

Handwritten text in a vertical column, likely a manuscript or document, showing dense, illegible script. The text is oriented vertically and appears to be written in a dark ink on a light background.

**NQ**

**7 6 4 3 3**

**U M I**  
**MICROFILMED 2003**

## **INFORMATION TO USERS**

**This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.**

**The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.**

**In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.**

**Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.**

**ProQuest Information and Learning  
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA  
800-521-0600**

**UMI<sup>®</sup>**



## **NOTE TO USERS**

**Page(s) missing in number only; text follows. The manuscript was microfilmed as received.**

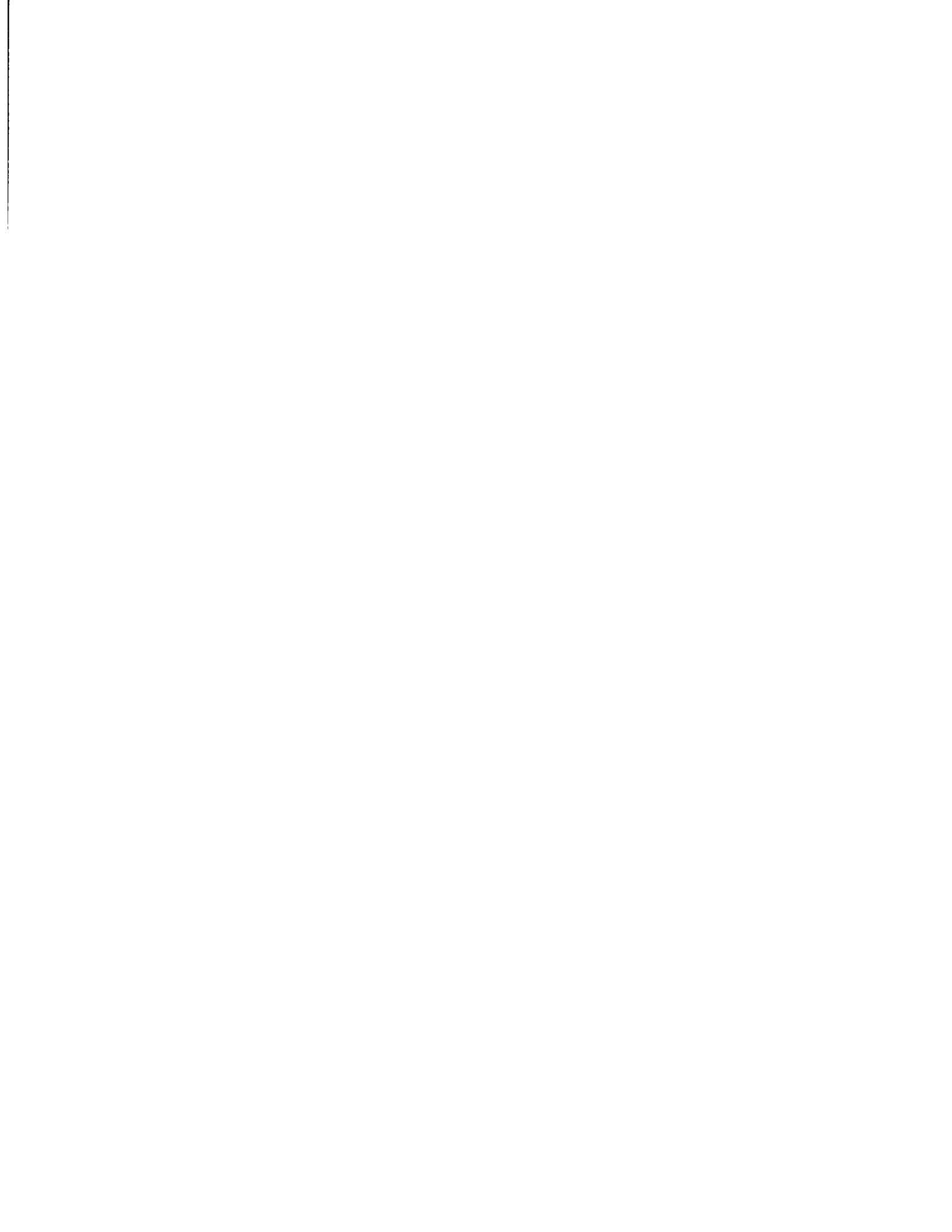
**74**

**This reproduction is the best copy available.**

**UMI**



Handwritten text in a vertical column, likely a manuscript or document, showing characters and symbols. The text is highly stylized and difficult to decipher, but appears to be a sequence of characters or a list of items. The characters are arranged in a vertical line, with some larger characters and some smaller ones. The background is black, and the text is white, making it stand out. The text is oriented vertically, reading from top to bottom.





**Stress and Coping Near the End of Life**

**Barbara J. de Faye**

**Dissertation submitted to the School of Graduate Studies  
University of Ottawa in partial fulfilment of the  
Requirements for the Ph.D. degree  
in Clinical Psychology**



**National Library  
of Canada**

**Acquisitions and  
Bibliographic Services**

**395 Wellington Street  
Ottawa ON K1A 0N4  
Canada**

**Bibliothèque nationale  
du Canada**

**Acquisitions et  
services bibliographiques**

**395, rue Wellington  
Ottawa ON K1A 0N4  
Canada**

*Your file Votre référence*

*Our file Notre référence*

**The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.**

**The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.**

**L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.**

**L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.**

0-612-76433-8

**Canada**

### Acknowledgements

I would like to thank my advisor, Dr. Keith Wilson, for his commitment to this study, and for the supervision and the support he gave me. Through his methodological expertise and attention to detail, he has made a substantial contribution to my work. The members of my thesis committee, Drs. Joyce D'Eon, Gail Crombie, and Tim Aubry, provided constructive criticism and made helpful recommendations. Recruitment was made possible by members of the palliative care consultation services at both the Civic and General Hospital Campus' of the Ottawa Hospital, the regional palliative care centre and The Hospice at May Court. I am especially grateful to Drs. Susan Chater, Ray Viola, Pippa Hall and Ms. Barbara O'Connor. Elyse Sevigny assisted by scoring all of the audiotapes. Dorothy Ann Curran from the Institute for Rehabilitation Research and Development of The Rehabilitation Centre facilitated data coding and analyses. Data tables were prepared diligently by Suzanne Pelletier.

A major contribution was made by that best of friends, Janet Belzile, who in addition to her support and encouragement, spent many hours transcribing tapes; thank you. A special thank you to my husband Tom, who supported, encouraged and endured throughout this process.

Finally, this endeavour would not have been possible without the participation of those 52 generous people who consented to take part in the interviews. Thank you for granting me some of your precious time and for sharing your stories with me.

## Stress and Coping Near the End of Life

### ABSTRACT

The stressors facing people who must deal with a terminal diagnosis and palliative care are complex and varied. However, relatively little is known about the manner in which people cope with these stressors. Additionally, there has been little research into those characteristics that may predispose individuals to cope in particular ways. Therefore, this study investigates the process of coping with various end-of-life stressors, while also considering individual differences in how people prefer to cope.

Fifty-two people who were receiving palliative care for advanced cancer underwent in-depth, semi-structured interviews. The interviews considered the tendency to monitor (focus on) or blunt (avoid) threat-relevant cues when dealing with stress, and whether this tendency was predictive of variations in actual coping behaviour, or variations in the experience of distress. Stress and coping were examined within three distinct conceptual dimensions comprising physical symptoms, social issues, and existential concerns. Specifically, participants were asked to identify their most significant problem in each dimension, and then to report how they coped with those problems. Their coping responses were then coded as reflecting either "problem-focused," emotion-focused approach" or "emotion-focused avoidance".

The results revealed that, unlike other health-related research, the tendency to "monitor" or "blunt" did not predict variations in the experience of psychological distress or variations in self-reported coping behaviour. Across the three dimensions of stress, physical symptoms received the highest severity ratings, but the dimensions were

significantly intercorrelated with one another. A consistent individual difference was also noted in terms of the numbers of coping strategies participants generated to manage stressors. That is, participants who reported using a high number of coping strategies to manage a social stressor also reported using a high number of strategies in response to stressors in the other two dimensions. Participants generally used a combination of specific coping strategies to deal with their stressors. However, there were clear differences across dimensions of stress in the relative use of problem-focused versus emotion-focused strategies. Problem-focused coping was uncommon for existential issues while emotion-focused approach and emotion-focused avoidance strategies were used less frequently for physical stressors. Coping efforts were not related to psychological distress or to discrete anxiety and depressive disorders, which were diagnosed in 44.2% of the participants.

## TABLE OF CONTENTS

|  |      |
|--|------|
| Acknowledgements .....   | i    |
| Abstract .....   | ii   |
| List of Figures .....  | viii |
| List of Tables .....   | ix   |
| Introduction .....   | 1    |
| Overview .....   | 1    |
| Review of the Literature .....                                   | 2    |
| Epidemiology and Treatment of Cancer .....                       | 3    |
| Conceptualization of sources of distress .....                   | 5    |
| Depression, Anxiety and Cancer .....                             | 7    |
| Depression .....   | 7    |
| Anxiety .....  | 8    |
| Stressors Associated with Cancer and the Prospect of Death ..... | 9    |
| Physical Symptoms .....  | 10   |
| Pain .....   | 10   |
| Fatigue and weakness .....                                       | 10   |
| Nausea .....   | 11   |
| Other symptoms .....   | 11   |
| Social Stressors .....   | 11   |
| Early stage disease .....  | 12   |
| Recurrent disease .....  | 12   |
| Advanced disease .....   | 13   |
| Existential Issues .....   | 13   |
| Early stage disease .....  | 14   |
| Recurrent disease .....  | 14   |
| Advanced disease .....   | 14   |
| The Transactional Model of Stress and Coping .....               | 15   |
| Factors influencing coping .....                                 | 17   |
| Other perspectives on coping .....                               | 19   |

|   |    |
|---|----|
| Coping with Cancer .....  | 19 |
| Coping with Cancer: Review of Studies Based on the<br>Transactional Model ..... | 20 |
| Coping after diagnosis .....  | 20 |
| Coping at later points .....  | 21 |
| Coping with advanced cancer .....   | 21 |
| Change over time .....  | 22 |
| Variables influencing choice of strategies .....                                | 23 |
| Coping and Adaptation to Cancer .....   | 25 |
| Cross-sectional studies .....   | 26 |
| Longitudinal studies .....  | 27 |
| Moderating variables .....  | 30 |
| Summary .....   | 31 |
| Methodological Considerations in Stress and Coping Research .....               | 32 |
| Dispositional Model .....   | 37 |
| Conclusion and Rationale .....  | 42 |
| Specific Hypotheses .....   | 43 |
| Dimensions of Stress .....  | 43 |
| Coping Strategies .....   | 44 |
| Perceptions of Efficacy and Control .....                                       | 44 |
| General Psychological Distress .....  | 45 |
| Clinical Psychological Disorders .....  | 45 |
| Method .....  | 46 |
| Participants .....  | 46 |
| Procedure .....   | 46 |
| Recruitment .....   | 46 |
| Interview Protocol: General Overview .....                                      | 47 |
| Interview Protocol: Specific Elements .....                                     | 48 |
| Demographic information .....   | 48 |
| Miller Behavioral Style Scale .....   | 49 |
| Social Concerns .....   | 50 |
| Pain and Symptom Assessment .....   | 50 |
| Existential Concerns .....  | 51 |
| Ratings of Control .....  | 51 |
| Assessment of Coping .....  | 51 |
| Ratings of Effectiveness .....  | 52 |

|   |    |
|---|----|
| Psychological Distress .....  | 52 |
| Assessment of Depressive and Anxiety Disorders .....                      | 53 |
| Debriefing .....  | 54 |
| Chart review .....  | 54 |
| Data Reduction .....  | 55 |
| Inter-Rater Reliability .....   | 55 |
| Coping responses .....  | 55 |
| Identification of monitors and blunters .....                             | 58 |
| Power .....   | 58 |
| Dimensions of stress .....  | 59 |
| Data Analytic Strategy .....  | 59 |
| Outliers .....  | 59 |
| Skewness .....  | 60 |
| Sphericity .....  | 60 |
| Post-hoc comparisons .....  | 60 |
| Correlational analyses .....  | 60 |
| Dimensions of stress .....  | 61 |
| Severity of worst stressors .....   | 61 |
| Coping .....  | 61 |
| Monitors, Blunters and coping with stress .....                           | 61 |
| Perceptions of efficacy and control .....                                 | 62 |
| General psychological distress .....                                      | 62 |
| Depressive and anxiety disorders .....                                    | 62 |
| Results .....   | 62 |
| Recruitment .....   | 62 |
| Participant Characteristics .....   | 63 |
| Prevalence of Mental Disorders .....                                      | 65 |
| Monitors and Blunters .....   | 65 |
| Sources of Stress Near the End of Life .....                              | 68 |
| Intercorrelations Between Measures of Stress .....                        | 72 |
| Demographic and Clinical Correlates of Stress .....                       | 72 |
| Monitors, Blunters and the Experience of Stress .....                     | 76 |
| Perceptions of Control and Effectiveness .....                            | 78 |
| Demographic and Clinical Correlates of Control<br>and Effectiveness ..... | 81 |
| Monitors, Blunters, Effectiveness and Control .....                       | 81 |
| Perception of control .....   | 81 |
| Perception of effectiveness .....   | 83 |
| Coping With Stress Near the End of Life .....                             | 83 |
| Numbers of Coping Strategies .....  | 88 |
| Coping Across Dimensions of Stress .....                                  | 91 |
| Demographic and Clinical Correlates .....                                 | 91 |
| Intercorrelations Between Measures of Stress and Coping .....             | 94 |
| Control, Effectiveness and Coping .....                                   | 94 |
| Monitors, Blunters and Coping With Stress .....                           | 94 |



|  |            |
|--|------------|
| Correlates of No Stress .....  | 99         |
| Debriefing .....   | 100        |
| <b>Discussion .....</b>  | <b>103</b> |
| Participants .....   | 104        |
| Interview .....  | 105        |
| Prevalence of Mental Disorders .....   | 107        |
| Sources of Stress .....  | 108        |
| Control and Effectiveness .....  | 110        |
| Coping .....   | 111        |
| Qualitative data .....   | 112        |
| Quantitative data .....  | 112        |
| Monitors and Blunters .....  | 119        |
| Clinical Implications .....  | 122        |
| Conclusions .....  | 123        |
| <b>References .....</b>  | <b>125</b> |
| <b>Appendices .....</b>  | <b>141</b> |
| <b>Appendix A:</b>   |            |
| Table A1 Major Stressors in the Terminally Ill .....                           | 141        |
| Table A2 Prevalence of Depressive Disorders in<br>Cancer Patients .....        | 142        |
| Table A3 Categorization of Coping Strategies .....                             | 143        |
| <b>Appendix B</b>  |            |
| Table B1 Information Sheet .....   | 144        |
| Table B2 Statement of Informed Consent .....                                   | 146        |
| Table B3 Notification of Research Participation ....                           | 147        |
| <b>Appendix C</b>  |            |
| Table C1 Interview Protocol .....  | 148        |
| Table C2 Diagnostic Criteria for PRIME-MD/DSM IV<br>Depressive Disorders ..... | 177        |
| Table C 3 Diagnostic Scoring Checklist .....                                   | 180        |
| Table C4 Power .....   | 181        |
| <b>Appendix D</b>  |            |
| Table D1 Categorization of Coping Strategies-Cheng,<br>Hui & Lam (2000) .....  | 182        |

List of Figures

**Figure 1 Percentages of Participants Using the Different Categories of Coping Behaviours Within Each of the Physical, Social and Existential Dimensions ..... 85**

**Figure 2 Mean Number of Coping Behaviours Within Each Type of Specific Strategy ..... 89**

## List of Tables

|          |   |    |
|----------|---|----|
| Table 1  | Characteristics of 52 Participants .....  | 63 |
| Table 2  | Prevalence of Mental Disorders .....  | 65 |
| Table 3  | Characteristics of Monitors and Blunters .....  | 67 |
| Table 4  | Inter-Rater Reliability of Individual Interview Items,<br>and Internal Consistency Reliability for Social,<br>Physical and Existential Scales ..... | 69 |
| Table 5  | Percentage of Participants Reporting Symptoms and<br>Concerns at Different Levels of Severity .....   | 70 |
| Table 6  | Intercorrelations Between Measures of Stress .....  | 72 |
| Table 7  | Intercorrelations Between Demographic, Clinical and<br>Stress Measures .....  | 74 |
| Table 8  | Means and Standard Deviations of Worst Stress and<br>Aggregate Stress Measures for Monitors and Blunters .....                                      | 76 |
| Table 9  | Intercorrelations Between Measures of Stressor Severity<br>and Ratings of Control and Effectiveness .....   | 77 |
| Table 10 | Intercorrelations Between Ratings of Control and<br>Effectiveness .....   | 79 |
| Table 11 | Intercorrelations Between Demographic, Clinical<br>Characteristics and Ratings of Control and Effectiveness .....                                   | 80 |
| Table 12 | Means and Standard Deviations of Control and Effectiveness<br>Ratings for Monitors and Blunters .....   | 82 |
| Table 13 | Comparison of Intercorrelations Between Coping Strategies ..  | 90 |
| Table 14 | Intercorrelations Between Demographic, Clinical<br>Characteristics and Number of Coping Strategies .....  | 92 |
| Table 15 | Intercorrelations Between Worst Stress, Aggregate Stress<br>and Number of Coping Strategies .....   | 94 |
| Table 16 | Intercorrelations Between Rating of Perceived Control and<br>Effectiveness, and Number of Coping Strategies .....                                   | 95 |

|                 |   |            |
|-----------------|---|------------|
| <b>Table 17</b> | <b>Means and Standard Deviations of Coping Strategies for Monitors and Blunters .....</b> | <b>97</b>  |
| <b>Table 18</b> | <b>Participant Responses to Debriefing Questions (n = 52) .....</b>                       | <b>101</b> |

## Introduction

### Overview

For patients who have progressive and eventually fatal diseases, the weeks and months before death can be the most stressful of the entire life span. In the case of cancer, and particularly when the disease advances to the final stages, the associated decline in health, the side-effects of palliative treatment, the fears that may be associated with the increasing imminence of death, as well as the changes in interpersonal relationships which can result from the demands placed on family caregivers, can all add to the individual's level of perceived strain (Classen, Koopman, Angell & Spiegel, 1996; Hinton, 1994; Houts et al., 1988; Silberfarb, Maurer & Crouthamel, 1980; Weisman & Worden, 1985-1986). In recognition of these concerns, a task force of the American Psychological Association (APA) has recently called for increased involvement by psychologists as contributors to end-of-life care (Gordon et al., 2000). The present research has been undertaken as a step in this direction.

In a broad sense, the question addressed by this study is "how do people cope with these various sources of stress as they approach the end of their lives?" In addition, there are a number of related questions that were also examined. For example, are there particular types of problems that patients tend to find more or less stressful? Are specific ways of coping associated with the experience of either more or less psychological distress? Do individual differences in how people prefer to cope with health-related stressors predict variations in actual coping behaviour, or variations in the experience of distress? In general, the issue of stress and coping is being studied with increasing frequency in the field of health psychology, and new methodologies have been developed

for investigating questions of this type. To date, however, there has been relatively little research that has applied this perspective to the unique circumstances of people who are dealing with the multiple stressors associated with advanced terminal illness.

### Review of the Literature

In preparation for the dissertation an extensive literature review was completed. The topics selected for review included the epidemiology and treatment of cancer, physical symptoms associated with cancer, psychological and psychosocial issues associated with cancer, adaptation to cancer, stress, coping, and palliative care. Both medical and psychological literatures were reviewed, using PsycINFO, Medline and CancerLit databases as a starting point. These databases were scanned from 1980 to 2001 using keywords such as stress, coping, cancer, adjustment, depression, anxiety, and palliative care. The reference lists of articles identified as relevant provided further material for review.

It should be noted that many of the studies cited have design limitations that are common in health research. These include the use of convenience or volunteer samples, which make the assumption that the participants are representative of a larger population. Additionally, many of the studies are correlational and or cross-sectional in design. Although studies of this type are useful for establishing the magnitude of relationships between constructs, they cannot determine causality between variables.

### Epidemiology and Treatment of Cancer

An estimated 134,100 new cases of cancer and 65,300 deaths from cancer will occur in Canada in 2001. Approximately 40% of Canadian men and 27% of women can expect to develop cancer in their lifetime, and 22-27% will die of it (National Cancer Institute of Canada: Canadian Cancer Statistics, 2001). Breast cancer is the most frequently diagnosed cancer among women, followed by lung and colorectal cancers. Among men, the most prevalent forms are prostate, lung and colorectal malignancies. Lung cancer is the leading cause of death from cancer for both sexes.

Broadly speaking, cancer is a group of diseases whose common characteristic is an abnormal growth of malignant cells. These abnormal cells proliferate and infiltrate surrounding areas, replacing normal tissue. Often these tumour cells break off and are carried by the bloodstream and lymphatic system to other parts of the body where they set up a secondary growth known as metastatic spread. Tumours are also classified by stage according to the size of the tumour, the involvement of nearby tissue and lymph glands and whether the cancer has metastasized. For instance, Stage I breast cancer refers to a small, localized tumour with a good prognosis and Stage IV means that the cancer has spread beyond the local lymph glands to other sites such as the liver, brain or bone. Tumours are usually named after the embryonic cells from which they develop. Major forms include carcinomas, which refer to cancers arising from epithelial cells; sarcomas, which develop from muscle, bone or fibrous tissue; leukemias which develop from blood cell elements in the bone marrow, and; lymphomas, which originate in the lymph glands (Laszlo, 1987).

Surgery, radiation therapy and chemotherapy are the three major forms of treatment for cancer and they may be used singly or in combination. If the cancer is localized then it

may be removed surgically, providing that surgery can be performed without harming vital organs. When the cancer is more widespread, a large primary tumour, and even a single metastasis, may be removed surgically to increase the effectiveness of chemotherapy. With some types of cancer, a combination of surgery and chemotherapy may reduce the amount of surgery that is required.

Radiation therapy kills tumour cells by damaging the DNA and proteins, and may be used for some localized tumours such as those of the larynx, prostate and some lymphomas. Unfortunately, radiation also damages the normal cells surrounding the cancer. For instance, high doses may eradicate a lung tumour but leave the individual with impaired lung function. High doses of radiation can also cause malaise, depression, nausea, diarrhea, loss of appetite, skin reactions, mouth and throat reactions, and hair loss. (Whipp, 1986).

Chemotherapeutic drugs destroy cancer cells either by interfering with their growth or by preventing them from reproducing. These medications circulate throughout the entire body in order to kill the malignant cells, and consequently normal cells are also exposed to their potentially harmful effects. Side effects include nausea and vomiting, loss of hair, sores in the mouth, diarrhea, fatigue, and depression.

Advanced disease is a term used to describe cancer that has continued to progress despite all curative efforts, or which was deemed to be incurable at initial diagnosis. At this point, palliative measures may arrest and control tumour growth for some time, but the goal becomes symptom relief rather than complete eradication of the disease. Palliative care refers to a philosophy of medical, social, emotional and spiritual support, which has arisen out of the Hospice movement (Dudgeon et al., 1995). It reflects an interdisciplinary



approach that is concerned with the control of pain and physical symptoms, the provision of comfort and support, and the enhancement of the patients' quality of life in the time that remains to them. In a palliative care setting or hospice the family, as well as the patient, typically becomes the unit of care (Waller & Caroline, 1996).

### Conceptualization of sources of distress

From a psychological perspective, concern for the care of the dying has focused largely on the emergence of emotional distress, including clinically significant mental disorders. According to Corr (1991-92), the distress associated with the prospect of death can be conceptualized as arising from four dimensions, encompassing physical, social, psychological, and existential problems and concerns. The physical dimension incorporates the many unpleasant symptoms associated with progressive disease and its treatment. The central feature of the social aspects of dying is relations among people as individuals and relations with individuals as members of groups or society. This embraces issues such as alienation, lack of information, fear of becoming a burden, and role loss. The psychological aspects focus on security, autonomy and life satisfaction, as well as mental health issues. Finally, the existential/spiritual dimension includes issues such as the implied threat of death associated with disease progression, loss of hope, and purpose in living (Corr, 1991-92). This broad conceptualization is important for the present research, which will investigate the sources of distress as they arise across different dimensions.

While Corr (1991-92) has taken a conceptual approach, other recent research has taken a more empirical approach to identifying the core dimensions of distress in the terminally ill. Cohen, Mount, Thomas, & Mount (1996) and Cohen et al. (1997), for

example, have used factor analytic strategies to classify stressors in the McGill Quality of Life Questionnaire (MQOL). They found physical and social dimensions analogous to those of Corr (1991-92); however, their factor analysis resulted in different structures for the psychological and existential dimensions. Specifically, issues of autonomy and life satisfaction were included in the existential dimension as opposed to the psychological dimension. Noyes et al. (1990) also constructed an Illness Distress Scale (IDS) that yielded a four-factor structure, albeit using a slightly different rationale. They found clear dimensions corresponding to physical, social, and existential concerns (which they labelled "loss of meaning"). However, they also found a factor related to concerns about medical treatment. They did not identify a separate psychological symptoms dimension, but this is because they were using independent measures of psychological state and excluded such symptoms from their scale. As with most studies from a mental health tradition, Noyes et al. (1990) were interested in isolating psychological symptoms separately as a criterion variable, and then investigating how the mental health dimension is related to the other three dimensions of stress.

In summary, there is a small but consistent body of literature, both conceptual and empirical, that supports the existence of independent dimensions of stress in patients with advanced terminal illness. These include physical (including medical) symptoms, social problems, and spiritual/existential concerns. Psychological symptoms are also held to be an independent source of stress by some investigators, but in psychological research they are more likely to be considered as criterion variables.

After considering the definitions of each dimension provided by Corr (1991-92) and the structure of both the MQOL and the IDS the relevant stressors for the present study

have been organised, on an a priori basis, into the physical, social, and existential dimensions shown in Table A1, Appendix A. For the present purpose, psychological distress, as reflected in depressive symptoms and clinically significant mental disorders, will be considered separately.

### Depression, Anxiety and Cancer

In fact, significant psychological distress occurs very commonly among people who are faced with a life-threatening illness. Some emotional responses of sadness, grief and fear are generally considered to be normal reactions to a diagnosis, or a recurrence, of cancer (Hughes, 1986; Massie, 1989). These reactions can be disturbing, but it appears that they do not necessarily progress into fully syndromal psychiatric disorders. However, research shows that psychiatric disorders nevertheless do occur in a very substantial minority of patients with cancer (Derogatis et al., 1983).

Depression. The most prevalent mental-health disorder in cancer patients is depression (Massie, Gagnon & Holland, 1994; Wilson, Chochinov, de Faye & Breitbart, 2000). Table A2, Appendix A, presents the results of nine studies reporting on the prevalence of depressive disorders in groups of patients being treated for cancer. Despite the use of structured interviews to provide formal criterion-based diagnoses of depressive syndromes, there is a great deal of discrepancy in the reported prevalence rates. As is evident in Table A2, the prevalence of major depression (the most widely studied of the depressive spectrum disorders) among various groups of cancer patients has ranged from a low of 4.5% (Lansky et al., 1985), which is comparable to general population estimates, to 42% (Bukberg, Penman & Holland, 1984). Differences in stage and type of cancer may

account for some of this discrepancy. For example, Derogatis et al. (1983) used the same interview protocol (DSM-III) across centres in a multisite study and found that the incidence of psychiatric disorders at one site was triple that noted at another site. Data on stage of disease and prognosis indicated that patients at the high diagnosis centre tended to have more advanced disease, which Derogatis et al. (1983) concluded might account for this unexpected finding.

Massie (1989) proposes that at least 25% of patients with advanced cancer will struggle with significant depressive symptoms at some level or another. Whether the severity of the patient's presentation is extreme enough to fulfil diagnostic criteria for a formal disorder appears to vary according to the ways in which these criteria have been applied or interpreted in different studies. For example, major depression in one study may have been called minor depression or adjustment disorder in another. In a recent review of the literature on depression in palliative care, Wilson, Chochinov et al. (2000) concluded that from 5% to 15% of patients with cancer will meet the criteria for major depression even when the most stringent criteria are used. Additionally, at least another 10% to 15% of patients present with symptoms that may be somewhat less severe.

Anxiety. Payne and Massie (2000) point out that while most individuals with cancer are "fearful and sad," symptoms of clinically significant anxiety often become more prominent with the realisation that the disease no longer responds to curative treatment. As the disease progresses, worsening physical symptoms, fear of death, and fear associated with further deterioration of their condition may lead to a heightened sense of anxiety.

Massie and Holland (1987) reported that evaluation of anxiety symptoms accounted for about 16% of referrals for psychiatric consultation. In that study, 25% of patients were

diagnosed with either an anxiety disorder (4%) or an adjustment disorder with anxious mood (21%). Derogatis et al. (1983) reported on the prevalence of psychiatric disorders in 215 cancer patients and noted that anxiety disorders accounted for 16% (prevalence rate of 7%) of the diagnoses. In a study that assessed patients with advancing disease, Brandberg, Bolund, Sigurdardottir, Sjoden, & Sullivan (1992) found that 28% of patients with advanced melanoma were anxious to a clinically significant extent. Cassileth et al. 1984 reported that anxiety and depression varied across the course of the illness in that patients who had been diagnosed for less than three months displayed greater anxiety than those who had been diagnosed for longer periods of time. However, they also noted that as physical health declined, symptoms of anxiety and depression increased. Anxiety was also tied to treatment in that those receiving active therapy for cancer were psychologically healthier than those receiving palliative care. In summary, therefore, there appears to be a general consensus that clinically significant problems with anxiety and depression are common among people who are facing death from cancer, although specific prevalence rates have varied quite widely across studies.

#### Stressors Associated with Cancer and the Prospect of Death

Saunders (1978) reminds us that every dying person is a complex and unique individual and consequently, while some of the needs or stressors facing the terminally ill cancer patient will be universal, others will be highly personal (Corr, Nabe & Corr, 1994). Much of the literature dealing with the stressors confronting cancer patients focuses on earlier phases of the disease. However, the available literature indicates that a mix of

physical, social, and existential issues confront the individual who has been told that the illness is incurable.

### Physical Symptoms

The clinical progression experienced by patients with advanced disease has typically been preceded by a course of aggressive therapy involving some combination of surgery, radiation and chemotherapy. Symptoms such as pain, nausea and vomiting, anorexia and generalised weakness, either caused by the tumour or occurring as side effects of treatment, are common sources of discomfort (Kornblith et al., 1995; Portenoy et al., 1994). In fact, most patients with advanced cancer experience multiple symptoms, irrespective of the primary site of the disease (Donnelly, Walsh & Rybicki, 1995; Portenoy et al., 1994). Unfortunately, the most common symptoms also tend to be the most severe (Donnelly et al., 1995).

Pain. Moderate to severe pain occurs in 60% to 90% of patients with advanced cancer, and the prevalence increases as the disease progresses (Noyes et al., 1990; Waller & Caroline, 1996). In fact, pain appears to be among the most common, and most severe, physical problems that are faced by this population (Donnelly et al., 1995; Portenoy et al., 1994; Seidman et al., 1995). In the final weeks of life, 51-95% of patients are likely to require medication for pain, often including escalating doses of narcotics (Coyle, Adelhardt, Foley, & Portenoy, 1990; Fainsinger, Miller, Bruera, Hansen & MacEachern, 1991; Lichter & Hunt, 1990; Morris et al., 1986).

Fatigue and weakness. Fatigue and weakness are distressing symptoms for those with advanced disease (Noyes et al., 1990). For instance, Portenoy et al. (1994) and

Donnelly et al. (1995) found that after pain, fatigue was the most common complaint, affecting 48% to 68% of patients. These symptoms may be even more prominent in the terminal phase, with Bruera and MacDonald (1988) reporting a prevalence of 72%.

Nausea. Nausea and vomiting are common in patients with breast, stomach or gynecologic cancers and they also occur in up to 60% of patients receiving opioids (Waller & Caroline, 1996). Various studies have reported prevalence rates ranging from 35% to 72% for patients with advanced disease, usually as an intermittent problem (Donnelly et al., 1995; Fainsinger et al., 1991; Portenoy et al., 1994; Reuben & Mor, 1983; Waller & Caroline, 1996).

Other symptoms. Dyspnea, anorexia, constipation, edema and sleep disturbances are other common physical symptoms that beset patients with advanced disease (Donnelly et al., 1995; Fainsinger et al., 1991; Portenoy et al., 1994), all of which become more numerous and more severe, as the disease progresses (Dudgeon et al., 1995; Houts et al., 1988; Mor, Masterson-Allen, Houts, & Siegel, 1991).

To summarize, patients with advanced cancer must cope with a variety of unpleasant physical symptoms. Pain, fatigue, weakness, nausea, as well as many other symptoms, are commonplace for these individuals, and their severity tends to increase as death approaches.

### Social Stressors

In addition to causing a wide range of serious physical symptoms, the crisis of cancer brings with it the potential for heightened levels of psychological and social stress.

These problems have now been studied in different groups of cancer patients, who have varied in their stage of disease.

Early stage disease. Several studies of patients receiving treatment for cancer have investigated the dimensions of psychosocial stress that are considered to be most salient. Among this group, which includes patients who have been recently diagnosed (Weisman & Worden, 1976-77) or who have early-stage (Gotay, 1984) or varying stage disease (Dunkel-Schetter et al., 1992), the most prominent concern has to do with the illness itself. This concern is reflected in worries about progression of the disease and the associated fear of becoming a burden for others. This concern about burdening others is also a prominent theme expressed by cancer patients who are referred for psychiatric evaluation and therapy (Hinton, 1973).

Among the other sources of psychosocial distress that have been documented in various studies are detrimental effects to one's job (Gotay, 1984; Hinton, 1973; Weisman & Worden, 1976-77), concerns about treatment side-effects, discomforting emotional reactions such as anxiety and depression (Gotay, 1984), and the fear of increasing isolation from others (Weisman & Worden, 1976-77).

Recurrent disease. A number of studies have reported that psychosocial issues remain significant, or become increasingly so, when there is a recurrence of cancer. For example, concern about becoming a burden to family members (Dudgeon et al., 1995; Mahon, Cella & Donovan, 1990; Silberfarb et al., 1980) and relationship issues, such as the prospect of not being able to fulfil social roles, appear to be prominent in more than 85% of patients. The fear of developing intractable pain, and concern about a lack of information concerning the disease process (Hinton, 1973; Mahon et al., 1990; Pattison,



1977), are also important stressors for some patients, although for the most part they are of secondary significance.

**Advanced disease.** Advanced disease appears to be associated with a greater number of problems overall, partly due to activity restrictions and functional disability, and partly due to the emergence of other psychosocial concerns (Gotay, 1984; Houts, 1988; Weisman & Worden, 1976-77). Compared to patients with more localized disease, patients with advanced cancer report greater concerns with loneliness and isolation, and more marital concerns (Dudgeon, 1995; Noyes et al., 1990). Davidson (1979), for example, asked terminally ill patients to rank their major problems, and found that for the majority, the prime area of concern was the fear of abandonment, followed by the loss of self-management and concerns about intractable pain.

The psychosocial concerns of patients with advanced terminal illness are also brought into focus by recent data from the Netherlands, where about 5% to 8% of patients with advanced cancer choose to die by legal acts of euthanasia or physician-assisted suicide (van der Maas, van Delden, Pijnenborg, & Looman, 1991). According to physicians who have participated in these practices, it is largely psychosocial, rather than physical, concerns that motivate patients to make euthanasia requests. These reasons include the experience of a loss of dignity, loss of control, and a concern about being a burden for others.

