Chapter 6
RELATIONSHIPS BETWEEN BREAKTHROUGH PAIN, PSYCHOLOGICAL FACTORS AND ADJUSTMENT - A PERSON-FOCUSED PERSPECTIVE

The first three studies used in this thesis used quantitative methods and found general support for a model that described relationships between predictors and adjustment among cancer patients experiencing pain (see Figure 1.2). However, a restricted range of scores on some outcome variables and small sample sizes in Studies 2 and 3 made it difficult to draw firm conclusions from the results. The qualitative methods used in Study 4, revealed diversity and complexity of meanings of pain that had not been portrayed in previous research (e.g., Chen, 1995; Studies 2 and 3). Therefore previous studies may have missed potentially important relationships between meaning of pain and adjustment. The final study in this thesis attempts to overcome some of the shortcomings of previous research by examining the model of relationships between coping, breakthrough pain (frequency, duration and intensity) and one psychological factor (meaning of pain) using a person-focused analysis. The focus on qualitative descriptive analysis continues (even though some quantitative data are used) in order to provide a detailed understanding of patients' pain experience.

The present study aimed to expand upon findings from Studies 1 to 4 by addressing three propositions. First, individual patients' experience of pain and adjustment may not be stable over time. Studies 2 and 3 and most previous research, have measured pain

(frequency, duration and intensity) and coping with questionnaires that use summative scores representing an average over the past one to two weeks. This method of measuring pain and coping may misrepresent the experience if pain and coping are highly unstable. An innovation of the present study is the measurement of pain (frequency, duration and intensity) and level of coping for a period of seven consecutive days, in addition to using the usual summative scores, so that daily variations in pain and coping are able to be identified and compared with summative data for each patient.

Second, because quantitative analyses normally rely on summative data, such analyses of the relationships between pain and coping may not provide clinically useful information, if patient experience of pain, and/or coping are not stable. The present study therefore uses a person-focused approach to examine individual patterns in breakthrough pain (frequency, duration and intensity) and coping over a period of seven days. The aim of adopting this approach was to provide insights into interventions with the potential to support patient adaptation.

Third, the range and complexity of patients' meaning of pain and therefore its relationship to pain and coping proved difficult to capture using quantitative methods. Although Studies 2 to 3 suggested that endorsement of some meanings of pain may be important to coping, important relationships between meaning of pain and adjustment may have been missed. The present study extends previous research by providing a greater understanding of the relationships between breakthrough pain characteristics,

meaning of pain and coping by using the qualitative meaning of pain themes found in Study 4.

Stability in Breakthrough Pain and Coping.

The present study examined the proposition that the patients' experience of breakthrough pain and adjustment may not be stable over time. Breakthrough pain characteristics are by nature, unpredictable and highly variable (e.g., Bhatnagar et al., 2010; Portenoy & Hagen, 1990; Zeppetella, 2008, in press). Despite the usefulness of summative reports for the exploration of relationships between pain characteristics and coping, these accounts of pain episodes may not meaningfully reflect the individual patient's experience of breakthrough pain, or its influence on the individuals' level of coping if pain and/or coping are unstable. A pain diary has the potential to demonstrate variability and predictability in pain episodes and level of coping, and is likely to be accurate, because recordings are as close as practical to each pain episode, however compliance among patients with advanced cancer is limited, particularly when pain is severe (de Wit et al., 1999). Therefore, the present study examined breakthrough pain characteristics and coping on a day-to-day basis, in order to provide insight into the stability of relationships between pain characteristics and coping for individual patients.

Comparisons between Summative Data and Data from Pain Diaries

The second aim of the present study was to compare summative reports of pain and coping from the previous week, with day-by-day accounts during the following seven days. Several retrospective and longitudinal studies of breakthrough pain characteristics and adjustment (using summative data and diary data) have been reported in previous

research (e.g., Bhatnagar et al., 2010; Green et al., 2009; Haugen et al., in press; de Wit et al., 1999; Portenoy et al., 1999; Zeppetella, 2008). Because different assessment tools were used, it is difficult to compare the findings. Moreover, these studies have not compared summative data and day-by-day accounts from the same sample of patients. An innovation of the present study is the comparison of summative and day-by-day data among the same sample of patients. This comparison is expected to highlight different relationships between breakthrough pain and coping for individual patients, thus providing valuable information about the benefits and disadvantages of both methods.

Relationships Between Breakthrough Pain Characteristics, Meaning of Pain and Coping

The third aim of the present study was to provide a greater understanding of the relationships between breakthrough pain characteristics, meaning of pain and coping. Although previous research has found meaning of pain to be important to adjustment among cancer patients, different patterns of relationships existed for some meanings. For example, a non-aversive meaning such as "challenge" was reported as having a positive influence on pain and adjustment, whereas aversive meanings such as "loss," "enemy" and "punishment" had a negative influence (Barkwell 1991; Studies, 2 and 3). In addition, poorer adjustment was reported when patients perceived an aversive meaning of pain as a signal of "impending death" (Ferrell & Dean, 1995). However, Study 4 revealed a range of complex and diverse meanings of pain which were not included in previous research. Therefore the present study proposes to extend existing knowledge about these differences in relationships between pain and adjustment by examining differences in patterns of breakthrough pain characteristics and level of coping for

patients with aversive versus non-aversive meanings of pain over a period of seven days. It incorporates the qualitative meaning of pain themes found in Study 4.

Like Studies 2 and 3, the present study examined interrelationships between breakthrough pain characteristics (frequency, duration and intensity), one psychological factor (meaning of pain) and one aspect of adjustment (level of coping). One of the difficulties faced by researchers trying to understand these relationships, is that an experiment cannot be run, in order to establish the role of breakthrough pain in causality in those relationships. It would not be ethical to manipulate breakthrough pain in order to examine changes in meaning of pain and coping. In addition, the relationships between breakthrough pain characteristics, meaning of pain and coping are likely to be multidirectional. This presents a further difficulty in establishing causality. The present study attempts to overcome some of these difficulties by examining meaning of pain at one point in time, and then comparing reported breakthrough pain characteristics and coping from the week before this time, with the days following this time (see Figure 6.2). If meaning of pain influences breakthrough pain characteristics (frequency, duration and intensity) and coping, then individual differences in meaning of pain at Time 1 should be reflected in reports of breakthrough pain and coping at subsequent times of measurement. A limitation of this method, however, is that the relationship between those variables is also likely to be influenced by changes in medical treatment, which may be made with the aim to improve pain and other symptom management (e.g., changes in medications).

Research Questions

Planned exploratory analyses using qualitative methods were designed to answer the following questions:

Stability of breakthrough pain and coping. Are breakthrough pain characteristics (frequency, duration and intensity) and coping, and the relationship between these variables, for a given patient stable, over a 7 day period?

Summative versus diary reporting about breakthrough pain and coping. Do summative reports about breakthrough pain and coping from the previous two weeks (Time 1) foretell breakthrough pain (frequency, duration and intensity) and level of coping for the subsequent week?

Relationships between breakthrough pain, meaning of pain and coping. Do patients reporting aversive meanings of pain at Time 2 report different experiences of breakthrough pain (frequency, duration and intensity) and coping during the following week than patients reporting non-aversive meanings of pain?

METHOD

Participants

A subsample of 15 of the patients who participated in Study 4 completed the present study. Derivation of the sample is illustrated in Figure 6.1. Eighteen of those who participated in Study 4, did not take part in this study. The most common reason for non-participation was that they had not experienced breakthrough pain. Another five patients were eligible to participate in this study and to participate in the initial interview, but were unable to commit to completion of a daily pain diary. About one half of those who consented to complete the diary were unable to do so due to physical decline or death. (see Figure 6.1).

Nine patients were recruited from Southern Adelaide Palliative Care Service and six from Lyell McEwin Palliative Care Service. The youngest patient was 44 years of age and the oldest was 79 (M = 61.13 years, SD = 11.72). The sample was balanced for gender (Females = 53.3%). Most patients had a primary diagnosis that was unique to the sample (Table 6.1).

Table 6.1

Primary Diagnosis of Participants (N = 15)

Primary site of neoplasm	**n**	**%**
Lung	3	20.00
Bone	2	13.33
Other*	10	66.67

* Single cases

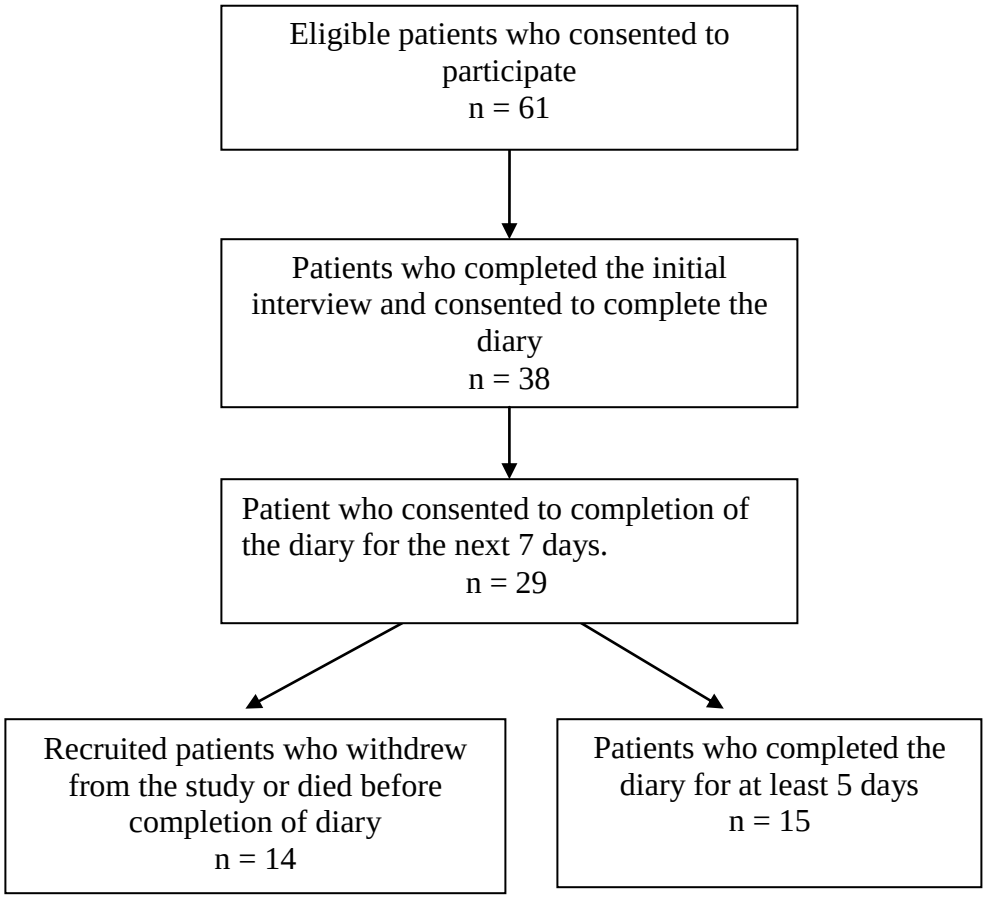


Figure 6.1. Flowchart showing derivation of the sample.

