# Chapter 2
# RELATIONSHIPS BETWEEN PAIN, OTHER SYMPTOMS, PSYCHOLOGICAL FACTORS AND ADJUSTMENT

## Overview.

This chapter reports an empirical study that examined the experience of pain in cancer patients receiving palliative care. There were two main aims. The first was to explore the influence of psychological factors on patients' adjustment. The second was to explore the possible moderation of the relationship between pain characteristics and patients' adjustment by psychological factors. This chapter examined these relationships in the context of the cumulative burden of other potentially distressing symptoms (e.g., dyspnoea, nausea, dry mouth, constipation, fever, dizziness). The stability of the relationships between pain characteristics, other physical symptoms, psychological factors and adjustment were also examined longitudinally.

The present study used a large archival dataset to explore these relationships. Although the data set was old, it was selected for two reasons. First, it is one of the few existing data sets sufficiently large to allow the examination of the relationships of interest. Second, although the prevalence of pain and other symptoms are likely to change with medical innovations and changes in access to treatments, there is little evidence to suggest that the predictors of adjustment also change (Derogatis, Morrow & Fetting, 1983; De Wit, van Dam, Litjens & Abu-Saad, 2001; Hoskins, Perez, Young, Barakat, Markman & Randall, 2005; Lawlor, 2003; Portenoy, Payne & Jacobsen, 1999).

Most research about cancer patients with pain report pain prevalence. The present study also reports prevalence of pain, but this is done in the context of describing the sample, rather than in attempting to estimate pain prevalence in the population. In addition, this research does not attempt to compare pain prevalence in this sample with that reported in other research. This was not feasible because only patients who suited narrow selection criteria were included in the current sample.

The proposed relationships between pain, other physical symptoms, psychological factors and adjustment draws upon a long history of psychological theories in which psychological factors intervene between stressors and outcomes pertaining to pain, coping and quality of life (Brennan, 2001; Folkman, 1997; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984). Figure 2.1 illustrates the expected relationship between pain variables, other symptoms, psychological variables and two dimensions of adjustment (level of coping and quality of life). Pain experienced by the patient, other symptoms and psychological variables are expected to directly influence adjustment. In addition, the relationship between adjustment, pain and other symptoms is expected to be moderated by psychological variables. That is, it is predicted that psychological factors may either strengthen or weaken the relationship between pain, other symptoms and adjustment.

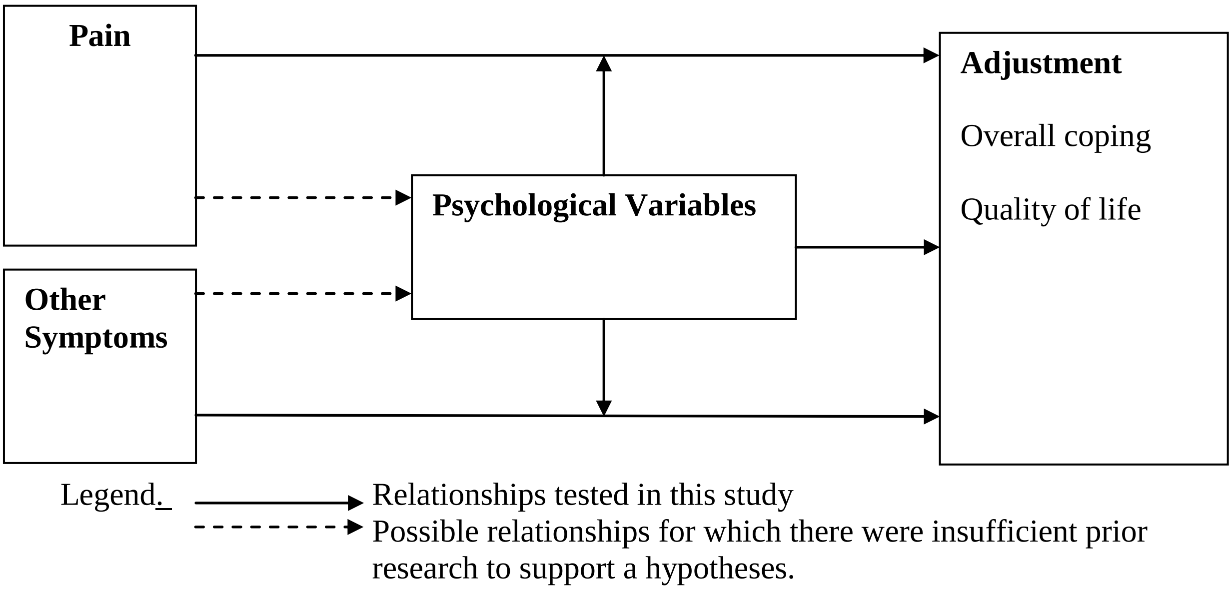

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*Figure 2.1.* The expected relationship between pain, other symptoms, psychological variables and adjustment.

A brief overview of the relevant psychological theories of pain and adjustment that form the basis of this model were summarised in the introductory chapter of this thesis. What follows is a summary of the literature that provides the background to the present study.

## Prevalence of Pain

Although pain prevalence was not the focus of the present study, it was necessary to explore the prevalence of pain in this sample in order to contextualise relationships that may be found between predictors and adjustment. Pain is highly prevalent among cancer patients (Bhatnagar, Upadhyay & Mishra, 2010; Breivik, Cherny, de Conno, Filbert, Foubert, Cohen et al., 2009; Caraceni & Portenoy, 1999; van den Beuken-van Everdingen, de Rijke, Kessels, Schouten, et al., 2007). It is also one of the most serious and feared symptoms experienced by patients receiving palliative care. Even when persistent background pain is adequately controlled, patients may experience transitory exacerbations of pain, which are termed “breakthrough pain”.

Some patients are more likely to experiences pain than others. Relevant factors include disease spread, stage of disease and primary site of cancer. Patients with metastatic disease (when a cancer spreads from its original site to another area of the body) have an elevated presence of cancer pain (e.g., Caracini et al., 1999; Rustoen, Moum, Padilla, & Miaskowski, 2005; Fine, 2008). The prevalence of pain among patients with advanced disease is higher (70-90%) compared to patients with early stage disease (30-40%) (Foley, 2004). Patients with cancers of the bone, pancreas, brain, lymphatic system, lung, head and neck report the most pain, whereas patients with leukaemia and prostate cancers are the least likely to experience pain (Brevik et al., 2009). The present study focuses on patients with advanced disease and includes patients with and without metastatic disease and with cancer with a heterogenous range of primary sites.

This study focuses on the impact of pain on adjustment, rather than the cause of the pain. However pain is not the only predictor of adjustment in patients with advanced cancer. The presence of other distressing symptoms and a range of psychological factors influence adjustment (Bruera, 1997; Coyle, Adelhardt, Foley, & Portenoy, 1990; Lidstone et al., 2003; Utne et al., 2010; Voogt et al., 2005). Pain, other symptoms and psychological factors are likely to have a cumulative effect on adjustment. Therefore, the relationships between pain characteristics, other symptoms, psychological factors and adjustment were explored.

### Adjustment Outcomes

This study explores two domains of adjustment: coping and quality of life.

Level of coping. Coping refers to the process of managing internal and external demands which are appraised as taxing or exceeding the resources of the individual (Lazarus & Folkman, 1984). That is, coping refers to efforts to manage and overcome demands and critical events that are perceived as a challenge, threat, harm, loss, or benefit to a person (Lazarus 1992). The present study focuses on level of coping, which refers to the perceived outcome of efforts to manage the demands.

Wide differences in coping have been reported among cancer patients with pain (Roberts, Lepore & Helgeson, 2006; Schaefer & Moos, 1992; Turk, Sist, Okifuji, Miner, Florio, Harrison et al., 1998). There have been two general approaches to this issue in past research: classification of adjustment or coping styles, and explanation of relationships between pain characteristics and coping strategies. In one example of the former, Turk et al. (1998) classified adjustment among cancer patients with pain into three categories: dysfunctional (coping characterised by high levels of pain, interference, and affective distress, and low levels of perceived control and activity), interpersonally distressed (coping characterised by high levels of affective distress, negative response from significant others, and low levels of perceived support) or adaptive (coping characterised by low levels of interference and affective distress, and high levels of perceived control and activity). In an example of the second approach to research, use of two coping strategies “catastrophing” and “reinterpreting pain” were found to be associated with higher perceived pain intensity (Lin, 1998) among patients with cancer pain. There has been a dearth of studies looking at the diversity of factors that are likely to influence use of coping strategies, the self-efficacy for use of specific strategies and coping styles. However, very few studies have examined the influence of these factors on the overall effectiveness of coping (Chapter 1). The relationships between predictors and overall coping effectiveness are likely to be a better indicator of adjustment than particular coping styles or strategies. Therefore, the present study examines the relationships between a variety of predictors and level of coping among cancer patients receiving palliative care.

Quality of life. The second aspect of adjustment measured in the present study is quality of life. Despite the debate over its definition and measurement, the concept of quality of life is widely used as an outcome variables in clinical trials for cancer treatment (Dworkin, Ngasako, Hetzal & Farrar, 2001; Portenoy, 1991; Turk, Rudy & Sorken, 1993). Some of the ways in which quality of life have been conceptualised were discussed in the introductory chapter. The present study defines quality of life as a global evaluation of satisfaction with life, and examines the relationships between a variety of predictors and quality of life among cancer patients receiving palliative care (e.g., Calman, 1984; Llobera, et al., 2003; Ventegodt et al., 2003).

## Factors that Influence Adjustment

A range of factors have been found to influence a person's ability to adapt and adjust to cancer pain. Pain adversely affects the quality of life of cancer patients (e.g., Boehmer, Lusczynska, & Schwarzer, 2007; Green, Montague, & Hart-Johnson, 2009; Tavoli et al., 2008; Utne et al., 2010; van den Beuken-van Everdingen et al., 2009). Patients experiencing cancer pain also report poorer coping (Boehmer, Lusczynska, & Schwarzer, 2007; Lin, 1998; Parle, Jones, & Maguire, 1996; Turk et al., 1998). A range of psychological and social factors also influence the patient's ability to adjust to any adverse event, including the experience of cancer pain. The present study examines two possible predictors of adjustment (coping and quality of life), pain characteristics, other symptoms and psychological factors. It also examines whether the relationships between pain characteristics, other symptoms and these aspects of adjustment are moderated by these psychological factors.

Pain characteristics. There is a very large body of research literature that demonstrates that pain influences adjustment (e.g., Anderson, Syrjala, & Cleeland, 2001; de Wit et al., 1999; Fine, Davies, & Fishman, 2008; Green et al., 2010; Turk et al., 1998). This research has included a comprehensive range of pain-related measures and variables. However, comparatively few studies of cancer patients have explored the influence of pain frequency and duration. This is despite research on non-cancer pain showing that pain that lasts for prolonged periods, or occurs many times per day, influences adjustment over and above the influence of pain intensity (e.g., Elander & Robinson, 2008; Melzack, 1975; Nezu et al., 2007). It is timely that some studies of cancer patients have included measures of both frequency and intensity of pain (e.g., Portenoy, 1996, van den Beuken-van Everdingen, de Rijke, Kessels & Schouten, 2007). However, the focus of this research has been on the efficacy of pharmacological treatments (e.g., Cleeland, Gonin, Baez, Loehrer & Pandya, 1997; Mitera et al., 2010) or on barriers to effective treatment (e.g., Ersek, Kraybil & Du Pen, 1999; Pargeon & Hailey, 1999). Little is known about how pain characteristics other than intensity are related to adjustment. The present study will therefore expand on previous research about the relationship between pain characteristics and adjustment among patients with advanced cancer by including a measure of pain frequency as well as pain intensity. However, cancer pain rarely occurs in isolation. It is often accompanied by other symptoms.