### **Existential Issues**

Existential issues at the end of life can be viewed as those that have to do with the maintenance of a grounded sense of self in the face of death. They may involve the

maintenance of dignity and control, satisfaction and meaning in life, a sense of spiritual comfort in one's final days, and one's capacity to cope with what the future will bring.

Early stage disease. Although other concerns arise frequently among patients with early-stage disease, they tend to be less significant than concerns about the threatening potential consequences of the illness itself. Weisman and Worden, (1976-77) found that recently diagnosed patients were less concerned about family and friends than about existential matters. Similarly, Hinton, (1973), Gotay, (1984) and Dunkel-Schetter et al. (1992) noted that the principal concerns have to do with worries about progression of the disease, physical deterioration, uncertainty about the future, worries about the family, and concern about the possibility of dying.

Recurrent disease. For patients who experience a recurrence of a previously treated tumour, fears related to disease progression and survival appear to become even more prominent (Mahon et al., 1990; Weisman & Worden, 1985-86). In fact, Weisman and Worden (1985-86) found that patients experiencing a first recurrence actually reported fewer concerns than newly diagnosed patients around such issues as finances, family, work and religion. Rather, a focus on survival was the pre-eminent concern.

Advanced disease. Among patients with advanced disease, the fear of illness progression continues to be an important source of stress (Gotay, 1984; Noyes et al., 1990; Weisman & Worden, 1976-77). Compared to patients with more localized disease, patients with advanced cancer report greater concerns about spiritual issues (Dudgeon, 1995; Noyes et al., 1990). The increasing salience of issues other than physical symptoms is supported by a quality of life study (Cohen et al., 1996) which found that problems associated with

existential and psychological issues had much stronger relationships with overall quality of life than did physical symptoms.

To summarize, at all stages of the disease, a major source of existential distress for patients with cancer is the prospect of disease progression with its implicit threat to survival. While fear of further progression continues to be distressing for patients with advanced disease, other concerns become apparent or achieve greater prominence. In particular, social issues centering around the family and the likelihood of becoming a burden appear to emerge as major themes with some patients at the time of recurrence and progression (Dudgeon et al., 1995; Silberfarb et al., 1980) but tend to be secondary issues up until that point (Dunkel-Schetter et al., 1992; Hinton, 1973; Weisman & Worden, 1976-77). Throughout all this, the individual must continue to deal with distressing physical symptoms that tend to worsen as the disease progresses. Clearly, there are multiple sources of stress for the individual with advanced cancer, which has led to an interest in the study of coping.

### The Transactional Model of Stress and Coping

Early stress research assumed that there is a direct link between environmental events and psychological distress. Life events, such as natural disasters or job loss, were construed as major environmental stressors that negatively affected individual well-being (Coyne & Holroyd, 1982; Lazarus & Folkman, 1984). The major emphasis of this early research was to examine the effect of these stressors on physiological, behavioural and emotional functioning. This approach was eventually criticised on the grounds that it ignored the fact that there are wide individual differences in the evaluation of and response

to potentially aversive events. As a result of this shortcoming, researchers began to consider the ways in which people appraise stressful events and adjust behaviourally to the demands that they present (Coyne & Holroyd, 1982).

Current research on stress and coping is influenced by the appraisal-based transactional model of Lazarus and colleagues (Folkman, 1992; Lazarus & Folkman, 1984). This model sees the person and the environment in an ongoing, bidirectional relationship. From this perspective, “stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p.19). That is, whether or not the relationship is judged to be stressful depends on the fit between the demands of the situation and the individual’s capacity to manage these demands.

Coping is defined as the person’s “. . . constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (Lazarus & Folkman, 1984, p.141). Three key features of this definition are that coping: (1) is seen as a changing process rather than a stable feature of personality; (2) focuses on ongoing thoughts and behaviors, rather than outcome; and (3) refers to efforts to manage stressors, not necessarily master them.

According to this model, coping has two major functions: management or alteration of the situation causing the distress, and the regulation of one’s emotional response to the situation. “Problem-focused” coping describes efforts to change environmental conditions or one’s own behaviour. It involves activities directed toward modification, or avoidance of the impact of an event, or cognitive activity that leads to the belief that an event can be controlled. Tactics include information seeking, confrontive coping, behavioural changes

and developing new skills (Folkman, 1984; Lazarus & Folkman, 1984). Individuals are more likely to engage in problem-focused coping when there is the perception that the impact of a stressor can be modified, minimised or avoided (Folkman & Lazarus, 1980).

“Emotion-focused” coping refers to strategies aimed at controlling emotional responses or physiological arousal. Strategies include positive reinterpretation, minimization, selective attention, seeking social support, wishful thinking, avoidance and distancing. These strategies change the way a problem is seen without necessarily changing the problem itself (Lazarus & Folkman, 1984). Emotion-focused forms of coping are likely to be engaged in when an individual determines that there is little that can be done to alter a potentially threatening event (Folkman & Lazarus, 1980).

During stressful encounters, problem and emotion-focused coping influence one another, and can facilitate or impede each other in the adaptation process. For instance, a diagnosis of cancer may lead an individual to persist in information gathering that leads to heightened levels of anxiety, perhaps resulting in a cycle of problem-focused coping that interferes with the capacity to engage in emotion-focused alternatives that might assist in the reduction of distress (Lazarus & Folkman 1984).

Factors influencing coping. Research based on the transactional model has shown that a combination of both forms of coping is used in most stressful situations (Folkman & Lazarus, 1980; Folkman & Lazarus, 1985). According to the theory, the relative amounts of each mode will vary depending on appraisals of control. If a situation is deemed to be controllable, then the tendency is for problem-focused coping to be the primary mode. However, when the individual perceives the situation to be uncontrollable, more emotion-focused coping is likely to be used. Several studies have found support for this proposition,

which has come to be known as the "goodness-of-fit" hypothesis (Folkman, 1992; Folkman & Lazarus, 1980; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986).

The fit between appraisals of control and the use of problem or emotion-focused coping has also been related to adaptation. In various contexts, researchers have found that problem-focused coping is associated with fewer behavioural problems and lower psychological symptom scores when the situation was judged to be controllable, and greater distress when the situation was seen as uncontrollable. Conversely, emotion-focused coping is related to lower symptom scores when little opportunity for control is perceived, and higher scores when the situation is perceived to be controllable (Compas, Malcarne & Fondarco, 1988; Forsythe & Compas 1987; Vitaliano, DeWolfe, Maiuro, Russo & Katon, 1990).

Several other factors appear to influence the coping process. The perceived stressfulness of the situation has been positively related to the use of avoidant emotion-focused strategies, such as escapism and self-blame which, in turn were related to more symptoms of anxiety and depression (Aldwin & Revenson, 1987; Compas, Worsham, Ey & Howell, 1996). Aldwin and Revenson (1987) have also suggested that the stress-buffering effect of coping strategies may be dependent on the belief that the coping strategy successfully managed the situation. In one study, Aldwin and Revenson (1987) asked community-dwelling adults to describe how they coped with the most stressful episode experienced in the last month. They found that the infrequent use of problem solving, combined with the perception that the problem was not handled well, was related to a dramatic increase in psychological symptoms. On the other hand, when it was believed

that the situation was handled well, low use of problem solving was associated with dramatically decreased symptoms.

Other perspectives on coping. While there appears to be a consensus in the literature that coping strategies fall into two broad categories – problem-focused coping and emotion-focused coping (Endler & Parker, 1990) – a distinction has also been made between emotion-focused strategies that can be subclassified as either "avoidant" or "nonavoidant" in nature (Suls & Fletcher, 1985), or alternatively, "approach" or "avoidant" (Moos & Moos, 1988). The approach dimension refers to the tendency to focus on or maximize the significance of the stressful event, whereas, the avoidance dimension refers to a tendency to avoid, ignore, deny or minimize the significance of the threat. When coping is categorised in this way, responses to potentially threatening events may be classified into three major types (Maes, Leventhal & De Ridder, 1996) encompassing problem-focused coping, active emotion-focused coping and avoidant emotion-focused coping. It should also be noted that there have been attempts to subdivide problem-focused coping into "engagement" and "disengagement" strategies in a manner parallel to approach and avoidant emotion-focused coping (Epping-Jordan et al., 1999). Indeed, there may be some problems that can be solved effectively by avoidance or disengagement, but the general applicability of this conceptualization to coping with the multiple stressors of established (and therefore unavoidable) medical illness is not yet clear.

### Coping with Cancer

Research on coping tends to be focused on the use of specific coping strategies and the impact of these strategies on adaptation. In patients with cancer, the relationship

between coping strategies and emotional well-being is the theme of much of the coping research (Classen et al., 1996; Maes et al., 1996). The results of this research suggest that although a wide range of coping strategies may be employed, emotion-focused methods such as escape-avoidance, wish-fulfilling fantasy or positive reappraisal are especially common. For the most part, samples have consisted of patients with early stage cancer, or patients with varying stages of disease.

#### Coping with Cancer: Review of Studies Based on the Transactional Model

Several studies grounded in the transactional model of stress and coping have attempted to identify the types of strategies that are used by patients with cancer, either in the period shortly after diagnosis, at various points in the progression of the illness, or at an advanced stage of the disease.

Coping after diagnosis. Studies of coping shortly after receiving a diagnosis of cancer, or in the early stages post-treatment, have generally found that emotion-focused approaches are used most frequently. However, there have been differences across studies with respect to the specific types of emotion-focused strategies that have been used. For example, Thomas, Turner and Madden (1988) compared the coping behaviours of patients who had received stoma surgery for colorectal cancer with those who had received stoma surgery for noncancerous conditions. Denial and stoic acceptance were the two dominant themes among both groups, with the use of denial being more common in patients with cancer. Carver et al. (1993) on the other hand, found that behaviours such as disengagement and denial were the least common responses for women with early stage breast cancer. Rather, they were more likely to engage in coping responses related to



acceptance, positive reframing, and finding comfort in religion. Burgess, Morris and Pettingale (1988) also found that efforts to regulate emotional distress were common coping responses in patients who had recently been diagnosed with cancer. Half of their sample used one or more confronting responses whereas the other half used none at all. These confronting responses included both behavioural and cognitive efforts to problem solve and to reduce the emotional impact of the diagnosis. Confronters appeared to be more resourceful and adaptive in their use of strategies, and were more likely to turn to religion or use cognitive strategies such as distraction, to reduce the emotional impact of the diagnosis.

Coping at later points. Studies of different designs have identified the coping strategies used by patients at various stages of disease progression. For instance, Filipp, Klauer, Freudenberg, & Ferring (1990) interviewed 332 patients on four occasions and found that emotion-focused coping activities, such as positive thinking and maintaining a sense of hopefulness concerning treatment, were highly frequent. Similarly, Dunkel-Schetter et al. (1992) found that emotion-focused strategies were favoured, with distancing being the most common primary method used within a group of 603 patients at various disease stages.

Coping with advanced cancer. Payne (1990) found that emotion-focused strategies were also used most often by women coping with palliative chemotherapy for advanced cancer. These strategies included such cognitive activities as minimizing the severity of the problem and selective attention to issues other than the need for chemotherapy. On the other hand, Classen et al. (1996) found that the most common response in a group of 101 breast cancer patients with advanced disease was the effort to maintain a “fighting spirit,”

which incorporates hope and the seeking of information and support. The use of denial was minimal in these patients.

Change over time. Gotay (1984) compared the coping mechanisms used by a group of women with early stage cancer to those used by women with advanced cancer. She found that most patients used more than one coping strategy in dealing with their illness. The most frequently used strategy for both groups was to take some firm action to resolve their most pressing concerns. Seeking social support, positive thinking and self-encouragement were also common across groups. The groups differed in that patients in the early stage engaged in more information seeking and positive reinterpretation, whereas religion provided more comfort to those at an advanced stage.

These findings indicate that patterns of coping may change as the disease progresses, a hypothesis that has been confirmed in two prospective studies. Morris, Greer and White (1977) found that among women with breast cancer, coping changed over time across a 2-year period. In this study, four mutually exclusive categories of psychological response to the diagnosis of cancer were reported; denial, a fighting spirit, stoic acceptance and helplessness/hopelessness. The most common and stable response to diagnosis and mastectomy was stoic acceptance, in which patients acknowledged their diagnosis while trying to ignore the illness and symptoms. The use of stoic acceptance increased over time, and the incidence of helplessness/ hopelessness also tended to increase over time. The use of denial decreased over time. Morris et al. (1977) also found that most women who responded initially with a “fighting spirit,” tended not to maintain this response over time.

Heim, Augustiny, Schaffner and Valach (1993) also found that over a 3-5 year period, coping patterns changed with the stage of illness for women with breast cancer. In

the early phase, the predominant modes of coping were seeking support and care, acceptance-stoicism and problem-analysis. In the middle phase, minimization and denial became more prominent and in the advanced stage, minimization and denial were used much more frequently and religious thoughts assumed greater prominence. Overall, seeking support was always the most common strategy while negative emotional strategies such as self-blame or release of anger were used least.

In summary, the majority of these studies indicate that patients living with cancer make more frequent use of emotion-focused than problem-focused strategies when coping with stressors associated with their illness. These strategies include approach coping methods such as positive reinterpretation and avoidant strategies such as distraction, denial and stoic resignation. Gotay (1984) found that the choice of strategies differed in patients with early versus advanced disease, with those at an earlier stage engaging in more information seeking and positive reinterpretation. This suggestion that coping patterns change over the course of the illness was verified by two studies which found that emotion-focused responses assumed greater prominence as the disease progressed (Heim et al., 1993; Morris et al., 1977).

### Variables influencing choice of strategies

Coping encompasses more than the cognitive and behavioural responses of an individual to a stressor. As noted earlier, the goodness-of-fit hypothesis suggests that situational appraisals influence the choice of coping strategies. For instance, the appraisal of the degree of control that the individual has over the outcome of the situation is thought to influence the relative amounts of problem-focused or emotion-focused strategies that are

used. Problem-focused coping is used more when the situation is seen as controllable; when control over the outcome is perceived to be limited or absent, more emotion-focused strategies are employed (Folkman & Lazarus, 1980; Folkman, Lazarus, Dunkel-Schetter et al., 1986).

In many respects, the progression of an eventually fatal disease can be seen as the epitome of a severe stressor in which the patient has little control over the outcome. Hence, the preponderance of emotion-focused coping strategies that have been observed in the literature is in keeping with this aspect of coping theory. Nevertheless, some studies of cancer patients have attempted to refine our understanding of coping behaviour by examining psychological issues related to the perceived sense of control.

In a sample of 227 women with breast cancer, Hilton (1989) found that women with a high perception of control over the course of their cancer used both problem and emotion-focused strategies. On the other hand, participants who had a low sense of control over the eventual outcome of the disease tended to use more emotion-focused strategies such as escape-avoidance and self-blame and less positive reappraisal.

Similarly, Feifel, Strack and Nagy (1987) found that avoidance was associated with little sense of control and a sense of not coping well when they compared patients with life-threatening diseases (cancer and myocardial infarction) to those with chronic but not life-threatening, diseases. They reported that individuals with life-threatening diseases who viewed their illness as more serious, engaged in a higher incidence of confrontive strategies than those whose illness was not life-threatening. The major components of confrontive coping in this instance were information seeking, cognitive redefinition and

maintaining an active involvement in treatment. Little expectation of recovery was related to the use of acceptance/resignation as a coping strategy.

In another large study (n = 603), Dunkel-Schetter et al. (1992) found that the perceived stressfulness of cancer-related problems was related to more coping through social support and the use of both cognitive and behavioural escape-avoidant responses.

As can be seen, in the cancer literature there are only a few studies which incorporate these variables. However, findings from three large studies indicate that a perception of control over the course of events, the perception of being able to cope, and the perceived severity of the stressor all appear to have an impact on the manner of coping (Dunkel-Schetter et al., 1992; Feifel et al., 1987; Hilton, 1989).

### Coping and Adaptation to Cancer

In the general literature on coping, a relationship has been shown between certain coping strategies and adaptation. For example, emotion-focused strategies that involve avoidance have been positively related to psychological symptoms, while positive reappraisal has been negatively associated with symptoms (Folkman & Lazarus, 1985). Similarly, when the situation is seen as controllable or low in stress, problem-focused coping has been negatively related to psychological symptoms (Aldwin & Revenson, 1987; Forsythe & Compas, 1987).

Indicators of adaptation or adjustment vary across studies but generally speaking, successful adjustment is characterized by the absence of psychological distress, the resumption of daily activities and the maintenance of supportive relationships (Payne, 1990). For instance, Bloom & Spiegel, (1984) found that women with advanced breast

cancer who used less avoidant coping methods functioned better socially. In this section, the cross-sectional studies will be reviewed first, then the longitudinal studies.

Cross-sectional studies. There are at least 14 studies that have examined the association between coping strategies and adjustment in cancer patients. This research shows that some strategies are consistently related to poor adaptation and others to better adaptation. For instance, escape-avoidant strategies, such as wishful thinking and the use of drugs or alcohol, have invariably been related to greater emotional distress (Ben-Zur, Gilbar & Level, 2001; Bloom & Spiegel, 1984; Dunkel-Schetter et al., 1992; Feifel et al., 1987; Friedman, Baer, Lewy, Lane & Smith et al., 1988; Manne et al., 1994). Similarly, the adoption of a helpless attitude toward the disease has been associated with more symptoms of depression and anxiety (Chaturvedi, Shenoy, Prasad, Senthilnathan & Premlatha, 1996; Watson et al., 1991).

On the other hand, distancing oneself from the situation has also been associated with better adaptation, (Dunkel-Schetter et al., 1992; Manne et al., 1994). Several authors propose that when a situation is seen as unalterable, strategies such as distancing and denial, which regulate emotional responses, may be the most adaptive ways of coping (Folkman & Lazarus, 1980; Manne et al., 1994; Meyerowitz, 1983). Similarly, the active emotion-focused strategies of minimization, positive reappraisal of the situation and self-control have also been associated with better adaptation (Ben-Zur et al., 2001; Dunkel-Schetter et al., 1992; Friedman et al., 1988; Manne et al., 1994; Taylor, Lichtman & Wood, 1984).

Taking an active role by seeking information (Lavery & Clarke, 1996), social support (Dunkel-Schetter et al., 1992) and engaging in active problem solving (Friedman et

al., 1988) have also been associated with less emotional distress in some studies. The adoption of a “fighting spirit” has been associated with less emotional distress in two large studies (Classen et al., 1996; Watson et al., 1991).

Conflicting findings have been recorded for strategies such as denial, repression, emotional control, anxious preoccupation with the illness and stoicism or fatalism. For example, denial was found to be related to better adjustment in that individuals were less distressed (Hughes, 1985; Meyerowitz, 1983), but also to poor adjustment in the area of health care orientation (Friedman et al., 1988). Ward, Leventhal and Love (1988) found that those chemotherapy patients who repressed feelings and thoughts associated with their disease reported fewer and less severe side-effects and less severe mood swings than nonrepressors. Similarly, Manne et al. (1994) reported that self-controlled coping (efforts to regulate feelings and hide them from others) was related to higher levels of positive affect. On the other hand, two studies found that emotional control was associated with mood disturbance (Classen et al., 1996; Watson et al., 1991).

Discrepant findings also exist for women who were anxiously preoccupied with their illness. Watson et al. (1991) found that these women displayed more symptoms of depression and anxiety. However, Lavery and Clarke (1996) found that women who were more worried and concerned about their diagnosis actually made a better adjustment. Finally, a fatalistic response has been associated with mood disturbance in one large study (Watson et al., 1991) and two smaller studies (Chaturvedi et al., 1996; Feifel et al., 1987). However, Classen et al. (1996) failed to find this association.

Longitudinal studies. In addition to the cross-sectional studies, there are 13 longitudinal studies that have examined the association between coping and adjustment in

cancer patients. As with the cross-sectional studies, some coping strategies have been consistently related to poor adaptation and others to better adaptation. Again, the use of escape-avoidant strategies was related to greater distress at follow-up in four prospective studies (Epping-Jordan et al., 1999; Felton & Revenson, 1984; Heim, Valach & Schaffner, 1997; Stanton & Snider, 1993). Similarly, the five studies which assessed helplessness/hopelessness were in agreement in that this response was related to subsequent affective disorders (Burgess et al., 1988; Greer, Morris & Pettingale, 1979; Parle, Jones & Maguire, 1996; Thomas et al., 1988). Weisman and Worden (1976-77) also noted that patients who were coping poorly tended to suppress worries, withdraw and passively submit to whatever was recommended by their physicians. In the prospective studies, stoicism or fatalism was related to poor adjustment at follow-up (Heim et al., 1997; Greer et al., 1979). The use of self blame and blaming the environment was also predictive of psychological distress at follow-up in two relatively small studies (Heim et al., 1997; Malcarne, Compas, Epping-Jordan & Howell, 1995).

Also consistent with the cross-sectional studies, Filipp et al. (1990) found that minimization (focusing on the positive) helped to maintain or elevate levels of emotional well-being, and Weisman and Worden (1976-77) found that redefinition of the situation was associated with positive affect. The use of denial appeared to be beneficial in three of the longitudinal studies, in that it bore no association with emotional distress regardless of the stage of disease (Burgess et al., 1988; Greer et al., 1979; Heim et al., 1997).

Findings regarding the adaptiveness of active coping strategies, such as information seeking and problem solving are equivocal. Two studies found that information seeking was associated with good psychosocial adaptation (Felton & Revenson, 1984; Heim et al.,



1997) but another large study found that information seeking was completely unrelated to levels of well-being (Filipp et al., 1990). Similarly, Heim et al. (1997) reported that taking the initiative in regards to treatment was associated with better adaptation. However, Carver et al. (1993) reported that although the frequency of problem solving was high early in their study, this did not appear to have a beneficial effect on adjustment. On the other hand, and in concurrence with the cross-sectional studies, two prospective studies found that a fighting spirit was an adaptive response to a diagnosis of cancer (Burgess et al., 1988; Greer et al., 1979). The seeking of social support also appeared to be adaptive in that it was associated with better adjustment at follow-up (Filipp et al., 1990; Heim et al., 1997).

A combination of strategies was found to be particularly adaptive in a small prospective study by Heim et al. (1997). They found an association between psychosocial adaptation and a combination of emotion-focused and problem-focused strategies that included seeking information and support, taking the initiative in regards to treatment, acceptance, denial and diversion. Poor adjustment was related to the use of negative emotional modes of coping such as resignation-fatalism, passive-avoidant behavior or blaming oneself and the environment. Dunkel-Schetter et al. (1992) also noted that a combination of emotion and problem-focused strategies (seeking information and support, focusing on the positive and distancing) was associated with less emotional distress.

Findings from a small prospective study by Manuel, Roth, Keefe and Brantley, (1987) suggest that patients who clearly prefer to use either approach or avoidant strategies cope well with the early stages of treatment. In this study, passive patients who tended to make little use of either approach or avoidant strategies were the most distressed. Patients

who used either high approach-low avoidance or low approach-high avoidance had low levels of emotional distress. The high approach-low avoidance patients spent much of their time thinking about the cancer and its impact. They implied they would like to be able to forget about it sometimes but were unable to do so.

Moderating variables. A number of studies have assessed the contribution that factors such as the perception of control make to adaptation. Two cross-sectional studies found that perceptions of control were related to adaptation. Taylor et al. (1984) found that the belief of personal control or the belief that others could control the course of the disease was associated with good adjustment. A study by Thompson, Sobolew-Shubin, Galbraith, Schwankovsky & Cruzen, (1993) suggests that perceived control should be assessed in more than one dimension. They examined the perception of control in four areas, emotions/symptoms, relationship control, medical care control, and progression of disease control. In this study, control over the consequences of the diagnosis, symptoms, seeking information, emotions, relations with others, rather than control over the course of the disease played a larger role in adjustment, suggesting that while it is important to believe that you can control the central outcome, it is more important to believe that you can influence some of the consequences of the event. Patients who were getting relatively poor outcomes (e.g., lower scores on measures of physical functioning), were as likely to experience good emotional adjustment as those with good outcomes, if they had a sense of control.

In contrast, Friedman et al. (1988) found that the extent to which participants believed they could control their own health or illness was not related to any of their psychosocial adjustment measures. In like manner, two studies which followed patients

over three weeks and four months post diagnosis, found that generalized and specific control expectancies were not related to psychological distress at diagnosis or at follow-up (Malcarne et al., 1995; Stanton & Snider, 1993). In both these studies, the role of control beliefs was examined much earlier in the process of adjustment to the illness and both sets of authors propose that the positive effects of control may not emerge until later in the process.

Summary. In this review, emotion-focused strategies appear to be typical responses when coping with the stressors associated with cancer. It also seems that these responses may become more prominent as the disease advances. As well, there is the suggestion that factors such as the perception of control over the course of events, the perception of being able to cope and the severity of the stressor has an impact on the manner of coping (Dunkel-Schetter et al., 1992; Feifel et al., 1987; Hilton, 1989). In general, the findings indicate that greater emotional distress is associated with the use of escape/avoidant strategies and better adaptation is related to the use of active emotion-focused strategies such as positive reappraisal. Taking an active role by seeking information and support and engaging in problem solving is generally adaptive, although the benefits of these strategies are not always evident. Interestingly, one of the earliest investigations (Weisman & Worden, 1976) noted that the use of some coping strategies such as seeking information and distraction worked for some individuals but not for others.

A helpless response in the face of stressors seems to be associated with depression, and the majority of studies that considered fatalism found that this response was related to poor adjustment. Similarly, the use of self blame and blaming the environment do not appear to be beneficial for successful adjustment.

In this population, strategies such as distancing and denial appear to be of some benefit. There are many distressing aspects to the diagnosis of cancer and Meyerowitz, Heinrich and Schag (1983) suggest that emotion-focused strategies such as denial may assist in adjusting to some aspects of the experience. In addition, it has also been proposed that when the situation is seen as uncontrollable, strategies which regulate emotional responses, including denial and distraction, may be the most effective way of coping (Folkman & Lazarus, 1980; Manne et al. 1994). Unfortunately, however, as will be reviewed later, other research shows that some individuals seem to have little capacity for distraction (Miller, 1996). In short, some individuals are disposed to cope in a manner that may inhibit them from engaging in strategies that help them regulate their emotional responses. Given that a major goal of such dispositional models is the early identification of individuals whose coping resources may be inadequate to the demands of the situation, it seems reasonable that any analysis of the coping process should include an investigation of individual differences in coping styles.

### Methodological Considerations in Stress and Coping Research

Although the transactional model has had a substantial impact on our general understanding of how people cope with stress, as well as on our specific understanding of how people cope with cancer, there are a number of conceptual and methodological issues that are important to consider. First, a significant conceptual consideration for research in this area pertains to the particular nature of the stressors that patients are coping *with*. For example, the illness experience (and consequently, the types of coping strategies used) may be quite different for patients with poorly controlled physical symptoms than for patients

whose central concerns are social or existential. Although the available research suggests that stressors at the end of life can be divided into several broad categories, no studies of coping to date have used this framework to examine how patients cope with different aspects of their illness and the stressors it presents across different dimensions. Rather, participants have been asked more broadly about how they cope with their illness generally, as opposed to coping with specific illness-related problems and concerns. In this broad context, however, emotion-focused strategies appear to be used most frequently, and tend to become more prominent as the disease advances.

A second issue pertains to the use of different scales and protocols, with disparate ways of classifying coping responses, which makes it difficult to compare studies. De Ridder (1997) has identified more than 20 measures for assessing coping, all based on different conceptual frameworks and covering different content dimensions. This points to a lack of consensus among researchers concerning the construct of coping. Nevertheless, the basic distinction that coping strategies may tend to be relatively more problem-focused or emotion-focused is one that has gained widespread acceptance in the literature. The distinction is no longer regarded as absolute, however; some strategies can have both problem-focused and emotion-focused aspects. In addition, the problem vs. emotion-focused dimension may not be the only relevant one to consider in this context, as Maes et al. (1996) have suggested. An associated issue is the vast number of individual coping behaviours that have been described. However, the three-dimension approach suggested by Maes et al. (1996) provides a conceptual basis for organizing these behaviours in a manner that seems applicable to the experience of people who are coping with advanced cancer. Table A3, Appendix A, shows how the individual coping strategies can be defined and

placed in categories of problem-focused coping, active emotion-focused coping and avoidant emotion-focused coping.

A fourth issue has been raised by Coyne and Gottlieb (1996) and Coyne and Racioppo (2000), who suggest that coping checklists provide a distorted and incomplete picture of coping and do not appropriately reflect the transactional model. Rather than being situation-specific, coping checklists are designed to be broadly applicable (Lazarus, 2000), and their wording often creates uncertainty as to whether or not an item really represents the individual's coping efforts (Coyne & Racioppo, 2000). In addition, the content of items conveys expectations as to what constitutes a desirable response and this can lead to choices based on self-presentation motives. Similarly, respondents may choose an item because they recognize previously used responses, rather than behaviours used to manage or alter the current situation (Pearson, Ross & Dawes, 1992).

Several authors have also raised a further concern (Aldwin, 1994; Labouvie-Vief, Hakim-Larson, & Hobart, 1987), which questions the adequacy of standard coping inventories to detect developmental changes. They submit that both cognitive and emotional complexity increase with age, affecting the manner in which older individuals cope with stress. They further propose that qualitative interviews may be necessary to understand the nature of coping in certain populations. For instance, Johnson and Barer (1993) found that older adults had learned to compensate for health limitation by reorganizing their environments and making the most of the capacities they retained. Aldwin points out that most coping questionnaires do not have items that tap these strategies.

A similar problem exists with self-report stress questionnaires. Aldwin (1994) found that when a self-report questionnaire was used, approximately 25% of men reported that they had no problems. However, when interviewed, many of these men revealed that they did indeed have problems. In fact, by using an interview rather than a self-report questionnaire the number of men reporting "no problems" fell below 10%. Aldwin suggests that some of these men dissociated their public self-presentation from their private selves. For example, it was acceptable to admit to having "concerns" but not to having "problems." Aldwin further proposed that "interviews may be especially useful when exploring a new area about which relatively little is known, when studying potentially very sensitive areas..... or when dealing with a population that might have very different views of what constitutes stressors, either owing to culture or age.." (p. 67). In view of these considerations, it seems that in the instance of patients approaching death from advanced cancer, an interview format would allow for an appropriate way of reporting stressors. Similarly, allowing patients to describe their actual coping efforts, rather than taxing them with a long list of possible coping behaviours which may or may not be applicable, may provide a more accurate description of what they perceive to be their ways of coping. It would also take into consideration the limited physical capabilities associated with advanced disease.

Finally, another central consideration involves the emphasis that the transactional model places on coping as a process, namely that coping behaviours vary over time and according to context. While this has been supported in various studies (Folkman & Lazarus, 1980; Folkman & Lazarus, 1985; Folkman, Lazarus, Dunkel-Schetter et al. 1986), stability for some types of coping is also indicated. For instance, Stone and Neale (1984)

asked 120 participants to complete a measure of daily coping for 21 consecutive days. They found a moderate degree of within-subject consistency in how participants coped with the same problem over time. Similarly, Compas, Forsythe and Wagner (1988) reported that college students tended to use a consistent pattern in coping with the same academic or interpersonal stressors on different occasions. However, consistency was lower when examined across different stressors. On the other hand, Folkman, Lazarus, Gruen and DeLongis (1986) reported a relatively high degree of stability for some coping responses across stressful encounters. Even, Lazarus (1993), a leading proponent of the transactional model, considers that the capacity to engage in positive reappraisal of stressful situations may be viewed as a stable coping disposition.

Although the transactional model acknowledges that coping is influenced in part by the attributes that the individual brings to the situation, there has been little research into those characteristics that may predispose individuals to cope in particular ways. The major exception in this regard is the monitoring-blunting hypothesis proposed by Miller (1980, 1987). In this model, Miller submits that a review of coping behaviours reveals two underlying dimensions that seem to reflect a preferred coping style. "Monitoring" refers to the extent to which an individual typically attends to, or monitors, the threatening aspects of stressful situations; and "blunting," which refers to the extent to which an individual cognitively avoids or blunts threatening cues (Miller, 1980, 1987; Miller & O'Leary, 1993). Researchers have argued that in order to increase our understanding of how individuals cope with threatening events, models of stress and coping should be expanded to include a consideration of coping styles (Ward et al., 1988).



### Dispositional Model

Underlying dispositional approaches is the assumption that relatively stable individual characteristics influence coping behaviour in a wide range of situations. These characteristic styles interact with, and, in some cases, appear to transcend situational factors (Miller, 1990). Miller's (1980b; 1987) model focuses on the individual's general disposition to seek out or avoid threat-relevant information. The term "monitoring" refers to the extent to which an individual typically attends to negative, potentially painful or dangerous aspects of a stressful situation. Blunting, on the other hand refers to the extent to which an individual uses cognitive strategies such as distraction, self-relaxation, denial, detachment, intellectualisation, and reinterpretation to blunt the psychological impact of threatening cues (Miller, 1992). Research in the laboratory and in health settings has shown that coping style does indeed affect how individuals respond to threatening situations. For example, in laboratory studies, the monitoring-blunting dimension has been shown to predict whether individuals actually do attend to or avoid information in situations involving both physical (shock) and ego-threatening stressors (Miller, 1987).

This line of research has now been extended to various medical populations, including patients facing gynaecological surgery (Miller & Mangan, 1983; Miller, Roussi, Altman, Heim & Steinberg, 1994), or cardiac catheterization (Watkins, Weaver & Odegaard, 1986), as well as with hypertensive patients (Miller, Leinbach, & Brody, 1989), patients with gastrointestinal disorders (Cheng, Hui, & Lam, 2000), and patients with cancer (Gard, Edwards, Harris & McCormack 1988; Lerman et al., 1990; Steptoe, Sutcliffe, Allen, & Coombes 1991). When faced with these health-related stressors, monitors consistently desire more information. For instance, following colposcopy or

cardiac catheterization, blunters were satisfied with the amount of preparatory information they had been given, whereas monitors would have preferred more (Miller & Mangan, 1983; Watkins et al., 1986). Similarly, among patients with metastatic cancer, monitors proved to be less satisfied than blunters with the information given about symptoms and treatment, despite a higher level of factual knowledge about these issues (Steptoe et al., 1991). Miller proposes that monitors may seek information in an effort to reduce uncertainty and not necessarily from a desire for greater control in their care. In fact, in one study conducted in a primary care setting, it was found that high monitors desired more information, but were also more likely to prefer playing a completely passive role in their medical care (Miller, Brody & Summerton, 1988).

In response to health-related threats, monitors generally show evidence of more sustained physiological and subjective distress than blunters. For example, monitors have been found to suffer more from nausea and vomiting in relation to chemotherapy, despite the fact that they were more likely to have received antiemetic medication (Gard et al., 1988). A similar result was reported by Lerman et al. (1990), who found that blunters not only suffered less nausea, but also less anticipatory anxiety and fewer symptoms of depression than monitors. Significantly less anxiety was also seen in blunters than monitors in a group of patients with metastatic cancer admitted for assessment and treatment modification (Steptoe et al., 1991). Similarly, distress levels were higher among monitors in a group of women undergoing ultrasound scans for ovarian cancer (Wardle et al., 1993). In that study, high monitors who received positive scans were more distressed by the results than low monitors who received positive results. In other settings, monitoring has been associated with greater subjective and behavioural distress during colposcopy (Miller

& Mangan, 1983), and amniocentesis procedures (Phipps & Zinn, 1986). In the primary care setting, monitors tend to present with less severe medical problems than blunters. However they report levels of dysfunction, discomfort and distress that are equivalent to those of blunters (Miller et al., 1988). Monitors also take longer to recover from medical procedures and acute episodes of illness (Miller & Mangan, 1983; Miller et al., 1988).

