before the trauma

versus now; and now versus their imagined future Objective 3. To look for the strengths in the stories

Suggested Strategies:

1.1 Facilitate story-telling by asking about the activities, smells, thoughts, sights, and sounds experienced before, during and after the traumatic event

For example, may ask," Some people find it helpful to talk about what has happened. We might begin by talking about how you are doing... Could you tell me how the memory of the trauma still affects you now?" How do you feel when you remember what happened to you? What images tend to replay inyour mind?

- 1.2 Begin to piece the facts together by reviewing where the patient and different family members were and the happenings leading up to the trauma event
- 1.3 Review how and when they learned about the trauma, what they did, what their first thoughts were; how they felt

1.4 Listen to and validate the importance of the patient's and each family member's experience

For example, nay state "There is no one right way of describing what happened"

- 1.5 Draw a genogram to become familiar with the patient and the family members as the story and points of clarification unfold
- 2.1 Ask whether they had ever experienced anything on the same magnitudeIf so, make the link between their thoughts and feelings now and then
- 2.2 Encourage patient and family to reminisce
- 2.3 Help patient to develop coping self-statements to use or identify a physically safe place to go during the intrusive, disturbing aspects
- 2.4 Encourage patient and family to examine the perceived impact of the trauma on their lives and relationships, and conversely, their influence on dealing with the trauma
- 3.1 Ask what has helped them get through this experience
- 3.2 Highlight and label their strengths
- 3.3 Make the link between these strengths and strengths they identified in other traumatic or distressing events
- 3.4 State given what you have gone through, how have you managed to do so well
- 3.5 Validate their strengths, affirm their capabilities

Key Dimension II. Break the story into manageable parts

Rationale: It is not the facts of the trauma per se that causes emotional distress, it is the interpretations of these facts. Breaking down global perceptions into its component parts allows the cognitive processing to proceed within a less overwhelming and more manageable, controllable pace. By identifying and labeling the often confusing elements, the patient is better able to distinguish the areas over which they have control and can change.

In general, one would progress by first exploring the facts, behaviors, and then the thoughts and feelings related to the traumatic event (i.e. from the not changeable, more objective, less threatening aspects of the outer world to the changeable, inner, intimate world of the patient.

Objective 1. To help break global statements into smaller, manageable, and specific components

Objective 2. To identify and label the facts, behaviors, thoughts, feelings Objective 3. To help patient see what can and cannot be changed

Suggested Strategies:

1.1 Identify global statements or perceptions Ask patient or family member whether they have recurring nightmares, etc.

For example, "I am at my breaking point", "I feel hopeless", "I feel out of control"

1.2 Respond to global statements by asking for further clarification using the Socratic method of inquiry

For example, "Could you clarify what that means?", "In what ways?"

- 2.1 Label the smaller components as a fact, behavior, thought, or feeling
 - Facts are objective, verifiable events of the traumatic experience that cannot be changed. Knowing 'the facts' provides an objective context for understanding what happened. It lends a sense of the tangible or real to a situation that still appears unreal (the denial, shock are still very evident)

- Behaviors are actions by the patient in response to the traumatic event. Behaviors can be interpreted as coping strategies in response to an event and therefore are open to change.
- Thoughts are interpretations of an event that are often shaped by beliefs and assumptions, and conveyed through the use of metaphors. The most powerful element within one's control, thoughts often direct behaviours and feelings.
- Feelings are emotions evolving from one's thoughts about an event; may be internally perceived (i.e. anxiety) or externally manifest (i.e. tachycardia). Changing the thought often changes the emotion.
- 3.0 Educate with respect to the relationship between thoughts and subsequent feelings and behaviors; the potential impact of feelings (anxiety, indicators of physiological response) on thoughts and behaviors
- 3.1 Facilitate the patient's understanding of what can and cannot be changed.
 - For example, the facts of the trauamtic event generally lie outside the ability to control them
 - Thoughts and feelings are part of our inner world, and thus lie within our ability to control them
 - Behaviors are closely influenced by thoughts and feelings and therefore also lie within our potential control.
 - Although one cannot change the fact of accident, one can change our response to it.
 - Distinguish the difference between a stated 'fact' about the self and a belief about the self. For example, 'I am ugly' versus 'I believe that am ugly
- 3.2 Distinguish between positive and negative thoughts and feelings.

- 3.3 Facilitate recognition of the relationship between affective and physiological arousal (increased heart rate, shallow breathing, inability to concentrate) and the presence of negative emotions and thoughts
- 3.4 Promote emotion-focused coping skills for things that cannot be changed

e.g. attention diversion procedures, use of humor, exercise, reframing

3.5 Initiate a discussion about what needs to be done, changed, modified in order to realize goals

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Key Dimension III. Link these behaviors, thoughts and feelings to underlying assumptions and beliefs

Rationale: One's behaviours, thoughts and feelings are often anchored to unquestioned and automatic fundamental beliefs and assumptions about ourselves and how we function in the world. A sudden unexpected traumatic event severely challenges these assumptions and beliefs. The emotional distress and other symptoms of post-traumatic stress reflect cognitive efforts to make sense of what happened. The intent is to externalize the innermost world of the person so that beliefs can be explored and linked to the external world. This process provides the patient and family with a beginning sense of order and control.

Objective 1. To identify the underlying assumptions and beliefs that shape behaviors, thoughts and feelings Objective 2. To strengthen the positive facilitative beliefs Objective 3. To identify the negative constraining beliefs

Suggested Strategies:

- 1.1 Revisit the trauma via repeated storytelling.
- 1.2 Educate the patient and family about the role of beliefs and assumptions
 - Explain that by externalizing the trauma by talking about it shifts it from a random to a controlled experience
 - Beliefs are a way to conceptualize the world
 - Beliefs provide a view that helps us to interpret the world in a way that we can accept
 - Beliefs shape emotions and behaviours
 - Beliefs are not facts or absolute reality
 - Intrusive thoughts are efforts to heal so person can go forward in life
 - Intrusive thoughts can come in the form of dreams, nightmares, etc
- 1.3 Surface core beliefs by identifying the automatic thoughts most closely linked to our emotions

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• By examining the content of their internal conversations

For example, "What kinds of things do you find yourself saying during the day?

• By identifying which parts of the story trigger certain emotions or thoughts For example, "When you have your

disturbing memories of what happened, what is the first thought that runs through your head?"

"You have mentioned how long the days seem in hospital. What thoughts run through your mind about yourself, family, work or school?

By asking for or recognizing the person's automatic thoughts (idiosyncratic, plausible thoughts that contain logical errors in reasoning that come unbidden into the consciousness, (M & G, p. 18)and feelings in a given situation

- overgeneralizations: seeing a single negative event as a never-ending pattern of defeat
- *magnification*: exaggerating the importance of some things, especially other people's strengths and coping abilities
- *minimization*: playing down some things until they appear insignificant, especially own efforts at coping
- *all-or-nothing-thinking*: seeing the world in black and white terms
- *selective attention*: selectively attending to only the negative parts of life while ignoring all the positive things that are happening
- *negative predictions*: assuming the worst
- mind-reading: jumping to conclusions, not finding out what others are actually thinking
- shoulds and oughts: unrealistic expectations of the self and of others that result in guilt, anger or resentment
- labeling: inaccurately applying a critical label to the self, not describing the situation as it is

- personalization: seeing the self as the cause of some negative event for which one is not necessarily responsible
- 1.4 Uncover core beliefs by identifying the metaphors used by the patient and family. Embedded within these metaphors are the thoughts and feelings leading to the core beliefs. Use whenever possible the patient's own words.

For example,

- I am at my breaking point
- I am going to explode
- I am emotionally dead
- I am walking on egg shells
- I am stuck

Distinguish between the fact and the belief that can be changed

Break down the metaphor into component parts

For example, can you clarify what you mean? In what ways do you feel....?

1.5 Ask directly about beliefs

For example, "What do you believe about your family, child, yourself based on our discussion today?"

For example, "What belief about yourself would need to be changed in order to change your thinking, your behaviour?"

- 1.6 Take an expressed core belief and trace it back to a fundamental assumption.
 - May require asking patient to consider what a) thoughts underlie their behaviours, b) what emotions underlie their thoughts, c) what beliefs underlie the emotions, d) what assumptions underlie the beliefs.
 - Be persistent. This may require uncovering beliefs that underlie other beliefs before arriving at the assumption

For example, 'I am going to die' 'Why do you believe that you are going to die?' 'Because I have always been unlucky'

'I think you are different if you are sick'

'In what way are you "different"? 'I always thought if you are sick, there is something weak about you' 'What do you mean by 'weak'? 'There is something defective about the person' "I am eager to get back in the driver's seat. I'm not used to being so inactive. "I think I can regain control of my life again." "I am willing to work at change"

"I still believe in a sense of order that hard work leads to positive results"

Category of Assumption Primary Assumption Postulate Benevolence of The world is basically Perceived positive or negative benevolence of the impersonal

1.7	Look for other fundamental assumptions might be
	variations of the following:

.1 11	11	1
the world	world	
	Benevolence of	People are basically
	people	good, kind, helpful and
		caring
Meaningfulness	Distributional	How good and moral
of the world	principle of	one is determines how
	justice	vulnerable one is
	Distributional	People can directly
	principle of	control their world
	controllability	through their own
		behaviours
	Distributional	There is nothing one can
	principle of	do or be that will protect
	randomness	someone form negative
		outcomes
Worthiness of	Self worth	I am basically a good,
the self		moral, worthy, decent
		individual
	Self	I act responsibly and
	controllability	always do only good
	_	
	Luck	I am basically a lucky
		person
		-
	-	

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families.
2.1 Acknowledge the patient and family's ability to manage in spite of what they have gone through

For example, may state "Given what you have told me about the last few days, what has been the hardest for your family and you to bear? What do you believe has made it most difficult? How did you manage to find the strength to cope with it all?

2.2 Identify the positive metaphors and highlight them as soon as the patient states them

For example, metaphors that signify the person wants to find closure are: I want to fill in the gaps I need a sounding board I want to find a future I want to join the world I want to get back in the driver's seat I want to take charge of my life again

- 2.3 Give positive feedback to model and reinforce the use of positive thoughts.
- 2.4 Create new metaphors to synthesize the essence of the patient's story or to highlight his or her strengths to reinforce a sense of control

For example, "I hear the rock of Gilbralter speaking. How did you do this given what you have been through already?"

2.5 Label facilitative beliefs as strengths that have sustained the patient or helped him or her to survive each day

For example, "What do you believe has helped you the most to deal with ...?" "You took the initiative to do... You were able to develop a strategy, How did this happen? What did you do, or tell yourself to get through that tough time?"

2.6 Explore and examine the ways that these strengths have aided the person in his or her own life

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2.7 Strengthen the facilitative belief by sharing a shared belief

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- 2.8 Strengthen the facilitative belief by making links between the belief and behaviour, thought or feeling
- 3.1 Link the negative thoughts, feelings, and metaphors to negative beliefs
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Key Dimension IV. Fitting new perceptions of the traumatic event within current framework of beliefs and assumptions

Rationale: When confronted with new information from the traumatic event, the natural tendency is to attempt to incorporate new information within an existing framework of beliefs and assumptions. This natural tendency toward assimilation rather than ccommodation (see Key Dimension VI) derives from a fundamental need to resist change, and to maintain a sense of stability, a sense of order and personal control.