Other symptoms. Cancer patients often experience a relatively large number of other symptoms in addition to pain (Coyle, Adelhardt, Foley & Portenoy 1990; Henoch et al., 2007; Potter, Hami, Bryan & Quigley 2003; van den Beuken-van Everdingen et al., 2009). These symptoms may predate the disease, be due to the disease, or be side effects of treatment. Although these other symptoms are not the primary focus of the program of research reported in this thesis, they were included in this study, because they are likely to present additional challenges to adjustment. Previous studies have reported the prevalence and severity of a number of other symptoms (Glare, Krech & Walsh, 1991; Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007; Lidstone, 2003; Potter, Hami, Bryan, & Quigley, 2003; Ströngren et al., 2006; van den Beuken-van Everdingen et al., 2009; Walling et al., 2010) and the impact these symptoms have on patient mood and general functioning (Anderson, Syrjala & Cleeland, 2001; Ersek, Kraybill & Du Pen, 1999; Tavoli et al., 2008). For example, a multi-site study conducted by Potter, Hami, Bryan, and Quigley

(2003) examined the prevalence and severity of distressing symptoms among palliative care patients. Commonly mentioned symptoms included, but were not limited to, shortness of breath/dyspnoea, nausea, constipation, fatigue, dizziness, fever, dry mouth and weakness. On average, patients reported seven symptoms in addition to pain. Considering the prevalence and severity of these other symptoms and the evidence that these symptoms have an adverse effect of general functioning, mood and adherence to treatment, it seems likely that the cumulative effect of these symptoms would also adversely influence patient quality of life and level of coping. Therefore, it seems prudent for them to be considered when examining patients' adjustment. Despite this, few studies have included other symptoms when exploring the relationship between pain and adjustment. The present study therefore aims to increase understanding of these relationships by exploring the additional burden of six of these other symptoms (nausea, dry mouth, constipation, fever, dizziness, shortness of breath) on two aspects of adjustment (coping and quality of life). These symptoms were chosen because they are commonly occurring symptoms experienced by patients with advanced cancer (Fainsinger, Nekolaichuk, Lawlor, Neumann, Hanson & Vigano, 2005; Lidstone, et al., 2003; Potter, Hami, Bryan, & Quigley, 2003; Stromgren et al., 2006).

Psychological factors. Previous research suggests that biomedical factors account for most of the variance in perceived pain among palliative cancer patients (Syrjala & Chapko, 1995; Woodruff, 1999). However, research from other populations shows that psychological and social variables are also predictors of the perception of pain. This relationship may be at least partially due to the small amount of research on adjustment.

The most commonly reported psychosocial factors that relate to pain and adjustment are pain coping responses, social support, attributions, mood and anxiety. Positive and negative emotions are also psychological factors associated with pain attenuation and adjustment (Henoch et al., 2007; Miaskowski, Kragness, Dibble, & Wallhagen, 1997; Syrjala & Chapko, 1995; Turk et al., 1998; Voogt et al., 2005). There is evidence of a direct relationship between pain, emotions and adjustment. For example, associations between higher pain intensity, poorer adjustment and higher mood disturbance have been reported among heterogenous cancer patients (Knudsen et al., 2010), cancer and non-cancer pain patients (Sist, Florio, Miner, Lema, & Zevon, 1998) and among women with advanced breast cancer (Koopman, Hermanson, Diamond, Angell, & Spiegal, 1998). In addition, negative emotions were shown to be associated with higher pain intensity and duration (e.g., Glover, Dibble, Dodd, & Miaskowski, 1995; Strang & Qvarner, 1990) and poorer adjustment (e.g., Lehto, Ojansen & Kellumpu, 2004). Similarly, cancer patients with high levels of pain reported higher levels of negative mood and lower levels of positive mood (Zaza & Baine, 2002). In contrast, positive emotions were found to be associated with better adjustment to rheumatoid arthritis pain (Strand et al., 2006). Similarly, one positive emotion, hope, was also found to be associated with lower pain intensity and higher quality of life among cancer patients with recently diagnosed non-terminal disease (Utne, Miaskowski, Bjordal, Paul & Rustoen, 2010). The present study extends the limited existing literature on the relationships between negative and positive emotions, pain characteristics and outcomes (coping and quality of life) exclusively in patients with advanced cancer.

<u>Potential moderators of pain, other symptoms and adjustment.</u> There is very little information about whether positive and negative emotions also moderate the relationship between pain characteristics and adjustment in patients with advanced cancer. However past research suggests that such a relationship is plausible. Several other psychological factors, such as personality and social interaction, have been shown

to moderate the relationships between pain and adjustment in patients with other diseases, such as arthritis (Edwards et al., 2010; Newth & de Longis, 2004). In addition, other psychological variables, such as social support, have been shown to moderate the relationships between pain and adjustment in patients with advanced breast cancer (Koopmanet et al., 1998). Although previous studies have examined negative and positive emotions in relation to pain and adjustment, their potential to moderate this relationship has not been reported. These relationships are complex in real life and therefore the potential moderation and mediation of relationships between these predictors and adjustment needs to be explored in order to advance the field. The present study explores one of these potential relationships, namely, the moderation of pain characteristics and adjustment by negative and positive emotions.

### Time.

Almost all the available research relates to patients with diseases other than cancer or to cancer patients in the early stages of disease (e.g., Lehto et al., 2004). The prevalence and relative importance of pain, other symptoms and psychological factors is likely to differ across the trajectory of illness. It seems useful to examine these relationships at different points in time, because variance in patients' adjustment may be explained by different predictors at different points in the trajectory of illness. The present study uses a longitudinal design to examine stability and change in the relationships between pain characteristics, other symptoms, psychological factors and adjustment among cancer patients with advanced cancer, across a five week period.

### Methodological Issues in the Study of Pain in Palliative Care.

All research involving cancer patients receiving palliative care encounters the difficulty of obtaining meaningful information from patients with advanced illness. Although the present study was not able to overcome all the challenges it entails, it attempted to address five main issues in previous research relating to sample, nature and context of data collection, time of data collection, and predictor and outcome measures.

Sample. Research on patient-reported pain characteristics is largely restricted to patients whose disease is less advanced, because the closer patients are to death, the less likely patients are to take part in research (e.g., Breivik, Cherry, de Conno, Filbert et al., 2009; Caraceni & Portenoy, 1999; Hagen et al., 2008; Portenoy, Payne & Jacobsen, 1999; van den Beuken-van Everdingen et al., 2009). In addition, at all stages of disease, the more severe the patients' symptoms, the less likely they are to participate. Moreover, most studies that successfully recruit patients with advanced cancer are limited by missing data and a high attrition rate. The available literature is therefore limited with respect to the conclusions that can be drawn about patients with advanced disease. First, the experiences of patients at the end stages of their cancer and those with a heavy burden of symptoms, may be different to those of the patients who usually participate in studies. The present study included only patients with advanced cancer who are receiving palliative care. Second, the sample sizes are usually relatively small and therefore allow only a small number of factors to be examined and preclude the exploration of moderated relationships. The present study minimised these shortcomings by using a very large database of cancer patients, who were experiencing pain.

Nature of the data. A second issue is that the amount of information that can be obtained from those patients with advanced disease who can be recruited, must be limited in order to minimise patient burden. This can be achieved in two ways: by using very brief measures, and by obtaining information from proxy and/or collateral sources.

Use of very brief measures will usually preclude the use of psychometrically validated measures and reduce the level of detail obtained. When a third person is asked to act as a collateral source, the response is intended to reflect the judgement of that person, usually a carer or clinician, rather than the patient. When the third person is asked to act as a proxy, biases often prevent proxies from accurately reflecting the patient's experience (Miaskowski et al., 1997; Nekolaichuk, Bruera, Spachynski, MacEachern, Hansen & Maguire, 1999; Snow, Cook, Lin, Morgan & Magaziner, 2005). Thus, in both cases, the strategy used to reduce patient burden does not result in data that represents the patient's experience. In the present study, most measures were very brief in order that they could be completed by the patient. However, two lengthier measures were completed by a collateral source, (i.e., the family carer). These were measures of pain frequency and quality of life, which are two important domains of pain and adjustment and therefore worthy of inclusion despite the problems associated with measures rated by those other than the patient.

### Challenges for measurement by collateral source.

Attempts to obtain meaningful information about experience of pain and its impact on palliative care patients face a number of difficulties. For example, studies about cancer pain do not always rely on patient report, either due to deterioration in their physical health status or cognitive impairment of the patient in the advanced stage of their illness. In particular, pain ratings are not uncommonly reported by caregivers, serving as proxies or collateral sources. These sources may underrate or overrate the intensity of pain and other symptoms because they use less reliable indicators of pain (e.g., facial expression, pain behaviours) (Lin et al., 2005; McMillan & Moody, 2003; Miaskowski et al.,1997; Porter, Keefe, McBride, Pollak, Fish & Garst, 2002). In addition, patients do not always indicate to caregivers that they are in pain, especially when the pain is mild. Patients may wait until pain becomes more serious before bringing it to the attention of others for many reasons (e.g., fear of appearing weak, being a burden upon others, of becoming dependent on medication, or being less able to be involved in day to day living if they are highly medicated). The present study attempts to overcome some of these difficulties by using predominantly patient-reported measures.

Place. A third issue is that participants are usually selected from a single site or from a variety of care contexts in a particular location (e.g., Hagen et al., 2008; Henoch et al., 2007; Mercandte, Villari, & Casuccio, 2010; Tavoli et al., 2008). Because of this, results may be influenced by local pain management practices or the socio-demographic characteristics of the population. This limits the generalisability of results to other care contexts. The present study addressed this problem by using data collected from multiple geographic locations within continental USA and from three different care contexts: conventional care facilities, privately funded hospices and government-funded hospices.

Time of data collection. A fourth issue is that data are often collected at only one point in time (Bhatnagar, Upadhyay & Mishra, 2010; Gauthier, Rodin, Zimmermann, Warr, Moore, Shepherd et al., 2009; Knudsen, Brunelli, Kaasa, Apolone et al., 2010; Lin, Lai & Ward, 2003). It is not possible to examine whether prevalence or relationships change over time if data are collected at only one time point. Yet it is likely that an awareness of changes over time in the relative importance of various predictors of adjustment would be useful to those involved in patient care. Ideally, research findings about pain in cancer patients approaching the end of their life, would be based on a large sample of patients with advanced disease that has been selected from multiple sites and would involve data collection at more than one point in time. The present study attempts to do this.

## Use of Archival Data

The present study uses archival data to examine the influence of psychological factors on the relationship between pain, other symptoms and adjustment in patients with advanced cancer. There are both advantages and disadvantages involved in working with archival data (Elder, Pavalko & Clipp, 1993; McMillan & Moody, 2003; Snow et al., 2005). One disadvantage is that archival data are usually in a format that reflects the perspective of the original investigators, as well as the social and cultural themes of the time. These sometimes need to be adapted in order to be relevant to the current research problem. On the other hand, archival datasets often allow the researcher to draw upon a large volume of quantitative and/or qualitative data than he/she would otherwise be able to access (Elder et al., 1993; McMillan & Moody, 2003; Snow et al., 2005). By exploiting the strengths of archival datasets and making attempts to overcome their limitations, secondary analyses can make a valuable contribution to the research literature.

*The National Hospice Study: Patient and Facility Data* (Greer & Mor, 1986) was selected as a source of data for the present study for a number of reasons. It focused on patients with advanced disease, contained variables relevant for testing the model (Figure 2.1), was drawn from a large multi-site sample, and contained longitudinal data. In particular, one advantage of this data set was the availability of patient-reported intensity of pain and other symptoms, mood ratings and ratings of level of coping at the initial and subsequent interviews. However, despite the many advantages of using this dataset, it required some compromises. First, the data are not recent. The data were collected between 1980 and 1986, and therefore prevalence of pain and other symptoms cannot be assumed to be representative of palliative patients in current times. Second, some of the measures were not the ones I would have chosen. It would have been advantageous to have used psychometric instruments to examine predictors and outcomes because the reliability and validity of custom-designed single-item measures may be compromised. Third, some of the data were obtained from a collateral source instead of directly from the patient. In particular, pain frequency and quality of life were reported by the principal caregiver. Despite the disadvantages of this data set, it offered a unique range of benefits.

## Summary

Pain continues to be a serious problem for palliative cancer patients. Despite a vast body of knowledge about the efficacy of particular pharmacological interventions for cancer pain, there are still a significant number of patients who experience moderate to severe levels of pain. This study has two aims. The first is to explore relationships between the pain characteristics, other symptoms, psychological factors and overall level of coping and quality of life. The second aim is to examine the stability of these relationships by comparing data at three different points in time.

### Research hypotheses.

Two hypotheses were tested.

1. The two measures of adjustment, coping and quality of life, will show negative associations with:
    (a) pain intensity and frequency;
    (b) intensity of other symptoms;
    (c) negative emotion.
2. In contrast, both measures of adjustment, coping and quality of life will show positive associations with positive emotion.

Planned exploratory analysis. Analyses will also be conducted to examine two issues for which there were insufficient previous research to support in a hypothesis.