Measures

The measures used during the initial interview have previously been described in Studies 2, 3 and 4. These included measures of breakthrough pain characteristics (frequency, intensity and duration) and of level of coping described in Studies 2 and 3 and the interview to elicit free responses concerning meaning of pain described in Study 4. Because there were differences in the scale of measurement of pain intensity and level of

coping used in Studies 2 and 3, harmonisation techniques were used to facilitate analysis of data from both studies. Harmonisation is a process of bringing together various types, levels and sources of data in such a way that they can be made compatible and comparable and therefore useful for decision making and analysis (Bowling & Ebrahim 2005; Food and Agricultural Organisation Corporate Directory, 1998; Giger, 2008; Hofer & Piccinn, 2009; Lantz, Ramstedt & Stebrant, 2001). The harmonisation of data from Studies 2 and 3, for pain intensity and level of coping, was made simpler because responses had been made to the same questions. Data for breakthrough pain intensity were recoded into four categories: from Study 2 (1-2 = mild, 3 = moderate, 4 = severe and 5 = excruciating pain) and from Study 3 (1-3 = mild, 4-6 = moderate, 7-9 = severe and 10 = excruciating). Level of coping with pain was recoded into four categories: Study 2 (1 = not coping, 3 = sometimes coping, 4 = coping moderately and 5 = coping very well) and Study 3 (1-3= not coping, 4-5 = sometimes coping, 6-7 = moderately coping and 8-9 = coping very well). These cut-off points were selected because the verbal labels of the analogue scales for breakthrough pain intensity and level of coping (Study 3) matched the descriptors of the verbal rating scales for these measures in Study 2.

Measures Obtained From Breakthrough Pain Diary

Additional data were collected in quantitative breakthrough pain diaries for a minimum of five consecutive days. There are two versions of the breakthrough pain diary because different scales of measurement were used at each site (see Appendix K). One version used a verbal rating scale and the other, an analogue scale with verbal and numerical

anchors. Again, minimising patient burden was paramount for choosing the diary measures. Three characteristics of breakthrough pain were assessed.

Breakthrough pain intensity. Peak intensity was measured by asking the patient to respond to a single question: "How bad was this pain at its worst moment?" The patient responded, based upon an analogue scale with verbal anchors ("slight discomfort," "mild pain," "moderately painful," "severe pain" and "excruciating pain"). These variables were subsequently recoded for ease of depiction (1 = slight discomfort and mild pain, 3 = moderate, 4 = severe and 5 = excruciating).

Breakthrough pain frequency. Daily frequency of breakthrough pain was obtained by summing the number of pains recorded on each day.

Breakthrough pain duration. Patients were instructed to record the time each pain started and when it ended. Breakthrough pain duration was obtained by calculating the number of minutes elapsed between the start and end of each breakthrough pain. This was subsequently recorded for ease of description in the analysis. Breakthrough pain duration has been described as (very short = up to 10 minutes, short = 10 to less than 20 minutes, medium = 20 to less than 60 minutes, long = 60 to 120 minutes and prolonged = more than 120 minutes. The time intervals and names assigned to breakthrough pain duration were selected for consistency with measures commonly used for assessment of breakthrough pain (e.g., Fine & Busch, 1998; Fine, Davies, & Fishman, 2008).

Level of coping with breakthrough pain. Level of coping was assessed each day. The patient was asked to record an answer to the question; "How well do you believe that you cope with the breakthrough pain you are experiencing" using a 5-point

verbal analogue scale (1 = not coping at all, 2 = barely coping, 3 = sometimes coping, 4 = moderately coping and 5 = coping very well). "Not coping" and "barely coping" were recoded as one variable "not coping" for consistency with the initial interview.

Stability of scores on variables. Scores for breakthrough pain (frequency, duration and intensity) and level of coping with pain were assessed as stable if the scores in the diary were the same on each variable for 5/7 days or 4/5 days. Likewise, scores for breakthrough pain (frequency, duration and intensity) and level of coping were assessed as consistent with summative scores, if the scores in the diary (on each variable for 5/7 days or 4/5 days) were the same as the scores in the summative data.

Meaning of Pain.

Meanings ascribed to pain were derived from qualitative analysis (Chapter 5). Meanings were described as aversive if they appeared to have a negative connotation. Positive or neutral meanings were deemed to be non-aversive. Aversive meanings of pain included "loss", "punishment", "fear/worry," "injustice", "enemy," "weakness," and "nuisance/burden." Non-aversive meanings of pain included "challenge," "pragmatism (e.g., just the disease)," "value," "relief," "spiritual," and "gratitude."

Procedures

The times of assessment are summarised in Figure 6.2. After completing the semi-structured interview, described in Studies 2 and 3, patients were asked to complete a breakthrough pain diary for the next seven days. Patients recorded the following information about each breakthrough pain: time of onset, how long the episode lasted,

pain intensity at its worst moment and the pain management strategies they used. At the end each day, patients indicated their level of coping.

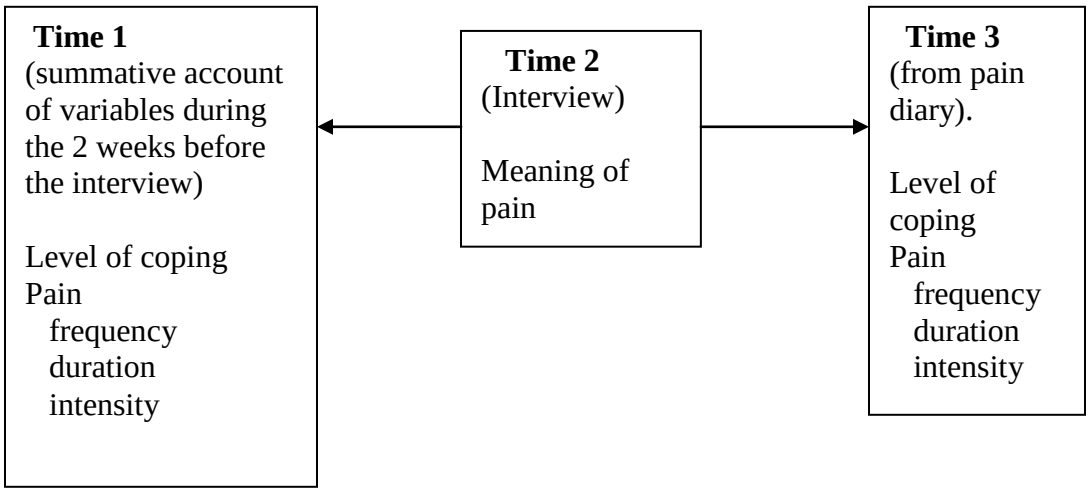


Figure 6.2. Flowchart showing times of assessment for Study 5.

Analysis Plan

Study 5 is a person-focused descriptive analysis of the relationship between level of coping and breakthrough pain characteristics (frequency, duration and intensity) and meaning of pain. There are two components to the analysis. The first examines graphical summaries of reported breakthrough pain characteristics (frequency, duration and intensity) and coping recorded by each patient in their diary. It also compares breakthrough pain characteristics and coping reported at the interview (Time 2) with the graphical summaries of breakthrough pain and coping recorded in the pain diaries for each patient. The second component presents case studies that discuss entries for

patients' breakthrough pain characteristics and coping in the context of one psychological factor (meaning of pain).

RESULTS

Only data for the 15 patients who provided diary entries about breakthrough pain and coping for at least 5 consecutive days were included in the results.

Part One

In order to summarise temporal patterns in breakthrough pain characteristics and coping, a unique method of summarising the data from the breakthrough pain diaries was developed. Custom-designed graphs were used to summarise breakthrough pain characteristics (frequency, duration, intensity) and level of coping. Each bar represents one instance of breakthrough pain. The height of the bar represents breakthrough pain duration in minutes, as shown on the left axis). The patient's numerical rating of breakthrough pain intensity is marked in black on each bar (1 = mild, 3 = moderate, 4 = severe and 5 = excruciating). Level of coping is marked as a green dot, as shown on the right axis (1 = not coping, 3 = sometimes coping, 4 = moderately coping, 5 = coping well).

Stability of Breakthrough Pain and Coping Over Five or More Days.