Objective 1. To help the patient see that there are different ways to perceive and interpret a situation Objective 2. To help patient and family reframe aspects of the traumatic event

Objective 3. To fit new perceptions within current framework of inner world

Suggested Strategies:

1.1 Educate about the mutability of beliefs

Beliefs are derived from myths, family legends, and Beliefs are frequently derived from an exaggerated or distorted sense of actual reality Beliefs tend to offer one rigid perspective but not the absolute truth

For example, may want to ask a patient to describe the characteristics of a prejudiced person: i.e. a) they attend selectively to data b) overgeneralize facts c) use stereotypes d) do not accept data incompatible with their own. T he nurse then wonders whether these characteristics are being used by the patient to describe himself/herself

- 1.2 Listen for, highlight and label the positive thoughts, behaviours and accomplishments of the person and family
- 1.3 Ask patient to imagine the consequences of the opposite of their negative beliefs

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- 1.4Repeatedly re-telling their story of their place during the crisis event by, general discussion, keeping a diary, writing down feelings, thoughts, facts may allow different perspectives to emerge
- 1.5Ask alternative-based questions

For example, Can you think of any other possible explanations for what happened? What would your pre-trauma self say to you now? What does it mean or suggest to you?

- 2.1 Re-frame patient/family meanings of event and its implications for the future
 - Reframe symptoms perceived as abnormal responses as normal 'protective coping mechanisms"
 For example, state "Given what you have been through, if you were not distressed, I would be worried.'
 - Reframe negative feelings as strengths For example, "I am depressed" is reframed as "The fact that you recognize you are feeling this way and you are talking about it is a strengths

3.1 Ask evidenced-based questions

• Collaborate with patient to test 'hypotheses' by asking for data to justify their beliefs

For example, if patient says, I must be a 'bad' person to have something like this happen to me. The nurse may point out the inconsistencies in this belief by drawing on patient's previous revelations: "I am a bit confused by what you have said given your acts of kindness to others, taking care of your sister, etc."

Ask for evidence that 'serves' as the alleged basis for the negative belief I am a bad person. I am a dumb person Ask for evidence that 'proves' the belief

For example, What makes you think this? What evidence from your life do you have? 269

You say but you also tell me that you managed to do...... I do not understand. How do you put these two things together?

- 3.2 Ask *implication-based* questions
 - Nurse helps patient to take their initial beliefs about themselves and carry them to their (il)logical conclusion.

Persist until patient realizes that she or he has magnified negative implications, that given all the good things they have done or the achievements they have had, that he 'negative' belief about the self simply does not fit.

For example, "... and if that were so, why would it be so upsetting to you? What would it mean to you?"

Key Dimension V. Letting go of the past, looking towards the future : the search for new beliefs and assumptions

Rationale: Pre-trauma assumptions and beliefs that previously provided a snse of order to one's life may no longer sustain the facts of the traumatic event. Therefore new beliefs and assumptions must be created to accommodate the traumatic event.

Objective 1. To recognize and grieve the losses, assumptions and beliefs that no longer fitObjective 2. To set the groundwork for being future-orientedObjective 3. To help patient and family search and adopt new assumptions and beliefs

Suggested Strategies:

- 1.1 Acknowledge the suffering and difficult aspects of the traumatic event
- 1.2 Explore fears about real or possible losses of the patient as formerly known
- 1.3 Acknowledge the physical and symbolic losses sustained in the present and in the envisioned future, related to the traumatic event
 - Ask how things were before the trauma, and what might have been
 - Explore concerns especially related to family roles, finances, future goals
 - Explore the impact of the changes in functioning since the traumatic event
- 1.4 Acknowledge the personal and individual nature of grief reactions across family members
- 2.1 Introduce the concept of "beginning with endings"
 - Acknowledge the paradox that good may sometimes be derived from bad
 - Invite the client and family to reflect on whether they can envision any good that can come out of the tragedy
 - Ask patient to describe the positive thoughts, feelings and experiences specific to the trauma

For example, "This next question may seem a little shocking or strange to some of you. But I have learned from other families who have been through similar experiences, that they are able to take away something positive from such negative experience. I've been wondering if that is so in our case, in your family?"

- 2.2. Draw a life line with the anchors "birth date" at one end and "today's date" at the other end. Ask client to label this line with pivotal, important happenings in his or her life which had a strong meaning for him or her in the past. How have these milestones been dealt with in the past? Are there any coping strategies that can be transferred from the past to the current situation?
- 2.3 Draw another life line with the anchors "today's date" at one end and "death date" at the other end. Ask client to label this second line with their projected future goals and aspirations. How does the current trauma influence or affect these goals?
- 2.4 Ask client to imagine who they were 5 years ago and to try to remember What they believed in, valued most, or their goals then. Ask whether these same beliefs, values, goals, still hold true or are some discarded as a result of changes? How are they different now? How have they grown as a result of these discarded beliefs that no longer "fit"? Have they noticed "gaining" anything as a result of past losses? In what ways specifically?
- 3.1 Identify the assumptions or beliefs that cannot explain the trauma
- 3.2 Label the new assumption to be adopted
- 3.3 Create or reinforce an ability to maintain control whenever possible

Emphasize the learning that has taken place May state, "You are the same person with capabilities to overcome adversity" 272

For example, for a patient who suffered a traumatic MVA, the assumption of being a lucky person, or of invulnerability can not account for the accident. The new assumption to be adopted is that he or she is vulnerable, etc. However, they have learned that they have strengths to be able to cope

3.4 When the conceptual leap is large, couch the facilitative belief in small increments

For example, For the next 10 minutes, if you were to believe that you had no pain, how would you feel? ", "What would happen if the pain was less 10%? … if you believed you were 50% more of a better person?"



Key Dimension VI. Embed new beliefs in future goals

Rationale: Finding meaning involves linking a sense of order with a sense of purpose.

Objective 1: To link new beliefs and assumptions with a sense of purposeObjective 2. To begin living with new beliefs and assumptions

Objective 3: To mobilize external resources

Suggested Strategies:

- 1.1 Identify important patient and family goals
- 1.2 Identify short and long terms goals
- 1.3 Explore with patient and family how new beliefs can be facilitators towards achieving a goal
- 1.4 Explore the goals and dreams of the previous life to reframe them to fit current realities
- 2.1 Highlight the implications of having found meaning for the future
 - Shift in defining the self from victim to survivor.
 - Acting as a helper to others
 - Becoming a spokesperson on behalf of others
 - Attribute recovery process to the person, commending person
- 2.2 Empower the client by strengthening coping strategies in general
 - Allow client to assert a sense of personal control whenever possible
 - Identify appropriate coping strategies to fit situation: use rehearsal, role-playing, modeling techniques
 - May ask what have they learned about their ability to survive from this experience
- 2.3 Help patient and family to anticipate possible situations in the future that may be difficult to experience (e.g. anniversary dates, reminders of trauma)

- 2.4 Help patient and family to anticipate how to problem-solve when future triggers are encountered
 - Encourage patient to identify coping strategies that they could apply to deal with each part
 - Distinguish coping strategies that are functional/dysfunctional versus beliefs interfering with recovery
 - Ascertain what actually is interfering with recovery (could be interpersonal or intrapersonal)
 - Ask patient to rank order and discuss each
 - Determine what contextual factors led to the use of a given coping strategy
 - Explore the outcome of using the coping strategy in terms of feelings, thoughts, beliefs about the self

2.5 Apply imaginary relapse exercises (Dolan, 1991)

- Imagine the causes of possible relapses occuring
- Imagine how they would feel, and what thoughts contribute to feeling that way
- Ask patient what he or she would do to 'contain' the relapse and prevent it from actually happening.
- Point out that these relapses are 'conditioned' response to special stimuli.
- 2.6 Rehearse the use self-monitoring and analytic techniques (stimuli, emotions, feelings, thoughts, internal dialogue)
- 2.7 Promote other possible problem-solving coping approaches (anxiety management, anger management)
- 2.8 Use modelling techniques (live or videotaped)
- 3.1 Identify external resources to enhance success of goal attainment
- 3.2 Underline the importance of allowing others to be present, close to the patient
- 3.3 Strengthen and use support from significant others; ask who has been most helpful to themWhat do they do that is helpfulWhether support was sufficient
- 3.4 Encourage a sense of connectedness among significant others.
- 3.5 Help patient develop own resources; role play, model supportive behaviors

Final session: Concluding the meaning intervention with beginnings

Rationale: Explicitly reviewing the areas of progress reinforces the idea that aspects of change can be positive and within one's control. Surviving significant losses can lead to opportunities for growth.

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Objective 1. To enhance the patient and family's feelings of empowerment and a renewed sense of control

- *Objective 2.* To highlight the significance of the patient's and family's new meanings to the choices they make in their personal life
- Objective 3. To highlight a future orientation and direction

Suggested Strategies:

- 1.1 Highlight evidence of healthy growth and development made by the patient and family
 - Review with the patient and family what they have learned during the intervention, particularly in relation to :
 - their inner world (assumptions, beliefs about ourselves and the world, feelings, personal strengths)
 - their outer world (comprised of facts, external resources)
 - the link between the inner and outer worlds (between feelings and behaviors; what we believe and what we can do or cannot do; what we can or cannot control)
 - new meanings (sense of order, sense of purpose, goals, and future directions)
 - strategies that can be used for dealing with challenging situations

1.2 Review strengths and reinforce a sense of personal control

- Review the ways that these strengths have aided the patient and family throughout their lives , and during this time of crisis
- Highlight the beliefs and meanings that have sustained the patient, helped him or her to survive each day. For example, review how situations that were within the control of the patient were reframed
- Punctuate situations where the patient and family made own contributions towards constructive changes

For example, statements like "You took the initiative to do......", "You were able to develop a strategy for...", "you willed yourself to get through that tough time", may be followed by asking the patient to identify his or her reasons, stimuli, or cues to make that choice, " How did this happen. What did you do..." Meaning intervention for trauma patients and their families.

2.5 Review the link between meanings and personal choice

- Encourage patient and family to tell their story of their experience of the traumatic event now as compared to how they told it before having found meaning in it
- Encourage patient and family to reflect on how these new meanings will influence their future responses to choices, and possibilities in the future
- Inquire about others noticing changes in the patient as a result of surviving these losses
- Invite patient to hypothesize about how others see him or her now since adopting new beliefs
- 2.6 Review different ways in which the patient and the family might put their learning to use

For example, by sharing their learned experiences with others, volunteering, raising money for similar cause, etc

- 2.7 What kinds of internal conversations do they have now?
- 2.8 Offer observations of how the nurse has seen client change and grow
- 2.9 Commend and highlight the client/ family's wisdom and progress
- 2.10 Point out how this client / family's strengths are significant from other families with similar experiences
- 3.1 Highlight the importance of living for the future and not in the past

- 3.2 Review and normalize anticipated aspects of the patient's and family's on-going process of adjustment and adaptation following the trauma
 - Reaffirm the notion that there will good and bad times in the future, but that they have acquired useful strategies to deal with them

For example, they may still experience general feelings of let down, feelings of discouragement, or vulnerability

- Reinforce strategies learned for dealing with negative intrusive thoughts and feelings
- 3.3 Explore patient and family's plans for the future

Appendix

Questions serve as clinical probes that enable the patient to come up with his or her own solutions, or ideas of what needs to be discussed. Generally begins with 'what' and 'how' questions, rarely 'why'.

i. Questions to help client tell the story

Can you tell me what happened?

Tell me everything you feel I need to know in order that you feel I understand what happened

Only tell me what you want to share, we can stop anytime Can you tell me how things were before the accident.

ii Questions aimed at the lingering aspects of the event

Could you describe how things have been, changed since we spoke

In what ways do you feel you were different before the accident Are there specific aspects of the event that have lingered for you, for your family and relationships

Could you tell me how the memory of the accident still affects you now

iii Questions aimed at re-framing

Although you have been through quite a terrible time, did any good come out of it?

Are there things that you have learned from this ordeal that makes it at least a more tolerable?

In your opinion, was the experience as bad as it could possibly be or could it have been worse?

