

THE UNIVERSITY OF HULL

Self-management of cancer pain

being a Thesis submitted in partial fulfilment of

the requirements for the Degree of

Doctor of Clinical Psychology

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by

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And finally, to my late father Anthony George Houlston, and our late dear friend Gary Irwin, this work is for you. Your battles made me fight harder.

## **Overview**

The portfolio has three parts: a systematic literature review, an empirical study and a set of appendices.

Part one: Comprises a systematic literature review in which studies relating to the use of self-initiated pain coping strategies in adults with cancer are reviewed. Fifteen studies were included in the review, including qualitative, quantitative and mixed methods designs. The studies reviewed had to have explored pain coping strategies and have included patient characteristics such as demographic, psychological or clinical variables that would allow for the investigation of possible relationships between the two.

Part two: Comprises an empirical paper which explores the experiences of older people who self-manage their cancer pain at home. Patients attended semi-structured interviews with the main researcher. These interviews were analysed using Interpretative Phenomenological Analysis (IPA). The data was analysed, emergent themes are presented and implications are discussed in regard to existing literature. Methodological limitations are discussed and potential areas for future research are identified.

Part three: Comprises the appendices which support the work of the first two parts, and includes a reflective statement on the research process, an epistemological statement, and a worked example of IPA analysis.

## **Word counts**

Systematic literature review (including references): 9787

Empirical paper (including references): 10,288

Total portfolio (including references, excluding appendices): 20,929

## Table of Contents

Acknowledgements.....	2
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Overview.....	3
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### Part one: Systematic literature review

A systematic literature review of self-initiated coping strategies in cancer pain: Who chooses what?

Abstract.....	8
Introduction.....	9
Method.....	12
Results.....	19
Discussion.....	40
References.....	44

### Part two: Empirical paper

An interpretative phenomenological analysis of the experiences of older people self-managing cancer pain at home

Abstract.....	51
Introduction.....	52
Method.....	55
Results.....	59
Discussion.....	73
References.....	87

### Part three: Appendices

Appendix A: List of excluded studies.....	94
Appendix B: Data extraction tool.....	97
Appendix C: Methodological quality assessment checklist .....	98
Appendix D: Summary of quality assessment checklist scores.....	102
Appendix E: Ethical approval.....	103
Appendix F: Research protocol flowchart.....	107
Appendix G: Participant information letter.....	108

Appendix H: Clinician information sheet.....	110
Appendix I: Clinician referral form.....	112
Appendix J: Participant consent form.....	113
Appendix K: Demographic and clinical information form.....	114
Appendix L: Hospital Anxiety and Depression Scale (HADS).....	115
Appendix M: GP letter.....	116
Appendix N: Participant research analysis questionnaire.....	117
Appendix O: IPA example of data analysis.....	118
Appendix P: Reflective statement.....	127
Appendix Q: Epistemological statement.....	136
Appendix R: Journal guidelines for authors.....	141

## List of Tables and Figures

### Part one: Systematic literature review

Figure 1. Summary of article selection.....	16
Table 1. Summary of reviewed studies.....	22
Table 2. Summary of studies with highest methodological quality scores.....	38

### Part two: Empirical paper

Figure 1. Themes in the process of older adult's successful cancer pain self-management.....	82
Table 1. Participant demographics.....	83
Table 2. Pain and mood demographics.....	84
Table 3. Themes in older adult's self-management of cancer pain.....	85
Table 4. Participants' analyses of the extent to which themes reflected their experience.....	86

## Part one – Systematic literature review

**A systematic literature review of self-initiated coping strategies in cancer pain:**

**Who chooses what?**

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This paper is written in the format ready for submission to

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Please see Appendix R for author guidelines.

## **Abstract**

**Objective:** Cancer pain is under-recognised and undertreated. People use a diverse range of strategies to cope with cancer pain. This systematic review aimed to investigate whether there may be variables that identify which people will cope in certain ways. The review was interested in identifying relationships between demographic, clinical or psychological variables with self-initiated pain coping strategies, in adults with cancer.

**Design:** Selection criteria were used to identify studies from three electronic databases (PsycInfo; CINAHL Plus; MEDLINE). A methodological quality assessment was used and data was summarised using narrative synthesis.

**Results:** Fifteen studies were included in the review: two qualitative, two mixed methods, and eleven quantitative studies. The main findings suggest there are differences in the types of pain coping strategies used by different groups of people. There is more evidence of a link between psychological factors and coping with cancer pain than there are for clinical or demographic factors. However there is a paucity of literature in this area, and the quality of the evidence as a whole is inconsistent.

**Conclusion:** The results suggest that more research is warranted to describe coping strategies used to manage cancer pain in different patient groups. Limitations and clinical implications are discussed.

**Keywords:** cancer; pain; coping; strategy; individual differences; self-manage

## **A systematic literature review of self-initiated coping strategies in cancer pain:**

### **Who chooses what?**

#### **Introduction**

Cancer affects many thousands of people each year, and in the UK there are a growing number of people living with, or beyond, cancer. This figure is estimated to be around 2 million and is increasing year on year (Macmillan Cancer Support, 2008). Pain in cancer is undertreated, under-recognised and contributes to reduced quality of life and increased psychological distress (Raphael et al., 2010). Pain is one of the most feared symptoms of cancer (van den Beuken-van Everdingen et al., 2007). Half of all cancer patients report pain, whilst 70-80% of advanced metastatic cancer patients are reported to suffer from pain (Kaasa & Haugen, 2011). Cancer pain can be acute or chronic, and is complex in nature due to various neuropathic, inflammatory, compression and ischemic factors affecting, for many people, multiple sites in the body (Raphael et al., 2010). In addition, cancer treatments such as surgery, chemotherapy and radiotherapy are known causes of persistent chronic pain (Raphael et al., 2010).

Coping with pain is therefore a key issue for many people living with cancer. There has been a wealth of previous psychological research into coping, although conceptualisations of coping are varied, complex and lack a unified definition (Somerfield & McCrae, 2000). Within health psychology, coping has been understood as a dynamic process within models of stress and illness (Lazarus & Folkman, 1984) and within illness representation models (Leventhal, Meyer & Nerenz, 1980). Coping strategies are understood to be part of an ongoing process involving cognitive or behavioural responses directed at managing perceived discrepancies between a person's personal resources and the internal and/or external demands being placed on them (Lazarus & Folkman, 1984). Coping strategies have been categorised as either emotion-focused (active on the emotional consequences of the stressor) such as distraction,

avoidance etc., or problem-focused (actively directed towards the problem itself) such as seeking information, social support etc. (Lazarus & Folkman, 1984). How people understand their illness, and appraise and perceive threat, is known to influence how they respond and adjust to illness (Leventhal et al., 1980). The stability of coping strategies can be understood from either a dispositional approach, whereby people have stable patterns of coping despite varying stressors, or from a situational approach (a dynamic and inconsistent process), whereby people choose various strategies dependent on the stressor (Endler, Parker & Summerfeldt, 1993).

Studies have shown that pain outcomes can be affected by the coping strategies people use. Catastrophising has been associated with increased pain and disability in osteo-arthritis (Somers et al., 2009) and musculoskeletal conditions (Benyon, Muller, Hill & Mallen, 2013). Passive coping strategies have been associated with increased psychological distress and depression, whilst active coping strategies have been associated with reduced distress in chronic pain syndromes (Snow-Turek, Norris & Tan, 1996). However, there are recognised inconsistencies and a general paucity in the literature base with regards to coping with cancer pain specifically and clarification has been recommended (Valeberg, 2009).

Whilst the literature has examined the use of various coping strategies in relation to positive or negative outcomes in cancer (e.g. measures of pain intensity or interference), there has been, to our knowledge, no systematic review that has looked specifically at whether relationships exist between particular patient group variables and the use of self-initiated cancer pain coping strategies (i.e. those that individuals choose to engage in, independent of the care or support provided by others). Increased psychological distress caused by poorly controlled pain, and inadequate or maladaptive pain coping strategies, has multiple implications for healthcare systems in terms of cost, inpatient stays and long term disability (Raphael et al., 2010). Identifying adaptive

coping strategies may help patients to positively adapt to the effects of cancer and its treatments. Understanding which patient variables may relate to (predict and/or are associated with) the selection of particular coping strategies (whether adaptive or maladaptive) would help inform clinicians and contribute to pain management service delivery.

Pain management for inpatients is largely under the control of healthcare professionals, and coping with pain at home has long been understood to be more challenging and difficult to manage (Ferrell & Schneider, 1988). Studies have described poorer pain coping in outpatient groups compared to inpatients (Rockett, Simpson, Crossley & Blowey, 2013). Patients are increasingly surviving cancer (Macmillan Cancer Support, 2008) and consequently are increasingly required to self-manage their cancer pain as an outpatient population. This review therefore specifically targeted studies that have examined pain coping strategies in outpatients.

It has been suggested that to investigate coping strategies, they should be measured separately from outcomes, as there are multiple difficulties in appraising the potential positive qualities of coping i.e. the measured outcome may not be the outcome that was intended when the coping strategy was selected (Lazarus, 1993). Pain outcome variables, such as pain intensity and pain interference, have been conceptualised as dependent variables which are predicted by factors such as pain appraisals and illness representations (Leventhal et al., 1980). We were therefore not interested in whether pain outcome variables predict, correlate with, or are associated with coping strategies (e.g. does high pain predict the use of a particular coping strategy), but rather whether it was possible to discover relationships between characteristic variables (e.g. particular clinical, psychological and or demographic factors) and cognitive or behavioural coping strategies utilised for the management of cancer pain. The research question underpinning this review was therefore:

What evidence is there that coping strategies with regard to cancer pain are associated with particular clinical, psychological or demographic factors, and how strong is the evidence?

## **Method**

### ***Data Sources***

This review was designed to identify studies that described the use of coping strategies for pain in adults with a current diagnosis of cancer. Studies had to describe demographic, clinical or psychological factors and report on whether there was a relationship between those characteristics and cognitive or behavioural pain coping strategies of some kind. In doing so, this would potentially identify individual differences in the selection of pain coping strategies. Three electronic databases were searched up to and including February 2014. PsycINFO, MEDLINE and CINAHL Plus were chosen to cover the fields of psychology, medicine and health respectively.

### ***Inclusion and exclusion criteria***

No temporal, geographical or linguistic limitations were used in the search protocol to ensure a wide range of studies could be included in the review. The following criteria were applied to all studies:

#### **Inclusion criteria:**

- Studies should be published in peer reviewed journals to ensure quality.
- Studies could involve qualitative, quantitative or mixed methods. Not excluding on the grounds of methodology ensured the widest capture of studies reporting variables of interest.
- Participants must be adults aged over 18years with a current diagnosis of cancer.

- The study had to have the investigation of pain as a primary focus.
- There had to be measurement, investigation and/or identification of at least one defined self-initiated cognitive or behavioural pain coping strategy.
- Studies had to involve or include the investigation of relationships between any identifiable demographic, clinical or psychological variable (e.g. age, cancer type etc.) and a pain coping strategy.

#### Exclusion criteria

- Systematic reviews, literature reviews, book reviews.
- Studies that only looked at relationships between coping and pain outcome variables (e.g. pain intensity, pain interference etc.).
- Studies investigating (or describing as coping strategies): pharmacological management; medication adherence; the use of complementary and alternative medicines; the use of vitamins or supplements; dietary management.
- Pain management intervention studies.
- Inpatient studies. Inpatients are a qualitatively different group to outpatients in terms of environment, available resources and degree of medical management. Our focus was outpatients as this is the group of people with the highest prevalence of cancer pain (Breivik et al., 2009).

#### *Search Strategy and Study Selection*

The search terms used were identified from consulting key studies in the areas of self-management of cancer pain and coping. An initial wide search of the literature was conducted using the following search terms (\*indicates truncation):

- pain
- AND cancer OR neoplasm\* OR oncolog\*
- AND strateg\* OR cop\* OR support\*
- AND manag\* OR self-manag\*

The search returned a total of 4600 studies. Following the application of age limiters (>18years), exclusion of non-peer reviewed studies, and removal of duplicates, the total number of abstracts read was 1675. A total of 1652 papers were rejected at abstract stage for failing to meet inclusion criteria, and 23 full text studies were obtained. The full text studies were read by both authors and inclusion and exclusion criteria applied. A total of 12 studies were excluded at this stage for failing to meet required criteria (see Appendix A). Agreement was reached regarding the included studies, total number 11.

Following the identification of these studies, a second search was conducted which aimed to narrow the search and identify any further studies investigating coping strategies in cancer pain. These terms were decided on after reading full texts of included studies from search 1 and identifying the most relevant keywords that may capture further studies. This second search therefore specifically focused on coping strategies using the terms:

- pain
- AND cancer OR neoplasm\* OR oncolog\*
- AND coping
- AND strateg\*

This second search identified 348 studies. Following the application of age limiters (>18years), exclusion of non-peer reviewed studies, and duplicates removed,

the total number of abstracts read was 133. A total of 119 were then rejected for failing to meet inclusion criteria, along with 4 studies that were duplicates (and already selected) from search 1. For the remaining 10 studies, full texts were obtained and read by both authors. A total of 4 were selected from search 2 for the final pool. Together with the 11 papers selected from search 1, the review's final total pool was 15. Figure 1 summarises the selection of studies. Appendix A details all excluded studies.

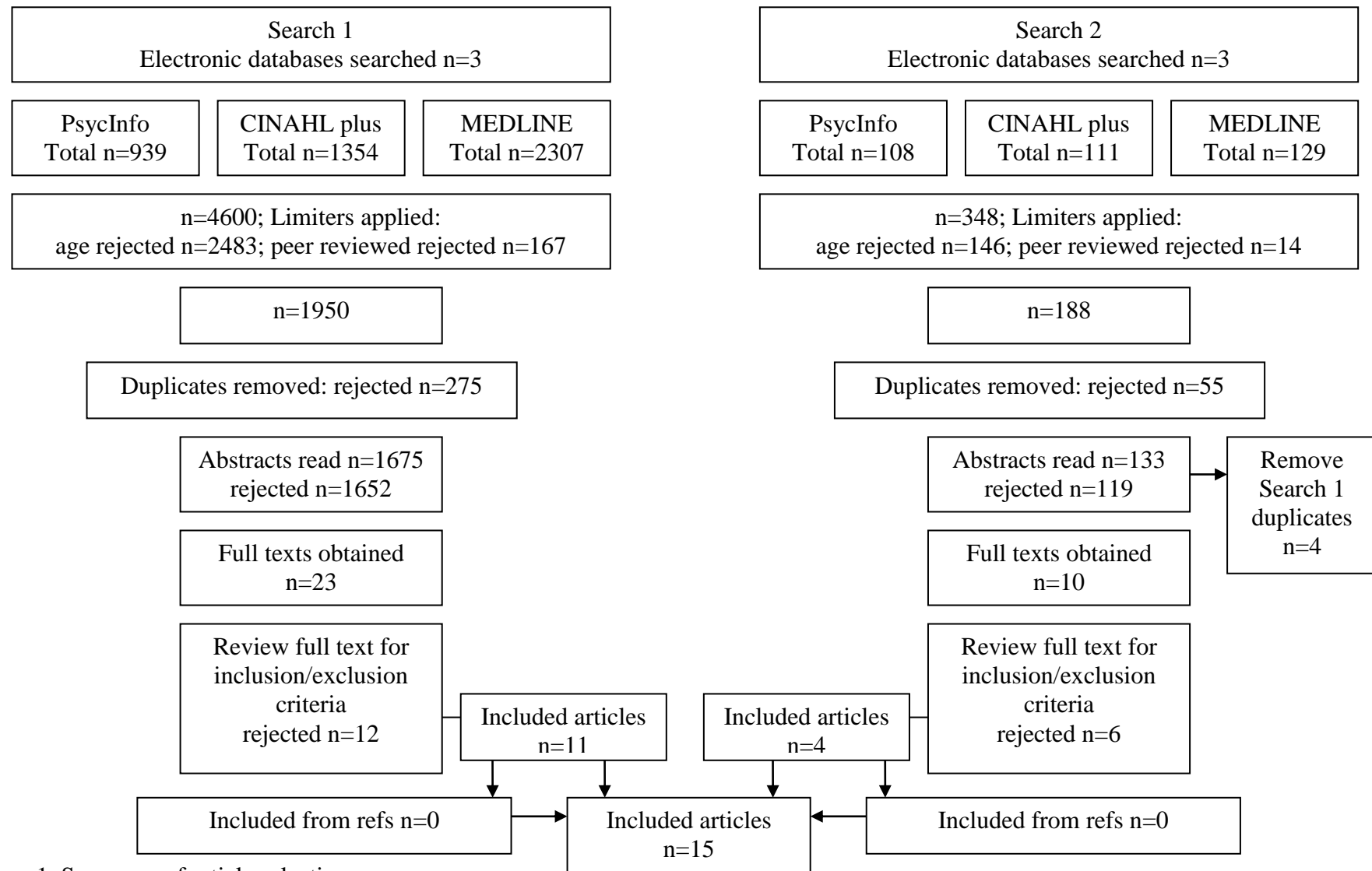


Figure 1. Summary of article selection.

### ***Data Extraction***

A data extraction form was created (Appendix B) to collect relevant information from the studies to be included in the review. This information is presented in Table 1.

### ***Methodological Quality Assessment***

Measuring the methodological quality of reviewed studies is an essential part of systematic literature reviews (Khan, Kunz, Kleijnen & Antes, 2003). Assessing quality enables the evaluation of a study's internal and external validity, in order to understand strengths and limitations, and the extent to which it is possible to rely on the study's findings (Carlson & Morrison, 2009).

A methodological quality assessment checklist was created (Appendix C). Questions from the Downs and Black (1998) quality checklist for quantitative studies were used along with questions from the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011). The checklists were integrated and modified in several ways to suit the review question. The Downs and Black (1998) checklist is comprehensive, reliable and validated for use with quantitative studies, and questions relating to aims, outcomes, characteristics of participants and findings of each study were used. The MMAT (Pluye et al., 2011) is a brief reliable and valid checklist used for mixed methods studies, and questions relating to the design of each study, and in particular sample bias, were used. Therefore, the original Downs & Black (1998) questions relating to quantitative analyses were removed and replaced with question 8ai-8ciii, modified from the MMAT (Pluye et al., 2011) to assess quality of studies in relation to specific methodologies (quantitative, qualitative or mixed methods).

For the purpose of our review question, question 3 awarded points if the study clearly described predictors, correlates or associates in the introduction or method.

Question 2 required that coping strategies be clearly described and given a clear

definition in the introduction or method. This was to give weight to studies where the primary aim was to investigate relationships between characteristic variables and coping strategies.

The resultant checklist used a point scoring system, with 0 for 'no' or 'not clear', 1 for 'partly' answering the question, and 2 for 'yes'. The overall score achievable by each study varied depending on its methodology. For quantitative and qualitative papers, the maximum score was 22, and for mixed methods papers the maximum score was 36. Scores were transformed into percentages to ensure they could be compared. A scoring guide, as part of the checklist, was created to ensure reliability across raters.

Appendix D summarises each of the 15 reviewed studies' scores on the methodological quality checklist. There was a wide variability in quality scores, which ranged between 39-82%, mean 62.47 (SD 13.73). For the purpose of this review, we categorised low and high quality scores as one standard deviation or more away from the mean: low <49%; moderate 50-75%; high >76%. Three studies scored in the low category (Bennett, Closs and Chatwin, 2008; Miaskowski & Lee, 1999; Whale, Lyne & Papanikolaou, 2001) and ten in the moderate category. The two studies that scored in the high category in terms of methodological quality were quantitative studies conducted by Fischer, Villines, Kim, Epstein and Wilkie (2009; 82%) and Prasertsri, Holden, Keefe and Wilkie (2011; 77%) as detailed in Table 2. The results are discussed in more detail below.

