

## **Chapter 5**

# **MEANING OF PAIN – A PERSON-FOCUSED QUALITATIVE STUDY**

Although the main aim of this thesis is to examine the influence of psychological factors on the relationship between pain and adjustment among cancer patients receiving palliative care, the present study is concerned with a detailed examination of one psychological factor, meaning of pain. The purpose of this temporary digression is to capture the full range of meanings ascribed to pain by patients with advanced cancer and to examine possible relationships between these meanings.

As has been discussed earlier, the meaning ascribed to pain is considered to be an important factor in coping with cancer pain (Barkwell, 1991; Ersek, 1994, Ersek & Ferrell, 1994; Lee, 2008; Steves, 1992). However, there has been only partial agreement about which of the meanings ascribed to pain influence coping. For example, poorer coping was associated with the meaning categories “punishment” and “enemy” and higher coping associated with the meaning “challenge.” In Study 2, poorer coping was associated with the meaning of pain category “weakness”, and in Study 3, the meaning “punishment.” However, in Study 3, the meaning categories “loss” and “spiritual” were associated with another aspect of adjustment (more symptoms of depression). These inconsistent findings make it difficult to draw firm conclusions about the relationship between meaning of pain and coping when patients are experiencing breakthrough pain.

Two other factors may have contributed to those inconsistencies: the instability of findings derived from small samples and the attribution of multiple meanings to pain by many patients. The latter phenomenon could not be examined in detail using the

variable-focused quantitative approach adopted in Studies 2 and 3. In such analysis, patients were the “carriers of variables” and relationships between these variables were examined across the sample. The results of Studies 2 and 3 suggest that the meaning of pain is a complex phenomenon showing marked individual differences that may not be able to be meaningfully conceptualised using a variable-focused approach. The present analysis was conducted in order to address some of these difficulties. It examined the meanings ascribed to pain, using a person-focused qualitative approach. The findings concerning meaning of pain will be incorporated into the next study, which examines their relationships with breakthrough pain characteristics, perception of pain management effectiveness and adjustment.

### Meaning of Pain

To recap, meaning-making involves a process of changing one’s perception of the stressful event, in the context of one’s life schemes so that a sense of order and purpose is restored (Richer & Ezer, 2000; Thomson & Janigian, 1988). It is therefore a complex process of adaptation that takes place within the context of an individual’s unique set of experiences. These include the individual’s personal, social and cultural experience (Ferrell & Dean, 1995). Therefore the present study provides a detailed examination of individual differences in the meanings that patients ascribe to their pain.

### Why Use a Qualitative Approach?

A qualitative approach has been adopted in the present study. The variable-focused quantitative methodologies used in Studies 2 and 3 have provided only limited insight into the meaning ascribed to pain. Quantitative methodologies attempt to describe the characteristics of a population and predict causal relationships, whereas qualitative

methodologies aim to describe and explain the nature of relationships, individual experiences and group trends. Quantitative approaches also use a more rigid style of eliciting and categorising information and therefore may not be ideal for providing insight into phenomena, such as meaning ascribed to pain, that are not yet fully documented. Qualitative approaches, on the other hand, are more flexible and iterative in their style of eliciting information and categorising responses and therefore, have greater ability to describe novel meanings (Birks & Mills, 2011; Corbin & Strauss, 1998; Trochim, 2006). This additional flexibility also allows more opportunity for patients to provide elaborated responses that allow fine distinctions to be identified. A variety of qualitative approaches are available, for example, Grounded Theory (Glaser & Strauss, 1967; Glaser, 1998), Narrative (Reissman, 1993), Discourse (Parker, 1994), Content (Weber, 1990) and Domain Analyses (Spradley, 1980). Grounded Theory was judged to be particularly suitable for the present study, because it is not theory driven; it has an individual focus, and does not attempt to describe a cultural or social context.

### Grounded Theory

Grounded Theory (GT) is a systematic qualitative research methodology which is used to develop theory through comparative analysis. It adopts a symbolic interactionism perspective, in which a persons' response to an event is seen as being determined by their understanding and interpretation of the meaning of an event and their ability to communicate this understanding (Blumer, 1969). Grounded Theory was initially developed by Glaser and Strauss (1967) who devised a set of essential procedures for generating theory from empirical data. These procedures are:

- a) Initial, intermediate and advanced coding (the categorising of data for describing implications and details of categories, eventually becoming more selective with respect to core concepts);
- b) Memoing (recording the evolving thoughts/ideas of the researcher with increasing focus on core concepts);
- c) Sorting (integrative diagrams and sessions to pull all the details together and to make sense with respect to emerging theory); and
- d) Writing up the theory that has been developed (theoretical integration).

Constant comparative analysis is undertaken using inductive and abductive logic. Data collection and analysis is conducted concurrently and guides further theoretical sampling, and continues until theoretic saturation is achieved. Further theoretical sampling checking may be performed by checking the accuracy of the codes and categories with the initial participants, by analysis performed by a different researcher, or by revisiting the data at a later time to check that the same codes emerge (Birks & Mills, 2011; Corbin & Strauss, 1998). However all of these approaches have both advantages and disadvantages and none are foolproof.

The trustworthiness of the GT research is influenced by three factors (Birks & Mills, 2011; Corbin & Strauss, 1998; Glasser & Strauss, 1967):

- a) Researcher expertise. Perhaps the most important influence of the research is the extent to which the researcher has developed reflexivity (an active process of systematically developing insight into your work as a researcher as a guide to your future actions), and theoretical sensitivity (a reflection of the sum of the researcher's personal, professional and experiential history. Reflexivity and theoretical sensitivity are essential to the trustworthiness of GT);

- b) Methodological congruence (i.e., the congruence between the researcher's personal philosophical stance, research aims and methodological approach); and
- c) Procedural precision (i.e., the extent to which the procedures for conducting GT were followed). The most important of these procedures are the maintenance of an audit trail, management of data and resources, and the demonstration of procedural logic (Birks & Mills, 2011; Corbin & Strauss, 1998).

The validity of GT is determined according to its fit (how closely concepts fit with the incidents they are representing), relevance (the extent to which it deals with concerns of the participants), workability (it explains how the problem is being solved with much variation) and modifiability (it can be altered when new relevant data is compared to existing data) (Glaser & Strauss, 1967; Glaser, 1998).

GT is still highly regarded as a method of social analysis and is among the most influential and widely used modes of qualitative research (Birks & Mills, 2011; Strauss & Corbin, 1997). However, since its development, there has been disagreement between Glaser and Strauss over the way research using GT should be conducted and interpreted. Glaser advocated for letting the theory emerge from the data (Glaser, 1998), whereas Strauss has focused on the validation criteria and the adoption of a systemic approach. Glaser considers that the latter force the data to form theory (Corbin & Strauss, 1990, 1998). Glaser's criticism of Strauss' approach has been supported by other grounded theorists (e.g., Melia, 1996; Robrecht, 1995).

Other researchers have also criticised GT. These have argued that the process of data analysis lacks transparency and that there is no systematic way of using codes to gain

insight into concepts and themes (Wasserman, Clair, & Wilson, 2009). Wasserman et al. (2009) developed their fractal analytic technique to address these alleged shortcomings, using structured formulae for analysis of data based upon Multi-level Integrated Cognition (MIC) (Wilson & Lowdes, 2004). Essentially, a theory emerges from a series of specified procedures, and the process can be used as a means of testing validity of one's results. Other researchers have challenged the status of the theories of the products (e.g., Thomas & James, 2006). In particular, Thomas and James (2006) challenged Grounded Theories as theories because they believed that GT involves the rejection of simple understanding and denial of existing ways of making sense, by elevating certain kinds of thinking and eschewing other kinds, in order to impose pattern, shape and rationality with categories and sub-categories. However, these and other criticisms have been answered by advocates of GT. For example, Thomas and James' criticisms are not unique to GT. All theories and methodologies have a preferred way of thinking and their own assumptions and structures. No research approach, quantitative or qualitative, is beyond criticism or without shortcomings. Therefore, the original approach to GT, as described by Glaser, has been adopted in the present study. It provides clear steps on the key principles of the method and does not impose any preconceived assumptions about meaning of pain. Second, unlike quantitative methodologies, GT can elicit and accommodate multiple meanings of pain. GT holds the promise of a depth of insight into the meaning of pain that has not been achieved through other methodologies. It also has the potential to demonstrate patterns in the way various meanings relate to each other. The present study employed GT to identify the range of meanings ascribed to pain and to explore patterns among these meanings.

## Method

### Participants

Patients were recruited through purposeful sampling from Lyell McEwin Palliative Care Service and Southern Adelaide Palliative Care Service in Adelaide, South Australia. All participants were adults diagnosed with terminal cancer and were receiving community-based palliative care. These patients also participated in Studies 2 and 3.

Patients were mainly middle aged or elderly ( $M = 65$  years,  $SD = 10.70$ ). The sample was balanced for gender (Females = 50%). All patients were of Caucasian descent and were residents of Australia. Patients had a wide variety of solid tumours (Table 5.1). The most commonly reported tumour sites were lung, colon, liver and pancreas.

Table 5.1

*Primary Diagnosis of Participants  $n = 38$*

Primary site of neoplasm	%
Lung	21.05
Colon	15.79
Liver, Pancreas	15.79
Bone	10.52
Prostate	7.89
Breast	5.26
Kidney	5.26
Other	18.42

### Measures

Information about the meaning ascribed to pain was obtained during an interview conducted by the author. Patients recruited for the study were very ill. It was necessary

to keep the interview as brief as possible. The overriding concern was to minimise the burden imposed upon these patients. Patients were asked to describe what it means to them to experience pain. The following introduction was provided so that patients were better able to understand what was required of them.

*“Now I am going to talk about the different ways that people view their pain. As you probably know, the same experience can mean different things to different people. For example, imagine that you had won lotto. To some people, this may be seen as a relief – they no longer have to work any more or worry about money problems. Someone else may see it as a challenge- to live a good life, to use the money wisely, to help others. Another person may think of it as a loss – that people will now treat them differently, they won’t know who their true friends are, and so on. It is possible that it means all of these things or none of these things to some people. There are many different ways that people can react to the same event. It is the same with pain and disease. Pain and disease can have different meanings to each of us and it can also have more than one meaning. So I am now going to ask you what meanings best describe the way you view your breakthrough pain. You may not have thought about this before (or tried not to think about it) so it is OK if you can’t answer.”*

The initial question was broad, followed by various prompts addressing the central features of the patient’s account. For example, the patients were first asked, “I would like you to tell me in your own words, what getting pain means to you?”

Depending on the response to the initial question, one or several prompts were used to elicit meaning of pain. Some examples of these prompts were,



*“What was going through your mind when you felt the pain?”*

*What images or memories do you have when you feel the pain?*

*What does this mean about your life, your future?*

*What does this mean about how other people see/feel/think about you?”*

The responses to questions about meaning of pain were audio-recorded and later transcribed verbatim for analysis.