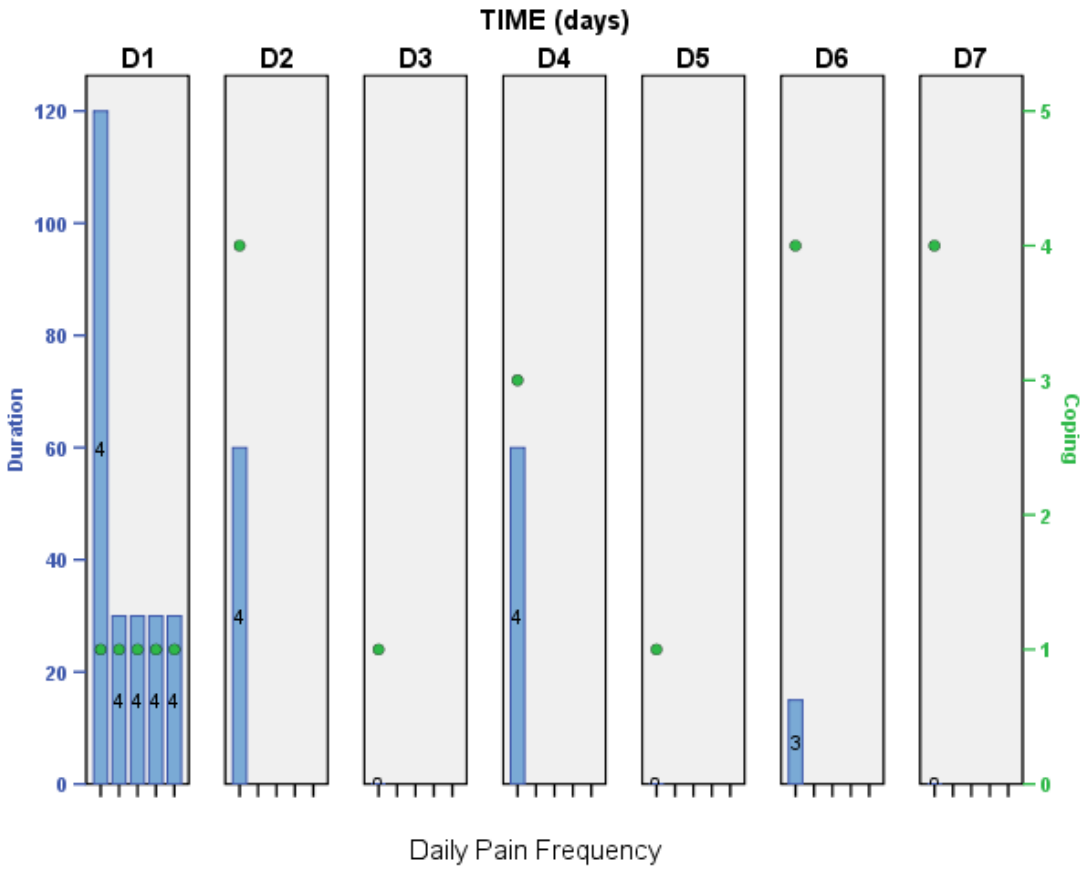
The "stability" of pain has different meanings medical and statistical contexts. In the medical context, the focus is on management of pain. Pain control is considered to be stable if breakthrough pain intensity is less than or equal to 3/10 on an 11-point scale for

three consecutive days and there are less than three doses of breakthrough pain medication required (Fainsinger et al., 2005). However, the focus of the present study was on stability of pain characteristics in a statistical sense (i.e., numerical stability of scores at any point on a continuum) and was unrelated to pain control or breakthrough pain medications. One of the aims of the present study was to determine the extent to which patients' pain characteristics and level of coping fluctuated over days. Therefore stability of scores for pain characteristics above 3/10 was also of interest. Breakthrough pain (frequency, duration and intensity) and level of coping were deemed to be stable if scores on these variables were identical for at least 5/7 or 4/5 days in the diaries. Scores that did not fall within these parameters were deemed to be unstable.

The first proposition was that breakthrough pain characteristics and coping may not be stable over time. As predicted, the diary records of most patients revealed that breakthrough pain characteristics were variable and unpredictable, that is, mostly unstable, however level of coping was mostly stable. In addition, a direct relationship between breakthrough pain characteristics and level of coping was not observed in any of the graphical summaries. There were four patterns observed in the data: unstable breakthrough pain characteristics and coping, unstable breakthrough pain characteristics or coping, stable breakthrough pain characteristics and coping, and stable breakthrough pain characteristics or coping. Graphical summaries of these patterns will be presented to address the first proposition. First, four examples of unstable patterns are presented, followed by four example of stable patterns.

Unstable patterns of breakthrough pain and coping. Five graphical summaries (Figures 6.3, 6.4, 6.5, 6.6, & 6.7) are presented to illustrate the highly unstable nature of breakthrough pain characteristics and levels of coping. Three patients (20%) reported inconsistent patterns on all variables. For these patients, level of coping varied over days from not coping to coping very well. In addition, the number of breakthrough pains (between 0 and 8 daily), duration of pains (very short to prolonged) and intensity (mild to severe) were highly variable.

An example of unstable patterns of breakthrough pain (frequency, duration and intensity) and unstable level of coping can be seen in Figure 6.3. This patient's level of coping fluctuates from not coping (Days 1, 3 & 5), to coping moderately well (Days 2, 6 & 7). Breakthrough pain occurred from zero (Days 2, 5 & 7) up to five times in one day (Day 1) and ranged from short (Day 6) to long duration (Day 1). Intensity varied from moderate (Day 1) to severe pain (Days 1, 2, & 4). However, it is clear from the example that breakthrough pain is not the only influence on coping. This patient reported that she was not coping both on days on which she experienced frequent breakthrough pain of severe intensity and medium to long duration, and on two days when no breakthrough pains were reported. In addition, the experience of the breakthrough pain did not necessarily result in low coping. High coping was not precluded by the presence of at least one moderate intensity breakthrough pain (Day 2).



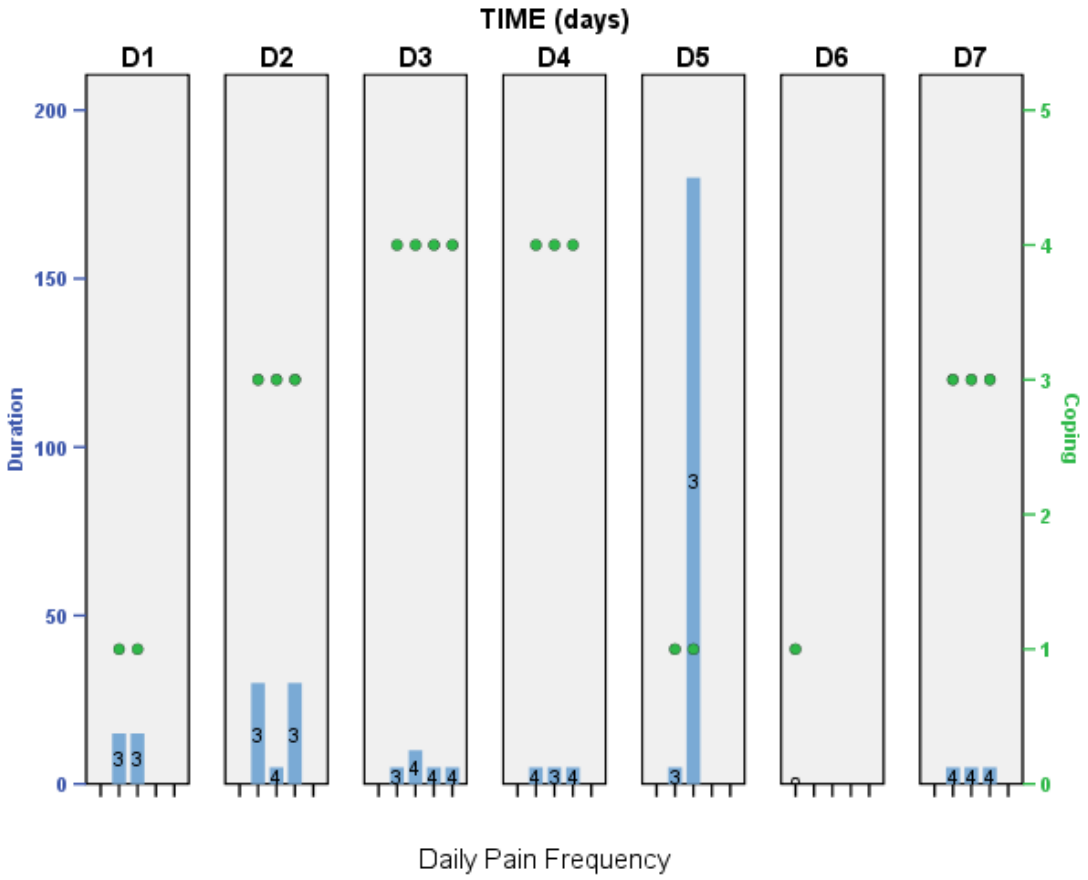
Legend

Intensity	1-5
Duration (mins)	height of the bars
Coping	●

Figure 6.3. Pattern of both unstable breakthrough pain characteristics and unstable coping over 7 days.

Unstable coping. Only four patients (26.67%) reported unstable levels of coping, that is, coping ranged from not coping to coping very well. All patients with unstable coping patterns reported days in which they did not cope with breakthrough pain.

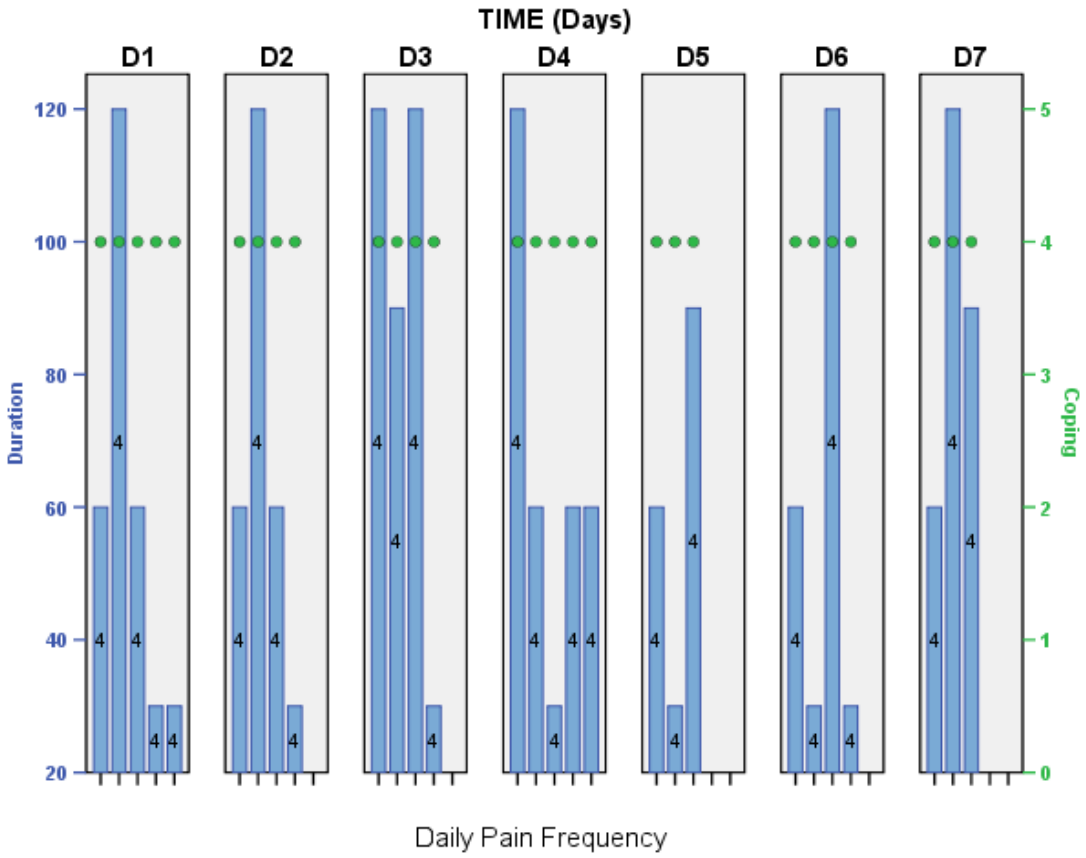
An example of an unstable pattern of coping is that of a patient reporting daily levels of coping ranging from not coping to coping moderately well (Figure 6.4). This patient reported not coping (on Days 1, 5, & 6) when breakthrough pains were absent or of very short to short duration and of moderate intensity or less. In contrast, she reported that she was coping moderately well (on Days 3 & 4) when breakthrough pains were more severe and frequent. Therefore, no direct relationship between breakthrough pain and coping was observed for this patient.