The scores used in this review were awarded by the lead author. An independent rater scored all 15 of the studies included in the review, to confirm the reliability of the adapted quality assessment checklist. Cohen's Kappa statistic (Cohen, 1960) was used to assess inter-rater reliability using SPSS software, version 21. It was not possible to run Kappa for the questions relating specifically to the qualitative studies (n=2) or the mixed methods studies (n=2) as there were insufficient studies to enable a meaningful

calculation. Kappa was applied to all the studies (n=15) on questions 1-7 and to the quantitative studies (n=11) on questions 12-15. Overall, Kappa values ranged from .63-1.00 (moderate to perfect), and the only question which showed poor agreement was question 3 with a Kappa value of 0.33. This represented disagreement on 3 studies (Buck and Morley, 2006; Kwekkeboom, 2001; Miaskowski and Lee, 1999) in regard to whether predictors, associates or correlates on interest were clearly described in the introduction or method, with one rater scoring yes (2 points) and one rater scoring partly (1 point). Five questions (1, 4, 12, 14, 15) had a Kappa value of 1.00, demonstrating perfect agreement across all 11 studies. We can be reasonably confident that the quality assessment checklist was a reliable measure.

### ***Data Analysis***

The heterogeneity of studies included in the review, which utilised a range of methodologies (including quantitative, qualitative and mixed methods), meant that meta-analysis was not viable. Therefore a narrative synthesis was used to summarise the findings of the review.

## **Results**

### ***Characteristics of included studies***

The data for each of the 15 reviewed studies is summarised in Table 1. There were 11 quantitative studies, two mixed methods studies and two qualitative studies. The majority of studies had taken place in the USA (10 studies). The remaining studies were conducted in the UK (three studies); Canada (one study); Taiwan (one study). The total number of included participants across all studies was 1243.

The following nine studies had the explicit aim of investigating predictors, correlates or associates of coping strategies in cancer pain: Arathuzik (1991) coping in

relation to pain appraisal; Buck and Morley (2006) coping in relation to attentional strategy; Fischer et al. (2009) coping in relation to primary cancer type; Gaston-Johansson, Ohly, Fall-Dickson, Nanda and Kennedy (1999) coping in relation to breast cancer type; Kwekkeboom (2001) coping in relation to breast and gynaecologic cancer type; Lin (1998) coping in relation to perceived self-efficacy; Prasertsri et al. (2011) coping in relation to coping style; Miaskowski and Lee (1999) coping in relation to bone metastases type; Wilkie and Keefe (1991) coping in relation to pain expression preference.

The following six studies reported investigating relationships between predictors, correlates or associates of coping strategies in cancer pain as secondary to the main aims of the study: Bennett et al. (2008) examined whether older people with cancer at home experienced poorer pain management, for the purpose of this review we were interested in the reported coping strategies used by older and younger participants; Gagliese et al. (2009) aimed to explore adaptation to cancer pain by age, for the purpose of this review we were interested in the description of accommodation strategies used to cope; Haozous, Knobf and Brant (2011) aimed to qualitatively explore cancer pain experience in an ethnic group; Im et al. (2009) aimed to qualitatively explore cancer pain experience by ethnic group; Reddick, Nanda, Campbell, Ryman and Gaston-Johansson (2005) aimed to explore the influence on coping with pain on depression, anxiety and fatigue, for the purpose of this review we were interested in the reporting of ethnic differences in coping strategies; Whale et al. (2001) aimed to investigate pain experience (incidence and nature of pain, attitudes to pain and pain relief) following treatment for head and neck cancer, for the purpose of this review we were interested in the reported coping strategies of this group.

The narrative synthesis of the review's findings draws on the information presented in Table 1. The narrative also divides the studies to be reviewed into three

categories: demographic variables (five studies), clinical variables (five studies), and psychological variables (five studies). Reference to each study's methodological quality and the implications of this for the interpretation and integration of findings is made throughout.

Table 1. Summary of reviewed studies.

Study	Aims	Participants	Design	Predictor, associate or correlate of interest	Key Findings re. coping strategies and predictor, associate or correlate of interest	Quality Score
Arathuzik (1991; USA)	To examine the relationships between appraisal of pain and selection of coping strategies in cancer pain.	Total n=80: females aged 30-80years (48.9% aged between 60-80years); metastatic breast cancer.	Quantitative correlational	Pain appraisal	Those who appraised pain as threat were likely to use acceptance or reappraisal; as harm were likely to use distraction, acceptance or reappraisal; as challenge were likely to use communication, relaxation, distraction, visualisation, acceptance, problem solving, reappraisal.	68%
Bennett et al. (2008; UK)	To examine whether older patients with cancer experienced poorer pain management than	Total n=90: younger patients n=32 (15 male) aged 37-60years, mean age 52 (SD 6.8) n=58 older people (38 male) aged 75-95years, mean age=81	Quantitative observational	Age	Coping strategies used were seeking help from family members; use of complementary and alternative medicine; use of exercise or different posture. No	45%

	younger patients with cancer.	(SD 4.25); various cancer types.			significant differences between age groups.	
Buck et al. (2006; UK)	Investigate the use of attentional control strategies in cancer pain using diary measures.	Total n=26 (12 male) aged 31-78years, mean age 55.5 (SD11.5); various cancer types.	Quantitative correlational	Self-efficacy	Self-efficacy was not correlated with the measured attentional coping strategies: diverting attention; ignoring pain; focused on pain.	64%
Fischer et al. (2009; USA)	Explore differences in pain, anxiety and depression by type of primary cancer.	Total n=320: lung cancer n=146 (101 male), mean age 61.2 (SD 10.4); head/neck cancer n=93 (68 male), mean age 53.9 (SD 12); prostate cancer n=63 (63 male), mean age 64.4 (SD 8.7).	Quantitative correlational	Cancer type: lung; head/neck; prostate	Most common coping strategies were coping self-statements, followed by praying/hoping and increasing pain behaviour. Least used strategies were catastrophising and reinterpreting pain sensations. No statistically significant differences in coping strategies amongst cancer groups.	82%
Gagliese et al. (2009; Canada)	Explore age-related patterns in adaptation to cancer	Total n=32: younger patients n=15 (5 male), aged 39-55years mean age 48.9 (SD	Mixed methods	Age	Older patients described adapting to cancer pain by using accommodation strategies including	61%

	related pain in younger and older patients.	4.9); older n=17 (10 male) aged 60-90years, mean age 72.4 (SD 9.2); various cancer types.			acceptance and modification of goals and activities. Younger patients were less likely to use these strategies.	
Gaston-Johansson et al (1999; USA)	Investigate relationships between pain, distress, health status and coping in cancer.	Total n=83: females aged 22-59years, mean age 44.47 (SD 7.29); breast cancer.	Quantitative correlational	Cancer type: breast	Most frequently used pain coping strategies: positive coping statements; diverting attention; praying and hoping; increasing activity level; ignoring pain.	64%
Haozous et al. (2011; USA)	Explore the experience of cancer pain in American Indians from the Northern Plains of the USA.	Total n=10 (1 male) aged 31-75years, mean age 54; various cancer types.	Qualitative	Ethnicity	Participants discussed the use of prayer and traditional medicine in coping with pain.	73%
Im et al. (2009; USA)	Explore similarities and differences in cancer pain	Total n=75 (10 male) aged 24-81years: White n=22 (2 male), mean age 45.09 (SD10.43);	Qualitative	Ethnicity	White participants focused on how to control pain and treatment selection process; ethnic minority	68%

	experience among four major ethnic groups in the USA.	African American n=11 (0 male), mean age 46.45 (SD 6.91); Hispanic n=15 (3 male), mean age 49.40 (SD 13.07); Asian n=27 (5 male), mean age 51.63 (SD 9.74); various cancer types.			participants tried to control pain by minimising and normalising.	
Kwekkeboom (2001; USA)	To describe steps taken by patients with breast and gynaecologic cancer to manage pain.	Total n=75: females aged 32-73years, mean age 52.12 (SD 11.13); breast and gynaecologic cancers.	Quantitative descriptive	Cancer Type : breast and gynaecologic	Found that strategies used to manage cancer pain were positioning, relaxation, distraction and heat.	64%
Lin (1998; Taiwan)	Explore the differences between chronic cancer pain and chronic low back pain and the use of coping strategies.	Total cancer group n=88 (30 male) aged 25-80years, mean age 55.1 (SD 11.6); various cancer types. Overall study n=173.	Quantitative correlational	Self-efficacy	Self-efficacy was positively correlated with the use of a range of cognitive and behavioural coping strategies.	59%

Miaskowski et al. (1999; USA)	Investigated pain, fatigue and sleep disturbances and behavioural self-care strategies to manage pain and fatigue in advanced cancer.	Total n=24 (12 male) mean age 56.6 (SD 13.0); various cancer types.	Quantitative correlational	Bone metastasis	Non-pharmacological behavioural pain coping strategies included relaxation exercises and physical exercise.	41%
Prasertsri et al (2011; USA)	Examine coping style and relationship to depression, pain and pain coping strategies in lung cancer.	Total n=107 (76 male) mean age 61.4 (SD 10.7); lung cancer.	Quantitative secondary bivariate analyses	Coping style	Found that participants in the defensive-high anxious style group and the high anxious coping style group had significantly higher catastrophising score than the repressive coping style group.	77%
Reddick et al. (2005; USA)	Examine the influence of coping with pain on depression, anxiety and fatigue in cancer between ethnic	Total n=138 females aged 22-60 years, mean age 45 (SD 7.7); Caucasian n=118; African American n=15; Other minorities n=3; breast cancer.	Quantitative correlational	Ethnicity	Both groups used a range of coping strategies for pain. African American participants scored significantly higher on praying and hoping to cope with pain.	73%

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groups.

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Whale et al. (2001; UK)	Investigate pain in people who had received radical treatment for head and neck cancer and explore attitudes to pain and pain relief.	Total n=50 (36 male) aged 43-87years for questionnaires; n=29 for qualitative interview.	Mixed methods	Cancer type: head and neck	Most common coping strategy was distraction from keeping busy whilst planning regular rest; prioritising good sleep; sipping warm fluids; warm baths; gentle massage or exercise; adjusting activity levels; adjusting position; waiting for pain to ease.	39%
Wilkie et al. (1991; USA)	Examine relationships between pain and psychological variables, and pain coping strategies in lung cancer.	Total n=45 (28 male) aged 40-80years, mean age 61; lung cancer.	Quantitative correlational	Verbalising	Found significant differences between for the use of various pain coping strategies e.g. diverting attention, in people who verbally express pain versus people who try not to express pain.	50%

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### *Demographic variables*

Five studies described the use of pain coping strategies in relation to two demographic variables: age (two studies: quantitative and mixed methods); ethnicity (three studies: quantitative and qualitative).

#### *Age*

Two studies reported on whether age is a factor in the selection of pain coping strategies. Bennett et al. (2008) explored whether older patients experienced poorer cancer pain management than younger patients. A total of 90 participants with 32 younger patients (15 male) and 58 older patients (38 male) with various cancer diagnoses took part in this descriptive observational study. Participants discussed using the following cognitive or behavioural coping strategies: seeking help from family members; use of exercise or different posture. The authors reported no significant differences between age groups in regard to the use of coping strategies, however, the investigation of predictors, correlates or associations with pain coping strategies was not a primary aim of the study. The study did not employ a validated coping strategy questionnaire, and used self-report regarding use of any coping strategies to manage pain. The study selected participants who were newly referred to specialist palliative services and the source was described, however it was not stated whether selection was consecutive, random or convenience and as such we were unable to establish whether bias was minimised and if the sample was representative of the population. In addition, study limitations and generalisability were only partly addressed in the discussion. This study scored in the low category in our quality assessment.

Gagliese et al. (2009) explored age-related patterns in adaptation to cancer related pain in younger and older patients in a mixed methods study. A total of 32 participants with 15 younger patients (5 male) and 17 older patients (10 male) with

various cancer diagnoses took part. Not all cancer diagnoses were reported, with 8 participants having an unclear primary cancer type. They found that older patients described adapting to cancer pain by using accommodation strategies including acceptance and modification of goals and activities. Younger patients were less likely to use these strategies. The investigation of predictors, correlates or associations with pain coping strategies was not a primary aim of the study. The study did not employ a validated pain coping strategy questionnaire and relied on self-report for strategy use within the qualitative component of the study (semi-structured interview).

Methodologically, selection bias was minimised during participant recruitment, although quality regarding integration of qualitative and quantitative components, and quality regarding the qualitative analysis was less clear. This study scored in the moderate category in our quality assessment.

### *Ethnicity*

Three studies reported ethnic factors in the selection of pain coping strategies. The first two studies utilised qualitative methodology. Haozous et al. (2011) explored the experience of cancer pain in 10 (1 male) American Indians from the Northern Plains of the USA with various cancer diagnoses (not detailed) in this well designed qualitative study. Contextual and researcher influences were made explicit. Whilst the investigation of predictors, correlates or associations with pain coping strategies was not a primary aim of the study, during semi-structured interviews the participants discussed strategies (particularly the use of prayer) to cope with pain, that were described as characteristic of this specific ethnic group. This study scored in the moderate category in our quality assessment.

Im et al. (2009) explored the similarities and differences in cancer pain experience among four major ethnic groups in the USA. A total of 75 (10 male)

participants with various cancer diagnoses took part in this qualitative study using online forums to collect data. They describe how white participants focused on how to control pain and also focused on selecting pain treatments, whilst ethnic minority participants coped by minimising and normalising pain. Again, the investigation of predictors, correlates or associations with pain coping strategies was not a primary aim of the study and thus coping strategies were not defined. However unlike the previous qualitative study, this study did not make context and researcher influences explicit. Both studies involved a predominantly female sample. This study scored in the moderate category in our quality assessment.

Reddick et al. (2005) examined the influence of coping with pain on depression, anxiety and fatigue in 138 females (118 Caucasian; 15 African American; 3 other minority; 2 unaccounted for in demographics) with breast cancer using correlational analyses. It was not a primary aim of the study to investigate the predictors, correlates or associations of pain coping strategies. The authors found that both groups used a range of coping strategies for pain, using the Coping Strategies Questionnaire (CSQ; Rosenstiel & Keefe, 1983). They also found that African American participants scored significantly higher on praying and hoping to cope with pain than Caucasian participants. Convenience sampling did not minimise bias and thus we were unable to establish whether participants were representative of the population. However, the study did acknowledge limitations to generalisability. Overall, this study scored in the moderate category in our quality assessment.

#### *Summary of findings related to demographic variables*

The five reviewed studies in this category varied in methodology and quality. Four studies were scored in the moderate category (Gagliese et al., 2009; Haozous et al., 2011; Im et al., 2009; Reddick et al., 2005) and one was scored low (Bennett et al.,

2008). There is some evidence in favour of age associated coping patterns in cancer pain (Gagliese et al., 2009) but the paucity of literature here is a key issue. In regards to ethnicity, there were mixed findings, though slightly more consensus. The findings of both Haozous et al. (2011) and Reddick et al. (2005) suggest that the use of prayer to cope with cancer pain is linked with ethnicity, whilst the findings of Im et al. (2009) suggest the possibility that how people attempt to control pain (perhaps a broader issue) could be linked with ethnicity. However, the general paucity of literature in our pool and methodological quality limitations suggests that it is not possible to state conclusively whether particular demographic variables are associated with the use of coping strategies.

### ***Clinical variables***

Five studies described the use of pain coping strategies in relation to two clinical variables: cancer type (four studies: quantitative and mixed methods); disease stage (one study: quantitative).

### ***Cancer Type***

Fischer et al. (2009) explored differences in pain, anxiety and depression in three types of cancer diagnosis (lung; head/neck; prostate). The study had the explicit aim of investigating predictors, correlates or associates of coping strategies in cancer pain and used correlational analyses on data from a total of 320 participants: lung cancer n=146 (101 male); head/neck cancer n=93 (68 male); prostate cancer n=63 (63 male). The study used a consecutive sample minimising bias (although response rate was <60%). The authors acknowledge there may be limitations to the study's generalisability. The CSQ (Rosenstiel & Keefe, 1983) was used as measure of coping strategies. The authors reported that the most common coping strategies were coping

self-statements, followed by praying/hoping and increasing pain behaviour. Least used strategies were catastrophising and reinterpreting pain sensations. The authors report that no statistically significant differences were found in coping strategies between the different cancer groups. This study scored in the high category in our quality assessment.

Gaston-Johansson et al. (1999) investigated relationships between pain, distress, health status and coping in 83 females with breast cancer using correlational analyses. The study had the aim of investigating correlates of coping strategies in cancer pain, however the use of a convenience sample did not minimise selection bias and the authors acknowledge limitations regarding generalisability of findings. Using the same measure as the previous study, the CSQ (Rosenstiel & Keefe, 1983), the authors found that the most frequently used pain coping strategies in this particular sample/type of cancer pain were: positive coping statements; diverting attention; praying/hoping; increasing activity level; ignoring pain. This study scored in the moderate category in our quality assessment.

Kwekkeboom (2001) described the steps taken by 75 female participants with breast and gynaecologic cancer to manage pain using descriptive statistics. Data regarding coping strategies was gathered from pain dairies in this study using secondary analyses from participants recruited for a randomised controlled trial although the authors acknowledge the results may not be generalisable due to the small sample recruited from one area in the Midwestern USA. Coping strategies were not clearly defined and no validated coping strategy measures were used. The author reported that strategies most used to manage cancer pain by participants with these particular types of cancer were positioning, relaxation, distraction and the use of heat. This study scored in the moderate category in our quality assessment.

Whale et al. (2001) investigated pain in people who had received radical

treatment for head and neck cancer and explored attitudes to pain and pain relief in this specific clinical group. The investigation of predictors, correlates or associations with pain coping strategies was not a primary aim of the study. This mixed methods study involved 50 participants (36 male), with 29 participating in a qualitative interview. It was unclear whether sample bias was minimised and the authors did not discuss whether the study findings could be generalised. During semi-structured interviews, it was found that the most common coping strategy was described as distraction (keeping busy) whilst planning regular rest periods. Other strategies used were: prioritising good sleep; sipping warm fluids; warm baths; gentle massage or exercise; adjusting activity levels; adjusting position; waiting for pain to ease. Relevance and methods regarding the integration of qualitative and quantitative data, and divergence and convergence of information were not made explicit. In addition, in the qualitative component of the study, contextual and researcher influences were unclear. This study scored in the low category in our quality assessment.

#### *Disease Stage – metastasised*

Miaskowski and Lee (1999) investigated pain, fatigue and sleep disturbances, and behavioural self-care strategies to manage pain and fatigue, and thus had the explicit aim of investigating correlates of coping strategies in cancer pain. The study used correlational analyses and had a total of 24 (12 male) participants with various cancer diagnoses, convenience sampled. The study used self-care activity logs to measure strategies, containing commonly used strategies for participants to identify which they used, but it is unclear as to the validity or reliability of the logs. Participants reported the most commonly used non-pharmacological behavioural pain coping strategies included relaxation exercises and physical exercises. The authors acknowledged limitations to the generalisability of the findings due to sample bias. This

study scored in the low category in our quality assessment.

### *Summary of findings related to clinical variables*

The five reviewed studies in this category described the use of pain coping strategies across cancer type and disease stage. In our quality assessment we scored one study in the high category (Fischer et al., 2009). Two studies were scored in the moderate category (Gaston-Johansson et al., 1999; Kwekkeboom, 2001) and two were scored low (Miaskowski and Lee, 1999; Whale et al., 2001). In regards to cancer type and coping strategies there were varied findings over the four studies. Whilst methodologically the Fischer et al. (2009) study is the strongest, general paucity and heterogeneity of literature in this pool, alongside methodological quality limitations of the other four studies in this category, and inability to generalise findings of any of the reviewed studies, again suggests that it is not possible to state conclusively which clinical variables influence coping strategies.