### Procedures

Informed consent was obtained from each participant prior to the interview and each patient was given an Information Sheet describing the study (see Appendices E, F, H and I). Patient medical details were obtained from the medical records of patients who consented to participation in the study and to the release of medical information to the researcher. The interview lasted approximately 30 minutes duration and took place in patients' own homes.

### Qualitative Data Analysis

Grounded theory methodology generates a theory through a constant comparative method of analysis (Birks & Mills, 2011; Glaser & Strauss, 1967). Steps in the analytic process are detailed below:

Coding. Multiple readings were made to identify recurrent themes. Line-by-line substantive coding was undertaken, looking for anything that may be potentially relevant (underlining and annotation of the transcripts and writing of theoretical notes or memos). Key points were then identified and selectively coded. A list of codes were

compiled with the key points of core variables in mind. Some examples of these codes are challenge, relief, spiritual and loss.

Categorising. The selective codes were then grouped into categories, which were eventually integrated into theory. Developing and integrating these categories occurred concurrently, in a process of constant comparison and reduction of categories, using theoretical sampling (i.e., going over old notes or memos for data that were already coded or by coding new data), theoretical coding, writing memos, drawing diagrams and using literature as data. Such theoretical codes provided a method of thinking about the data in theoretical rather than descriptive terms. They describe the links and relationships between categories and help to conceptualise how categories relate to each other, and eventually integrate into the theory. For example, the initial code “loss” was later upgraded to a category of “loss” which included which included more differentiated codes such as pain as a general loss, loss of independence/control, loss of opportunity/activity, of isolation and a reminder of past losses. Iterative processes of categorisation also led to the creation of categories relating to the context, and to the ways meanings of pain were reported.

Memoing. Memos were written to help capture ideas, capture relationships between categories, enhance the theoretical ordering of the categories and to integrate existing memos. For example, the memo “some patients are reporting a single meaning of pain and others multiple meanings” noted that for some patients, it was possible to identify patterns between categories that could guide the development of the emerging grounded theory.

Sorting. Mapping or linking of categories using diagrams pulled all of the detail together, captured thoughts on the data and provided a means of documenting tentative hypotheses. Such diagrams helped to discover relationships that may otherwise

not have been apparent in the development of the emerging theory about meaning of breakthrough pain. At this later stage, a further review of the literature was undertaken to enhance the analytic process by seeking to identify similarities and differences between the emergent categories and those that had previously been reported. Categories were mapped or linked according to core categories emerging between and within patients (e.g., meaning, context, patterns).

Theoretical sensitivity. Theoretical sensitivity is defined as the ability to recognise and extract relevant elements for the emerging theory from the data (Banister, Burman, Parker, Taylor, & Tindall, 1999; Birks & Mills, 2011). In the present study, theoretical sensitivity was achieved in two ways, thus enhancing the trustworthiness of the findings. The first method was memoing of the researcher's thoughts, feelings and reflections on the research from data collection through to theory development. The second was personal and functional reflexivity, a continuous, critical analysis of the researcher's writing, personal and professional attitudes and experiences and how these may influence the analyses and emerging theory (Bannister et al., 1999; Birks & Mills, 2011). Reflective memoing was instrumental to considering my personal impact (e.g., in terms of gender, age, values and experience as a researcher. An example of these processes of analysis is provided (Figure 5.1).

Achieving theoretical saturation. Saturation is defined as 'data adequacy' and is achieved by collecting data until coding data from additional participants no longer yields new information that helps to explain the major concept of interest (Glaser, 1978). Initial and intermediate codes and categories were developed from data generated from the interviews. Theoretical sampling (reviewing the interviews at a later time to verify the accuracy of these codes) was conducted to enhance the trustworthiness of the emerging theory. In the present study, a total of 38 interviews

were available. Thirty-four interviews were coded before no new meanings emerged.

Data from the remaining four interviews were coded in order to ensure that theoretical saturation had been achieved.

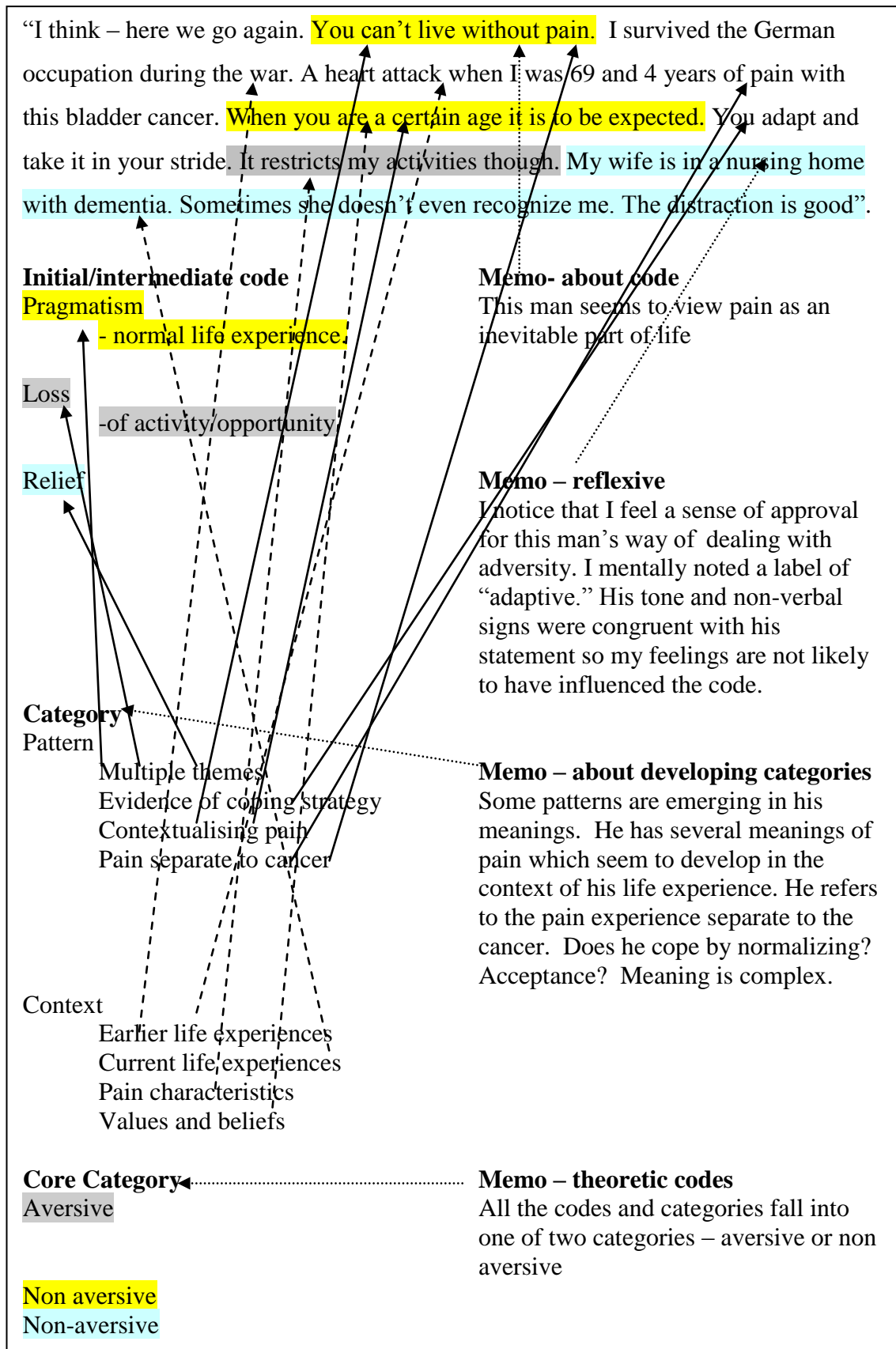


Figure 5.1. An example of coding and memoing of a report by a 37-year-old man with cancer of the bladder.

## Results and Discussion

There are two components to the results section. The first reports the development of codes and categories by identifying the range of meanings that patients ascribe to pain. The second presents case studies illustrating the patterns among meanings that were identified for individual patients.

### Development of Codes and Categories

Qualitative analysis revealed 13 distinct categories, relating to the meaning of pain (loss, pragmatism, fear/worry, challenge, injustice/unfairness, nuisance/burden, enemy/threat, relief, weakness, gratitude, value, punishment and a spiritual meaning). Although the focus of the current analysis was on qualitative data, it is noteworthy that one of these categories, loss, was far more prevalent than others (see Table 5.2).

Some patients made responses that clearly differentiated the meaning ascribed to their pain from the meaning ascribed to their cancer. For example, an 84-year-old woman with cancer in the breast and kidneys, stated,

*“Pain is horrible! It takes away my life. I can no longer be independent, doing things, enjoying life. It is separate to the cancer. Cancer means I haven’t got long to go – it’s hopeless”.*

However, approximately half the patients made responses that did not appear to differentiate between the symptom of pain and the disease. One example was provided by a 67-year-old woman with lung cancer:

*“Pain is a nuisance. It stops me doing what I want to do. It is frustrating. There is also fear – the thought of dying.”*

It is not clear from the data whether pain triggered the fear and was a reminder of mortality. Previous research has also reported that pain is interpreted by some patients as a signal of impending death (Ferrell & Dean, 1995).

Table 5.2

*Prevalence with which Patients Subscribed to Categories of Meaning of Pain (n = 38)*

Theme	n	%	
Loss	19	50.00	endorsed in Studies 2 and 3
Pragmatism	15	39.47	
Fear/worry	12	31.58	
Challenge	9	23.68	endorsed in Studies 2 and 3
Injustice/unfair	7	18.42	
Enemy/threat	6	15.79	endorsed in Studies 2 and 3
Nuisance/burden	6	15.79	
Relief	3	5.26	endorsed in Studies 2 and 3
Weakness	2	5.26	endorsed in Studies 2 and 3
Gratitude	2	5.26	
Value	2	5.26	endorsed in Studies 2 and 3
Punishment	2	5.26	endorsed in Studies 2 and 3
Spiritual	1	2.63	

Note: n adds up to more than 38 because many patients ascribed more than one meaning to their pain.

### Meanings Ascribed to Pain

This section documents the range of categories or meanings that patients ascribed to their pain. Meanings are presented in order of frequency. Examples of each meaning are provided. The extracts may represent more than one category.

Pain as loss. Most commonly, patients referred to their pain as signifying some type of loss. The loss may have been emotional or a restriction or inability to achieve or do something they desired. For some patients, the loss was expressed in general terms without elaboration (see Table 5.3). In some cases, these patients conveyed this meaning in simple statements without any explanation about the type of

loss incurred (e.g., Extract 1). Although Extract 2 may implicitly suggest loss of happiness, the context and manner of delivery of the data suggested a sense of general loss. Ideally, further exploration of her meaning would have been able to clarify this.