1. The possibility that a relationship between pain, other symptoms and adjustment outcomes (coping, quality of life) is moderated by psychological factors (negative and positive emotion) will be examined. This analysis will specifically examine whether the strength of the association between pain (intensity, frequency), lower coping and quality of life is stronger when negative emotion is high and weaker when positive emotion is high. It will also examine whether the relationship between the intensity of other symptoms, coping and quality of life is stronger when negative emotion is high and weaker when positive emotion is high.
2. Analysis will examine whether relationships between pain characteristics, other symptoms, psychological factors and adjustment outcomes (coping and quality of life) are stable over time.

# Method

## Participants

Archival data were drawn from the *National Hospice Study: Patient and Facility Data*; (Greer & Mor, 1980-1986) dataset. These data had been archived in the Inter-university Consortium for Political and Social Research and access to the data was purchased from the Social Science Data Archives at the Australian National University, Canberra.

The study collected data by interview from a non-random sample of adult cancer patients in the USA who were receiving palliative care through one of three health service models: “non-demonstration” hospices (n=14 services), which did not receive additional funding to cover services to low income patients, “demonstration” hospices (n=26 services) which received special funding to allow services to be delivered to patients who were eligible for Medicare benefits, and conventional care facilities (n=9 services) (e.g., acute care hospitals). Service providers were sampled from a wide diversity of geographic locations within continental USA.

The National Hospice Study randomly selected a large number of patients from each service for recruitment. Patients undertook an initial interview and then subsequent interview one week, and then three weeks later. However, when considering the generalisation of the findings of the present study, it should be noted that a large number of patients targeted for recruitment either had incomplete medical information or declined to participate in the study (see Figure 2.2). Still more agreed to participate but were unable to complete the first interview. The large attrition from the sample is noteworthy because it is unlikely to be random. Patients who were unable or unwilling to participate are more likely to have been experiencing more severe symptoms and have had shorter survival times than the patients who were able to be included in the analyses in the present study. Therefore the findings of this study may not be relevant to patients with more severe symptoms.

In addition, the quality of the data patients were able to provide was highly variable. The present study focused on the subset of the National Hospice Study sample with end-stage disease but restricted analyses to patients whose level of cognitive and physical functioning was unlikely to limit their ability to provide accurate answers. Questions about cognitive and physical functioning were used in making those judgements. Patients with low cognitive functioning were identified by their carers' response to a question about patient level of awareness. Level of physical functioning was determined from their Karnofsky scores. (The Karnofsky score allows the patient to be classified according to their functional capacity. Patients with scores of 20 are classified as very sick, requiring hospital admission, needing active support and unable to care for themselves. Many of these patients also showed cognitive impairments). Only patients with scores over 20 and who were rated by their carer as having the full range of mental faculties, were included. Patients who did not meet these criteria were excluded. As can be seen in Figure 2.2, these exclusion criteria further reduced the number of participants by more than 50%. The size of the sample that could be included in the main analyses was further reduced by the large amount of missing data for relevant variables. From an initial sample of 1214, only 522 of the patients were able to be included in the analyses that required data for at least two time periods. Moreover, although the database included longitudinal data, only 2.5% of those who took part in the initial interview were still alive 14 weeks later. Death was the most common reason for withdrawal from the study (89.5%) for those who agreed to participate.

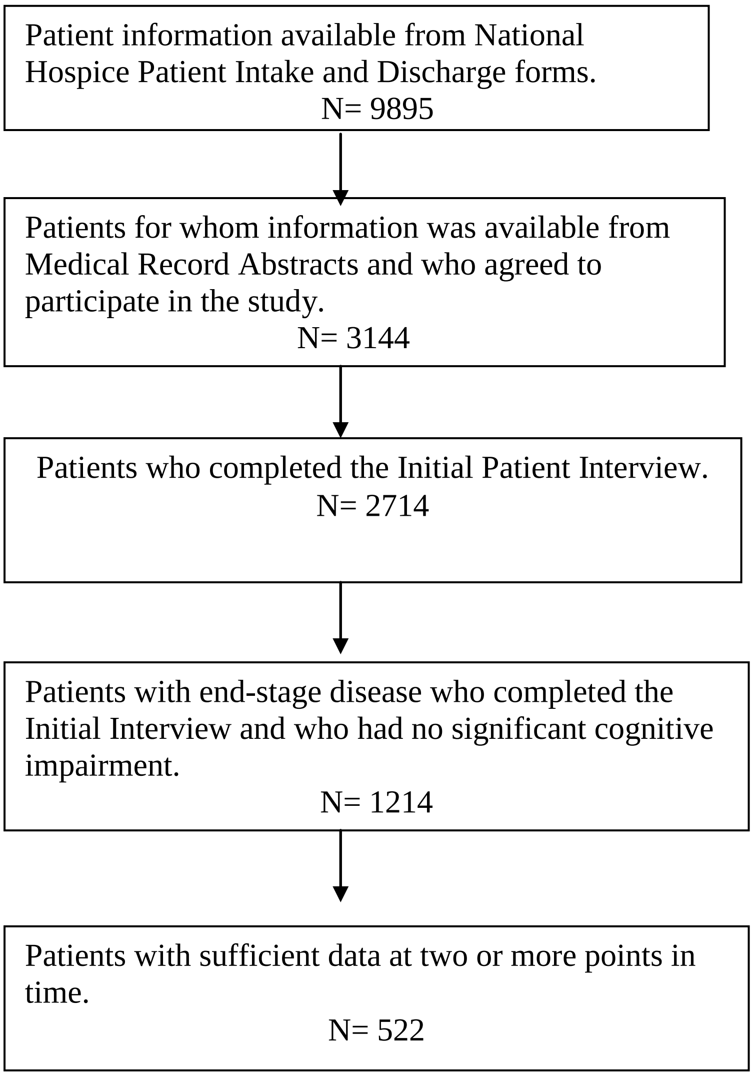

*Figure 2.2*. Flowchart showing derivation of the sample.

Demographic characteristics of the sample included in the main analyses are summarised in Table 2.1. There were approximately equal numbers of men and women, and that most patients were elderly. There were very few patients under 40 years of age and almost half the sample was over 70 years. Most patients lived with a relative who was also the primary carer and who was therefore able to provide detailed information about the patient. These patients are less culturally diverse than a representative sample of the US population at the time (Weicher, 1997). Almost all were Caucasian and more than half had completed secondary to tertiary education. However, because of the nature of the National Hospice Study, patients with low income (below $21K) and high income (over $80K) were both well represented. Despite this, high income earners are over-represented in this sample in comparison with the population of the USA at the time (Weicher, 1997). The sample consists predominantly of white (91.7%) and relatively affluent patients (over $80K) (68.2%), most of whom had health insurance. Thus, the participants' treatment may not be representative of most cancer patients in the USA receiving palliative care. On the other hand, the dataset includes details about a very large number of palliative care patients from a variety of settings and backgrounds over a period of up to 14 weeks, and therefore is able to provide valuable information about cancer patients during the final stages of their disease.

Table 2.1

*Demographic Characteristics of the Sample. (N = 522)*

| | **N** | **%** |
|---|---|---|
| Age | | |
| <41 years | 24 | 4.6 |
| 41-69 years | 279 | 49.1 |
| 70+ years | 219 | 46.3 |
| Missing | 0 | 0 |
| Gender | | |
| Male | 255 | 48.9 |
| Female | 266 | 51.1 |
| Race | | |
| | 474 | 91.7 |
| White/Caucasian | | |
| Other | 42 | 8.1 |

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| | | |
|---|---|---|
| Missing | 6 | 0.2 |

Table 2.1 *continues*

| | **N** | **%** |
|---|---|---|
| Age | | |
| | **N** | **%** |
| Marital Status | | |
| Married | 326 | 62.5 |
| Widowed | 112 | 21.5 |
| | 38 | 7.3 |
| Divorced/separated | | |
| Not married | 42 | 8.0 |
| Missing | 4 | 0.8 |
| Living Arrangements | | |
| Alone | 83 | 15.9 |
| With spouse | 12 | 2.3 |
| Other relative | 308 | 59.0 |
| Non-relative | 113 | 21.6 |
| Missing | 6 | 1.2 |
| Education | | |
| 1-8 years | 94 | 26.3 |
| 9-11 years | 59 | 16.5 |
| High School | 103 | 28.0 |
| Tertiary | 101 | 28.3 |
| Missing | 165 | 31.6 |
| Income | | |
| <$21K | 161 | 30.8 |
| $21-$40K | 91 | 17.4 |
| $41-$60K | 58 | 12.7 |
| $80K | 36 | 5.3 |
| $81-$100K | 47 | 9.0 |
| >$100K | 124 | 23.8 |
| Missing | 5 | 1.0 |

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Medical and diagnostic information about the sample is summarised in Table 2.2. Patients had a wide variety of solid tumours. Less than two percent of patients were able to look after themselves, and therefore the caregivers who were relied upon to provide some data, were deeply involved in caring for the patient. Most of the participants were severely impaired by their medical condition.

Table 2.2

*Medical and Diagnostic Information. (N= 522)*

| | **N** | **%** |
|---|---|---|
| Primary Cancer Diagnosis | | |
| Respiratory system | 124 | 24.2 |
| Colon-rectal | 71 | 13.8 |
| Prostate/ Gynacological | 69 | 13.4 |
| Breast | 62 | 12.1 |
| Liver, Pancreas | 42 | 8.2 |
| Other | 120 | 28.3 |
| Missing | 9 | 1.7 |
| Karnofsky Performance Status | | |
| Normal (100) | 0 | 0 |
| Minor symptoms (90) | 1 | 0.1 |
| Normal Activity (80) | 4 | 0.7 |
| Cares for self (70) | 5 | 0.9 |
| Occasional/considerable assistance (50-60 ) | 64 | 12.4 |
| Disabled/severely disabled (40) | 292 | 55.9 |
| Very sick, hospitalised (30) | 46 | 8.9 |
| Missing | 110 | 21.1 |

Note. The archival dataset provided Karnofsky scores as numerals and not a range.

## Measures

All data gathered in the National Hospice Study (Greer & Mor, 1986) used questionnaires administered in an interview format. Patients completed questions about the intensity of their pain, other symptoms and emotions and whether or not they perceived that they were coping. Information about pain frequency and patient quality of life was reported by the carers. These carers should be considered to be collateral sources of information because they were asked to give their own informed judgement rather than being asked to answer on the patient's behalf (proxy).

## Predictor Variables

Pain characteristics. At the initial interview, the patient reported on the presence and intensity of pain over the previous two week period. For subsequent visits, patients reported the presence and intensity of pain during the past week. Ratings were made using a single-item on a six point verbal analogue scale (1 = "no pain" to 6 = "excruciating.") At each visit, pain frequency during the past week, was rated by the carer and using a single item. Ratings were made on a four point verbal analogue scale (1 = "pain free" to 4 = "persistent pain").

Other symptoms. The patient also reported on the presence and intensity of six other symptoms: nausea, shortness of breath, dry mouth, constipation, dizziness and fever. Each symptom was assessed by a single item. Ratings were made using a 6-point verbal analogue scale (1 = "not present" to 6 = "unbearable"). Because it was the cumulative burden imposed by the presence of other symptoms that was of interest rather than the nature of the symptoms themselves, the scores for each symptom were added and then divided by 6 to create a new measure, “symptom burden,” which assessed the mean intensity of these symptoms.

Psychological factors. The analysis of psychological factors focused on patient emotions. Variables pertaining to patient emotions were obtained by patient self-report. Ten types of emotion were measured (felt: calm, frightened, lonely, hopeless, content, happy, blue, helpless, worthless and positive attitude). Patients were asked to rate the applicability of each item, using a three point verbal analogue scale (1 = “yes, a lot”, 2 = “sometimes” and 3 = “no, not at all”).

### Adjustment Outcomes

The present study included two measures of patient adjustment (level of coping and quality of life) which were measured at the initial and also subsequent interviews.

Level of coping. A single-item, custom-designed for the National Hospice Study, asked the patient to rate the applicability of the statement, “I feel that I can accept and cope somehow with all the problems I face” on a 3-point verbal analogue scale (1= “agreed”, 2 = “ambivalent” and 3 = “disagreed”). Although this measure has not been validated for use among patients with advanced cancer, single-item measures of coping effectiveness have been used in other populations (Aldwin, 1991; Aldwin & Reverson, 1987; Fisher et al., 2008). To allow level of coping to be used as the outcome variable in logistic regression, responses to the coping item were recoded to form a dichotomous variable (1 = “coping” and 2 = “not coping”or “ambivalent”). In all subsequent discussion of coping, it is this recoded dichotomous variable that is referred to.