### *Psychological variables*

Five studies described the use of pain coping strategies in relation to four psychological variables: pain appraisal (one study: quantitative); self-efficacy (two studies: quantitative); verbalising (one study: quantitative); coping style (one study: quantitative).

### *Pain Appraisal*

Arathuzik (1991) examined relationships between appraisal of pain and selection of coping strategies in 80 females with metastatic breast cancer using correlational analyses. The study therefore had the explicit aim of investigating correlates of coping strategies in cancer pain. Convenience sampling was employed and

as such the study did not minimise sample bias, although the author acknowledges that this compromises the ability to generalise the findings beyond the study's sample. The study found differences in the use of coping strategies depending on how people appraised their pain. Findings suggested that those who appraised pain as a threat were likely to use acceptance and/or reappraisal. It was also found that those who appraised pain as harm were likely to use distraction, acceptance and/or reappraisal. Additionally, people who appraised pain as challenge were likely to use communication, relaxation, distraction, visualisation, acceptance, problem solving and/or reappraisal. The study used a newly designed (by the author) coping measure, the Pain Coping Tool, to investigate coping strategies but the validity of this was unclear due to the piloting of the measure. This study scored in the moderate category in our quality assessment.

### *Self-efficacy*

Two studies reported on whether self-efficacy was correlated with the use of pain coping strategies. Buck and Morley (2006) aimed to investigate correlates of coping strategies in cancer pain. They investigated the use of attentional control strategies using diary measures with 26 participants (12 male) who had various cancer diagnoses. It was unclear from the demographic information what cancer types were under investigation, and whether participants were representative. The authors acknowledge difficulties with generalising from the sample. They found that self-efficacy was not correlated with the measured attentional coping strategies: diverting attention; ignoring pain; focusing on pain. Coping strategies were measured using a modified version of the Brief Coping Inventory (Stone & Neale, 1984). This study scored in the moderate category in our quality assessment.

Lin (1998) had the explicit aim of investigating correlates of coping strategies in cancer pain, exploring differences between chronic cancer pain and chronic low back

pain and the use of coping strategies in 173 participants in Taiwan. The cancer group consisted of 88 participants (30 male) with various cancer diagnoses, convenience sampled. It was unclear whether the sample was representative, although the authors report that 70% of the approached patient group participated. The authors did not discuss study limitations or the generalisability of findings in the discussion. In contrast to the above study, they reported that self-efficacy was positively correlated with the use of all of the eight measured cognitive coping strategies (e.g. diverting attention; imagery; catastrophising; ignoring pain) and eight behavioural coping strategies (e.g. activity; relaxation; use of heat; use of cold), using the CSQ to measure coping strategy use (Rosenstiel & Keefe, 1983). This study scored in the moderate category in our quality assessment.

### *Verbalising*

Wilkie and Keefe (1991) aimed to investigate correlates of coping strategies in cancer pain. They examined relationships between pain and psychological variables, and pain coping strategies in lung cancer using correlational analyses in 45 participants (28 male). Participants were convenience sampled and as such sample bias was not minimised, although the authors did not discuss the limitations of the study or the generalisability of the findings in the discussion. The study used the CSQ (Rosenstiel & Keefe, 1983) to investigate pain coping strategies. The authors reported finding significant differences ( $p < 0.05$ ) between people who verbally express pain versus people who try not to express pain in the use of the following pain coping strategies as defined by the CSQ: diverting attention; self-statements; ignoring pain; praying/hoping; increased activity; pain behaviours. They did not find a significant difference in the use of catastrophising between the groups. This study scored in the moderate category in our quality assessment.

### *Coping style*

Prasertsri et al. (2011) had the explicit aim of investigating predictors, correlates or associates of coping strategies in cancer pain. This study examined coping style and relationship to depression, pain and pain coping strategies using bivariate analyses to find associations in 107 (76 male) participants with lung cancer. It was unclear whether the sample used was representative although the study used cross-sectional secondary analysis data from a randomised controlled trial. The authors acknowledged limitations in the study's generalisability beyond the sample. Using the CSQ (Rosenstiel & Keefe, 1983) the authors found only one subscale score with a statistically significant difference as a function of coping style group: they report that participants in the 'defensive-high anxious style' group and the 'high anxious coping style' group had significantly higher catastrophising scores than a 'repressive coping style' group. This study scored in the high category in our quality assessment.

### *Summary of findings related to psychological variables*

The five reviewed studies in this category described the use of pain coping strategies across pain appraisal, self-efficacy, verbalising and coping style. In our quality assessment we scored one study in the high category (Prasertsri et al., 2011). Four studies were scored moderate quality (Wilkie & Keefe, 1991); Lin, 1998; Buck & Morley, 2006; Arathuzik, 1991). No studies were scored low quality. Findings in this category were varied across the moderate quality studies and the heterogeneity of studies and participants, the paucity of studies in our pool, methodological limitations and inability to generalise from any of the studies' findings suggests that we are unable state conclusively which psychological variables influence coping strategies. However, the quality overall in this category was higher than in other categories and suggests that overall, we can be more confident in the findings of psychological variables and their

relationship to coping strategies.

### *Overall summary of the methodological quality of reviewed studies*

The quality assessment examined each study's methodological quality and ability to answer our research question. There were two studies that scored in the high category, quantitative studies from Fischer et al. (82%) and Prasertsri et al. (77%) and their main findings and methodological strengths are detailed in Table 2. The implications of these findings are referred to in the discussion.

Table 2. Summary of studies with highest methodological quality scores.

Study	Aims	Key Findings	Methodological strengths
Fischer et al. (2009; USA)	Explored differences in pain, anxiety and depression by cancer type: lung; head/neck; prostate.	Most used strategies: coping self-statements, praying/hoping, increasing pain behaviour. No difference between groups.	Minimised selection bias (sample representative); used reliable and valid coping measure (CSQ)
Prasertsri et al (2011; USA)	Examined coping style and relationship to depression, pain and pain coping strategies.	Participants in the defensive-high anxious and high anxious coping style group had significantly higher catastrophising score than the repressive coping style group.	Minimised selection bias (sample representative); used reliable and valid coping measure (CSQ)

### *External validity*

Across all studies sample bias was apparent and as such, it was not possible to state that samples were representative of the populations they were recruited from.

Whilst most studies did acknowledge these limitations, it is apparent that the ability to generalise findings from any of the studies is limited and as such the external validity of the included studies in this review is compromised.

### *Internal validity*

It is not possible to be confident about the internal validity of the studies included in the review. It is not possible to establish causal relationships, and the quantitative studies could have potentially confounding variables that were not controlled for, due to their design. As such, relationships between reported correlates and coping strategies must be interpreted with caution.

Alongside interviews and diary measures, eight studies employed various coping strategy questionnaires to examine coping. One study: Buck & Morley, 2006, used the modified version of the Brief Coping Inventory (BCI; Stone & Neale, 1984). The BCI, initially conceived as a 55 item checklist, demonstrated unsatisfactory psychometric properties whilst under design. Further developed as an open-ended questionnaire format using 8 categories, Stone and Neale (1984) reported a moderate amount of within-subject consistency. They were unable to calculate internal reliability coefficients due to the categories being single items. However, they also questioned the usefulness of internal consistency in the measurement of coping processes which may vary over time, and acknowledged their inability to firmly establish reliability or validity for the measure. One study used a pilot of the self-designed Pain Coping Tool (Arathuzik, 1991) and again, reliability and validity cannot be established.

Six studies (Fischer et al. 2009; Gaston-Johansson et al., 1999; Lin, 1998; Prasertsri et al., 2011; Reddick et al., 2005; Wilkie & Keefe, 1991) used the CSQ (Rosenstiel & Keefe, 1983). This measure is a rationally constructed assessment, which measures the use of six different cognitive pain coping strategies and two behavioural pain coping strategies, and is one of the most widely used scales of coping (Swartzman,

Gwadry, Shapiro & Teasell, 1994). The CSQ reported subscale internal reliability with Cronbach's alphas ranging from 0.71 to 0.85, except for the increasing pain behaviour subscale which reported internal consistency of 0.28. Principal components analysis reported three factors accounting for 68% of the response variance (Rosenstiel & Keefe, 1983). The internal consistency and predictive validity of the CSQ has been confirmed (Keefe, Brown, Wallston & Caldwell, 1989).

## **Discussion**

There is a recognised paucity of research into the psychological factors that impact upon pain (Raphael et al., 2010). This review highlights the dearth of literature examining self-initiated coping strategies for cancer pain in people who are required to self-manage their pain as outpatients. The findings of this review in regard to coping strategies and characteristic variables were varied and, overall, the majority of studies scored in the low-moderate range in terms of methodological quality. Potentially, the findings of this review could indicate that aspects of ethnicity and certain internal psychological factors play more of a role in coping with cancer pain than do other clinical or demographic factors. However, paucity, the overall heterogeneity in all of the reviewed studies, along with various methodological limitations, means that we are unable to draw firm conclusions from the reviewed studies.

Many studies used mixed cancer types at various stages of disease progression. As such, there were potential confounding variables within the samples as participants potentially had multiple characteristic variables i.e. gender, cancer type and disease progression across clinical, psychological and demographic variables. Study findings in this regard would be strengthened if designs used well defined homogenous groups of participants. Ideally, studies would also investigate coping strategies in more than one group to compare coping strategies between groups. Additionally, all the studies included in this review were cross-sectional in design. Longitudinal designs would be

preferable as these could measure coping stability or instability over time, examine both long and short term cancer pain coping, and allow for the investigation of both trait and state coping (Lazarus, 1993).

From the findings of the review, the area with the strongest findings and which most warrants further investigation, is psychological variables and their relationship to coping strategies. The contradictory findings in regard to self-efficacy may especially be worthy of further research. Self-efficacy has long had an association as a pain mediator (Bandura, O'Leary, Taylor, Gauthier & Gossard, 1987), and research which could clarify whether self-efficacy could predict the use particular coping strategies would be useful clinically. Additionally, discovering whether catastrophising is associated with self-efficacy would be an interesting finding, as catastrophising has long been understood to be a maladaptive coping strategy and is associated with poor outcomes (Leung, 2012). Pain management programmes and cognitive behavioural therapy (CBT) interventions for cancer pain use coping skills training and identifying potentially adaptive or maladaptive coping strategies can inform clinicians and assist in the tailoring of psycho-educational material. Tailoring CBT interventions to patient characteristics has been shown to be beneficial (Dalton, Keefe, Carlson & Youngblood, 2004) and the ability to structure interventions informed by further research in this area would be advantageous.

All of the quantitative studies in this review used correlational analyses, and as such scored poorly on our measure of predictive or causal relationships with coping strategies. Future research could investigate further which characteristic variables predict the use of pain coping strategies. In addition, it is important to use reliable and valid measures of coping strategies to ensure consistency and clarity when describing coping. Additionally, there were methodological implications of sample bias in all of the reviewed studies. None of the reviewed studies were able to report that the samples they used were representative of the population they recruited from. Whilst most

authors acknowledged the limitations of biased sampling, the implications of this relate to the inability to generalise findings from any of the reviewed studies to the wider population.

The review benefitted from two raters scoring the methodological quality of included studies using the quality assessment checklist. The results of the Kappa statistic for inter-rater reliability suggest that the checklist was reliable. The Kappa did, however, highlight one question where agreement was poor. This related to question 3 on the checklist, assessing whether studies clearly described associates, predictors or correlates of interest in the introduction or method. This was clearly an area which was hard to assess in certain studies and relates to difficulties in defining characteristic variables of interest. The quality assessment was constructed using two validated measures, the Downs and Black (1998) and the MMAT (Pluye et al., 2011). However, as the quality assessment checklist was adapted and modified by the authors to suit the aims of the review, the validity of the checklist may have been compromised.

Whilst the review also benefitted from two thorough searches of the literature using three well respected databases in the fields of health, medicine and psychology, it is possible that studies could have been missed. Studies which mentioned the investigation of relationships between characteristic variables and coping strategies as secondary aims or analyses may have been missed, when titles and abstracts were read for further consideration. The review may also have been compromised by the inclusion of only peer reviewed studies. Grey literature and unpublished articles were not accessed, and as such, it is not possible to be certain that all relevant studies were included.

Future research is warranted in regard to qualitative studies. There is a paucity of qualitative studies investigating pain coping in people with cancer. The two studies included in this review (Haozous et al., 2011; Im et al., 2009) focused on specific ethnic groups in the USA (American Indians; African Americans). Research is needed on UK

adults self-managing cancer pain. Methodologically, it is important that qualitative studies investigating pain coping strategies ensure the widest possible exploration of cognitive and behavioural coping strategies to ensure a full understanding in this area. It is also important that qualitative studies are methodologically sound and well constructed using explicit and transparent methods of analysis, with researcher influences made clear.

It is recommended that future research also focus on targeting particular groups of community based adults to investigate how they cope with cancer pain. Establishing predictors, associates or correlates of coping strategies, and identifying those strategies, is of particular interest to clinicians working within oncology. Recognising which patient groups may be at higher risk of utilising potentially maladaptive coping strategies, and encouraging the acquisition of adaptive coping strategies, can inform the provision of appropriate interventions and help ensure better pain coping for cancer patients.

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\* Reviewed studies

## Part two – Empirical paper

**An interpretative phenomenological analysis of the experiences of  
older people self-managing cancer pain at home**

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## Abstract

**Objective:** This study aimed to explore the experiences of older adults who self-manage cancer pain at home.

**Design:** Eight older adults (aged 72-85years; seven male) with cancer were recruited from a specialist oncology hospital in the North of England. Semi-structured interviews were conducted and analysed using Interpretative Phenomenological Analysis (IPA).

**Results:** Two super-ordinate themes and eight sub-ordinate themes were identified. Themes suggest the self-management of cancer pain involves an initial perceived loss of control followed by a temporal process of gaining control over pain. Sub-ordinate themes reflected the excruciating nature of pain and resulting physical and social restrictions leading to fears regarding familial burden. Participants utilised inner strengths, past experiences and the support of others in order to cope. This appeared to help them move to positions of mastery, self-efficacy and perceived control, a process informed by an integration of medical and personal knowledge, and, consequently, a personally constructed self-management system.

**Conclusion:** Successful self-management of cancer pain in late life can be conceptualised utilising a broad positive psychology framework and with reference to the concept of perceived control. Pain adjustment involves a sequential process from a perceived loss of control, to gaining mastery and self-efficacy to manage pain.

**Keywords:** cancer; pain; self-management; coping; geriatric; interpretative phenomenological analysis (IPA)

## **An interpretative phenomenological analysis of the experiences of older people self-managing cancer pain at home**

### **Introduction**

Cancer is predominantly an illness of late life. In the UK, around three quarters of registered cancers affect people over the age of 60 (Chatwin, Closs & Bennett, 2009). Many people with cancer have insufficient pain management, especially in the last year of their life (Valeberg, Rustoen & Bjordal, 2008). There is a high prevalence of cancer pain (77%) in UK community patients (Breivik et al., 2009) and older people especially are at higher risk of under-treatment for cancer pain (Raphael et al., 2010). However, it has been suggested that up to 90% of patients could obtain sufficient pain relief (Jacobsen, Moldrup, Christrup, Sjogren & Hansen, 2010).

Cancer pain is complex in origin and can, especially at end of life, occur at multiple sites: it comprises neuropathic, inflammatory, ischaemic and compression mechanisms (Raphael et al., 2010). Pain can have multiple origins: it can be caused directly by the cancer; by the treatment for the cancer; general debility; or from existing (unrelated) conditions or disorders (Raphael et al., 2010). Older people are also at risk of age related co-morbid conditions that cause pain, such as arthritis, ulcers and circulatory disorders causing acute or chronic pain (Abdulla et al., 2013) and so the meaning and identification of pain may be problematic.

Older people are particularly vulnerable to experiencing poor cancer pain management, and frequently have to self-manage their cancer pain at home. Self-management refers to multiple activities a patient can be required to engage in to ensure active health protection in collaboration with healthcare providers (Foster & Fenlon, 2011) and comprises managing symptoms, adhering to treatment regimes, and coping with the impact of illness across functional, emotional and interpersonal domains. Whilst older cancer patients represent the highest proportion of those engaging in

cancer care services, relatively little is known about their beliefs, motivations and subjective experience of managing pain (Chatwin et al., 2009). There is a particular research need regarding how older people, cared for at home, experience the day-to-day management of their pain (Dunham, Ingleton, Ryan & Gott, 2013).

The reality that many older cancer patients do not receive adequate pain relief is suggested to be largely a result of various biopsychosocial influences including patient, physician, social and environmental factors (Deshields et al., 2010). Previous research into patient-related factors has identified certain attitudes, or barriers, to effective cancer pain self-management. These include: fear of addiction to medication; fear of medication tolerance; fear of unmanageable side effects; fatalistic beliefs about the inevitability of pain; the desire to be a ‘good patient’ and not complain; reluctance to distract the doctor from treating the cancer; fear that more pain indicates a worsening of the cancer; fear of injections (Ward, Carlson-Dakes, Hughes, Kwekkeboom & Donovan, 1998). Cohort effects can influence attitudes towards ageing, health and illness (Knight & McCallum, 1988) and it is recognised that in the current older adult cohort, stoicism is particularly evident and contributes to under-reporting pain (Abdulla et al., 2013).

The psychosocial effects of cancer are an acknowledged research priority (Department of Health, 2011) as the psychological factors that impact upon the subjective experience of pain are both under-researched and poorly understood (Raphael et al., 2010). However, as cultural influences also impact upon the experience and management of pain, and as most published studies in the area of cancer pain management originate from the USA, Australia, Scandinavia and Taiwan, effective comparisons for the UK population are more difficult to make (Chatwin et al., 2009). In addition, whilst previous research has concentrated on barriers and strategies, the personal facilitators (e.g. positive personal qualities, strengths, emotions and also

relationships with others) of effective cancer pain self-management are less well known, particularly in relation to ageing. Previous studies have investigated relationships between psychological distress and pain, demonstrating that poor adjustment is associated with increased pain (Keefe, Rumble, Scipio, Giordano & Perri, 2004), whilst chronic pain can also negatively affect sense of self, leading to increased disability (Smith & Osborn, 2007). Various positive internal psychological factors have been suggested to beneficially impact on pain, and as such may be involved in affecting pain self-management in cancer. Several such factors, e.g. hope (Snyder et al., 2005; Utne et al., 2008) and self-efficacy (Porter, Keefe, Garst, McBride & Baucom, 2008) are known to be associated with positive adjustment and well being across a range of illness conditions, and as such, their investigation in an older adult population required to self-manage their cancer pain is warranted.

### ***Rationale and research aims***

Self-management includes symptom management, adhering to treatment regimes, and coping with the impact of illness across functional, emotional and interpersonal domains, which patients are often required to actively engage in, in collaboration with healthcare providers (Foster & Fenlon, 2011). A shift towards supported self-management for people living with and beyond cancer has been identified as a priority by the National Cancer Survivorship Initiative (NCSI), who recognise that current follow-up needs, including social and psychological needs, are not being met (Department of Health, 2011). Enabling patients to have the confidence to self-manage is a principle that should underlie support and help avoid, as much as possible, hospital readmissions. There are considerable financial implications of inpatient stays for the NHS, and many patients wish to be cared for, and die, at home (Department of Health, 2011). Effective pain management reduces psychological

distress, and enables patients to stay at home. Identifying how older people manage their cancer pain at home could inform health services in the development of effective and compassionate psycho-social interventions.

There is a recognised paucity in studies that focus specifically on the pain experience of older adults (Abdulla et al., 2013). No research has looked specifically at how older adults in the UK successfully self-manage their pain at home. The paucity of previous research in this area suggests an exploratory stance to uncover the experiences, interpretations and meanings of cancer pain for older adults and a qualitative design was therefore selected as the most appropriate approach in this study. Exploring potential facilitators of self-management, including personal strengths and coping strategies was a key aim of this study. Our research question therefore aimed to answer the following question:

How do older people self-manage their cancer pain at home and what are their experiences in relation to potential facilitators, personal strengths and coping strategies?