Table 5.3

*Examples of the Category “Pain as a General Loss”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
1	48-year-old woman	Periteneum	It [pain] is a loss.
2	75-year-old woman	Lung, bone	I was happy before.

For other patients, this category suggested loss of control or independence (see Table 5.4). These patients reflected on being unable to do the things they used to enjoy doing, the need to rely on others, or loss of control over the choices they previously made for themselves. It is interesting to note that in this sample, more women than men mentioned loss of independence in their life as a result of pain. This is contrary to the general stereotype of women as being more dependent than men. It is important to acknowledge the potential impact of the researcher’s gender on patient responses. Gender stereotypes reported in previous research portray men as less likely to report pain or the impact that pain may have on their well-being (Courtenay, 2009; Eagly & Steffen, 1984). In addition, gender differences between interviewer and interviewee have been found to influence the responses to interview questions (Herod, 1993). Therefore the possibility that responses may have been influenced by the researcher’s gender must be considered. Patients may have felt more comfortable reporting contrary to gender stereotypes in the presence of a researcher of the same gender.



Table 5.4

*Examples of the Category “Pain as a Loss of Independence/Control”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
3	59-year-old woman	Bowel	Pain is a discomfort. It restricts my life and I have lost my independence. It’s disappointing – a real loss.
4	84-year-old woman	Kidney Breast	Pain is horrible. It takes away my life. I can no longer be independent, doing things, enjoying life.
5a	44-year-old man	Pancreas	I can’t do what I want to do. I can’t plan.

On the other hand, more men than women mentioned that their pain was isolating. They were likely to associate pain with loss of the opportunity to interact with others (see Table 5.5). This finding is also contrary to the stereotype that women acknowledge higher social needs than men. Again, the potential impact of the researcher’s gender on patient responses needs to be considered when interpreting the data (Courtenay, 2009; Eagly & Steffen, 1984; Herod, 1993).

Table 5.5

*Examples of the Category “Pain as Loss Through Isolation”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
5b	44-year-old man	Pancreas	I get frustrated due to inactivity. It’s isolating.
6	79-year-old man	Prostate	I can’t get out. The hardest thing is having to stay home, I can’t do anything. I used to and now I can’t.

Some categories refer to the loss of the ability to participate in valued activities (see Table 5.6). This category was noted in data obtained from both men and women and tended to focus upon the activities that they previously enjoyed, but were now unable to do.

Table 5.6

*Examples of the Category "Pain as Loss of Opportunity/Activity"*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
7	79-year-old woman	Bone	I suppose it is a loss too, because it has restricted me so much because there are so many things I would like to do but can't do. It is always like that now.
8	64-year-old man	Bone/ Liver	Pain means there are things I will never do. I have only half the freedom I used to have. I miss things like walking, the garden.

Some patients described pain as representing a loss of the ability to engage in planned activities or future opportunities. This category was reported by both men and women (see Table 5.7). Some patients made reference to loss of future in a very general manner (Extract 9). Others referred to specific sources of disappointment, such as not being alive to see their grandchildren born (Extract 10) or fulfill their retirement plans (Extract 11).

Table 5.7

*Examples of the Category “Pain as Loss of Future”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
9	70-year-old man	Lung	I have lost my future.
10	76-year-old woman	Breast	It makes me think of my grandchildren – I won’t get to see them.
11	55-year-old woman	Gallbladder	I won’t be around. I won’t be able to do what me and my husband planned to do. We were planning to travel around Australia. We bought a caravan to do it so I am so disappointed. I suppose I feel cheated.

Although nineteen patients reported pain as a loss, four patients associated pain with multiple losses (e.g., Table 5.8). The range of losses included reminders of past losses, lost opportunities, lost stamina, loss of intimacy, activity and loss of future.

Table 5.8

*Examples of the Category “Pain as Multiple Losses”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
12	72 - year-old woman	Lung, Bone	It [the cancer and the pain] has slowed me down, makes me tired. It is a loss – I have no energy. The hardest thing of all is having to ask for help. It is isolating – my family live in Queensland. It is a loss.
13	56 - year-old woman	Breast, Bone	I would like someone close who understands, but no one who lives close to me is understanding. It hurts. Loss of my independence, of the chance to develop a relationship with my daughter – it was damaged in the marriage break up. A loss of

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intimacy, love, closeness, understanding. Pain reminds me of all these losses and unresolved issues.

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In summary, patients in this sample referred to a range of losses. There was little evidence to suggest that the meaning of pain as a loss was influenced by age or primary site of the cancer. Although this meaning of pain has been reported in previous studies of cancer pain (Barkwell, 1991; Chen, 1995), and in Studies 2 and 3, the present analysis demonstrated the diverse range of losses that patients report. This diversity of losses was not evident in previous research.

Pragmatic responses to pain. “Pragmatism” was the category I assigned to data that either minimised the significance of, or contextualised pain in a very detached and logical manner (see Table 5.9). Some patients interpreted pain as merely evidence of the disease of which they were already aware.

Table 5.9

*Examples of the Category, Pragmatism. “Pain as Evidence of and Accepted Disease”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
14	79-year-old man	Prostate	It is the cancer. I take it in my stride.
15	75-year-old woman	Liver, Breast	I don't think about it really. It is something wrong with my body that's all. I have cancer. I accept it.
16	72-year-old man	Lung	It's just a pain in the chest, the lungs. The disease
17	54-year-old man	Lung	Pain means that I have a problem. It is a reminder a warning that there is something I have to deal with.

Other patients indicated that their pain was an accepted, expected and normal aspect of life, with or without cancer. Pain seemed to be perceived as one of the range of unavoidable experiences that people will inevitably encounter during their life time (see Table 5.10).

Table 5.10

*Examples of the Category, Pragmatism. "Pain as an Inevitable Part of Life"*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
18	66-year-old man	Bowel	We're all going to die. I just know how and when – well not exactly when but soon. I just want to make the most of the time I have left. Pain is part of life. Life has a lot of opposites. You can't have one without the other.
19	75-year-old man	Bladder	You can't live without pain. I survived the German occupation during the war. A heart attack when I was 69 and 4 years of pain with this bladder cancer. When you are a certain age it is to be expected. You adapt and take it in your stride.

Patients perceived the experience of pain as a consequence of cancer, and that the disease is a matter of bad luck (see Table 5.11).

Table 5.11

*Examples of the Category, Pragmatism. "Pain Occurring due to Disease Experienced by Chance"*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
20	75-year-old woman	Lung, Bone	My pain is caused by cancer. I take everything in my stride. I accept it. Somebody has to be unlucky and unfortunately it is me.

In summary, pragmatic responses to pain were evident among patients of both genders and across the age range. No pattern relating to primary cancer site was observed. More men than women in this sample mentioned pain as a sign of disease progression or a sign of the disease. Stoicism or minimising of symptoms is often associated with men (Murray et al., 2008; Yong, Gibson, Horne, & Helme, 2001). Therefore the provision of more data by men in this sub-category may have been influenced by gender differences. Pragmatic meanings of breakthrough pain have not been reported in previous research. However, the present study found them to be the second most commonly reported meanings of pain. Ascribing a pragmatic meaning of pain suggested acceptance of the unavailability of their pain and/or cancer and eventual death.

Pain as a source of fear/worry. Another meaning frequently ascribed to breakthrough pain was pain as a source of “fear/worry.” Some patients made general references to being worried by their pain, without any elaboration (see Table 5.12). For other patients, explicit references to fear of impending death and worry (about the future, how bad the pain would get, or about their families), were key features of this category (Extracts 23 to 28).

Table 5.12

*Examples of the Category “Pain as a General Fear/Worry”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
21	53-year-old man	Liver, Pancreas	Pain is a discomfort, a worry.
22	75-year-old man	Colon, Rectum	The pain is worrying, disconcerting.

Several patients made reference to fear of pain itself, in particular, pain they may experience in the future and their ability to cope with it (e.g., Extract 24). In one case, a woman expressed terror about the level of pain she may suffer before she eventually died from the cancer (e.g., Extract 23). However, she perceived her impending death differently, because her spiritual beliefs led her to expect eternal life after death (see Table 5.13).

Table 5.13

*Examples of the Category “Pain as a Source of Fear/Worry about Future Pain”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
23	75-year-old woman	Liver, breast	The only thing that scares me is the process to get there. Do I have to face a lot of suffering? That is something that terrifies me, but going home – no.
24	62-year-old man	Lung	Pain makes me think about my mother and how she died from cancer and the pain she had. How much pain can I cope with?

On the other hand, some women indicated that fear of pain reminded them of impending death. These extracts convey a sense of foreboding and dread that occurs whenever they experience pain (see Table 5.14).

Table 5.14

*Examples of the Category “Pain as a Source of Fear/Worry about Death”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
25	61-year-old woman	Leukaemia	I wish the pain would go away. It frightens me – could it be the beginning of the end?

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26	48-year-old woman	Periteneum	Pain means fear of the unknown, of death, of the future. It means time is running out for me.
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Pain caused some patients to worry or be concerned about loved ones. They worried about the emotional impact of their pain on their loved ones, or worried about how their family are coping. In the current sample, this sub-category was mentioned by only women (see Table 5.15).

Table 5.15

*Examples of the Category “Fear/Worry about Family”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
27	70-year-old woman	Kidney	I wish it would go away. I don’t want to upset my husband. I worry about the effect on other people – they will feel helpless. I am hurting them. I can’t help them.
28	60-year-old woman	Side	I think about what my family are going through. It worries me how my family are coping.

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Note: Although side is not organ, it was the only site of cancer listed in the medical records.

In summary, there was little evidence that perceiving the meaning of pain as a source of fear/worry, was influenced by age or primary site of cancer. Most fears/worries were reported by both women and men. The meaning of pain as a source of fear/worry about impending death was previously reported in a study by Ferrell and Dean (1995).

However, the present study demonstrated pain is associated with a range of fears and worries for patients in the terminal phase of their cancer.



Pain as a challenge. Some patients perceived pain as a challenge, that is, as an experience that the patient must fight, control or tolerate. Pain was perceived as an obstacle to be dealt with. Some patients mentioned pain as a challenge without elaboration (e.g., Extracts 31 and 32), whereas others provided more information (e.g., Extracts 29 and 31) (see Table 5.16.)

Table 5.16

*Examples of the Category “Pain as a Challenge”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
29	79-year-old woman	Bone	I suppose pain is usually a challenge in a way, because you either fight it, or deal with it, or just let it get you down completely.
30	53-year-old woman	Bone	It is a challenge mostly.
31	58-year-old man	Brain	I don’t like pain. But the more intensity, the more interesting and challenging it is.
32	75-year-old man	Colon, Rectum	I suppose you would say it is challenging. Definitely a challenge.