Quality of life. The patients’ quality of life was assessed using the *Hebrew Rehabilitation Center for Aged QL Index (HRCA-QL)*, (Llobera, Esteva, Benito, Terrasa, Rifa, Pons & Maya, 2003). This carer-completed measure assesses the patient's overall quality of life index and has five domains: mobility, daily living, health, support, outlook. An item relevant to each domain is rated on a 3-point scale (0 to 2) for the week preceding administration. The index is the sum of these scores and can range from 0 (worst) to 10 (best). In the standardisation sample, the HRCA-QL had high internal consistency (Cronbach's alpha coefficient ranging from 0.78 to 0.70) and correlated with the *Karnofsky Performance Status (KPS)* and the *Independence in Activities of Daily Living Index* (Llobera et al., 2003). The authors of the HRCA-QL interpret the latter as evidence of the measures criterion validity in populations with advanced cancer.  In the present study, the HRCA-QL had high internal consistency only at the initial interview (Cronbach's alpha 0.97). However, the internal consistency of the index remained satisfactory at weeks 3 and 5 (Cronbach's alpha 0.68 and 0.67 respectively).

### Procedures

Informed consent and a release of information agreement was obtained from each participant prior to the first interview to allow use of patient medical and demographic details from medical record abstracts and also patient intake and discharge forms.

All variables were measured by self-report and carer-report during an initial interview and at each follow-up interview. Follow-up interviews commenced one week after the initial interview and were repeated every two weeks until the patient's death or withdrawal from the study.

The present study draws on data from the initial interview and the follow-up interviews at Week 3 and Week 5. A trained field data collector conducted the interviews. Patients took part in an initial 30-minute semi-structured interview during which questionnaires were completed and information was collected about family status and background. Subsequent interviews were approximately 15 minutes in duration.

## Statistical Analysis Plan

This study used a repeated measures design in a sample with a high attrition rate due to death of participants. The stability and change in pain intensity was examined using a repeated-measures ANOVA. Stability and change in pain frequency was explored using Friedman two-way analyses of variance.

The present study also explores the relationship between psychological factors and adjustment outcomes. Because data were available for a large number of potentially relevant psychological factors, their number was reduced using exploratory factor analysis.

The main focus of this study was to examine the influence of psychological factors, on the relationship between pain and adjustment. Both direct and indirect relationships between pain, symptom burden, and psychological factors were explored. Logistic regression was used to assess the relationships between these predictors and coping because the scores on this outcome variable were dichotomous. The relationships between predictors and quality of life were examined using multiple regression, because these data were continuous. Pain variables were entered in the first step, and symptom burden in the second step. The direct and moderating effect of psychological variables were added in later steps.

## Data Reduction for Psychological Factors

Before analyses that included psychological factors could be conducted, the number of variables relating to patient emotions needed to be reduced to make the main analyses manageable and to preserve statistical power. Criteria for retention were: correlation coefficients of at least 0.3 with another variable and key theoretical interest or prior empirical evidence of importance. Principal factors were identified as having items loading ≥ 0.4 on each factor. To identify the model with the best fit, a principal components analysis was performed producing up to three factor solutions in the preliminary screening. Factor analysis assumptions were met: Bartlett's test of sphericity, $X(45) = 954.45$, $p < .001$, and Kaiser-Meyer-Olkin measure of sampling adequacy, $R = .82$. Because there was no reason to assume that the factors would be uncorrelated, a varimax rotation was used to create a simple structure. After examination of the scree plot, a two factor exploratory solution, which explained 46.73% of the total variance, was found to have the largest proportion of stable principal factors (see Appendix A). The first factor included six items and was interpreted as a measure of negative emotion, and the second factor included 3 items and was interpreted as a measure of positive emotion (See Table 2.3). Positive attitude did not load sufficiently on either factor and was therefore not retained. These factors also met the criteria for logical coherence and for theoretical interest. The relevance of negative and positive emotion (e.g., Miakowski et. al., 1997; Syrjala & Chapko, 1995; Turk et al., 1998) was outlined earlier in Chapter 1.

Table 2.3

*Factors Derived from Exploratory Factor Analysis of the Patient Items*

| Factor 1 | Factor Loadings | Factor 2 | Factor Loadings |
|---|---|---|---|
| Negative Emotions | | Positive Emotions | |
| Blue | 68 | Content | .81 |
| Frightened | .65 | Happy | .81 |

|  |  |  |  |
|---|---|---|---|
| Helpless | .64 | Calm | .67 |
| Worthless | .61 |  |  |
| Hopeless | .58 |  |  |
| Lonely | .55 |  |  |

Data reduction for psychological factors at Weeks 3 and 5. Data for the same variables were available from interviews conducted in Weeks 3 and 5. The main purpose of the analysis of data from subsequent weeks was to ascertain whether the relationships between predictors (pain, other symptoms and psychological factors) and adjustment were stable or whether they changed over time. In order to compare data over time, it was necessary to retain the same factor structure as used at the initial interview. The 2 factor scores for weeks 3 and 5 were calculated by multiplying the component score coefficients from the initial interview (produced in SPSS) by the Z score for each item. This is the same procedure as is used in the calculation of the initial factor scores by SPSS. These computations are included in Appendix B.

The appropriateness of this method was tested by assessing the internal consistency of the factors if they were treated as scales. Internal consistency of the negative emotions "scale" was satisfactory and stable (0.67 at week 1, 0.80 at week 3 and 0.74 at week 5). Similarly, the internal consistency of the positive emotions "scale" was satisfactory and stable (0.71 at week 1, 0.73 at week 3 and 0.73 at week 5). Thus, use of the same factor structure across weeks 1, 3 and 5 was justified.

## Conclusion

The results from the exploratory factor analyses indicate that two psychological factors can be used to summarise nine of the 10 available measures of emotions. Factor scores rather than scale scores were used in subsequent analysis because factor scores weight each relevant item, and therefore better reflect the results of the factor analysis.

An updated version of the model to be tested, incorporating the two factors derived from the factor analysis, is illustrated in Figure 2.3.

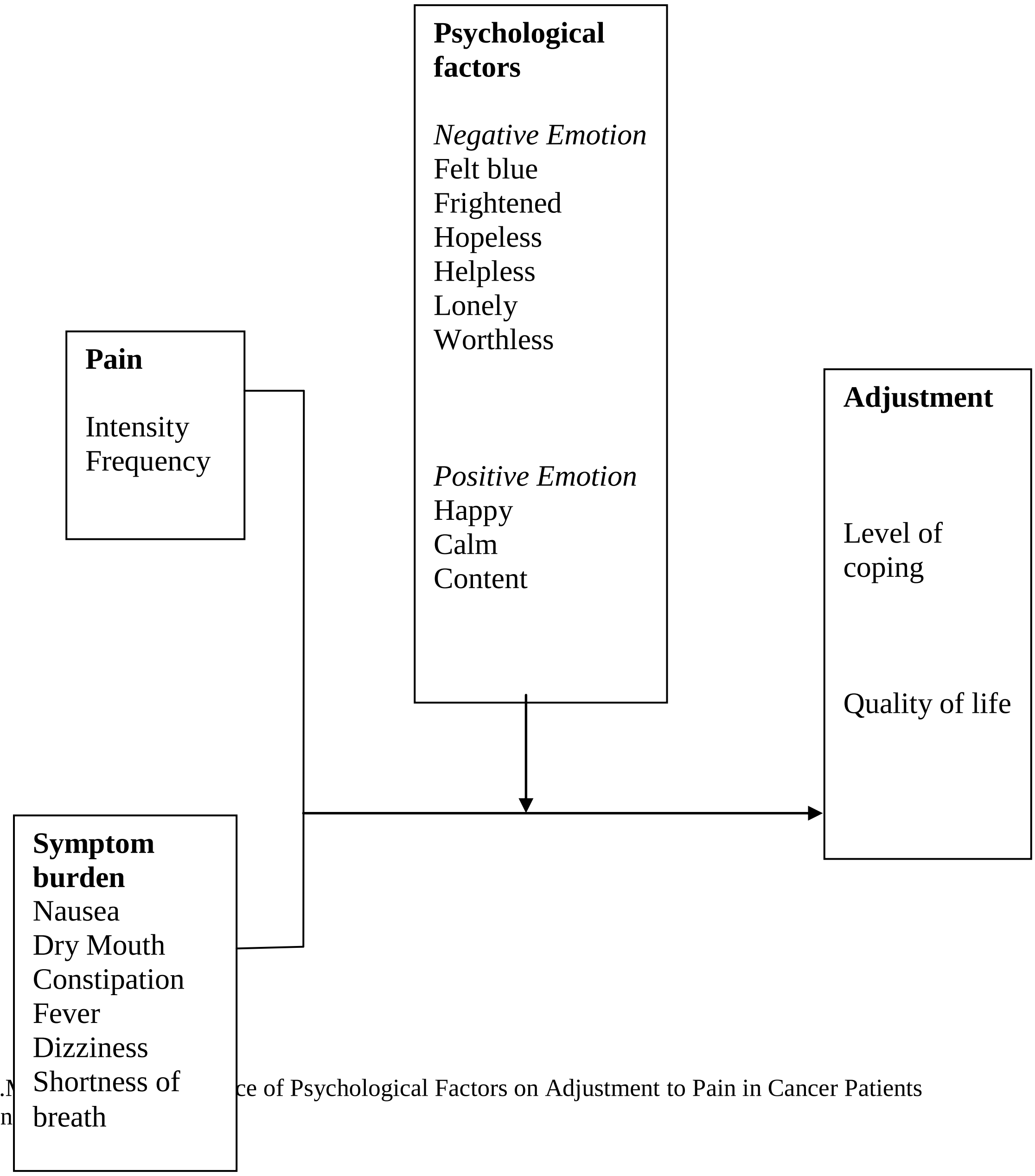

*Figure 2.3.* Revised model showing the expected relationship between pain, symptom burden, psychological factors and adjustment.
Note. This model is an expansion of the model presented earlier (Figure 2.1, p. 58).

## Results

The results are presented in two sections. The first section refers to the preliminary analyses conducted to ascertain the integrity of the data and to report descriptive analyses. The second section reports the main analyses.

### Preliminary Analyses

A series of preliminary analyses were conducted to check that a sufficient number of patients reported pain and other symptoms and that data were distributed in a way that met the assumptions of the planned statistical analyses. A number of criteria needed to be met for measures to be included in the analyses. The first was that at least 20% of the patients reported pain and one or more other symptoms, because symptoms are unlikely to explain individual differences in outcomes in populations in which they are very rare. This criterion was met. Second, data to be included in the multiple regression analysis needed to show a normal distribution, homogeneity of variance, linearity and independence of error. Examination of histograms, statistics for skewness and kurtosis, expected normal probability plots, detrended normal probability plots, residual plots and bivariate scatter plots indicated that two predictor variables did not meet these criteria. “Other symptoms” was positively skewed and was therefore subjected to a logarithmic transformation. Negative emotion was negatively skewed and after being reflected, was subjected to a square root transformation. The transformed data for both predictors met the assumptions of normality, linearity and homogeneity.

## Missing Data

The amount of missing data (Table 2.4) limits descriptions of the sample on which the main analyses were conducted. Missing data had two consequences. First, it reduced the statistical power of the main analyses. Second, it made results more difficult to interpret. It is unlikely that missing data reflect random processes. In particular, it is likely that patients who were experiencing more severe symptoms were the ones who were unable or unwilling to complete interviews.

Table 2.4

*Missing Data Within a Sample of 522 Patients*

| | Initial Interview | | Week 3 | | Week 5 | |
|---|---|---|---|---|---|---|
| Variable | % | n | % | n | % | n |
| Pain | | | | | | |
| Intensity | 41.0 | 214 | 38.9 | 203 | 37.5 | 196 |
| Frequency | 0.2 | 1 | 0.6 | 3 | 11.5 | 60 |
| Symptom burden | 41.8 | 218 | 37.7 | 197 | 34.1 | 195 |
| Level of coping | 45.2 | 236 | 42.5 | 222 | 21.7 | 117 |
| Quality of life | 4.4 | 23 | 2.7 | 14 | 2.5 | 13 |

## Descriptive Analyses

Predictor variables at the initial interview. The first criterion for inclusion in the analyses was that 20% or more patients reported pain and one or more other symptoms. Of the patients for whom data were available, more than half reported pain and approximately one third reported symptom burden (Table 2.5). Therefore the first criterion was met. The second criterion was that variables show a normal distribution of scores. Although most patients had no pain or mild and occasional to frequent pain, there were sufficient patients with pain intensity and frequency across the range to allow the research questions to be answered. However, almost all of the other symptoms reported were mild to distressing in intensity. Less than 2% reported symptoms which were distressing or worse. This was a somewhat unusual finding among a sample of patients with advanced disease (Coyle, Adelhardt, Foley & Portenoy, 1990; Henoch et al., 2007; Potter et al., 2003; van den Beuken-van Everdingen et al., 2009). Although symptom burden met this criterion after transformation, the ability to answer research questions pertaining to other symptom intensity was compromised by the restricted range of scores.