Legend
Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.4. Pattern showing unstable coping over 7 days.

Unstable breakthrough pain frequency. Nine patients (60%) reported unstable frequency of breakthrough pain during the diary week. Daily breakthrough pain frequency for these patients varied from 0 to 8. For example, one patient reported that the frequency of breakthrough pain varied between three (Days 5 & 7) and five (Days (1 & 4) per day (Figure 6.5). Despite unstable breakthrough pain duration, this patient consistently reported that she was coping "moderately well." Again, there was no evidence of a direct relationship between level of coping and breakthrough pain frequency.



Legend

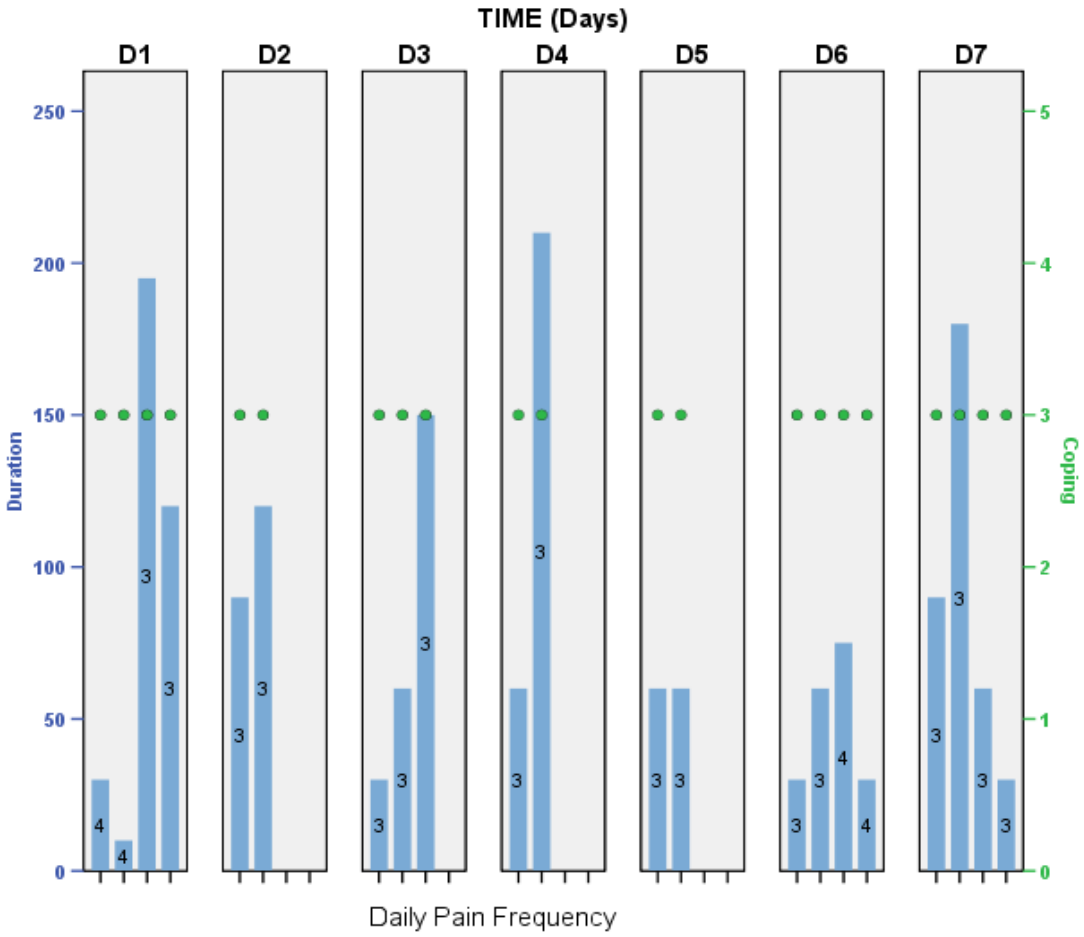
Intensity 1-5

Duration (mins) height of the bars

Coping

Figure 6.5. Pattern showing unstable breakthrough pain frequency over 7 days.

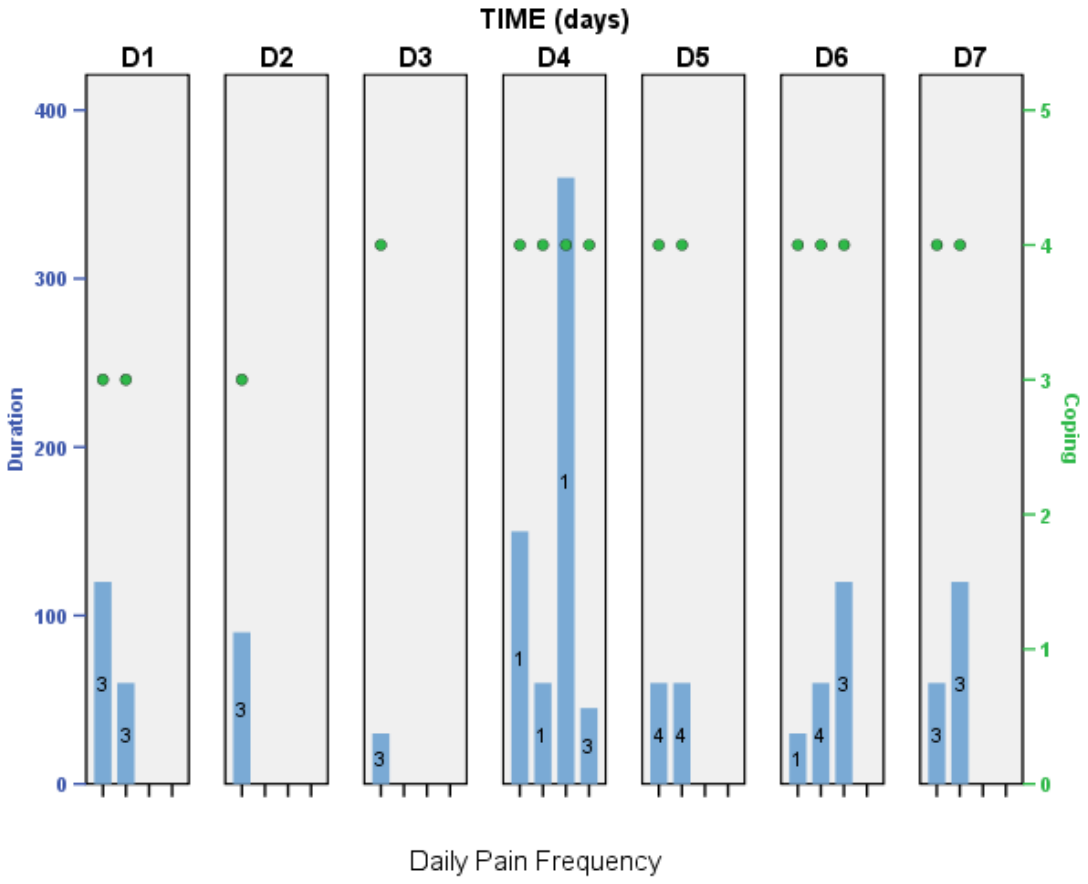
Unstable breakthrough pain duration. Ten patients (66.67%) reported unstable breakthrough pain duration. Daily breakthrough pain ranged from very short (less than 10 minutes) to prolonged (more than 120 minutes) in duration. For example Figure 6.6 illustrates a patient who reported breakthrough pain duration ranging from very short to prolonged. Again, it can be seen that there is no evidence of a direct relationship between breakthrough pain duration and level of coping with pain. Coping remained stable despite changes in breakthrough pain duration.



Duration (mins) height of the bars
Coping ●

Figure 6.6. Pattern showing unstable breakthrough pain duration over 7 days.

Unstable breakthrough pain intensity. About half of the patients (53.33%) reported unstable breakthrough pain intensity in the pain diaries. In one example, a patient reported daily breakthrough pain intensities that varied from mild to severe (Figure 6.7). Severe pain intensities tended to be of medium duration and mild to moderate intensities varied in duration from short to prolonged. This patient also reported coping moderately well, despite varying pain intensity, and therefore there is no evidence of a direct relationship between pain intensity and coping.