Pain was perceived to be a challenge by both men and women. Although it is unclear from the wording of the quotations, whether the category challenge has a positive or negative connotation for the patient, the manner in which the data was delivered suggests that the meaning is positive. Ideally, there would have been the opportunity to seek explicit clarification of quotations signifying pain as a challenge. Unfortunately, they were not explored in more detail to minimise the burden that would be imposed by a lengthy interview. The identification of the category of pain as a challenge is consistent with previous research about meaning of illness (Lipowski, 1970), and

meaning of cancer pain (Barkwell, 1991; Chen, 1995), and with the findings of Studies 2 and 3.

Pain as injustice. The category “injustice” was assigned to meanings of pain that implied feelings of anger or injustice or involved the blaming of others (see Table 5.17). These patients commented on the unfairness of experiencing cancer pain at a young age or in the absence of known disposition. This meaning of pain and the meaning of cancer were inextricably connected for some patients (e.g., Extracts 34, 35, 37). One of these patients blamed her pain (and disease progression) on lack of early diagnosis of her cancer (Extract 37).

For other patients, however, the injustice of pain was separate from meanings ascribed to the cancer (Extracts 33, 36). One of these patients commented on the unfairness of experiencing pain in the absence of behaviour that would trigger it (Extract 33). Another patient reported frustration and anger about the duration of her pain (Extract 36). Frustration about pain duration was also reported by one of the patients whose meaning of pain as injustice was inextricably connected to meaning of cancer (Extract 35).

In summary, pain was perceived as injustice by both men and women and did not appear to be influenced by primary site of the cancer. This meaning of pain as an injustice has not been reported in previous research.

Table 5.17

*Examples of the Category “Pain as Injustice”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
33	84-year-old woman	Kidney, Breast	Why me? Why does it happen to me? I haven't done anything to cause it.
34	59-year-old woman	Bowel	I ask “why me? No one else in my family had it, I am too young.
35	53-year-old man	Pancreas, Liver	I feel cheated, it's unfair. I think, “How much longer do I have to put up with it?”
36	76-year-old woman	Pancreas, Liver	When I get pain I think – “Not again! When is it going to go away!” I try to block it out. I get angry and frustrated. Why me?
37	56-year-old woman	Breast, Bone	I get angry. I am sick because of medical neglect. I should have been diagnosed sooner.

Pain as a threat/enemy. Some patients perceived pain to be a threat or enemy. This category was distinguished from the category of challenge by the absence of attempts to overcome it and because pain was usually perceived in a negative way (see Table 5.18). In some cases, patients reported that the pain was an enemy, due to its association with cancer (Extracts 38, 39). Other patients perceived pain to be a threat in its own right (Extracts 40, 41). Ideally, there would have been the opportunity to seek explicit clarification of quotations signifying pain as a challenge. Unfortunately, additional probing needed to be avoided in order to minimise patient burden. Meaning of pain as

an enemy/threat has been reported as a frequently endorsed meaning category in previous research (Barkwell, 1991; Chen, 1995; Ferrell & Dean, 1995). This meaning of pain was found in Study 2 (in which pain was reported to be an enemy by more than half the patients) and in Study 3 (in which more than half of the patients perceived breakthrough pain to be a threat). The present study extends previous research by showing that the category of pain as an enemy/threat does not always derive from its association with cancer.

Table 5.18

*Examples of the Category of Enemy/Threat*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
38	44-year-old man	Pancreas	The disease – it slowly destroys – takes over your body and pain is a part of it.
39	53-year-old man	Colon Rectum	It’s an enemy - like the cancer.
40	81-year-old man	Liver, Colon	It is certainly an enemy, there’s no doubt about that.
41	61-year-old woman	Leukaemia	I wish the pain would go away. It is hideous, a threat.

Pain as a nuisance. This category was comprised of meanings suggesting that pain is a relatively minor burden or inconvenience. Patients who reported this meaning acknowledged that they were affected by pain, but tended to minimise its importance (see Table 5.19).

Table 5.19

*Examples of the Category “Pain as a Nuisance”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
42	76-year-old man	Prostate	Pain – it’s just a nuisance, an inconvenience, it is the cancer – nothing else.
43	54-year-old man	Lung	The cancer cannot be treated and only the pain can be treated. But it is a problem, a pest, a nuisance.
43	67-year-old woman	Lung	Pain is a nuisance. It is frustrating.
44	79-year-old man	Prostate	Pain is a nuisance. I’d rather not have it of course. It’s just a headache – a nuisance.

In this sample, only a small number of patients reported this meaning and therefore there was little evidence to suggest that the category, pain as a nuisance was influenced by gender or primary site of cancer. The category of pain as a nuisance has not been reported in previous research.

Pain as a relief. Non-aversive categories were also ascribed to pain. Pain sometimes provided a welcome relief from other life concerns or worries (see Table 5.20). That is, pain was a means of escape from experiences perceived as even more unpleasant. In one case, the patient believed that pain due to cancer made him more

socially acceptable (Extract 45). This patient was alcohol dependent and believed that many people treated him with disdain or attributed his health problems to the effects of alcohol. However, they empathised with his experience of cancer pain. In other words, pain served as a relief from being judged unfavourably by others. Another patient reported that his cancer pain served as a welcome distraction from the anguish associated with his wife’s declining mental health (Extract 46).

Table 5.20

*Examples of the Category “Pain as a Relief”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
45	58-year-old man	Brain	Cancer legitimises the pain, the symptoms, and makes it OK. People treat you differently. Alcoholism makes you untouchable, Now I won’t die from alcoholism.
46	75-year-old man	Bladder	My wife is in a nursing home with dementia. Sometimes she doesn’t even recognise me. The distraction is good.

There was no evidence that meaning of pain as relief was influenced by gender or primary site of the cancer. Although it may appear to be counter intuitive, the interpretation of pain as a relief has also been reported in previous literature (Barkwell, 1991), and in Study 2. The present study extends previous findings by revealing some of the diversity within the meaning of pain as a relief.

Pain in the context of gratitude for life. A second category of non-aversive meanings, was identified when pain was described in a context that signified the patients’ appreciation for their lives so far (see Table 5.21). In the few examples found in the data, pain and overt cancer meanings were always interconnected.

Table 5.21

*Examples of the Category “Gratitude for Life”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
47	60-year-old woman	Side	Pain means the tumour is active. I have had a full meaningful life and never thought about cancer or pain. It is a phase and I don't let it get me down. I can prepare for everything. Some people don't have that opportunity and I am grateful I can do that.
48	48-year-old woman	Peretineum	Pain means fear of the unknown, of death, of the future. It means time is running out for me. It is a loss and a challenge. It is also enlightening. I feel gratitude for the people in my life, for my life. There's a sense of vitality in the meaning of life, to appreciate life. There's joy, gratitude in life – a feeling of acceptance.

The category of gratitude was reported implicitly by patients. This category was never identified as the only meaning category generated by a patient. It was always expressed in the context of other meaning categories. For example, Extract 47 also contained the category of pragmatism (pain as a sign of disease progression) and Extract 48 also contained the categories fear/worry, challenge and loss. The finding that pain was

interpreted with reference to gratitude for life only in the presence of other meanings may partly explain why this category has not been reported in previous research.

Pain as an experience of value. The third non-aversive meaning of pain indicated that patients had experienced personal growth as a result of their experience of pain and cancer (see Table 5.22). The category of pain as an experience of value was reported only twice: once in a quotation without elaboration (Extract 50) and once explaining pain had contributed to personal development (Extract 49). The perception that pain has value has been reported in previous research (Barkwell, 1991; Lipowski, 1979) and in Study 2. Of note, half of the patients in Study 2 reported pain as having some value for them when they were asked to rate this meaning for its relevance, yet, in the present study, only two of these patients spontaneously reported this meaning in response to open-ended questions. Patients in the present study were not presented with lists of meaning categories until after they had reported what meaning pain had for them without prompting. Therefore it appears that for some patients, meaning of pain may not have been a concept accessible in conscious awareness.

Table 5.22

*Examples of the Category “Pain as Having Value”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
49	79-year-old woman	Bone	I feel a better person for the attitude I’ve got to it because I know I can control it. But it has also made me a stronger, better person. When you are alone you are an only child and you tend to be a bit spoilt and become a bit self centred, and therefore a bit selfish as well, but now that I’m all on my own I’d say its (the pain) made me a bit stronger.



50	81-year-old man	Liver Colon	In some ways pain makes you a stronger and better person.
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Pain as a punishment. This category was assigned to quotations suggesting that the pain resulted from the patient’s own wrongful past actions or inaction (see Table 5.23). Only two patients in this sample ascribed the meaning “punishment” to their pain. One indicated this without any elaboration (Extract 51), and the other indicated that she perceived pain to be a punishment for being uncaring towards others in the past (Extract 52). The meaning category “punishment” has been reported in previous research about meaning of pain (Barkwell, 1991; Chen, 1995; Ferrell & Dean, 1995) and was also ascribed to pain by patients in Studies 2 and 3.

Table 5.23

*Examples of the category “Pain as a Punishment”*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
51	81-year-old man	Liver, Colon	Yes and maybe I am being punished too to some extent.
52	72-year-old woman	Lung, Bone	I saw pain as a punishment firstly. A family should be close and caring – this is my punishment for not being close and caring to them.

Pain as a “weakness”. Other patients perceived themselves to be weak because they felt pain. This category was only ever reported in brief statements, without elaboration (see Table 5.24). Ideally, there would have been the opportunity to seek explicit clarification of quotations signifying pain as a weakness. Unfortunately, additional probing needed to be avoided in order to minimise patient burden.

Table 5.24

*Examples of the Category “Pain as a Weakness*

Extract	Patient		Quotation
	Demographic information	Primary cancer site	
53	53-year-old man	Colon, Rectum	I suppose it is also a weakness.
54	49-year-old woman	Rectum	I am inadequate.

Patients in previous studies have also reported the meaning of pain as weakness (Barkwell, 1991; Study 2). However, in both studies, this meaning of pain was endorsed by relatively few patients.

Pain in the context of spirituality. This category encompasses responses indicating that suffering is necessary in order to gain eternal life after death. Pain in this spiritual context is illustrated by a statement by a 75-year-old woman with liver and breast cancer. For her, meaning of cancer and of pain were inextricably connected. She perceived pain as part of a divine plan and therefore something she must accept in return for forgiveness and eternal life.

*“I know God has his plans for me so, whatever it is, I accept it. We came back to God when my husband was diagnosed with prostate cancer and he gave us two years grace. My sins are forgiven.”* (Extract 55).

Spiritual context to meaning of pain has been reported in previous quantitative (e.g., Chen, 1995) and qualitative research (Strang, 1997; Taylor & Ersek, 1995), and also in Study 3. A spiritual context to meaning of pain was reported by only one patient in the present study, in the absence of any comments which may have primed the response. In

contrast, most patients in the Chen (1995) study, and approximately half the patients in Study 3 endorsed a spiritual meaning of pain, when they were asked to rate this meaning for its relevance. This inconsistency in reporting may have occurred, because for some patients, this meaning may not have been accessible in conscious awareness until prompted. Another explanation may be that many patients in this sample were not comfortable about disclosing their spiritual beliefs.