## **Method**

### ***Participants***

Eight participants were recruited from an oncology hospital in the North of England between July 2013 and March 2014. There were seven males and one female, aged between 72-85years, mean age 76.38 (SD=4.14). All participants were white British. Five participants lived with a spouse, and three lived alone. Gender details have been not been included in the participant demographic table (Table 1) in order to preclude participant identification.

Inclusion and exclusion criteria ensured participants were willing and able to attend an hour long interview, and had the relevant characteristics required for the study

(in particular be older people, managing cancer pain at home). The research methodology required that participants should be, as much as possible, a homogenous sample, purposefully sampled, to whom the research question is relevant (Smith & Osborn, 2003). Therefore, inclusion criteria were as follows: aged 70+ years<sup>1</sup>; fluent English speaker; diagnosis of cancer; experience of pain; currently living in the community (own home); capacity and willingness to give written informed consent. Exclusion criteria included: clinically significant cognitive impairment or dementia; history of functional psychosis; current diagnosis of psychosis, severe anxiety or depression.

Participants were identified and approached by referring clinicians in line with inclusion and exclusion criteria. A total of 13 people expressed an interest in the study and received information sheets detailing the study (Appendix H). Four people declined to take part when telephoned by the lead author two weeks after receiving the information sheets (one potential participant was too ill; three potential participants did not give a reason for declining), and one potential participant failed to fulfil inclusion criteria when telephoned (had not experienced any pain). All eight participants who agreed to take part completed the study in full.

### ***Procedure***

Participants who agreed to take part in the study were invited to attend for interviews at a convenient location, time and date. Two interviews were undertaken in a hospital setting, and six were undertaken at participants' homes. Interviews lasted

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<sup>1</sup> There is no definitive chronological age for determining old age. Definitions of old age have shifted over time. Whilst 65 years has been viewed in the twentieth century in the Western world as the onset of old age, coinciding with statutory retirement age, current shifts in the onset of retirement and increases to life expectancy have seen shifts in what is now understood to be old age (Sanderson & Scherbov, 2008). We selected adults over 70 years of age to explicitly exclude adults aged 65-69 years who may not conform to previously understood definitions of an 'older adult' and thus reflect increasing working age.

between 40-75 minutes; sufficient time was provided to fully explore participants' experiences, whilst also being sensitive to the physical health and abilities of individual participants.

Written consent was obtained at the start of the interview. Demographic, clinical and pain information was collected to enhance and illuminate contextual details in the sample (Table 2). The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; Appendix L) was administered to ensure the well-being of participants. This measure was scored post-participation in the study and participants who scored over clinical caseness (11 or higher; Snaith, 2003) for depression or anxiety were offered further support.

A semi-structured interview was conducted using open-ended questions to explore the perceived nature of pain, its impact, meaning, management and participants' future hopes regarding pain. The design of the interview was guided by clinical and conceptual literature relating to adjustment to illness and pain, and to positive psychology concepts (Lazarus & Folkman, 1984; Peterson & Seligman, 2004; Smith & Osborn, 2007). Questions were validated prior to commencing the study with service-users (accessed via a local Macmillan Survivorship Group meeting) to ensure clarity and accessibility of language, and to ensure that researcher influences during the interviews were reduced by keeping to a limited script. The interview questions were as follows:

Can you tell me about your pain?

What is the impact of your pain?

What does having this pain mean to you?

What is your attitude towards pain?

How do you manage your pain at home?

What personal strengths or qualities help you to manage your pain?

Have you received any advice on managing your pain?

What do you think would help you manage your pain better?

What are your hopes for the future in relation to your pain?

The researcher (lead author and interviewer), as a white British female, shared ethnic and cultural similarities with the sample. As such, there was a potential for assumptions and biased interpretations. This effect was mitigated by the use of a questionnaire in the data analysis (Appendix N). Participants who agreed to take part in the analysis stage were invited to comment on the degree to which the study's themes reflected their experiences as a measure of validity (Table 4).

### ***Data Analysis***

Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003) was selected as the research method in order to understand idiographic experience utilising face-to-face interviews. Giving patients a voice is at the heart of current Government cancer policies (Department of Health, 2011). IPA was first established in health psychology (Smith, 2011) and is a particularly useful method in researching illness topics, to broaden knowledge within a field traditionally dominated by the medical model (Brocki & Wearden, 2006).

The analysis of data using IPA (see Appendix O) begins with a verbatim transcription of the interview recordings, including pauses, and a detailed analysis of a 'first case' to identify significant or interesting words, ideas or phrases, which are noted in the margin (Smith & Osborn, 2003). Once this is done, a return is made to the start of the document, and initial descriptive notes are transformed into sub-themes. From the first case, a table of themes is created. This orients the analysis of further transcripts, allowing for the recognition of convergence and divergence from first case themes. The final stage of analysis involves the coding of higher level meanings and interpretations; sub-themes across cases are examined for connections between them, and subsequently

overarching super-ordinate themes are also created. A master table of super-ordinate and sub-ordinate themes for the whole group is constructed. These are refined and eventually linked to existing literature in the area under investigation (Smith & Osborn, 2003).

### ***Ethical approval***

This study was granted NHS ethical approval via The Proportionate Review Sub-Committee of the NRES Committee South West - Cornwall & Plymouth in April 2013 (Appendix E).

### **Results**

Two super-ordinate themes were identified along with eight sub-ordinate themes (Table 3). These themes suggested that the process of gaining successful self-management of cancer pain was experienced as a sequential, temporal journey, with personal control and self-determination emerging as central issues (Figure 1).

The first theme which we have termed ‘Losing control’ describes how participants initially found themselves in a position whereby excruciating pain robbed them of perceived control over their lives, through the unfathomable nature of their pain, and resulting restrictions that led them to feel a burden to their families.

The second theme ‘Taking back control’, however, presents a more optimistic picture, with participants describing how over time they began to regain control by adopting a positive state of mind, utilising past experiences, inner strengths and the support of others, to lead to a position of perceived control, self-efficacy and mastery over their pain.

### ***Losing Control***

The super-ordinate theme of losing control contains three sub-ordinate themes,

all relating to what the participants described as most negative in relation to having pain: the experience of excruciating pain; the restrictions imposed by pain; loss of independence and familial burden.

*The pain was excruciating*

All participants discussed the excruciating nature of their pain, especially in regard to the early stages of their illness or pre-diagnosis. This universal theme was described in various ways, from a simple statement conveying the magnitude of the pain, to the use of imagery and metaphor, highlighting how the pain was viewed as having an external force, rather than being internally generated and owned.

In many of the transcripts, it was striking how extreme the pain was, for example in this extract describing how a broken back was the first indication of myeloma:

Well when it first started it was very, very hard to bear because it was a very stern pain. When my back first broke I couldn't hardly walk...and during this time the pain levels were astronomic...the slightest jerk would make me almost scream with the pain, because it was so sharp, and it would almost stop me breathing it was that painful, and that really was pain like I've never felt before (participant 8, lines 3-4; 9-10; 87-89).

This describes in detail how acute pain was for participants, and in scaling the pain to a level of something that has never previously been experienced, we can understand the magnitude of their suffering. The pain is described as almost unbearable, and in describing it in terms of almost stopping the breath, it is as though the pain had a deadly force in itself. Pain was often described using imagery and metaphor, and externalised as though someone else was responsible for it:

It's a sharp pain, and it's, how can I say, I've never experienced this, but it's like someone has got a hold of my intestines and turning them, and they shouldn't be turned, if you know what I mean (participant 7, lines 16-20).

Such accounts indicate that because the pain is so intense, it is experienced as being generated from outside of the body itself, denying ownership of the pain, and is understood as so acute it can only be conceptualised as externally generated. The difficulty in locating the pain, or the source of the pain, is a common element. For many, because the pain is of such high intensity with an extensive nature, it is rendered unfathomable:

The pain is atrocious, you've got pain coming from all over, you can't really tell where it's coming from (participant 3, lines 29-30).

For some, the response to the pain was described as something that was 'endured'. Some participants described how, when reflecting back upon their journey, pain was seen as not only an integral part of the cancer story, but as something that had to be 'endured' to be understood, then overcome:

The pain I endured during the treatment was tremendous (participant 3, line 25).

### *The pain restricts life*

How pain had caused restrictions to life, in relation to activities, real or imagined, that were no longer possible, was a recurring theme. Life with pain had changed the content of leisure time, and the desirability of once enjoyed activities:

The pain really restricted what I was doing so I, I didn't want to go out particularly, I didn't want to sing in the choir, y'know, those sort of things, it just, it just knocked me, knocked me sideways really (participant 1, lines 60-62).

Pain placed limitations on what was now physically possible, therefore curtailing once familiar social activities:

I think it has affected me socially...walking...I mean we used to walk right down to our friends every Saturday night, and I couldn't walk round there now...I'm just trying to think of the things I used to do. Rambling and bowling and all this that and the other (participant 6, lines 57-67).

In this segment, it is as though even remembering the activities that were once possible was difficult, as though they are part of a half-remembered past with no relevance in the present. The last section of the quote, 'all this that and the other' almost feels dismissive of previous activities, as though there is a distance between what was once normal life, and what now exists.

Moving on from the familiar activities of a once-lived life, one participant spoke poignantly about restrictions in relation to future hopes and dreams. The once possible dreams of travelling abroad are now viewed as impossible, and a much reduced world takes the place of a wide open one:

I'd have loved to have gone to Russia, but now my life, my world, is an electric recliner (participant 2, lines 488-489).

The image of a life which is now restricted to a sitting in a chair is extremely powerful, illustrating the reductive nature of illness and pain for these participants, affecting not only the present, but also the future.

### *Burden*

Issues in regard to loss of independence and fears of burdening families were apparent. Burden was expressed in a variety of ways, from fear of emotionally burdening others, to the physical burdens placed on family members when mobility and self-care is compromised by pain.

A decision was made by one participant to withhold emotions from the family due to fears they may be burdened by the content:

I try to hide a lot of the feelings I was getting 'cause I didn't want to be a burden to my family, so I sort of kept it a secret to some extent, and tried to carry on as normal y'know (participant 3, lines 123-125).

The issue of whether a loss of independence, with resultant physical dependence, would mean familial burden, was a prevalent theme:

You are dependent on a lot of help, and in my case as I said before, I was lucky to have a lot of family support and help, so I think that was the only thing with me, that I felt as though I was becoming a burden on my family (participant 3; lines 85-88).

The loss of independence, particularly in regard to self-care, was hard to bear for some participants. It was described in the following extract as a regression, becoming a child again, as though loss of independence fundamentally changed self-image, leading to shame:

I'm not independent, I can't wash, you know, not properly, well, I'm just starting to be able to, to do that, but my wife had to wash me. That is significant you know,

for anybody I think, because even though it's your nearest and dearest, to have to strip off in the kitchen and be washed, like a little child, you know, it can be a bit embarrassing (participant 8, lines 67-72).

In this extract, burden is implied rather than explicitly stated, 'my wife had to wash me', as though this was an act that was undertaken only through necessity. This also suggests a change in relational dynamics, although participants did not discuss how they felt this change affected their partners, perhaps in order to shield themselves from further distress.

### ***Taking back control***

The super-ordinate theme of taking back control contains five sub-ordinate themes, all relating to what the participants describe as positive strategies in relation to self-managing pain: inner strengths; using past experiences; behavioural coping; utilising support networks; establishing their own pain management system.

#### ***Inner strengths***

This theme was one of the most prevalent throughout all of the transcripts. All participants discussed how they utilised a variety of positive inner strengths to cope with their pain. A positive state of mind in the present and utilising hope and optimism regarding the future, was important to many of the participants:

That's another key factor, being positive y'know. I never look on the negative side, and again I think that's really important, for everyone to adopt a positive attitude (participant 3, lines 396-398).

For some, being positive and using inner strengths seemed linked to a desire to fight on. In the following extract, persistence and bravery is highlighted, and illuminates an

opposing struggle between not wanting to live with the pain, but not wanting to die:

I'm a fighter y'know, I'm determined. I don't want to die, but I sometimes think I don't want to live with this, but no, I plod on. I never sit feeling sorry for myself (participant 4, lines 203-205).

A fighting spirit, and determination in the face of pain, is also illustrated in the following extract. Pain is described as though an enemy, who could be engaged in battle:

My attitude towards it is, if I could strangle the bugger, I would (participant 7, lines 199-200).

One participant described his determination as inherent to his personality, although it is apparent that his self-image, as a strong individual, had undergone some revision:

I'm a very determined sort of a person, fortunately, and I had to alter a few views, because I had to realise...that I am just human, I'm not invincible you know (participant 8, lines 310-312).

Another participant described how inner strength to bear pain was an inherent character trait, and that the concept of making others aware of personal suffering was unacceptable. This apparent stoicism was not only to be expected of themselves, but also of others:

I've never believed in showing pain to other people, y'know, take this to extremes now, say I cut my finger off, I'd go ow, and I'd wrap it up, and that would be it. I wouldn't go ooh, ooh. I don't like doing that, and I don't like people who do it

(participant 7, lines 282-285).

Other strengths, especially optimism and hope, were described by participants. This was in relation to the situation improving, and focusing on a brighter future seemed to enable coping in the present:

You've got to have hope haven't you? Y'know, you've got to, you've always got to think well there's an answer around the corner to this problem y'know. I haven't found it yet, well, I must've done because I cope. I don't know what it is, why I cope, I'm not brave, I'm nothing special, but I just try and not let it get me down (participant 2, lines 737-741).

As the above extract shows, it was apparent that some participants felt they were not particularly brave or special in regards to their coping. Using one's inner strength was described as something expected by others, and perhaps participants did not want to let others down, or face having others recognise a change in their abilities:

When you are required to be a strength to other people, you tend to think that that's the norm that they expect of you (participant 8, lines 304-306).

It may be that keeping up appearances, or maintaining a previously held positive character trait, was important, especially in terms of maintaining self-image. Other participants spoke about their position in relation to others they knew, and social comparisons seemed to be important in maintaining a positive self-image and sense of optimism:

The pain has taught me that there are people worse off than me, although I think I

am badly done to. But, you know, when you see some of them struggling around, y'know, I think well, I can't be too bad (participant 6, lines 104-106).

*Using the past to shape the present*

Participants discussed many past events, which they related to how they coped in the present, not only with pain, but also with their cancer diagnosis and treatment. Fears regarding future coping ability, if the situation worsened, were prevalent, although many suggested that past coping could be drawn on:

What I fear is that this cancer at some stage is gonna get worse, and I don't know how I shall cope with it then, but I'll just try as I've done in the past (participant 1, lines 620-623).

Several participants spoke of the memory of their late partners, many of whom had also had cancer. In this extract, coping is framed as an obligation to honour the memory of the deceased:

She went through all these illnesses, including pancreatic cancer, and she never cried, she was so brave, she was such an example, and I've got to be careful I don't let her down (participant 1, lines 526-528).

The implication is that if others can bear great pain and cope, then they (the participants) should also be able to, almost as if drawing strength from the past to help cope in the present:

If the wife can go through what she went through, then I can go through with this. I mean, I don't do pain very well, I'll tell you now, but if she could cope... (participant 2, lines 573-576).

For one participant however, it was drawing on past coping ability, in relation to self-sufficiency in the context of a lack of parental care, which enabled a sense of being able to ‘get on with it’:

I’ve never had motherly or fatherly love, they were too busy going to the pub boozing...I looked after myself virtually...I had to go and make my own appointment for dentist and I had to go myself. Well I knew it was no good asking my mother and father, they wouldn’t be bothered...so that’s why I think...I’ll just get on with it (participant 7, lines 296-308).

Other participants spoke about their experiences with religion in enabling them to maintain a sense of strength and self-efficacy. Again, this appears to be an ability to draw positives from past experiences and apply in times of need. It is interesting that in this extract, belief in religion has been interpreted and transformed into belief in one’s own abilities:

I was brought up as a Roman Catholic, so you’ve got belief, and my religion doesn’t come into it at all, doesn’t affect me at all, but I think that there is an inner belief there, that gives you strength, so maybe that’s part of it...I think it gives you strength to deal with things (participant 6, lines 241-248).

#### *What I do can help with the pain*

Participants discussed utilising behavioural strategies to cope with the pain. These were focused particularly with getting on with life, partaking in normal physical activities, despite pain, and were connected with a sense of moving towards recovery:

I have to focus on something y'see, all the time, and somebody said this to me about getting better, do the things you normally do...I'm also focusing on picking me brambles and doing the garden. I can't just sit y'see, even though I'm poorly I have to try and do something (participant 1, lines 372-381).

It also appears that physical activity could be a distraction from focusing on the pain, whilst acknowledging that pain is still present:

Doing hands-on things around the house, and that, has helped me tremendously. In fact I'd say that's the key y'know, getting on with something what's not going to make you think about your pain. It doesn't make the pain go away, I'm quite aware of that, but you can cope with it more (participant 3, lines 259-263).

There is a clear sense that as participants came to understand that they were not as helpless as they once perceived themselves to be they discovered that their actions could positively affect their pain. The ability to undertake normal physical activity may therefore contribute to regaining both a sense of agency and emerging self-efficacy. For some, however, it was the pure distraction from the pain, in the form of activities, which gave relief:

I do watch the tele, and I do read books...while I'm reading them, I don't notice the pain, but then when I put the book down, I suddenly think, ooh, I've got that pain again (participant 7, lines 374-376).

### *Support networks*

Many participants talked about the support they received from others. These support networks could be ever present (partners), periodically called on for assistance

(extended family members), or could be accessed when required (the medical team).

The ability to easily access or call on each of these was a factor in patients' lives:

I've really got good kids and good sons-in-law, who are very very good, you know, they always want to help (participant 8, lines 496-497)

Family members were also able to ensure that participants were able to take a realistic view of the situation:

Bless my wife, she's a very patient and good lady and she would always just stop everything and just sit with me...she has been excellent at making sure I don't lose sight of reality (participant 8, lines 50-54).

And for some, the family was also able to provide a welcome distraction from the pain, echoing the distraction techniques described in the preceding theme:

The family makes me forget it, takes my mind off it (participant 6, line 148).

Organisational support was often required from family members, as it was apparent that medication regimes were complex and difficult for many participants to comply with without assistance:

I mean, I have more than twenty tablets taken at different times of the day and you just can't remember to take them. Luckily my wife is very good at that kind of thing and she made out a graph, what time of day to take each tablet (participant 5, lines 219-223).

Support was also experienced in terms of having a 'back-up team', knowing that

medical help was accessible. The knowledge that the hospital team was available, if the situation deteriorated and circumstances rendered it necessary, appeared to enable participants to stay at home, comfortable in the knowledge that help could be accessed:

It depends on how severe the pain is, but like I said, you've always got a back-up here to ring, which is comforting, very comforting, because you know, if the worst comes to the worst, you can always come back here (participant 3, lines 375-378).

It is interesting that in all of these extracts, participants experienced certainty in the availability of support. Many of the above extracts contain the word 'always', suggesting that an important component of their support was reliability. It is also clear just how much love was expressed for families and partners:

The main thing is my girlfriend, she's the great salvation, she's the angel...we all need to love somebody (participant 1, lines 506-507).

### *Establishing one's own system*

Our participants described the process of self-managing pain involving, first, reaching an understanding of their pain. They were then able to selectively take medical knowledge, knowledge of their own pain and body, and find a system that worked for them, effectively mixing the two in an idiosyncratic way.

This extract demonstrates the perceived importance of coming to understand the pain and its causes, when once it had been unfathomable:

I think the first thing that you need to know is what's caused the pain, you need to know that, so you can understand what the pain is, and I think if you understand what the pain is, you can cope with it better (participant 6, lines 192-194)

There was divergence in how participants viewed medical advice. Some participants viewed the doctor as holding all the knowledge, and believed doctor's orders should be followed:

I'm assuming that the medical people in my life like the doctor and the district nurse, they know what they are doing with the pills, and they are doing the best they can for me (participant 7, lines 201-203).