Differences have also been found between monitors and blunters in the degree of concern that they express in regard to their medical problems. For instance, high monitors undergoing colposcopy were found to be significantly more concerned about the seriousness of their problem (Miller et al., 1994). This also applied for hypertensive patients who were high monitors (Miller et al., 1989). Although they were actually feeling and functioning better than normotensive patients, they reacted to their medical problems with higher levels of concern, and were more likely to request treatment for both medical and stress-related symptoms. As well as a desire for more information, monitors have been found to request more investigations, new prescriptions and counselling, despite the fact that their medical problems were deemed by the physician to be less severe than those of blunters (Miller et al., 1988; Miller et al., 1989).

In short, monitors and blunters do not differ from each other on initial measures of state or trait distress or on measures of initial psychophysiological arousal (Miller, 1987; Miller & Mangan, 1983; Phipps & Zinn 1986; Watkins et al., 1986). Rather they seem to become more aroused and distressed in the face of threat which activates their tendency to scan for threatening cues. Interestingly, it appears that monitors can be protected from this tendency for greater arousal in the face of threat. Several studies show that when the level of information is consistent with their preference, monitors show reduced physiological

and subjective distress (Miller & Mangan, 1983; Gattuso, Litt & Fitzgerald, 1992; Watkins et al., 1986). In a range of medical procedures including colposcopy (Miller & Mangan, 1983), cardiac catheterization (Watkins et al., 1986) and gastrointestinal endoscopy (Gattuso et al., 1992) it has been demonstrated that both monitors and blunterners show less physiological and subjective arousal when the level of information provided is consistent with their preference.

The level of information that monitors and blunterners are exposed to has also been shown to affect coping behaviours. Shiloh, Mahlev, Dar & Ben-Rafael, (1998) found that monitors reported less pain when viewing a contraction recorder during childbirth than when the recorder was hidden from view. Conversely, viewing the recorder interfered with the ability of blunterners to make use of distraction and thus reduced their ability to cope with pain.

According to the goodness-of-fit hypothesis, when an individual perceives the situation to be uncontrollable, more emotion-focused coping is likely to be used. However a recent study (Cheng et al., 2000), would appear to support the contention that some individuals are disposed to cope in a manner which may inhibit them from engaging in strategies which help them regulate their emotional responses (Miller, 1996). This study found that patients with gastrointestinal disorders displayed a pattern of action-oriented coping behaviours regardless of the perceived controllability of the stressful event, a characteristic that Cheng et al. (2000) interpreted as a stable individual difference that may have implications for the management of their illness.

It would seem that depending on the circumstances, these individual differences in the tendency to monitor or blunt in the face of potentially threatening situations may have

either positive or negative consequences for the individual. When there is a need to cope with chronic severe health threats, as with advanced cancer, the tendency to continue to monitor for anxiety producing threatening information may inhibit that person from engaging in those emotion-focused coping strategies which could help reduce their level of distress (Cheng et al., 2000; Lazarus & Folkman 1984; Miller, 1990, 1995). Similarly, problem-focused coping may be inhibited by their tendency to focus on and amplify threat-relevant cues, resulting in a cycle of information seeking rather than in efforts to change environmental conditions or their own behaviour. On the other hand, monitors are more likely to seek medical help, report symptoms, and engage in health screening practices (Steptoe & O'Sullivan 1986). The ability of blunters to avoid or distance themselves from threatening cues, thus suffering less interference from distressing emotions, may help them to cope more effectively with chronic severe health threats such as advanced cancer. However, it may have negative consequences as they are more inclined to avoid health screening (Steptoe & O'Sullivan 1986) and less likely to adhere to treatment protocols (Christensen, Smith, Turner & Cundick 1994).

Overall then, the fit between an individual's preferred coping style and the amount of information provided when faced with various medical procedures appears to affect how well that individual copes. High monitors appear to be less distressed when they receive more information, and blunters do better with less information. Identifying an individual's preferred coping style should help to identify those persons who may encounter difficulties in coping, and would seem a reasonable adjunct in the planning of interventions.

In general, it seems that blunters tend to avoid or distance themselves from threatening cues and suffer less interference from distressing emotions. On the other hand,

monitors appear to scan for, focus on and amplify health-relevant information and potential threats. They exhibit higher levels of state anxiety than blunters (Miller & Mangan, 1983; Phipps & Zinn, 1986) and become more distressed when faced with uncontrollable events (Miller, 1996; Sparks, 1989). It is conceivable that these elevated distress levels might interfere with effective problem solving and adaptive coping (Lazarus & Folkman 1984). Given this premise, it seems logical to consider individual differences in coping style in any study on coping behaviour.

### Conclusion and Rationale

A variety of potentially stressful physical, existential and social issues confront the individual with advanced cancer. The cognitive and behavioural strategies used to manage these stressful situations are thought to play a role in how well people adapt to these stressors. The apparent high levels of stress and the incidence of dysphoria and depression (Cassileth et al., 1984; Pinder et al., 1993) indicate that some individuals do indeed have considerable difficulty adapting. A fundamental reason for the study of coping is to determine how to reduce the negative impact of stressful events, with the further assumption that adaptation can be improved by addressing deficiencies in coping skills when planning and implementing interventions. Although this conceptualization is relevant to the issue of coping with impending death, as yet there are few studies of patients dealing with the stressors of advanced terminal illness.

With advanced disease many stressors, such as those associated with treatments or the immediacy of death, can be seen as essentially uncontrollable. The transactional model posits that when individuals perceive a situation to be uncontrollable, a greater use of

emotion-focused coping may be more adaptive (Lazarus & Folkman, 1984). However, Miller (1996) proposes that some individuals appear to have little capacity for engaging in strategies that help them regulate their emotional responses in the face of serious health threats. Therefore, the present study attempted to integrate the transactional model of coping with the dispositional model to examine the coping process in patients with advanced cancer. The goals were to (1) identify patients with preferences for either monitoring or blunting styles of coping; (2) catalogue the stressors facing these individuals across the physical, social and existential dimensions; (3) determine how monitors and blunners differ in coping with stressful events; (4) examine the association between types of stressors, coping responses, and psychological distress, including clinically significant mental disorders; and (5) determine whether monitors and blunners with advanced cancer differ with respect to the level of distress that they experience.

### Specific Hypotheses

#### Dimensions of Stress

1. Miller et al. (1994) and Miller et al. (1989) found that monitors react to their problems with higher levels of concern. Therefore, it was hypothesised that monitors would give higher ratings of severity to their stressors across dimensions of stress.
2. Given their propensity to scan for, focus on and amplify health-relevant information and potential threats (Miller et al., 1989; Miller et al., 1988), it was further proposed that monitors would attach a higher severity rating than blunners to their most severe individual stressor within each dimension of stress.

### Coping Strategies

3. It was proposed that blunterns would engage in more emotion-focused avoidance coping than monitors, given that blunterns tend to distance themselves from threatening cues and suffer less interference from distressing emotions.
4. It was hypothesised that different types of stressors would impose different demands on coping behaviours. For physical symptoms, it was proposed that patients would take a more problem-focused approach to try to directly reduce the source of distress. For social concerns, which by definition involve an interaction with others, a greater mix of problem-focused and emotion-focused strategies was expected. For existential concerns, which involve more intangible, psychological considerations, less direct problem solving was anticipated in favour of more emotion-focused coping.

### Perceptions of Efficacy and Control

5. Following the goodness-of-fit hypothesis, it was predicted that stressors rated low in controllability would elicit more emotion-focused than problem-focused coping. However, the literature does not provide enough information to support a specific hypothesis regarding which dimension of stress -- physical, social or existential -- will be seen as more or less controllable.
6. It was also hypothesized that blunterns would see their coping efforts as more successful overall than monitors. It was further proposed that blunterns would be more likely to feel that they had higher levels of control over stressful issues than



monitors. These proposals were based on the findings that blunters prefer and are able to distance themselves from threatening cues and are apparently less distressed when faced with uncontrollable events (Miller, 1996; Miller & Mangan, 1983; Sparks, 1989).

#### General Psychological Distress

7. Given the Noyes et al. (1990) finding that higher levels of psychological distress were associated with existential concerns, it was predicted that the existential dimension of stress would show a higher correlation with psychological symptoms than either social or physical dimensions of stress.
8. It was further posited that monitors would display greater levels of general psychological distress than blunters. This and hypothesis 7 are based on the findings that monitors display higher levels of anxiety and become more distressed when face with uncontrollable events (Miller, 1996; Miller & Mangan, 1983; Phipps & Zinn, 1986; Sparks, 1989).

#### Clinical Psychological Disorders

9. A corrolary hypothesis was that more monitors than blunters would fulfill diagnostic criteria for a depressive or anxiety disorder.

## Method

Prior to recruitment, the ethics review boards of all participating institutions gave their approval to the study.

### Participants

Fifty two participants were recruited from three Ottawa hospitals and a day Hospice: (1) The Elizabeth Bruyère pavilion of the SCO Hospital; (2) The Ottawa Civic Hospital; (3) The Ottawa General Hospital; and (4) the Hospice at May Court. The criteria for inclusion were that (1) in the opinion of the referring clinician, the patient was not impaired cognitively; (2) the patient's physical condition permitted participation; (3) the patient's primary diagnosis was cancer; (4) the patient was aware that treatment was palliative in nature; and (5) the patient was able to understand and read English.

### Procedure

Recruitment. Potential participants were identified by palliative care clinicians (physicians or nurse specialists), who reviewed consecutive patients admitted or referred to their services. These clinicians discussed the project with the patients that they considered to be eligible, thus serving as the first point of contact about the study. Only patients who were willing to be contacted by the research interviewer had their names passed along to the research team. Patients who agreed to participate were contacted, and an appointment was made for them to be interviewed at the hospital or in their homes.

After ensuring that the participant's capacity to consent had not diminished, the interviewer explained the purpose of the study, answered questions, and read out the

information and consent form (see Table B1, B2 in Appendix B). Those individuals who agreed to participate were asked to sign three statements of informed consent. A copy of the consent form and the information sheet were given to the participant. The second copy was for the hospital records and the third for the research file. The information obtained in the interviews was kept confidential; however, the participant's attending physician and care team were informed that their patient had taken part in the study. This was accomplished by placing the notification form shown in Table B3, Appendix B on the patient's chart. This ensured that the care team was aware of the individual's participation in the study if the patient chose to discuss aspects of the interview with the staff.

Every effort was made to ensure privacy and minimal disruption of the interview. For hospital inpatients the interviews were conducted in the most private area available on the ward.

Two interviewers were engaged in the data collection, with the majority of interviews carried out by the principal investigator (46 interviews, 88.5%).

#### Interview Protocol: General Overview

The interview (see Appendix C) first recorded basic demographic information. Next it identified the preferred coping style of the participants using the Miller Behavioral Style Scale (MBSS) short form, which was used to classify participants as having a monitoring or blunting style. The interview then moved on to a discussion of sources of stress within each of the social, physical, and existential dimensions. Within each dimension, the single most severe stressor was identified. For these "most severe stressors" the subject was asked to rate his/her perception of control over these particular problems,

the strategies used to cope with them, and his/her view of how effective these coping efforts were in dealing with the problem.

The format of the interview was based on a protocol developed for use with palliative care patients in a study of patient attitudes toward euthanasia and physician-assisted suicide (Wilson, Scott et al., 2000). This interview was designed with a regard for the limited physical capacity of most patients with advanced cancer, which limits the applicability of research using lengthy questionnaires. In general, each interview item followed a common pattern: a lead question followed by probing in order to aid in the rating of symptom severity on a 7-point ordinal scale. Prompts were included to allow for extensive probing, but the interviewer terminated the questioning as soon as the patient had provided enough information for a rating to be made. This format was adapted from common structured interviews for mental disorders, such as the Schedule for Affective Disorders and Schizophrenia (SADS) (Endicott & Spitzer, 1978). Although most items have been used in previous research with this population, some had been constructed specifically for the present study.

Each interview was tape-recorded to allow verbatim transcription of responses to open-ended questions, which was required for content analyses. After the coding was completed, the tapes were erased.

#### Interview Protocol: Specific Elements

Procedurally, the interview proceeded as follows:

Demographic information. Basic information was obtained for descriptive purposes.

**Miller Behavioral Style Scale.** The patient's preferred coping style was identified with the abbreviated form of the MBSS (Miller, 1987). Originally, the MBSS was a self-report measure that reflected an individual's preference for information or distraction in the face of four hypothetical stressful events: the threat of job loss; handling dental phobia; being held hostage; and, flying in a plane when something goes wrong. Each situation is followed by eight responses, four of which are considered indicative of a monitoring (information seeking) style and four of a blunting (information avoiding) style. Individuals are asked to check all of the responses that might apply to them personally. Miller (1987) reported that test-retest reliability was moderately stable over a four-month period, both for the monitoring subscale ( $r = .72$ ); and for the blunting subscale ( $r = .75$ ), and that the MBSS has good predictive and discriminative validity. Steptoe (1989), however, reported that some individuals have difficulty relating to two of the items on the MBSS. He found that seriously ill patients in particular, did not react well to the hostage and flying scenarios. To determine if the questions concerning job loss and fear of dentists would adequately reflect the two coping dispositions, Steptoe administered the MBSS to a group of undergraduate students and to a group of patients hospitalized with metastatic cancer. He reported that the abbreviated monitoring subscale correlated significantly with the total monitoring subscale for both the students and the cancer patients ( $r = 0.84$  and  $r = 0.90$  respectively), and that the correlations for the abbreviated blunting subscale and the total blunting subscale were  $r = 0.79$  for the students, and,  $r = 0.84$  for the cancer patients. Hence, he concluded that the abbreviated form of the MBSS provided an "adequate estimate of responses to the complete questionnaire." Consequently, this study used the abbreviated version of the MBSS.

The ratings for all the items assessing social concerns, pain and symptom assessment and existential concerns were based on a common set of verbal descriptors modelled on the Memorial Pain Assessment Card (Fishman et al., 1987). This results in a 7-point ordinal scale (0 = None; 1 = Minimal; 2 = Mild; 3 = Moderate; 4 = Strong; 5 = Severe; 6 = Extreme). As noted earlier, each interview item followed a common pattern: a lead question followed by probing in order to aid in the rating of symptom severity and the amount of distress associated with that problem. For example, a rating of 3 on any given item indicates that the concern is experienced at a severity that the participant considers to be "generally a significant concern."

Social Concerns. This section addressed the major social aspects of dying that have been discussed most extensively in previous research. Conceptually, "social" issues were defined at the outset as issues involving relationships with people as individuals, and relations with people as members of groups or society (Corr, 1991-92).

Included under this heading were the sense of isolation from family and friends, the concern that one has become a burden to others, concerns about role loss within the family or community, economic concerns, and finally, satisfaction with the amount of information concerning their illness provided by health professionals. Although these items have been grouped together into a common dimension on conceptual rather than empirical grounds, the internal consistency of the items, when considered as a scale, was acceptable at  $\alpha = .67$ .

Pain and Symptom Assessment. All of the items pertaining to pain and other physical symptoms were taken from the Structured Interview Assessment of Symptoms and Concerns (Wilson, Graham et al., manuscript submitted for publication). The authors report that this is a reliable and valid instrument with excellent inter-rater reliability

(intraclass  $r \geq .92$  for all items) and good criterion validity when correlated with visual analogue scales of the same constructs (correlations ranging from  $r = .71$  to  $.90$ ). In addition to pain, four other physical symptoms were assessed, based on their high prevalence in patients with advanced disease (Coyle et al., 1990; Curtis, Krech, & Walsh, 1991; Ventafridda, Ripamonti, De Conno, & Tamburini, (1990). The symptoms of weakness, drowsiness, nausea and breathlessness were assessed with items modelled on the pain severity assessment. The internal consistency of the physical symptom items was  $\alpha = .62$ .

Existential Concerns. This section focused on the existential sources of distress associated with terminal illness, including such issues as one's sense of control, sense of dignity and life satisfaction (Cohen et al., 1996). Also included were items that addressed concerns including fears for the future, loss of hope and loss of meaning (Cohen et al., 1996; Dunkel-Schetter et al., 1992). Overall, the internal consistency of these items was  $\alpha = .78$ .

Ratings of Control. At the end of each section (social, physical, existential) the subject was asked to identify the single most significant stressor in that particular area. The participant was then asked to indicate the amount of perceived control that he/she had over that problem. These ratings were made on a 7-point ordinal scale that ranged from 0 = no control to 6 = extremely high level of control.

Assessment of Coping. The assessment of coping was approached using methods derived from Compas, Malcarne et al. (1988), Wertlieb, Weigel, and Feldstein (1987), and Wilson et al. (1995). Specifically, the subject was asked to identify the particular coping strategies that were used to manage the most distressing issue in each of the three

dimensions (physical, social, existential). The subject was asked to describe each strategy in detail, in order to clarify the intent of the action as representing an effort to alter/solve the problem (i.e., problem-focused coping) or to manage the feelings associated with the problem, in either an avoidant (i.e., avoidant, emotion-focused coping) or confrontive (i.e., approach, emotion-focused coping) way.

**Ratings of Effectiveness.** After describing how they coped with their most significant stressor, participants were then asked how well they thought they were managing that particular issue. Ratings were made on a 7-point ordinal scale that ranged from 0 = not at all effectively to 6 = extremely effectively.

**Psychological Distress.** The 7-item Beck Depression Inventory for Primary Care (BDI-PC) was used as an index of general distress. The seven items on the BDI-PC reflect non-somatic symptoms of depression, which some authors suggest are most valid for assessments with seriously ill patients (Endicott, 1983). These items are Sadness, Loss of Pleasure, Pessimism, Past Failure, Self-Dislike, Self-Criticalness, and Suicidal Thoughts and Wishes. The patient's were asked to describe themselves for the "past two weeks, including today." The BDI-PC is scored by summing all of the ratings on the seven items. Each item is rated on a 4-point scale ranging from zero to three, and the maximum score is 21. Beck, Guth, Steer and Ball (1997) report that a cut-off score of 4 and above correctly classified patients who were independently diagnosed with or without major depression 82% of the time. The internal consistency is reportedly high ( $\alpha = 0.86$ ), and in the present study was  $\alpha = .77$ . The BDI-PC is also correlated moderately with the Depression subscale from the Hospital Anxiety and Depression Scale (HADS). However, Beck et al. (1997)



found that it was more closely associated with a diagnosis of major depression ( $r = 0.66$ ) than was the HADS ( $r = 0.37$ ).

Assessment of Depressive and Anxiety Disorders. Although the BDI-PC is associated with a clinical diagnosis of major depression, many investigators consider that self-report measures of this type are best regarded as indices of general distress rather than substitutes for more formal diagnostic assessment based on accepted criteria for discrete syndromal mental disorders (Fechner-Bates, Coyne, & Schwenk, 1994). Hence, the present study also examined depression at the diagnostic level, using an adaptation (Wilson, Scott et al., 2000) of the Anxiety and Depression Modules from the Primary Care Evaluation of Mental Disorders (PRIME-MD) (Spitzer et al., 1994). The PRIME-MD is a rapid measure for diagnosing mental disorders in primary care. Spitzer et al. (1994) reported that with 95% of people, the PRIME-MD can be administered within 20 minutes, and has an overall concordance rate of 88% when evaluated against the criterion of independent diagnostic assessments conducted by mental health professionals. The PRIME-MD has been recommended as a suitable instrument for both clinical and research use in palliative care because of its brevity and comprehensiveness (Wilson, Chochinov et al., 2000). The present modification consists of the use of ordinal severity rating scales for the core criterion symptoms of anxiety, depression and loss of interest in activities. This adaptation allows for a more detailed assessment of these particular symptoms. These items have been extracted from the SADS (Endicott & Spitzer, 1978) which permits the careful application of specific symptom severity thresholds specified in the Diagnostic and Statistical Manual of Mental Disorders (fourth edition; DSM-IV) (American Psychiatric Association, 1994).

The system for identifying the 13 specific disorders using this method is shown in Table C2, Appendix C. also contains the Diagnostic Scoring Checklist (see Table C3).

Debriefing. At the conclusion of the interview, the subject was debriefed. It was recognised that some patients would perhaps find the disclosure of personal information about these issues to be a stressful or emotional experience. Care was taken that patients were not left in a state of obvious distress at the conclusion of the interview. If issues emerged in the course of the interview (e.g., undisclosed depression or pain), which in the opinion of the interviewer could lead to better clinical care if brought to the attention of the hospital staff, this was discussed with the patient. If the patient consented, then the appropriate palliative care clinician was informed.

Chart Review. After the interview, the patient's chart was reviewed to record the primary type of malignancy, as well as the medications that had been administered in the preceding 24 hours. This included medications given on a regular routine and those given on an as needed basis. Medications of particular interest were morphine or other opioids, antidepressants, and benzodiazepines. Doses for opioids other than morphine were converted to morphine equivalents. Finally, the functional status of the patient was rated using the Karnofsky Functional Performance Status Scale (Schag, Heinrich & Ganz 1984). The Karnofsky Scale is a widely used, clinical observer's rating of the current physical status of a medically ill person. Ratings are made on a ten-point scale ranging from 0 to 100. A score of 100 indicates no complaints and no evidence of disease, whereas 0 represents death. Moderate interrater reliability ( $r = 0.69$ ) and substantial validity have been reported for this scale (Yates, Chalmer & McKegney, 1980).

The status of each participant was followed for up to six months. For patients who died during this period, the date of death was obtained from hospital records or from newspaper obituaries.

### Data Reduction

Inter-Rater Reliability. The inter-rater reliability of all measures based on the interview assessments was determined by having an independent rater (a registered nurse) score audiotapes of every interview. Poor sound quality of the tapes led to the exclusion of data from two interviews and part of the content from two more. For interview items that required ordinal ratings (sources of distress and the perception of control and effectiveness), intraclass correlations were computed between the scores of the two raters.

Coping responses. The tape-recorded interviews were typed out verbatim to facilitate the identification of coping responses. The interviewer's notes were used to create transcripts in the instances where tape sound quality was poor. The written narratives were then reviewed independently by the principal investigator and a second coder (a registered psychologist). These coders parsed each narrative into distinct conceptual statements that reflected individual examples of coping behaviour. Overall, the coders agreed that 1,258 statements reflected examples of individual coping behaviours, and they disagreed on 166. Disagreements were resolved by a third coder, resulting in a final pool of 1,347 distinct statements to be categorised into specific ways of coping.

The starting point for the categorisation of coping strategies was the Cheng et al. (2000) adaptation of Stone and Neale's (1984) description of coping behaviours (see Table D1, Appendix D). This framework was adopted because, like the present study, it used

semi-structured interviews and content analysis to examine the coping behaviors of medical patients (although not patients with life-threatening illness). However, there have been no studies that have examined these specific dimensions of stress with terminally ill individuals. Therefore, the Cheng et al. (2000) conceptualization was only used as a starting point, and its appropriateness to the present purpose was reviewed periodically through the course of the content analysis. Specifically, the two coders met after completing the scoring of successive groups of 13 participants, and they discussed whether or not the original framework provided an accurate depiction of coping themes that emerged from the present data. This type of iterative process, in which narratives may be continually reviewed and the framework modified on the basis of new information, is a common analytic strategy in qualitative research in which a definitive conceptualization may not be known a priori (Chamberlain, 1999).

The discussions between the reviewers were addressed to the adequacy of the framework, rather than to the coding of specific statements. This level of narrative coding was done independently by the two coders, with disagreements resolved by a third rater.

The iterative review process resulted in several modifications to the original Cheng et al. (2000) model. Using the dimensions of problem-focused coping, approach emotion-focused coping and avoidant emotion-focused coping, it was found that a number of the common coping behaviours were not adequately incorporated into the Cheng et al. (2000) model. For example, "seeking social support" could include seeking primarily instrumental assistance with a problem, or seeking primarily emotional support. For the present purpose, therefore, these two different aspects of support were coded separately. Instrumental support was classified as a problem-focused strategy, while seeking emotional support was

classified as an emotion-focused approach strategy. In the Cheng et al. (2000) model "relaxation" was defined as a separate coping behaviour, however in this study, it was found that participants sometimes used relaxation to help in symptom control and sometimes to divert attention. Therefore, relaxation was defined either as a "direct action" or as a "divert attention" strategy, depending on the purpose for which it was used. Additionally, the strategy of "escape" (leaving the stressful situation) did not appear to be a viable option for the stressors facing patients receiving palliative treatment and it occurred too infrequently to merit inclusion. Finally, coping strategies reflecting "hope" and "emotional control" were not defined in the Cheng et al. (2000) model. Focus groups with terminally ill patients have demonstrated the importance of maintaining hope for people who are facing death (Wenrich et al., 2001), and it emerged often enough to be included here as a separate coping behaviour. Some examples of the specific strategies reflecting hope were statements about positive outcome expectancies, hope for palliation of symptoms, confidence that one would find the strength to persevere, and belief in an ability to heal oneself. The use of "emotional control" as a coping strategy has been reported in a number of studies, although reports concerning its benefits as an adaptive strategy are conflicting (Classen et al., 1996; Manne et al., 1994; Ward et al., 1988; Watson et al., 1991). Emotional control was considered to be an emotion-focused avoidance strategy in which an individual held back from expressing an emotional experience.

The final rating system comprised 12 different categories of coping behaviour, which could be further classified into three dimensions of problem-focused, emotion-focused approach and emotion-focused avoidant behaviours (see Table A3, Appendix A). Two independent coders agreed on the classification of coping strategies in 88.3% of the

cases,  $\kappa = .77$ . This represents a substantial level of agreement according to guidelines recommended by Landis and Koch (1977).

The analysis of the coping data was conducted in two ways. First, the differential use of specific categories of coping was examined in order to provide a general qualitative sense of the kinds of strategies used by participants across the dimensions of stress. Second, parametric statistical analyses were conducted on the numbers of coping strategies reported by participants within the broader dimensions of problem-focused, emotion-focused approach, and emotion-focused avoidance coping (i.e., the number of strategies of different types was the variable of interest).

Identification of monitors and blunters. Each participant's preferred coping style, monitoring or blunting, was identified by subtracting the number of items endorsed on the blunting subscale of the MBSS (Miller, 1987) from the number of items endorsed on the monitoring subscale. A median split was performed and patients were then classified as monitors if they scored above the median, or blunters if they scored below the median (Lerman et al., 1990; Bijttbier, Vertommen & Steene, 2001). An internal consistency of  $\alpha > .80$  has been reported for this instrument (Lerman et al., 1990). In the present study however, the alpha coefficients were much lower, with  $\alpha = .50$  for the monitoring scale and  $\alpha = .54$  for the blunting scale. The Monitoring and Blunting scales were not significantly correlated with one another ( $r = -.04, p > .10$ ).

Power. Based on previous empirical research with the monitoring and blunting theory, the effect sizes associated with between-group differences was expected to be large (Table C4, Appendix C). With this expectation, an alpha set at .05, and desired power of .80, it appeared that a sample size of 52 participants would meet the recommended power

requirements for the major hypotheses (Cohen, 1988), although it did not permit the use of conservatively corrected significance tests. However, it should be noted that for some analyses of how people coped with stress, a number of participants ( $n = 15$ ) were excluded because they indicated that they actually had no stress in at least one of the social, physical or existential dimensions. This resulted in equal groups of monitors and blunterns ( $n = 19$ ) for these analyses.

Dimensions of stress. The prevalence and severity of problems within the social, physical, and existential dimensions were determined by summing the ratings across symptoms within each dimension. As the number of stressors within each dimension differed (with 6, 5 and 6 items per dimension) an aggregate stress score was computed by dividing this sum by the number of stressors. Thus, two scores were examined within each dimension of stress: an aggregate score and a single score related to the severity rating of the worst individual stressor.

### Data Analytic Strategy

Prior to data analysis, a number of statistical considerations were reviewed.

Outliers. In order to identify individuals with markedly deviant scores, the mean and standard deviation of each variable were examined. An outlier was defined as a score  $\geq 3$  SD from the mean (Tabachnick & Fidell, 1983). A total of three outlying values was identified (one high BDI-PC score, one high number of problem-focused strategies to manage a social stressor and one very high opioid regimen). In these cases a raw score one unit larger than the next most extreme score in the distribution was assigned.

**Skewness.** It should be noted that many variables were positively skewed, including the severity ratings for the various symptoms and concerns (i.e., many participants reported these problems as occurring at relatively low levels). This statistical issue was less marked when considering aggregate stress scores rather than scores on individual items. Similarly, this deviation from normality was also less marked when "worst" stress ratings were considered, for which there were, by definition, no 0 responses. When considering departures from normality, it is important to recall that the t test is considered to be robust even when there are fairly large departures from normality. If sample sizes are approximately equal and not too small, a skewed distribution will have little effect on the t statistic (Runyon & Haber, 1984, Gravetter & Wallnau, 1985).

The F statistic is also robust with respect to the normality assumption, and the critical values when sampling from normal and non-normal distributions will not vary by much (Stevens, 1986). From a practical perspective, Tabachnick and Fidell (1983) suggest that the researcher need only be concerned about flagrant violations of the assumption.

**Sphericity.** For repeated measures Analyses of Variance (ANOVA), potential violations of the sphericity assumption were addressed by using significance tests that were corrected by the Huyn-Feldt epsilon adjustment. However, nominal degrees of freedom are reported in the text.

**Post-hoc comparisons.** Whenever a main analysis revealed a significant omnibus F-test that required post-hoc testing, the pairwise comparisons were conducted on the marginal means using the Least Significant Difference procedure.

**Correlational analyses.** For descriptive and exploratory purposes, a number of correlational analyses were also undertaken. Because many correlations were computed



without specific hypotheses, only those that were significant at  $p < .01$  are reported as statistically significant.

Dimensions of stress. The hypothesis that there would be a significant difference between the mean stress severity scores was tested using a 2 X 3 (2 groups x 3 dimensions of stress) ANOVA. It was proposed that existential and social issues would be seen as more stressful than physical symptoms, and that monitors would report more severe problems across dimensions.

Severity of the worst stressors. Using the specific scores from the single most distressing issue within each dimension, the hypothesis that monitors would perceive their problems to be more severe than blunters was also tested using a 2 x 3 ANOVA (2 groups x 3 dimensions) design.

Coping. In order to determine whether different ways of coping were used for different problems, the frequencies with which individual strategies were used were analysed in a series of Cochran's Q analyses. These analyses compared the frequency of use of specific strategies across the social, physical and existential dimensions. When necessary, pairwise comparisons in these frequency data were conducted using McNemar's  $\chi^2$  technique.

Monitors, Blunters and coping with stress. It was proposed that blunters would engage in more emotion-focused avoidant coping than monitors. A 2 X 3 X 3 (2 groups x 3 dimensions x 3 types of coping) ANOVA, with repeated measures on the last two factors, was used to determine if there were differences between monitors and blunters in the total numbers of emotion-focused and problem-focused coping strategies that were employed.

**Perceptions of efficacy and control.** A 2 X 3 ANOVA was used to determine if there was a difference in the perception of the efficacy of coping efforts between monitors and blunters. It was hypothesized that blunters would see their coping efforts as more successful overall than monitors.

It was further proposed that blunters would be more likely to feel that they had more control over stressful issues than monitors, and a 2 X 3 ANOVA (2 groups x 3 dimensions) was used to test this hypothesis.

**General psychological distress.** A t-test was conducted on the BDI-PC scores to test the hypothesis that monitors would display greater levels of general distress than blunters.

**Depressive and anxiety disorders.** Depressive and anxiety disorders were diagnosed using the PRIME-MD. The overall prevalence of any psychological disorder was determined. Differences between monitors and blunters were examined with the chi-square statistic. It was proposed that more monitors than blunters would fulfil diagnostic criteria for a clinically significant disorder.

## Results

### **Recruitment**

During the period of recruitment the possibility of participation was raised with 87 patients referred to palliative care services. Nine patients refused to participate, and the condition of 17 others deteriorated before an interview could be arranged. Additionally nine patients were not interviewed due to illness of the interviewer. The 52 participants who did take part in the interview represent 59.8% of the patients who were approached.

Of the 52 participants, 22 (42.3%) were recruited through the palliative care consultation service at the Civic Hospital Campus, 3 (5.8%) through the palliative care consultation service at the General Hospital Campus, 13 (25%) were recruited through the regional palliative care centre and 14 (26.9%) through The Hospice at May Court.

### Participant Characteristics

The demographic and clinical characteristics of the 52 participants (19 men and 33 women) are shown in Table 1. Their average age was 65.7 years (SD = 14.45, range = 37 to 87 years). Generally speaking, participants were highly educated, with 28 (53.8%) having attended college or university. The majority of individuals were of the Roman Catholic ( $n = 24$ ; 46.2%) or Protestant ( $n = 14$ ; 26.9%) faiths. The remaining participants indicated that they came from other religious backgrounds ( $n = 11$ ; 21.2%) or had no religious affiliation ( $n = 3$ ; 5.8%). Twenty-five participants (48.1%) attended church services "frequently" or "always."

The participants' primary tumour sites were situated in the female breast ( $n = 10$ ; 19.2%); lung and bowel (each site,  $n = 8$ ; 15.4%); gastrointestinal system ( $n = 6$ ; 11.5%); head and neck ( $n = 5$ ; 9.6%); genitourinary sites ( $n = 7$ ; 13.5%); other sites ( $n = 3$ ; 5.8%), while the site of the primary tumour was unknown for 7.7% ( $n = 4$ ).

Approximately three-quarters ( $n = 38$ ; 73%) of the participants were receiving morphine or other opioids for pain, 25% ( $n = 13$ ) had been prescribed antidepressants and 42.3% ( $n = 22$ ) had been prescribed benzodiazepines for anxiety or sleep.

**Table 1**  
**Characteristics of 52 Participants**

| <b>Characteristic</b>      | <b>Mean (SD)</b>     | <b>% (n)</b>     |
|----------------------------|----------------------|------------------|
| <b>Mean Age (years)</b>    | <b>65.7 (14.4)</b>   |                  |
| <b>Gender</b>              |                      |                  |
| Male                       |                      | 36.5 (19)        |
| Female                     |                      | 63.5 (33)        |
| <b>Married/Cohabiting</b>  |                      | 48.2 (25)        |
| <b>First Language</b>      |                      |                  |
| English                    |                      | 55.8 (29)        |
| French                     |                      | 28.8 (15)        |
| Other                      |                      | 15.4 (8)         |
| <b>Education</b>           |                      |                  |
| Less than high school      |                      | 36.5 (19)        |
| High school                |                      | 9.6 (5)          |
| More than high school      |                      | 53.9 (28)        |
| <b>Primary tumour site</b> |                      |                  |
| Breast                     |                      | 19.2 (10)        |
| Lung                       |                      | 15.4 (8)         |
| Bowel                      |                      | 15.4 (8)         |
| Other gastrointestinal     |                      | 11.5 (6)         |
| Head & neck                |                      | 9.6 (5)          |
| Other                      |                      | 28.9 (15)        |
| <b>Karnofsky Scale</b>     | <b>63.6 (14.6)</b>   |                  |
| <b>BDI-PC</b>              | <b>3.3 (3.6)</b>     |                  |
| <b>Medication</b>          |                      |                  |
| Morphine Equivalents       | <b>100.8 (179.8)</b> | <b>73.1 (38)</b> |
| Antidepressants            |                      | <b>25.0 (13)</b> |
| Benzodiazepines            |                      | <b>42.3 (22)</b> |

**Note:** BDI-PC = Beck Depression Inventory for Primary Care

After the interview, the condition of each participant was monitored through the referring service for up to six months. During this time, 27 participants died, for an overall median survival duration of 168.5 days (range = 13 days to > one year).