Has anything happened that makes you feel a little lucky

iv Questions aimed at identifying and developing strengths

Can you recall a time in your life when you were almost overwhelmed/overcome by/ swallowed up by a problem and you managed to cope / manage it/ stay the course

What effect did these strategies have on your feelings/ emotions/ thoughts ?

What have you done to cope with..... what worked what did not....an you use what did work again

What helps you recognize 'signs' of recovery?

What will you be doing, thinking, feeling, saying that are signs of recovery?

What else needs to happen for you to feel(better, safe, etc) What could you do feel think or say when you feel this way? What do you need to remember *to tell yourself* in order to feel okay?

How did you get past the last set of flashbacks?

v. Questions aimed at generating coping strategies (getting patients to id coping efforts by describing his or her relationship with a significant other

Get person to describe a 'special' relationship with a significant other

Ask them "what this person sees/ likes about the patient (encourage specificity)

What would this person's advice to the patient consist of? Agree with this good advice

Discuss ways to implement this advice

Discuss possible obstacles that could get in the way What could be done to get rid of these obstacles?

vi. Questions to help the client set goals

What do you feel you need to do in order to take more control, ...more responsibility of your life?

Have you ever wondered what are the risks if you do not change?

How would you like to change things

What goals do you think you should be working on? Given your new knowledge and what you have learned about yourself, what things can you do to start taking more charge of your life? ...use the patient's own positive metaphors What difference will doing this make to your next steps in healing?

vii. Questions designed to help the client take a different perspective

Do you know others who have experienced this.....How did they handle it?

What other explanations could account for what happened Of the explanations we have talked about, which one do you think makes the most sense to you.

viii. Questions designed for family members

How have members of the family been doing What has been the impact on the family How committed are family members How much affection is there in the family How flexible are family roles How much do family members support one another

Appendix E. A Meaning-Making Intervention (MMI) for Cancer Patients



A Meaning-Making Intervention for Cancer Patients

Introduction

Through the process of meaning-making strategies, this manual provides health professionals with a cognitive-based intervention to accompany people in the process of coming to terms with a diagnosis of cancer. Careful session by session strategies are described to guide patients through the normal and sometimes disturbing psychological reactions associated with the diagnosis and experience of living with cancer. These strategies are supported by broad theoretical models and empirical evidence derived from the oncology and trauma related literature.

A sense of meaning is a basic, human motivation that allows one to understand the self and one's relationship to the world against a constantly changing backdrop of life events. Often one's beliefs and assumptions about the self and the world are unquestioned and tacitly applied on a daily basis. Only when these beliefs and assumptions are challenged, such as with the diagnosis of an unexpected life threatening event, does one become aware of the order that is required in one's surroundings to reach important life goals. Finding a sense of meaning in a life-threatening situation has been shown to minimize the potential to develop more serious symptomatology in the future.

Purpose

The overall purpose of this intervention is to facilitate the cognitive transition of knowing a life free of cancer to preparing to live a life of uncertainty because of cancer. The objectives of the meaning intervention are to 1) provide a secure context from which to revisit what has happened since the diagnosis of cancer, and grieve shattered assumptions, 2) incorporate the cancer experience within a familiar framework of past challenges, and discover resources in past traumas, and 3) reestablish a sense of commitment towards life goals in the face of uncertainty and one's mortality.

Theoretical Framework

The theoretical framework for the meaning intervention is based on an integrative model that synthesizes the cognitive processing model of post-trauma reactions (Creamer, Burgess & Pattison, 1992), the cognitive models of life schema (Thompson & Janigian, 1988) and assumptive worlds (Janoff- Bulman, 1989) and the McGill Model of Nursing (Gottlieb & Rowat, 1987). The life schema is an abstract representation developed over the course of one's life that provides the basis of one's understanding (i.e. a sense of order), goals and expectations about oneself _

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and of the world (i.e. a sense of purpose). The life schema is also thought to include the basic assumptions about the self, the world and one's relationship to the world. In particular, the content of this assumptive world involves basic beliefs about one's self-esteem, sense of control, the benevolence of the world and the benevolence of people in general.

The experience of an unexpected traumatic event threatens the physical integrity and security of one's life by presenting the previously unquestioned life scheme with challenging and inconsistent information. The attempt to assimilate and accommodate the new information is believed to occur through the processing of intrusive reminders of the event. Escape and avoidance are coping strategies in response to the discomfort caused by the intrusive reminders. The cognitive processing usually initiates a search for meaning to reconstruct the shattered life scheme.

Finding meaning involves a two component process. First, it helps the patient to understand how the facts of the trauma follow in an orderly fashion from one's behaviours, thoughts, feelings, beliefs and assumptions. Secondly, it allows the patient to use this understanding to reach important life goals. Finding meaning is linked to learning to cope with traumatic life events via the strategies of repeated storytelling and Socratic questioning. These strategies embrace a collaborative approach in working with patients and families to work towards achieving life goals in the face of adversity, and are consistent with the concepts of health, collaboration, growth and development, important elements of the McGill Model of Nursing.

Assumptions

The meaning intervention is based on the assumptions that: 1) The mind and body are an integrated, communicating whole, 2) people are motivated and capable of working towards self-healing and higher levels of health, 3) a sense of meaning in life is a basic, fundamental human need.

Philosophical Underpinnings

The meaning intervention is based on a philosophy of constructivism which subscribes to the notion of multiple subjective realities. This position believes that each person views an event or object through a pair of subjective lenses. What is claimed to be "objective" is actually interpreted and translated through a person's set of values, beliefs, and past experiences. There can be many constructions and views of any one event, the ultimate truth or falsity of which cannot be determined. Alternatively, the possibilities for change expand when equally legitimate views and "realities" can be appreciated. MMI for cancer patients

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The philosophy of constructivism is characterized by two aspects: hermeneutics and dialectics (Guba, 1990). The hermeneutic aspect attempts to capture the individual constructions as accurately as possible through detailed storytelling. The dialectical aspect consists of comparing and contrasting these individual constructions, including that of the facilitator's, with the aim of generating one or a few constructions on which there is substantial consensus.

Timing

The search for meaning is theorized to begin immediately upon impact of experiencing a life threatening event, and therefore, needs to be addressed as early as the patient feels ready. Some people experience post- trauma reactions such as recurrent intrusive thoughts, disturbing memories, or feelings of numbness that challenge the person's representation of a meaningful world (i.e. beliefs and assumptions of how the world works), and undermine the patient's integrity as a person (Janoff-Bulman, 1989; Thompson & Janigian, 1988). The unexpected and immediate nature of these symptoms are hypothesized to represent a natural and requisite cognitive processing of an unexpected, lifethreatening event (Creamer, Burgess & Pattison, 1992). Patients can be educated about and accompanied through the experiencing of these distressing symptoms as part of the healing process.

The strategies associated with the first task in this intervention are designed to be delivered as soon after the cancer diagnosis has been received by the patient. Patients are provided with at least a beginning context from which to understand the mind's attempts to process information and to recoup a sense of security to move forward. Evidence that the patient has entered into a secure context with the facilitator is indicated by the patient's voice predominating the discussion, presence of cues of engagement such as eye to eye contact, upper body leaning forward, lowered voice, and perception of timelessness.

Strategies

The change agent in the process of searching for and finding meaning is not the health care professional. The change agent is the patient who is the expert in living with the illness. The health care professional is merely the facilitator of this process. Because each individual is unique, each lived experience of cancer will unfold uniquely. Each of the strategies are respectfully offered and it is left to the discretion of the patient to decide which to implement and experiment with.

The strategies used to facilitate the search for meaning are embedded within the deliberate construction of personal narratives via the Socratic questioning technique. This is a form of inquiry that encourages the patient to describe how events unfolded as he or she understands it, and to verbally translate into language his or her perceptions and feelings about what happened. The rich, detailed narratives in turn provide the health professional with a window to understanding the inner world of the patient. One advantage to this form of story-telling is to provide the patient with the discretion to revisit and master only those elements that he or she is ready to acknowledge. Another benefit to storytelling is that events are circumscribed which then require the same idea or event to be rephrased and viewed from potentially adaptive alternative perspectives. It is believed that the repetitive narratives allow the patient to shape and shift new perspectives to fit their current and altered life scheme. This cognitive approach is directed primarily at reshaping the feelings, thoughts, and beliefs under a set of circumstances that cannot be undone. These strategies are embedded in a life review process that centers on the person's previous experiences, current life events, and future implications for the person.

The storytelling and Socratic questioning techniques are guided by four main interviewing principles: circularity, hypothesizing, neutrality, and strategizing (Tomm, 1987a,b; 1988). Circularity refers to the conversational flow between the intervener and the patient which involves a continual back and forth cycle of asking questions, paraphrasing answers, and noting verbal and non-verbal responses. Hypothesizing refers to the cognitive processes involved in seeking connections among observations, reported data, personal experiences, and prior knowledge in order to formulate explanations of the phenomenon one wishes to understand. Neutrality refers to the balancing of the multiple realities that are explored and the openness to receive multiple perspectives. Strategizing refers to the facilitator's constant evaluation of the effects of past actions, construction of new plans of action, anticipation of possible consequences to various alternatives, and decisions as to how to proceed at any given moment in order to maximize therapeutic utility.

Sequence

Integrating a traumatic event can sometimes be impeded by the patient's belief system. Core beliefs that promote and / or interfere with the patient's assimilation of the cancer event may need to be explored in further depth. Situating how these beliefs facilitate or impede one's present acceptance of the cancer diagnosis (Task I), tracing back to when these beliefs about perceived control, self-efficacy and self-esteem developed (Task II) are important to understanding one's responses in the future (Task III). 286

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Task II : Contemplate the Past

Figure 1. The three tasks to cognitive integration of a traumatic event

Although some strategies may be revisited in subsequent sessions, it is necessary to follow the order of tasks as presented. The sequence of tasks is designed to reflect the natural direction of transitions. For example, it is necessary to acknowledge and grieve one's losses prior to recognizing new opportunities. The strategies also follow a sequence of exploration that separates and examines events from the least threatening to the most threatening. The less threatening elements refer to the facts and symptoms which are objective, not amenable to change and are not a reflection on the patient's sense of self. These are explored first. In contrast, the feelings and beliefs about what the cancer means are more distressing and more threatening to acknowledge because these have implications for the patient's definition of self and future goals. These elements may be examined only after therapeutic trust is established and the patient feels sufficiently secure to engage in further self-exploration.

It is possible to address each task within one session. However each session should not exceed more than 2 hours. Patients can be advised about the possible drain of energy and fatigue following discussions that exceed 2 hours. Whenever possible, a summary of the topics already covered and objectives for the next session should be provided to the patient several minutes prior to terminating each session. It is recommended that each session begin by asking the patient for feedback about the last session. For example, whether the patient continued to think about what was discussed after the last session or whether the last session was discussed with a third party following the session. It is recommended that the patient is provided with the time line exercise, and a letter that highlights the strengths and goals as a way to terminate in the last session.

Definitions

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Automatic thoughts are rapid, brief thoughts, words or images that pass through one's mind. The most superficial level of cognition Usually inaccurate or uncritically accepted as true.

Behaviors are actions by the patient in response to the traumatic event. Behaviors can be interpreted as coping strategies in response to an event and therefore are open to change.

Beliefs are the interpretations or explanations created by the patient. Beliefs may take the form of automatic thoughts, intermediate beliefs or core beliefs. These beliefs are thought to shape the perception of an event, the emotional reaction, and the type of coping strategy to be employed. An ability to come to terms with shocking and senseless situations depends on the fit between the person's beliefs and assumptions about the world and the self, the stressful situation, and the social context. 'Positive' beliefs promote the patient's recovery by strengthening the person's belief in him or herself to accomplish important goals. In contrast, 'negative' beliefs impede recovery by limiting one's potential to accomplish important goals.