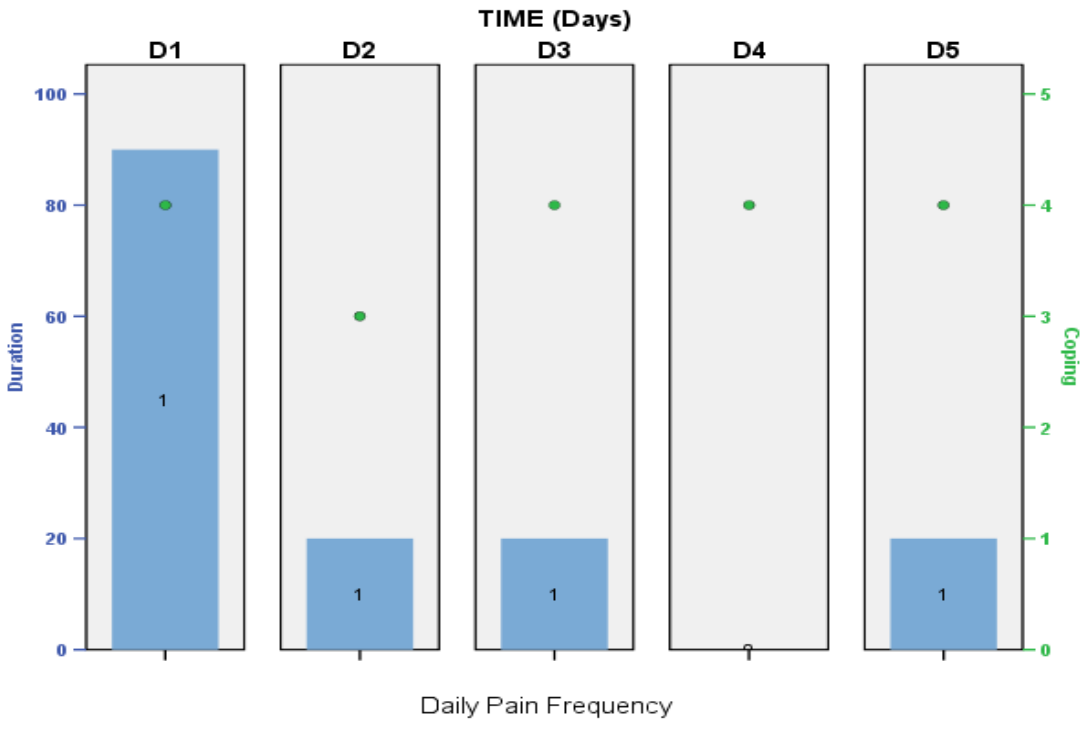


Legend
Intensity 1-5

Duration (mins) height of the bars
Coping ●

Figure 6.7. Pattern showing unstable breakthrough pain intensity over 7 days.

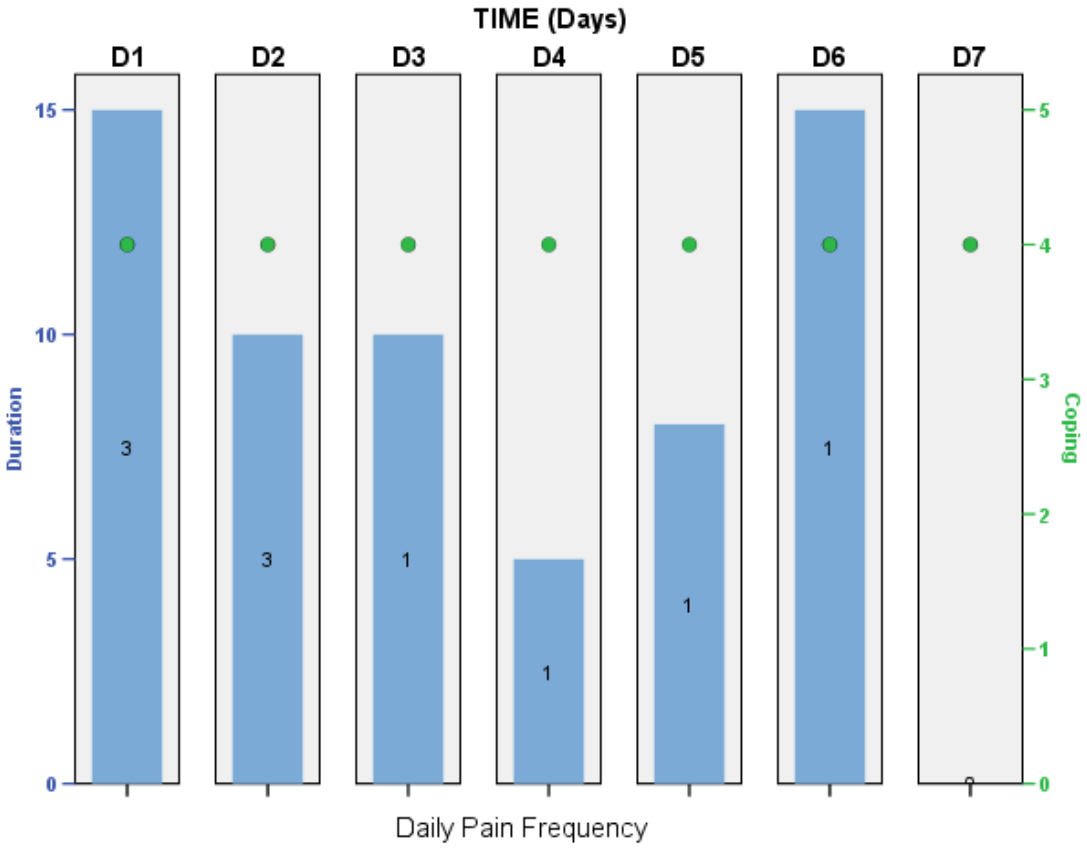
Stable patterns for breakthrough pain characteristics. The pattern of variables is deemed to be stable if scores are the same for 5/7 or 4/5 days in the diaries. Four case graphical depictions are presented to illustrate stable patterns of pain and/or coping. Only four patients (26.67%) reported consistent patterns of on all variables: breakthrough pain (frequency, duration and intensity) and level of coping. Of note, patients with consistent pain and coping patterns all reported mild, infrequent (one per day or less) breakthrough pain of short to medium in duration. They were also coping moderately well. Figure 6.8 illustrates patterns of pain and coping for a patient who was coping moderately well, and reported breakthrough pain that was infrequent and usually medium in duration.



Legend
Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.8 . Pattern showing both stable breakthrough pain and coping over 5 days. Stable coping.

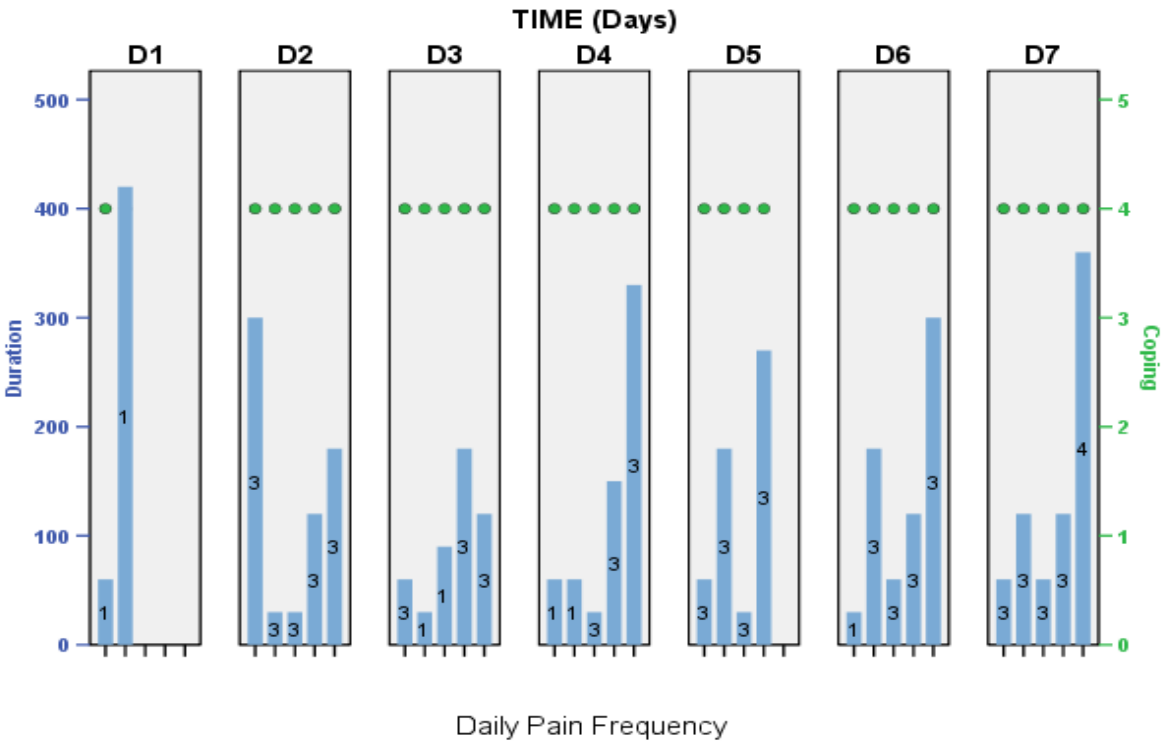
Eleven patients (73.33%) reported consistent patterns of coping, despite unstable breakthrough pain characteristics. All but two of the patients with consistent coping patterns reported coping moderately well. No patients reported consistently not coping. One patient (6.7%) reported consistently coping very well and one patient reported consistently coping sometimes. Figure 6.9 summarises data for a patient with consistent levels of coping. This patient usually experienced infrequent mild breakthrough pains of very short to short duration.



Legend
Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.9. Pattern showing stable coping with pain over 7 days.

Stable breakthrough pain frequency. Six patients (40%) reported stable patterns of daily breakthrough pain frequency (range: 0-5). Only one patient (6.7%) reported consistently frequent severe pain and three (20%) patients reported infrequent mild pain. Figure 6.10 illustrates a pattern of stable pain frequency. This patient reported about five breakthrough pains per day of variable intensity and duration. Level of coping with pain was consistently rated as moderately well. No direct relationship between pain frequency and level of coping was observed for this patient.