### Prevalence of Mental Disorders

The prevalence of the individual PRIME-MD/DSM-IV depressive and anxiety disorders is shown in Table 2. There was no disagreement between raters on the diagnostic classification for 50 of the participants; ratings for the remaining two were not possible because of poor quality of sound on the tapes. As is evident in Table 2, the prevalence of mental disorders in this sample was relatively high with 23 participants (44.2%) fulfilling the PRIME-MD/DSM-IV diagnostic criteria for at least one of the disorders. This included 19 people (36.5%) with depressive disorders, 10 of whom (19.2%) were diagnosed with major depression. Additionally, there were 12 (23.1%) participants with anxiety disorders. Comorbidity of anxiety and depression was common, as reflected in the fact that 10 of the 23 participants (43.5%) who were given any diagnosis were given more than one.

### Monitors and Blunters

Table 3 shows the demographic and clinical characteristics of monitors (7 men and 18 women) and blunters (12 men and 15 women). Monitors and blunters differed significantly on only three variables. The first two were the scores on the monitoring and blunting scales themselves, ( $t(50) = -5.19, p < .001$ ), and ( $t(50) = 4.86, p < .001$ ) respectively. However, they also differed in that monitors were prescribed higher opioid doses than blunters ( $t(50) = -2.14, p = .038$ ). As is evident in Table 3, a series of

Table 2

Prevalence of Mental Disorders

| Disorder  | Number of Participants | (%)    |
|---|------------------------|--------|
| <b>Depressive disorders</b>                     |                        |        |
| Major depression                                | 10                     | (19.2) |
| Minor depression                                | 1                      | (1.9)  |
| Major depression in partial remission           | 4                      | (7.7)  |
| Dysthymia                                       | 11                     | (21.2) |
| Any depressive disorder                         | 19                     | (36.5) |
| <b>Anxiety disorders</b>                        |                        |        |
| Panic disorder                                  | 4                      | (7.7)  |
| Panic disorder secondary to a medical condition | 1                      | (1.9)  |
| Generalized anxiety disorder                    | 8                      | (15.4) |
| Any anxiety disorder                            | 12                     | (23.1) |
| Any disorder                                    | 23                     | (44.2) |
| More than one disorder                          | 10                     | (19.2) |

Table 3

Characteristics of Monitors and Blunters

| Characteristic                                | Monitors        | Blunters         | t or $\chi^2$<br>Value | Significance |
|---|-----------------|------------------|------------------------|--------------|
| <b>Demographics</b>                           |                 |                  |                        |              |
| Males/Females                                 | 7/18            | 12/15            | .88                    | >.10         |
| Mean Age $\pm$ SD                             | 68.1 $\pm$ 12.5 | 63.0 $\pm$ 16.12 | -1.28                  | >.10         |
| Marital Status (Married,<br>common law/other) | 12/13           | 15/12            | .07                    | >.10         |
| Education (University/less than)              | 14/11           | 14/13            | .00                    | >.10         |
| <b>Clinical</b>                               |                 |                  |                        |              |
| Opioids (n, %)                                | 19 (76.0)       | 19 (70.4)        | .21                    | >.10         |
| Opioid dose                                   | 150.4 $\pm$ 229 | 47.3 $\pm$ 77.1  | -2.14                  | .03          |
| Benzodiazepines (n, %)                        | 13 (52.0)       | 9 (33.3)         | .37                    | >.10         |
| Antidepressants (n, %)                        | 6 (24.0)        | 7 (25.9)         | .03                    | >.10         |
| Mental Disorder (n, %)                        | 12 (48.0)       | 11 (40.7)        | .00                    | >.10         |
| <b>Rating scales</b>                          |                 |                  |                        |              |
| Mean BDI-PC $\pm$ SD                          | 4.19 $\pm$ 4.0  | 2.3 $\pm$ 2.7    | - 1.93                 | .059         |
| Mean Karnofsky $\pm$ SD                       | 64.1 $\pm$ 13.2 | 63.0 $\pm$ 16.3  | - 2.63                 | >.10         |
| Mean Monitoring $\pm$ SD                      | 5.37 $\pm$ 1.28 | 3.52 $\pm$ 1.29  | -5.19                  | <.001        |
| Mean Blunting $\pm$ SD                        | 1.26 $\pm$ 0.98 | 3.08 $\pm$ 1.66  | 4.86                   | <.001        |

Note: BDI-PC = Beck Depression Inventory for Primary Care

chi-square analyses (with continuity corrections) showed that monitors and blunterns did not differ with respect to gender, religious affiliation or education. Additionally, there were no significant differences in the proportion of monitors and blunterns who were prescribed benzodiazepines or antidepressants (all  $p$ 's  $> .10$ ).

The chi-square statistic was also used to test the hypothesis that more monitors would fulfil diagnostic criteria for depressive or anxiety disorders. No difference between monitors and blunterns was evident in this analysis,  $\chi^2(1) = .02$ ,  $p > .10$ . The 7-item BDI-PC was used as an index of general distress. To test the proposal that monitors would display greater levels of distress than blunterns, a  $t$  test for independent samples was used to make a comparison between the means of their BDI-PC scores. While there was a tendency for monitors to have higher BDI-PC scores, this did not achieve conventional levels of statistical significance with these sample sizes,  $t(50) = -1.93$ ,  $p = .059$ .

### Sources of Stress Near the End of Life

In general, the inter-rater reliability of the interview items was excellent, with intraclass  $r \geq .97$  (see Table 4) for every variable that required an ordinal rating.

Table 5 shows the prevalence and severity of different sources of social, physical, and existential stress. As is evident in Table 5, the most prevalent social issue was the feeling of being a burden to others. This was cited by 67.3% ( $n = 35$ ) of participants as a problem that occurred with at least a minimal level of severity. Other common social stressors (reported by at least a third of participants) were role loss (an issue for 40.4% of participants), and lack of information (a concern for 36.5% of



Table 4

**Inter-Rater Reliability of Individual Interview Items, and Internal Consistency Reliability for Social, Physical and Existential Scales**

| <b>Item</b>        | <b>Coefficient</b> |
|--------------------|--------------------|
| <b>Social</b>      |                    |
| Isolation          | .99                |
| Information        | .99                |
| Consultation       | .99                |
| Role loss          | .97                |
| Finances           | .99                |
| Sense of burden    | .99                |
| Chronbach's Alpha  | .67                |
| <b>Physical</b>    |                    |
| Pain               | .99                |
| Drowsiness         | .99                |
| Nausea             | .98                |
| Weakness           | .98                |
| Breathlessness     | .99                |
| Chronbach's Alpha  | .62                |
| <b>Existential</b> |                    |
| Sense of control   | .99                |
| Life satisfaction  | .99                |
| Hopelessness       | .99                |
| Sense of dignity   | .99                |
| Loss of meaning    | .99                |
| Worry about future | .99                |
| Chronbach's Alpha  | .78                |

Note: Inter-rater reliability coefficients are intraclass correlations.



Table 5

**Percentage of Participants Reporting Symptoms and Concerns at Different Levels of Severity**

| Symptom or Concern | Severity |         |      |          |        |        |         |              |
|--------------------|----------|---------|------|----------|--------|--------|---------|--------------|
|                    | None     | Minimal | Mild | Moderate | Strong | Severe | Extreme | Most Severe* |
| <b>Social</b>      |          |         |      |          |        |        |         |              |
| Isolation          | 78.8     | 5.8     | 9.6  | 3.8      | 0.0    | 1.9    | 0.0     | 5.8          |
| Information        | 63.5     | 3.8     | 19.2 | 5.8      | 5.8    | 1.9    | 0.0     | 13.5         |
| Consultation       | 78.8     | 5.8     | 9.6  | 1.9      | 0.0    | 1.9    | 1.9     | 0.0          |
| Role Loss          | 59.6     | 7.7     | 13.5 | 11.5     | 3.8    | 3.8    | 0.0     | 15.4         |
| Finances           | 76.9     | 3.8     | 9.6  | 3.8      | 5.8    | 0.0    | 0.0     | 0.0          |
| Burden             | 32.7     | 13.5    | 34.6 | 5.8      | 5.8    | 1.9    | 5.8     | 48.0         |
| <b>Physical</b>    |          |         |      |          |        |        |         |              |
| Pain               | 26.9     | 9.6     | 28.8 | 21.2     | 5.8    | 7.7    | 0.0     | 17.3         |
| Drowsiness         | 38.5     | 9.6     | 19.2 | 9.6      | 17.3   | 3.8    | 1.9     | 9.6          |
| Nausea             | 63.5     | 13.5    | 13.5 | 7.7      | 0.0    | 0.0    | 1.9     | 3.8          |
| Weakness           | 17.3     | 11.5    | 19.2 | 9.6      | 19.2   | 15.4   | 7.7     | 42.3         |
| Breathlessness     | 44.2     | 13.5    | 19.2 | 1.9      | 5.8    | 9.6    | 5.8     | 17.3         |
| <b>Existential</b> |          |         |      |          |        |        |         |              |
| Sense of Control   | 53.8     | 11.5    | 21.2 | 5.8      | 3.8    | 1.9    | 1.9     | 11.5         |
| Life Satisfaction  | 65.4     | 7.7     | 13.5 | 3.8      | 3.8    | 0.0    | 5.8     | 5.8          |
| Hopelessness       | 59.6     | 1.9     | 23.1 | 7.7      | 1.9    | 5.8    | 0.0     | 3.8          |
| Dignity            | 75.0     | 3.8     | 11.5 | 7.7      | 1.9    | 0.0    | 0.0     | 3.8          |
| Loss of Meaning    | 75.0     | 5.8     | 9.6  | 3.8      | 3.8    | 0.0    | 1.9     | 1.9          |
| Concern for Future | 32.7     | 11.5    | 26.9 | 7.7      | 9.6    | 7.7    | 3.8     | 59.6         |

\*Entries in the Most Severe column represent the percentage of patients who reported that symptom or concern as being their "most severe" within each of the social, physical, and existential categories.

participants). The issues cited least often as sources of stress were isolation and lack of consultation ( $n = 11$ , 21.2% in both cases), and financial concerns ( $n = 12$ , 23%). The single most distressing issue within the social dimension proved to be a sense of burden, with 48.1% ( $n = 25$ ) of participants identifying this as their most troublesome social concern. Eight (15.4%) participants were not distressed by any of the social issues included in the interview.

All of the physical symptoms occurred commonly and were reported by 36.5% to 82.7% of participants. Weakness was the most prevalent physical symptom (82.7%), followed by pain, which was an issue for 73.1%. Weakness was also identified most frequently as the single most severe physical symptom; 42.3% ( $n = 22$ ) of participants identified this as their most troublesome concern. Overall, the least prevalent symptom was nausea, which was experienced by 36.5% of participants. It is noteworthy that although most of the physical symptoms were common, they were not necessarily severe or poorly controlled. For instance, only 9 (17.3%) participants rated pain as their "most severe" symptom. Only 4 (7.7%) participants reported that they had no physical symptoms at all.

The most prevalent existential issue was worry and concern regarding the future, which was cited as a source of stress by 67.3% ( $n = 35$ ) of participants. Of all the items in the existential dimension, this was the issue creating the most distress for 59.6% of the participants. It is important to note, however, that "concerns about the future" meant different things for different people. For 21 (39.6%) participants, worry about the future was directed toward concerns about death and dying (e.g., not being ready to die; uncertainty about the time they had left; fear of a painful, prolonged death; being alone and

concerns about the hereafter). Concern for the future welfare of family members was cited as the primary issue for 9 (17%) others, suggesting that for some participants there was also a social component to this existential concern. The existential issues that were reported least often were loss of meaning and loss of dignity, which were only acknowledged, even at minimal levels, by 13 (25%) participants. Seven (13.5%) participants reported that they experienced no distress at all as a result of existential issues.

### Intercorrelations Between Measures of Stress

Table 6 shows the intercorrelations between different measures of the worst stress and the aggregate stress scores across the social, physical, and existential dimensions. The worst physical stressor was not correlated with any index of social stress, but all other measures of stress severity were correlated significantly with one another (all  $p$ 's  $< .01$ ). In general, therefore, the stress experience seems to have some communality across dimensions, in the sense that participants who reported high levels of distress in one dimension also tended to report high levels of distress in the others.

### Demographic and Clinical Correlates of Stress

Table 7 displays the intercorrelations between demographic, clinical and stress measures. As is evident from Table 7, younger people were more likely to give higher stress ratings across the social ( $r(42) = -.51, p < .001$ ), and physical dimensions ( $r(46) = -.38, p < .01$ ). A similar trend, although not as reliable, was also evident for the existential dimension ( $r(43) = -.31, p = .03$ ). There is also the indication that individuals who report more psychological symptoms on the BDI-PC tend to report higher levels of distress across

Table 6

Intercorrelations Between Measures of Stress

| Measure            | Measure        |                   |                  |                    |                       |
|--------------------|----------------|-------------------|------------------|--------------------|-----------------------|
|                    | Worst Physical | Worst Existential | Aggregate Social | Aggregate Physical | Aggregate Existential |
| Worst Social       | .22            | .38*              | .55*             | .45*               | .45*                  |
| Worst Physical     | -              | .42*              | .30              | .66*               | .54*                  |
| Worst Existential  | -              | -                 | .36*             | .40*               | .62*                  |
| Aggregate Social   | -              | -                 | -                | .31*               | .57*                  |
| Aggregate Physical | -              | -                 | -                | -                  | .52*                  |

\* $p < .01$

## **NOTE TO USERS**

**Page(s) missing in number only; text follows. The manuscript was microfilmed as received.**

**74**

**This reproduction is the best copy available.**

**UMI**

Table 7

Intercorrelations Between Demographic, Clinical and Stress Measures

|                       | Age   | Education | BDI-PC | Monitoring | Blunting | Karnofsky | Morphine Equivalents |
|-----------------------|-------|-----------|--------|------------|----------|-----------|----------------------|
| <b>Demographics</b>   |       |           |        |            |          |           |                      |
| Education             | .27   | -         | -      | -          | -        | -         | -                    |
| <b>Clinical</b>       |       |           |        |            |          |           |                      |
| BDI-PC                | -.09  | -.28      | -      | -          | -        | -         | -                    |
| Monitoring            | -.07  | -.13      | .30    | -          | -        | -         | -                    |
| Blunting              | -.04  | -.26      | -.02   | -.04       | -        | -         | -                    |
| Karnofsky             | -.25  | -.06      | -.18   | -.05       | -.03     | -         | -                    |
| Morphine Equivalents  | -.22  | -.14      | .25    | .20        | -.13     | -.02      | -                    |
| <b>Stress</b>         |       |           |        |            |          |           |                      |
| Worst Social          | -.23  | -.18      | .45*   | .13        | -.29     | .06       | .22                  |
| Worst Physical        | -.26  | -.29      | .45*   | .28        | -.12     | -.17      | .40*                 |
| Worst Existential     | -.31  | -.16      | .28    | -.05       | .08      | -.18      | .18                  |
| Aggregate Social      | -.51* | -.27      | .53*   | .16        | .03      | .18       | .29                  |
| Aggregate Physical    | -.38* | -.21      | .42*   | .06        | -.04     | -.08      | .33*                 |
| Aggregate Existential | -.31  | -.28      | .67*   | .12        | -.21     | -.01      | .18                  |

Note: BDI-PC = Beck Depression Inventory for Primary Care \*P &lt; .01



the social ( $r(42) = .53, p < .001$ ), physical ( $r(46) = .42, p = .003$ ) and existential dimensions of stress ( $r(43) = .67, p < .001$ ). The use of opioids was correlated only with the scores on the worst ( $r(46) = .40, p < .01$ ) and aggregate ( $r(46) = .33, p = .01$ ) physical stress scores.

### Monitors, Blunters and the Experience of Stress

A 2 x 3 (2 groups x 3 dimensions of stress) ANOVA was conducted on the aggregate stress ratings to test the hypothesis that monitors would experience more severe stress than blunters. This analysis showed a significant main effect of dimensions of stress,  $F(2, 72) = 15.62, p < .001$ . However, no differences between monitors and blunters were evident in either the main effect of group  $F(1, 36) = <1$ , or the group x dimensions of stress interaction,  $F(2, 72) = <1$ . Post-hoc comparisons conducted across dimensions of stress revealed that the physical dimension received higher severity ratings than either the social ( $p < .001$ ) or existential dimensions ( $p < .001$ ), which in turn did not differ from one another. Table 8 displays the means and standard deviations of the aggregate severity ratings for monitors and blunters.

The hypothesis that monitors would perceive their problems to be more severe than blunters was also tested using a 2 x 3 (2 groups x 3 dimensions of stress) ANOVA on the ratings of the most severe individual stressor within each dimension. This analysis also revealed a significant main effect of dimensions of stress,  $F(2, 72) = 5.07, p = .01$ . No difference between monitors and blunters was evident in the main effect of group  $F(1, 36) = <1$ . There was a significant group x dimensions of stress interaction,  $F(2, 72) = 3.67, p = .03$ , indicating a difference between monitors and blunters in perceived problem severity

Table 8

**Means and Standard Deviations of Worst Stress and Aggregate Stress Measures for Monitors and Blunters**

|                    | Monitors |      | Blunters |      |
|--------------------|----------|------|----------|------|
|                    | Mean     | SD   | Mean     | SD   |
| <b>Social</b>      |          |      |          |      |
| Worst Stress       | 3.21     | 1.58 | 2.37     | 1.17 |
| Aggregate Stress   | 1.18     | .86  | 1.06     | .80  |
| <b>Physical</b>    |          |      |          |      |
| Worst Stress       | 4.00     | 1.37 | 3.21     | 1.69 |
| Aggregate Stress   | 2.07     | .87  | 1.93     | 1.12 |
| <b>Existential</b> |          |      |          |      |
| Worst Stress       | 2.68     | 1.34 | 3.16     | 1.77 |
| Aggregate Stress   | 1.36     | 1.01 | 1.31     | 1.08 |

in at least one dimension of stress. However, t-tests conducted to follow up the significant interaction failed to reach significance (all  $p$ 's  $>.05$ ). In pairwise comparisons, the most severe physical stressor received higher severity ratings than either the most severe social ( $p = .011$ ) or existential stressor ( $p = .02$ ), which did not differ from one another. Table 8 also displays the means and standard deviations of the severity ratings assigned to the worst stressor.

### Perceptions of Control and Effectiveness

Table 9 shows the correlations between measures of stress and ratings of control and effectiveness. With one exception, ratings of control and effectiveness were not correlated with ratings of stress severity. The exception was that more severe stress in the physical dimension was associated with low ratings of perceived control,  $r(46) = -.39$ ,  $p <.01$ .

The intercorrelations between ratings of control and effectiveness are displayed in Table 10. In general, the ratings of control and effectiveness were not correlated consistently with one another, although there were a few exceptions. Control ratings for social and existential concerns were correlated significantly,  $r(37) = .48$ ,  $p = .002$ , but neither was correlated with control ratings for the most severe physical symptom ( $p$ 's  $>.10$ ). On the other hand, ratings of coping effectiveness in the social dimension were related to higher ratings of coping effectiveness in the physical dimension,  $r(40) = .60$ ,  $p <.001$  but not in the existential dimension,  $r(37) = .09$ ,  $p >.10$ .

Table 9

**Intercorrelations Between Measures of Stressor Severity and Ratings of Control and Effectiveness**

| <b>Worst Stressor</b> | <b>Control</b> | <b>Effectiveness</b> |
|-----------------------|----------------|----------------------|
| <b>Social</b>         | <b>-.12</b>    | <b>.01</b>           |
| <b>Physical</b>       | <b>-.39*</b>   | <b>-.04</b>          |
| <b>Existential</b>    | <b>-.02</b>    | <b>.03</b>           |

**\*p < .01**

Table 10

Intercorrelations Between Ratings of Control and Effectiveness

|                           | Social  |               | Physical |               | Existential |
|---------------------------|---------|---------------|----------|---------------|-------------|
|                           | Control | Effectiveness | Control  | Effectiveness | Control     |
| Social Effectiveness      | .19     | -             | -        | -             | -           |
| Physical Control          | .14     | .13           | -        | -             | -           |
| Physical Effectiveness    | .04     | .60*          | .20      | -             | -           |
| Existential Control       | .48*    | .16           | .28      | -.00          | -           |
| Existential Effectiveness | -.12    | .09           | -.10     | .26           | .30         |

\* $p < .01$

Demographic and Clinical Correlates of Control and Effectiveness

Table 11 displays the correlations between demographic and clinical characteristics and ratings of control and effectiveness. In general, the interview ratings on these measures were not correlated with any of the demographic variables. Among the clinical characteristics, the BDI-PC scores were correlated significantly with the perceived effectiveness of coping with existential distress,  $r(43) = -.36, p = .01$ . That is, low ratings of effectiveness in coping with existential concerns were related to greater levels of depressive symptomatology. The correlation between the Karnofsky Functional Performance Status Scale and perceived control of the worst physical symptom approached significance ( $r(46) = .33, p = .02$ ); that is, patients with better physical status reported greater control over their worst physical symptom. However, this correlation was not robust enough to attain significance at the more conservative level of  $p < .01$ .

Monitors, Blunters, Effectiveness and Control

Perception of control. A 2 x 3 (2 groups x 3 dimensions) ANOVA was conducted on the perceived control ratings to test the hypothesis that blunters would feel that they have more control than monitors over stressful issues. In this analysis, there was no significant interaction effect,  $F(2, 72) = 1.45, p > .10$ . However there were significant main effects for both groups,  $F(1, 36) = 9.46, p < .004$ , and dimensions of stress,  $F(2, 72) = 4.05, p = .02$ . The group main effect indicated that blunters felt that they had more control over their stressors than monitors. Follow-up analyses to the main effect of stress revealed that blunters' perception of control was significantly higher for the social dimension than

Table 11

**Intercorrelations Between Demographic, Clinical Characteristics and Ratings of Control and Effectiveness**

| Characteristic     | Social  |               | Physical |               | Existential |               |
|--------------------|---------|---------------|----------|---------------|-------------|---------------|
|                    | Control | Effectiveness | Control  | Effectiveness | Control     | Effectiveness |
| <b>Demographic</b> |         |               |          |               |             |               |
| Age                | .05     | -.07          | -.12     | .07           | -.20        | -.09          |
| Education          | .20     | -.09          | -.13     | .01           | .01         | .15           |
| <b>Clinical</b>    |         |               |          |               |             |               |
| BDI-PC             | -.07    | -.13          | -.23     | -.27          | -.09        | -.36*         |
| Monitoring         | -.01    | .19           | -.15     | .31           | -.24        | -.10          |
| Blunting           | .22     | -.13          | -.02     | -.05          | .30         | .19           |
| Karnofsky          | -.09    | -.17          | .33      | -.02          | .04         | -.03          |
| Opioids            | -.23    | .17           | -.14     | .06           | -.15        | -.03          |

\*Note: BDI-PC = Beck Depression Inventory for Primary Care

\*p < .01

the physical ( $p = .017$ ). Mean control scores for the existential stressor were intermediate, and did not differ significantly from those in either of the other two dimensions ( $p > .10$ ). The means and standard deviations of perceived control for monitors and blunterners are included in Table 12.

**Perception of effectiveness.** The hypothesis that blunterners would view their coping efforts as more successful than monitors was tested with a 2 x 3 (2 groups x 3 dimensions) ANOVA on the effectiveness ratings. There was no significant main effect for dimensions of stress  $F(2, 72) = < 1, p > .10$ . Similarly, no differences between monitors and blunterners were evident in either the main effect of group  $F(1, 36) = < 1, p > .10$ , or the group x dimensions of stress interaction  $F(2, 72) = < 1, p > .10$ . Therefore, the participants did not feel consistently that they were coping more effectively with one type of stressor than another, and monitors and blunterners maintained comparable views as to how effectively they were coping. Table 12 also displays the means and standard deviations of perceived effectiveness for monitors and blunterners.

### **Coping With Stress Near the End of Life**

There are several ways in which the data regarding coping strategies could be analysed. Perhaps the most straightforward way is to simply document the percentage of participants who used coping behaviours of each of the different types. Those data are summarised in Figure 1, which shows the percentages of participants who reported using



Table 12

**Means and Standard Deviations of Control and Effectiveness Ratings for Monitors and Blunters**

|                    | Monitors |      | Blunters |      |
|--------------------|----------|------|----------|------|
|                    | Mean     | SD   | Mean     | SD   |
| <b>Social</b>      |          |      |          |      |
| Control            | 2.16     | 1.98 | 3.26     | 1.78 |
| Effectiveness      | 3.95     | 1.47 | 3.74     | 1.59 |
| <b>Physical</b>    |          |      |          |      |
| Control            | 1.32     | 1.89 | 2.05     | 1.84 |
| Effectiveness      | 4.00     | 1.53 | 3.63     | 1.83 |
| <b>Existential</b> |          |      |          |      |
| Control            | 1.11     | 1.38 | 3.05     | 1.93 |
| Effectiveness      | 3.47     | 1.58 | 4.16     | .69  |

Figure Legend

**Figure 1**

**Problem-focused strategies**

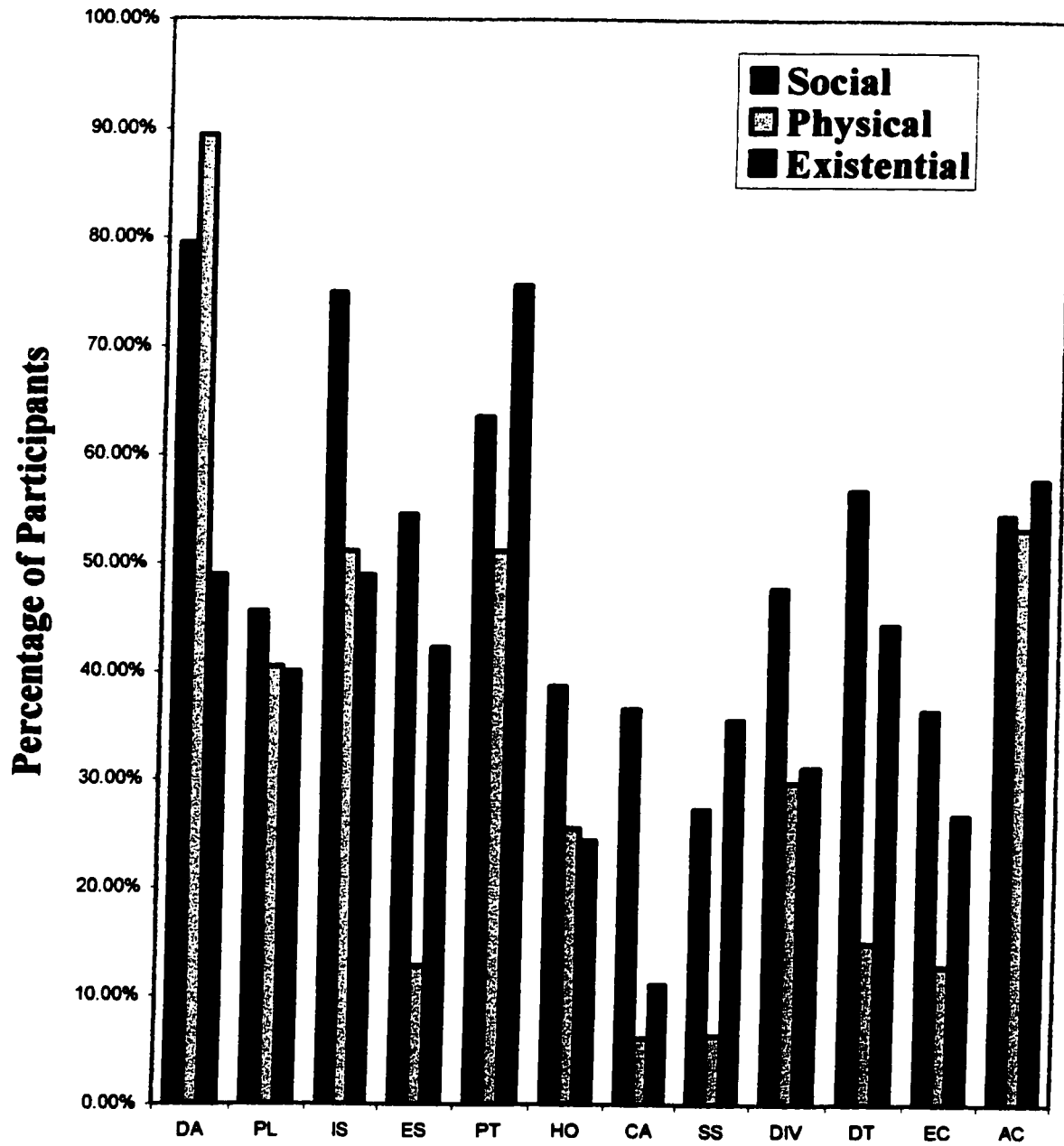
DA    **direct action**  
PL    **planning**  
IS    **instrumental support**

**Emotion-focused approach strategies**

ES    **emotional support**  
PT    **perspective taking**  
HO    **hope**  
CA    **catharsis**  
SS    **spiritual support**

**Emotion-focused avoidant strategies**

DIV   **divert attention**  
DT    **distancing**  
EC    **emotional control**  
AC    **acceptance/resignation**



**Figure 1. Percentages of participants using different categories of coping behaviours**

the different categories of coping behaviours within each of the physical, social and existential dimensions. This summary does not incorporate the overall number of coping strategies; rather, in this figure, a participant is counted as having used a particular strategy as long as a relevant coping behaviour was used at least once.

With social stressors, over half the participants reported at least one coping strategy of direct action, seeking instrumental support, seeking emotional support, perspective-taking, distancing and acceptance/resignation.

With physical stressors, direct action strategies were reported most commonly, with at least one such strategy being reported by over 85% of the participants. Other common strategies (used by over half the respondents) were seeking instrumental support, perspective-taking, and acceptance/resignation. Some strategies were used quite infrequently for coping with physical stressors. For example, fewer than 20% of the participants reporting seeking emotional or spiritual support for a physical symptom, and catharsis, distancing and emotional control strategies were also reported infrequently.

For existential stressors, only two strategies, perspective-taking and acceptance/resignation, were used by as many as half the participants, whereas catharsis was the most infrequent coping strategy.

In order to determine whether different ways of coping were used for different problems, these frequency data were analysed in a series of Cochran's Q analyses. Because these analyses involved 12 tests, the false discovery rate associated with multiple comparisons was controlled using the conservative correction described by Benjamini and Hochberg (1995). Significant Q values were followed up with McNemar's  $\chi^2$  for pairwise contrasts.

Differences across the dimensions of stress were found for Direct Action coping,  $Q(2) = 15.10$ ,  $p = .001$ , Emotional Support,  $Q(2) = 15.3$ ,  $p < .001$ , Spiritual Support,  $Q(2) = 17.20$ ,  $p < .001$ , Catharsis,  $Q(2) = 14.29$ ,  $p = .001$ , and Distancing,  $Q(2) = 15.74$ ,  $p < .001$ . Distancing, Emotional Support and Spiritual Support were all used by fewer participants in response to physical stressors than to either social or existential concerns (all  $p$ 's  $< .005$ ). Catharsis was used more frequently in the context of social stressors than physical or existential issues ( $p$ 's  $< .005$ ). Finally, Direct Action was used by fewer participants to cope with an existential concern than with social or physical concerns ( $p$ 's  $< .02$ ).

#### Numbers of Coping Strategies

Another way of examining the data about ways of coping is to consider the total number of strategies of each type reported by each participant (i.e., recognising that an individual participant might use more than one coping strategy of a particular type). The mean numbers of coping behaviours within each type of specific strategy are shown in Figure 2. In practice, the mean number of strategies was quite highly correlated with the percentage of participants who used any given strategy at least once. For example, the Spearman's rho correlation showed that the relative rankings of how frequently the strategies were used were  $\rho = .85$ ,  $.97$ , and  $.80$  (all  $p$ 's  $< .001$ ), for the social, physical and existential dimensions, respectively. Nevertheless, an advantage of analyses based on the numbers of strategies is that they could be undertaken appropriately with parametric statistical techniques. For the analyses on the overall numbers of coping strategies, however, the data were first collapsed into the problem-focused, emotion-focused approach, and emotion-focused avoidant dimensions.

**Figure Legend**

**Figure 2**

**Problem-focused strategies**

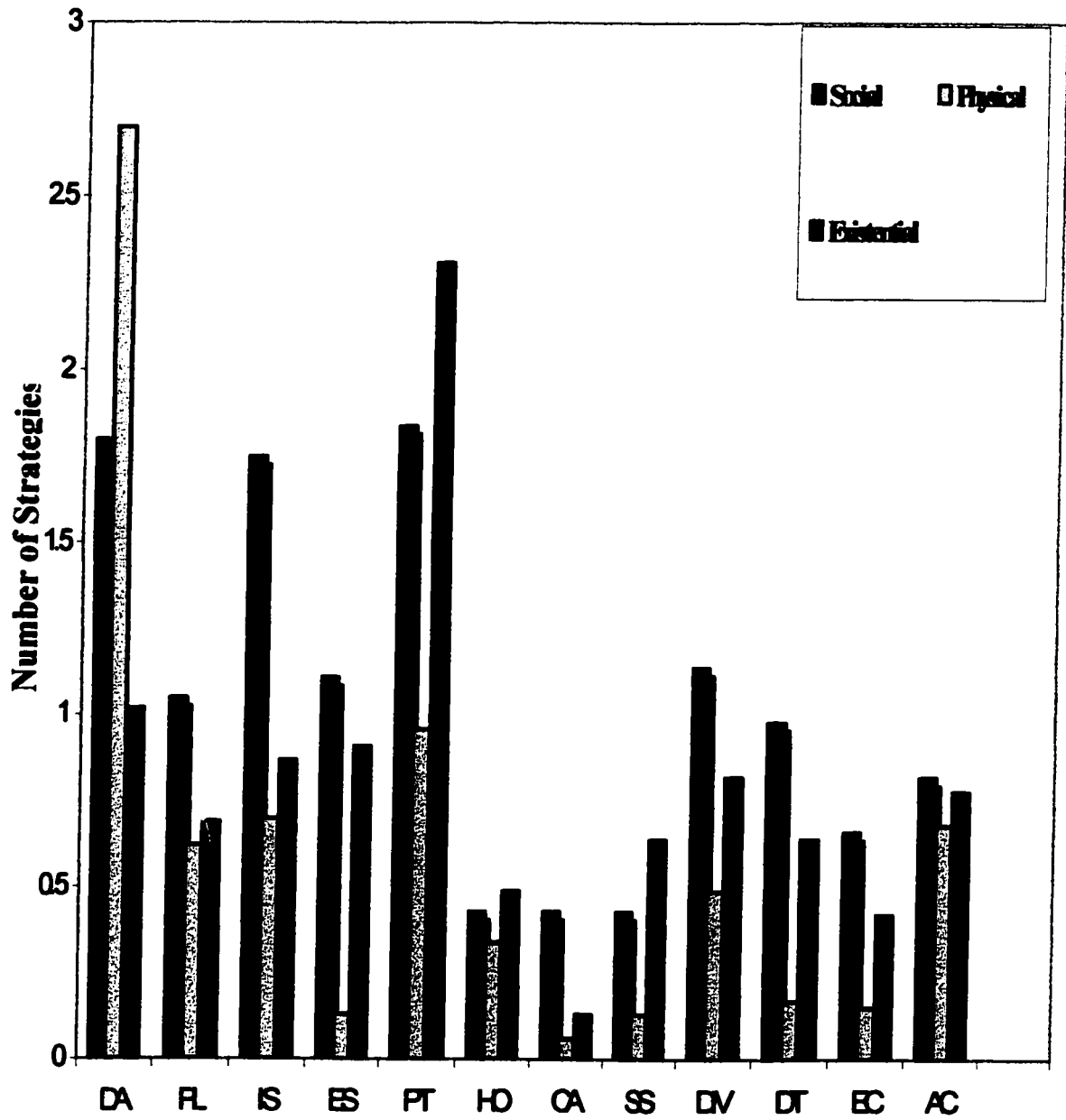
DA    direct action  
PL    planning  
IS    instrumental support

**Emotion-focused approach strategies**

ES    emotional support  
PT    perspective taking  
HO    hope  
CA    catharsis  
SS    spiritual support

**Emotion-focused avoidant strategies**

DIV    divert attention  
DT    distancing  
EC    emotional control  
AC    acceptance/resignation



**Figure 2** Manner of coping behaviors within each type of specific category.

### Coping Across Dimensions of Stress

The intercorrelations between the number of coping strategies across the dimensions of stress are presented in Table 13. Except in the case of emotion-focused avoidant strategies to manage physical symptoms, the number of coping strategies that participants generated was highly correlated across dimensions (correlations from  $r(37) = .37$  to  $r(37) = .66$ ,  $p's < .01$ ). Therefore, the number of coping strategies generated is a rather consistent individual difference across sources of stress; participants who generated a high number of strategies to a social stressor also generated a high number of strategies in response to stressors in the other two dimensions.