### Summary of Emerging Categories

Thirteen distinct categories were identified in the meanings patients ascribed to their pain. However, for many patients, the meaning of pain and cancer were inextricably connected. The present study confirmed nine categories of meaning that have been reported in previous literature (Barkwell, 1991; Chen, 1995; Ferrell & Dean, 1995; Park, 2010) and also in Studies 2 and 3: loss, challenge, enemy/threat, relief, weakness, value, punishment, fear/worry and spiritual. However, the present study added to our understanding of those meanings by revealing their diversity and complexity. For example, pain as a loss may refer to loss of activity, loss of future, loss of independence, loss of social interactions and multiple losses. This diversity and complexity cannot be captured in quantitative studies (Chen, 1995) such as Studies 2 and 3, and has not been reported in previous qualitative studies (Barkwell, 1991; Ferrell & Dean, 1995). Some meanings, such as loss were reported by many patients. Others, such as meaning in a spiritual context, were unique to a single patient. A further contribution of this study was the identification of four categories of meaning that had not been reported in previous literature or in Studies 2 and 3: pain as an injustice, a nuisance, one of a variety of pragmatic meanings, and as a trigger for gratitude for life. It should be noted that

although a large number of these categories were identified, not all were equally common.

### Case Studies Showing Patterns Between Meaning Categories

Several patterns between the categories of meaning of pain were identified. This section reports these patterns in content and process using case studies. For example, many patients revealed that pain had multiple meanings, and for many of these patients, one category was often dominant. Some meaning categories were congruent or showed evidence of coping strategies. Other categories did not. In some cases, meaning of pain and meaning of cancer were distinct, and in others, these meanings were inextricably connected. Some meanings were reported in an elaborative or brief way, and others were delivered with different levels of emotion. The case studies that follow illustrate the different patterns within the meaning categories and how these meanings were reported by individual patients.

### Patterns in Content

#### Single Category

Four patients made reference to only one meaning of pain. An example was a 70-year-old man who had been diagnosed with cancer of the bones. He adopted a pragmatic approach, reporting that pain was a signal of disease and a prompt for him to take some remedial action.

*“It means that there is something wrong with me. What do I need to do to get rid of it? That’s all”.*

In this case, the delivery and content of the quotation seemed to suggest that he minimised the significance of pain.

### Two Categories

Almost half of the patients (17/38) ascribed two distinct meanings to pain. Of these patients, 10 made statements that suggested that one of these categories was dominant. One case was that of a 54-year-old man with lung cancer. A pragmatic category of meaning was dominant. Pain was a signal of a problem in his body, in this case, cancer. In addition, he reported that the pain itself was a nuisance.

*“Pain means that I have a problem. It is a reminder, a warning that there is something I have to deal with. The cancer cannot be treated and only the pain can be treated. But it is a problem, a pest, a nuisance.”*

These categories of meaning (pragmatism, nuisance) tend to minimise the significance of pain. Stoicism is a trait which is often found in men and they may be less inclined to report pain (Murray et al., 2008; Yong et al., 2001). It is also possible that minimising the significance of pain is a coping strategy, that is, an attempt to avoid thinking about pain.

One case that illustrated patients reporting two categories of meaning with no dominant category was that of a 76-year-old woman with breast cancer. Both worry about her husband and loss of her opportunity to see her future grandchildren were associated with her pain and described at similar length with words of similar intensity.

*“I think of my husband. Who will care for him when I’m gone. It makes me think of my grandchildren – I won’t get to see them”*

Both categories are future oriented and both refer to other people. These categories are also aversive.

### Subcategories Within One Meaning

Some patients reported two distinct subcategories from within a single category. For example, one woman reported multiple facets of one category: pain as loss. She was a 56-year-old woman with cancer of the breast and bone metastases. Her multiple losses included loss of independence, of the opportunity to mend damaged relationships, to develop intimate relationships and to experience things that were denied to her during her youth because of her family's religious beliefs. Her account was emotional and sad as she expressed both her physical and emotional pain. While these sub-categories of the meaning of pain as a loss were dominant, this patient also reported that pain was an injustice. This was exhibited through the act of blaming others for her pain (and disease). For this woman, the meaning of pain was not only inextricably connected to the meaning of cancer but also to other painful life experiences.

*“Breakthrough pain and all pain for that matter. I don't think about it and what it means. Just, oh – here it goes again! I try NOT to reflect on it. I get angry, I am sick because of medical neglect. I should have been diagnosed sooner. I would like someone close who understands, but no-one who lives close to me is understanding. It hurts. I hurt, and have a lot of sadness. Loss of my independence, of the chance to develop a relationship with my daughter – it (their relationship) was damaged in the marriage break up. A loss of intimacy, love, closeness, understanding. The result of a Roman Catholic upbringing – touching and the expression of love was considered dirty! Pain reminds me of all these losses and unresolved issues. Cancer means pain. It's all the same”.*

These categories of meaning were all aversive and oriented in the past, present and future. The delivery was emotional and exhibited profound sadness for herself, and anger directed at others. Although the quotation “just – oh here it goes again” could arguably be understood as having a pragmatic meaning, the tone of her voice and the emotion expressed in its delivery was not consistent with having a pragmatic meaning.

### Multiple Categories

Fifteen patients reported three or more categories of meaning of pain. More than half of these patients reported a dominant category of meaning, and two or more secondary categories. One case study that illustrated dominant and secondary categories was that of a 62-year-old man with lung cancer. His mother had died in pain from cancer and pain as a source of fear was his dominant meaning category. He also reported, without elaboration, that pain was a nuisance, a signal of disease progression, and a source of fear of loss of control. It should be noted that while these meaning categories (fear of loss of control, nuisance) were aversive, the patient also reported a non-aversive meaning (pragmatic- disease progression). The non-aversive nature of this meaning was evident by the change in tone of delivery when speaking of pain as a signal of disease progression.

*“Pain makes me think about my mother and how she died from cancer and the pain she had. How much pain can I cope with? I must control it. I am anxious. Pain is a nuisance. It is a sign that lets you know how bad the cancer is getting.”*

### Relationship between meaning of pain and meaning of cancer

Eight patients explicitly differentiated between meanings of cancer and pain. For example, a 53-year-old woman with cancer of the bones, distinguished meaning of pain from meaning of cancer on the basis that she had control of pain but not the cancer.

*“It is a challenge mostly. An enemy too. I haven’t really thought about it that much. Meaning of pain is different to meaning of the cancer. The cancer is beyond my control but the pain – I have some degree of control over that.”*

In contrast, four patients explicitly stated that pain meant nothing more than the presence of cancer. One example, was that of a 76-year-old man with prostate cancer, whose response was brief and unelaborated.

*“It’s just a nuisance, an inconvenience, it is the cancer – nothing else.”*

The remaining six patients who reported multiple meanings of pain did so without conveying an obvious dominant category. For example, a 49-year-old woman with rectal cancer revealed categories of meaning of pain as a loss, a weakness and a pragmatic understanding of pain as a signal that something was wrong. A spiritual meaning of cancer (not pain) was also reported. However meaning of pain and meaning of cancer appeared to be distinct for this woman.

*“Pain is abnormal. It means something is wrong. It means discomfort, loss of control, I am inadequate. The cancer is an enemy, the black bastard! I feel a sense of spiritual betrayal. I stopped believing in God the day I was diagnosed with cancer. And I am angry at my Father. Why hasn’t He protected me?”*

### Congruency of Categories of Meaning

Most data contained congruent categories of meaning of pain. One case study was that of a 59-year-old woman with bowel cancer. She perceived pain as loss (loss in general,



loss of independence, loss of activity) and as an injustice, because she was experiencing pain and cancer at a young age. For her, the pain (and cancer) were unexpected and unfair because there was no family history of cancer. The categories, “loss” and “injustice” are congruent because they both refer to an undesirable experience or outcome for the patient.

*“Pain is a discomfort. It restricts my life and I have lost my independence. I ask “Why me? No one else in my family had it, I am too young. It’s disappointing – a real loss.”*

On the other hand, other patients reported meanings that seemed to be incongruent. A 75-year-old woman with liver and breast cancer indicated a variety of meanings, only some of which appeared to be consistent.

*“I don’t think about it really. It is something wrong with my body that’s all. I have cancer. I accept it. I know God has his plans for me so what ever it is I accept it. We came back to God when my husband was diagnosed with prostate cancer and he gave us two years grace. My sins are forgiven I did a lot of bad things as a teenager in the country during the war time. But I can’t forgive myself and these things just keep coming back. But I start praying and I get strength from that. But I also fight the pain, resist it. I get a lot of depression I think the loneliness is the worse part. I grieve now for my husband, now, 12 years later –now more than I did at the time. Before I had a business and I did not have time to grieve. I am weak. I can’t do the things I used to. I have been lonely since my husband died. Death doesn’t scare me. I look forward to the everlasting life. The only thing that scares me is the process to get there. Do I have to face a lot of suffering? That is something that terrifies me, but going home – no.”*

This case study contained consistent aversive categories of meaning of pain, such as pain being an enemy she has to fight, and a source of fear. However, she also ascribed non-aversive meanings to pain (relief and the neutral pragmatic meaning “just the disease”) to her pain. Furthermore, pain and cancer are both viewed in the context of her spirituality. Both aversive and non-aversive meaning categories were reported by an individual patient.

### Patterns of Process

The previous section focused on what meaning categories were identified. The section that follows focuses on differences in the way the meanings were reported. One of the most dramatic differences in reporting was the extent to which patients explained or elaborated on the meaning of pain. The significance of these differences in reporting are explored.

#### Brief or Elaborated Reporting of Categories

Six patients reported meanings of pain without any elaboration. All but one of these patients were male. A 53-year-old man with cancer of the colon and rectum provided a typical example of unelaborated meanings of pain.

*“Meaning of pain – it’s an enemy like the cancer. I suppose it is also a weakness”.*

The brevity and lack of elaboration in this quotation may indicate that this man had not previously considered meaning of pain and therefore the concept was not accessible to conscious awareness. However, this man later withdrew from the pain diary study (Chapter 6) because completion of the diary forced him to focus on the pain and hence made him feel worse. Therefore it is also likely that the brevity of his report signified an attempt to distract himself from pain.

However, most patients provided detail about the meanings they ascribed to pain. One of these examples was a statement by a 79-year-old woman with bone cancer. This woman reported that her pain was a challenge, a loss, and a source of value and provided some elaboration on each of these meanings.