Table 2.5

*Frequency of Ratings for Pain Characteristics and Symptom Burden at Initial Interview*

| | N | % |
|---|---|---|
| Pain intensity (n = 308) | | |
| No Pain | 96 | 31.2 |
| Mild | 70 | 22.7 |
| Discomforting | 68 | 22.1 |
| Distressing | 42 | 13.6 |
| Horrible | 17 | 5.5 |
| Excruciating | 15 | 4.9 |
| Pain frequency (n = 521) | | |
| Pain Free | 119 | 22.8 |
| Occasional | 182 | 34.9 |
| Frequent | 200 | 38.4 |
| Persistent | 20 | 3.8 |
| Symptom burden (n = 299) | | |
| Not present | 178 | 66.2 |

|  |  |  |
|---|---|---|
| Mild | 72 | 27.4 |
| Discomforting | 14 | 4.7 |
| Distressing | 4 | 1.3 |
| Horrible | 1 | 0.3 |
| Unbearable | 0 | 0 |

For inclusion in the analyses, scores on the psychological variables needed to show a normal distribution. Scores for the two psychological variables were calculated on the basis of factor loadings, positive emotion (Median -0.07, range -2.06 to 2.26) and negative emotion (Median 1.64, Range -2.69 to 1.80). Lower scores represent more frequently reported emotions.

Scores on positive emotion and also negative emotion (after reflection and square root transformation) were distributed relatively evenly throughout the range. Therefore psychological variables met the criterion for inclusion in the main analyses.

Stability of predictor variables over time. There was no change in pain characteristics over time. A related samples ANOVA found no differences in pain intensity across weeks, F (2,230) = 0.45, p > .05. Similarly, Friedman 2-way analysis of variance found no differences in pain frequency between initial and two subsequent interviews, $\chi^2$ (2) = 2.59, p > .05. In addition, both psychological variables were stable across time, negative emotion, (F (2.95) = .55, p > .53) and positive emotion, (F (2, 99) = 1.38, p >.05. In contrast, a related samples ANOVA found that the mean intensity of symptom burden changed over time, F (2, 226) = 9.74, p < .05, Eta sq = .97. Symptom burden increased from the initial interview to Week 3, t(2) = .23, (p < .01), and the initial interview to Week 5, t(2) =.31, (p < .01). However, it remained stable from

Weeks 3 and 5, t(2) = .07, ($p > .05$). Of note, most symptoms were only mild in intensity.

Outcome variables at the initial interview. For inclusion in multiple regression analyses variables needed to show a normal distribution of scores. The vast majority of patients reported that they were coping and therefore did not meet this criterion (Table 2.6). Therefore the influence of predictors on level of coping was explored using logistic regression. In contrast, carers reported approximately half the patients having moderate quality of life (Table 2.6). However, scores were sufficiently distributed across the range and therefore suitable for inclusion in multiple regression analysis.

Table 2.6

*Frequencies for Adjustment Outcomes– Initial Interview*

| Adjustment | N | % |
|---|---|---|
| Level of coping | | |
| Not coping | 17 | 5.9 |
| Sometimes | 29 | 10.1 |
| Is coping | 240 | 83.9 |
| Quality of life | | |
| Low (0 – 3) | 92 | 38.5 |
| Moderate (4-6) | 244 | 49.0 |
| High (7-10) | 62 | 12.4 |

Stability of outcome variables over time. There was no change in level of coping over time. A Friedman 2- way analysis of variance found no differences in coping over weeks, ($\chi^2$ (2) = 1.23, p = .54). However, a related samples ANOVA found that the mean quality of life changed over time, F (2, 946) = 461, $p < .05$, Eta sq = .21). Quality of life increased from the initial interview to Week 3, t(2) = 1.31, ($p < .001$), and from the initial interview to Week 5, t(2) = 1.92, ($p < .001$); and from Weeks 3 to 5, t (2) = .62, ($p < .05$), indicating that quality of life improved over time.

## Main Analyses

The first set of analyses that addressed the study's aims, explored the relationships between two predictors (pain and other symptoms), two psychological factors (negative and positive emotions) and two measures of adjustment (level of coping and quality of life). The second set of analyses examined the stability of the relationships between these variables over periods of 3 and 5 weeks. Relationships between predictors and level of coping will be reported first, followed by relationships between predictors and quality of life.

### Predictors of Patient Coping at the Initial Interview.

Hypothesis 1 predicted that level of coping will show negative associations with (a) pain characteristics (intensity and frequency), (b) intensity of other symptoms and (c) negative emotion. Hypothesis 2 predicted that level of coping will show a positive association with positive emotion. The first exploratory analysis examined the possibility that the relationship between pain characteristics, other symptoms and level of coping is moderated by psychological factors. Specifically it examined whether the strength of the association between pain (intensity and frequency) and lower level of coping is stronger when negative emotion is high and weaker when positive emotion is high. It also examined whether the strength of the association between intensity of other symptoms and lower level of coping is stronger when negative emotion is high and weaker when positive emotion is high. These were examined using a Sequential Logistic Regression. Pain characteristics were entered in the first step, followed by symptom burden in the second step, psychological factors in the third step and in the fourth step, six interaction terms (pain intensity x negative emotion, pain intensity x positive emotion, pain frequency x negative emotion, pain frequency x positive emotion, other symptoms x negative emotion and symptom burden x positive emotion). “Coping” was coded as “0,” while “Not coping” was coded as “1.”

After deleting cases with missing data and outliers, data for 430 patients were available for analysis. The Hosmer and Lemeshow goodness of fit test indicated that there was a good model fit for pain variables alone, $X^2(8, N=430) = 5.41$, $p = 0.71$, and after adding other symptoms, $X^2(8, N=430) = 15.96$, $p = 0.43$, psychological factors, $X^2(8, N=430) = 5.50$, $p = 0.70$, and the interaction terms, $X^2 (8, N=430) = 8.50$, $p = 0.39$. Taken together, the variables in Figure 2.3 were able to successfully explain level of coping. Examination of the correlations between saved probabilities with actual group membership indicates that 58% of the variance in level of coping is explained by pain characteristics and other symptoms. When psychological variables and the interaction terms are entered in the analysis, 74.0% of the variance in coping is explained, $r (432) = .864$, $p < 001$.

The amount of independent variance in coping accounted for by each step in the Sequential Regression was explored (Table 2.7). In the first step, pain explained a significant proportion of the variability in the log odds of not coping, $X^2 (2, N=430) = 11.46$, $p < 0.01$, however, the effect was small (Nagelkerke $R^2 = 0.04$). The odds of not coping increased as pain intensity increased. In the second step, other symptoms did not explain the additional variability in coping, $X^2 (1, N=430) = 2.01$, $p = 0.16$. In the third step, psychological factors explained independent variance in the log odds of not coping, $X^2 (2, N=430) = 134.87$, $p < 0.01$ and the effect size was moderate to large (Nagelkerke $R^2 = 0.49$). The odds of not coping increased as negative emotion increased. Conversely, as positive emotion increased, the odds of not coping decreased.

In the fourth step, interaction terms involving the two psychological variables, explained additional independent variance in the log odds of not coping, $X^2$ (6, N=430) = 13.67, $p < 0.05$ and the effect size was large (Nagelkerke $R^2 = 0.53$). When all variables were entered into the equation, the odds of not coping in the presence of high pain intensity increased when negative emotion was high (Figure 2.4). In addition, the odds of not coping in the presence of higher intensity of other symptoms decreased when reports of positive emotion were high (Figure 2.5).

In summary, the results of the analysis of relationships between predictors and level of coping for the initial interview supported Hypothesis 1(c) and Hypothesis 2, partially supported Hypothesis 1(a), but Hypothesis 1(b) was not supported. In addition, the first planned exploratory analysis was partially supported. The strength of the association between pain intensity and lower level of coping was stronger when negative emotion was high. In addition, the strength of the association between symptom burden and lower level of coping was weaker when positive symptoms were high. However, no interactions were found between level of coping, pain frequency and psychological variables, or between level of coping, symptom burden and negative emotion.

Table 2.7

*Results of Logistic Regression. Coping at the Initial Interview (N= 430)*

| Step Variable | B | SE | Wald Test Ratio | Odds Ratio |
|---|---|---|---|---|
| Step 1 | | | | |
| Pain | | | | |
| Intensity | 0.27 | 0.08 | 10.40*** | 1.31 |
| Frequency | 0.16 | 0.15 | 1.12 | 1.17 |
| Step 2 | | | | |
| Pain | | | | |

| | | | | |
|---|---|---|---|---|
| Intensity | 0.24 | 0.09 | 8.00** | 1.28 |
| Frequency | 0.17 | 0.15 | 1.30 | 0.19 |
| Symptom burden | 0.26 | 0.18 | 2.06 | 1.02 |
| Step 3 | | | | |
| Pain | | | | |
| Intensity | 0.06 | 0.11 | 0.25 | 1.06 |
| Frequency | 0.30 | 0.19 | 2.54 | 1.35 |
| Symptom burden | -0.26 | 0.24 | 1.11 | 0.77 |
| Negative emotion | -1.23 | 0.18 | 48.62*** | 0.29 |
| Positive emotion | 1.57 | 0.22 | 49.47*** | 4.81 |

Table 2.7 *continues*

| Step Variable | B | SE | Wald Test Ratio | Odds Ratio |
|---|---|---|---|---|
| Step 4 | | | | |
| Pain | | | | |
| Intensity | 0.38 | 0.17 | 5.28* | 1.47 |
| Frequency | 0.59 | 0.29 | 4.03 | 1.80 |
| Symptom burden | -0.17 | 0.48 | 5.93* | 0.31 |
| Negative emotion | -1.70 | 0.82 | 4.28* | 0.18 |
| Positive emotion | 1.59 | 1.02 | 2.42 | 4.88 |
| IntXneg emotion | 0.28 | 0.12 | 5.83* | 1.33 |
| IntXpos emotion | 0.25 | 0.15 | 2.95 | 0.78 |
| FreqXneg emotion | 0.10 | 0.21 | 0.21 | 1.10 |
| FreqXpos emotion | -0.31 | 0.25 | 1.54 | 0.73 |
| SympXneg emotion | -0.38 | 0.28 | 1.78 | 0.69 |
| SympXpos emotion | 0.84 | 0.38 | 4.78* | 2.31 |

Note: * p<.05; ** p < .01; *** p<.001.

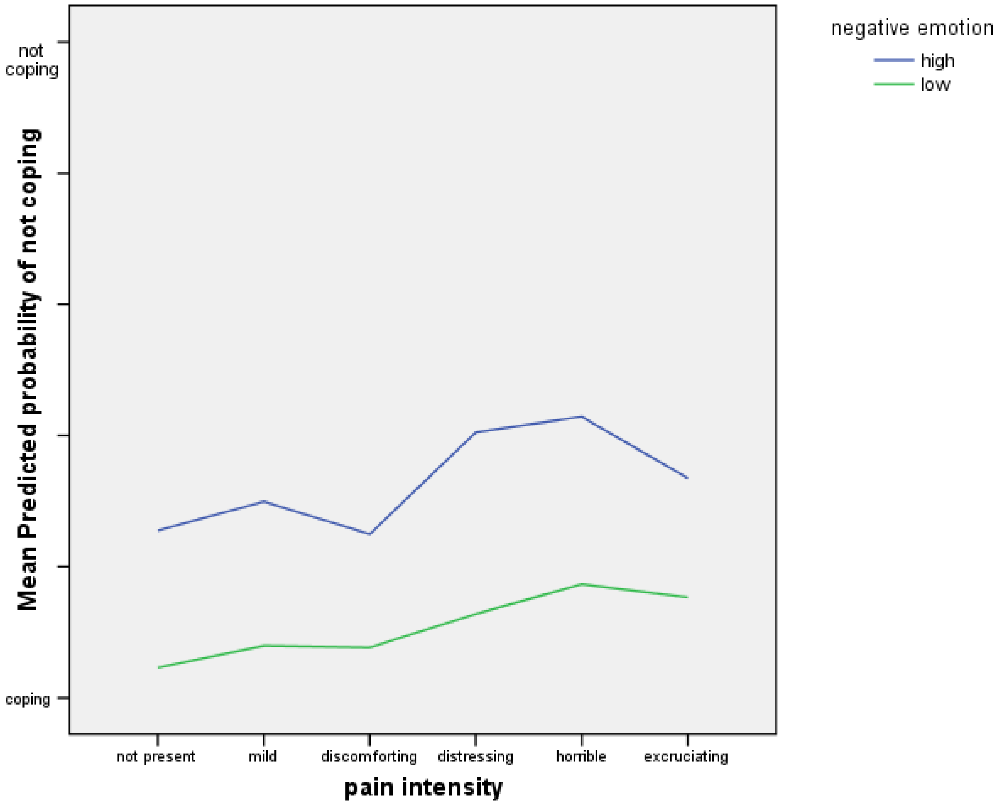

*Figure 2.4.* Interaction between pain intensity and negative emotion relative to coping.