### Demographic and Clinical Correlates

Table 14 displays the correlations between demographic and clinical characteristics and the number of coping strategies generated across the dimensions of stress. As can be seen in Table 14, demographic factors of age and education were correlated with some aspects of coping but it depended on the specific dimension of stress. Younger participants tended to generate more emotion-focused approach strategies to their worst existential stressor,  $r(43) = -.44$ ,  $p = .003$ , while the more highly educated participants tended to approach their worst social stressor with a higher number of problem-focused strategies,  $r(42) = .50$ ,  $p = .001$ . Among the clinical variables, the only significant correlations involved the Karnofsky Functional Performance Status Scale. Participants who were less functionally debilitated tended to report more emotion-focused approach strategies overall, particularly with respect to the social  $r(42) = .44$ ,  $p < .01$ , and existential  $r(43) = .39$ ,  $p < .01$ ,



Table 13

Comparison of Intercorrelations Between Coping Strategies


---

| <u>Number of Strategies</u>      |          |             |
|----------------------------------|----------|-------------|
|                                  | Physical | Existential |
| <b>Problem-focused</b>           |          |             |
| Social                           | .53*     | .37*        |
| Physical                         | -        | .64*        |
| <b>Emotion-focused approach</b>  |          |             |
| Social                           | .60*     | .66*        |
| Physical                         | -        | .58*        |
| <b>Emotion-focused avoidance</b> |          |             |
| Social                           | .29      | .50*        |
| Physical                         | -        | -.07        |

---

\*p &lt; .01

Table 14

Intercorrelations Between Demographic, Clinical Characteristics and Number of Coping Strategies

| Characteristic | Social          |                          |                           | Physical        |                          |                           | Existential     |                          |                           |
|----------------|-----------------|--------------------------|---------------------------|-----------------|--------------------------|---------------------------|-----------------|--------------------------|---------------------------|
|                | Problem-Focused | Emotion-Focused Approach | Emotion-Focused Avoidance | Problem-Focused | Emotion-Focused Approach | Emotion-Focused Avoidance | Problem-Focused | Emotion-Focused Approach | Emotion-Focused Avoidance |
| Age            | -.23            | -.16                     | -.28                      | -.20            | -.28                     | -.09                      | -.17            | -.44*                    | -.20                      |
| Education      | .50*            | .01                      | -.01                      | .31             | .01                      | -.01                      | .28             | -.01                     | -.04                      |
| Clinical       |                 |                          |                           |                 |                          |                           |                 |                          |                           |
| BDI            | -.01            | .25                      | .06                       | .03             | -.04                     | .06                       | -.05            | .09                      | .17                       |
| Karnofsky      | .23             | .44*                     | .38                       | .20             | .25                      | .14                       | .24             | .39*                     | .18                       |
| Monitor Scale  | .04             | -.02                     | .01                       | .08             | -.02                     | .12                       | .08             | .05                      | -.14                      |
| Blunter Scale  | -.21            | .11                      | .01                       | -.09            | -.13                     | -.20                      | -.09            | .07                      | .17                       |
| Opioids        | -.15            | -.09                     | -.00                      | -.09            | .06                      | .03                       | -.09            | .05                      | -.01                      |

\* $p < .01$

dimensions. The level of psychological distress as indicated by the BDI-PC scores was not associated with the number of coping strategies generated in any dimension.

### Intercorrelations Between Measures of Stress and Coping

The correlations between the worst stressor, aggregate stress scores and the corresponding number of coping strategies generated in each dimension of stress are shown in Table 15. Only one of these correlations was statistically significant. When considering the aggregate stress severity scores, participants who experienced high levels of social stress overall tended to generate more emotion-focused avoidant strategies in response to this stress,  $r(42) = .43, p < .01$ .

### Control, Effectiveness and Coping

Table 16 shows the correlations between perceived control, effectiveness and the number of coping strategies generated across dimensions of stress. None of these correlations was statistically significant.

### Monitors, Blunters and Coping With Stress

It was hypothesised that blunters would engage in more emotion-focused avoidant coping than monitors. To test this proposal a 2 X 3 X 3 ANOVA was conducted, with groups (monitors vs. blunters) as the between subjects factor, and dimensions of stress (social, physical and existential) and type of coping strategies (problem-focused vs. emotion-focused approach vs. problem-focused avoidant) as within-subject factors. The

Table 15

Intercorrelations Between Worst Stress, Aggregate Stress and Number of Coping Strategies

| Stress Measure        | Social          |                          |                           | Physical        |                          |                           | Existential     |                          |                           |
|-----------------------|-----------------|--------------------------|---------------------------|-----------------|--------------------------|---------------------------|-----------------|--------------------------|---------------------------|
|                       | Problem-Focused | Emotion-Focused Approach | Emotion-Focused Avoidance | Problem-Focused | Emotion Focused Approach | Emotion-Focused Avoidance | Problem-Focused | Emotion-Focused Approach | Emotion-Focused Avoidance |
| Worst Social          | .06             | .26                      | .26                       | -               | -                        | -                         | -               | -                        | -                         |
| Aggregate Social      | .12             | .29                      | .43*                      | -               | -                        | -                         | -               | -                        | -                         |
| Worst Physical        | -               | -                        | -                         | -.05            | -.19                     | .13                       | -               | -                        | -                         |
| Aggregate Physical    | -               | -                        | -                         | .01             | -.04                     | .01                       | -               | -                        | -                         |
| Worst Existential     | -               | -                        | -                         | -               | -                        | -                         | .12             | .14                      | .21                       |
| Aggregate Existential | -               | -                        | -                         | -               | -                        | -                         | .01             | .21                      | .35                       |

\*p < .01

Table 16

Intercorrelations Between Rating of Perceived Control and Effectiveness, and Number of Coping Strategies

| Strategies               | Social  |               | Physical |               | Existential |               |
|--------------------------|---------|---------------|----------|---------------|-------------|---------------|
|                          | Control | Effectiveness | Control  | Effectiveness | Control     | Effectiveness |
| Social                   |         |               |          |               |             |               |
| Problem-focused          | .33     | -.07          | -        | -             | -           | -             |
| Emotion-focused approach | .18     | .00           | -        | -             | -           | -             |
| Emotion-focused avoidant | .14     | .00           | -        | -             | -           | -             |
| Physical                 |         |               |          |               |             |               |
| Problem-focused          | -       | -             | -.01     | -.15          | -           | -             |
| Emotion-focused approach | -       | -             | .12      | .12           | -           | -             |
| Emotion-focused avoidant | -       | -             | .15      | .10           | -           | -             |
| Existential              |         |               |          |               |             |               |
| Problem-focused          | -       | -             | -        | -             | .07         | .22           |
| Emotion-focused approach | -       | -             | -        | -             | .16         | .11           |
| Emotion-focused avoidant | -       | -             | -        | -             | .07         | -.04          |

\*  $p < .01$

analysis showed a significant main effect of dimensions of stress,  $F(2, 70) = 13.51, p < .001$ , a significant main effect of types of coping,  $F(2, 70) = 4.70, p < .01$ , and a significant effect for the stress x coping interaction,  $F(4, 140) = 11.34, p < .001$ . However, no significant differences between monitors and blunterners were apparent in either the main effect of group or any interaction effect. Pairwise comparisons across dimensions of stress revealed that all comparisons were significantly different from one another (all  $p$ 's  $< .05$ ).

The greatest number of coping strategies was generated for the social dimension, followed by the existential dimension, and, finally by the physical dimension. When the overall numbers of strategies were collapsed across sources of stress, pairwise comparisons demonstrated that participants generated significantly more problem-focused than emotion-focused avoidant strategies. Table 17 displays the means and standard deviations of the overall number of coping strategies across dimensions of stress for monitors and blunterners.

With the overall number of coping strategies collapsed into problem-focused, emotion-focused approach, and emotion-focused avoidant dimensions, a series of three repeated measures ANOVA's was also conducted to further investigate the significant interaction effect of stress x coping. The results of the first ANOVA demonstrated that the use of problem-focused strategies differed across social, physical, and existential dimensions,  $F(2, 72) = 8.09, p = .003$ , such that participants used less problem-focused coping to manage existential stressors than they used to manage either the social or physical stressors. The second ANOVA, on the emotion-focused approach scores, also resulted in a significant effect,  $F(2, 72) = 16.20, p < .001$ . In this instance, participants used fewer emotion-focused approach strategies in the face of physical stressors than they used

**Table 17**  
**Means and Standard Deviations of Numbers of Coping Strategies for Monitors and Blunters**

|                                  | Monitors |          |             | Blunters |          |             |
|----------------------------------|----------|----------|-------------|----------|----------|-------------|
|                                  | Social   | Physical | Existential | Social   | Physical | Existential |
| <b>Problem-focused</b>           |          |          |             |          |          |             |
| M                                | 4.89     | 4.26     | 2.32        | 4.33     | 4.00     | 2.78        |
| (SD)                             | (4.57)   | (3.48)   | (2.63)      | (3.55)   | (2.47)   | (2.69)      |
| <b>Emotion-focused approach</b>  |          |          |             |          |          |             |
| M                                | 3.68     | 1.58     | 3.95        | 5.11     | 1.33     | 5.44        |
| (SD)                             | (3.14)   | (2.27)   | (5.20)      | (4.51)   | (1.33)   | (5.19)      |
| <b>Emotion-focused Avoidance</b> |          |          |             |          |          |             |
| M                                | 3.32     | 1.95     | 1.79        | 4.06     | 1.22     | 3.67        |
| (SD)                             | (2.26)   | (1.18)   | (1.84)      | (3.12)   | (1.06)   | (3.53)      |

for either existential or social stressors. A significant effect, ( $F(2, 72) = 9.55, p < .001$ ), was also evident in the final ANOVA, conducted on the emotion-focused avoidant scores. In this instance, participants used significantly fewer emotion-focused avoidant strategies to manage physical stressors than social stressors. The mean score for the existential dimension was intermediate, and did not differ from those in either of the other two dimensions.

### Correlates of No Stress

As mentioned previously a number of participants ( $n = 15, 28.85\%$ ) were excluded from some of the analyses of coping behaviour because they indicated that they had no stress in at least one of the social, physical or existential dimensions and therefore, had no problems to cope with in these areas. Several analyses were conducted in which these participants were compared with those who did acknowledge at least one relevant stressor in each dimension. These individuals did not differ on any of the demographic variables, and they were not more likely to be classified as either monitors or blunters (Fisher's Exact Test,  $p = .28$ ). However, analyses revealed a number of important differences as far as other clinical variables were concerned. Specifically, a Fisher's Exact Test was conducted to assess whether these participants were more or less likely to fulfil diagnostic criteria for depressive or anxiety disorders. The results of this test were significant (Fisher's Exact Test,  $p = .03$ ), indicating that people who were deleted from an analysis were also less likely to fulfil diagnostic criteria for a mental disorder (3 of 15 = 20%) than were people who were included (20 of 37 = 54.1%). Follow up analyses showed that the lack of



existential stress was most closely associated with mental health. Specifically, none of the seven participants who reported no existential stress at all met the criteria for a mental disorder, compared to 23 of the 45 participants (51%) who did acknowledge an existential stress (Fisher's Exact Test,  $p = .01$ ). This was not the case for the social or physical dimensions of stress (Fisher's Exact Test,  $p = .28$  and  $p = .37$ , respectively).

A t-test was also conducted on the BDI-PC scores to determine whether these same 15 participants suffered more or less general psychological distress. This test was also significant ( $t(50) = -2.76$ ,  $p = .008$ ), demonstrating that people who were deleted from an analysis suffered less general psychological distress.

Finally, one further t-test was conducted on the Karnofsky Functional Performance Scale scores to determine whether these participants were more or less functionally debilitated. This test revealed a significant difference between the two groups ( $t(50) = 2.33$ ,  $p = .024$ ) indicating that people who were deleted from an analysis were less functionally limited.

### Debriefing

On average, the interview took 69.4 minutes to complete (range = 25 to 172 minutes). At the conclusion of the interview, participants were asked whether the experience had been stressful or upsetting, and whether the interview items had been difficult to understand. The responses to these questions are shown in Table 18. Most respondents reported that the interview was "not at all upsetting" (86.5%,  $n = 45$ ), while

11.5% (n = 6) found it to be mildly or moderately upsetting. Only one participant (1.9%) found the experience to be "very upsetting." The interview items were generally easy to understand for this well-educated group of participants. Most of them reported that the questions were "not at all difficult" to understand (94.2%; n = 49), while the remaining three participants (5.7%) found them to be mildly or moderately difficult. None of the participants found the questions to be "very" difficult to understand.

Table 18

**Participant Responses to Debriefing Questions (n = 52)**

| Question  | Not At All | Mildly  | Moderately | Very    |
|---|------------|---------|------------|---------|
|   | % (n)      | % (n)   | % (n)      | % (n)   |
| Did you find that answering these questions was stressful or upsetting? | 86.5 (45)  | 9.6 (5) | 1.9 (1)    | 1.9 (1) |
| Were the questions difficult to understand?                             | 94.2 (49)  | 3.8 (2) | 1.9 (1)    | 0 (0)   |

## Discussion

The stressors facing people who must deal with a terminal diagnosis and palliative care are complex and varied (Classen et al., 1996; Hinton, 1994; Houts et al., 1988; Silberfarb et al., 1980; Weisman & Worden, 1985-1986). However there is little research about the ways in which people cope with such stressors during this difficult period of their lives. The need for research in this area has been emphasised in a recent task force report submitted to the American Psychological Association (Gordon et al., 2000). The present study adds to the limited research base by exploring the manner in which people cope with the variety of stressors associated with a terminal diagnosis and palliative care. The semi-structured interview began by cataloguing the stressors facing study participants across the physical, social and existential dimensions and then asking how they coped with the worst stressor within each dimension. The association between types of stressors, coping responses, and psychological distress, including clinically significant mental disorders was examined. Of major interest was whether individual differences in how people preferred to cope with health-related stressors, in the sense of monitoring or blunting, predicted variations in actual coping behaviour and variations in the experience of distress.

Generally speaking, patients who are receiving palliative care for cancer have limited physical capacity and because of the advanced stage of illness, the opportunity for prospective research is limited. Consequently, the nature of this study is that of a cross-sectional/convenience sample, in keeping with those commonly found in the health field (Grady & Wallston, 1988). Thus, it should be noted that any general

conclusions must be tempered by an appreciation of the methodological aspects of the study that could have influenced the results. Foremost among these are (1) the characteristics of the participants and (2) the characteristics of the interview.

### Participants

Although participants were recruited from a variety of hospital and community services they were all receiving palliative care for cancer. The types of cancer varied, as did the degree of functional disability. In this sense the participants in the study might be considered representative of individuals who have received a terminal diagnosis and recognize that the nature of any further treatment is palliative only. After the interviews, their survival varied, with some dying within a few weeks and others living for over a year. However, more women than men participated in this study. In addition, most participants were well educated, with over half having attended college or university. Although it was beyond the scope of the present study to address differences in stress and coping that might be associated with education and gender, it is possible that such differences exist and account, in part, for some of the observed results.

Another factor to be considered is that all participants were volunteers. Therefore, it must be conceded that participants who did not volunteer to take part in this research may have differed in terms of their levels of stress, their coping behaviours or levels of psychological distress from those who chose to do so. Furthermore, patients were initially approached about the study by palliative care clinicians involved in their care. A stronger methodology for future research would be to take more extensive steps

to ensure a representative sample of palliative care patients to limit the possibility of a systematic referral bias influencing the initial selection of participants.

### Interview

Concerns have been raised as to whether self-report stress and coping checklists actually reflect the individual's coping efforts, or whether they are contaminated by the level of distress (Aldwin, 1994; Coyne & Racioppo, 2000). Further to this, a number of authors have proposed that qualitative interviews may be necessary to understand the nature of stress and coping in certain populations (Aldwin, 1994; Johnson & Barer, 1993; Labouvie-Vief et al., 1987). The semi-structured interview used in this study attempted to address some of these concerns.

The interview was context-specific in the sense that it addressed issues identified as relevant to people with a terminal illness. In general, the items showed excellent inter-rater reliability. In comparison to self-report stress and coping instruments, the format, wording and response options of this situation-specific questionnaire helped to reduce complications that arise from common method variance and overlapping constructs. For example, Coyne, & Racioppo (2000) have cautioned that inflated correlations in measures of stress, coping and distress can arise when the measures are all assessed the same way (e.g., by questionnaire), or when certain behaviours that can be scored as coping strategies (e.g., crying, using medication, social withdrawal) may also be characteristic of depression. The use of a situation-specific semi-structured interview contributed to the internal validity of the study by allowing participants to

describe their actual coping efforts. The structure of the interview also allowed for clarification of the intent of coping efforts to help with the problem-focused vs. emotion-focused categorisation. Additionally, self-presentation motives were counteracted to some extent by avoiding the presentation of a long list of items that could contain cues as to what constituted a socially desirable response. Finally, the format of the interview was such that it could be administered comfortably, in a conversational manner, at the bedside of participants who were otherwise unable to fill out lengthy questionnaires.

Nevertheless, the interview did rely on individuals having conscious awareness of their coping behaviours and being able to recall and report them accurately (Tennen, Affleck, Armeli, & Carney, 2000). Another limiting factor may be the individual's capacity to conceptualise and articulate responses adequately. For instance, participants who were more functionally debilitated, according to their Karnofsky Index, tended to report fewer strategies. This could suggest that patients who are most ill may have a restricted range of coping strategies available to them by virtue of their disability. However, it may also mean that the cognitive effort of participating in the interview was more taxing for these individuals.

There is also the question of whether the number of strategies reported is the most relevant variable for the assessment of coping. For the present purpose all strategies were given equal weight and the relative importance of individual strategies was not considered. For instance, a simple action such as a change of position to help ease pain was given the same weight as a more global strategy, such as finding comfort

in religion, which might influence one's overall approach to the challenge of facing impending death. Indeed, there may be different options for coding coping behaviour, including the total number of strategies used, the frequency of use of individual strategies (as is commonly done in coping questionnaires), or asking participants to weigh the importance of specific strategies within their coping repertoire. Each of these methods might yield different patterns of results.

### Prevalence of Mental Disorders

Research has shown that psychiatric disorders occur in a very substantial minority of patients with cancer (Derogatis et al., 1983) and that the most prevalent mental-health disorder in this group is depression (Massie et al., 1994; Wilson, Chochinov et al., 2000). While the prevalence of depressive disorders in this study was actually higher than that noted in an earlier study that used similar methods with a palliative care population (Wilson, Scott et al., 2000) it is comparable to rates reported by several other researchers (Evans et al., 1986; Golden et al., 1991; Power et al., 1993). The prevalence of anxiety disorders was also high but in keeping with the rates reported by Brandberg et al. (1992) and Massie and Holland (1987). To summarise then, clinically significant symptoms of anxiety and depression were very prevalent among the individuals who took part in this study, with fully 44% of the participants meeting criteria for one or more DSM-IV disorders.



### Sources of Stress

One of the main goals of the study was to document the prevalence and severity of different sources of stress among people who are nearing the ends of their lives.

Distress associated with the prospect of death was conceptualised as arising from three dimensions: social, physical, and existential.

One noteworthy finding in this regard was that 15 participants reported a complete absence of stress in at least one of the three dimensions. These individuals also suffered less general psychological distress and were less likely to fulfil diagnostic criteria for a depressive or anxiety disorder. This was particularly so for the 7 participants who reported an absence of stress in the existential dimension. Overall, these participants also had higher Karnofsky Scale scores, indicating that they were less functionally disabled than other participants. Thus, the lack of stress may be unique to people who are remaining well physically. Nevertheless, it is rather remarkable that some people -- about 8% in the present study, who reported no stress in any dimension - - are able to carry on with great equanimity in the face of a terminal diagnosis. Evidently, the experience of advanced cancer is not invariably stressful in all domains, and there may even be potential for self-discovery, deepening relationships and personal growth (Cunningham, 1992; Engelman, 1993).

For those participants who were experiencing stress, this study helps us appreciate the nature and severity of symptoms and concerns. Concern about being a burden to others was the most disturbing social issue, and was acknowledged at some

level by about two-thirds of the participants. Weakness was reported as a symptom by 84% of participants and represented the most prominent physical symptom. Pain was the second most troublesome physical symptom and, while 73% of participants suffered with pain to some degree, it appeared to be relatively well controlled for most. This pattern replicates a finding by Wilson, Scott et al., (2000) that while subjects expressed a fear of uncontrollable pain, their most severe current problem was actually weakness. Finally, earlier research has shown that a major source of existential distress for patients with cancer is the prospect of disease progression with its implicit threat to survival (Dunkel-Schetter et al. 1986; Gotay, 1984; Noyes et al., 1990; Weisman & Worden, 1976-77). This was also evident in the present study, with about two-thirds of participants citing worry and concern about the future as an issue at some level of severity. For the majority of participants worry about the future was directed toward concerns about death and dying (e.g., not being ready to die; uncertainty about the time they had left; fear of a painful, prolonged death; being alone and concerns about an afterlife).

Among the three dimensions, physical symptoms received the highest severity ratings but it was also observed that the dimensions were significantly intercorrelated. Similar findings have also been reported in other research, Cohen et al., (1996), for example reported that several of the subscales on the McGill Quality Of Life Questionnaire were at least moderately correlated. Thus, the experience of stress shows some consistency across dimensions, which suggests that there may be a general factor of global distress that cuts across specific dimensions. This finding is analogous,

perhaps, to the concept of "total pain" at the end of life that has been described by Twycross and Lack (1999). This suggestion is further reinforced by the finding that scores on the BDI-PC were correlated significantly with the aggregate stressor severity ratings for all three dimensions. Consistent with a finding by Noyes et al., (1990), the BDI-PC was correlated most highly with the aggregate score of the existential dimension, but the correlations with the social and physical dimensions were also substantial.

Also as reported by Noyes et al., (1990), younger participants experienced more distress across the social and physical dimensions. This is not unexpected given the emotional turmoil (frustration, rage and a sense of unfairness) a number of authors have noted in young and middle aged individuals facing the threat of death (Pattison, 1977; Rando, 1984, Weisman & Worden, 1977). As Wilson, Chochinov et al., (2000) have reviewed elsewhere, when studies of patients with cancer do find an age effect on measures of distress, it tends to be in the direction of younger individuals reporting the greatest problems.

### Control and Effectiveness

Although various measures of stressor severity were intercorrelated, measures of control and effectiveness were generally not correlated with stressor severity. The exception was that a high degree of physical stress was associated with a perception of low control over that problem. Earlier studies that have incorporated the construct of control have used either a measure of global locus of control or a single item such as

"how much control do you believe you have over the progression of your cancer?" (Feifel et al., 1987; Hilton, 1989; Osowiecki & Compas, 1998; Taylor et al., 1984). The use of a problem specific approach to assessing control (suggested by Thompson & Collins, 1995) in this study, revealed that participants judged that they had more control over their social stressors than their physical symptoms. However, participants did not feel consistently that they were coping more effectively with one type of stressor than another. Despite this, scores on the BDI-PC correlated only with perceived effectiveness of coping with existential stress. People who felt that they were not coping well with their most severe existential stressor had higher scores on the BDI-PC. Thus it would seem that the existential dimension of stress, and the effectiveness with which one copes in that dimension, may have the strongest association with depression.

### Coping

To date, few studies have addressed the issue of how patients deal with the stressors of advanced terminal illness. The high incidence of clinically significant anxiety and depressive disorders (Cassileth et al., 1984; Pinder et al., 1993) indicate that some individuals do indeed have considerable difficulty adapting to the variety of stressful physical, existential and social issues inherent in their circumstances. The cognitive and behavioural strategies used to manage these stressful situations are thought to play a role in how well people adapt to these stressors. In the present study, the content-analysis approach to the assessment of coping permitted both a qualitative

review of the kinds of strategies that people use, and also a more quantitative investigation into broader categories of coping behaviour.

Qualitative data. In a review of the literature on coping with cancer, Maes et al. (1996) concluded that mainly passive/avoidant emotion-focused strategies, such as escape-avoidance or wish-fulfilling fantasy, were used when attempting to cope with this illness. The present findings, on the other hand, suggest a more complex view of the coping process, which was dependent on the specific type of stressor that was being coped with. For instance, perspective-taking and acceptance/resignation were used commonly across all dimensions in the sense that the majority of participants used both strategies in each dimension. With regard to social and physical problems, direct action and instrumental support were also used by a majority of participants.

On the other hand, some strategies were used infrequently. For example, when coping with physical stressors, distancing, emotional support, and spiritual support were used less often. It is interesting, in fact, that tactics of distancing or distraction were not reported more frequently. Research has shown that the ability to distance oneself from physical symptoms can help individuals to reinterpret noxious symptoms as less intense (Spiegel & Bloom, 1983; Turk & Feldman, 2000). Techniques such as distraction, relaxation, hypnosis, and guided imagery have all been shown to be effective in this regard and would perhaps benefit those individuals who tend to use mainly problem-focused approaches as they attempt to cope with their physical stressors.

Quantitative data. In this research a consistent individual difference was noted in terms of the numbers of strategies generated to manage stressors. That is, participants

who generated a high number of strategies to a social stressor also generated a high number of strategies in response to stressors in the other two dimensions.

Research based on the transactional model has shown that a combination of problem-focused and emotion-focused coping is used in most stressful situations (Folkman & Lazarus, 1980; Folkman & Lazarus, 1985). Indeed, participants in this study generally did use a combination of approaches to deal with their stressors. However, there were clear differences across dimensions of stress in the relative use of problem-focused versus emotion-focused strategies. Problem-focused coping was uncommon for existential issues while emotion-focused approach and emotion-focused avoidance strategies were used less frequently for physical stressors. As predicted by the transactional model of coping, people cope with different problems in different ways (Lazarus & Folkman, 1984; Lazarus, 1999). In the context of advanced cancer, the use of specific coping strategies was determined by whether the particular stressful aspect of their terminal illness arose from the social, physical or existential dimension. This finding has important implications for coping research in health psychology. Although the general topic of "coping with cancer" has been the focus of many studies, it may be overly broad and general to ask, "How do people cope with cancer?" Any life-threatening illness may have multiple specific impacts, all of which must be coped with in various ways.

According to the goodness-of-fit hypothesis, if a situation is deemed to be controllable, then the tendency is for problem-focused coping to be the primary mode of coping. Conversely, if the situation is seen to be uncontrollable, more emotion-focused

coping is likely to be used (Folkman, 1992; Folkman & Lazarus, 1980; Folkman, Lazarus, Dunkel-Schetter et al., 1986). Therefore it was predicted that stressors rated low in controllability would elicit more emotion-focused than problem-focused coping. In general, however, there was no evidence to support that hypothesis, and in fact, there was evidence against it. Specifically, participants' perception of control did differ across dimensions of stress in that perceived control was significantly higher for the social dimension than for the physical. Contrary to prediction, however, in the area where participants reported the least control -- physical stress -- they actually generated the most problem-focused strategies. This finding indicates that there may be limits to the kind of circumstances that the goodness-of-fit hypothesis applies to. For example, it may be more relevant to social or psychological stressors of different degrees of controllability, rather than to the physical symptoms of advanced illness, which nevertheless place considerable demands on the individual to cope.

Although the goodness-of-fit hypothesis was not supported, other hypotheses were. For example, it was hypothesised that participants would take a more problem-focused approach in trying to directly reduce the source of distress associated with physical symptoms. This hypothesis was confirmed in the finding that participants used predominantly direct action strategies to manage this stressor. The hypothesis that a greater mix of problem-focused and emotion-focused strategies would be used for social concerns was also confirmed. It was further proposed that because existential concerns involved more intangible, psychological considerations, less direct problem-solving would be used. This proposal was also upheld in that participants used predominantly

emotion-focused approach strategies in the management of their most significant existential stressor.

Aldwin and Revenson (1987) have suggested that the stress-buffering effect of coping strategies may be partially dependent on the belief that the coping strategy successfully managed the situation. This appeared to be so only so far as existential stress was concerned; in this case, participants who felt that they were not coping very effectively were more likely to report greater levels of depressive symptomatology. It is also noteworthy that, although the BDI-PC was correlated with all dimensions of stress, the highest correlation was with aggregate ratings of existential distress. Furthermore, it was also observed that participants with no existential distress were less likely than other participants to be diagnosed with an anxiety or depressive disorder. Overall, then, it appears that of the three dimensions, existential concerns show the strongest association with symptoms of depression. Although the specific nature of this association remains to be determined in future research, one stark reality of a diagnosis of a terminal illness is that the issue of mortality changes from an intellectual exercise to something very real; for some, but by no means all, the contemplation of "no tomorrow" can be devastating (Nyberg, 2002).

Several other findings from earlier studies were not replicated in this research. For instance, Dunkel-Schetter et al. (1986) found that the perceived stressfulness of the problem influenced coping in that a higher level of distress was associated with more coping through the use of social support and escape-avoidant strategies. In the present study, there was no relationship between severity ratings of the worst stressor in any



dimension and the number of problem-focused, emotion-focused approach or avoidant strategies generated to cope with that problem.

Similarly, a number of studies have shown that some strategies are consistently related to poor adaptation and others to better adaptation (Ben-Zur et al., 2001; Bloom & Spiegel, 1984; Dunkel-Schetter et al., 1992; Epping-Jordan et al., 1999; Feifel et al., 1987; Friedman et al., 1988; Manne et al., 1994). Of particular relevance is one other investigation which, like the present study, used a semi-structured interview to measure coping efforts, and found that problem-focused coping was related to lower psychological symptoms and emotion-focused coping was associated with higher symptoms (Osowiecki & Compas, 1998). In contrast, the present study found there was no association between the level of psychological distress and the use of problem-focused, emotion-focused approach or emotion-focused avoidant strategies. Coping, at least as assessed in this manner, was not related to distress.

As noted earlier, this negative finding may be related to various methodological issues. For example, in previous research, coping has usually been measured with questionnaires which share method variance with depression self-reports. On the other hand, the raw number of coping strategies may not be the most relevant aspect of coping to relate to distress. As a broad conclusion based on the present results, however, the lack of association between coping and distress suggests that, for specific social, physical, and existential problems facing people with terminal illness, there is not necessarily any pattern of coping that is best for mental health.

Nevertheless, other demographic and clinical characteristics, including age, education and functional status were correlated with the number of coping strategies. Some previous research has found that younger adults use more escapist or avoidant strategies when dealing with problems (Aldwin, Sutton, Chiara, & Spiro, 1996; Folkman, Lazarus, 1980, 1985; McCrae, 1982). However, in this study younger participants actually generated more emotion-focused *approach* strategies when coping with their worst existential stressor. Several factors could lead to this style of coping. For instance, Feifel et al. (1987) noted that individuals with life-threatening diseases tend to engage in a higher incidence of direct confrontive coping than people with illnesses that are not life-threatening; however, the intangible nature of existential stressors, may impede the use of direct action problem-solving strategies. If there is an impetus to engage in more approach strategies when faced with existential stress, then emotion-focused approach strategies (attending to and expressing emotions) would seem to be the likely alternative.

Education was related to coping in that the more highly educated participants used more problem-focused strategies to manage their worst social stressor. Higher education is generally considered to be a resource in support of coping (Lararus& Folkman, 1984); in the case of social stressors, this may have contributed to the ability to identify solvable aspects of the situation in the course of stress appraisals, and use information and instrumental support more efficiently in efforts to problem solve.

The functional status of participants was related to coping in that the more functionally debilitated participants tended to report fewer strategies overall, particularly

with respect to the social and existential dimensions. As noted earlier, this may indicate that there are fewer coping alternatives available to those who are more ill and less ambulatory. However, it may also reflect a lower capacity to marshal the cognitive effort required to review one's use of coping strategies and articulate them in a well-developed way.

In summary, the proposals that the use of problem-focused strategies would predominate as participants attempted to manage physical stressors, and that a greater mix of problem-focused and emotion-focused strategies would be used to handle social concerns, were confirmed. The hypothesis that participants would use primarily emotion-focused strategies to manage existential concerns was also upheld. In addition, a consistent individual difference was noted in terms of the numbers of strategies generated to manage stressors.

In general, participants used a combination of problem-focused and emotion-focused strategies to handle stressors in all three dimensions. However, the finding of other investigators that cancer patients use *mainly* passive/avoidant emotion-focused strategies to manage their stress (Maes et al. 1996) was not replicated. Rather, study participants coped quite differently with different issues, depending on whether the particular stressor fell within the social, physical or existential dimension. Overall, there were fewer emotion-focused avoidant strategies generated and similar numbers of problem-focused and emotion-focused approach strategies. However, coping was not related to psychological distress.

### Monitors and Blunters

It has been suggested that in order to increase our understanding of how individuals cope with threatening events, models of stress and coping should be expanded to include a consideration of individual differences in how people prefer to cope with stressors (Ward et al., 1988). The monitoring-blunting hypothesis proposed by Miller (1980, 1987) suggests that two underlying dimensions seem to reflect a preferred coping style. "Monitoring" refers to the extent to which an individual typically attends to, or monitors, the threatening aspects of stressful situations, whereas "blunting," refers to the extent to which an individual cognitively avoids, or blunts, threatening cues (Miller, 1980, 1987; Miller & O'Leary, 1993).

Research based on the monitoring-blunting hypothesis has shown that individual differences in how people prefer to cope with health-related stressors does indeed predict variations in actual coping behaviour and variations in the experience of distress (Miller & O'Leary, 1993). Therefore a number of hypotheses based on this model were formulated.