*“I suppose pain is usually a challenge in way because you either fight it or deal with it or just let it get you down completely. But I feel that, you know, I have overridden it with certain medication. But my attitude to it, you know, I feel a better person for the attitude. I’ve got it because I know I can control it. I suppose it is a loss too because it has restricted me so much. Because there are so many things I would like to do but can’t do. It is always like that now. But it has also made me a stronger, better person. When you are alone, you are an only child, you tend to be a bit spoilt and become a bit self-centred and therefore a bit selfish as well. But now that I’m all on my own, I’d say it’s made me a bit stronger”.*

Despite the challenges and losses she experienced as a consequence of cancer pain, she acknowledged some positive aspects about the experience. Her comments suggest that she has grown from adversity, and may have spent some time contemplating the meaning of pain.

On the basis of these case studies, it appears that patients who provided brief responses may have not previously contemplated meaning of pain, or may avoid thinking about meaning of pain. In contrast, those patients who provided elaborated responses had considered what pain meant for them, in the context of past experiences.

### Level of Emotion in Reporting Themes

Half of the patients reported meaning of pain in a dispassionate or matter-of-fact style. Most (80%) of these patients were men. One example was the report of a 44-year-old man with cancer of the pancreas. He reported pain as a loss of activity, loss of social interaction, loss of ability to set future goals, a nuisance/burden and as a sign of disease progression in non-emotive statements of the facts as he perceived them.

*“Pain – well it’s a discomfort. I can’t do what I want to do. I get frustrated due to inactivity. It’s like a burden, a sense of loss. I can’t plan. It’s isolating. The disease – it slowly destroys, takes over your body and pain is a part of it.”*

Although these comments were delivered in a detached and unemotional manner, their content suggests the presence of emotions that was not expressed in the quotation. Furthermore, the data revealed that this man was experiencing symptoms of depression.

The data for almost as many patients were emotionally charged in their presentation and content. Most (78%) of these accounts were made by women. This observation is congruent with the social stereotype of women being more willing than men to express strong emotions. One example of a patient who made emotionally charged statements was of a 58-year-old woman with bowel and liver cancer. There was a tone of deep sadness and regret in her voice as she reported meaning categories of loss and fear. However, she balanced these negative meanings by mentioning positive relationships. This patient was very close to death. Indeed, she died during the night, after the interview.

*“Pain is restricting, debilitating. There is uncertainty, the ups and downs, how bad it may get. It stops me doing things, it gets me down. There are things I still want to do, like go horse riding, but I don’t know whether I will ever be able to do that again. I feel a deep sadness and loss because, even now, my mother still*

*doesn't love me – she has never told me that – never showed any love or affection to me. But my husband is kind and supporting and so is my son.”*

The differences in the level of emotion expressed in the delivery of the data may be explained by gender stereotypes in society about expression of emotion. In Western cultures, it has typically been more acceptable for woman than for men to express emotion publically (Murray et al., 2008).

### Evidence of Coping Strategies

Another pattern which emerged provided evidence of the patients' two different coping strategies; contextualising, and balancing the negative and positive aspects of pain.

Contextualising pain. Some patients explicitly interpreted their cancer pain in the context of a life-time of other sources of pain. One example was that of a 75-year-old man with cancer of the bladder. He viewed his pain in the context of pain experienced during World War 2, a previous medical condition, and the emotional pain resulting from his wife's dementia.

*“I think – here we go again. You can't live without pain. I survived the German occupation during the war. A heart attack when I was 69 and 4 years of pain with this bladder cancer. When you are a certain age it is to be expected. You adapt and take it in your stride. It restricts my activities though. My wife is in a nursing home with dementia. Sometimes she doesn't even recognize me. The distraction is good.”*

For this man, pain was perceived as a normal part of life. He appeared to cope by accepting pain and adapting to the changes in his life as a consequence.

Balancing positive and negative aspects of pain. The data for four patients suggested that they attempted to balance the negative aspects of pain with an appreciation of some positive outcome. One example was an 81-year-old man with cancer of the liver and colon. This man reported many negative meanings, such as enemy, punishment and loss to his pain. However, he counterbalanced these by stating that he can control his pain and his belief that pain had some value.

*“I’ve had very little pain in my life before getting cancer, well maybe in the war years, the odd headache, backache. I can’t remember what I did about it. I had a gall bladder operation about 4 years ago. There was strong pain then. What it means? It is certainly an enemy. There’s no doubt about that would be the main meaning. Yes, and maybe I am being punished too to some extent. Sometimes it is a sign of losing something I will never get back but I can control my pain by using tablets. In some ways pain makes you a stronger and better person.”*

In this case, coping well with pain appears to be aided by seeking some positive aspects of pain to counterbalance the negative. These case studies illustrate meaning of pain that suggest two distinct ways of coping with adversity. These men were among the few participants who ascribed meanings to pain that were distinct from meaning of cancer, however for most, the meaning of cancer and meaning of pain were inextricably connected.

### Summary of Findings

In summary, 13 categories of meaning of pain were found, of which loss and pragmatic meanings were the most common. There were often multiple dimensions to a single category of meaning and, for most patients, pain had more than one meaning. For most patients who reported multiple categories of meaning of pain, those categories were

congruent. In addition, the categories of meaning were delivered in different ways by individual patients. Different levels of elaboration and emotion were apparent, and sometimes the manner of delivery was indicative of the patient's coping strategies.

### Reflective Practice

Reflective practice is an active process of systematically developing insight into your work as a researcher to guide future actions (Birks & Mills, 2011). It is considered to be an important part of GT to assure the quality of the theory. Reflective practice facilitates the understanding of the influence of the method of data collection and the researcher characteristics (gender, profession, beliefs, concerns, and experience) on the data obtained. It attempts to grapple honestly with the likelihood that the data obtained has been influenced by the researcher. This influence is seen as inevitable in all research. The idea is not to dismiss it or ignore it, but to identify the direction and extent to which particular aspects of the data may have been influenced.

### Method of Data Collection

Reflection on patterns in patients' responses raised the possibility of three sources of bias in the data. First is the possibility that patients were less likely to admit to less "acceptable" meanings of pain (e.g., as a relief from otherwise onerous tasks) in the presence of a partner, and therefore these meanings of pain may be more common than the data would indicate, since most interviews took place in the presence of a partner. Meanings of pain as a "relief" or "strategy" were among the meaning categories least reported in previous research (Barkwell, 1991), but it was not clear whether these meanings were reported in the presence of others. Nevertheless, at least one patient in the present study reported the meaning category "relief" in the presence of her husband.

Therefore, it is possible that these “less acceptable” meanings of pain may be more common than has been revealed by the data.

Second, the method of data collection may have influenced the phenomenon it attempted to document. In particular, questions about meaning of pain may require patients to consider issues that they may have been avoiding, or that may not be in conscious awareness. For example, one patient decided not to continue completing the pain diary for Study 5. He believed that thinking about the pain made it worse for him. In a similar way, it is possible that patients who try to distract themselves or avoid thinking about pain may not be able to report meaning of pain as easily as others. For example, a 78-year-old woman with cancer of the lung stated,

*“I try not to think about it. If you take your mind off it, you get over it and deal with it.”*

She was unable to provide a meaning of pain because of her conscious attempts to avoid thinking about it. In contrast, two patients who reported effective use of distraction as a pain management strategy were able to report meanings of pain. In summary, there is inconsistent evidence, about whether patients’ ability to report meaning of pain was influenced by their level of awareness or conscious efforts to avoid thinking about pain.

Third, there is the possibility that the data were influenced by the way the interview was introduced. Patients may have been primed to report the meanings “relief,” “challenge” and “loss” by inclusion of these as examples of meanings in the introduction (see Method, p. 208), even though scenarios unrelated to pain and cancer were deliberately chosen to reduce the likelihood of priming to respond in a particular way. Two of the nine patients who ascribed to the meanings “relief,” “challenge,” and “loss” did so in brief and unelaborated statements. Therefore it is possible that these reports were



influenced by the introduction to the interview. However, most patients did not choose meanings for which there was the potential for priming. Thirteen meanings categories were reported, yet there were only three potential primes. Only three patients reported the meaning of pain “relief”. Moreover, these patients did not explicitly used the term “relief” indicating that this meaning did not occur in response to prompting. In addition, it is unlikely that patients would have been able to grasp the concept of meaning of pain without some form of introduction. An unstructured interview may have eliminated any potential priming, however my presence may still have helped to call forth some meanings and suppress others.

Fourth, there is the possibility the findings of the analyses were influenced by the small sample size. A small sample size may produce results that are not generalisable to other groups. Only 38 patients participated in the study, and one of the more frequently reported meanings, “pragmatism,” has not been previously reported. This meaning may be unique to the Australian population. However, large sample sizes are not essential when a qualitative approach is adopted. This approach aims to provide depth of understanding of a phenomenon and how it manifests in individuals, and is not concerned with establishing causal relationships in populations. Theoretical saturation was reached after 34 of the 38 interviews. Furthermore, most of the meanings reported (including the most common meaning, loss) have been reported in previous research in Canadian (Barkwell, 1991) and Taiwanese (Chen, 1995) populations. Therefore, although it is possible that some of the findings are unique to this Australian sample, some of the findings also appear to be relevant to other populations.

### Researcher Characteristics

Reflection suggested that four researcher characteristics had the potential to influence the data. First, there is the possibility that the data were influenced by the way the researcher was introduced to the patients. The researcher was introduced as a psychologist who was not directly involved in patient care. This may have had advantages. Patients may have been more willing to disclose some thoughts and feelings to a professional who was not involved in their care. For example, two patients blamed delay in diagnosis by their medical practitioners for their pain and the development of incurable disease. These patients may have been less likely to disclose this information to someone directly involved in their health care. In addition, patients' perception of the role of a psychologist may have encouraged disclosure of some information. For example, one woman reported feelings of shame about some things she had done during a war, many years ago. On the other hand, the introduction may have had some disadvantages. Some patients may have refrained from disclosure of relevant information because of their beliefs about the psychological profession, or about mental health issues. Such patients may not have elaborated upon their responses. Moreover, there is the possibility that some patients who were potentially eligible for the study, may have declined to participate because the research was conducted by a psychologist. On the basis of the data, it is not possible to determine the extent to which the data may have been influenced by the researcher's profession.

Second, trends in the patients' reports that were contrary to gender stereotypes, prompted the reflection that the data may have been influenced by the gender of the researcher. Previous research has reported that gender differences between the researcher and the interviewee influenced responses (Herod, 1993). Men were reported to typically display the trait of stoicism (Murray et al., 2008; Yong et al., 2001). In

addition, women were generally considered to be less independent than men (Eagly & Steffen, 1984). Some of the responses by patients were consistent with these stereotypes (e.g., males who provided brief responses that minimised the impact of pain, and women who acknowledge the impact in elaborated reports). However, more reports by men did not exhibit evidence of stoicism (e.g., the man whose wife had dementia, p. 245). In a similar way, more women than men reported loss of independence as a meaning of pain (e.g., Extract 4, p.217). Although it is possible that those patients who reported contrary to the gender stereotypes may have believed that a female researcher would be more accepting of beliefs contrary to social norms, and vice versa, it is not clear from the evidence whether the data were influenced by the gender of the researcher.