Core beliefs are the most fundamental beliefs in one's view of the world. These core assumptions guide the formation of facilitative or constraining beliefs which are generally unquestioned and unchallenged prior to a crisis event.

Facts are objective, verifiable events of the traumatic experience that cannot be changed. An awareness of the facts provides an objective context for understanding what happened. It lends a sense of the tangible or reality to a situation that still appears unreal.

Feelings are emotions evolving from one's thoughts about an event; may be internally perceived (i.e. anxiety) or externally manifest (i.e. tachycardia). Changing the thought often changes the emotion.

Finding meaning refers to both the ability to find a sense of order and a sense of purpose. A sense of order refers to the beliefs in an orderly, predictable, and stable world in which resides a perceived sense of control. A sense of purpose refers to a sense of commitment to pursue important life goals. Thus finding a sense of meaning following a traumatic event refers to the ability to find and weave together three central elements of order, control and purpose in seemingly senseless circumstances. Because meanings are also thought to shape the person's use of cognitive and behavioral coping strategies, they are a key determinant of the patient's psychological recovery.

Intermediate beliefs are often unarticulated attitudes, rules or expectations about the self, others, or the world.

Life scheme refers to the person's cognitive framework or representation of life in terms of the events that have happened to them, the goals they have reached, and the goals they wish to attain (Thompson & Janigian, 1988). It is based on an evolving set of values, beliefs and assumptions shaped by personal experiences as well as by family and significant others. The purpose of a life scheme is to provide an interpretative context for events that happen. It shapes how we see oneself (i.e. the self-concept), how we 'understand' the world (i.e. the world view), and helps create a sense of order and purpose.

Strengths are personal and social resources that the patient draws on to actualize his or her potential. Among the patient's potential personal resources are the values and beliefs that may be viewed as positive meanings in stressful situations.

Traumatic event refers to any unexpected threat to one's psychological or physical integrity which may be accompanied by temporary or permanent changes to one's personal life. A traumatic event challenges a person's values, beliefs, and assumptions about the world and the self. It challenges beliefs that the world is orderly, controllable, just, and stable. A traumatic event lies outside one's life scheme.

Thoughts are interpretations of an event that are often shaped by beliefs and assumptions, and conveyed through the use of metaphors. The most powerful element within one's control, thoughts often direct behaviours and feelings.

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Meaning Making Strategies for Cancer Patients

Task I : Acknowledge the present

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OBJECTIVE:	To provide a secure context to revisit what has happened since the diagnosis of cancer
RATIONALE:	 Telling one's story allows the mind to slowly accommodate and assimilate new and possibly threatening material Telling one's story allows the patient to selectively revisit disturbing aspects in a controlled rather than random manner Understanding what happened to the self reestablishes a sense of order in the present Grieving one's losses initiates the process of acceptance and growth
STRATEGIES :	1. Normalize and explain the significance of symptoms
	The aftermath of a diagnosis of a life- threatening illness is like a psychological wound that is similar to a physical wound that needs to heal
	These reactions may consist of repetitive thoughts about parts of the cancer experience, feeling numb, anxious, angry, out of control, or sick to the stomach
	Reactions may be immediate or delayed
	The inability to think of nothing else except the cancer is actually one strategy used by the brain to try to process the information and attempt to make sense of what happened
	The feelings of numbness, disconnectedness, and dreamlike state are the mind's way of saying 'Time out, this is too overwhelming and I need a break'

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- These symptoms are a normal response and are concrete evidence that the person has been through an unexpected shock
- Does any of this sound familiar to you? Have you experienced anything of this sort recently?
- Sometimes it may feel like it is getting worse before it gets better

2. Introduce concept of transitions

- The transition process consists of 3 stages that must be traveled at one's own pace
 - Endings: A time to recognize losses. The acknowledgment of endings may be saddening, uncomfortable and stressful.
 - The Neutral Zone: A time for reorientation. One may feel disconnected from the past and unconnected to the present. This may feel like a lonely, solitary process.
 - New Beginnings: A time to recognize opportunities and launch new priorities. A sense of rebirth is often experienced.
 - □ Where do you see yourself now in this transition?

3. Introduce cognitive model with specific focus on meaning

A person's emotions and behaviours are influenced by his or her perception of events. It is not the actual situation that determines what people feel, but rather the way they construe, interpret or think about the situation. 291

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- The usual course of exploration involves identifying and examining the outermost layer and then, proceeding to the innermost core, presumably from the least threatening to the more threatening aspects of the cancer experience.
- Less threatening are facts and symptoms which are objective and not amenable to change. In contrast, how a person feels or what he or she thinks the cancer means is more threatening to acknowledge and should be explored after a sense of security has been established.
- The patient may need to be educated about the role of beliefs
 - Beliefs are not facts but they do provide a view that helps interpret the world
 - Beliefs are learned expectations, values, obligations from our family and society
 - Beliefs shape emotions, behaviors and even physiological responses. For example, what we ordinarily believed to be automatic body responses, like blood pressure, heart rate, respiratory rate, has been shown to be regulated by one's mind through techniques of biofeedback, hypnosis, relaxation
- Beliefs provide the greatest leverage for insight and change
 - Sometimes it is not the illness that is the problem, it is what you believe about it that is the problem
 - When your body feels run down, you feel stressed, sad maybe miserable.

That means that your body can influence how you think and feel. What about the other way around? Can your thoughts influence your body?

An awareness of our beliefs provides a mechanism for the validity of their existence and their influence on how the patient is reacting to their diagnosis and living with cancer

> □ It may feel like your life is on hold now because it is hard to envision what the future may look like. It can be difficult to change the way we think because who we are has been shaped by our past experiences early in life. It is hard to go against lifelong emotional habits. However, it is important to remember that if these thoughts were learned. they can be unlearned, especially if they are not useful for your recovery. It would therefore be worthwhile to try to step back as an observer of your own emotions and responses to examine what is happening to yourself.

4. Encourage storytelling of cancer experience

- A chronological review of the events that occurred from the diagnosis up until the present allows the patient to review only those parts that he is ready to deal with and provides the perception of a sense of control and order that may have been lost.
- Help complete gaps in narrative by helping patient seek out missing information from family, staff, and others whenever possible
 - □ This is an opportunity for you to talk and to help you make sense of what

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happened. We might start by talking about when your experience with cancer began?

- □ How would you describe how the cancer affected your life ?
- Enrich recall of experience by asking pt to describe :
 - Emotions
 - How did you feel when you first noticed the first symptom or first heard the word 'cancer' from your doctor?
 - Behaviours
 - Do you remember what you were doing or what you did immediately after?
 - Physiological responses
 Did you experience any physical reactions when...?
 - Thoughts
 - When you think about the cancer, what are some of the thoughts or memories that pop into your head?
- Enrich recall of experience by asking pt to consider :
 - First recognition / discovery of symptoms leading to seeking medical help
 - □ What happened or how did you discover the cancer?
 - What did you think it was initially?
 - Influence of age at time of diagnosis
 Would your response be any different had you been diagnosed earlier (or late) in your life?

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- Family history
 - □ Is there a history of cancer in your family?
 - □ Had there been other kinds of major illnesses your family before?
- Intrusive / recurrent thoughts
 - Some people can think of nothing else but the cancer when they are first told of their diagnosis.
 Did that happen to you?
 - What percentage of the day would you say you are preoccupied with thinking about the cancer?
 - When do you think about the cancer the most?
 - When you have disturbing memories of the cancer, what do you think about? How does it leave you feeling?
 - How did you sleep the first night you found out you had cancer? Do you have any strange or recurring dreams?
 - What kinds of internal conversations did you have in the beginning?
- Experience of time and of waiting
 - How did the days pass for you until the surgery/ your doctor's appointment?
 - Do you remember how you got to the doctor's office or how you got home?
- Relationship with hospital personnel and how it affected their response

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- Reactions of others and how it affected their response
 - Who have you told about the cancer? Who did you not tell? What influenced your decision to tell them and not others?
 - When and how did they react when you told them ? How did that make you feel?
- Surroundings and how it affected their response
 - What do you remember about your environment and how did it affect how you felt or what you thought?
- Disruption of normal life routine and how it affected their response
 - How has the cancer altered or not altered your routine in your everyday life?
- Reaction to cancer treatment (surgery, chemotherapy, anticipatory nausea, radiation therapy)
 - What was it like for you waiting for/ actually undergoing X therapy?
 - What were you expecting the treatment to be like?
 - What was the worst part about X? And what did that mean to you? What did that mean about you?

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- Clarification of myths or misconceptions with facts may diminish fears and allow open discussion
- Help identify and acknowledge the physical and symbolic losses sustained in the present and envisioned future as a result of the cancer (for example, hair, breast, normal bowel pattern, career, friends, daily routine certainty, control, etc).
- Help patient to imagine him /herself confronting the aftermath of his or her greatest fear. Then jump ahead in time, envision what might happen in 6 months, 5 years, 10 years and 15 years after the great fear has happened. Follow up with asking how he or she feels after having envisioned confronting it ?

6. Listen for, highlight, and label metaphors

- Listen for the metaphors the patient uses to name and frame their life with cancer. Metaphors often describe the problem as well as imply possible solutions
 - What does this experience remind you of ? What is it like for you to live day by day?
 - For a person who feels slowed down by the cancer, the solution must have the quality of helping to get things going again
- Positive metaphors suggest a core belief that indicates the person has a 'fighting spirit'
 - o For example,
 - □ I'm just sort of putting one foot in front of the other
 - □ I want to think that I'm on track

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- I'm now a caterpillar in my cocoon and one day I'll be that butterfly.
- 7. Identify automatic thoughts, intermediate beliefs and core beliefs about the self, other people and the world by use of Socratic questioning techniques
 - Listen and look for beliefs underneath "affective leakage"
 - Ask "what underlies that belief?" to delve into core beliefs
 - Automatic thoughts: Rapid, brief thoughts, words, or images that go through a person's mind in a specific situation. The most superficial level of cognition. Usually inaccurate and uncritically accepted as true (See Appendix A)
 - What was your first thought when ---? What went through your mind when ...eg .you were first given your diagnosis?
 - □ What things trigger strong emotions within you?
 - What images remain with you since you've been in hospital or in treatment? What thoughts accompany those images?
 - What kinds of things do you think about when you wake up in the middle of the night?
 - What kinds of things do you find yourself saying to yourself during the day or when you have more time to think?

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 Intermediate beliefs: Often unarticulated attitudes, rules and expectations by which one lives

- Did you ever ask yourself 'why' this happened to you?
- □ What is the reason you believe you have cancer?
- What did cancer mean to you before you were diagnosed?
- □ What does cancer mean to you now?
- Where do you think the cancer came from? What do you believe caused the cancer?
- □ Where did you learn about your current knowledge of cancer?
- Listen for if -then", or "should" statements
 eg. If you get older, you have more money but then you have worse health and more fragile
 eg. I should cry and be in a deep depression
 eg. If I didn't drink, didn't smoke, then this would not have happened
- Core beliefs : Global, rigid, most fundamental ideas about the self, others and the world. Can be facilitative or debilitating to one's sense of self and perception of goal attainment. Provides the (See Appendix B)
 - What does having cancer mean <u>about</u> you?