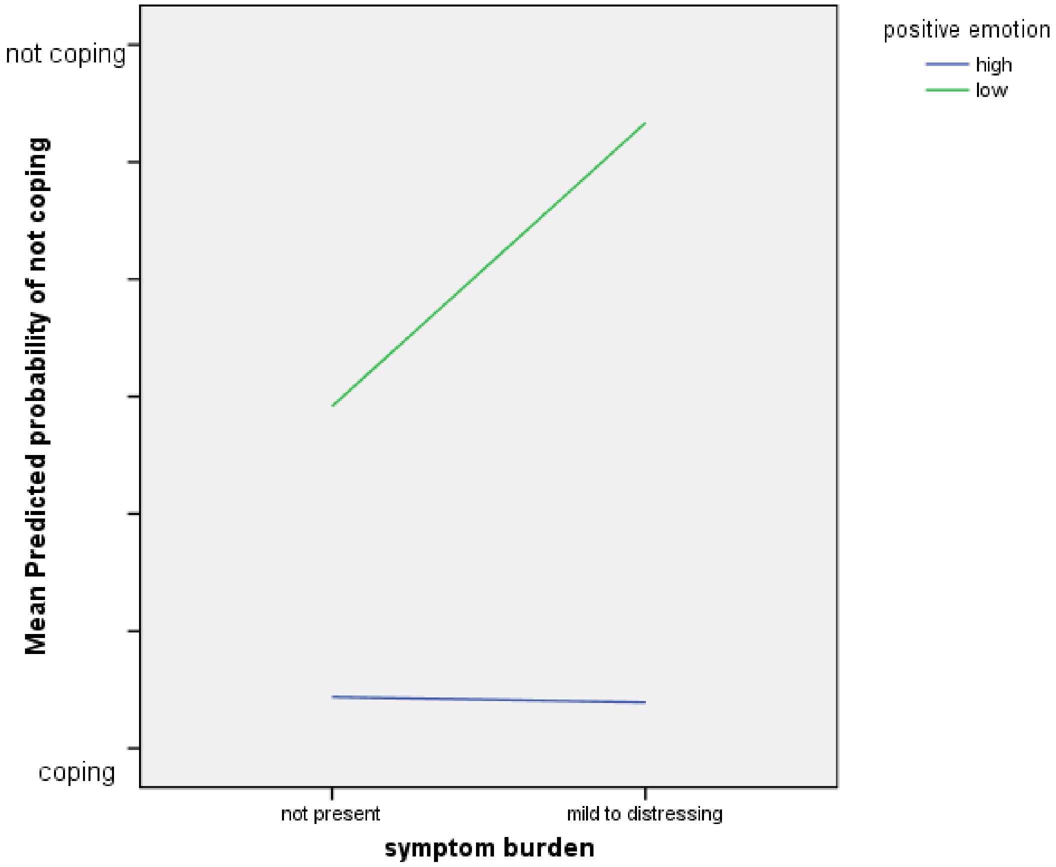

*Figure 2.5.* Interaction between symptom burden and positive emotions relative to coping.

Predictors of Coping at Subsequent Interviews.

Parallel analyses were conducted for data from Weeks 3 and 5 to examine the second planned analysis, that is, whether relationships between pain characteristics, other symptoms, psychological factors and level of coping are stable over time.
Sequential Logistic Regressions were conducted to determine if it was possible to predict whether cancer patients would either report that they were coping or not coping on the basis of pain characteristics (step 1), intensity of other symptoms (step 2), psychological factors (step 3), the interaction terms involving psychological variables (step 4) between these variables, using data from interviews at Weeks 3 and Weeks 5.

After deleting cases with missing data and outliers, data from 264 patients were available for analysis at Week 3 and from 231 patients at Week 5. The Hosmer and Lemeshow goodness of fit test indicated that there was a good model fit for pain variables alone, at Week 3, $X^2$ (8, N=264) = 8.09, p = 0.43; at Week 5, $X^2$ (8, N=231) = 7.45, p = 0.49; and after adding symptom burden at Week 3, $X^2$ (8, N=264) = 8.54, p = 0.38; at Week 5 , $X^2$ (8, N=231) = 5.21, p = 0.74; psychological factors, Week 3 $X^2$ (8, N=264) = 8.65, p = 0.37;at Week 5, $X^2$ (8, N=231) =15.07, p = 0.6; and the interaction terms at Week 3, $X^2$ (8, N=264) = 4.47, p = 0.81; and Week 5, $X^2$ (8, N=231) = 9.78, p = 0.28.

Pain characteristics. In step 1, pain characteristics explained a significant proportion of the variability in the log odds of not coping [at Week 3, $X^2$ (2, N=264) = 20.93, p < 0.001; and at Week 5, $X^2$ (2, N=231) = 12.46, p < 0.002] although the effect was small in both cases (Nagelkerke $R^2 = 0.12$) and (Nagelkerke $R^2 = 0.10$) respectively.

Other symptoms. In step 2, the relationship between symptom burden and coping was not consistent over time. Contrary to the results for the initial interview, the intensity of other symptoms had a small main effect at Week 3, $X^2$ (1, N=264) = 4.59, $p < 0.05$ (Nagelkerke $R^2 = 0.15$). However, consistent with the results of the initial interview, other symptoms had no main effect at Week 5, $X^2$ (1, N=231) = 0.07, $p > 0.05$.

Psychological factors. Consistent with the initial interview, there was also a large main effect for psychological factors for Week 3, $X^2$ (2, N=264) = 65.98, $p < 0.001$ (Nagelkerke $R^2 = 0.47$); and a moderate main effect for Week 5, $X^2$ (2, N=231) = 32.87, $p < 0.001$ (Nagelkerke $R^2 = 0.32$).

Interactions. Contrary to the initial interview, the interaction variables in the fourth step did not significantly explain variance in coping, $X^2$ (2, N=264) = 8.51, $p > 0.05$ for Week 3; and for Week 5, $X^2$ (2, N=231) = 11.29, $p > 0.05$.

Regression coefficients, standard error, Wald statistics odds ratio for each step in subsequent interviews are summarised in Appendix C. Taken together, the variables in Figure 2.3 were able to successfully explain level of coping at subsequent interviews. Examination of the correlations between saved probabilities with actual group membership indicates that only 2.5% of the variance in level of coping explained by pain characteristics and other symptoms at Week 3. However, when psychological variables are entered in the analysis, 85.0% of the variance in coping is explained, r (264) = .849, p < 001. At Week 5, however, variance in coping (54.8%) was accounted for only after the addition of psychological factors, r (231) = .733, p < .001. In summary, relationships between pain characteristics, other symptoms, psychological factors and coping were stable over time, but interactions were observed at the initial interview only.

Summary concerning coping. Results showed a direct relationship between coping and pain characteristics at all interviews. However, psychological factors explained additional independent variance in coping at every interview. Indeed, the effect of psychological factors on coping was larger than the effect of pain characteristics. There was a main effect for other symptoms at Week 3 only. In addition, interactions between other symptoms and psychological factors explained additional variance in coping at the initial interview only.

### Predictors of Quality Of Life at The Initial Interview

Hypothesis 1 predicted that quality of life will show negative associations with pain characteristics (intensity and frequency), intensity of other symptoms and negative emotion. Hypothesis 2 predicted that quality of life will show a positive association with positive emotion. The first exploratory analysis examined the possibility that the relationship between pain characteristics, other symptoms and quality of life is moderated by psychological factors. Specifically it examined whether the strength of the association between pain (intensity and frequency) and lower quality of life is stronger when negative emotion is high and weaker when positive emotion is high. It also examined whether the strength of the association between intensity of other symptoms and lower quality of life is stronger when negative emotion is high and weaker when positive emotion is high. Sequential multiple regression was employed to examine these relationships. Pain variables were entered in the first step, the logarithmic transformation of other symptoms in the second step, psychological factors (raw scores for positive emotion and reflected square root transformation of negative emotion) in the third step and the six interaction terms, involving pain characteristics, other symptoms and psychological factors were entered in the fourth step. Results for the initial interview showed that there were no main effects or interaction effects (Table 2.8). Even with all variables included in the analyses, the model did not explain any variance in quality of life, $R^2 = 0.03$, F (6, 393) = .84, p >.05. In summary, at the initial interview, Hypotheses 1 and 2 and the first planned exploratory analysis were not supported for quality of life.

Table 2.8
*Regression Analysis for Predictors of Quality of Life at the Initial Interview (N = 405)*

| Variable | | | B | SE | β |
|---|---|---|---|---|---|
| Step 1 | | | | | |
| | Pain | | | | |
| | | Intensity | -0.03 | 0.06 | -0.02 |
| | | Frequency | -0.23 | 0.10 | -0.11* |
| Step 2 | | | | | |
| | Pain | | | | |
| | | Intensity | 0.01 | 0.06 | 0.00 |
| | | Frequency | -0.24 | 0.10 | -0.11* |
| | Symptom burden | | -1.13 | 0.68 | -0.09 |
| Step 3 | | | | | |
| | Pain | | | | |
| | | Intensity | 0.01 | 0.07 | 0.01 |
| | | Frequency | -0.24 | 0.10 | -0.13* |
| | Symptom burden | | -1.13 | 0.68 | -0.09 |
| | Patient Factors | | | | |
| | | Negative emotion | 0.03 | 0.31 | -0.04 |
| | | Positive emotion | -0.02 | 0.10 | -0.56 |

|  |  |  |  |
|---|---|---|---|
| Step 4 |  |  |  |
| Pain |  |  |  |
| Intensity | -0.01 | 0.07 | -0.01 |
| Frequency | -0.26 | 0.10 | -0.13* |
| Symptom burden | -1.15 | 0.69 | -0.09 |
| Patient Factors |  |  |  |
| Negative emotion | -0.22 | 2.04 | -0.04 |
| Positive emotion | 1.04 | 0.57 | 0.56 |
| IntXneg emotion | 0.07 | 0.21 | 0.02 |
| IntXpos emotion | 0.02 | 0.07 | 0.01 |
| FreqXneg emotion | 0.00 | 0.03 | 0.05 |
| FreqXpos emotion | -0.02 | 0.01 | -0.58 |
| SympXneg emotion | -2.14 | 2.26 | -0.05 |
| SympXpos emotion | 0.29 | 0.68 | 0.02 |

Note: * p<.05; ** p < .01; *** p<.001.

Predictors of Quality of Life at Subsequent Interviews

These analyses used the same procedures as those outlined for the initial interview, in order to examine the second planned analysis, that is, whether relationships between pain characteristics, other symptoms, psychological factors and adjustment were stable over time. For quality of life N = 260 at Week 3 and N = 235 at Week 5.

At Week 3, some of the predicted relationships were found. There were small main effects for pain variables, $R^2 = 0.14$, F (2, 257) = 20.97, p < .001, other symptoms, $R^2 = 0.02$, F (1, 256) = 4.75, p < .05, and for psychological factors, $R^2 = 0.04$, F (2, 254) = 6.08, p < .01 (Table 2.9). However, consistent with findings from the initial interview, there were no interaction effects, $R^2 = 0.02$, F (6, 248) = .84, p > .05. With all variables in the equation, pain variables accounted for 14% of the variance in quality of life, other symptoms accounted for an additional 2% and psychological factors accounted for a further 4% of the variance in quality of life. The variance in quality of life accounted for by pain, is best explained by the moderate effect of pain frequency, β = -0.37, p = .001, and the variance in quality of life accounted for by psychological factors is best explained by the small effect of negative emotion, β = 0.29, p = .01. Of note, the effect of other symptoms at Week 3 was very small and less than the standard error. In summary, for quality of life, Hypothesis 1(c) was supported at Week 3 and there was partial support for Hypotheses 1 (a). However Hypotheses 1(b) and 2 were not supported.