Specifically, it was hypothesised that more monitors than blunters would fulfil diagnostic criteria for a depressive or anxiety disorder; that monitors would display greater levels of general psychological distress as indicated by scores on the BDI-PC; and that monitors would report more severe problems across dimensions of stress and attach a higher severity rating to their most severe individual stressor within each dimension. It was also proposed that blunters would see their coping efforts as more successful overall than monitors and would be more likely to feel that they had higher

levels of control over stressful issues. It was further hypothesised that blunTERS would engage in more emotion-focused avoidance coping than monitors, which is the type of behaviour that lies at the heart of the blunting construct. Importantly, there was only limited evidence from the present results to support these hypotheses. Although there was a tendency for monitors to have higher BDI-PC scores than blunTERS, this fell short of conventional levels of statistical significance with the present sample size.

Furthermore, an association with depression did not extend to the clinical diagnostic measures. However, the present findings did confirm that, as hypothesized, blunTERS, perceived more control over their stressors. It was also observed that they were prescribed lower doses of opioids. Previous research has found that monitors tend to focus on and react to their medical problems with higher levels of concern than blunTERS, and are more likely to request new prescriptions for both medical and stress-related symptoms (Miller et al., 1988; Miller et al., 1989). Therefore, monitors in the present study may have made more requests for medications for pain, even if their pain was not necessarily more severe than that of blunTERS. In general, therefore, the strongest support for the importance of the monitoring/blunting dimension was that blunTERS felt more in control of their circumstances, and perhaps felt better able to manage with their physical symptoms on more modest opioid regimens.

Unlike other health-related research (Miller & O'Leary, 1993), however, the tendency to "monitor" or "blunt" did not predict variations in coping behaviour or in the experience of distress. This is not simply due to restrictions on power associated with a small sample size. As noted previously, the exclusion of participants who indicated that

they actually had no stress in at least one of the social, physical or existential dimensions resulted in cell sizes of only 19 for these analyses. With this cell size only very large effects would have been found. However, the means (e.g., Table 8 and Table 12) for monitors and blunners are very close. This indicates that if there is any difference it is very small and it would require a very large sample to detect that difference.

Additionally, the correlations of the monitoring and blunting scales with other relevant variables were uniformly very low. Rather, it seems that the monitoring and blunting constructs are not relevant to the dimensions of stress examined in the present study. Generally speaking, the stressors facing the present participants were numerous and complex. Perhaps as Epping-Jordan et al. (1999) suggested recently, monitoring may play a less important role when it comes to complex stressors than it does with more circumscribed health threats. That is, the MBSS may be more relevant in the prediction of responses to specific procedures such as cardiac catheterization and gastrointestinal endoscopy (Watkins et al., 1986; Gattuso et al., 1992), but less relevant when people are trying to adapt to the many issues associated with approaching death.

Another consideration is whether the use of the shortened version of the MBSS rather than the full scale, might have influenced the outcome. Admittedly, the short form has less of a body of validating research, but it has been recommended as appropriate for patients with advanced disease (Steptoe, 1989). However, the low alpha coefficients found in this study indicate that the items on these abbreviated scales may not reflect the tendency to monitor or blunt in this particular group of people nearing the end of their lives. Some investigators have turned recently to focusing only on the monitoring

dimension (Epping-Jordan et al., 1999), but even then, the relevance of the monitoring scale to the variables in the present study appeared to be modest. Therefore, the issue of individual differences in coping near the end of life remains an important one that must be addressed in future research.

### Clinical Implications

This series of interviews with individuals attempting to cope with multiple stressors of advanced disease confirmed that there are many problems that must be managed. The majority of participants, although not all, experienced distress associated with social concerns, physical symptoms and existential issues. The interviews also revealed that the prevalence of clinically significant mental disorders was high. Severity ratings across the dimensions of stress were significantly correlated, suggesting some communality across dimensions in the experience of stress. In fact, some investigators have proposed bi-directional influences in which social, psychological and existential concerns exacerbate physical symptoms and vice versa (Spiegel & Bloom, 1983; Rousseau, 2000; Turk & Feldman, 2000). Some research has also shown that the manipulation of psychological variables can help some individuals to reinterpret noxious symptoms as less intense, and that individual and group therapy can be effective in helping patients work through issues related to terminal illness (Moorey & Greer, 1989; Spiegel & Bloom, 1983; Turk & Feldman, 2000). In general, however, controlled research into the efficacy of psychotherapeutic approaches with dying patients is in its infancy. Nevertheless, it is in keeping with the holistic tradition of palliative care that

psychological or existential suffering be regarded as critical dimensions of care. Given these facts, the provision of either individual or group psychotherapeutic interventions would seem appropriate for those individuals who suffer significant psychological distress in the face of impending death.

One particular clinical issue that arises in the present study has to do with the adoption of problem-focused coping strategies for physical symptoms. It makes both intuitive and theoretical sense that if a problem can be solved directly, then it certainly should be. On the other hand, some of the physical problems facing terminally ill individuals may not be directly solvable. In this context, emotion-focused avoidance strategies may actually be under-utilised by patients as they try to cope spontaneously with these stressors, but there may be relevant skills that can be taught. It is possible that the introduction of interventions which focus on stress reduction for instance, distraction, relaxation, hypnosis, guided imagery would be of benefit to these individuals as they attempt to adapt to their circumstances. All of these interventions have been shown to be effective in the reduction of psychological distress as individuals explore and work through emotions related to their illness (Spiegel & Bloom, 1983; Turk & Feldman, 2000).

### Conclusions

The experience of advanced cancer was not stressful in all domains for all participants; however approximately 71% did experience distress across each of the three dimensions (social, physical and existential). In addition, the correlational analyses



suggest that there is a general factor of global distress that may cut across specific dimensions. While physical symptoms received the highest severity ratings, it would seem that concerns associated with the meaning of one's life and death, and the perception of coping ineffectually with those issues, have the strongest association with symptoms of depression as one nears the end of life. While people coped quite differently with different aspects of their experience, depending on whether the specific stressors were within the social, physical or existential dimension, overall, participants generated more approach (problem-focused and emotion-focused approach strategies) than avoidant strategies. They continued efforts to problem-solve, and to focus on and attend to their emotions regardless of perceived control. Using the present methodology, these coping efforts were not related to mental disorders, the prevalence of which was high. Further research will be necessary, therefore, to unravel the role of coping and its association with depression in people with advanced cancer. This may be particularly true of the existential domain. While much of the success of palliative care has been with respect to advances in the medical management of pain and other physical symptoms, specific interventions for the existential dimension of suffering are much less developed. However, from a mental health perspective, this may be an important area to pursue as psychologists attempt to increase their contribution to the care of those who are approaching the end of life.

## References

- Aldwin, C. M. (1994). *Stress, coping, and development: an integrative perspective*. New York: The Guilford Press.
- Aldwin, C. M., & Revenson, T. A. (1987). Does coping help? A reexamination of the relation between coping and mental health. *Journal of Personality and Social Psychology*, *53*(2), 337-348.
- Aldwin, C. M., Sutton, K. J., Chiara, G., & Spiro, A. (1996). Age differences in stress, coping, and appraisal: findings from a normative aging study. *Journal of Gerontology*, *51B*, 179-188.
- Alexander, P. J., Dinesh, N., & Vidyasagar, M. S. (1993). Psychiatric morbidity among cancer patients and its relationship with awareness of illness and expectations about treatment outcome. *Acta Oncologica*, *32*, 623-626.
- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington: American Psychiatric Association.
- Beck, A. T., Guth, D., Steer, R. A., & Ball, R. (1997). Screening for major depression in medical inpatients with the Beck Depression Inventory for primary care. *Behaviour Research and Therapy*, *35*(8), 785-791.
- Beck, A. T., Rial, W. Y., & Rickels, K. (1974). Short form of Depression Inventory: Cross-validation. *Psychological Reports*, *34*, 1184-1186.
- Benjamini, Y., & Hochberg, Y. (1995). Controlling the false discovery rate: a practical and powerful approach to multiple testing. *Journal of the Royal Statistical Society B*, *57*, 289-300.
- Ben-Zur, H., Gilbar, O., & Lev, S. (2001). Coping with breast cancer: Patient, spouse and dyad model. *Psychosomatic Medicine*, *63*, 32-39.
- Bijttebier, P., Vertommen, H., & Steene, G. V. (2001). Assessment of cognitive coping style: A closer look at situation-response inventories. *Clinical Psychology Review*, *21*(1), 85-104.
- Bloom, J. R., & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with breast cancer. *Social Science and Medicine*, *19*(8), 831-837.

Brandberg, Y., Bolund, C., Sigurdardottir, V., Sjoden, P., & Sullivan, M. (1992). Anxiety and depressive symptoms at different stages of malignant melanoma. Psycho-Oncology, 1, 71-78.

Bruera, E., & MacDonald, N. (1988). Asthenia in patients with advanced cancer. Journal of Pain and Symptom Management, 3(9), 9-14.

Bukberg, J., Penman, D., & Holland, J. C. (1984). Depression in hospitalized cancer patients. Psychosomatic Medicine, 46(3), 199-212.

Burgess, C., Morris, T., & Pettingale, K. W. (1988). Psychological response to cancer diagnosis- II. Evidence for coping styles (Coping styles and cancer diagnosis). Journal of Psychosomatic Research, 32(3), 263-272.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., Ketchman, A. S., Moffat, F. L., & Clark, K. C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. Journal of Personality and Social Psychology, 65(2), 375-390.

Cassileth, B. R., Lusk, E. J., Strouse, T. B., Miller, D. S., Brown, L. L., Cross, P. A., & Tenaglia, A. N. (1984). Psychosocial status in chronic illness. The New England Journal of Medicine, 311(8), 506-510.

Chamberlain, K. (1999). Using grounded theory in health psychology: Practices, premises and potential. In M. Murray & K Chamberlain (Eds.), Qualitative Health Psychology (pp. 183-201). London: Sage.

Chaturvedi, S. K., Shenoy, A., Prasad, K. M. R., Senthilnathan, S. M., & Premlatha, B. S. (1996). Concerns, coping and quality of life in head and neck cancer patients. Support Care Cancer, 4, 186-190.

Cheng, C., Hui, W., & Lam, S. (2000). Perceptual style and behavioral pattern of individuals with functional gastrointestinal disorders. Health Psychology, 19(2), 146-154.

Chochinov, H. M., Wilson, K. G., Enns, M., & Lander, S. (1997). "Are you depressed?" Screening for depression in the terminally ill. American Journal of Psychiatry, 154(5), 674-676.

Christensen, A. J., Smith, T. W., Turner, C. W., & Cundick, K. E. (1994). Patient adaptation in renal dialysis: A person by treatment interactive approach. Journal of Behavioral Medicine, 17(6), 549-566.

Classen, C., Koopman, C., Angell, K., & Spiegel, D. (1996). Coping styles associated with psychological adjustment to advanced breast cancer. Health Psychology, 15(6), 434-437.

Cohen, J. (1988). *Statistical power analysis for the Behavioral Sciences* (2nd ed.). Hilldale, NJ: Academic Press.

Cohen, S. R., Mount, B. M., Bruera, E., Provost, M., Rowe, J., Tong, K. (1997). Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. Palliative Medicine, 11(1), 3-20.

Cohen, S. R., Mount, B. M., Thomas, J. J. N., & Mount, L. F. (1996). Existential well-being is an important determinant of quality of life. Cancer, 77(3), 576-586.

Compas, B. E., Forsythe, C. J., & Wagner, B. M. (1988). Consistency and variability in causal attributions and coping with stress. Cognitive Therapy and Research, 12(3), 305-320.

Compas, B. E., Malcarne, V. L., & Fondacaro, K. M. (1988). Coping with stressful events in older children and adolescents. Journal of Consulting and Clinical Psychology, 56(3), 405-411.

Compas, B. E., Worsham, N. L., Ey, S., & Howell, D. C. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients. Health Psychology, 15(3), 167-175.

Corr, C. A. (1991-1992). A task-based approach to coping with dying. Omega-Journal of Death and Dying, 24(2), 81-94.

Corr, C. A., Nabe, C. M., & Corr, D. M. (1994). Death and dying: Life and living. Belmont, CA: Brooks/Cole.

Corr, C. A., Nabe, C. M., & Corr, D. M. (1997). Death and dying: Life and living (2<sup>nd</sup> ed.). Belmont, CA: Brooks/Cole.

Coyle, N., Adelhardt, J., Foley, K. M., & Portenoy, R. K. (1990). Character of terminal illness in the advanced cancer patient: Pain and other symptoms during the last 4 weeks of life. Journal of Pain and Symptom Management, 5(2), 83-93.

Coyne, J. C., & Gottlieb, B. H. (1996). The mismeasure of coping by checklist. Journal of Personality, 64(4), 956-991.

Coyne, J. C., & Racioppo, M. W. (2000). Never the twain shall meet? Closing the gap between coping research and clinical intervention research. American Psychologist, *55*(6), 655-663.

Coyne, J. C., & Holroyd, K. (1982). Stress, coping, and illness. In T. Millon, C. Green & R. Meagher (Eds.), Handbook of Clinical Health Psychology (pp. 103-127). New York: Plenum Press.

Cunningham, A. J. (1992). The healing journey. Toronto: Key Porter Books.

Curtis, E. B., Krech, R., & Walsh, T. D. (1991). Common symptoms in patients with advanced cancer. Journal of Palliative Care, *7*, 25-29.

Davidson, G. W. (1979). Hospice care for the dying. In H. Wass (Ed.), Dying: Facing the facts (pp. 158-181). New York: Hemisphere.

De Ridder, D. (1997). What is wrong with coping assessment? A review of conceptual and methodological issues. Psychology and Health, *12*, 417-431.

Derogatis, L. R., Morrow, G. R., Fetting, J., Penman, D., Piasetsky, S., Schmale, A. M., Heinrichs, M., & Carnicke, C. L. M. (1983). The prevalence of psychiatric disorders among cancer patients. JAMA, *249*(6), 751-757.

Donnelly, S., Walsh, D., & Rybicki, L. (1995). The symptoms of advanced cancer: Identification of clinical and research priorities by assessment of prevalence and severity. Journal of Palliative Care, *11*(1), 27-32.

Dudgeon, D. J., Raubertas, R. F., Doerner, K., O'Connor, T, Tobin, M., & Rosenthal, S. N. (1995). When does palliative care begin? A needs assessment of cancer patients with recurrent disease. Journal of Palliative Care, *11*(1), 5-9.

Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, R. L. (1992). Patterns of coping with cancer. Health Psychology, *11*(2), 79-87.

Endicott, J. (1983). Measurement of depression in patients with cancer. Cancer, *53*(Suppl), 2243-2248.

Endicott, J., & Spitzer, R. L. (1978). A diagnostic interview: the Schedule for Affective Disorders and Schizophrenia. Archives of General Psychiatry, *35*, 837-844.

Endler, N. S., & Parker, J. D. A. (1990). Multidimensional assessment of coping: A critical evaluation. Journal of Personality and Social Psychology, *58*(5), 844-854.

Engelman, S. R. (1993). The spiritual dimensions of working with families. In S. R. Engelman, (Ed.), Confronting life-threatening illness, (pp. 104-117).

Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K. & Krag, D. N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. Health Psychology, 18(4), 315-326.

Evans, D. L., McCartney, C. F., Nemeroff, C. B., Raft, D., Quade, D., Golden, R. N., Haggerty, J. J., Holmes, V., Simon, J. B., Droba, M., Mason, G. A., Fowler, W. C., & (1986). Depression in women treated for gynecological cancer: Clinical and neuroendocrine assessment. American Journal of Psychiatry, 143(4), 447-452.

Fainsinger, R., Miller, M. J., Bruera, E., Hansen, J., & Maceachern, T. (1991). Symptom control during the last week of life on a palliative care unit. Journal of Palliative Care, 7(1), 5-11.

Fechner-Bates, S., Coyne, J. C., & Schwenk, T. L. (1994). The relationship of self-reported distress to depressive disorders and other psychopathology. Journal of Consulting and Clinical Psychology, 60, 550-559.

Feifel, H., Strack, S., & Nagy, V. T. (1987). Coping strategies and associated features of medically ill patients. Psychosomatic Medicine, 49, 616-625.

Feifel, H., Strack, S., & Nagy, V. T. (1987). Degree of life-threat and differential use of coping modes. Journal of Psychosomatic Research, 31, 91-99.

Felton, B. J., & Revenson, T. A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. Journal of Consulting and Clinical Psychology, 52(3), 343-353.

Filipp, S-H., Klauer, T., Freudenberg, E., & Ferring, D. (1990). The regulation of subjective well-being in cancer patients: An analysis of coping effectiveness. Psychology and Health, 4, 305-317.

Fishman, B., Pasternak, S., Wallenstein, S. L., Houde, R. W., Holland, J. C., & Foley, K. M. (1987). The Memorial Pain Assessment Card: a valid instrument for the evaluation of cancer pain. Cancer, 60, 1151-1158.

Friedman, L. C., Baer, P. E., Lewy, A., Lane, M., & Smith, F. E. (1988). Predictors of psychosocial adjustment to breast cancer. Journal of Psychosocial Oncology, 6(1/2), 75-94.

Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. Journal of Personality and Social Psychology, 46(4), 839-852.

Folkman, S. (1992). Making the case for coping. In B. Carpenter (Ed.), Personal Coping: Theory, research and application (pp.31-46). Westport CT: Praeger.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior, 21, 219-239.

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. Journal of Personality and Social Psychology, 48(1), 150-170.

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. Journal of Personality and Social Psychology, 50(5), 992-1003.

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. Journal of Personality and Social Psychology, 50(5), 571-579.

Forsythe, C. J., & Compas, B. (1987). Interaction of cognitive appraisals of stressful events and coping: Testing the goodness of fit hypothesis. Cognitive Therapy and Research, 11(4), 473-485.

Gard, D., Edwards, P. W., Harris, J., & McCormack, G. (1988). Sensitizing effects of pretreatment measures on cancer chemotherapy nausea and vomiting. Journal of Consulting and Clinical Psychology, 56(1), 80-84.

Gattuso, S. M., Litt, M. D., & Fitzgerald, T. E. (1992). Coping with gastrointestinal endoscopy: Self-efficacy enhancement and coping style. Journal of Consulting and Clinical Psychology, 60, 133-139.

Golden, R. N., Mc Cartney, C. F., Haggerty, J. J., Raft, D., Nemeroff, C. B., Ekstrom, D., Holmes, V., Simon, J. S., Droba, M., Quade, D., Fowler, W. C., & Evans, D. L. (1991). The detection of depression by patient self-report in women with gynecologic cancer. International Journal of Psychiatry in Medicine, 21, 17-27.

Gordon, J. R., Canetto, S. S., Gallagher-Thompson, D., Rando, T., Stillion, J., Werth, J. L., & Anderson, J. (2000). Report to the board of directors of the American Psychological Association (APA) from the APA working group on assisted suicide and end-of-life decisions. Available: [www.apa.org/pi/aseolf.html](http://www.apa.org/pi/aseolf.html)

Gotay, C. C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. Social Science and Medicine, 18(7), 605-613.

Gravetter, F. J., & Wallnau, L. B. Statistics for the behavioral sciences. New York: West.

Greer, S., Morris, T. & Pettingale, K. W. (1979). Psychological response to breast cancer: Effect on outcome. Lancet, 785-787.

Heim, E., Augustiny, K. F., Shaffner, L., & Valach, L. (1993). Coping with breast cancer over time and situation. Journal of Psychosomatic Research, 37(5), 523-542.

Heim, E., Valach, L., & Schaffner, L. (1997). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. Psychosomatic Medicine, 59, 408-418.

Hilton, B. A. (1989). The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. Journal of Behavioral Medicine, 12(1), 39-54.

Hinton, J. (1973). Bearing cancer. British Journal of Medical Psychology, 46, 105-113.

Hinton, J. (1994). Which patients with terminal cancer are admitted from home care? Palliative Medicine, 8, 197-210.

Houts, P. S., Yasko, J. M., Harvey, H. A., Kahn, S. B., Hartz, A. J., Hermann, J. F., Schelzel, G. W., & Bartholomew, M. J. (1988). Unmet needs of persons with cancer in Pennsylvania during the period of terminal care. Cancer, 62, 627-634.

Hughes, J. E. (1985). Depressive illness and lung cancer. I. Depression before diagnosis. European Journal of Surgical Oncology, 11, 15-20.

Hughes, J. (1986). Depression in cancer patients. In B. A. Stoll (Ed.), Coping with cancer stress (pp.39-44). Hingham, MA: Kluwer Academic Publishers.

Johnson, C. L. & Barer, B. M. (1993). Coping and a sense of control among the oldest old: an exploratory analysis. Journal of Aging Studies, 7(1), 67-80.

Kornblith, A. B., Thaler, H. T., Wong, G., Vlamis, V., McCarthy Lepore, J., Loseth, D. B., Hakes, T., Hoskins, W. J., & Portenoy, R. K. (1995). Quality of life of women with ovarian cancer. Gynecologic Oncology, 59, 231-242.

Labouvie-Vief, G., Hakim-Larson, J., & Hobart, C. (1987). Age, ego level, and the life-span development of coping and defense processes. Psychology and Aging, 2, 286-293.



Laszlo, J. (1987). Understanding Cancer. Washington: Harper and Row.

Lavery, J. F., & Clarke, V. A. (1996). Causal attributions, coping strategies, and adjustment to breast cancer. Cancer Nursing Feb;19(1), 20-28.

Landis, J. R. & Koch, G. G. (1977). The measurement of observer agreement for categorical data. Biometrics, 33, 159-174.

Lansky, S. B., List, M. A., Hermann, C. A., Ets-Hokin, E. G., Das Gupta, T. K., Wilbanks, G. D., & Hendrickson, F. R. (1985). Absence of major depressive disorder in female cancer patients. Journal of Clinical Oncology, 3, 1553-1560.

Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. Psychosomatic Medicine, 55, 234-247.

Lazarus, R. S. (1999). Stress and emotion: a new synthesis. New York: Springer.

Lazarus, R. S. (2000). Toward better research on stress and coping. American Psychologist, 55(6), 665-673.

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal and coping. New York : Springer.

Lerman, C., Rimer, B., Blumberg, B., Cristinzio, S., Engstrom, P. F., MacElwee, N., O'Connor, K., & Seay, J. (1990). Effects of coping style and relaxation on cancer chemotherapy side effects and emotional responses. Cancer Nursing, 13(5), 308-315.

Lichter, I., & Hunt, E. (1990). The last 48 hours of life. Journal of Palliative Care, 6(4), 7-15.

Maes, S., Leventhal, H., & De Ridder, D. T. D. (1996). Coping with chronic disease. In M. Zeidner & N. S. Endler (Eds.), Handbook of coping, theory, research, applications (pp. 221-251). New York: Wiley.

Mahon, S. M., Cella, D. F., & Donavon, M. I. (1990). Psychosocial adjustment to recurrent cancer. Oncology Nursing Forum, 17(3), 47-52.

Malcarne, V. L. Compas, B. E., Epping-Jordan, J. E., & Howell, D. C. (1995). Cognitive factors in adjustment to cancer: Attributions of self-blame and perceptions of control. Journal of Behavioral Medicine, 18(5), 401-417.

Manne, S. L., Sabbioni, M., Bovbjerg, D. H., Jacobsen, P. B., Taylor, K. L., & Redd, W. H. (1994). Coping with chemotherapy for breast cancer. Journal of Behavioral Medicine, 17(1), 41-55.

Manuel, G. M., Roth, S., Keefe, F. J., & Brantley, B. A. (1987). Coping with cancer. Journal of Human Stress, 13, 149-158.

Massie, M. J., & Holland, J. C. (1987). Consultation and liaison issues in cancer care. Psychiatric Medicine, 5, 343-359.

Massie, M. J. (1989). Depression. In J. C. Holland & J. H. Rowland (Eds.), Handbook of psychooncology: psychological care of the patient with cancer (pp. 283-290). New York: Oxford University Press.

Massie, M. J., Gagnon, P., & Holland, J. C. (1994). Depression and suicide in patients with cancer. Journal of Pain and Symptom Management, 9(5), 325-340.

McCrae, R. R. (1982). Age differences in the use of coping mechanisms. Journal of Gerontology, 37, 454-460.

Meyerowitz, B. E. (1983). Postmastectomy coping strategies and quality of life. Health Psychology, 2(2), 117-132.

Meyerowitz, B. E., Heinrich, R. L., & Schag, C. C. (1983). A competency-based approach to coping with cancer. In T. G. Burish & L. A. Bradley (Eds.), Coping with chronic stress (pp. 137-158). New York: Academic Press.

Miller, S. M. (1980). Why having control reduces stress: If I can stop the roller coaster, I don't want to get off. In J. Garber & M. E. P. Seligman (Eds.), Human helplessness: Theory and applications. (pp. 71-95). New York: Academic Press.

Miller, S. M. (1980b). When is a little information a dangerous thing? Coping with stressful events by monitoring versus blunting. In S. Levine & H. Urish (Eds.), Coping and Health (pp. 145-169). New York: Plenum Press.

Miller, S. M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. Journal of Personality and Social Psychology, 52(2), 345-353.

Miller, S. M. (1990). To see or not to see: Cognitive informational styles in the coping process. In M. Rosenbaum (Ed.), Learned resourcefulness: On coping skills, self-control, and adaptive behavior (pp. 95-126). New York: Springer.

Miller, S. M. (1992). Monitoring and blunting in the face of threat: Implications for adaptation and health. In L. Montada, S. H. Phillip & M. J. Lerner (Eds.), Life crises and experiences of loss in adulthood (pp. 255-273). Hillsdale, NJ: Erlbaum.

Miller, S. M. (1995). Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. Cancer, *76*(2), 167-77.

Miller, S. M. (1996). Monitoring and blunting of threatening information: Cognitive interference and facilitation in the coping process. In I. G. Sarason, G. R. Pierce & B. R. Sarason (Eds.), Cognitive interference: Theories, methods and findings (pp. 175-190). Mahwah, New Jersey: Lawrence Erlbaum.

Miller, S. M., Brody, D. S., & Summerton, J. (1988). Styles of coping with threat: Implications for health. Journal of Personality and Social Psychology, *54*(1), 142-148.

Miller, S. M., Leinbach, A., & Brody, D. S. (1989). Coping style in hypertensive patients: Nature and consequences. Journal of Consulting and Clinical Psychology, *57*(3), 333-337.

Miller, S. M., & Mangan, C. E. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: Should the doctor tell all? Journal of Personality and Social Psychology, *45*(1), 223-236.

Miller, S. M., & O'Leary, A. (1993). Cognition, stress, and health. In K. S. Dobson, & P. C. Kendall (Eds.), Psychopathology and cognition (pp 159-189). San Diego: Academic Press.

Miller, S. M., Roussi, P., Altman, D., Helm, W., & Steinberg, A. (1994). Effects of coping style on psychological reactions of low-income, minority women to colposcopy. The Journal of Reproductive Medicine, *39*(9), 711-718.

Moorey, S., & Greer, S. (1989). Psychological therapy for patients with cancer: a new approach. Oxford: Heinemann.

Moos, R. H., & Moos, B. S. (1988). Coping Responses Inventory Manual. Palo Alto, CA.

Morris, T., Greer, S., & White, P. (1977). Psychological and social adjustment to mastectomy. Cancer, *40*, 2381-2387.

Morris, J. N., Mor, V, Goldberg, R. J., Sherwood, S., Greer, D. S., & Hiris, J. (1986). Effect of treatment setting in patient characteristics on pain in terminal cancer

patients: A report from the national hospice study. Journal of Chronic Diseases, 39(1), 27-35.

Mor, V., Masterson-Allen, S., Houts, P., & Siegel, K. (1991). The changing needs of patients with cancer at home. Cancer, 69(3), 829-838.

National Cancer Institute of Canada. (2001). Canadian cancer statistics. Toronto, Canada.

Noyes, R., Kathol, R. G., Debelius-Enemark, P., Williams, J., Mutgi, A., Suelzer, M. T., & Clamon, G. H. (1990). Distress associated with cancer as measured by the illness distress scale. Psychosomatics, 31(3), 321-330.

Nyberg, J. (2002). The terminally ill adult patient. In R. B. Gilbert (Ed.), Health care and spirituality: listening, assessing, caring. New York: Baywood.

Osowiecki, D. M., & Compas, B. (1999). A prospective study of coping, perceived control, and psychological adaptation to breast cancer. Cognitive Therapy and Research, 23(2), 169-180.

Parle, M., Jones, B., & Maguire, P. (1996). Maladaptive coping and affective disorders among cancer patients. Psychological Medicine, 26, 735-744.

Pattison, E. M. (1977). The experience of dying. In E. M. Pattison (Ed.), The experience of dying (43-59). Englewood Cliffs, NJ: Prentice-Hall.

Payne, D. K., & Massie, M. J. (2000). Anxiety in palliative care. In H. M. Chochinov & W. Breitbart (Eds.), Handbook of psychiatry in palliative medicine, (pp. 63-74). Oxford University Press.

Payne, S. A. (1990). Coping with palliative chemotherapy. Journal of Advanced Nursing, 15, 652-658.

Pearson, R. W., Ross, M., & Dawes, R. M. (1992). Personal recall and the limits of retrospective questions in surveys. In J. M. Tanur (Ed.), Questions about questions (pp. 65-94). New York: Sage.

Phipps, S., & Zinn, A. B. (1986). Psychological response to amniocentesis: II. Effects of coping style. American Journal of Medical Genetics, 25, 143-148.

Pinder, K. L., Ramirez, A. J., Black, M. E., Richards, M. A., Gregory, W. M., & Rubens, R. D. (1993). Psychiatric disorder in patients with advanced breast cancer: Prevalence and associated factors. European Journal Of Cancer, 29A, 524-527.

Portenoy, R. K., Kornblith, A. B., Wong, G., Vlamis, V., McCarthy Lepore, J., Loseth, D. B., Hakes, T., Foley, K. M., & Hoskins, W. J. (1994). Pain in ovarian cancer patients. Cancer, 74(3), 907-915.

Power, D., Kelly, S., Gilseman, J., Kearney, M., O'Mahoney, D., Walsh, J. B., & Coakley, D. (1993). Suitable screening tests for cognitive impairment and depression in the terminally ill-a prospective prevalence study. Palliative Medicine, 7, 213-218.

Rando, T. A. (1984). Grief, dying, and death. Champaign, IL: Research Press Company.

Razavi, D., Delvaux, N., Farvacques, C., & Robaye, E. (1999). Screening for adjustment disorders and major depressive disorders in cancer in-patients. British Journal of Psychiatry, 156, 79-83.

Reuben, D. B., & Mor, V. (1983). Nausea and vomiting in terminal cancer patients. Archives of Internal Medicine, 146, 2021-2023.

Rousseau, P. (2000). Spirituality and the dying patient. Journal of Clinical Oncology, 18(9), 2000-2002.

Runyon, R. P., & Haber, A. (1984). Fundamentals of behavioral statistics (5<sup>th</sup> ed.). Reading, MA: Addison-Wesley.

Saunders, C. (1978). Appropriate treatment, appropriate death. In C. M. Saunders (Ed.), The management of terminal disease (pp.1-10). Chicago: Edward Arnold.

Schag, C. C., Heinrich, R. L., & Ganz, P. A. (1984). Karnofsky performance status revisited: Reliability, validity, and guidelines. Journal of Clinical Oncology, 2, 187-193.

Sears, R. S. & Stanton, A. L. (2001). Physician-Assisted dying: Review of issues and roles for health psychologists. Health Psychologist, 20(4), 301-310.

Seidman, A. D., Portenoy, R., Yao, T.-J., Lepore, J., Mont, E. K., Kortmansky, J., Onetto, N., Ren, L., Grecho, J., Beltangady, M., Usakewicz, J., Souhrada, M., Houston, C., McCabe, M., Salvaggio, R., Thaler, H., & Norton, L. (1995). Quality of life in Phase II trials: a study of methodology and predictive value in patients with advanced breast cancer treated with paclitaxel plus granulocyte colony-stimulating factor. Journal of the National Cancer Institute, 87(17), 1316-1322.

Shiloh, S., Mahlev, U., Dar, R., & Ben-Rafael, Z. (1998). Interactive effects of contraction monitor and information-seeking style on reported childbirth pain. Cognitive Therapy and Research, *22*(5), 501-516.

Silberfarb, P. M., Maurer, H., & Crouthamel, C. S. (1980). Psychosocial aspects of neoplastic disease: I. Functional status of breast cancer patients during different treatment regimens. American Journal of Psychiatry, *137*(4), 450-455.

Sparks, G. G. (1989). Understanding emotional reactions to a suspenseful movie: The interaction between forewarning and preferred coping style. Communication Monographs, *56*, 325-339.

Spiegel, D., & Bloom, J. R. (1983). Group therapy and hypnosis reduce metastatic breast carcinoma pain. Psychosomatic Medicine, *45*(4), 333-339.

Spitzer, R. L., Williams, J. B. W., Kroenke, K., Linzer, M., deGruy, F. V., Hahn, S. R., Brody, D., & Johnson, J. G. (1994). Utility of a new procedure for diagnosing mental disorders in primary care. The PRIME-MD 1000 study. JAMA, *272*(22), 1749-1756.

Stanton, A. L., & Snider, P. R. (1993). Coping with a breast cancer diagnosis, a prospective study. Health Psychology, *12*, 16-23.

Step toe, A., Sutcliffe, I., Allen, B., & Coombes, C. (1991). Satisfaction with communication, medical knowledge, and coping style in patients with metastatic cancer. Social Science and Medicine, *32*(6), 627-632.

Step toe, A. (1989). An abbreviated version of the Miller Behavioral Style Scale. British Journal of Clinical Psychology, *28*, 183-184.

Step toe, A., & O'Sullivan, J. (1986). Monitoring and blunting coping styles in women prior to surgery. British Journal of Clinical Psychology, *25*, 143-144.

Stevens, J. (1986). Applied multivariate statistics for the social sciences. Hillsdale, NJ: Erlbaum.

Stone, A. A., & Neale, J. M. (1984). New measure of daily coping: Development and preliminary results. Journal of Personality and Social Psychology, *46*(4), 892-906.

Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: A meta-analysis. Health Psychology, *4*(3), 249-288.

Tabachnick, B. G., Fidell, L. S. (1983). Using multivariate statistics. New York: Harper & Row.

Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. Journal of Personality and Social Psychology, 46(3), 489-502.

Tennen, H., Affleck, G., Armeli, S., & Carney, M. A. (2000). A daily process approach to coping. American Psychologist, 55(6), 626-636.

Thomas, C., Turner, P., & Madden, F. (1988). Coping and the outcome of stoma surgery. Journal of Psychosomatic Research, 32(4/5), 457-467.

Thompson, S. C. & Collins, M. A. (1995). Applications of perceived control to cancer: an overview of theory and measurement. Journal of Psychosocial Oncology, 13, 11-26.

Thompson, S. C., Sobolew-Shubin, A., Galbraith, M. E., Schwankovsky, L. & Cruzen, D. (1993). Maintaining perceptions of control: Finding perceived control in low-control circumstances. Journal of Personality and Social Psychology, 64(2), 293-304.

Twycross, R.G., & Lack, S. A. (1999). Therapeutics in terminal cancer (2<sup>nd</sup>. ed.). New York: Churchill Livingstone.

van der Maas, P. J., van Delden, J. J. M., Pijnenborg, L., & Looman, C. W. N. (1991). Euthanasia and other medical decisions concerning the end of life. Lancet, 338, 669-674.

Ventafridda, V., Ripamonti, C., De Conno, F., & Tamburini, M. (1990). Symptom prevalence and control during cancer patients' last days of life. Journal of Palliative Care, 6(3), 7-11.