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8. Relate automatic thoughts, intermediate and core beliefs to emotions and behaviours > Encourage patient to observe rather than react to their thoughts □ What is your gut feeling about how you are going to get through this? • How do you think you would feel if you believe in a positive belief? • How would believing in a negative belief affect how you will act? • What belief needs to be reconsidered and possibly changed in order to change any behaviours or thoughts to help you feel stronger? 9. Help distinguish what can or cannot be changed Although we cannot change the facts of the cancer, we can change our response to it. Offer copy of the "serenity prayer" (Appendix C) • Our feelings and behaviors lie within our ability to change because they are closely influenced by our thoughts which lie within our control. Help patient to label facts, behaviours, feelings, and thoughts, and one's potential for change **D** There is a process of learning what you can change and when to take a "we'll see" attitude. Your rights, your individuality, insisting on being treated with

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respect, having your questions answered, are things you owe to yourself that can be changed. Then there are some outcomes of the cancer that cannot be changed. For this, consider taking a 'we'll see' attitude because maybe the reason for its occurrence may not be apparent immediately, or it may be apparent in a few days, maybe a year later, even maybe for the next generation.

- □ What percentage of the future is under your control ?
- What percentage of the daily decisions is under your control?
- Which decisions do you need to control to be able to meet your daily tasks?
- Help patient to distinguish the difference between a perceived 'fact' about the self and a "belief" about the self. For example, 'I am worthless' versus 'I believe that I am worthless'
- When patient is attributing cause to what happened, listen for statements of behavioural self blame (which are actions that are amenable to change in the future) as opposed to characterological self blame (which refer to a stable personality characteristic and is less amenable to change)
- Promote emotion- focused strategies for things that cannot be changed
 - What can you do to allow you to learn to live with what cannot be changed?

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OBJECTIVE: To incorporate the new cancer experience within an existing framework of past challenges **RATIONALE:** 1. Reflection upon one's life acknowledges what was previously perceived as improbable and incompatible with one's understanding of the self and the world 2. Symptoms reflect the mind's way of challenging the natural tendency to resist change and maintain a sense of stability 3. Reflecting on how past challenges were overcome may allow one to realize similarities and strengths that can be applied to the present challenge of living with the cancer Strategies: 1. Formulate a timeline by identifying significant turning points from birth to present > Draw a life line with the anchors "birth" at the extreme left, "today" in the middle, and "death" at the extreme right. Ask the patient to think of pivotal life events in his or her past which had a strong impact on his/her life. (Use Appendix D) Possibilities for the future are opened up through the uncovering of past illness experiences Label these events with the date as they are described For example, Birth Father's Cancer diagnosis Death (Today's date) Death (Year) • *Have you ever experienced anything* of this magnitude before?

Task II : Contemplating the past

- What do you remember about your childhood?
- Can you think of another time when you felt the same way as you do now?

2. Encourage story telling of pivotal life events

- Enrich recall of events by asking to describe the emotions, behaviours, physiological responses they remember feeling
- Identify automatic thoughts, intermediate beliefs, core beliefs for each event identified in timeline
 - Can you describe some of these experiences?
 - What do you remember feeling at the time?
 - What do you remember thinking at the time?
- 3. Identify coping strategies used in the past (eg. sense of humour, religious faith, hope, downward comparison vs upward comparison, alternative treatments)
 - When strengths are identified, they are more likely to be maintained.
 - Considering all that has happened to you recently, how have you managed to get this far?
 - What do you suppose has allowed you to lead this good life so far? How much do you attribute your success to your effort and how much to luck?

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What do you believe allowed you to overcome/survive these earlier challenges?

- Where do you believe you derive your strength?
- What do you believe others remark on when they say that you are strong?
- What is your definition of strong?
- The fact that you were able to make it to this point is evidence or testament to your strength.
- Do you surprise yourself with what you are able to get through?
- Perhaps you had accumulated a lot of strength from having lived through the past challenges, but these were not called upon until something of this magnitude happened to you.

4. Bring to light any links between prior life experiences and present experience

- Enquire about the patient's interpretation of these prior life events
- Enquire if he or she notices any similarities and /or differences
 - Considering all that you had been through, how do you think you dealt with all these challenges?
 - Is the cancer a different challenge on a different level? Or are there similarities with what you have experienced in the past?
- Explore the present significance of the links for the patient

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- What do you feel or think about when you look back at these past events? How is this past event connected to how you feel now?
- Do you think you made the right decisions in hindsight?
- Let's imagine that (these past pivotal events) did not happen in your past, how do you think you might handle the cancer now?

5. Explore the degree of fit between prior core beliefs and present situation

- Identify inconsistencies between what happened now and the patient's previous belief system
 - There is a tendency to accept information that fits with existing views and to reject information that contradict with existing views
 - What "psychological grooves or ruts" do you see yourself returning to in times of stress or uncertainty?
 - Sometimes we need to let go of living the life as we perceived it before and view life in another way.
 - What did cancer mean to you before you were diagnosed? What does it mean to you now? It sounds like your beliefs are changing.
 - Prior to this experience, did you think that bad things only happened to other people?

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- Are you living differently from how another person you know with cancer is living it?
- Who do you believe is in charge of your medical decisions? Who would you like to be in charge?
- Had you ever thought about your own mortality?

6. Challenge negative core beliefs with Socratic questioning

- Help patient assess the impact that a negative core belief is having on his or her experience with cancer.
 - □ When does this belief surface?
 - How does it make you feel?
 - □ What do you do when you think about that?
 - How much does this belief have over you? How much control do you have over this belief?
- Assess whether patient wants to change the belief
 - On a scale of 0-100%, how strongly do you believe in that belief?
 - On a scale of 0-100%, how much is it affecting your life?
 - □ On a scale of 0-100%, how much do you want to change this belief?
- When the conceptual leap is large, entertain new beliefs in small doses
 - Imagine just for the next 10 minutes, ...
 How do you think you would feel if you were more _____ 50% of the time?

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- Provide strategies to challenge rigid core beliefs.
 - How useful is it to have that belief?
 What would be a more useful response to have?
 - □ If that's true, so what?
 - □ What's so bad about __?
 - □ What's the worst part about __?
 - What purpose is this belief serving for you?
 - What if this happened to your best friend? Would you expect the same rules apply?
 - Is that a fair comparison to you? Do you suppose your best friend should be as hard on herself as you are to yourself?
 - Try jumping ahead in time and imagine carry that belief to its conclusion. What will you do? How would you feel? Your loved ones may feel grief, but not emptiness.
 - What percentage of what happens is due to luck versus as a result of your own effort?
 - □ What if you thought the opposite of what you think may happen?
 - What is the evidence to support your belief that---? We have a tendency to find support what we already believe.

7. Reinforce positive core beliefs

Acknowledge that the patient's ability to manage despite all that he/ she has gone through is linked to positive core beliefs about the self

- Identify positive core beliefs (eg. You can be healthy despite physical illness) or offer hypothetical facilitative beliefs
- Provide evidence from previous assessment of patient's story to substantiate core beliefs
- Highlight positive core beliefs and meanings that have sustained the patient to survive each day
- Identify situations where the patient made own initiative towards constructive changes. Ask what these decisions were based upon?
 - Every day since the diagnosis is now proof or evidence that you are able to fight the cancer
 - Your beliefs demonstrate you have a fighting spirit
 - Given all that you have been through, the fact that you surviving one day at a time, is testimony to your strength as a person
 - What do you think of when you are going through that difficult event?
 - What do you think of afterwards?
 - Would you describe yourself as a sick or healthy person?

8. Identify learning that had taken place (greater perspective on life, mortality, making self a priority, etc)

The ability to find something positive out of the cancer experience provides a sense of order and purpose to the suffering 310

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- Acknowledge the paradox that something good can sometimes come out of bad
 Invite reflection on whether anything useful
- or helpful for themselves or for others can be learned from this event

eg I thought I needed to control everything to live.

eg. I think we put too much emphasis on everything having to have an answer.

- Invite reflection on any opportunities to take something positive out of this cancer experience
 - Illness will, not can, but will change your life. Let it change it in a positive way.
 - It seems as if you realize now that some things have changed now about how you define cancer, about your sense of vulnerability, about who is in charge of your health...
 - What were some assumptions about yourself or about other people that have changed after these events?
 - What have you learned about yourself / other people / the world after having gone through these past turning points?
 - What have you learned from seeing other people deal with or surmount similar or other major illnesses?
 - Do you believe you are a different person since being diagnosed with cancer and all that you have experienced?
 - Have you grown as a result of these discarded beliefs that no longer "fit" with how you view life?

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- Are you better off with this way of thinking?
- It sounds like you have learned about the limits of your control, about when to change when to leave something and take a 'we'll see' attitude.

9. Finding meaning

- Cancer gives some people the opportunity to re-evaluate their lives as to what is meaningful and do something about it if they are not satisfied
 - A serious illness is about putting your life back on the path to self-realization
 - It makes you stop and wonder if you are still on-purpose or off-purpose?
 - What place in your life have you made for the illness ? (How much effort, time and attention are you giving it?)
 - Are you living alongside the illness? (Is it not as overwhelming anymore?)
 - Have you put it in its place? (Have you integrated it in your life?)
- Provide analogy of cancer as a touchstone a fine-grained black stone that merchants would scratch gold across to determine the value of the gold. The cancer is like the stone you pull your life across to decide what is of value to you.
 - What was meaningful for you before the cancer happened? What is meaningful for you now ?
 - What do you love to do? What is stopping you from doing what you want? How can you retain what you love to do?

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MMI for

- What would make this all worthwhile for you?
- Now more than ever, you realize you are mortal. Think of the value of your time.
- How far can you imagine your future? Imagine yourself X years from now, the worst thing that can happen is to have regrets. What do you not want to regret X years from now?
- Awareness of automatic thoughts are also a clue for identifying or prioritizing what is important at this time in life
 - So much has happened to you so far. What has kept you going? How have you endured or persevered the way you have?
 - When you notice that you are feeling anxious, sad, or angry, what is going through your mind?
- Identify thoughts or images of the patient's story that recur or trigger strong emotions
 - What do you suppose causes you to have such an intense reaction?
 - What kinds of thoughts are you preoccupied with during the day

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MMI for

Task III : Live th	e present, for	r the future		MMI for cancer
OBJECTIVE:	To reestabl meeting at mortality	reestablish a sense of commitment towards beeting attainable goals in the context of one's contrality		
RATIONALE:	 Acknow an impetus meaningfu Acknow life prioriti Acknow decisions to 			
STRATEGIES:	1. Comple future	ete timeline from present to er	ivisioned	
	•	· · · · · · · · · · · · · · · · · · ·	— —•	
	Birth	Today Goals:	Death	
		Spend more time w Work less, play mo	ith son re	
	➢ To of u to a	be able to focus on the future ir uncertainty and life threatening allow the patient to experience h	1 the face illness, is 10pe	
	> Ide	entify goals in light of uncertain	ty	
	> Exp	plore different paths towards go	als	
	> Bre	eak down goals into steps		
	List to	sten for statements beginning wi	th "I want	
		What do you see in your future	?	
		When we are faced with our or mortality, how does that influe you will live now?	wn ence how	

- What are your goals for the future?
 Which ones take priority?
- What is important for you to focus on now?
- □ What are your responsibilities now?
- How easy is it to say 'no' to family and friends?

2. Help confront future fears

- Identify and explore fears in the future
- Help to anticipate how she or he would problem solve when future fears are encountered
- Inform patient that distress is a conditioned response to familiar stimuli
- What are the strategies that he's learned to deal with them?
 - □ How do you feel when you think about the future?
 - Are there any questions left that are going through your mind but that we had not talked about yet?
 - Sometimes, people believe that if we talk negatively about the future, the negative will happen. So they don't talk about it as a way controlling it and keeping it at bay. On the other hand, by talking about it, saying it out loud, we can examine this belief, and see how useful it is to believe that. We can reduce the power and grip of fear by speaking about it.
 - What thoughts would contribute to how you might feel when you confront a fear like recurrence?