Table 2.9

*Regression Analysis for Predictors of Quality of Llife at Week 3 (N = 260)*

| Variable | B | SE | β |
|---|---|---|---|
| Step 1 | | | |
| Pain | | | |
| Intensity | -0.04 | 0.85 | - 0.03 |
| Frequency | -0.83 | 0.13 | -0.37*** |
| Step 2 | | | |
| Pain | | | |
| Intensity | -0.11 | 0.09 | 0.07 |
| Frequency | -0.81 | 0.13 | -0.36*** |
| Symptom burden | 1.94 | 0.90 | 0.13* |
| Step 3 | | | |
| Pain | | | |
| Intensity | - 0.22 | 0.09 | -0.02 |
| Frequency | -0.77 | 0.13 | -0.35*** |
| Symptom burden | 2.36 | 0.90 | 0.16** |
| Psychological factors | | | |

| | | | |
|---|---|---|---|
| Negative emotion | 0.20 | 0.08 | 0.29** |
| Positive emotion | 0.08 | 0.09 | 0.11 |
| Step 4 | | | |
| Pain | | | |
| Intensity | -0.03 | 0.09 | -0.18 |
| Frequency | -0.79 | 0.13 | -0.35*** |
| Symptom burden | 2.44 | 0.92 | 0.17** |
| Patient Factors | | | |
| Negative emotion | 0.18 | 0.08 | 0.26* |
| Positive emotion | 0.06 | 0.09 | 0.08 |
| IntXneg emotion | - 0.01 | 0.05 | - 0.02 |
| IntXpos emotion | -0.12 | 0.06 | -0.02 |
| FreqXneg emotion | 0.02 | 0.09 | 0.02 |
| FreqXpos emotion | 0.01 | 0.10 | 0.02 |
| SympXneg emotion | -0.13 | 0.61 | -0.03 |
| SympXpos emotion | -0.80 | 0.70 | -0.15 |

Note: * p < .05; ** p < .01; *** p < .001.

At Week 5, the results were very similar to those at the initial interview (Table 2.10). There were no main effects or interaction effects. Even when all variables were entered into the analyses the model did not explain any variance in quality of life, $R^2 = 0.02$, F (6, 223) = .82, p >.05.

Table 2.10

*Regression Analysis for Predictors of Quality of Life at Week 5 (N = 235)*

| Variable | B | SE | β |
|---|---|---|---|
| Step 1 | | | |
| Pain | | | |
| Intensity | -0.23 | 0.10 | - 0.15* |
| Frequency | 0.03 | 0.15 | 0.01 |
| Step 2 | | | |
| Pain | | | |
| Intensity | -0.23 | 0.11 | -0.15* |

|  |  |  |  |
|---|---|---|---|
| Frequency | 0.03 | 0.15 | -0.01 |
| Symptom burden | -0.29 | 1.08 | 0.79 |
| Step 3 |  |  |  |
| Pain |  |  |  |
| Intensity | -0.23 | 0.11 | -0.15* |
| Frequency | 0.03 | 0.15 | -0.01 |
| Symptom burden | -0.39 | 1.14 | -0.03 |
| Psychological Factors |  |  |  |
| Negative emotion | 0.03 | 0.08 | 0.04 |
| Positive emotion | 0.02 | 0.10 | 0.02 |
| Step 4 |  |  |  |
| Pain |  |  |  |
| Intensity | -0.26 | 0.11 | -0.18* |
| Frequency | 0.02 | 0.15 | -0.01 |
| Symptom burden | -0.64 | 1.15 | 0.04 |

Table 2.10 *continues*

| Variable | B | SE | β |
|---|---|---|---|
| Patient Factors |  |  |  |
| Negative emotion | 0.03 | 0.09 | 0.03 |
| Positive emotion | 0.02 | 0.10 | 0.03 |
| IntXneg emotion | -0.01 | 0.06 | - 0.01 |
| IntXpos emotion | 0.02 | 0.07 | -0.03 |
| FreqXneg emotion | -0.10 | 0.09 | -0.11 |
| FreqXpos emotion | -0.08 | 0.11 | -0.08 |
| SympXneg emotion | 1.14 | 0.63 | .20 |
| SympXpos emotion | 0.84 | 0.82 | 0.11 |

Note: * p < .05; ** p < .01; *** p < .001.

### Post-hoc Analysis

As the relationships observed between the predictors and quality of life at Week 3 appeared to differ from those at the initial interview and Week 5, a Fisher r to z transformation was used to determine whether this was the case. R values for the association between pain variables and quality of life did not differ between the initial interview and Week 5, z = -.48, p > .05. R values for the association between pain variables and quality of life differed between Week 3 and both the initial interview and Week 5 (z = -3.54, p < .001, z = 2.66, p < .001 respectively). This suggests that the relationship between quality of life and other variables changed over time.

Summary concerning quality of life. Results showed direct relationships between quality of life and pain characteristics at Week 3 only. Although psychological factors accounted for additional variance in quality of life at Week 3, the effect of pain characteristics was larger. No interactions were found at any of the interviews.

### Summary Of Results

This study tested a model that summarises relationships in previous research between pain variables, other symptoms, psychological factors and two aspects of adjustment (level of coping and quality of life) (Figure 2.3). The study tested the application of this model to patients with advanced cancer. Overall, the results provided supported for the proposition that psychological factors are important in predicting of adjustment in patients with advanced cancer. In particular the presence of high negative emotion is associated with poorer adjustment. The findings are summaries in Figure 2.6 and 2.7. In Figure 2.6 the values represent regression coefficients from Logistic Regression.

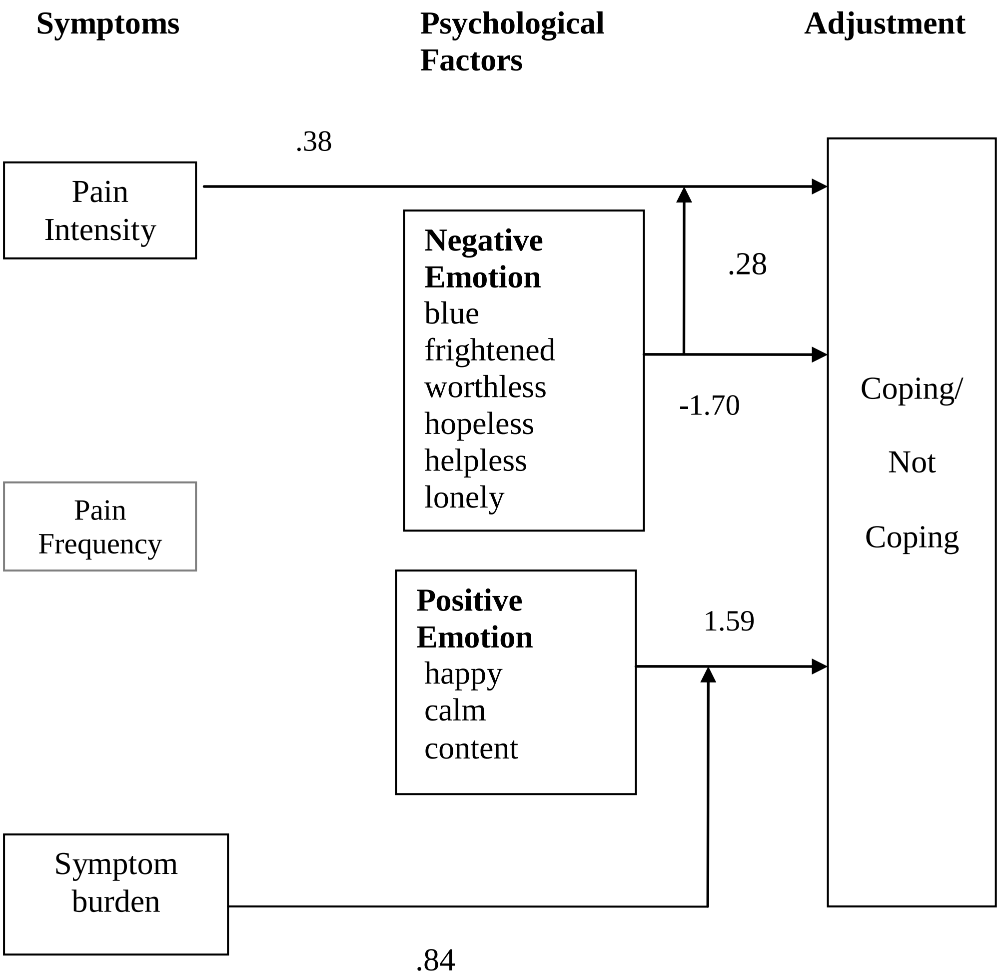

*Figure 2.6.* Final model of the relationship between predictors and coping.

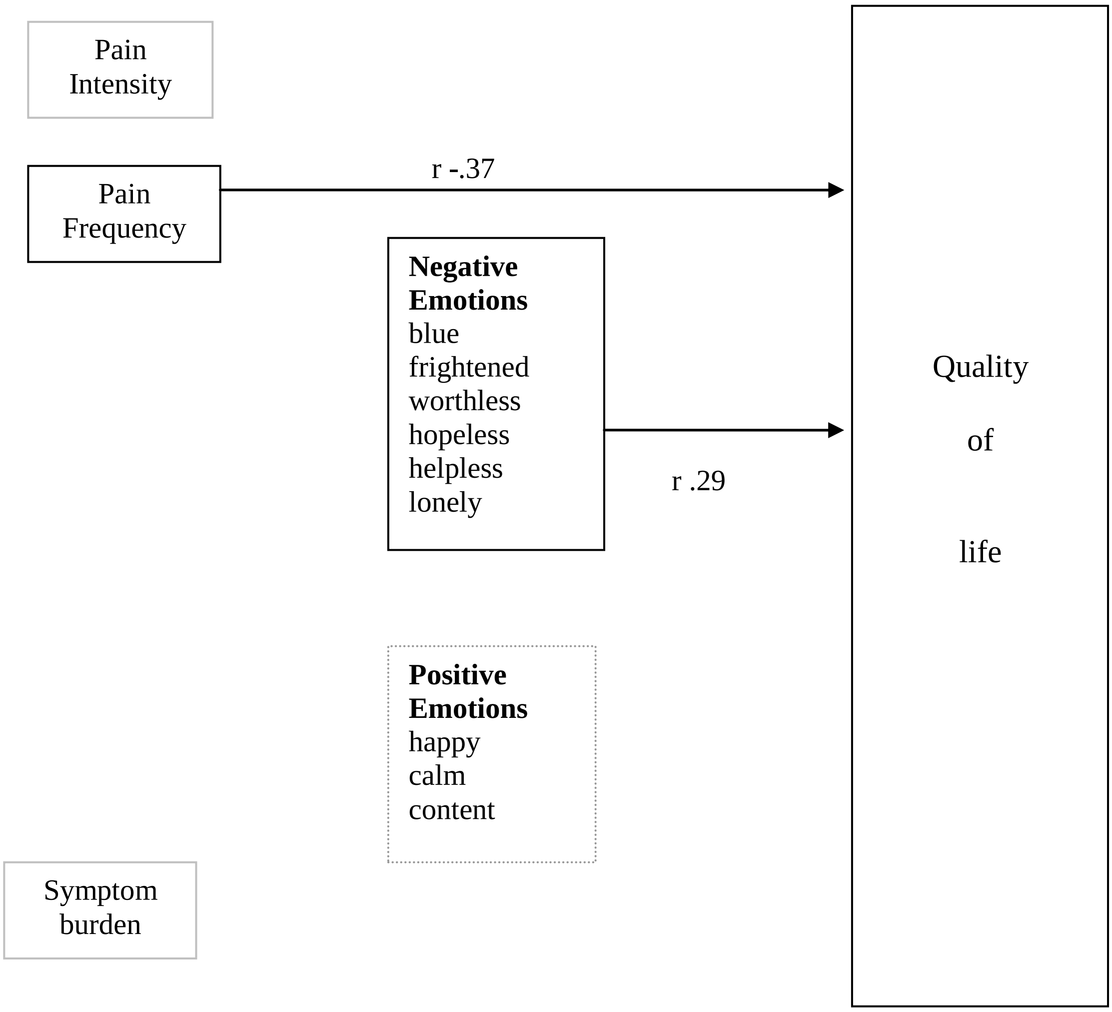

*Figure 2.7.* Final model of the relationship between predictors and quality of life.