This was linked to trust, having faith that others knew what was best. Participants also seemed to recognise that they needed to follow doctor's orders because they were 'good' at managing pain:

I'm on every word the doctor says y'know, 'cause they've been so damn good, they've had it right all this time y'know, and I go on every word they say (participant 2, lines 316-318)

However, for participants who did not feel that the doctor had got the medication dose correct, they did not follow medication regimes and adjusted the dose to their own requirements:

I'm taking double the dose of the capsules in the morning than the doctor advised, because it wasn't doing any good, and double the dose on the night (participant 3, lines 613-615)

It was certainly apparent that for some participants, they did not feel pressurised into accepting the doctor's regimes as definite. It was generally felt that participants were experts themselves in regard to their pain and their needs:

I know what to do and what not to do, but because the doctor says I got to do this I don't necessarily have to do it...I know what suits me (participant 7, lines 421-423)

This suggests that self-determination and self-efficacy underpinned successful adjustment and coping for several of these participants. However, it was also apparent that for some, reclaiming agency may contribute to conflicts with medical services:

They play holy war with me at the hospital for not taking more medicine to dam the pain (participant 5, lines 33-34).

For most participants however, there was a balance to be found between adherence to medication regimes, and listening to one's own body to find a personalised system of management:

I've just developed a system where I take my medication at certain times and I don't wait for the pain to start and then take the medication. I take it before it starts, and that's been the secret of it working for me (participant 3, lines 184-187).

These extracts demonstrate how important it is that participants were able to use both their own knowledge, and medical knowledge, to create a personal system of cancer pain management.

## **Discussion**

The participants in this study described how the experience of pain, and managing pain, had been pervasive throughout their cancer journey. Whilst it is acknowledged that not all people diagnosed with cancer will experience pain, for many

the pain experience is dreadful (Larsson & Wijk, 2007). This was certainly the experience for some of our participants, who described how the pain had been often excruciating and debilitating. Uncontrolled pain is particularly distressing when inevitable changes impact upon work production, family life and social interactions (Chapman & Gavrin, 1999).

It was clear that the issue of control, ranging over time from uncontrollability to gaining control, was central to our participant's experiences. The struggle to gain control has long been linked to pain management at home (Ferrell, Taylor, Grant, Fowler & Corbisiero, 1993). Having an internal locus of control (the degree to which one believes they are in control of events and experiences) has been associated with lower distress, functional impairment and intensity in chronic pain (Crisson & Keefe, 1988). Our participants described the process of managing their cancer pain as a sequential journey, starting from a position of losing control to a position of gaining control. We suggest that in the early days of investigations and diagnosis, locus of control for our participants was external and their journey to successful management of their pain involved a shift in control perceptions, which potentially became more internalised.

Related to locus of control, self-efficacy (the belief in one's own abilities to achieve goals) has also been shown to be influential in the ability to endure pain (Bandura, O'Leary, Taylor, Gauthier & Gossard, 1987) and in reducing distress and functional impairment in chronic pain (Turner, Ersek & Kemp, 2005). Some participants discussed beliefs in regard to pain being something that should be endured, but most participants recognised that controlling pain through both the use of cognitive and behavioural coping strategies alongside medication was a suitable goal. For our participants, there was a sense that self-efficacy emerged over time and enabled them to engage in more positive coping. Self-efficacy is gained through various facilitators

including, particularly, mastery experiences (Bandura, 1982) and we suggest that successful coping experiences increased participants' self-efficacy perceptions. It could also be that viewing pain as a test of endurance, relates to resilience in the face of adversity, and may play an important part in future perceptions of pain self-efficacy.

The ability to endure pain or hardship, termed stoicism, has previously been identified in the literature as a feature of older people's experiences of cancer pain (Dunham, Collins & Allmark, 2014). Stoicism has been described as a particular feature of current cohorts of older people, perhaps related to attitudes forged during the war era, although exactly how stoicism affects health behaviour and whether it is likely to have a positive or negative effect with regard to adjusting to illness and pain is less clear (Moore, Grime, Campbell & Richardson, 2013). Attitudes labelled as stoic could mask an inability to ask for help and assistance, especially in older people with cancer. Research has suggested that stoicism could be therefore be maladaptive (Murray et al., 2008). For our participants there was a sense that stoicism could actually be employed to shield their families from possible burden. Fears were expressed regarding burdening families with either emotional or physical demands. Burden is a recognised feature of caregiving, especially for the families of older people with cancer and can confer significant psychological distress on carers (Haley, 2003).

However, it was also clear that support networks, including family and medical professionals, were important to our participants for several reasons. Seeking social support has previously been linked to greater perceived stress, functional limitations and worry in relation to cancer than other coping strategies (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992), whilst receiving adequate social support has been positively associated with both adjustment and disease progression in cancer (Usta, 2012). For our group, knowing that medical professionals could be accessed when required appeared to give a sense of security. This, we suggest, is important in enabling patients to have

confidence in self-managing pain at home. In addition, acquiring medical knowledge of pain and analgesic knowledge, including addressing barriers to medication use (such as beliefs regarding addiction and tolerance) appears an important factor (Paice, Toy & Shott, 1998).

In regard to cognitive and behavioural coping to manage pain, our participants described a range of strategies including physical tasks (gardening and housework), relaxation and distraction (e.g. watching television and reading). This is in line with previous research (Porter & Keefe, 2011) which has described how a diverse range of strategies is often employed to manage pain, with no particular evidence for the superiority of any one strategy over another, aside from self-efficacy (positive effects) and catastrophising (negative effects).

Coping strategies have been conceptualised as a cognitive or behavioural efforts to manage perceived discrepancies between external or internal demands and personal resources (Lazarus & Folkman, 1984). Coping strategies can be either emotion-focused e.g. distraction, avoidance etc., or problem-focused e.g. seeking information, social support etc., (Lazarus & Folkman, 1984). Our participants discussed the use of both types. Previous research has suggested that people with more severe illness may use a wider variety of coping strategies in cancer (Dunkel-Schetter et al., 1992). It may be that the ability to undertake, and experience success with, both types of strategy is an important factor in gaining a sense of control and mastery over cancer pain.

Alternatively, it may be that our participants, in terms of age and disease, appraised their illnesses as particularly severe and this influenced the use of multiple coping strategies. Illness representations are known to be of particular influence in how people respond to disease (Leventhal, Meyer & Nerenz, 1980). Research has found consistent relationships between beliefs, coping, and adjustment to pain, and it appears that those who believe they can control pain have increased functionality and a reduction in the

experience of pain severity (Jensen, Turner, Romano & Karoly, 1991).

Many of our participants spoke about character strengths, which have been explored previously within the positive psychology movement and in relation to adjustment to illness. Six classes of virtue, involving twenty-four character strengths, were identified by Peterson and Seligman (2004). Our participants particularly discussed the importance of acquiring knowledge of their conditions and treatments (virtue of wisdom and knowledge); described bravery and persistence (virtue of courage); love and kindness (virtue of humanity); acknowledged a sense of teamwork with their medical team (virtue of justice); often demonstrated modesty in regard of their abilities, and their use of self control (virtue of temperance); and hope, humour, spirituality and gratitude (virtue of transcendence) flowed throughout the transcripts. Previous research has found that recovery from major physical illness (including cancer) resulted in higher scores on a multitude of strengths including bravery, gratitude, humour, kindness and spirituality (Peterson, Park & Seligman, 2006). Focusing on the positive has been shown to be one of several coping patterns in cancer patients (Dunkel-Schetter et al., 1992). Our sample appeared to utilise these strengths in various ways, such as in order to adjust to pain, in order to reach a position of perceived control and mastery within the context of recovery.

It was clear that a prevalent theme amongst participants' experiences was a sense of fighting spirit. This links to the virtue of courage described by Peterson and Seligman (2004). Initially conceptualised as an attitude, the literature now suggests fighting spirit is utilised as a coping strategy (Coyne & Tennan, 2010). Fighting spirit has been shown to be a strategy employed by optimists (Schou, Ekeberg & Ruland, 2005) and dispositional optimism has been implicated in the ability to effectively manage both pain severity and fatigue in cancer patients (Kurtz, Kurtz, Given & Given, 2008). It has been suggested that optimism and fighting spirit may affect the appraisal

of adverse events as challenge rather than threat, leading to physiological benefits (Bower, Epel & Moskowitz, 2009). However, whether fighting spirit has any influence on long term health outcomes in cancer is unclear, and some authors suggest caution regarding the popular notion that adopting positive coping strategies such as fighting spirit may alter disease progression (Coyne & Tennan, 2010).

### *Limitations*

There are methodological limitations in regard to our small study group. Whilst a sample of eight is normative in size for an IPA study (Smith, 2011), our sample is homogenous in terms of age and disease, therefore limiting generalisability. The eight participants also demonstrated heterogeneous features, however, particularly in regard to gender mix, which again could suggest limitations. Our sample was predominantly male, with mixed primary cancers, and disease status was advanced in six participants. However, it could be argued that strict homogeneity in samples for IPA studies is an unrealistic goal and depends on the context under exploration and the aims of the research itself. Achieving a representative and coherent sample is arguably a better goal. Our sample was certainly coherent in terms of our research aims, namely older adults with cancer pain who are required to self-manage pain at home. Participants' experiences also shared many features, as can be seen in the multiple examples from each subtheme, and whilst there were examples of divergence, no uniquely ideographic themes or accounts regarding personal experiences were observed during the interviews, and this included those potentially related to gender. Research has been varied in relation to gender effects and pain, although it has been reported that there is increased pain prevalence in older females (Abdulla et al., 2013). Gender differences have been reported regarding the expression, tolerance and perception of pain, which may be influenced by varied psychosocial factors including self-efficacy and lifespan experiences (Miller & Newton, 2006). We can be reasonably confident, however, that

the understandings described in our study accurately reflect the experiences of our sample group. Future research may seek to clarify gender specific attitudes and coping strategies in regard to cancer pain self-management.

IPA provided a structured framework with which to design an exploratory study investigating experiences within a research area with recognised paucity. The richness of data and themes suggests that this methodology was suitable for achieving the research aims. However, whilst the semi-structured interview was able to prompt conversation within multiple areas of interest, it may have been possible that participants were guided by the language of the questions and less likely to explore other areas that may have been important within the area. Previous research has identified religious beliefs, spirituality and the use of complementary medicine as being important to older adults in the self-management of cancer pain (Chatwin et al., 2009). Whilst some participants touched upon religion, this was not an area that was particularly explored or discussed in our study.

A further limitation in the study may have been related to the researcher's (lead author and interviewer) influences. It is acknowledged that as a white British female, sharing ethnic and cultural similarities with the sample, assumptions and interpretations regarding the meaning of language may have been made. This effect was mitigated by the use of a questionnaire to validate the data analysis (Appendix N). Seven participants agreed to take part in the analysis to comment on the degree to which the study's themes reflected their experience (Table 4). The researcher must also acknowledge assumptions and influences in regard to British cultural attitudes towards older people in regard to positive coping ability (e.g. 'fighting spirit/stiff upper lip'), and brings experience from clinical placements working as a trainee clinical psychologist with both older people, and with cancer patients. The researcher also acknowledges her personal experiences of family members who have experienced significant cancer pain,

and a personal interest in positive psychology. The effects of these experiences were mitigated as much as possible by the use of a semi-structured questionnaire during the interviews, previously validated by a service-user group, to ensure that the researcher did not unduly influence conversations. In addition, reflection and supervision were utilised during all parts of the study to ensure focus was maintained and bias reduced.

### *Future research*

This research adds to the limited corpus of research into the experiences of older adults with cancer pain and is the first to explore and document how older people might adjust positively to cancer pain. Future research could focus on further expanding this knowledge particularly in regards to self-managing cancer pain at home amongst those at different stages of disease progression, including those in survivorship and reaching end-of-life. Our participants also spoke about their past lives, and seemed to draw on the memory of previous successful coping, as well as the memory of loved ones' abilities to cope, to enable coping in the present. Future research could further explore how reminiscence, and drawing on coping memories, can help to increase coping self-efficacy in the present.

### *Conclusions & clinical implications*

The themes found within this study help to illustrate the lived experiences of older adults who are required to self-manage their cancer pain at home. Positive psychological character strengths such as optimism, hope and courage are important personal factors which these older people used, along with social support and knowledge gained from medical professionals, to construct a personal pain self-management system that hinged on having a sense of personal control and self-efficacy. Clinically, if this process can be generalised it may be facilitated by psycho-educational

programmes (Fawzy & Fawzy, 2011) or cognitive behavioural therapy (CBT) for cancer pain management, which would include teaching coping strategies and increasing self-efficacy (Horne & Watson, 2011). The findings of this study suggest that therapeutic interventions should be aimed at ensuring patients who are required to self-manage their cancer pain at home develop and sustain personal control and self-efficacy, as well as having access to analgesics and medical support, to ensure successful management and as comfortable, and pain free, an experience as possible.

#### *Acknowledgements*

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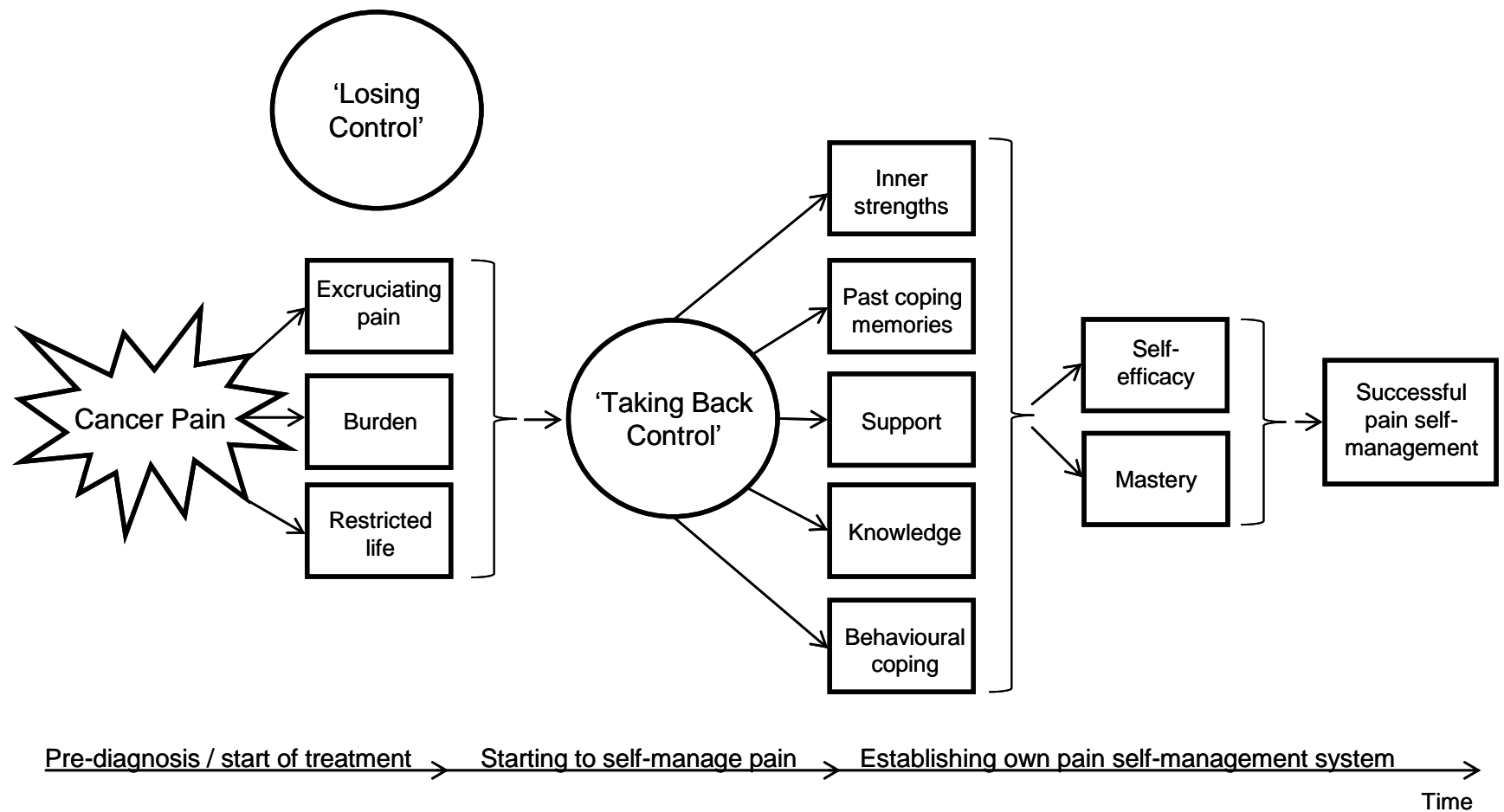


Figure 1. Themes in the process of older adults' successful cancer pain self-management.

Table 1. Participant demographics.

Participant	Age	Marital Status	Living Arrangements	Primary Cancer	Disease Status
1	77	Widowed	Alone	Prostate	Metastasised
2	73	Widowed	Alone	Bowel	Metastasised
3	73	Widowed	Alone	Myeloma	Stable
4	76	Married	With spouse	Bladder	Non-metastasised
5	78	Married	With spouse	Myeloma	Progressive
6	85	Married	With spouse	Prostate	Metastasised
7	77	Married	With spouse	Prostate	Metastasised
8	72	Married	With spouse	Myeloma	Progressive

Table 2. Pain and mood demographics.

Participant	Length of time in pain	Pain interference score /10	Pain at time of interview /10	Worst pain in past week /10	Current Treatment	Pain Medications	Pain Team	HADS Anxiety	HADS Dep
1	7 months	5	0	2	Hormone	Morphine (liquid)	GP	7	3
2	6 years	6	3	6	None	Morphine (tablet)	GP; Pain Clinic	10	6
3	4 years	5	2	5	None	Morphine (liquid& tablet), tramadol, paracetamol	Haematology Consultant	2	1
4	6 years	6	8	6	None	Solpadeine, paracetamol, co-codamol	GP	10	6
5	2 years	2	0	4	None	Morphine (tablet), oxycodone, pregabalin, paracetamol	Palliative consultant	7	4
6	4 months	8	0	6	Zoledronic acid injections:	Zytega, domperidone, prednisolone, paracetamol, codeine	GP	1	5
7	1 year	6	1	10	None	Morphine (liquid & tablet)	GP; Macmillan nurse	5	9
8	8 months	10	1	2	Chemotherapy, thalidomide	Morphine (tablet), paracetamol	GP	9	3

Note: Pain interference ratings: 0=pain has not stopped me doing anything, 10= pain has stopped me doing everything; pain ratings: 0=no pain, 10=high pain.

Table 3. Themes in older adults' self-management of cancer pain.

Super-ordinate Themes	Sub-ordinate Themes	Illustrative Quotation	Theme Prevalence
Losing control	1.The pain was excruciating	'The pain is atrocious, you've got pain coming from all over.'	8/8
	2.The pain restricts life	'My life, my world, is an electric recliner.'	7/8
	3.Burden	'I didn't want to be a burden to my family.'	5/8
Taking back control	4.Inner strengths	'You've got to have hope haven't you?'	8/8
	5.Using the past to shape the present	'If the wife can go through what she went through, then I can go through with this.'	6/8
	6.What I do helps with the pain	'Doing hands-on things around the house, and that, has helped me tremendously.'	7/8
	7.Support networks	'I've really got good kids and good sons-in-law...they always want to help.'	4/8
	8.Establishing one's own system	'Because the doctor says I got to do this I don't necessarily have to do it...I know what suits me.'	8/8

Table 4. Participants' analyses of the extent to which themes reflected their experience.