Vitaliano, P. P., DeWolfe, D. J., Maiuro, R. D., Russo, J., & Katon, W. (1990). Appraised changeability of a stressor as a modifier of the relationship between coping and depression: A test of the hypothesis of fit. Journal of Personality and Social Psychology, 59(3), 582-592.

Waller, A., & Caroline, N. L. (1996). Palliative care in cancer. Boston: Butterworth-Heinemann.

Ward, S. E., Leventhal, H., & Love, R. (1988). Repression revisited: Tactics used in coping with a severe health threat. Personality and Social Psychology Bulletin, 14(4), 735-746.

Wardle, F., Collins, W., Pernet, A., Whitehead, M., Bourne, T., & Campbell, S. (1993). Psychological impact of screening for familial ovarian cancer. Journal of the National Cancer Institute, 85, 653-657.

Watkins, L. O., Weaver L., & Odegaard, V. (1986). Preparations for cardiac catheterization: Tailoring the content of instruction to coping style. Heart & Lung, 15(4), 382-389.

Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J. M., & Tunmore, R. (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. Psychological Medicine, 21, 51-57.

Weisman, A. D., & Worden, J. W. (1976-77). The existential plight in cancer: Significance of the first 100 days. International Journal of Psychiatry in Medicine, 7(1), 1-15.

Weisman, A. D., & Worden, J. W. (1985-86). The emotional impact of recurrent cancer. Journal of Psychosocial Oncology, 3(4), 5-16.

Wenrich, M. D., Curtis, J. R., Shannon, S. E., Carline, J. D., Ambrozy, D. M., & Ramsey, P. G. (2001). Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. Archives of Internal Medicine, 161, 868-874.

Wertlieb, D., Weigel, C., & Feldstein, M. (1987). Measuring children's coping. American Journal of Orthopsychiatry, 57(4), 548-560.

Whipp, E. (1986). Coping with radiation therapy. In B. A. Stoll (Ed.), Coping with cancer stress (pp.45-51). Hingham, MA: Kluwer Academic Publishers.

Wilson, K. G., Chochinov, H. M., de Faye, B. J. & Breitbart, W. (2000). Assessment and treatment of depression in palliative care. In H. M. Chochinov & W. Breitbart (Eds.), Handbook of psychiatry in palliative medicine, (pp. 25-49). Oxford University Press.

Wilson, K. W., Graham, I. D., Viola, R. A., Chater, S., Kozak, J. F., de Faye, B. J., Allston, J., & Weaver, L. A. (2000). Structured interview assessment of symptoms and concerns in palliative care. (Submitted to Palliative Medicine).

Wilson, K. W., Scott, J. F., Graham, I. D., Kozak, J. F., Chater, S., Viola, R. A., de Faye, B. J., Weaver, L. A., & Curran, D. (2000). Attitudes of Terminally Ill Patients Toward Euthanasia and Physician-Assisted Suicide. Archives of Internal Medicine, 160, 2454-2460.



Wilson, K. G., Stelzer, J., Bergman, J. N., Kral, M. J., Inayatullah, M., & Elliot, C. A. (1995). Problem solving, stress, and coping in adolescent suicide attempts. Suicide and Life-Threatening Behavior, 25(2), 241-252.

Wilson, K. G., Viola, R. A., Scott, J. F., & Chater, S. (1998). Talking to the terminally ill about euthanasia and physician-assisted suicide. Canadian Journal of Clinical Medicine, 68-74.

Yates, J. W., Chalmer, B., & McKegney, P. (1980). Evaluation of patients with advanced cancer using the Karnofsky Performance Status. Cancer, 45, 2220-2224.

**Appendices**

**Appendix A**

**Table A1**

**Major Stressors in the Terminally Ill**

| <b>Physical</b>       | <b>Social</b>               | <b>Psychological/Existential</b> |
|-----------------------|-----------------------------|----------------------------------|
| <b>Pain</b>           | <b>Fear of isolation</b>    | <b>Loss of dignity</b>           |
| <b>Weakness</b>       | <b>Burden to others</b>     | <b>Loss of control</b>           |
| <b>Nausea</b>         | <b>Role Loss</b>            | <b>Life satisfaction</b>         |
| <b>Drowsiness</b>     | <b>Economic concerns</b>    | <b>Fears for the future</b>      |
| <b>Breathlessness</b> | <b>Lack of information</b>  | <b>Loss of meaning/purpose</b>   |
|                       | <b>Lack of consultation</b> | <b>Loss of hope</b>              |

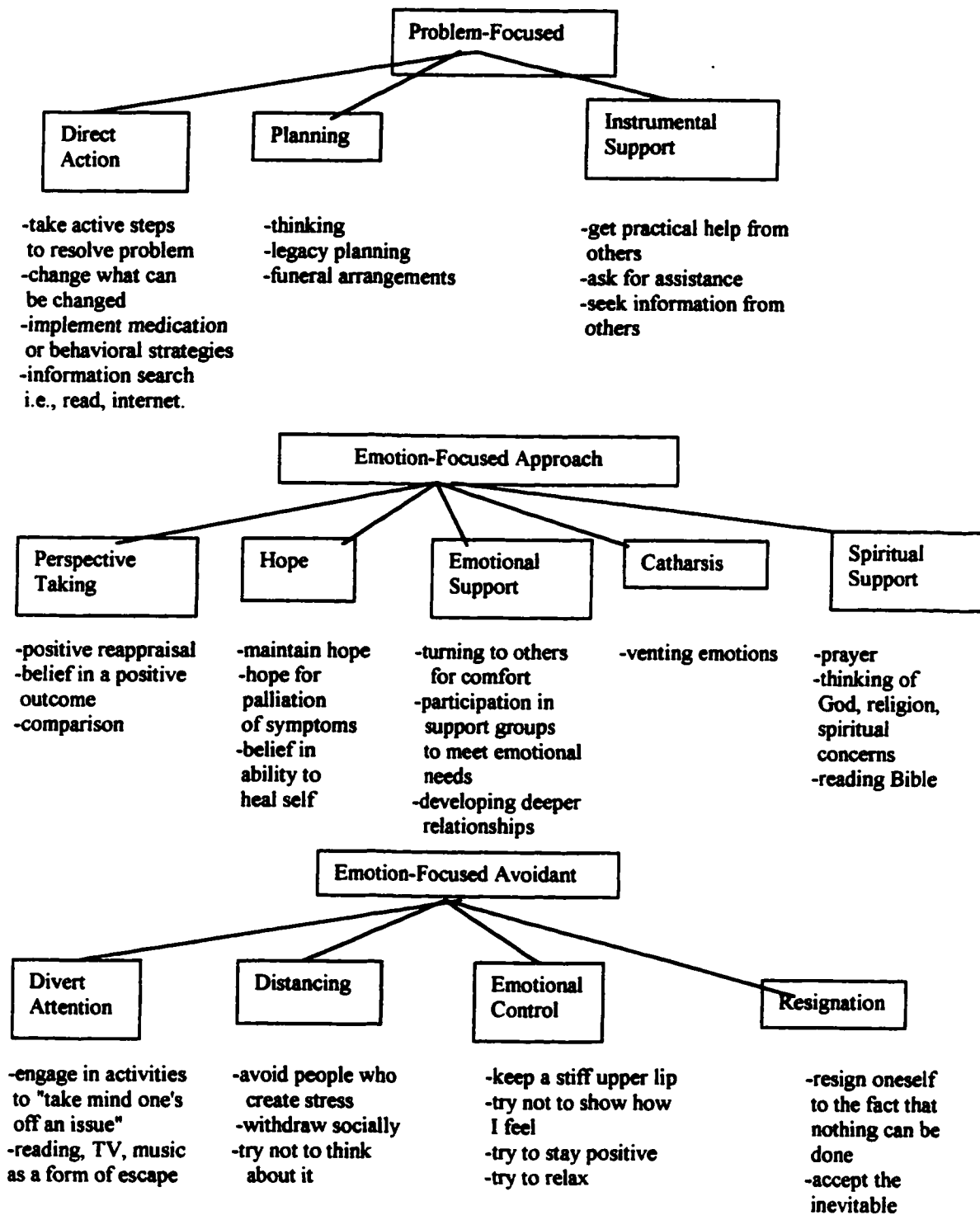
Table A2

Prevalence of Depressive Disorders in Cancer Patients

| Study                                       | Population                               | N   | Diagnosis Criteria                     | Prevalence  |
|---|--|-----|--|---|
| Alexander, Dinesh and Vidyasagar (1993)     | Inpatients                               | 60  | DSM-III-R                              | 13% (major depression)<br>2% (dysthymia)<br>17% (adjustment disorder with depression) |
| Bukberg, Penman and Holland (1984)          | Mixed inpatients                         | 62  | DSM-III (excluding somatic symptoms)   | 42% (Major depression)  |
| Chochinov et al. (1997)                     | Mixed palliative care inpatients         | 200 | RDC                                    | 8% (major depression)<br>5% (minor depression)  |
| Derogatis et al. (1983)                     | Mixed inpatients and outpatients         | 215 | DSM-III                                | 6% (major depression)<br>25% (adjustment disorder with depression)                    |
| Evans et al. (1986)                         | Gynecology inpatients                    | 83  | DSM-III                                | 23% (major depression)<br>5% (dysthymia)<br>13% (adjustment disorder with depression) |
| Golden et al. (1991)                        | Gynecology inpatients                    | 83  | DSM-III                                | 23% (major depression)  |
| Lansky et al. (1985)                        | Mixed; female inpatients and outpatients |     | DSM-III                                | 4.5% Major Depression   |
| Power et al. (1993)                         | Mixed palliative care inpatients         |     | DSM-III-R (excluding somatic symptoms) | 26% (major depression)  |
| Razavi, Delaux, Farvaques and Robaye (1990) | Mixed inpatients                         | 122 | Endicott Criteria/DSM-III              | 8% (major depression)<br>52% (any adjustment disorder)                                |

Table A3

Categorization of Coping Strategies



## Appendix B

### Table B1

#### **INFORMATION SHEET**

This research project addresses the issue of coping with a serious illness. Specifically, we are asking people to tell us how they cope with the most stressful problems associated with being ill, and whether they feel that they are able to resolve or manage these problems.

The interview will take about an hour. However, if you are too tired to talk to someone for that long, it can be split up into shorter sessions. The interview will be done in a private area on the ward or in your home. A part of the interview will be tape-recorded to ensure that your responses are accurately recorded on the questionnaire, and then the tape will be erased.

The interview will start off by asking you different questions about yourself and your background. You will then be asked about the issues/problems associated with your diagnosis that have been most stressful for you.

Next, you will be asked some questions about how you are feeling physically at the present time. For example, you will be asked about pain and other physical symptoms that you might have, and also about your emotional health. Then you will be asked about how you manage these symptoms or problems.

If you agree to take part in the study, we will also look at information in your hospital chart, and talk to the staff here who are helping to care for you. This will help us to know about your medical condition and the kind of care you have been getting.

The study involves no physical risks. However, the interview does involve talking about how you feel emotionally, and some people might find that to be stressful or upsetting. You may not benefit personally from taking part in the study, but the results may help others who have to cope with similar problems.

Your participation is completely voluntary. If you choose not to take part, the care you are getting will not be affected in any way. Also, if you find that you would like to stop the interview at any point once it has begun, or if you would prefer not to answer any particular question, please feel free to say so.

Any information you tell us will be kept confidential. Your name or other identifying information will not appear in any reports or presentations that come out of this work. We will inform your doctor and nurse here at the hospital that you have agreed to take part in the study, but only the people who are working on the research project will be able to look at the records we keep. However, it could happen that someone might tell us something during an interview that the hospital's doctors and nurses should know in order to give the best possible care. If this happens, we will talk to you about whether you would agree to let us share that information with them.

Table B2

**STATEMENT OF INFORMED CONSENT**

I have read the information sheet and I have been told about the purpose of this study. I understand that I will be taking part in an interview about one hour long. Some of the questions may be stressful or upsetting; I know that I can withdraw my consent at any time and the interview will be stopped. I also agree that the research people working on this project can look over my hospital chart and talk to the doctors and nurses on my care team.

I agree to take part in this study with the understanding that information will be collected and used for research purposes only and will be treated as confidential. I understand that I am under no obligation to participate and may withdraw at any time. I also understand that I can refuse to answer any individual question in the interview. I may choose not to participate or withdraw from the study at any time, and it will in no way affect my present and/or future treatment at the Ottawa Hospital.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Witness: \_\_\_\_\_

If you would like more information about this study, please contact:

Keith G. Wilson, Ph.D.  
Associate Professor  
Department of Medicine  
And School of Psychology  
University of Ottawa  
c/oThe Rehabilitation Centre  
505 Smyth Road  
Ottawa, Ontario  
K1H 8M2  
737 7350 (ext: 5608)

Barbara J. de Faye, M.A.  
Doctoral Student  
University of Ottawa  
(613) 562 1269

Susan Chater, MB  
Medical Director  
Palliative Care Service  
The Ottawa Hospital  
c/o Civic Site  
1053 Carling Avenue  
Ottawa, Ontario  
K1Y 4E9  
761-4555

Table B3

**COPING STUDY****NOTIFICATION OF RESEARCH PARTICIPATION**

(To be placed on participant's hospital chart)

Your patient \_\_\_\_\_ has voluntarily agreed to be a subject in a research study that examines the coping behaviours of people receiving palliative care. A major aim of this study is to determine if differences in coping styles are predictive of actual coping behaviours and variations in the experience of distress.

As part of the study protocol, your patient took part in an interview that asked them to identify the problems associated with their diagnosis that have been most stressful. Issues such as physical symptoms, personal relationships, and psychological distress were addressed.

Although the responses to the interview are confidential, we would like you to know about your patient's participation. For some people, disclosing personal information of this type may raise issues that they would like to discuss further with members of their clinical care team.

If you would like more information about this study, please contact:

Keith G. Wilson, Ph.D.  
The Rehabilitation Centre  
(613) 737 7350 (ext: 5608)

Barbara J. de Faye, M.A.  
Doctoral Student  
University of Ottawa  
(613) 562 1269



Appendix C

Table C1

**INTERVIEW PROTOCOL**

Subjects Initials: \_\_\_\_\_

ID Number: \_\_\_\_\_

Hospital Site:           1 = SCO Hospital  
                              2 = Ottawa Hospital - General Campus  
                              3 = Ottawa Hospital - Civic Campus  
                              4 = Ottawa Regional Cancer Centre - General Campus  
                              5 = Ottawa Regional Cancer Centre - Civic Campus  
                              6 = Hospice at May Court

Date of Interview:    \_\_\_\_/\_\_\_\_/\_\_\_\_  
                                  (Year)    (Month)    (Day)

Name of Interviewer: \_\_\_\_\_

Time Interview Started: \_\_\_\_\_

Time Interview Ended: \_\_\_\_\_

**DEMOGRAPHIC INFORMATION**

**GENDER**                      **MALE = 1**                      **FEMALE = 2**

**1. Date of Birth** \_\_\_\_\_ day \_\_\_\_\_ month \_\_\_\_\_ year

To begin I would like to ask you a few questions about your background.

- 2. Is English your native language?**  
(What is your native language?)
- 1 = English  
2 = French  
3 = Other (specify) \_\_\_\_\_
- 3. Were you born in Canada?**  
(What country were you born in?)
- 1 = Canada  
2 = Other (specify) \_\_\_\_\_
- 4. How far did you get through school?**
- 1 = Less than Grade 7  
2 = Junior High (Grades 7-9)  
3 = Partial High School (Grades 10-12)  
4 = High School Graduate  
5 = Partial College (at least one year)  
6 = College or University Graduate  
7 = Graduate Professional Training (Grad. Degree)
- 5. Are you married?**  
(Have you ever been married?)
- 1 = Married  
2 = Common-Law  
3 = Never Married  
4 = Widowed  
5 = Separated  
6 = Divorced
- 6. What is your religious denomination?**
- 1 = Roman Catholic  
2 = Mainstream Protestant  
3 = Fundamentalist Christian  
4 = Jewish  
5 = Moslem  
6 = None  
7 = Other (specify) \_\_\_\_\_
- 7. Before you became ill, how active were you in your church/synagogue/temple?**  
(How often did you attend service?)
- 1 = Never or almost never  
2 = Rarely (1 or 2 times a year)  
3 = Occasionally (3 to 6 times a year)  
4 = Often (6 to 12 times a year)  
5 = Frequently (more than 12 times a year)  
6 = Always or almost always

8.

**MILLER BEHAVIORAL STYLE SCALE**

Now I am going to describe a number of situations. After each situation I will read a number of statements that describe what you might do in each situation. After I read each statement, please say yes if you would do it and no if you wouldn't. Okay.....

1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do? Check **all** the statements that might apply to you.

- I would ask the dentist exactly what he was going to do.
- I would take a tranquilizer or have a drink before going.
- I would try to think about pleasant memories.
- I would want the dentist to tell me when I would feel pain.
- I would try to sleep.
- I would watch all the dentist's movements and listen for the sound of the drill.
- I would watch the flow of water from my mouth to see if it contained blood.
- I would do mental puzzles in my mind.

2. Vividly imagine that, due to large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor had turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days.

Check **all** the statements that might apply to you.

- I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.
- I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
- I would go to the movies to take my mind off things.
- I would try remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.
- I would push all thoughts of being laid off out of my mind.
- I would tell my spouse that I'd rather not discuss my chances of being laid off.
- I would try to think which employees in my department the supervisor might have thought had done a worse job.
- I would continue doing my work as if nothing special was happening.

Now I'd like to ask you some questions about your illness.

**\*Interviewer:** When specific ratings are unclear, it may be helpful to have the participant select his or

**9. What role do you prefer to play in your medical care?**

- 0 None at all;** completely passive, allow physician/medical staff to make decisions.
- 1 Be informed** but physician decides.
- 2 Decisions made jointly** by physician and self.
- 3 Have the final say.**

**Insight into Illness**

**10. What do you understand about your illness?**

**(How serious do you believe things are?)  
(What have you been told?)**

- 0 No information**
- 1 No insight;** believes illness is curable; no awareness of terminal condition.
- 2 Limited insight;** understands that illness is terminal, but has unrealistic expectations of time remaining
- 3 Good insight;** has a full understanding of the gravity of the illness and the imminence of death.

**SOCIAL CONCERNS**

**ISOLATION CONCERNS**

**11. Are you concerned that your illness is isolating/will isolate you from your family and friends?**

**(Do you worry about becoming isolated from them? Losing the closeness?)**

**(How strongly do you feel that way?)**

**(Does it come and go, or do you feel that way all the time?)**

**(How distressing is it for you?)**

**(How much does it bother you?)**

**(Are there any problems with family and/or friends that are troubling you?)**

- 0. No distress** associated with this issue.
- 1. Minimal,** e.g. occasionally feels some distress associated with isolation; but it is not regarded as a particular problem.
- 2. Mild,** e.g. often experiences low-grade distress associated with isolation; occasionally (but infrequently) feels isolated; regarded as a minor problem.
- 3. Moderate,** e.g. most of the time is distressed over this issue; often feels isolated; regarded as a significant problem.
- 4. Strong,** e.g. most of the time very distressed over this issue; frequently feels isolated; regarded as a significant, prominent and ongoing problem.
- 5. Severe,** e.g. almost all the time distress is present; almost always feels isolated; this is regarded as a troubling, serious, and ongoing problem.
- 6. Extreme,** e.g. constantly distressed over this issue; almost always feels isolated; isolation is regarded as pervasive, consuming and ongoing problem.

**Comments:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**LEVEL OF INFORMATION**

**12. Do you have any concerns about the level of information given to you concerning your illness and treatment?**

**(Are you satisfied with the amount of information you have been given?)**

**(Have you been able to get all the information you would like? Or is**

**lack of information a problem for you?)  
(If so.... how distressing is this for you?)**

**(How much does it bother you?)**

**0. No distress associated with this issue.**

**1. Minimal, e.g. occasionally feels some distress associated with this issue; but it is not regarded as a particular problem.**

**2. Mild, e.g. often experiences low-grade distress associated with this issue; may occasionally (but infrequently) be concerned about level of information; occasionally regarded as a minor problem.**

**3. Moderate, e.g. most of the time is distressed over this issue; lack of information may often be a concern; regarded as a significant problem.**

**4. Strong, e.g. is distressed most of the time over this issue; lack of information is regarded as a significant, prominent and ongoing problem.**

**5. Severe, e.g. almost all the time is distressed over the lack of information; this is regarded as a troubling, serious, and ongoing problem.**

**6. Extreme, e.g. constantly distressed over the lack of information; almost always feels the need for more information; this is regarded as a pervasive, consuming and ongoing problem.**

**DEGREE OF CONSULTATION**

**13. When decisions are made concerning your illness and treatment, do you ever feel left out of the decision making?**

**(Would you like to have the final say in how your illness is managed, or do you prefer to leave it to the experts?)**

**(Do feel that you are not consulted enough?)**

**(How strongly do you feel that way?)**

**(How distressing is this for you?)**

**(How much does it bother you?)**

**No distress associated with this issue.**

**1 Minimal, e.g. occasionally feels some distress associated with being left out of the decision making; but it is not regarded as a particular problem.**

**2 Mild, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel left out of the decision making; occasionally regarded as a minor problem.**

**3. Moderate, e.g. most of the time is distressed being left out of the decision making; this is regarded as a significant problem.**

**4. Strong, e.g. is distressed most of the time over being left out of the decision making; this is regarded as a significant, prominent and ongoing problem.**

**5. Severe, e.g. almost all the time is distressed over being left out of the decision making; this is this is regarded as a troubling, serious, and ongoing problem.**

**6. Extreme, e.g. constantly distressed over being left out of the decision making; this is regarded as a pervasive, consuming and ongoing problem.**

**ROLE LOSS**

**14. What do you see as your most important role or function?**

**(For instance, we each have a number of roles. We can be breadwinners/homemakers or husband or wife/mate. We can also be mother/father/daughter/son/friend. Which one of your roles has the most meaning for you?)**

**15. Do you have any concerns about your ability to continue to fill this role?**

**(Even though you are not feeling well, do you generally feel that you are managing to fill your role as \_\_\_\_\_?)**

**(Do you feel that your illness prevents you from filling that role?)**

**(How strongly do you feel that way?)  
(How distressing is this for you?)**

**(How much does it bother you?)**

**0. No distress** associated with this issue.

**1. Minimal**, e.g. only occasionally feels some distress associated with this issue; not regarded as a particular problem.

**2. Mild**, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel that illness prevents them from filling role; occasionally regarded as a minor problem.

**3. Moderate**, e.g. most of the time is distressed over not being able to fill role; this is regarded as a significant problem.

**4. Strong**, e.g. is distressed most of the time over not being able to fill role; this is regarded as a troubling, significant and ongoing problem.

**5. Severe**, e.g. almost all the time is distressed over not being able to fill role; this is regarded as a troubling, serious, and ongoing problem.

**6. Extreme**, e.g. constantly distressed over not being able to fill role; this is regarded as a pervasive, consuming and ongoing problem.

**16. FINANCIAL CONCERNS**

**What about economic concerns?**

**(Has your illness resulted in financial worries for you/your family?)  
your worries about money?)**

**(How strongly do you feel that way?)  
(How distressing is this for you?)**

**(How much does it bother you?)**

**0. No distress** associated with this issue.

**1. Minimal**, e.g. only occasionally feels some distress associated with financial worries; not regarded as a particular problem.

**2. Mild**, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel worried over finances; occasionally regarded as a minor problem.

**3. Moderate**, e.g. most of the time is distressed over finances; this is regarded as a significant problem.

**4. Strong**, e.g. is distressed most of the time over finances; this is regarded as a significant, prominent and ongoing problem.

**5. Severe**, e.g. almost all the time is distressed over finances; this is regarded as a troubling, serious, and ongoing problem.

**6. Extreme**, e.g. constantly distressed over finances; this is regarded as a pervasive, consuming and ongoing problem.

**17. SENSE OF BURDEN**

**With your current illness, do you feel that you have become a physical or emotional burden for your family?**

**(Do you think you make things hard for other people?)**

**(How strongly do you feel that way?)**

**(How distressing is this for you?)**

**(How much does it bother you?)**

0. **No distress** associated with this issue.
1. **Minimal**, i.e. only occasionally feels some distress associated with being a burden; not regarded as a particular problem.
2. **Mild**, e.g. sometimes experiences low-grade distress associated with being a burden; may occasionally (but infrequently) worry about being a burden; occasionally regarded as a minor problem.
3. **Moderate**, e.g. most of the time is distressed about being a burden; this is regarded as a significant problem.
4. **Strong**, e.g. is distressed most of the time over being a burden; this is regarded as a significant, prominent and ongoing problem.
5. **Severe**, e.g. almost all the time distressed about being a burden; this is regarded as a serious, and ongoing problem.
6. **Extreme**, e.g. constantly distressed about being a burden; this is regarded as a pervasive, consuming and ongoing problem.

**\*Interviewer:** If interviewee indicates more than one symptom/problem, have them identify the one that causes most distress.

**18. MOST SEVERE STRESSOR**

Okay, we just went over a number of different problems:--concerns about being isolated from others, concerns about lack of information, concerns about input into medical decisions, concerns about the ability to fulfil the important roles in your life, financial concerns, and concern about being a burden to others.

**Which one of these problems distresses/bothers you the most?** \_\_\_\_\_

**CONTROL**

**How are you managing this problem?**

- 19. How much control do you feel you have over it?**

**(Do you feel that there are things you can do to improve the situation, or that there are things you can tell yourself to make you feel better about the situation?)**

0. **No control**, e.g. "nothing I can do."
1. **Minimal**, e.g. "little I can do to alter things."
2. **Mild**, e.g. sometimes feels they can do something to improve the situation.
3. **Moderate**, e.g. often feels they can do something to improve the situation.
4. **Strong**, e.g. most of the time feels they have some control over the situation.
5. **Very strong**, e.g. sense of being in control is almost always present.
6. **Extreme**, e.g. always feels totally in control of the situation.

**COPING STRATEGIES**

20. When stressful things like \_\_\_\_\_ happen to us, we usually look for ways of handling the situation, or ways of coping.

What do you do when this problem \_\_\_\_\_ is really causing you distress, how do you handle it?

Basically, I want to know every single thing you do to cope with this problem. It can be anything you do to deal with the problem directly or something you do to deal with your feelings about the situation.

It could be things you think or tell yourself, or it could be any other kind of things that you try to do.

---

---

---

---

---

---

---

---

---

---

**\*Interviewer: if response is a form of information seeking, ask how they used the information.**

---

---

---

**(Are there any other things that you do?)**

---

---

**(Could you tell me more about that?)**

---

---



### **COPING EFFECTIVENESS**

- 21. Do you think the way you handle this situation is generally effective or do you believe that you could be handling it better?**  
**(Given the circumstances, how well do you think you're handling that problem?)**  
**(Do these coping activities help to solve the problem or make you feel better about it?)**
- 0. Not at all effective, e.g. unable to cope with the problem.**
  - 1. Minimal, e.g. most of the time thinks they are not coping well with the problem.**
  - 2. Mild, e.g. sometimes feels that they are coping well with the problem.**
  - 3. Moderate, e.g. often feels that they are coping effectively with the problem.**
  - 4. Strong, e.g. most of the time feels that they are coping effectively with the problem.**
  - 5. Very strong, e.g. sense that they are coping effectively is almost always present.**
  - 6. Extremely effective, e.g. always feels that they are coping well with the problem.**

### **PAIN AND SYMPTOM ASSESSMENT**

Now I'm going to ask you about some physical problems that you may or may not be having.

#### **22. PAIN**

**Do you have any pain?**  
**(How bad does it get?)**

**(Is it a problem for you?)**  
**(Does it interfere with activities you would like to do?)**

**(How distressing is it for you?)**  
**(How much does it bother you?)**

- 0. No distress associated with this issue.**
- 1. Minimal, e.g. only occasionally feels some distress associated with pain; does not interfere with activities; not regarded as a particular problem.**
- 2. Mild, e.g. sometimes experiences low-grade distress associated with pain; may on occasionally interfere with activities; occasionally regarded as a minor problem.**
- 3. Moderate, e.g. most of the time is distressed about pain; interferes with some activities; this is regarded as a significant problem.**
- 4. Strong, e.g. is distressed most of the time about pain; interferes with many activities; this is regarded as a significant, prominent and ongoing problem.**
- 5. Severe, e.g. almost all the time is distressed over pain; interferes with almost all activities; this regarded as a troubling, serious, and ongoing problem.**
- 6. Extreme, e.g. constantly distressed over pain; interferes with all activities; this is regarded as a pervasive, consuming and ongoing problem.**

**23. DROWSINESS****Do you feel drowsy or sleepy?****(How strong does it get?)****(Is it a problem for you?)****(Does it interfere with activities you would like to do?)****(How distressing is it for you?)****(How much does it bother you?)**

0. **No distress** associated with this issue.
1. **Minimal**, e.g. only occasionally feels some distress associated with drowsiness; does not interfere with activities; not regarded as a particular problem
2. **Mild**, e.g. sometimes experiences low-grade distress associated with drowsiness; may on occasion interfere with some activities; occasionally regarded as a minor problem.
3. **Moderate**, e.g. most of the time is distressed over drowsiness; interferes with some activities; this is regarded as a significant problem.
4. **Strong**, e.g. is distressed most of the time over drowsiness; interferes with many activities; regarded as a significant, prominent and ongoing problem.
4. **Severe**, e.g. almost all the time is distressed over drowsiness; interferes with almost all activities; this is regarded as a troubling, serious, ongoing problem.
5. **Extreme**, e.g. constantly distressed over drowsiness; interferes with all activities; this is regarded as a pervasive, consuming and ongoing problem.

**24. NAUSEA****Do you get nauseous, or feeling like you could throw up?****(Is it a problem for you?)****(How bad does it get?)****(Does it interfere with activities you would like to do?)****(How distressing is it for you?)****(How much does it bother you?)**

- 0 **No distress** associated with this issue.
1. **Minimal**, e.g. only occasionally feels some distress associated with nausea; does not interfere with activities; not regarded as a particular problem.
2. **Mild**, e.g. sometimes experiences low-grade distress associated with nausea; may on occasional interfere with some activities; occasionally regarded as a minor problem.
3. **Moderate**, e.g. most of the time is distressed over nausea; interferes with some activities; this is regarded as a significant problem.
4. **Strong**, e.g. is distressed most of the time over nausea; interferes with many activities, regarded as a significant, prominent and ongoing problem.
5. **Severe**, e.g. almost all the time is distressed over nausea; interferes with almost all activities; is regarded as a troublesome, serious, and ongoing problem.
6. **Extreme**, e.g. constantly distressed over nausea; interferes with all activities; is regarded as a pervasive, consuming and ongoing problem.

**25. WEAKNESS**

**Do you feel weak?**

**(How bad does it get?)**

**(Is it a problem for you?)**

**(How bad does it get?)**

**(Does it interfere with activities you would like to do?)**

**(How distressing is it for you?)**

**(How much does it bother you?)**

**0 No distress** associated with this issue.

- 1. Minimal**, e.g. occasionally feels some distress associated with weakness; does not interfere with activities; not regarded as a particular problem
- 2. Mild**, e.g. sometimes experiences low-grade distress associated weakness; may on occasion interfere with some activities; occasionally regarded as a minor problem.
- 3. Moderate**, e.g. most of the time is distressed over weakness; interferes with some activities; this is regarded as a significant problem.
- 4. Strong**, e.g. is distressed most of the time over weakness; interferes with many activities; this is regarded as a significant, prominent and ongoing problem.
- 5. Severe**, e.g. almost all the time is distressed over weakness; interferes with almost all activities; regarded as a troubling, serious, and ongoing problem.
- 6. Extreme**, e.g. constantly distressed over weakness; interferes with all activities; this is regarded as a pervasive, consuming and ongoing problem.

**26. BREATHLESSNESS**

**Do you feel breathless or have trouble breathing?**

**(Is it a problem for you?)**

**(How bad does it get?)**

**(Does it interfere with activities you would like to do?)**

**(How distressing is it for you?)**

**(How much does it bother you?)**

**0 No distress** associated with this issue.

- 1. Minimal**, e.g. only occasionally feels some distress associated with breathlessness; does not interfere with activities; not regarded as a particular problem.
- 2. Mild**, e.g. sometimes experiences low-grade distress associated with breathlessness; may on occasion interfere with some activities; occasionally regarded as a minor problem.
- 3. Moderate**, e.g. most of the time is distressed over breathlessness; interferes with some activities; this is regarded as a significant problem.
- 4. Strong**, e.g. is distressed most of the time over breathlessness; interferes with many activities; this is regarded as a significant, prominent and ongoing problem.
- 5. Severe**, e.g. almost all the time is distressed over breathlessness; interferes with almost all activities; regarded as a troubling, serious, and ongoing problem.
- 6. Extreme**, e.g. constantly distressed over breathlessness; interferes with all activities; this is regarded as a pervasive, consuming and ongoing problem.

**\*Interviewer:** If interviewee indicates more than one symptom/problem have them identify the one that causes most distress.

**27. MOST SEVERE STRESSOR**

Now, we've just talked about a number of different physical problems:-- pain, drowsiness, nausea, weakness, and breathlessness.

Which one of these problems/symptoms distresses/bothers you the most? \_\_\_\_\_

**CONTROL**

How are you managing this problem?

**28. How much control do you feel you have over it?**

(Do you feel that there are things you can do to improve the situation, or that there are things you can tell yourself to make you feel better about the situation?)

- 0. No control, e.g. "nothing I can do."
- 1. Minimal, e.g. "little I can do to alter things."
- 2. Mild, e.g sometimes feels they can do something to improve the situation.
- 3. Moderate, e.g. often feels they can do something to improve the situation.
- 4. Strong, e.g. most of the time feels they have some control over the situation.
- 5. Very strong, e.g. sense of being in control is almost always present.
- 6. Extreme, e.g. always feels totally in control of the situation.

**29. COPING STRATEGIES**

When this problem \_\_\_\_\_ is really causing you distress, how do you cope with it?

Again, I want to know every single thing you do to cope with this problem. It could be something you think or tell yourself, or it could be any other thing that you do to help make things easier for yourself.

---



---



---



---



---



---



---



---

**\*Interviewer:** if response is a form of information seeking, ask how they used the information.

---



---



---



---



---

**(Are there any other things that you do?)**

---



---

**(Could you tell me more about that?)**

---



---



---

### **COPING EFFECTIVENESS**

- 30. Do you think the way you handle this situation is generally effective or do you believe that you could be handling it better?  
(Given the circumstances, how well do you think you're handling that problem?)  
(Do these coping activities help to solve the problem or make you feel better about it?)**
- 0. Not at all effective, e.g. unable to cope with the problem.**
  - 1. Minimal, e.g. most of the time thinks they are not coping well with the problem.**
  - 2. Mild, e.g. sometimes feels that they are coping well with the problem.**
  - 3. Moderate, e.g. often feels that they are coping effectively with the problem.**
  - 4. Strong, e.g. most of the time feels that they are coping effectively with the problem.**
  - 5. Very strong, e.g. sense that they are coping effectively is almost always present.**
  - 6. Extremely effective, e.g. always feels that they are coping well with the problem.**

**PSYCHOLOGICAL/EXISTENTIAL CONCERNS**

Now I'd like to ask you about some other kinds of issues.