MMI for

- □ How will you deal with uncertainty?
- □ How will you live between doctor's appointments?
- □ When will you know when to put this ordeal behind you?
- □ Goals are to experience life, not to avoid dying.
- Some people believe that death is not the worst outcome, it is not living fully is the worst.
- Are you asking to cure yourself? Or to care for yourself?
 If you are asking to cure yourself, what are you curing yourself for? What is stopping you from doing that now instead of waiting until later?
 If you are caring for yourself, you reap the rewards now, and maybe living this way may increase survival time too. You win both ways.

3. Review survival tools

- Highlight cognitive tools, internal resources
- Label facilitative beliefs as strengths that have sustained the patient or helped him or her to survive each day
- Reinforce support system, external resources
- Imagine how survival tools can be useful or called forth in times of future stressors
- Suggest writing these down
 - Acknowledging past losses and past vulnerabilities is proof that you had found the means or strength to get through it.

MMI for cancer patients

- Knowledge is frightening for some people. However it is what you do with the knowledge that makes a difference. Do you use it to support your positive beliefs or as evidence for your negative beliefs?
- How do you feel when you think of a positive belief? How does it feel to think of a negative belief?
- □ What do you believe has helped you the most to deal with this ordeal?
- Who has been there the most for you to deal with this?
- You took the initiative to You were able to think things through, problem solve, develop a strategy to...
- □ What did you tell yourself to get through that particular tough time?
- Who do you listen to now? Yourself? Your friends? Your body?

4. Create new positive metaphors

Use patients' own words or analogies from patient's life to symbolize new perspective in life

> Eg. While on vacation in Hawaii , one patient had to prepare for a possible hurricane, which never happened. However, her preparations to live safely through the hurricane became a perfect analogy to her preparations for a possible recurrence.

MMI for

cancer



5. Introduce concept of wisdom

- Provide definition of wisdom as being able to make important life decisions in the face of uncertainty
- Inquire how they think others see them and explain why
- Highlight and commend progress and changes made since first session
- Offer time line exercise to keep and therapeutic summary letter
- Introduce idea of using this wisdom to heal the self, others, because it provides a sense of hope
 - Those who have looked death in the eye are those who know most about living
 - What would you say are your pearls of wisdom?
 - How do you think what you have been through has affected or can affect other people's lives?
 - How would you have responded if someone like yourself approached you early when you were first diagnosed and told you how they survived this whole ordeal?
 - What do you know now that you didn't know before you had cancer?
 - What experiences do you need to cultivate now?
 - □ It is your attitude that makes you exceptional.

MMI for cancer

Appendix AA

Examples of Automatic Thoughts

Overgeneralizations: seeing a single negative event as a never-ending pattern of defeat Magnification: exaggerating the importance of some things, especially other people's strengths and coping abilities

Minimization: playing down some things until they appear insignificant, especially own efforts at coping

All-or-nothing-thinking: seeing the world in black and white terms

Selective attention: selectively attending to only the negative parts of life while ignoring all the positive things that are happening

Negative predictions: assuming the worst

Mind-reading: jumping to conclusions, not finding out what others are actually thinking Shoulds and oughts: unrealistic expectations of the self and of others that result in guilt, anger or resentment

Labeling: inaccurately applying a critical label to the self, not describing the situation as it is Personalization: seeing the self as the cause of some negative event for which one is not necessarily responsible

Appendix BB Examples of Core Beliefs

Category of	Primary Postulate	Core Belief
Assumption		
Perceived	Benevolence of the impersonal	The world is basically
benevolence of	world	positive or negative
the world		People are basically good,
	Benevolence of people	kind, helpful and caring
Meaningfulness	Distributional principle of justice	How good and moral one is
of the world		determines how vulnerable
	Distributional principle of	one is
	controllability	People can directly control
		their world through their own
	Distributional principle of	behaviours
	randomness	There is nothing one can do
		or be that will protect
	2	someone form negative
		outcomes
Worthiness of the	Self worth	I am basically a good, moral,
self		worthy, decent individual
	Self controllability	I act responsibly and always
		do only good
	Luck	I am basically a lucky person

MMI for cancer

Appendix CC. Lifeline exercise.

MMI for cancer patients



Appendix EE. Meaning Intervention Audit

Task 1: Acknowledge	the Pres	sent		
Date	Sessio	n		
1	1	2	3	4
Normalize				
psychological				
trauma				
Explain symptoms of				
psychological trauma				
Introduce cognitive				
model				
Introduce concept of				
transitions				
Begin narrative of				
cancer experience				
Acknowledge present				
losses				
Highlight metaphors				
Identify automatic				
Thoughts (AT)				
Identify intermediate				
beliefs (IB)				
Identify core beliefs				
(CB)				
Link ATs, IBs, CBs to				
emotions, behaviours				
Coping strategies:				
Distinguish what can				
or cannot change				

MMI for cancer patients

Date	Sessior	<u>ן</u>		
	1	2	3	4
1. Begin timeline from				
birth to present				
2. Begin narrative of				
pivotal life events				
Identify past coping				
strategies				
Acknowledge past				
losses				
Identify link between				
past life events and				
present cancer				
experience				
6. Explore fit between				
beliefs and present				
cancer experience				
7. Help challenge				
negative core beliefs				
Reinforce positive core				
beliefs				
9. Identify learning				
10. Introduce concept				
of finding meaning				

MMI for cancer patients

Date	Sessio	n			
	1	2	3	4	
1. Complete timeline from present to future					
2. Review survival tools					
3. Confront future fears					
Create new positive Metaphors					
Introduce concept of					
wisdom					

Appendix F. Certificates of Ethical Approval

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Appendix F1. Ethical approval for pilot study from the McGill Institutional Review Board and independent hospital sites



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Subject Identification # _____

Consent to participate in a research study

A NURSING CARE STUDY BASED ON FINDING MEANING

IN THE EXPERIENCE OF CANCER

INVESTIGATORs:

Virginia Lee, N., M.ScA., Ph.D. (candidate), School of Nursing, McGill University

- Robin Cohen, Ph.D. Medical Scientist, McGill University Health Centre Assistant Professor, Dept. Oncology, McGill University
- Linda Edgar, Ph.D. Assistant Professor, Nursing, McGill University Research Associate, Dept. of Psychiatry, SMBD Jewish General Hospital Research Consultant, Hope and Cope, SMBD Jewish General Hospital

This study is being conducted at the Montreal General Hospital, Royal Victoria Hospital, SMBD Jewish General Hospital and St. Mary's Hospital Center.

DESCRIPTION:

Sometimes people find it difficult to make sense of the cancer experience and all that is involved, and wonder how this illness will affect or change their lives. One way that some people have found useful to cope is to talk to someone else about what is happening to try to make some sense out of it. You are being invited to take part in this study because of your personal experience with cancer.

The purpose of this research study is to provide an opportunity for you to discuss whether and how the cancer experience has changed your outlook and goals in life, and for you to gain any benefits that may result if you feel you have been able to make sense of your experience. For the researcher, the purpose is to learn whether nursing care that offers this type of discussion is helpful and how it can be improved.

PROCEDURE:

If you agree to take part in this study, you will be asked to answer a set of 11 questionnaires the first time we meet and then the last time we meet. These

Subject Identification #_

questionnaires include information about your background and your thoughts and feelings related to the impact of cancer on your life. Answering the questionnaires will take approximately 60 minutes to complete each time. You may complete the questionnaires at home, and I will pick them up from you 24 - 72 hours later.

You will also be asked to meet with me for a minimum of 3 and a maximum of 8 times. Each session can last between 10 minutes to one hour. How long and how frequently we meet will be decided at your discretion. We may meet on a daily or weekly basis, but we should meet at least once every 2 weeks. These meetings can take place in the privacy of your own home, or at a private location in the hospital or clinic before or after you meet with your physician.

Your permission is needed for me to audio tape our sessions so that I and my supervisors may study the content of the discussions, and to make sure that the interviews are being conducted in a similar fashion across participants. The tapes will be erased after studying them, and no one but the researchers will have access to them. There will be no identifying information on the tapes.

Your permission is also requested for me to access your medical chart to obtain information about your disease status.

BENEFITS:

It is not known at this time whether this type of nursing care, as given in this study, will be helpful. However, we are hoping that this care will help you make sense of what is happening and help you to cope with it.

You may not directly benefit from participating in this study. However, the results of this study might help health professionals better understand and design ways to help people with cancer.

RISKS:

There are no known risks associated with this study. However, you may feel sad during some of the meetings because of the nature of the discussion. You are free to stop the interview, continue at a different time, or withdraw from the study at any time without interfering with the nursing or medical care you are receiving. You will be provided with the name of a psychologist or nurse should you wish to have further follow-up at the end of the study.

CONFIDENTIALITY

Everything that you discuss and all identifying information that will be collected from the medical charts will be kept strictly confidential. Your anonymity will be assured by having only the study identification number appear on the questionnaires. Only the investigators associated with this study will have access to the information gathered in the study.

Subject Identification # _

SUBJECT RIGHTS:

Your participation in this study is completely voluntary. *Refusal to participate will involve no penalty or loss of benefits and will not affect your care in any way.* You have the right to ask questions at any time. You have the right to refuse to answer any question that is upsetting or difficult to answer. Should you need help or more time, this will be provided to you.

A member of the Research Ethics Committee may check our records to make sure that your rights are protected.

If you have more questions about the study, please feel free to call Virginia Lee at 304-7767 or Dr. Robin Cohen at 842-1231 ext. 5158. Any questions about the study may also be directed to the Patient Representative of your hospital. At the *Royal Victoria Hospital*, the Patient Representative is Pat O'Rourke and can be reached at 842-1231 ext. 5655. At the *Montreal General Hospital*, the Patient Representative is Ms. Danielle Lamy. She may be reached at 934-8306. At the *SMBD Jewish General Hospital*, the Patient Representative is Ms. Liane Brown. She may be reached at 340-8222 ext. 5833. At *St. Mary's Hospital Center*, the Patient Representative is Ms. Monique Robitaille. She may be reached at 734-2618.

You will be given a copy of this form for your records. At the end of the study, you may receive a written summary of our findings at your request.

STATEMENT OF THE PARTICIPANT:

By signing this form, I agree to participate in this study as outlined above. I am satisfied with the information that I have received about the study. My decision to be a part of this study is completely voluntary. My signature means that I give permission for Virginia Lee to audio-tape the interview sessions as well as to consult my medical chart. I also have had an opportunity to ask questions and they were answered to my satisfaction.

		/ /
Name of Participant (print)	Signature	Yr/Mio/Day
		<u>/ /</u>
Name of Investigator	Signature of Investigator	Yr/Mo/Day
	Page 3 of 3	

Subject Identification =



THE SIR MORTIMER B. DAVIS -

JEWISH GENERAL HOSPITAL

A NURSING CARE STUDY BASED ON

FINDING MEANING

IN THE EXPERIENCE OF CANCER

CONSENT FORM - PAGE 1 OF 4

Investigators:

Virginia Lee, N., M.ScA., Ph.D. (candidate), School of Nursing, McGill University

Robin Cohen, Ph.D. Medical Scientist, McGill University Health Centre Assistant Professor, Dept. Oncology, McGill University

Linda Edgar, Ph.D., Assistant Professor, Nursing, McGill University Research Associate, Dept. of Psychiatry, SMBD Jewish General Hospital Research Consultant, Hope and Cope, SMBD Jewish General Hospital

This study is being conducted at the Montreal General Hospital, Royal Victoria Hospital, SMBD Jewish General Hospital and St. Mary's Hospital Center.

DESCRIPTION:

Sometimes people find it difficult to make sense of the cancer experience and all that is involved, and wonder how this illness will affect or change their lives. One way that some people have found useful to cope is to talk to someone else about what is happening to try to make some sense out of it. You are being invited to take part in this study because of your personal experience with cancer.