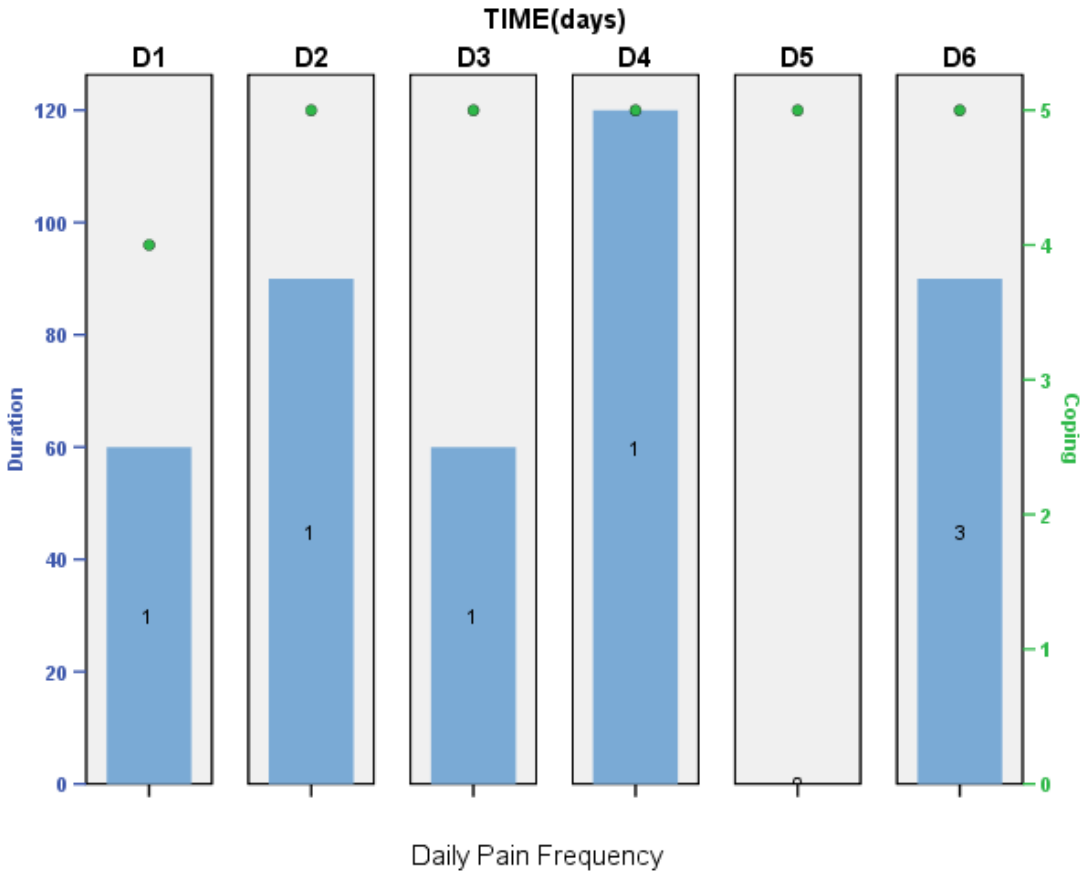


Legend

Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.10. Pattern showing stable breakthrough pain frequency over 7 days.

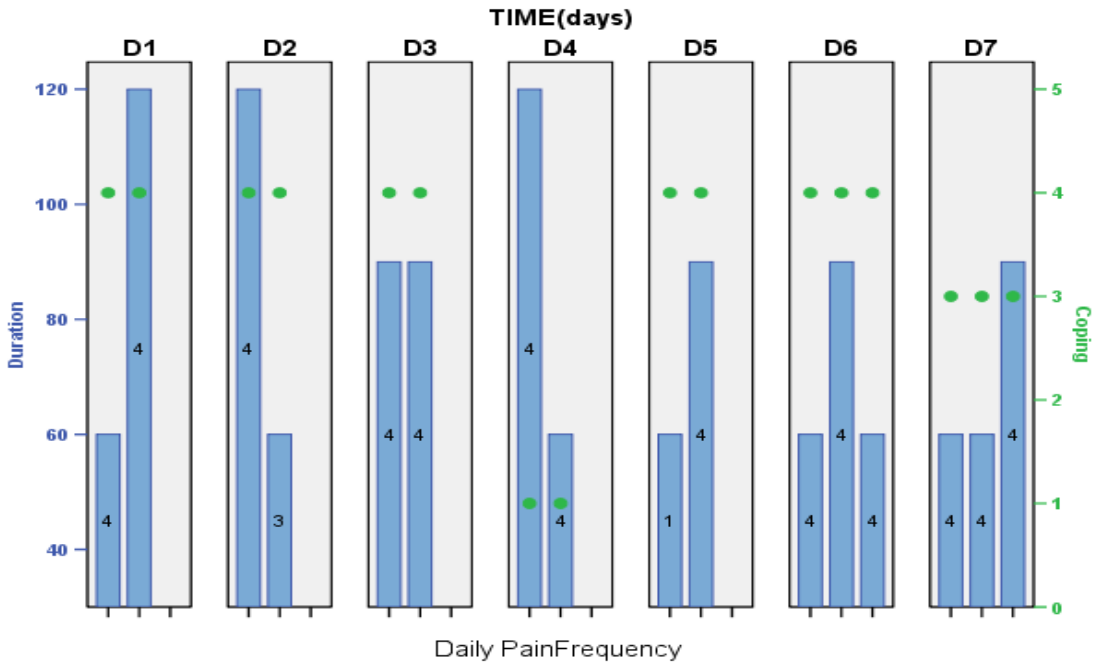
Stable breakthrough pain duration. Five patients (33.33%) reported stable ratings of breakthrough pain duration. In only one case (6.67%) was there stable brief breakthrough pain (see Figure 6.9.) Figure 6.11 on the other hand, illustrates a patient whose breakthrough pain was always of long duration (i.e., 60-120 minutes in duration). Although this patient's breakthrough pain episodes were long in duration, they were mild in intensity and occurred infrequently. Self-rated level of coping indicated that the patient was consistently coping "very well".



Legend
Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.11. Pattern showing stable breakthrough pain duration over 6 days.

Stable breakthrough pain intensity. Seven patients (46.67%) reported stable breakthrough pain intensity in the pain diaries.Two patients (13.33%) reported breakthrough pain intensity that was consistently severe for at least five days, and two patients (13.33%) reported breakthrough pain intensity that was consistently mild. Figure 6.12 provides an example of a patient with stable breakthrough pain intensity. This patient experienced at least one severe breakthrough pain of long duration per day over a period of seven days. Although the patient was coping moderately well overall, he reported that he was not coping with his pain on Day 4 and only coping sometimes on Day 7. No direct relationship was observed between pain intensity and level of coping with pain during the period of the diary.



Legend
Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.12. Pattern showing stable breakthrough pain intensity over 7 days.

In summary, contrary to expectations, most patients reported stable levels of coping over five or more days. Most were coping moderately well. However, as expected, at least one characteristic of breakthrough pain was unstable for most patients. Most breakthrough pains were variable and unpredictable. Although patients were asked to identify any triggers of their pain, in most cases none could be identified. However, despite these trends, there were exceptions for individual patients, who showed stability in coping, whether breakthrough pain was stable or unstable. There was no evidence of a direct relationship between level of coping and any breakthrough pain characteristic (frequency, duration or intensity). This result is likely to reflect the many other factors that impinge on this relationship, some of which were reported in Part 2.

Comparisons between Summative Reports and Diary Reports of Breakthrough Pain and Coping.

This section explored the second aim, to compare summative retrospective data from the previous two weeks (reported at the interview) with accounts of breakthrough pain characteristics and coping in the diaries. Results indicated that despite most patients reporting that they cope relatively well in the summative accounts, only four of these patients (26.67%) reported levels of coping in their diaries that were consistent with these reports (i.e., four patients reported either higher or lower levels of coping in their diary than reported on the day of interview). There was even less consistency between summative scores and reports in diaries for breakthrough pain characteristics. Only two patients (13.33%) made reports of consistent breakthrough pain frequency, one patient (6.67%) consistent duration, and one (6.67%) intensity. These patients reported episodes of breakthrough pain which were infrequent, medium in duration and moderate (or less) in intensity.

Summary. For most patients, prospective day-by day reports of breakthrough pain characteristics (frequency, duration and intensity) and level of coping reported in the diaries were not consistent with patients' retrospective summative reports of breakthrough pain and coping from the interview. It is not surprising that reports of breakthrough pain characteristics were inconsistent given the extent to which it was unpredictable from day to day. However, these patients also exhibited inconsistent patterns of coping (despite most reporting a relatively high level of coping). For these

patients, summative accounts of breakthrough pain and coping from the previous week were very poor predictors of the levels of breakthrough pain frequency, duration and intensity, or coping that were experienced in the following week. Those few patients whose reports in the interview and pain diaries were consistent, were experiencing breakthrough pain that was infrequent, less intense and of short to moderate duration. I concluded that the widespread practice of using retrospective summative reports of breakthrough pain and coping to guide clinical care may not provide information that captures the patients' experience when breakthrough pain intense, frequent and longer in duration.

Part Two

The second component of this study presents case studies that illustrate patient experience of breakthrough pain and coping in the context of the meaning of pain. It addresses the third aim of this study, to provide a greater understanding of the relationships between breakthrough pain characteristics, meaning of pain and coping. Specifically, it examined whether patients who subscribe to aversive meanings of pain report different experiences of breakthrough pain (frequency, duration and intensity) and coping than patients reporting non-aversive meanings of pain, during the following week the initial interview.