Super-ordinate theme	Sub-ordinate theme	Participant Analysis					
		Score /10					Mean (SD)
Losing control		2	3	8	0	0	2.6 (3.29)
	1.The pain was excruciating	1	8	8	0	0	3.4 (4.22)
	2.The pain restricts life	1	10	10	0	0	4.2 (5.31)
	3.Burden	0	10	10	5	0	5.0 (5.00)
Taking back control		3	7	8	10	0	5.6 (4.04)
	4.Inner strengths	5	8	8	10	0	6.2 (3.90)
	5.Using the past to shape the present	1	3	10	10	0	4.8 (4.87)
	6.What I do helps with the pain	5	7	10	10	0	6.4 (4.16)
	7.Support networks	10	10	9	10	0	7.8 (4.38)
	8.Establishing one’s own system	3	8	9	10	0	6.0 (4.30)

Note: Score of 0/10 = does not reflect my experience; score of 10/10 = fully reflects my experience.  
 Five participants were involved in the analysis out of eight original participants. One participant declined to take part in the analysis, and two participants died prior to analysis.

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### Part three – Appendices

### Appendix A. List of excluded studies.

	Study	Reason for Exclusion
1	Arraras, J.I., Wright, S.J., Jusue, G., Tejedor, M. & Calvo, J.I. (2002). Coping style, locus of control, psychological distress and pain-related behaviours in cancer and other diseases. <i>Psychology, Health &amp; Medicine</i> , 7 (2), 181-187.	No investigation or measure of demographic, clinical or psychological variables and relationship to coping strategies
2	Awasthil, P., Mishra, R.C. & Shahi, U.P. (2006). Health beliefs and behaviour of cervix cancer patients. <i>Psychology and Developing Societies</i> , 18 (1), 38-58.	Not a primary pain study
3	Barkwell, D.P. (1991). Ascribed meaning: A critical factor in coping and pain attenuation in patients with cancer-related pain. <i>Journal of Palliative Care</i> , 7 (3), 5-14.	No investigation or measure of demographic, clinical or psychological variables and relationship to coping strategies
4	Dar, R., Beach, C.M., Barden, P.L. & Cleeland, C.S. (1992). Cancer pain in the marital system: A study of patients and their spouses. <i>Journal of Pain and Symptom Management</i> , 7 (2), 87-93.	No identification of particular coping strategies
5	Davies, A., Zeppetella, G., Andersen, S., Damkier, A., Vejlgard, T., Nauck, F., Radbruch, L., Sjolund, K-F., Stenberg, M. & Buchanan, A. (2011). Multi-centre European study of breakthrough cancer pain: Pain characteristics and patient perceptions of current and potential management strategies. <i>European Journal of Pain</i> , 15, 756-763.	Included participants recruited from inpatient population
6	Ersek, M., Miller-Kraybill, B. & Du Pen, A. (1999). Factors hindering patients' use of medications for cancer pain. <i>Cancer Practice</i> , 7 (5), 226-232.	No identification of particular coping strategies

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| 7  | Ferrell, B.R. & Schneider, C. (1988). Experience and management of cancer pain at home. <i>Cancer Nursing</i> , 11 (2), 84-90.  | No investigation or measure of demographic, clinical or psychological variables and relationship to coping strategies |
| 8  | Ferrell, B.R., Taylor, E.J., Grant, M., Fowler, M. & Corbisiero, R.M. (1993). Pain management at home. <i>Cancer Nursing</i> , 16 (3), 169-178.   | No investigation or measure of demographic, clinical or psychological variables and relationship to coping strategies |
| 9  | Genc, F. & Tan, M. (2011). Symptoms of patients with lung cancer undergoing chemotherapy and coping strategies. <i>Cancer Nursing</i> , 34 (6), 503-509.  | Focused on symptoms, did not specifically investigate pain coping strategies  |
| 10 | Get-Kong, S., Hanucharurnkul, S., McCorkle, R., Viwatwongkasem, C., Junda, T. & Ittichaikulthol, W. (2010). Symptom experience, palliative care and spiritual well-being among Thais with advanced cancer. <i>Pacific Rim International Journal of Nursing</i> , 14 (3), 219-234. | Included participants recruited from inpatient population   |
| 11 | Jacobsen, P.B. & Butler, R.W. (1996). Relation of cognitive coping and catastrophising to acute pain and analgesic use following breast cancer surgery. <i>Journal of Behavioural Medicine</i> , 19 (1), 17-29.   | Included participants recruited from inpatient population   |
| 12 | Jagannathan, A. & Juvva, S. (2009). Life after cancer in India: coping with side-effects and cancer pain. <i>Journal of Psychosocial Oncology</i> , 27 (3), 344-360.  | Participants were inpatients  |
| 13 | Kiteley, C.A. & Fitch, M.I. (2006). Understanding the symptoms experienced by individuals with lung cancer. <i>Canadian Oncology Nursing Journal</i> , 16 (1), 25-30.   | Focused on symptoms, did not specifically investigate pain coping strategies  |

- |    |  |   |
|----|--|---|
| 14 | Kornguth, P.J., Keefe, F.J., Wright, K.R. & DeLong, D.M. (1999). Mammography pain in women treated conservatively for breast cancer. <i>Journal of Pain</i> , 1 (4), 268-274.  | Study focuses on pain during mammography, not coping with general cancer pain   |
| 15 | van Laarhoven, H.W.M, Schilderman, J., Vissers, K.C., Verhagen, C.A.H.H.V.M. & Prins, J. (2010). Images of God in relation to coping strategies of palliative cancer patients. <i>Journal of Pain and Symptom Management</i> , 40 (4), 495-501.  | Not a primary pain study  |
| 16 | Tsai, Y-F., Wei, S-L., Lin, Y-P. & Chien, C-C. (2005). Depressive symptoms, pain experiences, and pain management strategies among residents of Taiwanese public elder care homes. <i>Journal of Pain and Symptom Management</i> , 30 (1), 63-69.  | Not a cancer study  |
| 17 | Turk, D.C., Sist, T.C., Okifuji, A., Miner, M.F., Florio, G., Harrison, P., Massey, J., Lema, M.L. & Zevon, M.A. (1998). Adaptation to metastatic cancer pain, regional/local cancer pain and non-cancer pain: Role of psychological and behavioural factors. <i>Pain</i> , 74, 247-256. | No investigation or measure of demographic, clinical or psychological variables and relationship to coping strategies |
| 18 | Utne, I., Miaskowski, C., Bjordal, K., Cooper, B.A., Valeberg, B.T. & Rustoen, T. (2009). Confirmatory factor analysis of the coping strategies questionnaire-revised in samples of oncology outpatients and inpatients with pain. <i>Clinical Journal of Pain</i> , 25 (5), 391-400.    | Study primarily compares inpatients with outpatients  |
-

## Appendix B. Data extraction tool.

<b><i>Study Characteristics</i></b> Title Authors Date Country of Origin	
<b><i>Study Aims</i></b> Key aims	
<b><i>Participant Characteristics</i></b> Sample size Age range, means (SD) Gender Cancer type	
<b><i>Design</i></b> Study design	
<b><i>Predictor, associate or correlate of interest</i></b> Demographic, clinical or psychological variable	
<b><i>Key Findings</i></b> In relation to self-initiated/self-selected coping strategy and relevant predictor, associate or correlate of interest	

### Appendix C. Methodological quality assessment checklist.

Modified from Downs & Black (1998); MMAT (Pluye et al., 2011)

Questions 1-5 modified from Downs & Black (1998)

Questions 6-7 written by author

Question 8 modified from MMAT (2011), 8biv written by author

Quality Assessment Tool							
	No.	Criteria	Response				
			Yes	Partly	No	Not clear	N/A
			2	1	0	0	
All studies	1	Is the hypothesis/aim/objective of the study clearly described?					
	2	Are the main outcomes of interest (coping strategies) to be investigated clearly defined?					
	3	Are associates, correlates or predictors of interest clearly described in the Introduction or Method?					
	4	Are the characteristics of the included participants clearly described? Must include sample number, age, sex, cancer diagnosis (type)					
	5	Does the study summarise the main findings in the discussion?					
	6	Does the study discuss the generalisability of the findings in the discussion (external validity)					
	7	Were the limitations of the study acknowledged in the discussion?					

			Yes	Partly	No	Not clear	N/A
			2	1	0	0	
Qualitative studies only	8ai	Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?					
	8aii	Is the process for analysing qualitative data relevant to address the research question?					
	8aiii	Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?					
	8aiv	Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?					

Quantitative studies only	8bi	Were participants recruited in a way that minimises selection bias?					
	8bii	Were coping strategies clearly measured using a valid and reliable measure?					
	8biii	Is there an acceptable response rate (60% or above)?					
	8biv	Did the study establish a causal or predictive relationship between demographic/clinical/ psychological variables and coping strategy?					

Mixed methods studies only	8ci	Is the mixed methods research design relevant to address the qualitative and quantitative research questions?					
	8cii	Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?					
	8ciii	Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results) in a triangulation design?					
	<i>Appropriate criteria for the qualitative component (8ai-8aiv), and for the quantitative component (8bi-8biv), must be also applied, depending on the nature of the study.</i>						

Total (divided by)  
Total Possible Score  
=  
x 100  
Total Score


**Guide for using the Quality Assessment Tool (Questions 1-8; adapted from Downs & Black, 1998)**

All studies:

**1. Is the hypothesis/aim/objective of the study clearly described?**

Introduction

**2. Are the main outcomes of interest (coping strategies) to be investigated clearly defined in the Introduction or Method?<sup>1</sup>**

Are particular ways of coping clearly described e.g. avoidance, distraction?

**3. Are associates, correlates or predictors of interest clearly described in the Introduction or Method?<sup>1</sup>**

Are particular identifying demographic, clinical or psychological variables that predict, correlate or are associated with the use of particular coping strategies clear (e.g. younger and older patients; specified ethnic group)

**4. Are the characteristics of the included participants clearly described?**

Are the characteristics of the patients included in the study clearly described (sample number, age, sex, cancer diagnosis<sup>1</sup>)?

**5. Does the study summarise the main findings in the discussion?<sup>1</sup>**

**6. Does the study discuss the generalisability of the findings in the discussion (external validity)<sup>2</sup>**

**7. Were the limitations of the study acknowledged in the discussion?<sup>2</sup>**

<sup>1</sup> wording modified to suit review question    <sup>2</sup> new question added

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O’Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Retrieved 2<sup>nd</sup> March 2014 from <http://mixedmethodsappraisaltoolpublic.pbworks.com>.

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non randomised studies of health care interventions. *Journal of Epidemiological and Community Health*, 52(6), 377-384.

**Guide for using the Quality Assessment Tool (Question 9; adapted from  
MMAT: Pluye et al., 2011)**

**Qualitative**

**8ai. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?**

E.g., consider whether (a) the selection of the participants is clear, and appropriate to collect relevant and rich data; and (b) reasons why certain potential participants chose not to participate are explained.

**8aii. Is the process for analysing qualitative data relevant to address the research question?**

E.g., consider whether (a) the method of data collection is clear (in depth interviews and/or group interviews, and/or observations and/or documentary sources); (b) the form of the data is clear (tape recording, video material, and/or field notes for instance); (c) changes are explained when methods are altered during the study; and (d) the qualitative data analysis addresses the question.

**8aiii. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?**

E.g., consider whether the study context and how findings relate to the context or characteristics of the context are explained (how findings are influenced by or influence the context). The notion of context may be conceived in different ways depending on the approach (methodology) tradition.

**8aiv. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?**

E.g., consider whether (a) researchers critically explain how findings relate to their perspective, role, and interactions with participants (how the research process is influenced by or influences the researcher); (b) researcher's role is influential at all stages (formulation of a research question, data collection, analysis and interpretation); (c) researchers explain their reaction to critical events that occurred during the study.

**Quantitative**

**8bi. Were participants recruited in a way that minimises selection bias?**

E.g., consider whether the sample is representative of the population. The study must identify the source population and describe how patients were selected. Were inclusion/exclusion criteria explained? Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

**8bii. Were coping strategies clearly measured using a valid and reliable measure**

E.g., a validated coping strategy questionnaire? At data collection stage: consider whether (a) the variables are clearly defined and accurately measured; (b) the measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.

**8biii. Is there an acceptable response rate (60% or above)?**

**8biv. Did the study establish a causal or predictive relationship between demographic/clinical/psychological variables and coping strategy e.g. regression analysis?**

E.g. does the study specifically establish that a variable of interest (i.e. female gender) predicts the use of a specific coping strategy (i.e. distraction) rather than a correlation.

**Mixed Methods**

**8ci. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?** E.g., rationale for integrating qualitative and quantitative methods explained.

**8cii. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?**

E.g., there is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration.

**8ciii. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?**

Are limitations noted?

# Appendix D. Summary of quality assessment checklist scores.

Study	Question																		Score	
	All studies							Qualitative only				Quantitative only				Mixed				
	1	2	3	4	5	6	7	8ai	8aii	8aiii	8aiv	8bi	8bii	8biii	8biv	8ci	8cii	8ciii		
Arathuzik (1991)	2	2	2	2	2	2	2	-	-	-	-	0	1	0	0	-	-	-	15/22	68%
Bennett et al. (2008)	2	0	2	2	2	1	1	-	-	-	-	0	0	0	0	-	-	-	10/22	45%
Buck et al. (2006)	2	2	1	1	2	2	2	-	-	-	-	2	0	0	0	-	-	-	14/22	64%
Fischer et al. (2009)	2	2	2	2	2	2	2	-	-	-	-	2	2	0	0	-	-	-	18/22	82%
Gagliese et al. (2009)	2	1	2	1	2	2	2	2	2	0	0	2	0	2	0	2	0	0	22/36	61%
Gaston-Johansson (1999)	2	2	2	2	2	2	0	-	-	-	-	0	2	0	0	-	-	-	14/22	64%
Haozous et al. (2011)	2	0	2	1	1	0	2	2	2	2	2	-	-	-	-	-	-	-	16/22	73%
Im et al. (2009)	2	0	2	2	2	2	1	2	2	0	0	-	-	-	-	-	-	-	15/22	68%
Kwekkeboom (2001)	2	0	2	2	2	2	2	-	-	-	-	2	0	0	0	-	-	-	14/22	64%
Lin (1998)	2	2	2	2	2	0	0	-	-	-	-	0	1	2	0	-	-	-	13/22	59%
Miaskowski et al. (1999)	2	0	1	2	2	2	0	-	-	-	-	0	0	0	0	-	-	-	9/22	41%
Prasertsri et al (2011)	2	2	2	2	2	2	2	-	-	-	-	1	2	0	0	-	-	-	17/22	77%
Reddick et al. (2005)	2	2	0	2	2	2	2	-	-	-	-	0	2	2	0	-	-	-	16/22	73%
Whale et al. (2001)	2	0	2	2	2	0	1	1	1	0	0	0	0	2	0	1	0	0	14/36	39%
Wilkie et al. (1991)	2	1	2	2	2	0	0	-	-	-	-	0	2	0	0	-	-	-	11/22	50%
Column total	30	16	26	27	29	21	19	7	7	2	2	9	12	8	0	3	0	0	218	-
Column maximum	30	30	30	30	30	30	30	8	8	8	8	26	26	26	26	4	4	4	358	-

**Appendix E. Ethical approval.**

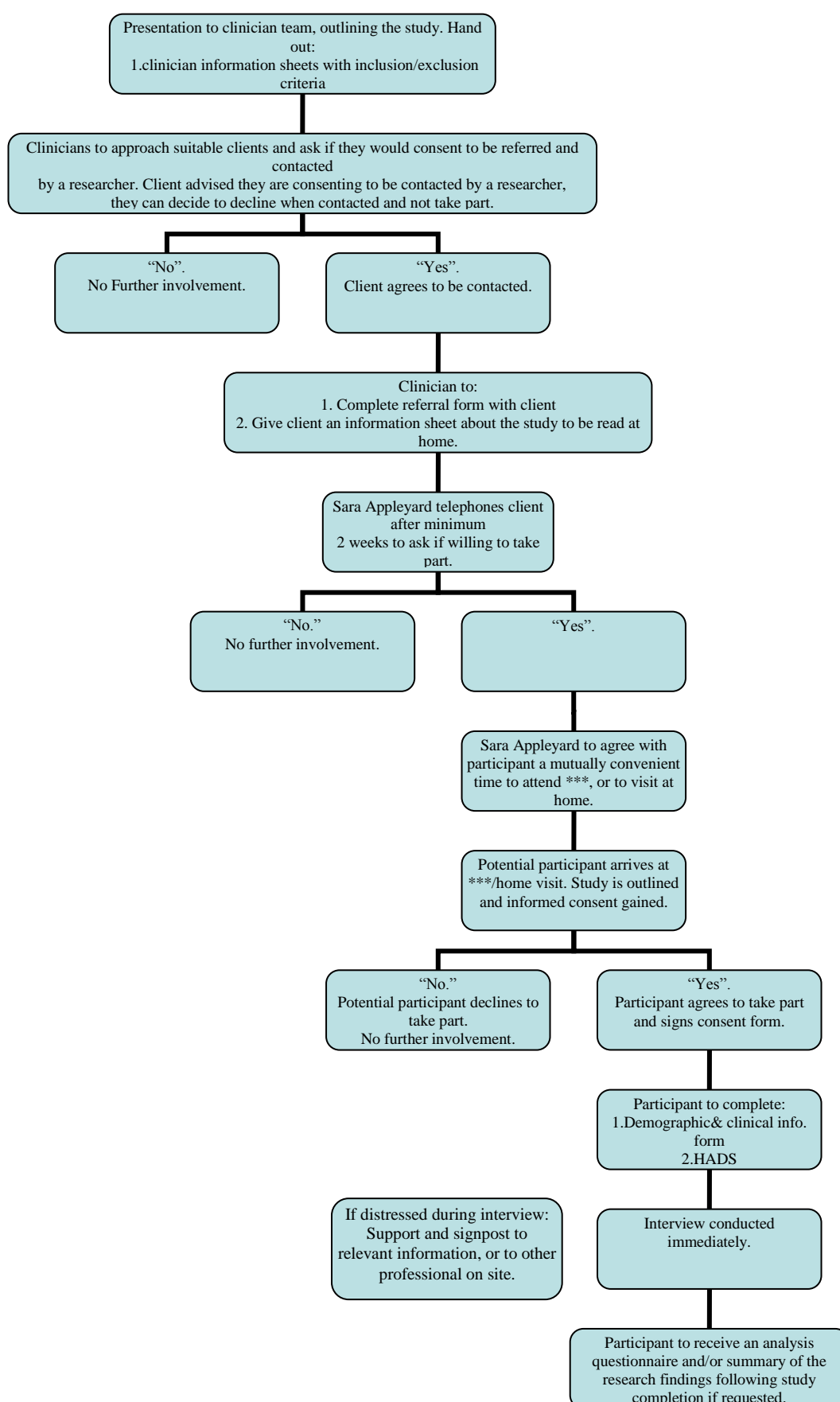
**Removed prior to hard binding.**







## Appendix F. Research protocol flowchart.



## Appendix G. Participant information letter.



### Patient Information Sheet

#### An Invitation to Take Part in a Research Study

*The experience of older people self-managing cancer pain at home – what helps?*

#### Introduction

You have been invited to take part in a doctoral research study. We would like to give you more information about the study, what it involves, and why we think it is important. This is so you can decide if you would like to take part. Please read this information sheet carefully, and feel free to discuss it with others if you wish. If anything is unclear, or if you would like further information, please get in touch with us. *You have already expressed some interest in the study and you have agreed for a researcher to contact you by telephone. You do not have to take part if you do not want to, and are free to decline when the researcher contacts you.*

#### Background

Cancer affects many people, most of whom are aged over 65. Many people are cared for within the community and manage their own pain at home. However, for many people, especially older people, their cancer pain is undertreated. Effective pain management reduces psychological distress, and enables patients to stay at home. We would like to find out more about this.