# Discussion

Pain and other distressing symptoms are frequently reported by patients with advanced cancer. In addition, several psychological factors have been found to be a challenge to adjustment. Although it is generally accepted that pain, other symptoms and psychological factors influence adjustment, relatively little is known about the cumulative burden of these variables on adjustment or whether these relationships change over time among patients with advanced cancer. The present study applied a model that summarised previous research, to examine the influence of these predictors on adjustment. The model described relationships between pain characteristics (intensity and frequency), symptom burden, psychological factors (negative and positive emotion) and two aspects of adjustment (level of coping and quality of life). The model predicts that psychological symptoms have a direct relationship with adjustment and that they moderate the relationship between pain characteristics and other symptoms. Collection of sufficient data to test the moderation hypothesis and to examine relationships over time is beyond the scope of a single researcher. Therefore the model was applied to a large archival dataset containing longitudinal data for cancer patients receiving palliative care from multiple sites in the USA. This allowed the model to be tested at three different points in the trajectory of illness.

The data base held a number of features which had important implications for this research, but which were not obvious until after the analysis began. Although the data base was described as containing almost 10,000 patients (Greer & Mor, 1986), data for the first interview was collected from fewer than one third of these. Moreover, more than half of the patients who completed at least the first interview were rated as having cognitive impairments that were likely to compromise the accuracy of the data they provided. In the end, data from approximately 500 patients were able to be used. This dramatic reduction from the expected sample size required further data reduction before potential moderation could be examined, and raised questions about the representativeness of the findings.

The model predicted that pain characteristics, other symptoms, psychological factors and the interaction between psychological factors and pain characteristics, and other symptoms and psychological factors influence adjustment for patients with advanced cancer. This was broadly supported for only one aspect of adjustment, level of coping. For this outcome, a large amount of the variance was accounted for by the model at one or more points in the trajectory of illness. However, very few of the model's predictions were supported for the other aspect of adjustment (quality of life).

Pain characteristics and adjustment. In the present study, pain characteristics were negatively associated with adjustment. However, the characteristic of greatest relevance differed for the two aspects of adjustment. Higher pain intensity was associated with poorer coping and higher pain frequency was associated with lower quality of life. The expected relationships between pain frequency and coping and pain intensity and quality of life were not found. In addition, the relationships between pain characteristics and coping were observed at all time points. However, this relationship was observed only at Week 3 for quality of life. These results reveal both consistencies and inconsistencies with existing literature. The relationship between pain intensity and coping is consistent with previous research (Roberts, Lepore, & Helgeson, 2006; Schaefer & Moos, 1992; Turk et al., 1998). However, unlike previous research, there was no relationship between pain intensity and lower quality of life (Green et al., 2009; Rustoen et al., 2005). On the other hand, lower quality of life has previously been associated with higher pain frequency (Rummans et al., 1998).

The observed relationships between higher pain intensity and poorer coping confirm findings from previous research and also highlight the importance for clinicians to ask questions about these variables to guide treatment. However, the relationships between pain frequency and quality of life were less clear. It is beyond the scope of this study to explain the differences observed between pain and quality of life over time, or the failure to find significant relationships between pain intensity and quality of life. Further research pertaining to the relationships between pain characteristics and adjustment is needed to explain this phenomenon. Nevertheless, the discovery of a relationship between increased pain frequency and lower quality of life at Week 3 (despite an increase in quality of life since the previous week) suggests that clinicians should regularly enquire about both changes in pain characteristics and quality of life and coping. This information may highlight the need for additional interventions for some patients.

Symptom burden and adjustment. Unlike earlier research, this study found relatively little evidence of a relationship between symptom burden and adjustment. This was surprising, but the result may be an artefact of the way the variable “symptom burden” was created (summation of scores for the six symptoms). Ideally, each of these symptoms and their relationship with adjustment would have been explored separately. On the other hand, the result may reflect the unusual nature of the sample. For example, other symptoms (besides pain) did not appear to be as prevalent or intense as reported in previous research. Less than half of the patients reported the presence of other symptoms and most of those who did, reported symptoms of mild intensity. In contrast, previous research indicates palliative cancer patients experience an average of 7-12 other symptoms in addition to pain (e.g., Lidstone et al., 2003; Potter et al., 2003, Ströngren et al., 2006). These other symptoms are typically reported to be distressing in intensity (van den Beuken-van Everdingen et al., 2009) and associated with lower quality of life (e.g., Anderson, Syrjala & Cleeland, 2001; Henoch et al., 2007; van den Beuken-van Everdingen et al., 2009). It is likely that the restricted range of scores for each of the other symptoms (and the new variable symptom burden) in this sample did not allow this relationship to be adequately explored. Further research, in a sample in which there is a greater presence and intensity of symptoms is required before conclusions can be drawn about the relationship between other symptoms and adjustment.

Psychological factors and adjustment. A direct relationship between psychological factors and adjustment was found at all interviews for coping. Greater negative emotion was associated with poorer coping at all three interviews, but was associated with lower quality of life only at Week 3. (However, at Week 3, relatively few patients reported low quality of life). In addition, the presence of more positive emotions was associated with higher levels of coping at the initial interview only, but was not associated with quality of life at any time. These findings are only partially consistent with previous research. Previous research has also found associations between emotions and use of coping strategies (Folkman, 1997; Folkman & Moskowitz, 2000; Lehto, Ojanen, & Kellokumpu-Lehtinen, 2004; McMillan, 1996; Voogt et al., 2005). However, contrary to the findings of the present study, previous research has also that negative emotion is associated with lower quality of life (Lehto et al., 2004; Rustoen et al., 2005).

Moderators of adjustment. The present study extended knowledge in the field by demonstrating that psychological factors sometimes moderate the relationship between pain characteristics, other symptoms and one aspect of adjustment, level of coping.

Poorer coping was associated with higher pain intensity in the presence of high levels of negative emotion. Poorer coping was also associated with higher intensity of other symptoms in the presence of lower levels of positive emotions. However, the latter needs to be interpreted with caution because none of the patients reported other symptoms which were more than mild in intensity. These relationships were only observed at the initial interview, suggesting that the relationships may change over time. No previous research has reported that the relationship between pain and adjustment is influenced by the interaction between psychological factors and pain characteristics with adjustment. However, some previous research has reported data consistent with this model of relationship. For example, moderation is suggested by findings that, in the presence of positive emotions, intense other symptoms contributes to poorer coping (van den Beuken-van Everdingen et al., 2009).

Wide differences in patterns of results relating to coping have been reported in previous literature pertaining to cancer patients with pain (Roberts, Lepore, & Helgeson, 2006; Schaefer & Moos, 1992; Turk et al., 1998). These differences may be, in part, explained by the different ways in which coping was conceptualised and operationalised. For example, studies measured coping capacity (Henoch et al., 2007), coping strategies (Lin, 1998; Turk et al., 1998) or coping styles (Folkman & Greer, 2000; Merluzzi, Nairn, Hedge & Sanchez, 2001; Voogt et al., 2005). The present study on the other hand, examined the relationships between patients' perception of their level of coping and predictors. Comparisons between studies are therefore difficult, because they are not measuring the same construct (e.g., Anderson et al., 2001; Henoch et al., 2007; Roberts et al., 2006; Turk et al., 1998, Rustoen et al., 2005; van den Beuken-van Everdingen et al., 2009). The present study examined patients' perception of their level of coping, regardless of their choice of coping capacity, strategy or style, because this is the aspect of coping of greatest relevance to service providers. Therefore, previous findings cannot be generalised to this sample of palliative care cancer patients with advanced disease.

Before assessing the contributions made by this study, it is important to consider its four main methodological limitations. The data set is old and therefore the mean scores for variables may not be representative of cancer patients today who benefit from improved pain and cancer treatments. However, the model should apply, irrespective of the age of the dataset because the relationships it depicts were reported in both earlier (Coyle et al., 1990; Lin, 1998; Miaskowski et al., 1997; Schaefer & Moos, 1992) and more recent research (Boehmer et al., 2007; Roberts et al., 2006; Utne et al., 2010; Voogt et al., 2005; Walling et al., 2010).

Second, the measures used in data collection are not ideal for the purpose of the present study. In addition, measures were obtained from a mixture of sources. Although most measures were based on patient reports, two key measures (pain frequency and quality of life) were reported by carers from the perspective of a collateral source. Although collateral sources are commonly used in research among palliative care patients when patients are too ill to participate, it is preferable to use patient report because collateral sources may under-estimate or over-estimate patient experience (Fine & Busch, 1998; Lin et al., 2005; McMillan & Moody, 2003; Snow et al., 2005). It is unclear whether similar patterns of findings would have been obtained if pain frequency and quality of life had been reported by the patient.

Third, several important measures were not included in the data set, or were not measured in an optimal fashion. For example, many of the measures consisted of only one question with three response options. Ideally, psychometrically validated instruments which yielded a wider range of scores would have been used. There was also no measure of pain duration, even though it is widely assessed in studies of the efficacy of pain treatment (Green, 2009; Portenoy, Payne & Jacobsen, 1999; Rustoen et al., 2005; Zeppetella, O'Doherty & Collins, 2000) and evidence that it is associated with poorer adjustment (e.g., Rustoen et al., 2005). Furthermore, the psychological variables had a very narrow focus. A wide range of other psychological variables of relevance were not assessed. In particular, there was no measure of 'meaning of pain.' Meaning has been reported to be an important predictor of adjustment (Barkwell, 1991; Chung, 2000; Ersek, 1994; Ersek & Ferrell, 1994; Lee, 2008; Liposwski, 1970; Park, 2010; Park et al., 2008; Steves 1992). Therefore, ideally, it would be included when examining the influence of psychological factors on pain and adjustment. These shortcomings may have resulted in important relationships between pain, psychological factors and adjustment being missed.

Fourth, the extent of missing data was unexpected and made it difficult to interpret findings, since the missing data are unlikely to be random. Patients who were experiencing more severe symptoms are more likely to be unable or unwilling to answer all questions in the interviews. As a result, relationships that were found are relevant for populations with relatively low levels of pain and other symptoms. It also resulted in restricted range of scores, which has implications for the analyses. It seems likely that stronger relationships between symptoms, psychological factors and adjustment apply when populations include many patients with symptoms that are more distressing.

In summary, the benefits of using an archival data base in order to access information about a large number of people over time was compromised by the quality of the measures, missing data and high attrition. Despite this, the sample was large enough to allow the model to be tested and contained a uniquely relevant range of variables. Despite some additional unexpected shortcomings, the benefits of the dataset continued to outweigh its disadvantages.

Nevertheless, the present study has demonstrated broad support for the proposed model. It has made three important contributions. First, it demonstrated that variables in the model can explain independent variance in adjustment among palliative care patients with advanced cancer. More than 67% of the variance in coping was explained by pain characteristics, other symptoms, psychological factors and the interaction of psychological factors and pain and other symptoms. There was a small effect size (less than 0.3) for pain characteristics, and a moderate effect size for psychological factors, and when it was present, a large effect size for the interaction between psychological factors and pain and other symptoms on coping. That is, the study confirmed that pain characteristics are important predictors of adjustment, but showed that psychological factors often have an even stronger relationship with coping. Both high levels of negative emotion (pain intensity) and low levels of positive emotion (other symptoms) can exacerbate the effect of pain and symptoms on coping.

Second, the study demonstrated the complexity of identifying predictors of adjustment. Coping and quality of life showed different patterns of predictors and different patterns of relationships over time. Third, the present study demonstrated that patterns in relationships between predictors and adjustment can show considerable change even over short periods of time. Moreover, some relationships between variables were more stable than others.

The present study has found different relationships between specific pain characteristics, intensity and frequency, and the two aspects of adjustment. Therefore it is likely that relationships may exist for other pain characteristics and other aspects of adjustment. Furthermore, the present study found a single domain of psychological factors, emotion, was important to adjustment in patients with advanced cancer. Other psychological factors may also be important predictors of adjustment. The field of research pertaining to predictors of adjustment among patients with advanced diseased may be extended by exploring the influence of additional measures of pain characteristics (e.g., duration), psychological factors beyond emotion to aspects of adjustment.

A second study was conducted to further test the model of the relationships between pain characteristics, psychological factors and adjustment in a smaller contemporary population. Pain duration was included as an additional pain characteristic and two other psychological factors (e.g. meaning of pain, perceived effectiveness of pain management strategies) will be examined. In Study 3, the model will be further tested by including an additional aspect of adjustment (symptoms of depression) at a different site.