Third, some patients gave very brief responses to questions about meaning of pain, to which I did not elicit more detail. Therefore, I considered the possibility that the data may have been influenced by the researcher's concern about distressing patients, or about potential conflict with those directly involved in patient care. Over one third of the patients provided brief responses to the semi-structured interview questions. Further exploration of these responses was not undertaken for fear of distressing the patients, or producing conflict with "gatekeepers," thus risking withdrawal of access to patients. Although, some of these patients clearly did not have the capacity to elaborate further, others may have done so if prompted. Therefore, it is acknowledged that further exploration of the brief responses may have elicited further information and enhanced the quality of the data for some patients.

Fourth, it is possible that the data may have been biased by the researcher's values and beliefs. Although the researcher was experienced at interviewing people about a range of sensitive subjects, and had been trained to do so in a non-judgemental manner, it was possible that the researcher's tone or body language may have encouraged or discouraged certain responses. For example, some patients who reported meanings that were inconsistent with the values of the researcher responded only briefly. In addition, some of the more elaborated responses were consistent with my values and beliefs. However, not all patients who provided brief responses reported views that were inconsistent with the values and beliefs of the researcher, nor were all elaborated responses consistent with those of the researcher. Therefore there is limited evidence to suggest that the data was strongly influenced by the researcher's values and beliefs.

In summary, upon reflection on the possible ways in which the data may have been biased, limited evidence was found to indicate that the data was strongly influenced by sample size, the need for patients to consider phenomenon they were avoiding, or by researcher profession, gender, values or beliefs. However, for a small number of patients, the researcher's efforts to prevent excessive burden on patients, method of introduction of the concept of meaning and to a lesser extent, the presence of a third party at the interview may have led to some potentially relevant meanings of pain not being detected.

### A Grounded Theory of Meaning of Pain

The present study has employed the techniques of GT to identify meanings of pain reported by a sample of patients with advanced cancer who are experiencing breakthrough pain. Thirteen categories of meaning of pain were identified and only half

of these were aversive. Patients interpreted their pain in four contexts: the context of earlier life experience, their current life issues, their values and beliefs, and the characteristics of their pain. The GT developed in this study contains four propositions about meaning of pain and attempts to explain patterns between meanings of pain and the way individual patients interpret pain. These propositions pertain to the context, aversiveness and number of meanings, and individual differences in meanings ascribed to pain. Figure 5.2 provides a visual summary of meanings of pain and the ways in which they were reported by patients. The upper panel depicts the meanings that were reported. These meanings developed in the context of a range of positive and negative experiences, contribute to the development of both aversive and non-aversive meanings of pain. The lower panel illustrates the various ways in which patients reported these meanings. Some reported a single meaning and others more than one meaning. There were also patterns in the ways in which these meanings were reported (e.g., congruency of meanings, the level of emotion when describing, contextualising and balancing the meanings).

### Context of Meaning of Pain

Observations led to the deduction of the proposition that meaning was ascribed to pain with reference to four contexts: earlier life experiences, current life issues, pain characteristics and values and beliefs. About two thirds of the patients reported pain in at least one of these contexts.

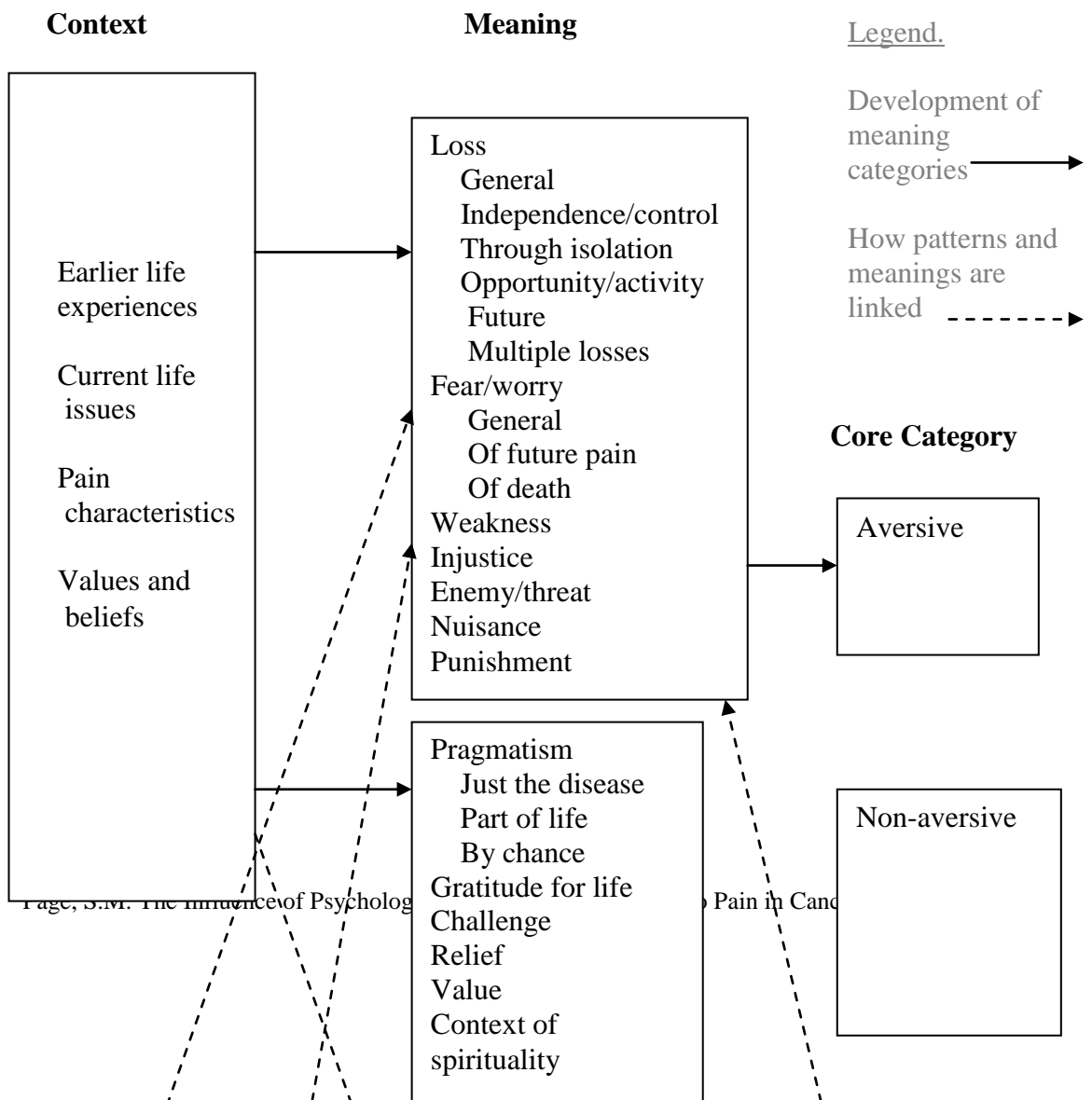
The proposition that meaning was often interpreted in the context of earlier life experiences derived from the reports of nine patients. It was vividly illustrated by the case study of a woman reporting multiple meanings of loss and injustice. She

interpreted pain (and cancer) in the context of a range of painful past experiences, including misdiagnosis of her condition (p. 238). She reported meaning of pain in the context of the perceived injustice of the medical system failing her, the adverse impact of her family's religious beliefs on her unsuccessful relationships, and the loss of intimacy, independence and future opportunities. The meanings of pain interpreted in this context were aversive. Patients' past experiences, and their responses to these experiences appear to exert considerable influence over the meanings they ascribe to their present cancer pain.

The proposition that meaning of pain was also often interpreted in the context of current life issues was derived from the reports by eight patients. An example of meaning of pain in the context of current life experiences was provided by a man who was diagnosed with cancer of the bladder (p.245). He interpreted his pain in a positive manner (i.e., a welcome distraction), in the context of his current emotional challenge (his wife's dementia). In contrast, another man interpreted his pain in the context of changes in the way he was treated by others since he was diagnosed with cancer. He reported, "*People treat you differently. Alcohol makes you untouchable. Now I won't die of alcoholism.*" This man perceived his diagnosis of cancer and the associated pain to be positive events, and reported a non-aversive meaning of pain, "relief." In summary, although negative circumstances influence the way in which meaning is made, a negative event does not always result in the development of an aversive meaning of pain.

The proposition that meaning ascribed to pain was sometimes influenced by the pain characteristics was derived from the reports of four patients. One of these patients (who

reported breakthrough pain lasting 90 minutes) referred to pain in the context of its duration, “*how long do I have to put up with it?*” This man ascribed aversive meanings (fear, injustice) to pain. Another patient reported meaning of pain with reference to breakthrough pain of moderate intensity, “*how bad will it get?*” She also reported aversive meanings of pain (loss, fear). Although these patients made reference to pain characteristics when reporting meaning of pain, pain characteristics were not central to their interpretation. It is noteworthy, that despite the focus on pain characteristics in the literature, relatively few patients reported meaning of pain in the context of its characteristics. It is therefore likely that other factors may exert greater influence on meaning of pain than pain characteristics themselves.



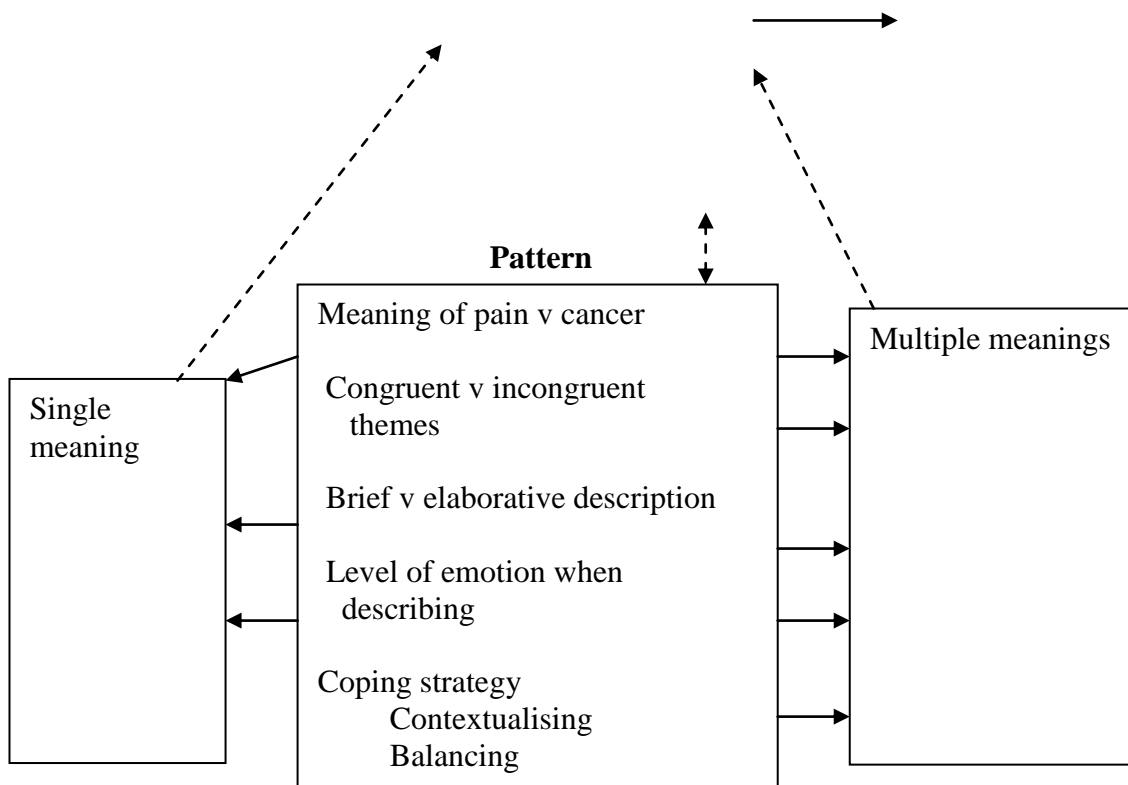


Figure 5.2. Model of the grounded theory of meaning of pain.