#### The purpose of the study

The study aims to find out about the experiences of older people who manage their cancer pain on a day-to-day basis at home, and particularly what helps them. The information gathered will be used to inform and help others, and the results may be published in the scientific literature.

#### Study methods

We wish to conduct short interviews to discover how day-to-day pain is managed. These interviews will last around 1 hour, and will be conducted by one researcher. The interviews will be tape recorded for analysis, however, all information is confidential and personal details will be kept separate from the transcripts. The tape recordings will be deleted at the end of the study. We hope to find themes and ideas to discover what helps people manage their cancer pain. We will use some direct quotations in the write-up of the study, however, these will be kept anonymous.

#### What the study involves

If you agree to take part, we will arrange a good time to meet. This will involve you attending \*\*\*\*\* on **one occasion**. If it is not possible for you to get to \*\*\*\*\*, then arrangements can be made to meet at your home. The interviews for the study will be between June and October 2013. There will be opportunity to

Updated: 15/4/2013 Version 1.3

participate in the analysis of the study. This would involve a postal questionnaire. The findings of the study will be shared in July 2014, and you will be asked if you would like to receive a summary of the findings in the post.

When you arrive for the interview, you will be greeted by the researcher (Sara Appleyard) and the interview will take place in one of our meeting rooms. You will be asked to complete a consent form and questionnaires about your personal circumstances, your pain and your mood. The interview will then take place and will last around one hour, although you can take a break at any time during the interview if you would like. The interview is often described as being like a conversation between two people. However, if at any time you do not wish to answer a question, or wish to end the interview, you are free to do so.

We wish to let you know that taking part in this study will not alter your medical treatments in any way. All the facilities at \*\*\*\*\* will be available to you both before and after the study. The atmosphere is warm and welcoming, and the kettle is always on! We do not think that taking part in the study will be upsetting or cause you distress, however, should you wish to talk to a nurse or access further help and support from the psychology team, there will be the opportunity to do this.

### **Participation is voluntary**

Please note that you are not under any obligation to take part in this study. If you agree to take part, you are free to withdraw your consent at any time. You would not have to give a reason for this. Withdrawing from the study would not affect any aspect of your treatment. Whatever your decision, you will still be able to use \*\*\*\*\*.

### **Confidentiality of information**

All information will be treated 'in confidence'. Only the researcher and the research supervisors will have access to any personal information you provide. This information will be kept separate from the taped interviews. Any quotations we use in the write-up of the study will be anonymous and your name will not be used.

### **Approval**

NHS Ethics have approved the study.

### **Further information**

Thank you for taking the time to read this information sheet and in considering this research study. If you wish further details, please contact \*\*\*\*\* and ask for Dr Emma Lewis, Clinical Psychologist and Supervisor for the study, or the researcher Sara Appleyard, Trainee Clinical Psychologist.

### **What now?**

You can expect a telephone call from the researcher (Sara Appleyard) to ask whether you would like to take part in the study. Any questions you may have will be answered. This will be between 2 weeks and 1 month from receiving this information sheet. This is to give you enough time to think about whether you would like to take part. Thank you for your consideration.

## Appendix H. Clinician information sheet.



### Clinician Information Sheet

#### Research Study

#### *The experience of older people self-managing cancer pain at home – what helps?*

##### Introduction

A trainee clinical psychologist, Sara Appleyard, is running a research study at \*\*\*\*\* in conjunction with the University of Hull. The study is interested in recruiting older adults with cancer, and who manage their pain at home. The help of clinicians to refer relevant participants is vital to the success of this project.

Cancer affects hundreds of thousands of people in the UK each year, most of whom are older people. Due to a combination of patient wishes, government policy on palliative care, and advances in community care, many people are required to manage their own pain. Research has shown there is, however, a very high prevalence of undertreated cancer pain in UK community patients, especially in older adults. The reasons for this are poorly understood and researched. We do know, however, that effective pain management reduces psychological distress, and enables patients to stay at home longer.

##### The purpose of the study

The study aims to find out more about the experiences of older people who are required to manage their cancer pain on a day-to-day basis at home, and particularly what helps older people to effectively manage their pain. The findings could help clinicians and services to provide more tailored support to community based older adults with cancer in the future.

##### Study methods

We would like to conduct short interviews with patients to discover how they manage their day-to-day pain and explore their subjective experiences using a qualitative methodology. The interviews will last around one hour, and will be conducted by one researcher (Sara Appleyard). The interviews will be tape recorded for transcription and analysis, however, all information is confidential and no patient identifiers will be kept with the transcripts. Tape recordings will be destroyed after transcription. The analysis of the transcripts will involve identifying themes and ideas, and we hope to discover what helps people to effectively manage their cancer pain.

##### What the study involves

The study will involve the patient attending \*\*\*\*\* on **one occasion** at a mutually agreed time. If it is not possible to meet at \*\*\*\*\*, then alternate arrangements will be made to meet at the patient's home if agreed.

The study is envisaged to run between June and October 2013. The findings will be disseminated in July 2014, with all participating patients invited to receive a summary.

Participants will first be asked to complete a consent form and a couple of short questionnaires about their personal circumstances, pain and mood e.g. "I am restless and can't keep still". The interview will then take place and will last around one hour. The interview is often described as being like a conversation between two people. However, if at any time participants do not wish to answer a question, or wish to end the interview, they are free to do so.

We wish to emphasise that taking part in this study will not alter any medically prescribed treatments in any way. All the facilities at \*\*\*\*\* will be available to participants both before and after the study. Referrals can still be made to \*\*\*\*\* whether or not your client wants to participate in this study, and whether they withdraw at any time.

### **Participation is voluntary**

Participants are free to withdraw their consent at any time and would not have to give an explanation for their decision.

### **Confidentiality of information**

All information will be kept confidential. Patient information will be stored separately from the audio recordings and transcripts, which will be anonymised.

### **Approval**

Hull and East Riding Local Ethics Committee and Humber NHS Trust R&D have approved the study.

### **Further information**

Thank you for taking the time to read this information. The support of our local colleagues is very much appreciated for this research. If you wish to have further details, please contact \*\*\*\*\* and ask to speak to the researcher Sara Appleyard (Trainee Clinical Psychologist) or the clinical supervisor for this research Dr Emma Lewis (Clinical Psychologist). The academic supervisor for this study is Dr Christopher Clarke, University of Hull, Department of Clinical Psychology and Psychological Therapies, Hertford Building, Cottingham Road, Hull HU6 7RX.

### **PLEASE SEND COMPLETED REFERRAL FORMS TO:**

**POST:** Sara Appleyard c/o Dr.Emma Lewis \*\*\*\*\*  
\*\*\*\*\*

Or **FAX:** Sara Appleyard c/o Dr.Emma Lewis \*\*\*\*\*

**Appendix I. Clinician referral form.**

Patient ID  .....
-------------------------

**Referral Form**

***The experience of older people self-managing cancer pain at home –  
what helps?***

**Clinician/referrer to complete:**

Name of clinician/referrer.....Position.....

Team/Base.....Telephone No.....

**IMPORTANT: Study Inclusion/exclusion criteria.**

Age over 70 years. Diagnosis of cancer. Living at home (not residential care).  
Reporting cancer pain. Not currently experiencing psychosis or dementia, and not  
currently being treated for severe depression.

**Patient Details**

Name of Patient.....Date of Birth .....

Telephone No.....

*I hereby give my consent for my details to be passed to the researcher for the above study. I understand I will be contacted by telephone after a minimum of 2 weeks, and asked if I would consent to taking part in the study. I understand I am free to decline participation and this will not affect any treatments I am currently receiving. I have received a Patient Information Sheet detailing the study.*

**Name of Patient****Date****Signature****SEND THIS COMPLETED FORM TO:**

**POST:** Sara Appleyard c/o Dr.Emma Lewis\*\*\*\*\*

**Or FAX:** Sara Appleyard c/o Dr.Emma Lewis \*\*\*\*\*

**Appendix J. Participant consent form.**

Patient ID

.....

**Consent Form**

***The experience of older people self-managing cancer pain at home –  
what helps?***

*Initial all that apply*

1. I confirm that I have read the Patient Information Sheet (**Date: 15/4/2013 Version 1.3**) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical or legal rights being affected.
3. I authorise audio material, transcripts and information obtained about me for this study to be stored and analysed on a computer for as long as is necessary to complete the research. I understand this information will be stored safely and securely.
4. I authorise the researchers to have access to my medical records, and I understand that data may be looked at by individuals from the regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research.
5. I would like my General Practitioner informed of my participation in this study.
6. I agree to take part in the above study.
7. I understand that one questionnaire will ask about anxiety and depression. If my scores are high I would like to be informed of this by telephone. I understand that support will be discussed at this time.

☐☐☐☐☐☐☐\_\_\_\_\_  
**Name of Participant**\_\_\_\_\_  
**Date**\_\_\_\_\_  
**Signature**

**I would/would not\* like to be involved in the analysis of the research (this  
would involve receiving a postal questionnaire).  
I would/would not\* like to receive a summary of the research findings in the  
post in July 2014.**

*\*please delete as necessary*\_\_\_\_\_  
**Name of Person taking consent**\_\_\_\_\_  
**Date**\_\_\_\_\_  
**Signature**

**Appendix K. Demographic and clinical information form.**

Patient ID  .....
-------------------------

**Demographic and Clinical Information Form**

***The experience of older people self-managing cancer pain at home –  
what helps?***

Age..... Gender: Male / Female (please delete)

Marital Status..... Who do you live with?.....

How do you rate your pain today out of 10? (0= no pain, 10=worst pain).....  
 What is the worst pain you have had in the past week out of 10 (0=lowest, 10=highest).....

How long have you had pain?.....

How much has pain interfered with your life out of 10 (0=not stopped me at all, 10=stopped me doing everything).....

What is your cancer diagnosis?.....

What treatment(s) are you currently accessing?.....

Who is your GP?.....

Who is your consultant?.....

Are you currently receiving any support from health professionals for your pain?.....

Who are they?.....

Current pain medications taken and how often.....

.....  
 .....

**Date: 6/2/2013 Version 1**

**Appendix L. Hospital Anxiety and Depression Scale (HADS).****Removed prior to hard binding.**

**Appendix M. GP letter.**

Dear (GP)

**RE. Name:**

**NHS Number:**

**DOB:**

I am writing to let you know that the above patient has given written, informed consent to participate in a research study entitled “The experience of older people self-managing cancer pain at home – what helps?”. The study has received the approval of the NHS Ethics Committee.

I am enclosing a copy of the Patient Information Sheet for the study and also information about \*\*\*\*\*.

In brief, this is an interview based qualitative study investigating how older adults manage their cancer pain at home. Interviews will be audio recorded and transcriptions will be analysed for themes.

If you wish further details of this study, please do not hesitate to contact Dr. Lewis or myself.

Yours sincerely

Sara Appleyard  
Trainee Clinical Psychologist

Under the supervision of  
Dr Emma Lewis  
Clinical Psychologist

**Date: 6/2/2013 Version 1**

## Appendix N. Participant research analysis questionnaire



Dear Participant

### Research Analysis Questionnaire

Thank you for taking part in the research study “The experience of older people self-managing cancer pain at home – what helps?” You agreed to be contacted to help us in the analysis of the results. We have identified certain themes in the interviews and we would like to know how well they match with your experience. For each theme we would like you to rate it between 0-10, with 0=it does not match my experience, to 10=it fully matches with my experience.

Theme	How well does this match with your experience? (please circle 0=does not match, 10=fully matches)	Any other comments
When I was first diagnosed, the pain made me feel as if I had lost control	0 1 2 3 4 5 6 7 8 9 10	
The pain I experienced was terrible – very painful	0 1 2 3 4 5 6 7 8 9 10	
The pain stopped me doing things I used to enjoy	0 1 2 3 4 5 6 7 8 9 10	
I was afraid I would be a burden to my family	0 1 2 3 4 5 6 7 8 9 10	
I used my inner strengths (hope, optimism etc) to cope	0 1 2 3 4 5 6 7 8 9 10	
I used memories of how I, and others, had coped in the past to help me cope with the pain	0 1 2 3 4 5 6 7 8 9 10	
I do things that help with the pain: eg keeping busy/distracted	0 1 2 3 4 5 6 7 8 9 10	
I have support networks I can rely on: eg family, doctors etc.	0 1 2 3 4 5 6 7 8 9 10	
It was important to work out my own system for managing pain: I adjust medications etc. to suit me	0 1 2 3 4 5 6 7 8 9 10	
Now I feel like I have gained back control over my pain	0 1 2 3 4 5 6 7 8 9 10	

Please post this questionnaire back to us in the stamped addressed envelope. Thank you for your help with this research.

Yours sincerely

Sara Appleyard  
Trainee Clinical Psychologist

Date: 30/3/2014 Version 1.2

## Appendix O. Example of data analysis

The following example demonstrates the process of creating themes using Interpretative Phenomenological Analysis (IPA). Listening to and transcribing audio recorded interviews is the first stage in an IPA analysis. The transcript below is an excerpt from the interview with Participant 8. The excerpt is from 9.41minutes to 20.09minutes, from a total interview length 43.17minutes.

### Transcription

<b>Researcher:</b>	<b><i>And I wonder if you can tell me a little bit more about the impact of the pain, and how it impacted on you not just physically, but emotionally as well</i></b>
Participant:	It was awful because I could not, because, even though you want to define the two, they are both locked together, because the very fact that I couldn't do anything, that I couldn't get from one part of the house to the other, I just couldn't get to the toilet very well, I couldn't write and I couldn't do anything because it was so painful and I couldn't sit at my desk and I couldn't do anything, that in itself was, well awesome, but, the pain in itself was so acute that I didn't want to do anything, and that was, I wanted to achieve, but I couldn't, I knew I couldn't get to the point of achievement because the pain was going to stop me, and er, and even thinking about that now is making me feel quite shaky you know, I never want to go through that again
<b>Researcher:</b>	<b><i>Emotionally, how was that, going through it?</i></b>
Participant:	Terrible.
<b>Researcher:</b>	<b><i>How did it affect your mood?</i></b>
Participant:	It made me feel very sad. I never got angry, but I certainly became extremely sad, very low, hopeless, I didn't think that life had anything left for me at all, and erm, and for me that is dreadful you know, because I like life to be one of discovery and moving on, enjoyment, and I was always just jumping in my car and going off to see people, you know, I think that the pastoral side of my work has always been my favourite side, and that stopped abruptly. So that made me feel very low as well. But you know, I couldn't drive, and er, all these normal things went by the board, and I had to become dependent on other people when I wanted, you know, to keep the work going, back to instruction rather than me doing it, but then I found I didn't even have to power to instruct, I didn't, I couldn't concentrate long enough to do, be able to tell people what I wanted them to do, so I started to lose control, and when you lose control, you know, in anything, kind of organisation, lose the sense that you could be responsible enough to do what you are supposed to do, well it's dreadful, you know, and the pain and the stress put together was unnerving for me, and it's only in the last, what, last two or three days that I've started to feel powerful again, and that's a long time
<b>Researcher:</b>	<b><i>I'm interested a little bit, and I think it probably ties to what you have just be talking about, about your attitudes towards pain, and I wonder what your attitude towards your pain is, or was, and did you have any beliefs about pain?</i></b>
Participant:	Well my attitude towards to the pain was that there was not much I could do about it really, erm, but I, let me just put it like this, the best time of the day

	for me was going to bed, because then I disappeared, I escaped, because I could get comfortable and I would read, and I would go to sleep, and I, it was a wonderful feeling, except for the moment when I put my book down, and I knew I would have to get up in the morning, and that was acutely stressful for me, you know, going to sleep, knowing I would have to get up in the morning. And what I was doing, at one o'clock in the afternoon, I was going to bed, erm, because I thought that that was a good way of getting through the day
<b>Researcher:</b>	<b>Yes</b>
Participant:	But then I realised, I'm just escaping again, because I felt really ill when I got up after having a couple of hours sleep in the afternoon. So I had to stop doing that, I've only just stopped doing that about a month ago, but I feel a ton better by not doing that, by forcing the issue, but the, it's the stress of not being able to achieve, attached to the pain, but the, I don't think people can even begin to understand what stress is like, because stress is a pain in itself
<b>Researcher:</b>	<b>Yes</b>
Participant:	It's not just that sharp jabbing pain when you think about pain, but stress is painful, it makes you feel sick. People keep saying, well are you nauseous? (laughs) I get fed up with that question. I say no, I don't feel nauseous, I feel ill, and I just feel as though nothing I do is making anything feel better, and that makes me feel ill
<b>Researcher:</b>	<b>Yes</b>
Participant:	And I just want to, I shake and you know, and I tremble, and I, and it's all blooming stress, it's nothing else, there's no reason why I should do that, but, I can sit here and my legs go ten to the dozen, and it's simply because that distracts me, you know. But erm, the stress is, is just as hard to bear as the pain itself
<b>Researcher:</b>	<b><i>Did you have any kind of attitudes or beliefs about pain sort of prior to having pain?</i></b>
Participant:	When you say attitudes or beliefs about pain, what do you mean?
<b>Researcher:</b>	<b><i>I kind of wonder what the pain actually means to you, did you have any thoughts about pain or people in pain before you had it?</i></b>
Participant:	Well that's funny, yeah, I didn't understand what people meant, I know quite a lot of people who'd been in pain, rheumatoid arthritis and things of that kind, I never quite believed that they were in so much pain as they said, now I understand
<b>Researcher:</b>	<b>Yes</b>
Participant:	You know, I never appreciated what people felt like when they said they were in pain, I do now, you know, it's increased my understanding of what other people are having to go through, so yeah, I guess I just didn't really appreciate what pain was, I really didn't
<b>Researcher:</b>	<b><i>And you think you view it differently now?</i></b>
Participant:	Yeah I do, I think very much differently now. I look at people with a great deal more empathy. I always had sympathy for people, but you could never be empathetic because you had never shared in that kind of thing, and now I have, I look at people in a different light altogether. It's made me a lot softer towards people, I, you know, because I look at them and I think, this is terrible for you isn't it, and now I understand, not only that they are in pain, but I understand the stress that they are going through, and one of the things that really exercises my thoughts is the fact that there are an awful lot of people who don't have a (wife) to support them, you know, they are on their own
<b>Researcher:</b>	<b>Yes</b>
Participant:	And I ruminate on the idea that if I didn't have (wife), where the heck would I be?
<b>Researcher:</b>	<b>Yes</b>
Participant:	You know, I couldn't live here, could I? I'd be stuck in some hospice somewhere, and everything would be really bad, and dark, and I have a lot of

Researcher:	<p>people in our ward in the church who are single people, or elderly, and who are ill, my it made me feel different towards them, and now when I go, when I see them and they stop me in the church and we, and they want to talk, I'm much more willing to stand and give them time, you know, more than I ever would have before, and it's all that, that has been a good thing, because now I can understand, so yeah, the belief in that sense, and the understanding has increased tremendously</p> <p><b><i>I wonder if I can ask you a little bit about how you manage your pain at home? I know you was telling me a little bit about your medications, and you told me a little bit that you were trying to use distraction, I wonder if you could tell me a little bit more about that, or if there is anything else that you use to manage your pain at home?</i></b></p>
Participant:	<p>Now, well I don't take the pain killers just because I like taking them, I mean some days I don't have a lot of pain and I forget, I just forget to take the damn stuff, but that's a dangerous thing to do in actual fact, because all of a sudden you suddenly start to hurt and you think oh gosh, you know, I've gone too long here really, and where it's not been a terrible pain, it's more than it needs to be. So I have to be a bit careful and a bit more responsible, but erm, but the distraction side, there are things that I do, you know, going beyond, I have icecream (laughs), you know (wife) will often say do you want some icecream? And she brings me a bowl of icecream in, and I just peck at it with a small spoon, because that distraction is quite wonderful, and I've got a son-in-law who is a doctor, and he er, he said well that's not helping anything, I said hey, well you don't understand, of course it's helping, it's distracting, you know, it's taken my mind away from it and therefore I get a few minutes of erm, of peace without any stress because I'm eating the icecream. And that must be good, you know, and after I've had the icecream I'll probably have a teacake or something, you know, because it's, I'm introducing a bit of fun into it, you know what I mean?</p>

### Initial notes

The next stage of analysis is when the researcher reads the transcript and notes initial interesting words or phrases, ideas and thoughts in the left hand margin.