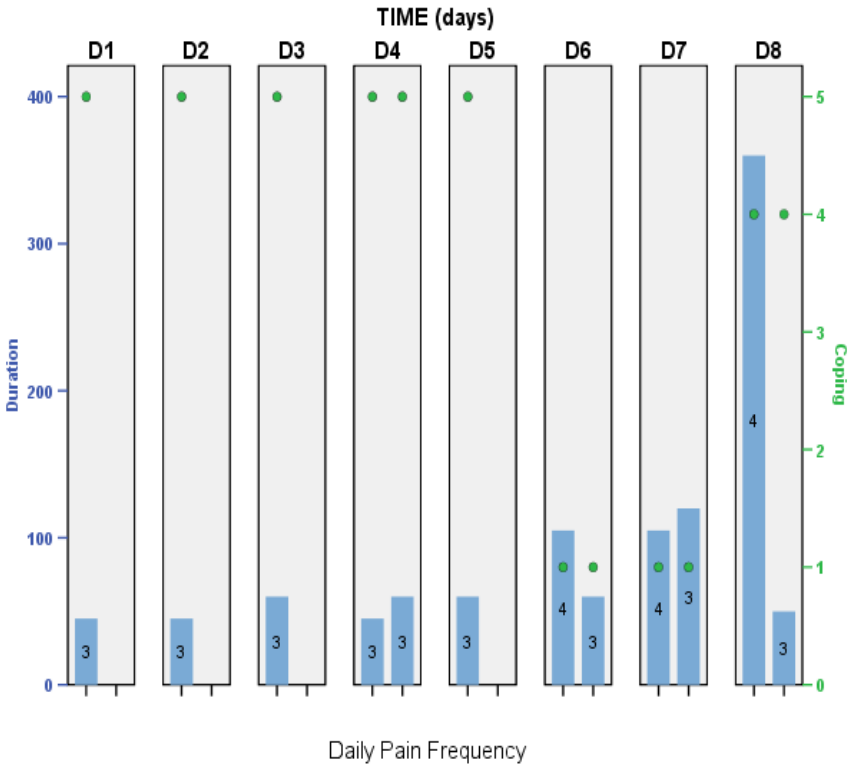
Breakthrough Pain Characteristics, Meaning of Pain Coping

Breakthrough pain was variable and unpredictable for most patients. It occurred between 0 and 8 times per day with mild to excruciating intensity and lasted from a very short to

a prolonged duration. Despite this, it was relatively rare for patients to report that they were not coping well. More than half the sample (53.3%) reported coping moderately well, or better. In addition, most patients reported multiple meanings of pain, of which one meaning was dominant, and one patient described both aversive and non-aversive meanings, with equal detail. In general, patients who reported non-aversive meanings of pain also reported more consistent levels of coping in their diaries. Direct relationships between breakthrough pain and coping, and meaning of pain were not observed in any of the summary graphs.

Aversive meanings of pain. Approximately half the patients (53.3%) reported dominant aversive meanings of pain, such as "loss," "punishment," and "fear/worry." Although reports of low levels of coping were rare, all patients who reported "loss" as the dominant meaning of breakthrough pain reported that they were not coping well on at least one of the days for which they completed the diary. Half of the patients with aversive meanings of pain also reported inconsistent and variable patterns of coping and worse patterns of breakthrough pain frequency, duration and intensity in their pain diaries, relative to reports at the initial interview. Examination of the case studies revealed that inconsistent (fluctuating) levels of coping were associated with aversive meanings of pain, when breakthrough pain was reported as being more extreme in frequency, duration and intensity reported during the period in which the diary was completed. An example of a patient with aversive meanings of pain was provided by a 72-year-old woman with cancer of the lungs and bones, who made diary entries over 16

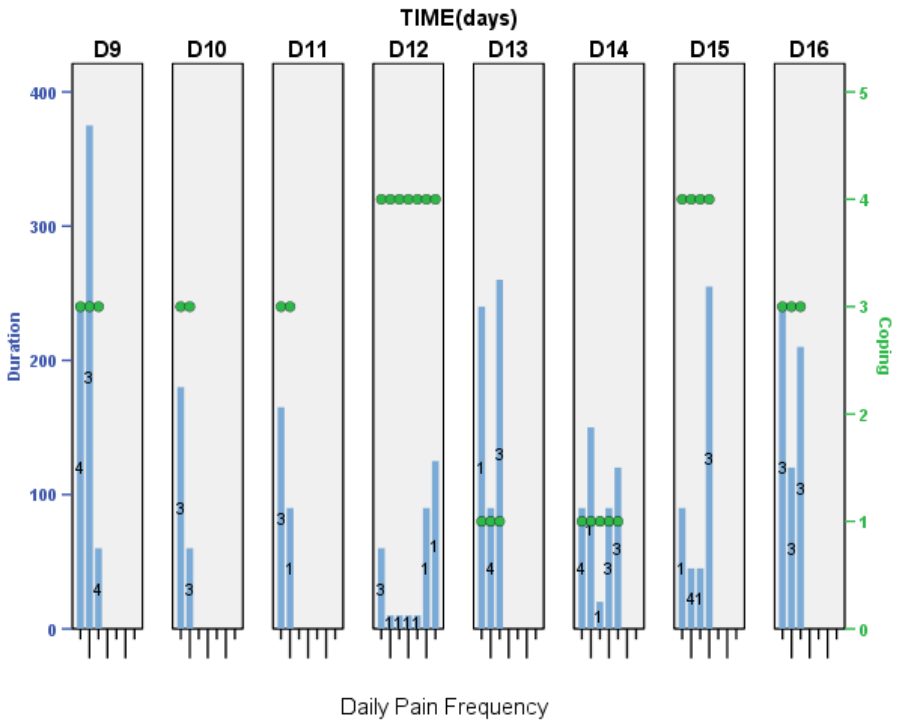
consecutive days (Figure 6.13a, 6.13b).



Legend
Intensity 1-5
Duration (mins) height of the bars
Coping ●

Figure 6.13a. Pattern of breakthrough pain and coping for a 72-year-old woman with an aversive meaning of pain over 8 days.

She reported a dominant meaning that pain had "multiple losses" and secondary meanings of punishment and challenge. At the initial interview, this patient reported an average of two severe breakthrough pains per day which lasted one hour each, and was coping very well. However, in her breakthrough pain diary, her level of coping was observed to fluctuate as breakthrough pain frequency and duration increased and breakthrough pain intensity became more variable. Furthermore, level of coping was generally lower when breakthrough pain was more frequent and longer lasting (Days 9-16).



Legend

Intensity	1-5
Duration (mins)	height of the bars
Coping	●

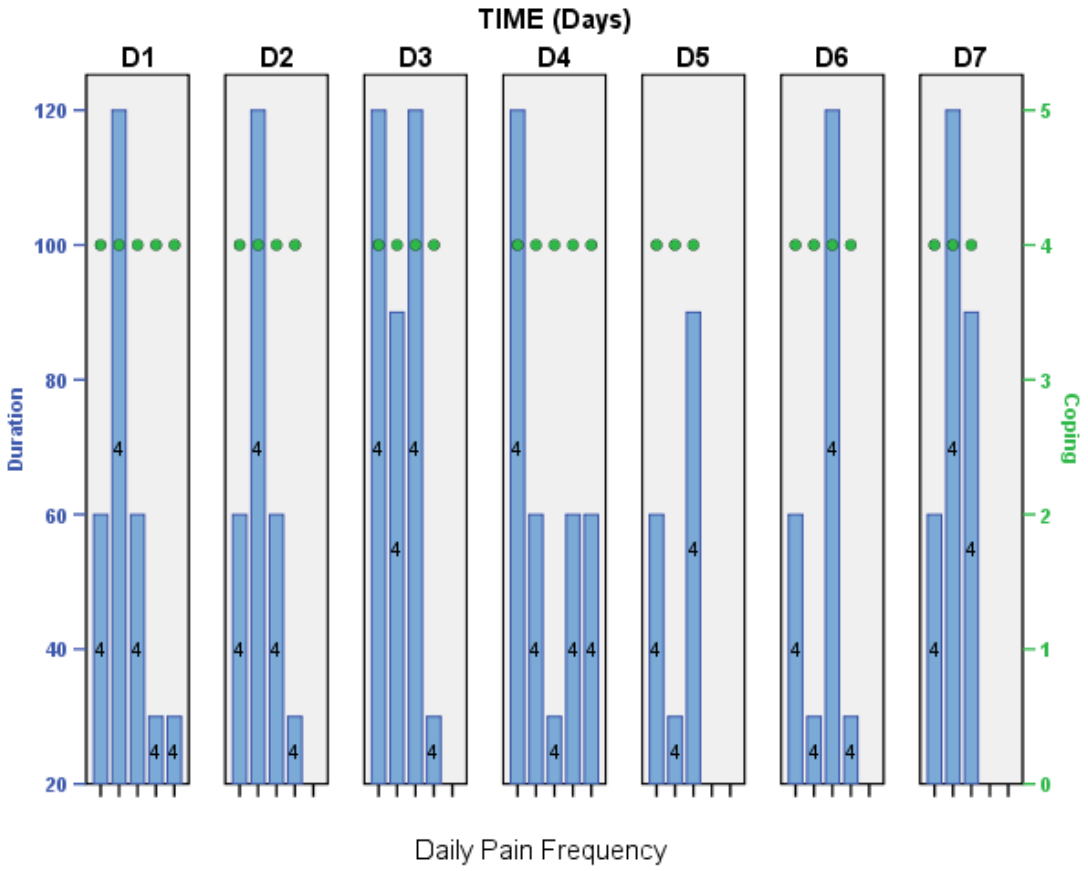
Figure 6.13b. Pattern of breakthrough pain and coping for a 72-year-old woman with an aversive meaning of pain for a further 8 days.

However, half of the patients reporting aversive meanings of pain also reported higher levels of coping. Two case studies illustrate this. One example is provided by a 66-year-old man with cancer of the prostate, and for whom pain signified "loss." At the initial interview, he reported that he was only coping sometimes and was experiencing severe and prolonged breakthrough pains occurring about 3 times per day. However, his breakthrough pain frequency, duration and intensity decreased during the week in which the diary was completed. During this period his level of coping increased (see Figure 6.11). A second example was provided by a 53-year-old man with cancer of the colon

and rectum, and aversive meanings of pain (enemy and weakness), reported at his initial interview that he was coping sometimes. He had excruciating breakthrough pains which was of very short duration but occurred up to 4 times per day. Yet as his breakthrough pain became more variable in frequency and intensity, (mild to severe) and longer in duration during the week of the diary, his level of coping increased to moderately well (see Figure 6.7). In summary, examination of these case studies did not reveal a relationship between level of coping and aversive meanings of pain when breakthrough pain intensity was relatively mild, less frequent or shorter.

Non-aversive meanings of pain. A little under half of the patients (46.67%) reported non-aversive dominant meanings of pain, such as "challenge", "just the disease" and "value." It is noteworthy that all of these patients reported consistently coping moderately well in the breakthrough pain diaries, in spite of worsening breakthrough pain (60%). In contrast, relationships between non-aversive meanings of pain and coping were not evident from the graphs when breakthrough pain was mild, infrequent and short in duration (Figures 6.8, 6.9, & 6.10). However, examination of the case studies, and the graphical summaries, for patients with non-aversive meanings of pain revealed different patterns of breakthrough pain and coping when breakthrough pain characteristics were more severe. For example, Figure 6.14 represents patterns of breakthrough pain and coping reported by a 79-year-old woman with cancer of the bone. She reported a dominant meaning of pain as having "value" and secondary meanings of "challenge" and "loss." At the initial interview she reported coping very well, and had an average of one breakthrough pain of moderate intensity and short duration per day.