The proposition that meaning of pain was interpreted with reference to personal values and beliefs was derived from the reports of seven patients. Two examples which illustrate meaning of pain in the context of values and beliefs were those of patients who perceived pain as an inevitable part of life (Extracts 18 & 19, p. 221). In both cases, pain was interpreted as another of life's experiences, some of which are unpleasant. These men ascribed non-aversive meanings to pain. In contrast, one woman reported an aversive meaning of pain in the context of her belief that pain (and cancer) were unfair, because she did not do anything to increase her risk factors for cancer, "*Why me? Why does it happen to me? I haven't done anything to cause it, Pain is horrible!*" Hence, it can be seen that beliefs about pain may exert influence on the meaning that is ascribed to pain, and whether pain is interpreted in a negative way. In short, pain is interpreted in the context of a range of individual values, beliefs and experiences. Even when these experiences are negative, the meanings ascribed to pain are not always aversive.



### Aversive or Non-aversive Meanings of Pain

The second proposition is that pain does not always have an aversive meaning. Almost as many patients reported meanings of pain that were neutral or positive, and most reported both aversive and non-aversive meanings. A positive meaning of pain was vividly illustrated by a man with diagnoses of cancer of the brain and alcohol dependence (Extract 45, p. 230). He ascribed a positive meaning to pain (relief) in the context of current changes in the way he was received by others. Prior to his diagnosis of cancer, he perceived that others shunned him because of his alcohol addiction. In addition to a dominant non-aversive meaning of pain, this man also reported an aversive meaning (pain as a source of fear). In contrast, another man reported both aversive and non-aversive meanings of pain with reference to relatively positive past experiences. Pain was interpreted as an enemy, punishment and loss. He then counterbalanced these aversive meanings with a non-aversive meaning (value), reporting that the experience of pain had made him a stronger and better person (p. 245). In summary, patients have ascribed both aversive and non-aversive meanings to pain, regardless of positive or negative past and present circumstances. The mechanisms which determine whether non-aversive or aversive meanings develop are not apparent from these findings and are a possible area for exploration in future research.

### Number of Meanings

Although four patients reported only one meaning of pain, for most patients, pain had multiple meanings. These meanings were either aversive, non-aversive or a combination of aversive and non-aversive meanings. Many patients who ascribed to multiple meanings of pain provided elaborated reports interpreted in the context of

personal experiences and beliefs. For example, the man with cancer of the bladder reported multiple meanings of pain (p.245). He reported a dominant non-aversive meaning (relief) in the context of distraction from his wife's deteriorating health. Another non-aversive meaning (pragmatic, accepted part of life) emerged in the context of past experiences in his war-ravaged homeland during his youth, and also a heart attack six years earlier. In addition, he also reported one aversive meaning (loss) because he was no longer able to engage in many enjoyable activities. In contrast, several patients reported multiple meanings of pain without providing the context in which it was interpreted. For example, one woman with cancer of the lung reported three aversive meanings of pain (fear, loss and nuisance). There was no dominant meaning, and she did not distinguish between meaning of pain and meaning of cancer. *"Pain is a nuisance. It stops me doing what I want to do. It is frustrating, There is also the fear of dying."* However, no patients who ascribed to multiple meanings of pain reported only non-aversive meanings. In summary, the GT has revealed that most patients ascribed to multiple meanings of pain some of which were more dominant than others. Multiple meanings have not been reported in previous research. The relative importance of these meanings and their influence on adjustment is an area worthy of future research.

#### Individual Differences in Meaning of Pain

The fourth proposition is that there are large individual differences in the meaning ascribed to pain. These differences were evident in the context in which meaning of pain was interpreted, the number of meanings that were generated, and how meanings were reported. At one extreme, a single meaning of pain was reported with very limited emotional expression or context. For example, one man reported a pragmatic meaning

of pain, “just the disease” (p. 236). For this man, meaning of pain was separate to meaning of cancer. At the other extreme, some patients reported multiple meanings of pain, of which some were incongruent and reported with emotion. For example, a woman with cancer of the liver and breast reported multiple aversive (enemy, fear and weakness) and non-aversive (relief, spiritual and pragmatic) meanings (pp. 240-241). Meaning of pain was inextricably connected to meaning of cancer. In addition, some patients reported multiple sub-categories of one particular meaning. This was illustrated by a woman with cancer of the breast and bone metastasies (p. 238). She reported multiple sub-categories of the meaning category, “loss.” In short, it can be seen that meaning of pain is a diverse and complex phenomenon. The range of individual differences in meanings ascribed to pain, and the numerous ways in which patients report meaning of pain were not adequately explained in previous research, by exploring group trends using quantitative analyses.

#### Summary of the Grounded Theory of Meaning of Pain

Meaning ascribed to pain by patients with advanced cancer and experiencing breakthrough pain is interpreted in the context of past and current experiences, pain characteristics and the patients’ values and beliefs. Despite occurring in positive or negative contexts, the meanings that emerge are not necessarily aversive. Moreover, most patients ascribe to multiple meanings. There are wide individual differences in both meanings ascribed to pain and the ways in which patients reported meanings of pain. In short, meaning of pain is a complex and diverse phenomenon that is not adequately explained by exploring group averages. Qualitative approaches are more likely to provide greater depth of understanding of meanings ascribed to pain by patients with advanced cancer.

## Limitations

It is important to acknowledge three shortcomings of this study. First, attempts were not made to elicit further information from patients who provided brief responses to the questions and prompts at the semi-structured interviews. Ideally, brief or unelaborated responses would have been explored further for clarification. However it was clear that some patients did not have the capacity to engage in a lengthier interview. Therefore clarification was not obtained from any of the patients who did not offer additional details. Consequently, potentially relevant data may have been missed for some patients. It may be difficult to ascertain whether a patient does indeed have the capacity for an extended interview, however, in future research, the quality of data may be enhanced by soliciting further details from those patients who do.

A second shortcoming of this study was that theoretical sampling was not guided by the constant comparative analysis of earlier interviews. Most texts on GT advocate that qualitative research leading to a grounded theory, ideally, collects and analyses data from the initial purposeful sampling, which then guides interview revision for subsequent interviews. The trustworthiness of the study may have been increased if subsequent interviews were guided by the codes and categories emerging from the earlier interviews. However, before any additional questions could be asked, the initial interview questions would still have been needed to introduce the concept of meaning of pain to the patients. The participants in the present study also provided data for other studies in the thesis. A lot of data was needed and it had to be obtained in a relatively short time, to minimise patient burden and to comply with ethical requirements.

Therefore it was decided that additional questions would not be asked in order to

increase the likelihood that patients complete the interview. Based on this experience, it is recommended that further qualitative research on meaning of pain in this population, focus exclusively on meaning of pain, to allow time to gather additional data.

Third, greater attention to attempting to tease apart meaning of pain and meaning of cancer could have been made. Although some links between meaning of pain and meaning of cancer are to be expected, the data did not permit this distinction to be made. Ideally, further exploration of these concepts would have enhanced the trustworthiness of the findings, but this was not undertaken because of concern about placing excessive burden on the patients. However, for some patients who provided elaborated responses, the meaning of pain was inextricably connected to meaning of cancer. Therefore the meaning of cancer and meaning of pain may sometimes be inseparable. A greater understanding of the distinction between meaning of pain and meaning of cancer is a possible area for future research.

#### Extensions to the Understanding of Meaning of Pain

Despite the shortcomings mentioned earlier, the present study has extended the understanding of meaning of pain in three ways. First, most patients reported multiple meanings of pain. There were wide individual differences in meanings and the ways in which meanings were reported. Meaning of pain was found to be a complex and diverse phenomenon, often interpreted in context of each patient's unique experience. Some meanings were dominant and others less strongly endorsed. There was even diversity even within a single meaning category (e.g., for loss). This diversity was not captured by a list of potential meanings, as used in quantitative research (e.g., Barkwell, 1991; Chen, 1995, Studies 2 and 3). Moreover, the mismatch between prompted endorsement,

and spontaneous generation of meanings (e.g., enemy/threat) provides additional evidence that the range and diversity of meanings of pain were not captured using quantitative measures.

Second, patients reported both aversive and non-aversive meanings of pain. Although these have been reported in previous research (Barkwell, 1991; Chen, 1995; Ferrell & Dean, 1995; Park, 2010), the present study extends previous research by revealing the range of aversive and non-aversive meanings. In some cases, aversive and non-aversive meanings were reported by the same patient. Third, for many patients, meaning of pain and meaning of cancer were inextricably linked. This connection was not obvious in previous research which referred to specifically meaning of cancer pain (Barkwell, 1991; Chen, 1995; Fife, 1994, 1995; Lee, 2008; Lipowski, 1970).

### Conclusion

In summary, the present study met the essentials of GT in the sense that there was some initial generation of codes before further data collection, and a theory developed that explained meaning of pain among patients with advanced cancer, and who are experiencing breakthrough pain. Although, the findings may have been enhanced if the questions asked in future interviews were guided by earlier analysis, the present study has still provided a greater understanding of meaning ascribed to pain in this population.

A qualitative approach to analysis accommodated multiple meanings and provided a depth of insight into the complexity, diversity and unique context of meaning of pain for the individual patient. This was not achievable using quantitative techniques. Although quantitative analyses were able to identify relationships between some meanings of pain

and other variables (breakthrough pain characteristics and level of coping) in Studies 2 and 3, these analyses did not capture the range of, and patterns in reporting of meanings of pain. Potentially important relationships may have been missed. Therefore the meanings of pain derived from the qualitative analysis in the present study will be incorporated into a further study which explores the relationships between meaning of pain, breakthrough pain characteristics and level of coping. A person-focused quantitative approach is adopted to facilitate a greater understanding of these relationships within individual patients.