**31. SENSE OF CONTROL**

**With the problems associated with your illness, do you still basically feel that you are in control of yourself and that you can handle the situation? (Even though you are not feeling well can you still tolerate things?)**

**(Do you feel like you are managing to cope?)**

**(Do you tend to get overwhelmed to the point that you feel like you are losing control?)**

**(How distressing is it for you?)  
(How much does it bother you?)**

0. No distress associated with this issue
1. Minimal, e.g. occasionally feel some distress associated with this issue; not regarded as a particular problem.
2. Mild, e.g. often experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel that they are losing control; occasionally regarded as a minor problem.
3. Moderate, e.g. most of the time is distressed over this issue; most of the time has concerns about not being able to cope; may sometimes feel overwhelmed; this is regarded as a significant problem.
4. Strong, e.g. is distressed most of the time over this issue; most of the time feels on the edge of not being able to cope; often feels overwhelmed; this is regarded as a significant, prominent and ongoing problem.
5. Severe, e.g. almost all the time is distressed over this issue; sense of losing control is almost always present; frequently feels overwhelmed and unable to cope; this is regarded as a troubling, serious, and ongoing problem.
6. Extreme, e.g. constantly distressed over this issue; sense of being out of control is virtually constant; very frequently overwhelmed; this is regarded as a pervasive, consuming and ongoing problem.

**LIFE SATISFACTION**

- 32. When you look at your life to this stage, do you have a sense of satisfaction or fulfilment, or do you feel somewhat disappointed?**

**(Would you say that generally your life is full and satisfying?)**

**(Are you managing/have you managed to meet the goals that are important to you?)**

**(If you could go back and alter things, would make any/many changes?)**

**(If regretful..... How distressing is this for you?)  
(How much does it bother you?)**

0. No distress associated with this issue.
1. Minimal, e.g. only occasionally feel some distress associated with this issue; not regarded as a particular problem.
2. Mild, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel a sense of dissatisfaction; occasionally regarded as a minor problem.
3. Moderate, e.g. most of the time experiences distress associated with this issue; may often feel somewhat disappointed; this is regarded as a significant problem.
4. Strong, e.g. is distressed most of the time over this issue; frequently feels a sense of dissatisfaction with life; this is regarded as a significant, prominent and ongoing problem.
5. Severe, e.g. almost all the time is distressed over this issue; very frequently feels a sense of dissatisfaction; this is regarded as a troubling, serious, and ongoing problem.
6. Extreme, e.g. constantly distressed over this issue; almost always feels a sense of dissatisfaction; this is regarded as a pervasive, consuming and ongoing problem.

**HOPELESSNESS**

33. **Do you get discouraged, to the point of feeling hopeless? (Can you see your situation getting any better?)**

**(Does the future seem meaningless and without hope, or can you take things as they come?)**

**(How bad does it get?)  
(How distressing is this for you?)**

**(How much does it bother you?)**

0. **No distress** associated with this issue.
1. **Minimal**, e.g. only occasionally feel some distress associated with this issue; not regarded as a particular problem.
2. **Mild**, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel discouraged or hopeless; occasionally regarded as a minor problem.
3. **Moderate**, e.g. most of the time is distressed over this issue; may often feel discouraged or hopeless; this is regarded as a significant problem.
4. **Strong**, e.g. is distressed most of the time over this issue; frequently feels a sense of hopelessness; this is regarded as a significant and ongoing problem.
5. **Severe**, e.g. almost all the time is distressed over this issue; very frequently feels a sense of hopelessness; this is regarded as a troubling, serious, and ongoing problem.
6. **Extreme**, e.g. constantly distressed over this issue; almost always feels a sense of hopelessness; this is regarded as a pervasive, consuming and ongoing problem.

**SENSE OF DIGNITY**

34. **Do you feel that you are able to maintain your dignity and self-respect?**

**(Even though you may need help with some things, is your sense of dignity basically intact?)**

**(Do your medical problems make you feel ashamed, degraded, or embarrassed?)  
(How distressing is this for you?)**

**(How much does it bother you?)**

0. **No distress** associated with this issue.
1. **Minimal**, e.g. only occasionally feel some distress associated with this issue; not regarded as a particular problem
2. **Mild**, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel some degree of shame or degradation because of symptoms or situation; occasionally regarded as a minor problem.
3. **Moderate**, e.g. most of the time is distressed over loss of dignity; may often feel some degree of shame or degradation because of symptoms or situation; this is regarded as a significant problem.
4. **Strong**, e.g. is distressed most of the time over loss of dignity; issue; frequently feels some degree of shame or degradation because of symptoms or situation; this is regarded as a significant, prominent and ongoing problem.
5. **Severe**, e.g. almost all the time is distressed over loss of dignity; very frequently feels some degree of shame or degradation because of symptoms or situation; this is regarded as a troubling, serious, and ongoing problem.
6. **Extreme**, e.g. constantly distressed over loss of dignity; almost always feels some degree of shame or degradation because of symptoms or situation; this is regarded as a pervasive, consuming and ongoing problem.

**RELIGIOUS OR SPIRITUAL BELIEFS**

- 35. Do you consider yourself to be a religious or spiritual person?  
(Do you believe in a higher intelligence, purpose or order?)  
(Do you believe there's an underlying order in the world -  
that the world is a meaningful place?)  
(Do you feel at one with God/a higher being or  
the environment?)**

---



---



---



---

**36. COMFORT FROM BELIEFS/LOSS OF MEANING**

**Do you ever feel that life has lost it's  
meaning, or are you able to find  
meaning and comfort?**

**(Do they help you find meaning in life,  
in what is happening to you?)**

**(Do you find yourself questioning  
the purpose of life).**

**(How distressing is this for you?)**

**(How much does it bother you?)**

- 0. No distress associated with this issue.**
- 1. Minimal, e.g. only occasionally feel some distress associated with this issue; not regarded as a particular problem.**
- 2. Mild, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) feel that life has lost it's meaning; occasionally regarded as a minor problem.**
- 3. Moderate, e.g. most of the time is distressed over this issue; may often feel that life has lost it's meaning; this is regarded as a significant problem.**
- 4. Strong, e.g. most of the time is distressed over this issue; frequently feels that life has lost it's meaning; this is regarded as a significant, prominent and ongoing problem.**
- 5. Severe, e.g. almost all the time is distressed over this issue; very frequently feels that life has lost it's meaning; this is regarded as a troubling, serious, ongoing problem.**
- 6. Extreme, e.g. constantly distressed over this issue; almost always feels that life has lost it's meaning; this is regarded as a pervasive, consuming and ongoing problem.**



**WORRY AND UNCERTAINTY ABOUT THE FUTURE**

**37. When you think of the future, what is your greatest concern?**

---



---

**38. Is this something that is a source of worry and distress for you?  
(How bad does it get?)**

**(How distressing is this for you?)  
(Does it come and go?)**

**(How distressing is this for you?)**

**(How much does it bother you?)**

- 0. No distress associated with this issue.**
- 1. Minimal, e.g. only occasionally feel some distress associated with this issue; not regarded as a particular problem.**
- 2. Mild, e.g. sometimes experiences low-grade distress associated with this issue; may occasionally (but infrequently) worry about it; occasionally regarded as a minor problem.**
- 3. Moderate, e.g. most of the time is distressed over this issue; may often worry about it; this is regarded as a significant problem.**
- 4. Strong, e.g. is distressed most of the time over this issue; very frequently worries about it; regarded as a significant, prominent, and ongoing problem.**
- 5. Severe, e.g. almost all the time is distressed over this issue; very frequently worries about it; this is regarded as a troubling, serious, and ongoing problem.**
- 6. Extreme, e.g. constantly distressed over this issue; almost always worries about it; this is regarded as a pervasive, consuming and ongoing problem.**

**\*Interviewer: If interviewee indicates more than one symptom/problem, have them identify the one that causes most distress.**

**39. MOST SEVERE STRESSOR**

**We just covered a few different kinds of issues there. For example, questions to do with a sense of control, a sense of dignity, feelings of hopelessness, life satisfaction, whether you find meaning in spiritual beliefs, and whether you have any concerns about the future.**

**Which one of these problems/issues distresses/bothers you the most? \_\_\_\_\_**

**40. CONTROL**

**How are you managing this problem?  
How much control do you feel you  
have over it?**

**(Do you feel that there are things you  
can do to improve the situation, or that  
there are things you can tell yourself  
to make you feel better about the  
situation?)**

- 0. No control, e.g. "nothing I can do."
- 1. Minimal, e.g. " little I can do to alter things."
- 2. Mild, e.g. sometimes feels they can do something to improve the situation.
- 3. Moderate, e.g. often feels they can do something to improve the situation.
- 4. Strong, e.g. most of the time feels they have some control over the situation.
- 5. Very strong, e.g. sense of being in control is almost always present.
- 6. Extreme, e.g. always feels totally in control of the situation.

**COPING STRATEGIES**

**41. How do you cope with this particular issue \_\_\_\_\_.  
Again, I'd like to know every single thing you do to manage the stress associated with this concern. What you think or tell yourself, or anything else you might do when this issue is really causing you distress**

---



---



---



---



---



---



---



---

**\*Interviewer: if response is a form of information seeking,  
ask how they used the information.**

---



---

**(Are there any other things that you do?)**

---



---

**(Could you tell me more about that?)**

---



---

**COPING EFFECTIVENESS**

- 42. Do you think the way you handle this situation is generally effective or do you believe that you could be handling it better?**

**(Given the circumstances, how well do you think you're handling that problem?)**

**(Do these coping activities help to solve the problem or make you feel better about it?)**

- 0. Not at all effective, e.g. unable to cope with the problem.**
- 1. Minimal, e.g. most of the time thinks they are not coping well with the problem.**
- 2. Mild, e.g. sometimes feels that they are coping well with the problem.**
- 3. Moderate, e.g. often feels that they are coping effectively with the problem.**
- 4. Strong, e.g. most of the time feels that they are coping effectively with the problem.**
- 5. Very strong, e.g. sense that they are coping effectively is almost always present.**
- 6. Extremely effective, e.g. always feels that they are coping well with the problem.**

**PRIME - MD ASSESSMENT OF ANXIETY AND DEPRESSION**

Now I am going to ask you some questions about your emotional health.

**PANIC DISORDER**

43. In the past month, have you ever had an anxiety attack where you had a sudden feeling of fear or panic?  
(What was that like?)
- 1 = YES  
2 = NO → Go to Generalised Anxiety Disorder
44. Has this ever happened before?
- 1 = YES  
2 = NO → Go to Generalised Anxiety Disorder
45. Does the attack sometimes come suddenly out of the blue, for no apparent reason?  
(Even in situations where you don't expect to be nervous or uncomfortable?)
- 1 = YES 2 = NO

**\*\*INTERVIEWER:** Establish that an attack is experienced as a sudden onset of panic rather than a state of heightened fear or anxiety because of intense medical symptoms.

- 46.
- 1 = Probably medical  
2 = Probably psychological
47. Have you worried a lot about having another attack?                      1 = YES 2 = NO
48. Think about your last really bad attack.

**\*Interviewer:** once 4 of the following symptoms have been coded YES go to GENERALISED ANXIETY DISORDER

- |   |                |
|---|----------------|
| a) Were you short of breath?  | 1 = YES 2 = NO |
| b) Did you heart race, skip or pound?   | 1 = YES 2 = NO |
| c) Did you have chest pain or pressure?   | 1 = YES 2 = NO |
| d) Did you sweat?   | 1 = YES 2 = NO |
| e) Did you feel as if you were choking?   | 1 = YES 2 = NO |
| f) Did you have hot flashes or chills?  | 1 = YES 2 = NO |
| g) Did you have nausea or an upset stomach,<br>or feel like you were going to have diarrhoea? | 1 = YES 2 = NO |
| h) Did you feel dizzy, unsteady or faint?   | 1 = YES 2 = NO |
| i) Did you have tingling or numbness in   |                |

- parts of your body?  
 j) Did you tremble or shake?  
 k) Were you afraid you were dying?

1 = YES 2 = NO  
 1 = YES 2 = NO  
 1 = YES 2 = NO

### **GENERALIZED ANXIETY DISORDER**

#### **49. ANXIETY**

**Have you been feeling nervous, anxious, or on edge?**  
**(How bad does it get?)**  
**(Does it come and go?)**  
**(Do you feel that way most of the time?)**  
**(Is it a problem for you?)**

#### **0. No anxiety**

- 1. Slight**, e.g. occasional but infrequent feelings of anxiety at a low level; not regarded as a particular problem.
- 2. Mild**, e.g. sometimes experiences periods of anxiety, but not excessively and not most of the time; occasionally regarded as a minor problem.
- 3. Moderate**, most of the time feels nervous or anxious; generally regarded as a significant problem.
- 4. Strong**, e.g. most of the time feels very anxious; anxiety is regarded as a significant, prominent and ongoing problem.
- 5. Severe**, e.g. almost all of the time feels intense anxiety; regarded as a troubling, serious, and ongoing problem.
- 6. Extreme**, e.g. constant, unrelieved feelings of severe anxiety, regarded as a pervasive, consuming and constant problem.

**If ≥ 3:**

- 50. Do you feel this way every day, or nearly every day? (On more than half the days in the past month?)**

1 = YES      2 = NO

- 51. Does it come and go with your physical symptoms or do you feel nervous even when your other problems are not so bad?**

1 = Probably medical  
 2 = Probably psychological

**\*\*INTERVIEWER: Establish that anxiety is not tied entirely to pain, breathlessness or other medical symptoms.**

**If item # 49 is <3 then go to MAJOR DEPRESSION**

**52. In the last month, have you been bothered by any of these problems nearly every day?**

**\*Interviewer: Once 3 of the following symptoms have been coded YES go to Item # 53.**

- |   |         |        |
|---|---------|--------|
| a) Feeling restless so that it is hard to sit still?                                    | 1 = YES | 2 = NO |
| b) Getting tired very easily?   | 1 = YES | 2 = NO |
| c) Muscle tension, aches, or soreness?  | 1 = YES | 2 = NO |
| d) Trouble falling asleep or staying asleep?  | 1 = YES | 2 = NO |
| e) Trouble concentrating on things such as<br>ward activities, reading, or watching TV? | 1 = YES | 2 = NO |
| f) Becoming easily annoyed or irritated?  | 1 = YES | 2 = NO |

**\* Interviewer: If fewer than 3 are checked then go to MAJOR DEPRESSION**

**53. In the past month, has your anxiety made it hard for you to be with people, take care of things you wanted to do, or get along with people?** 1 = YES 2 = NO → Go to MAJOR DEPRESSION

**54. In the last six months, have you been worrying a great deal about different things? (What kind of things have you been worrying you?)** 1 = YES 2 = NO → Go to MAJOR DEPRESSION

**\*Interviewer: Code as YES only if also YES to : "Has this been on more than half the days in the last six months?"**

**55. When you are worrying this way do you find that you cannot stop?** 1 = YES 2 = NO

**MAJOR DEPRESSION****DEPRESSION**

**Have you been feeling "down" or depressed?**

**(How bad does it get?)**

**(Does it come and go?)**

**(Do you feel that way most of the time?)**

**(Is it a problem for you?)**

**0 No depression.**

**1 Slight, e.g. occasional but infrequent feelings of depression at a low level, not regarded as a particular problem.**

**2 Mild, e.g. sometimes experiences periods of depression, but not excessively and not most of the time; occasionally regarded as a minor problem.**

**3 Moderate, e.g. most of the time feels depressed; generally regarded as a significant problem.**

**4 Strong, e.g. most of the time feels very depressed; depression is regarded as a significant, prominent and ongoing problem.**

**5 Severe, e.g. almost all of the time feels deeply depressed, depression is regarded as a troubling, serious and ongoing problem.**

**6 Extreme, e.g. constant unrelieved feelings of severe depression; regarded as a pervasive, consuming and constant problem.**

**If  $\geq 2$**

**57. Do you feel this way every day, or nearly every day?**

Nearly Every Day

1 = YES

2 = NO

**58. How long have you felt this way? (For more than two weeks?)**

Duration  $\geq 2$  weeks

1 = YES

2 = NO

**59. LOSS OF INTEREST OR PLEASURE**

**Do you find that you have little interest or pleasure in doing things?**

**(How bad does it get?)**

**(Does it come and go?)**

**(Have you lost interest in almost all activities, or only a few?)**

**(Is it a problem for you?)**

**(I'm not thinking so much about your ability to do things as about your interest in them.)**

**(Even activities that don't require much physical effort, like enjoying your family, friends, reading, or watching T.V.?)**

**0 No Loss of Interest or Pleasure.**

**1 Slight, e.g. occasional but infrequent loss of interest or pleasure at a low level; not regarded as a particular problem.**

**2 Mild, e.g. sometimes experiences a loss of interest or pleasure in some activities but retains interest in others, occasionally regarded as a minor problem.**

**3 Moderate, e.g. most of the time feels a loss of interest or pleasure in most activities; generally regarded as a significant problem.**

**4 Strong, e.g. most of the time feels a markedly diminished interest or pleasure in almost all activities; regarded as a significant, prominent and ongoing problem.**

**5 Severe, e.g. almost all of the time feels no interest or pleasure in any activities; regarded as a troubling, serious and ongoing problem.**

**6 Extreme, e.g. complete inability to experience any interest or pleasure in any activities e.g. virtually all the time; regarded as a pervasive, consuming and constant problem.**

**If  $\geq 3$**

**60. Do you feel this way every day or nearly every day?**

Nearly Every Day

1 = YES

2 = NO

**61. How long have you felt this way? (For more than a couple of weeks?)**

Duration  $\geq 2$  weeks

1 = YES

2 = NO

**62. Do these problems of feeling depressed, or having no interest in things come and go with your physical symptoms, or do you feel that way even when your other problems are not so bad?**

1 = PROBABLY MEDICAL  
2 = PROBABLY PSYCHOLOGICAL

**\*Interviewer: If Item # 56 is scored  $\geq 2$  or Item # 59  $\geq 3$  then continue with Item # 63. Otherwise go to Item # 64.**

**\*Interviewer: Give credit without asking for symptoms already acknowledged in the Generalised Anxiety Module**

**63. For the last two weeks, have you had any of the following problems nearly every day?**

- |   |         |        |
|---|---------|--------|
| a) Trouble falling or staying asleep, or sleeping too much?   | 1 = YES | 2 = NO |
| b) Feeling tired or having little energy?   | 1 = YES | 2 = NO |
| c) Poor appetite or overeating?   | 1 = YES | 2 = NO |
| d) Feeling bad about yourself – or that you are a failure or have let yourself or your family down? | 1 = YES | 2 = NO |
| e) Trouble concentrating on things, such as reading the newspaper or watching television?           | 1 = YES | 2 = NO |
| f) Being so fidgety or restless that you were moving around a lot more than usual?                  | 1 = YES | 2 = NO |

**\* If no: What about the opposite – moving or speaking so slowly that other people could have noticed.**

**\*Interviewer: Code as YES if YES to either question or if psychomotor agitation or retardation is observed during interview**

**g) In the last 2 weeks, have you had thoughts that you would be better off dead, or of hurting yourself in some way?**      1 = YES      2 = NO

**\*\*Interviewer: If YES, ask "Tell me about it."**

**Comments:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



**\*Interviewer:** If criteria are already met for MAJOR DEPRESSION, then go to DYSTHYMIA (item # 65)

**MAJOR DEPRESSION IN PARTIAL REMISSION**

64. Have you recently had a time when you were either much more down or depressed or had even less interest or pleasure in doing things? 1 = YES      2 = NO

**IF YES:** At that time, did you have many of the problems that I just asked you about, like trouble sleeping, concentrating, feeling tired, poor appetite, little interest in things? (When was that? How long did it last?)

Comments: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**\*Interviewer:** Code as YES only if, in the recent past, subject probably had five criterion symptoms and acknowledges some current depressed mood or little interest or pleasure.

**DYSTHYMIA**

65. Over the last two years, have you often felt down or depressed or had little interest or pleasure in doing things? 1 = YES      2 = NO → Debrief  
 (Have you felt depressed more days than not?)

66. In the last two years, has that often made it hard for you to be with people, take care of things you wanted to do, or get along with people? 1 = YES      2 = NO

67. BECK Depression Inventory (over page).

**\*Interviewer:** End interview and debrief.

67.

**BECK DEPRESSION INVENTORY for PRIMARY CARE - (BDI-PC)**

On the questionnaire are a group of statements. Read the entire group of statements in each category. Then pick out the one statement in that group which best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have chosen.

- A. Sadness**  
 0 I do not feel sad.  
 1 I feel sad much of the time.  
 2 I am sad all the time.  
 3 I am so sad or unhappy that I can't stand it.
- B. Pessimism**  
 0 I am not discouraged about my future.  
 1 I feel more discouraged about my future than I used to be.  
 2 I do not expect things to work out for me.  
 3 I feel my future is hopeless and will only get worse.
- C. Past Failure**  
 0 I do not feel like a failure.  
 1 I have failed more than I should have.  
 2 As I look back, I see a lot of failures.  
 3 I feel I am a total failure as a person.
- D. Loss of Pleasure**  
 0 I get as much pleasure as I ever did from the things I enjoy.  
 1 I don't enjoy things as much as I used to.  
 2 I get very little pleasure from the things I used to enjoy.  
 3 I can't get any pleasure from the things I used to enjoy.
- E. Self-dislike)**  
 0 I feel the same about myself as ever.  
 1 I have lost confidence in myself.  
 2 I am disappointed in myself.  
 3 I dislike myself.
- F. Self-Criticalness**  
 0 I don't criticise or blame myself more than usual.  
 1 I am more critical of myself than I used to be.  
 2 I criticise myself for all of my faults.  
 3 I blame myself for everything bad that happens.
- G. Suicidal Thoughts or Wishes**  
 0 I don't have any thoughts of killing myself.  
 1 I have thoughts of killing myself, but I would not carry them out.  
 2 I would like to kill myself.  
 3 I would kill myself if I had the chance.

**DEBRIEFING FORM**

1. Did you find that answering these questions was stressful or upsetting?  
(How upsetting was it?)
- 0 = Not at all upsetting  
1 = Mildly upsetting  
2 = Moderately upsetting  
3 = Very upsetting
2. Were the questions difficult to understand?  
(How difficult were they?)  
(Were they clear?)
- 0 = Not at all difficult  
1 = Mildly difficult  
2 = Moderately difficult  
3 = Very difficult

**\*INTERVIEWER**  
Did any concerns arise that should be disclosed to the clinical staff?

1 = YES 2 = NO

**If YES specify:**

---

---

---

---

---

---

---

---

---

---

**CHART REVIEW**

**Date of Hospital Admission:**  
(inpatient)

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
(day) (month) (year)

**Primary Tumour Site:**

- |                   |                      |
|-------------------|----------------------|
| 1 = Lung          | 7 = Urinary Tract    |
| 2 = Bowel         | 8 = Head & Neck      |
| 3 = Other G.I.    | 9 = Hematological    |
| 4 = gynecological | 10 = Other (Specify) |
| 5 = Breast        |                      |
| 6 = Prostate      | 11 = Unknown Primary |

**DNR indicated on chart**

- 1 = YES  
2 = NO

**Karnofsky Functional Performance Status Scale: Percentage** \_\_\_\_\_

|   |             |   |
|---|-------------|---|
| <b>ABLE TO CARRY ON NORMALLY<br/>NO SPECIAL CARE IS NEEDED</b>  | <b>100%</b> | <b>Normal, no complaints; no evidence of disease.</b>                                       |
|   | <b>90%</b>  | <b>Able to carry on normal activity, minor signs or symptoms of disease.</b>                |
|   | <b>80%</b>  | <b>Normal activity with effort, some signs or symptoms of disease.</b>                      |
| <b>UNABLE TO WORK; ABLE TO LIVE<br/>AT HOME; CARES FOR MOST<br/>PERSONAL NEEDS</b>  | <b>70%</b>  | <b>Cares for self; unable to carry on normal activities or do active work.</b>              |
|   | <b>60%</b>  | <b>Requires additional assistance but he/she is able to care for most of his/her needs.</b> |
| <b>VARYING AMOUNT OF<br/>ASSISTANCE IS NEEDED</b>   | <b>50%</b>  | <b>Requires considerable assistance and frequent medical care.</b>                          |
| <b>UNABLE TO CARE FOR SELF;<br/>REQUIRES EQUIVALENT OF<br/>INSTITUTIONAL OR HOSPITAL<br/>CARE<br/>DISEASE PROGRESSING<br/>RAPIDLY</b> | <b>40%</b>  | <b>Disabled; requires special care and assistance.</b>                                      |
|   | <b>30%</b>  | <b>Severely disabled; hospitalisation is indicated; death not imminent.</b>                 |
|   | <b>20%</b>  | <b>Very sick; hospitalisation necessary.</b>  |
|   | <b>10%</b>  | <b>Moribund; fatal process progressing rapidly.</b>   |
|   | <b>0%</b>   | <b>Dead.</b>  |

**Opioid Medication**

| <b>Medication</b> | <b>Daily Dose (mg/day)</b> | <b>Route (oral, IM, IV)</b> | <b>Morphine equivalent</b> |
|-------------------|----------------------------|-----------------------------|----------------------------|
| 1.                |                            |                             |                            |
| 2.                |                            |                             |                            |
| 3.                |                            |                             |                            |
| 4.                |                            |                             |                            |
| 5.                |                            |                             |                            |
| 6.                |                            |                             |                            |
| 7.                |                            |                             |                            |

**Other Medications**

| <b>Medication</b> | <b>Daily Dose (mg/day)</b> | <b>Comment (Problem)</b> |
|-------------------|----------------------------|--------------------------|
| 1.                | _____                      |                          |
| 2.                | _____                      |                          |
| 3.                | _____                      |                          |
| 4.                | _____                      |                          |
| 5.                | _____                      |                          |
| 6.                | _____                      |                          |
| 7.                | _____                      |                          |

Table C2

Diagnostic Criteria for PRIME-MD/DSM IV Depressive Disorders

| Diagnosis   | PRIME-MD/DSM IV Criteria  | Interview Operational Criteria   |
|---|---|--|
| 1. Panic Attacks  | <p>A. Recurrent unexpected panic attacks</p> <p>B. Not caused by a general medical condition</p> <p>C. No persistent worry about further attacks</p> <p>D. 4 criterion symptoms of panic</p>  | <p>A. Item # 43, 44, 45 = YES</p> <p>B. Item # 46 = probably psychological</p> <p>C. Item # 47 = NO</p> <p>C. 4 symptoms from Item # 48 coded YES</p>  |
| 2. Panic Attacks (Probably due to general medical condition)  | <p>A. Recurrent unexpected panic attacks</p> <p>B. Panic attacks judged to be a direct physiological consequence of a general medical condition</p> <p>C. No persistent worry about further attacks</p> <p>D. 4 criterion symptoms of panic</p> | <p>A. Item # 43, 44, 45 = YES</p> <p>B. Item # 46 = probably medical or chart review/staff discussion shows clear evidence of hyperthyroidism, hyperparathyroidism, pheochromocytoma, vestibular dysfunction, seizure disorders, or poorly controlled cardiac arrhythmia</p> <p>C. Item # 47 = NO</p> <p>D. 4 symptoms from Item # 48 coded YES</p>  |
| 3. Panic Disorder   | <p>A. Recurrent unexpected panic Attacks</p> <p>B. Not caused by a general medical condition</p> <p>C. Persistent worry about further Attacks</p> <p>D. 4 criterion symptoms of panic</p>   | <p>A. Item # 43, 44, 45 = YES</p> <p>E. Item # 46 = probably psychological</p> <p>F. Item # 47 = YES</p> <p>E. 4 symptoms from Item # 48 coded YES</p>   |
| 2. Panic Disorder (Probably due to general medical condition) | <p>A. Recurrent unexpected panic attacks</p> <p>B. Panic attacks judged to be a direct physiological consequence of a general medical condition</p> <p>C. Persistent worry about further attacks</p> <p>D. 4 criterion symptoms of panic</p>    | <p>A. Item # 43, 44, 45 = YES</p> <p>B. Item # 46 = probably medical or chart review/staff discussion shows clear evidence of hyperthyroidism, hyperparathyroidism, pheochromocytoma, vestibular dysfunction, seizure disorders, or poorly controlled cardiac arrhythmia</p> <p>C. Item # 47 = YES</p> <p>D. 4 symptoms from Item # 48 coded YES</p> |

| Diagnosis  | PRIME-MD/DSM IV Criteria  | Interview Operational Criteria  |
|--|---|---|
| 3. Generalized Anxiety Disorder                                      | <p>A. Excessive anxiety and worry more days than not</p> <p>B. Not caused by a general medical condition</p> <p>C. 3 criterion symptoms</p> <p>D. Clinically significant distress or impairment</p> <p>E. Worry about a number of events for at least 6 months</p> <p>F. Difficulty controlling worry</p> | <p>A. Item # 49 <math>\geq</math> 3</p> <p>B. Item # 51 = probably psychological</p> <p>C. 3 symptoms from item # 52</p> <p>D. Item # 53 = YES</p> <p>E. Item # 54 = YES</p> <p>F. Item # 55 = YES</p>  |
| 6. Generalized Anxiety (Probably due to a general medical condition) | <p>A. Same criteria as for Generalized Anxiety Disorder, except anxiety is judged to be a direct physiological consequence of a general medical condition</p>   | <p>A. Same criteria as for Generalized Anxiety Disorder, except Item # 51 = probably medical or chart review/staff discussion shows condition clear evidence of a relevant medical condition</p>  |
| 7. Anxiety Disorder Not elsewhere specified (NOS)                    | <p>A. With limited symptom panic Attack</p> <p>B. With generalized anxiety</p>  | <p>A. Items # 43, 44, 45, 47 = YES<br/>Item #51 = probably psychological<br/>Fewer than 4 symptoms from Item #52 coded YES</p> <p>B. Item #49 <math>\geq</math> 3<br/>Item #51 = probably psychological<br/>Item #53 = YES<br/>Item #54 or 55 = NO</p>  |
| 8. Anxiety Disorder NOS (Probably due to general medical condition)  | <p>A. With limited symptom panic attacks judged to be a direct physiological consequence of a general medical condition</p> <p>B. With generalized anxiety</p>  | <p>A. Same criteria as for 7 (A) except Item #51 = probably medical or chart review/staff discussion shows clear evidence of relevant medical condition</p> <p>B. Same criteria as for 7 (B) except Item #51 = probably medical or chart review/staff discussion shows clear evidence of relevant medical condition</p> |

| Diagnosis  | PRIME-MD/DSM IV Criteria   | Interview Operational Criteria  |
|--|--|---|
| 9. Major Depression  | <p>A. Depressed mood or loss of interest/pleasure in all or almost all activities</p> <p>B. Duration most of the day, nearly every day, for at least two weeks</p> <p>C. 4 additional criterion symptoms</p>   | <p>C. Item # 56 <math>\geq</math> 3 or Item # 59 <math>\geq</math> 4</p> <p>B. Qualifiers for Item # 56 or Item # 59 both coded YES (#57, 58 or 60, 61 = YES)</p> <p>C. 4 symptoms from Item # 63 coded YES.</p>            |
| 10. Major Depression in Partial Remission                        | <p>A. Falls short of meeting severity threshold criteria for current major depression</p> <p>B. Recent history of more severe depression with many associated symptoms.</p>  | <p>A. Item # 56 = 2 or Item # 59 = 3</p> <p>B. Item # 64 = YES</p>  |
| 11. Dysthymia  | <p>A. At least a 2 year history of depressed mood more days than not.</p> <p>B. Clinically significant distress or impairment</p>  | <p>A. Item # 65 = YES</p> <p>B. Item # 66 = YES</p>   |
| 12. Minor Depression   | <p>A. Depressed mood or loss of interest/pleasure in all or almost all activities</p> <p>B. Duration most of the day, nearly every day, for at least 2 weeks</p> <p>C. Only 2 or 3 additional criterion symptoms</p>   | <p>A. Item # 56 <math>\geq</math> 3 or Item # 59 <math>\geq</math> 4</p> <p>B. Qualifiers for Item # 56 or Item # 59 both coded YES (#57, 58 or 60, 61 = YES)</p> <p>C. 2 or 3 symptoms from Item # 63 coded YES</p>        |
| 13. Mood Disorder due to general medical condition or medication | <p>A. Technically, any mood disorder in patients with advanced cancer may due to the general medical condition. For our purposes, code only if diagnostic criteria are met for one of the above mood disorders <u>and</u> the disturbance in mood is judged to be caused by the direct physiological effects of general medical condition.</p> | <p>A. Chart review/staff discussion gives clear evidence that the mood disturbance is probably due to a concurrent medical problem (e.g., stroke, hypothyroidism, Cushing's syndrome, brain metastases, severe anemia).</p> |



Table C 3

**DIAGNOSTIC SCORING CHECKLIST****Anxiety Disorders**

- |   |                |
|---|----------------|
| 1. Panic Attacks (do not code if criteria are met for Panic Disorder)   | 1 = YES 2 = NO |
| 4. Panic Attacks due to medical condition (do not code if criteria are met for Panic Disorder due to medical condition) | 1 = YES 2 = NO |
| 3. Panic Disorder   | 1 = YES 2 = NO |
| 4. Panic Disorder due to medical condition  | 1 = YES 2 = NO |
| 5. Generalized Anxiety Disorder   | 1 = YES 2 = NO |
| 6. Generalized Anxiety due to medical condition   | 1 = YES 2 = NO |
| 7. Anxiety Disorder NOS with limited symptom panic attacks  | 1 = YES 2 = NO |
| 8. Anxiety Disorder NOS with generalized anxiety  | 1 = YES 2 = NO |
| 9. Anxiety Disorder NOS with limited symptom panic attacks, due to medical condition                                    | 1 = YES 2 = NO |
| 10. Anxiety Disorder NOS with generalized anxiety, due to medical condition   | 1 = YES 2 = NO |
| 11. No anxiety disorder   | 1 = YES 2 = NO |

**Depressive disorders**

- |   |                |
|---|----------------|
| 1. Depressive disorder due to a general medical condition (if coded YES, all other depressive disorders should be coded NO) | 1 = YES 2 = NO |
| 2. Major Depression   | 1 = YES 2 = NO |
| 5. Major Depression in Partial Remission (do not code if criteria are met for Major Depression)                             | 1 = YES 2 = NO |
| 4. Dysthymia  | 1 = YES 2 = NO |
| 5. Minor Depression (do not code if criteria are met for Major Depression or Major Depression in Partial Remission)         | 1 = YES 2 = NO |
| 6. No depressive disorder   | 1 = YES 2 = NO |

Table C4

## Power

| Range                | Value of ES | Midpoint |
|----------------------|-------------|----------|
| "Small" (lower 33%)  | .00 to .32  | .15      |
| Medium" (middle 34%) | .33 to .55  | .45      |
| "Large" (upper 33%)  | .56 to 1.20 | .90      |

Note. Effect size ranges taken from Design sensitivity: statistical power for experimental research (p. 56), by M. W. Lipsey, 1990, London: Sage

## Appendix D

Table D1

Categorization of Coping Strategies-Cheng, Hui & Lam (2000)

| Strategy           | Definition   |
|--------------------|--|
| Divert Attention   | Thinking about or doing something to divert your attention from the stressful situation. |
| Perspective taking | Viewing the stressful situation from a new perspective.                                  |
| Direct Action      | Actually doing something to manage the stressful situation.                              |
| Catharsis          | Venting your emotions aroused from the stressful situation.                              |
| Acceptance         | Accepting that there is nothing you can do to handle the stressful situation.            |
| Social support     | Seeking support from loved ones, friends, or professionals.                              |
| Relaxation         | Doing something to relax.  |
| Spiritual support  | Seeking support or comfort by spiritual means.   |
| Escape             | Leaving the stressful situation.   |