However, her breakthrough pain frequency increased to three to five pains per day of severe intensity and of medium to long duration during the next seven days. Despite the worsening of all breakthrough pain characteristics, she consistently reported that she was coping moderately well. These results suggest that non-aversive meanings of pain may increase the likelihood of better coping, when some or all of the breakthrough pain characteristics are problematic.



Legend

Intensity 1-5

Duration (mins) height of the bars

Coping ●

Figure 6.14. Pattern of breakthrough pain and coping for a 79-year-old woman with a non-aversive meaning of pain.

In summary, the relationship between level of coping with breakthrough pain and meaning of pain is complex, and there is considerable variability in the strength of this relationship between individuals. Non-aversive meanings of pain may have a positive relationship with level of coping despite worsening breakthrough pain. On the other hand, aversive meanings of pain seem to be associated with inconsistent and variable levels of coping when breakthrough pain frequency, duration or intensity is higher. A relationship between meaning of pain and coping was not evident when breakthrough pain was mild, infrequent and of short duration.

DISCUSSION

The present study examined patterns between breakthrough pain characteristics, one psychological factor, adjustment and relationships between these variables, from a person-focused perspective. It should be noted, however, that most of the patients in this sample were coping moderately well to very well. A sample that is skewed towards those patients who are functioning well is not ideal to answer the research questions. Of note, the experience of data collection was time consuming, even when the number of questions was minimised in order to limit the burden on patients. Patients exhibited an enormous need to talk with someone who was not connected with their primary care, or their family. Consequently, in some cases, the interview took up to 60 minutes. This need to talk with an independent person has been documented in the palliative literature (Davy & Ellis, 2000). However, this experience during data collection has not been reported in previous pain research in palliative care. Although it did not prevent the collection of relevant data, it was an unexpected additional burden on patients' energy.

Anticipation of such an effect highlights the importance of using brief measures with patients in the advanced stage of illness.

The present study addressed three research questions. The first explored the consistency of breakthrough pain characteristics (frequency, duration and intensity) and adjustment (level of coping) over seven consecutive days. Most patients were consistently coping moderately to very well. However, even among a sample of patients who were coping well, most episodes of breakthrough pain were unpredictable, and variable in frequency, duration and intensity. Therefore breakthrough pain is a challenging symptom for patients, carers and health providers. Its unpredictable nature, as well as frequency, duration and intensity renders pain management decisions difficult. Does the patient take strong opiates which may not take effect until the pain episode is over, leaving them drowsy and less able to engage in enjoyable activities? Or should they delay taking the medication, risking prolonged periods of severe or worse pain intensity?

The unpredictability and variability in breakthrough pain is evident in existing literature. Breakthrough pain was reported as unpredictable and usually distressing in intensity occurring on average 4-7 times per day and lasting about 1-35 minutes (Davies et al., 2008; Mercadante et al., 2002; Portenoy & Hagen, 1990; Portenoy, Payne & Jacobsen, 1999; Zeppetella, 2008; Zeppetella, O'Doherty & Collins, 2000). In Study 2 most patients reported moderate intensity breakthrough pain occurring five times per day and lasting between 1 and 6 minutes, while in Study 3, most patients reported moderate breakthrough pains that occurred once per day and lasted between 1 and 120 minutes.

However, these studies utilised summative and retrospective reports about breakthrough pain characteristics. In the present study, use of breakthrough pain diaries demonstrated the unpredictability and variability in breakthrough pain characteristics for the individual patient over a period of at least five days. In contrast to Studies 2 and 3, direct relationships between breakthrough pain characteristics and adjustment were not detected from the graphs constructed from breakthrough pain diary data.

The second research question explored the consistency between retrospective summative measures of breakthrough pain characteristics and level of coping, and daily records of breakthrough pain and coping. This comparison revealed that level of coping and breakthrough pain characteristics reported at the initial interview did not foretell breakthrough pain characteristics and adjustment during the following seven days. The finding was consistent with existing literature that suggests that diaries are a more appropriate way of assessing fluctuating pain intensities (de Wit et al., 1999; Foley, 2004; Schumacher, Koresawa, Dodd, Tripathy, Koo, & Miaskowski, 2004). However, previous studies have not compared summative data with daily reports of level of coping and breakthrough pain characteristics, and most have not been conducted exclusively among patients with advanced cancer. The present study extended existing knowledge in this area, by demonstrating that, although retrospective and summative reports of breakthrough pain and adjustment provide general understanding of breakthrough pain characteristics and adjustment among patients with advanced cancer, a weekly average of breakthrough pain characteristics and coping does not reflect day-to-day fluctuations and individual differences in these variables for patients with more severe pain. This

finding may have particular relevance to future research and clinical practice, both of which usually obtain information about breakthrough pain characteristics and adjustment from retrospective measures.

The third question examined differences in pain characteristics (frequency, duration and intensity) and adjustment (level of coping), between patients reporting aversive and non-aversive meanings of pain. Aversive meanings of pain were reported by a little over half of the patients. All patients who reported that they were not coping as well reported aversive meanings of pain. However, a relationship between level of coping and aversive meanings of pain was not observed when breakthrough pain was infrequent, shorter in duration and milder in intensity. Lower and less consistent levels of coping were reported by patients with aversive meanings of pain and also more severe breakthrough pain characteristics. In contrast, all patients reporting non-aversive meanings of pain reported consistent levels of coping (moderately well) even with worsening breakthrough pain intensity and increased breakthrough pain frequency and duration.

These results are consistent with previous literature. The meaning "challenge" (non aversive) was found to be associated with lower pain intensity and better coping (Barkwell, 1991). Similarly, poorer outcomes were reported when meaning of pain was associated with death (aversive meaning) (Ferrell & Dean, 1995). The aversive meanings of pain, "weakness" (Study 2) and "punishment" (Study 3) were also found to be associated with poorer adjustment. Study 2 found a relationship between meaning of

pain as an "enemy" and a "weakness" (aversive). Higher breakthrough pain frequency and the meaning of pain as a "punishment" (aversive) were associated with higher breakthrough pain intensity (Study 3). The present study extended existing knowledge about the relationships between breakthrough pain characteristics, meaning of pain and adjustment, by finding different patterns in these relationships for patients with aversive and non-aversive meanings of pain. Although direct and indirect relationships between predictors and adjustment were not able to be tested using qualitative data, these results allude to the possibility that non-aversive meanings of pain may temper the influence of breakthrough pain characteristics on adjustment. Similarly, aversive meanings of pain may have the opposite effect, when breakthrough pain (frequency, duration and/or intensity) is worse.

The present study has three limitations. First, the sample was biased towards those who were coping well and therefore the resulting restricted range on scores precluded answering the research questions for patients across the range. Second, the results cannot be generalised to other populations. The sample was very small and derived from two palliative care services in Adelaide with two distinct features that are not characteristic of palliative care services throughout the world. The socio-demographics and the treatment protocols (e.g., pertaining to the administration of opiate medication, availability of alternative therapies) in Australia differ between countries. For example, the Australian sample consisted of patients who all had access to affordable health care and opiate medications under the National Health Insurance Scheme. The level of access to this treatment, and its affordability varies from country to country. In addition, despite

the high degree of diversity in the Australian population, all patients in the sample were Caucasian. It is important to note the absence of non-Caucasians in the sample, because their beliefs and attitudes to pain and its treatment may differ, and these beliefs and attitudes are likely to be reflected in the meanings they ascribe to pain. Furthermore, the attitude to, and availability of alternative therapies is likely to differ in a Western population to that of Eastern Countries (e.g., Taiwan). Such differences in socio-demographic characteristics and treatment protocols may influence the meaning that patients ascribe to pain, and the likelihood that they will report specific pain characteristics, and their level of coping. Consequently the generalisability of the findings of the present study may be limited. Third, a measure of coping was used on a daily basis only. Therefore it is possible that the level of coping may have been more variable that the results have indicated. Ideally, it would have been desirable for the breakthrough pain diary to have been continued for at least two weeks, and a measure of coping recorded for each breakthrough pain. Most patients, however, were not able to manage more than five to seven days. Further research in a larger sample, with scores across the range, and using a measure of coping for each breakthrough pain episode over a longer period of time, may confirm these findings.

Despite its limitations, the present study offers three main contributions to the field. First, the person-focused quantitative approach provided rich insights in meaning of pain that have not previously been reported in quantitative or qualitative methods. The strength of this person-focused approach is that it explores these phenomena on an individual basis, revealing patterns and relationships that were otherwise not evident

when reporting group averages. The person-focused approach allowed the extent of variability of breakthrough pain characteristics (frequency, duration and intensity) and adjustment, and the relationship with meaning of pain to be demonstrated both in individual patterns and as group trends. Second, the present study extended existing knowledge of breakthrough pain characteristics (frequency, duration and intensity) among patients with advanced cancer, by demonstrating that the common practice of asking patients for retrospective summative reports of breakthrough pain may not provide information that captures the experiences of individual patients, or predict subsequent needs. Third, different patterns of adjustment were revealed for patients with aversive, compared to non-aversive meanings of pain. Patients with non-aversive meanings of pain generally reported higher and more stable levels of coping. These observations are consistent with previous research among cancer patients in active treatment (e.g., Ferrell & Dean, 1995) and patients with advanced cancer (Barkwell, 1991). Poorer coping was associated with aversive meanings of pain in Studies 2 and 3, however relationships with non-aversive meanings were not found.

These findings are worthy of further exploration and need to be confirmed in a larger study that includes patients who are not coping well. A mixed methods study, utilising qualitative measures of meaning of pain may establish the independent variance in adjustment, accounted for by aversive and non-aversive meanings of pain, above and beyond that accounted for by breakthrough pain characteristics. The ability to identify patients who ascribe aversive meanings to pain may alert clinicians to patients who are at risk of poorer adjustment, and who would benefit from additional interventions.