The purpose of this research study is to provide an opportunity for you to discuss whether and how the cancer experience has changed your outlook and goals in life, and for you to gain any benefits that may result if you feel you have been able to make sense of your experience. For the researcher, the purpose is to learn whether nursing care that offers this type of discussion is helpful and how it can be improved.

PROCEDURE:

We intend to recruit 40 participants for this study. If you agree to take part in this study, you will be asked to answer a set of 11 questionnaires the first time we meet and then the last time we meet. These questionnaires include information about your background and your thoughts and feelings related to the impact of cancer on your life.

(Version, May 1, 2000)

Subject Identification #



THE SIR MORTIMER B. DAVIS -

🖇 JEWISH GENERAL HOSPITAL

A NURSING CARE STUDY BASED ON

FINDING MEANING

IN THE EXPERIENCE OF CANCER

CONSENT FORM - PAGE 2 OF 4

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Answering the questionnaires will take approximately 60 minutes to complete. You may complete the questionnaires at home, and I will pick them up from you 24 – 72 hours later.

You will also be asked to meet with me between 3 and 8 times. Each session can last between 10 minutes to one hour. How long and how frequently we meet will be decided at your discretion. We may meet on a daily or weekly basis, but we should meet at least once every two weeks. These meetings can take place in the privacy of your own home, or at a private location in the hospital or clinic before or after you meet with your physician.

Your permission is needed for me to audio tape our sessions so that I and my supervisors may study the content of the discussions, and make sure that the interviews are being conducted in a similar fashion across participants. No one but the researchers will have access to the tapes and there will be no identifying information on the tapes. The tapes will be kept for a duration of one year following completion of the study and will be erased after studying them.

Your permission is also requested for me to access your hospital medical chart to obtain information about your disease status that is relevant to the study.

BENEFITS:

It is not known at this time whether this type of nursing care, as given in this study, will be helpful. However, we are hoping that this care will help you make sense of what is happening and help you to cope with it.

You may not directly benefit from participating in this study. However, the results of this study might help health professionals better understand and design ways to help people with cancer.

(Version, May 1, 2000)



THE SIR MORTIMER B. DAVIS – JEWISH GENERAL HOSPITAL

A NURSING CARE STUDY BASED ON

FINDING MEANING

IN THE EXPERIENCE OF CANCER

CONSENT FORM - PAGE 3 OF 4

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Subject Identification #

RISKS:

There are no known risks associated with this study. However, you may feel sad during some of the meetings because of the nature of the discussion. You are free to stop the interview. continue at a different time, or withdraw from the study at any time without interfering with the nursing or medical care you are receiving. You will be provided with the name of a psychologist or nurse should you wish to have further follow-up at the end of the study.

CONFIDENTIALITY

Everything that you discuss and all identifying information that will be collected from the medical charts will be kept strictly confidential. Your anonymity will be assured by having only the study identification number appear on the questionnaires. Only the investigators associated with this study will have access to the information gathered in the study.

SUBJECT RIGHTS:

Your participation in this study is completely voluntary. *Refusal to participate will not affect your medical or nursing care in any way.* You do not give up any of your legal rights by signing this form. You have the right to ask questions at any time. You have the right to refuse to answer any question that is upsetting or difficult to answer. Should you need help or more time, this will be provided to you.

A member of the Research Ethics Committee may check our records to make sure that your rights are protected. If you have any questions regarding your rights as a research participant, you may contact the patient representative, Ms. Lianne Brown at 340-8222 ext. 5833

If you have more questions about the study, please feel free to call Virginia Lee at 304-7767 or Dr. Robin Cohen at 842-1231 ext. 5158. A copy of this form will be given to you for your records. At the end of the study, you may receive a written summary of our findings at your request. ST.MARY'S HOSPITAL CENTER 3830 Avenue Lacombe, Montreal, Quebec, H3T 1M5

Consent to participate in a research study

A NURSING CARE STUDY BASED ON

FINDING MEANING IN THE

EXPERIENCE OF CANCER

Subject Identification #				

Investigators:

Virginia Lee, N., M.ScA., Ph.D. (cand.), School of Nursing, McGill University

- Robin Cohen, Ph.D. Medical Scientist, McGill University Health Centre Assistant Professor, Dept. Oncology, McGill University
- Linda Edgar, Ph.D., Assistant Professor, Nursing, McGill University Research Associate, Dept. of Psychiatry, SMBD Jewish General Hospital Research Consultant, Hope and Cope, SMBD Jewish General Hospital

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DESCRIPTION:

Sometimes people find it difficult to make sense of the cancer experience and all that is involved, and wonder how this illness will affect or change their lives. One way that some people have found useful to cope is to talk to someone else about what is happening to try to make some sense out of it. You are being invited to take part in this study because of your personal experience with cancer.

The purpose of this research study is to provide an opportunity for you to discuss whether and how the cancer experience has changed your outlook and goals in life, and for you to gain any benefits that may result if you feel you have been able to make sense of your experience. For the researcher, the purpose is to learn whether nursing care that offers this type of discussion is helpful and how it can be improved.

PROCEDURE:

If you agree to take part in this study, you will be asked to answer a set of 11 questionnaires the first time we meet and then the last time we meet. These

Subject No. ____

questionnaires include information about your background and your thoughts and feelings related to the impact of cancer on your life. Answering the questionnaires will take approximately 60 minutes to complete each time. You may complete the questionnaires at home, and I will pick them up from you 24 – 72 hours later.

You will also be asked to meet with me for a minimum of 3 and a maximum of 8 times. Each session can last between 10 minutes to one hour. How long and how frequently we meet will be decided at your discretion. We may meet on a daily or weekly basis, but we should meet at least once every two weeks. These meetings can take place in the privacy of your own home, or at a private location in the hospital or clinic before or after you meet with your physician.

Your permission is needed for me to audio tape our sessions so that I and my supervisors may study the content of the discussions, and to make sure that the interviews are being conducted in a similar fashion across participants. The tapes will be erased after studying them, and no one but the researchers will have access to them. There will be no identifying information on the tapes.

Your permission is also requested for me to access your medical chart to obtain information about your disease status.

BENEFITS:

It is not known at this time whether this type of nursing care, as given in this study, will be helpful. However, we are hoping that this care will help you make sense of what is happening and help you to cope with it.

You may not directly benefit from participating in this study. However, the results of this study might help health professionals better understand and design ways to help people with cancer.

RISKS:

There are no known risks associated with this study. However, you may feel sad during some of the meetings because of the nature of the discussion. You are free to stop the interview, continue at a different time, or withdraw from the study at any time without interfering with the nursing or medical care you are receiving. You will be provided with the name of a psychologist or nurse should you wish to have further follow-up at the end of the study.

CONFIDENTIALITY

Everything that you discuss and all identifying information that will be collected from the medical charts will be kept strictly confidential. Your anonymity will be assured by having only the study identification number appear on the questionnaires. Only the investigators associated with this study will have access to the information gathered in the study.

Subject No.

SUBJECT RIGHTS:

Your participation in this study is completely voluntary. *Refusal to participate will involve no penalty or loss of benefits and will not affect your care in any way.* You have the right to ask questions at any time. You have the right to refuse to answer any question that is upsetting or difficult to answer. Should you need help or more time, this will be provided to you.

A member of the Research Ethics Committee may check our records to make sure that your rights are protected. Any questions about the study may be directed to the Patient Representative of your hospital. At the Royal Victoria Hospital, the Patient Representative is Pat O'Rourke who can be reached at 842-1231 ext. 5655. At the Montreal General Hospital, the Patient Representative is Danielle Lamy. She may be reached at 934-8306. At the SMBD Jewish General Hospital, the Patient Representative is Liane Brown. She may be reached at 340-8222 ext. 5833. At St. Mary's Hospital Center, the Patient Representative is Monique Robitaille. She may be reached at 734-2618. Also at St. Mary's Hospital Center, you may contact Maureen Fitzgerald at 345-3511 ext.5010 if you require further answers to questions related to the research.

If you have more questions about the study, please feel free to call Virginia Lee at 304-7767 or Dr. Robin Cohen at 842-1231 ext. 5158.

You will be given a copy of this form for your records and another copy will be placed in your medical chart. At the end of the study, you may receive a written summary of our findings at your request.

Appendix F3. Ethical approval for randomized controlled trial from the McGill Institutional Review Board and independent hospital sites
Appendix F4. Approved consent forms used for RCT



Centre universitaire de santé McGill McGill University Health Centre

A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

CONSENT FORM

INVESTIGATORS:

Virginia Lee, N., M.ScA., Ph.D. (candidate), School of Nursing, McGill University
 Robin Cohen, Ph.D. Medical Scientist, McGill University Health Centre
 Assistant Professor, Dept. Oncology, McGill University
 Assistant Professor, School of Nursing, McGill University
 Linda Edgar, Ph.D. , Assistant Professor, School of Nursing, McGill University
 Research Associate, Dept. of Psychiatry, SMBD Jewish General
 Hospital, Research Consultant, Hope and Cope, SMBD Jewish

This study is being conducted at the Montreal General Hospital, Royal Victoria Hospital, SMBD Jewish General Hospital and St. Mary's Hospital Center.

DESCRIPTION :

Sometimes people find it difficult to make sense of the cancer experience and all that is involved, and wonder how this illness will affect or change their lives. One way that some people have found useful to cope is to talk to someone else about what is happening to try to make some sense out of it. You are being invited to take part in this study because of your personal experience with cancer.

The purpose of this research study is to provide an opportunity for you to discuss whether and how the cancer experience has changed your outlook and goals in life, and for you to gain any benefits that may result following these discussions. For the researcher, the purpose is to learn whether nursing care that offers this type of discussion is helpful.





A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER



CONSENT FORM

PROCEDURE:

We intend to recruit 136 participants for this study. If you agree to take part in this study, you will be asked to answer a set of 6 questionnaires the first time we meet and the last time we meet. These questionnaires include information about your background and your thoughts and feelings related to the impact of cancer on your life. The questionnaires usually take less than 30 minutes to complete.

After you have completed the questionnaires, you will be randomly assigned to either the "treatment group" or the "control group". If you are assigned to the "treatment group", the sessions with the nurse will begin as soon as the questionnaires are returned within 48 hours. You will be asked to meet with the nurse between 1 and 4 times. How long and how frequently you meet will be decided at your discretion. These meetings can take place in the privacy of your own home, or at a private location in the hospital or clinic. You will then be asked to complete the set of questionnaires a second time after the sessions end. If you are assigned to the "control group", you will be asked to complete the questionnaires a second time after an approximate one month delay. Following this, the nurse will offer to meet with you for one session lasting up to 2 hours, to discuss how you are coping, which some people find helpful.

Your permission is needed to audio tape the sessions so that the nurse and her supervisors may study the content of the discussions to make sure that the interviews are being conducted in a similar fashion across participants. No one but the researchers will have access to the tapes and there will be no identifying information on the tapes. The tapes will be kept in a locked cabinet for a duration of one year following completion of the study and will be erased after studying them.

Your permission is also requested to access your hospital medical chart to obtain information about your disease status that is relevant to the study.

PAGE 2 OF 4

A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER



CONSENT FORM

BENEFITS:

It is not known at this time whether this type of nursing care, as given in this study, will be helpful. However, we are hoping that this care will help you make sense of what is happening and help you to cope with it.

You may not directly benefit from participating in this study. However, the results of this study might help health professionals better understand and design ways to help people cope with cancer.

RISKS:

There are no known risks associated with this study. However, you may feel sad during some of the meetings because of the nature of the discussion. You are free to stop the interview, continue at a later time, or withdraw from the study at any time without interfering with the nursing or medical care you are receiving. You will be provided with the name and phone number of a psychologist or nurse at your hospital should you wish to have further follow-up at the end of the study.

CONFIDENTIALITY:

Everything that you discuss and all identifying information that will be collected from the medical charts will be kept strictly confidential. Your anonymity will be assured by having only the study identification number appear on the questionnaires and information collected from the chart. Only the investigators associated with this study will have access to the information gathered from the individuals in this study.

SUBJECT RIGHTS:

Your participation in this study is completely voluntary. *Refusal to participate will not affect your medical or nursing care in any way.* You do not give up any of your legal rights by signing this form. You have the right to ask questions at any time or you may refuse to answer any question that is upsetting or difficult to answer.

A member of the Research Ethics Committee may check the study records to make sure that your rights are protected. If you have any questions regarding your rights as a research participant, you may contact the patient representative, <u>Danielle Lamy</u> at <u>934.8306</u> (extension —) at your hospital <u>Monthead</u> General Hespited

PAGE 3 OF 4

A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER



CONSENT FORM

Subject # :

If you have more questions about the study, please feel free to page Virginia Lee at 304-7767, or call her supervisor, Dr. Cohen at 842-1231 (ext. 5158). A copy of this form will be given to you for your records. At the end of the study, you may request a written summary of the study findings.

STATEMENT OF THE PARTICIPANT:

Date: / / / ___ / ___

I agree to participate in this study as outlined above. I am satisfied with the information that I have received about the study. My decision to be a part of this study is completely voluntary. I have had an opportunity to ask questions and they were answered to my satisfaction.

Print Name of Participant

Signature of Participant

This consent form was administered and explained in person by:

Print Name of Investigator

Signature of Investigator

By signing this form, I also give permission for Virginia Lee to :

(b) consult my hospital (a) audio-tape the interview sessions medical chart. __1

YES NO YES NO SMBD – JEWISH GENERAL HOSPITAL DEPARTMENT OF NURSING



A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

CONSENT FORM

Investigators:

Virginia Lee, N., M.ScA., Ph.D. (candidate), School of Nursing, McGill University
 Robin Cohen, Ph.D. Medical Scientist, McGill University Health Centre
 Assistant Professor, Dept. Oncology, McGill University
 Assistant Professor, School of Nursing, McGill University
 Linda Edgar, Ph.D., Assistant Professor, School of Nursing, McGill University
 Research Associate, Dept. of Psychiatry, SMBD Jewish General
 Hospital, Research Consultant, Hope and Cope, SMBD Jewish
 General Hospital

This study is also being conducted at the Montreal General Hospital, Royal Victoria Hospital, and St. Mary's Hospital Center.

What you should know about a research study

We give you this consent so that you may read about the purpose, risks and benefits of this research study.

Routine care is based upon the best known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.

- We cannot promise that this research will benefit you.
- You have the right to refuse to take part, or agree to take part now and change your mind later on.
- Whatever you decide, it will not affect your regular care.
- Please review this consent form carefully and ask any questions before you make a decision.
- Your participation is voluntary.



SMBD – JEWISH GENERAL HOSPITAL DEPARTMENT OF NURSING



A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

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Why is this research being done?

Sometimes people find it difficult to make sense of the cancer experience and wonder how this illness will affect or change their lives. One way that some people have found useful to cope is to talk to someone else about what is happening to try to make some sense out of it. You are being invited to take part in this study because of your personal experience with cancer.

The purpose of this research study is to provide an opportunity for you to discuss whether and how the cancer experience has changed your outlook and goals in life, and for you to gain any benefits that may result following these discussions. For the researcher, the purpose is to learn whether nursing care that offers this type of discussion is helpful.

What will happen to you if you take part in the study?

We intend to recruit 136 participants for this study. If you agree to take part in this study, you will be asked to answer a set of 6 questionnaires the first time we meet and the last time we meet. These questionnaires include information about your background and your thoughts and feelings related to the impact of cancer on your life. The questionnaires usually take less than 30 minutes to complete.

After you have completed and returned the questionnaires, you will be randomly assigned to either the "treatment group" or the "control group". If you are assigned to the "treatment group", the sessions with the nurse will begin as soon as the questionnaires are returned within 1 week. You will be asked to meet with the nurse between 1 and 4 times. How long and how frequently you meet will be decided at your discretion. These meetings can take place in the privacy of your own home, or at a private location in the hospital or clinic. You will then be asked to complete the set of questionnaires a second time after the sessions end. If you are assigned to the "control group", you will be

SMBD – JEWISH GENERAL HOSPITAL DEPARTMENT OF NURSING



A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

CONSENT FORM

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asked to complete the questionnaires a second time after an approximate one month delay. Following this, the nurse will offer to meet with you for one session lasting up to 2 hours, to discuss how you are coping, which some people find helpful.

Your permission is needed to audio tape the sessions so that the nurse and her supervisors may study the content of the discussions to make sure that the interviews are being conducted in a similar fashion across participants. No one but the researchers will have access to the tapes and there will be no identifying information on the tapes. The tapes will be kept in a locked cabinet for a duration of one year following completion of the study and will be erased after studying them.

Your permission is also requested to access your hospital medical chart to obtain information about your disease status that is relevant to the study.

What are the possible risks and discomforts?

There are no known risks associated with this study. However, you may feel sad during some of the meetings because of the nature of the discussion. You are free to stop the interview, continue at a later time, or withdraw from the study at any time without interfering with the nursing or medical care you are receiving. You will be provided with the name and phone number of a psychologist or nurse at your hospital should you wish to have further follow-up at the end of the study.

What are the possible benefits?

We cannot promise any benefits from your being in the study. However, we are hoping that this type of nursing care will help you make sense of what is happening and help you to cope with your experience of cancer.

You may not directly benefit from participating in this study. However, the results of this study might help health professionals better understand and design ways to help people cope with cancer.

SMBD - JEWISH GENERAL HOSPITAL DEPARTMENT OF NURSING



A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

CONSENT FORM

What information will be kept private?

We will keep all research records that identify you private to the extent allowed by law. Everything that you discuss and all identifying information that will be collected from the medical charts will be kept strictly confidential. Your anonymity will be assured by having only the study identification number appear on the questionnaires and information collected from the chart. Only the investigators associated with this study will have access to the information gathered from the individuals in this study. Results of the study may be published; however, we will keep your name and other identifying information private.

Can your taking part in the study end early?

Your participation in this study is completely voluntary. You may withdraw from the study at any time without affecting your medical or nursing care. You have the right to ask questions at any time or you may refuse to answer any question that is upsetting or difficult to answer. You do not give up any of your legal rights by signing this form.

If you have any questions or problems, whom can you call?

If you have any questions about your rights as a research participant, you may call the Jewish General Hospital patient representative, Ms. Lianne Brown, at (514) 340-8222 (ext. 5833). If you have more questions about the study now or later, please feel free to page Virginia Lee at 304-7767, or call her supervisor, Dr. Cohen at 842-1231 (ext. 5158). A copy of this form will be given to you for your records. At the end of the study, you may request a written summary of the study findings.

SMBD – JEWISH GENERAL HOSPITAL DEPARTMENT OF NURSING



A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

CONSENT FORM

SUBJECT #: ____

STATEMENT OF THE PARTICIPANT:

Date: ___/_/__ Yr / M o / Day

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Print Name of Participant

Signature of Participant

Consent form administered and explained in person by:

Print Name of Investigator

YES

Signature of Investigator

By signing this form, I also give permission for Virginia Lee to :

NO

(a) audio-tape the interview sessions (b) consult my hospital medical chart.

Page 5 of 5

YES	NORESEARCH
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	NITIALS/

CENTRE HOSPITALIER de ST.MARY ST.MARY'S HOSPITAL CENTER 3838 Avenue Lacombe, Mtl, Qc, H3T 1M5



A NURSING CARE STUDY BASED ON FINDING MEANING IN THE EXPERIENCE OF CANCER

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CONSENT FORM

Investigators:

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 Robin Cohen, Ph.D.
 Medical Scientist, McGill University Health Centre
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 Assistant Professor, School of Nursing, McGill University
 Linda Edgar, Ph.D., Assistant Professor, School of Nursing, McGill University
 Research Associate, Dept. of Psychiatry, SMBD Jewish General
 Hospital, Research Consultant, Hope and Cope, SMBD Jewish

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What are the possible risks and discomforts?

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If you have any questions or problems, whom can you call?

If you have any questions about the study now or later, please feel free to contact **Virginia Lee** at 304-7767, or her supervisor, **Dr. R.Cohen** at 842-1231 (ext. 5158), or you may wish to speak to **Barbara Laurent**, Oncology Nurse at St. Mary's Hospital, at 734-2679. If you have specific questions about your rights as a research participant, you may call the patient representative at St. Mary's Hospital Center's, **Monique Robitaille**, at (514) 734-2618. A copy of this consent form will be given to you for your records and a copy will be placed in your medical chart. At the end of the study, you may request a written summary of the study findings.





Centre universitaire de santé McGill McGill University Health Centre la santé... c'est pour la vie ve care for life

Andrea Laizner

05/02/2005 12:22:46 PM

From: Andrea Laizner on 05/02/2005 12:22 PM

To: Virginia Lee/CUSM/Reg06/SSSS@SSSS

cc: aml@primus.ca

Subject: Re: URGENT Request 🖺

Hi Virginia

I have no objection to my name as a co-author of the manuscript entitled " Meaning -making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self -efficacy", which was

submitted to Social Science and Medicine. I certaintly contributed to the manuscript as described in your PhD thesis.

Andrea Maria Laizner, RN, PhD

Virginia Lee



Centre universitaire de santé McGill McGill University Health Centre la santé... c'est pour la vie we care for life

Virginia Lee 05/02/2005 10:36:17 AM

 To:
 Robin Cohen <robin.cohen@mcgill.ca>, "Linda Edgar" <linda.edgar@sympatico.ca>

 cc:
 Andrea Laizner/CUSM/Reg06/SSSS@SSSS, anita.gagnon@mcgill.ca

 Subject:
 URGENT Request

Hi everyone

I have an urgent request for you in order to complete my final thesis submission to the Thesis Office.

Because it is a manuscript style thesis, I need to provide signed waivers from everyone listed as a co-author on my papers submitted to publication. This includes accepted and non-published papers. I have your Copyright Transfer Forms from Journal of Palliative and Supportive Care as well as from Oncology Nursing Forum. However, since the last paper to Social Science and Medicine is still under review, I did not ask for your Copyright Forms yet. However, the Thesis Office still requires that I submit a letter or an email from each of you stating that you agree to be a co-author on the last paper, entitled " Meaning -making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self -efficacy".

Could you please send me your emails by this Wed May 4 at the latest?

Thank you!



Virginia



Anita Gagnon <anita.gagnon@staff.mcgill.ca> on 05/03/2005 11:13:27 AM

Please respond to anita.gagnon@mcgill.ca

 To:
 Virginia Lee <virginia.lee@muhc.mcgill.ca>

 cc:
 Diane Habbouche <diane.habbouche@muhc.mcgill.ca>

 Subject:
 co-author confirmation

Hello Virginia,

I agree to be a co-author on the paper, entitled " Meaning -making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self -efficacy".

Anita Gagnon

Anita J. Gagnon, Inf/RN, MPH, PhD Chercheur-boursier du FRSQ / FRSQ Research Scholar Boursier William Dawson / William Dawson Scholar Professeure adjointe / Assistant Professor McGill, École des sciences infirmières & Dépt. Ob/Gyn McGill, School of Nursing & Dept. Ob/Gyn Infirmière chercheure / Nurse Scientist CUSM / MUHC Prog.Ob/Gyn 3506, rue Université Montréal, Québec, Canada H3A 2A7 McGill Tél.: (514) 398-8994 Fax: (514) 398-8455 CUSM Tél.: (514) 843-1419 Fax: (514) 843-1439 Courriel: anita.gagnon@mcgill.ca