Initial notes	Transcript
Physical and emotional pain linked  Prevented from doing normal activities Very painful Scared Frustrated Anxiety	<p><b><i>And I wonder if you can tell me a little bit more about the impact of the pain, and how it impacted on you not just physically, but emotionally as well</i></b></p> <p>It was awful because I could not, because, even though you want to define the two, they are both locked together, because the very fact that I couldn't do anything, that I couldn't get from one part of the house to the other, I just couldn't get to the toilet very well, I couldn't write and I couldn't do anything because it was so painful and I couldn't sit at my desk and I couldn't do anything, that in itself was, well awesome, but, the pain in itself was so acute that I didn't want to do anything, and that was, I wanted to achieve, but I couldn't, I knew I couldn't get to the point of achievement because the pain was going to stop me, and er, and even thinking about that now is making me feel quite shaky you know, I never want to go through that again</p> <p><b><i>Emotionally, how was that, going through it?</i></b></p> <p>Terrible.</p> <p><b><i>How did it affect your mood?</i></b></p>

<p>Sad  Hopeless  Life empty  Previous self  fun, life of  discovery  Able</p>	<p>It made me feel very sad. I never got angry, but I certainly became extremely sad, very low, hopeless, I didn't think that life had anything left for me at all, and erm, and for me that is dreadful you know, because I like life to be one of discovery and moving on, enjoyment, and I was always just jumping in my car and going off to see people, you know, I think that the pastoral side of my work has always been my favourite side, and that stopped abruptly. So that made me feel very low as well. But you know, I couldn't drive, and er, all these normal things went by the board, and I had to become dependent on other people when I wanted, you know, to keep the work going, back to instruction rather than me doing it, but then I found I didn't even have to power to instruct, I didn't, I couldn't concentrate long enough to do, be able to tell people what I wanted them to do, so I started to lose control, and when you lose control, you know, in anything, kind of organisation, lose the sense that you could be responsible enough to do what you are supposed to do, well it's dreadful, you know, and the pain and the stress put together was unnerving for me, and it's only in the last, what, last two or three days that I've started to feel powerful again, and that's a long time</p> <p><b><i>I'm interested a little bit, and I think it probably ties to what you have just be talking about, about your attitudes towards pain, and I wonder what your attitude towards your pain is, or was, and did you have any beliefs about pain?</i></b></p>
<p>Normal life ceased  Depend on others  Unable to carry on  as normal  Loss of power</p>	<p>Well my attitude towards to the pain was that there was not much I could do about it really, erm, but I, let me just put it like this, the best time of the day for me was going to bed, because then I disappeared, I escaped, because I could get comfortable and I would read, and I would go to sleep, and I, it was a wonderful feeling, except for the moment when I put my book down, and I knew I would have to get up in the morning, and that was acutely stressful for me, you know, going to sleep, knowing I would have to get up in the morning. And what I was doing, at one o'clock in the afternoon, I was going to bed, erm, because I thought that that was a good way of getting through the day</p>
<p>Lose sense of self?</p>	<p><b>Yes</b></p>
<p>Stress/anxiety  Regaining power</p>	<p>But then I realised, I'm just escaping again, because I felt really ill when I got up after having a couple of hours sleep in the afternoon. So I had to stop doing that, I've only just stopped doing that about a month ago, but I feel a ton better by not doing that, by forcing the issue, but the, it's the stress of not being able to achieve, attached to the pain, but the, I don't think people can even begin to understand what stress is like, because stress is a pain in itself</p>
<p>Fatalistic about  pain/powerless</p>	<p><b>Yes</b></p>
<p>Distraction/  escapism through  sleep</p>	<p>It's not just that sharp jabbing pain when you think about pain, but stress in painful, it makes you feel sick. People keep saying, well are you nauseous? (laughs) I get fed up with that question. I say no, I don't feel nauseous, I feel ill, and I just feel as though nothing I do is making anything feel better, and that makes me feel ill</p>
<p>Pain seems never  ending  Sleep=relief</p>	<p><b>Yes</b></p>
<p>Sleep not that  helpful  Recognising  maladaptive coping  Unable to achieve  Pain=stress</p>	<p>And I just want to, I shake and you know, and I tremble, and I, and it's all blooming stress, it's nothing else, there's no reason why I should do that, but, I can sit here and my legs go ten to the dozen, and it's simply because that distracts me, you know. But erm, the stress is, is just as hard to bare as the pain itself</p>
<p>Helpless/ powerless  Others don't  understand  Lack of self-  efficacy</p>	<p><b>Did you have any kind of attitudes or beliefs about pain sort of prior to having pain?</b></p>
<p>Anxiety/  stress/  fear  Reframe as  positive?</p>	<p>When you say attitudes or beliefs about pain, what do you mean?</p> <p><b><i>I kind of wonder what the pain actually means to you, did you have any thoughts about pain or people in pain before you had it?</i></b></p>

Gained new understanding/empathy	Well that's funny, yeah, I didn't understand what people meant, I know quite a lot of people who'd been in pain, rheumatoid arthritis and things of that kind, I never quite believed that they were in so much pain as they said, now I understand <b>Yes</b>
Social comparison/empathy/new understanding	You know, I never appreciated what people felt like when they said they were in pain, I do now, you know, it's increased my understanding of what other people are having to go through, so yeah, I guess I just didn't really appreciate what pain was, I really didn't <b>And you think you view it differently now?</b>
Social comparison/empathy/new understanding	Yeah I do, I think very much differently now. I look at people with a great deal more empathy. I always had sympathy for people, but you could never be empathetic because you had never shared in that kind of thing, and now I have, I look at people in a different light altogether. It's made me a lot softer towards people, I, you know, because I look at them and I think, this is terrible for you isn't it, and now I understand, not only that they are in pain, but I understand the stress that they are going through, and one of the things that really exercises my thoughts is the fact that there are an awful lot of people who don't have a (wife) to support them, you know, they are on their own
Appreciate family support	<b>Yes</b>
Social comparison	And I ruminate on the idea that if I didn't have (wife), where the heck would I be? <b>Yes</b>
Thankful for wife – gratitude?	You know, I couldn't live here, could I? I'd be stuck in some hospice somewhere, and everything would be really bad, and dark, and I have a lot of people in our ward in the church who are single people, or elderly, and who are ill, my it made me feel different towards them, and now when I go, when I see them and they stop me in the church and we, and they want to talk, I'm much more willing to stand and give them time, you know, more than I ever would have before, and it's all that, that has been a good thing, because now I can understand, so yeah, the belief in that sense, and the understanding has increased tremendously
Grateful for situation – compares to others less fortunate	<b>I wonder if I can ask you a little bit about how you manage your pain at home? I know you was telling me a little bit about your medications, and you told me a little bit that you were trying to use distraction, I wonder if you could tell me a little bit more about that, or if there is anything else that you use to manage your pain at home?</b>
Common understanding Understand what others go through	Now, well I don't take the pain killers just because I like taking them, I mean some days I don't have a lot of pain and I forget, I just forget to take the damn stuff, but that's a dangerous thing to do in actual fact, because all of a sudden you suddenly start to hurt and you think oh gosh, you know, I've gone too long here really, and where it's not been a terrible pain, it's more than it needs to be. So I have to be a bit careful and a bit more responsible, but erm, but the distraction side, there are things that I do, you know, going beyond, I have icecream (laughs), you know (wife) will often say do you want some icecream? And she brings me a bowl of icecream in, and I just peck at it with a small spoon, because that distraction is quite wonderful, and I've got a son-in-law who is a doctor, and he er, he said well that's not helping anything, I said hey, well you don't understand, of course it's helping, it's distracting, you know, it's taken my mind away from it and therefore I get a few minutes of erm, of peace without any stress because I'm eating the icecream. And that must be good, you know, and after I've had the icecream I'll probably have a teacake or something, you know, because it's, I'm introducing a bit of fun into it, you know what I mean?
Analgesic use Adjusting dose – forget	
Need to take care of medications	
Distraction Family helps with distractions	
Doctor (son) dismissing my methods I know what helps me Enjoy the distractions	



	<i><b>I'm interested a little bit, and I think it probably ties to what you have just be talking about, about your attitudes towards pain, and I wonder what your attitude towards your pain is, or was, and did you have any beliefs about pain?</b></i>	
Fatalistic about pain/powerless Helpless Distraction/ escapism through sleep	Well my attitude towards to the pain was that there was not much I could do about it really, erm, but I, let me just put it like this, the best time of the day for me was going to bed, because then I disappeared, I escaped, because I could get comfortable and I would read, and I would go to sleep, and I, it was a wonderful feeling, except for the moment when I put my book down, and I knew I would have to get up in the morning, and that was acutely stressful for me, you know, going to sleep, knowing I would have to get up in the morning. And what I was doing, at one o'clock in the afternoon, I was going to bed, erm, because I thought that that was a good way of getting through the day <i><b>Yes</b></i>	What I do helps with the pain Behavioural coping
Pain seems never ending Sleep=relief		
Sleep not that helpful Recognising maladaptive coping Unable to achieve Pain=stress	But then I realised, I'm just escaping again, because I felt really ill when I got up after having a couple of hours sleep in the afternoon. So I had to stop doing that, I've only just stopped doing that about a month ago, but I feel a ton better by not doing that, by forcing the issue, but the, it's the stress of not being able to achieve, attached to the pain, but the, I don't think people can even begin to understand what stress is like, because stress is a pain in itself <i><b>Yes</b></i>	Establishing own system
Helpless/ powerless Others don't understand Lack of self-efficacy	It's not just that sharp jabbing pain when you think about pain, but stress is painful, it makes you feel sick. People keep saying, well are you nauseous? (laughs) I get fed up with that question. I say no, I don't feel nauseous, I feel ill, and I just feel as though nothing I do is making anything feel better, and that makes me feel ill <i><b>Yes</b></i>	Acute pain
Anxiety/ stress/ fear	And I just want to, I shake and you know, and I tremble, and I, and it's all blooming stress, it's nothing else, there's no reason why I should do that, but, I can sit here and my legs go ten to the dozen, and it's simply because that distracts me, you know. But erm, the stress is, is just as hard to bear as the pain itself	Pain and stress
Reframe as positive?	<i><b>Did you have any kind of attitudes or beliefs about pain sort of prior to having pain?</b></i> When you say attitudes or beliefs about pain, what do you mean? <i><b>I kind of wonder what the pain actually means to you, did you have any thoughts about pain or people in pain before you had it?</b></i>	
Gained new understanding/ empathy	Well that's funny, yeah, I didn't understand what people meant, I know quite a lot of people who'd been in pain, rheumatoid arthritis and things of that kind, I never quite believed that they were in so much pain as they said, now I understand <i><b>Yes</b></i>	Knowledge – inner strength
Social comparison/ empathy/new understanding	You know, I never appreciated what people felt like when they said they were in pain, I do now, you know, it's increased my understanding of what other people are having to go through, so yeah, I guess I just didn't really appreciate	Knowledge – inner strength

Social comparison/empathy/new understanding	what pain was, I really didn't <b><i>And you think you view it differently now?</i></b> Yeah I do, I think very much differently now. I look at people with a great deal more empathy. I always had sympathy for people, but you could never be empathetic because you had never shared in that kind of thing, and now I have, I look at people in a different light altogether. It's made me a lot softer towards people, I, you know, because I look at them and I think, this is terrible for you isn't it, and now I understand, not only that they are in pain, but I understand the stress that they are going through, and one of the things that really exercises my thoughts is the fact that there are an awful lot of people who don't have a (wife) to support them, you know, they are on their own <b><i>Yes</i></b> And I ruminate on the idea that if I didn't have (wife), where the heck would I be? <b><i>Yes</i></b> You know, I couldn't live here, could I? I'd be stuck in some hospice somewhere, and everything would be really bad, and dark, and I have a lot of people in our ward in the church who are single people, or elderly, and who are ill, my it made me feel different towards them, and now when I go, when I see them and they stop me in the church and we, and they want to talk, I'm much more willing to stand and give them time, you know, more than I ever would have before, and it's all that, that has been a good thing, because now I can understand, so yeah, the belief in that sense, and the understanding has increased tremendously <b><i>I wonder if I can ask you a little bit about how you manage your pain at home? I know you was telling me a little bit about your medications, and you told me a little bit that you were trying to use distraction, I wonder if you could tell me a little bit more about that, or if there is anything else that you use to manage your pain at home?</i></b>	Humanity – inner strength  Compassion – inner strength Support networks - family
Appreciate family support		
Social comparison		
Thankful for wife gratitude?		Gratitude – inner strength
Grateful for situation – compares to others less fortunate		Compassion – inner strength Kindness – inner strength Positive effects Understanding
Common understanding Understand what others go through		
Analgesic use		
Adjusting dose – forget		Importance of regular medication system Behavioural coping Distraction Family support Establish my own system – I know what works Self-efficacy Self-determination Taking control - choice
Need to take care of medications		
Distraction Family helps with distractions		
Doctor (son) dismissing my methods I know what helps me		
Enjoy the distractions		

### Supporting quotations

All of the emerging themes (sub-ordinate themes) are collected along with supporting quotations. This is repeated for each participant. This step can identify areas of convergence and divergence within a theme, identify themes which show ideographic experience, and establish theme prevalence.

Emerging theme	Supporting quotation
Sometimes the pain is very bad	‘the pain in itself was so acute’ P8
The restrictions pain places on me	‘I couldn’t do anything... I couldn’t get from one part of the house to the other’ P8
Being a burden/loss of independence	‘I had to become dependent on other people’ P8

### Creation of super-ordinate themes

Following the analysis of all the transcripts, a master table of themes is created. Themes are examined for overarching themes and the coding of higher levels meanings and interpretations. These become sub-ordinate and super-ordinate themes. A master table is then created and linked to existing literature in the discussion.

Super-ordinate Theme	Sub-ordinate Themes
1. Losing control	1.The pain was excruciating 2.The pain restricts life 3.Burden

## **Appendix P. Reflective Statement**

### **The Start**

#### ***Research topic***

Choosing a research area was the easy part. I had promised myself during my undergraduate years that if I ever had the chance to take psychology further, and gain a place on the clinical psychology doctorate course, I would like to conduct research within the field of oncology. Cancer has touched the lives of many people, and it had a profound impact on my family, and me personally. I wanted to be in a position to do something positive within this field, something that would add to psychological knowledge in the area.

#### ***Field Supervision***

Knowing that I wanted to research within oncology, as soon as I started the doctorate course in September 2011 I approached one of our clinical lecturers enquiring about a local collaborator. I met with Dr Emma Lewis at \*\*\*\*\* in October 2011, just a few weeks after starting the course, and before many fellow trainees had even thought about a topic area. We soon had an agreement that she would field supervise my doctoral research. Emma has been a wealth of knowledge and support, and forming good alliances with the hospital and staff so early, whilst the research was being developed, meant that we could be thinking about the recruitment process from the very start.

#### ***Academic Supervision***

I feel very fortunate that I was offered the opportunity to have Dr Chris Clarke as my research supervisor at the University. Chris has been, without fail, a source of

inspiration. Many hours have been spent discussing research, methodologies, and philosophy. Chris's patience in encouraging, and teaching me, has enabled my understanding of the research process to not only grow, but to be an enjoyable journey. Whilst Chris's main research interest lay outside the field of oncology, we were able to construct research questions that would draw on both of our interests. I was especially mindful of making the best use of Chris's considerable expertise with older people. A shared interest was found within the field of positive psychology and this naturally led to the shaping of the research to include positive factors.

### ***Finalising the research topic***

Starting to narrow the area was more difficult. I was drawn to investigating pain in cancer, as again, this area had profound personal meaning for me. Many hours were spent reading, and scoping the literature, to understand the field and try and identify areas for future research. I was also initially drawn to hope. This positive inner strength has a lot of resonance for me, and the research previously conducted on hope and cancer was fascinating. My first plans were to conduct a quantitative study measuring hope and pain in older adults with cancer, and investigating how these were linked. However, taking this forward, and after discussions with peers following my research proposal presentation, I decided to widen the area of interest. Very little had been previously researched into older adults' experiences of managing cancer pain. It made sense to explore this area as widely as possible, and Chris had suggested that using a qualitative method to explore personal facilitators would open the research into more areas than hope alone. As a year group, we had had teaching on qualitative methods, and interpretative phenomenological analysis (IPA) had been introduced to us. I found this method fascinating. The ability to meet, and interview in depth, patients who were managing their cancer pain, and explore meaning from two perspectives, the

participants' and the researcher's, meant that this method felt a natural fit for the research question. IPA has also been used particularly within the field of health psychology, and the approach was an interesting contrast to the often used quantitative methods that dominate medical research. Initially I was daunted by learning a new research method, however, the more I read, and the more Chris and I talked about the methodology, the more excited I became about using IPA. Initial research proposals were submitted in February 2012 and July 2012, with the research question finalised at last, in November 2012, after more than a year of reading and planning. Peer review followed in December 2012 following a final research proposal and presentation. I was going to explore the experiences of older people who self-manage their cancer pain.

## **The Middle**

### ***Ethics***

The ethics process was a remarkably straightforward one. I had spent a lot of time preparing the ethics application over Christmas 2012 and continued to write well into the New Year. Writing the application was a lengthy job and required lots of thought into the 'nuts and bolts' of the research. This included writing procedures and producing a remarkable amount of documentation. I was determined to ensure a timely application however, and having readied the application by March 2013, I submitted to NHS proportionate review. This felt at the time to be a bit of a gamble, as I was unsure whether I would have to resubmit to full panel. However I was able to fulfil criteria for the shorter process of proportionate review. This process was very straightforward, and following request to adjust the wording of a couple of documents, I was granted NHS ethical approval in April 2013. The next step was gaining research and development (R&D) approval from the local trust that was hosting the research. The process of getting the go ahead took much longer than I had hoped. There was a long hold-up

waiting to get a vital honorary contract, however, once this was granted I received R&D approval very quickly. By July 2013 I was ready to start recruiting.

### ***Recruitment***

In common with many who conduct research, recruitment did not happen nearly as quickly as I hoped it would. I had hoped to conduct interviews over the summer of 2013. However, by the time I had final go ahead from R&D, it was mid summer and we needed to ensure everything was in place for clinicians to be able to refer. I had lots of good contacts within the teams built up over the previous year, thanks to Emma, but it was also necessary to speak to all of the referrers directly. This ensured referring clinicians understood the referral process and inclusion and exclusion criteria with potential participants. I believe that sharing my enthusiasm and rationale for the study with referring clinicians helped to ensure that recruitment for the study was kept in mind, and several referrers were particularly interested in the study. I also requested, and was given, my final year placement within \*\*\*\*\* and started work there in October 2013. This was essential for continuing good relationships with referring clinicians, and enabled me to have a deeper understanding of the hospital and the extensive reach of psychology within oncology.

### ***Interviews***

The first interview took place in September 2013, and by Christmas I had conducted five interviews, with another three following into the New Year. I found the interviews were the most interesting and rewarding part of the study. I was grateful that participants were willing to give their valuable time to take part in the study, despite many of them also having other medical commitments due to their cancer. For most of the interviews, I was invited to participants' homes. This, I felt, enabled people to really

open up and feel comfortable. The process of interviewing for IPA, however, was quite a personal challenge initially. I had to put aside my therapeutic skills, and concentrate on a more 'journalistic' style of interviewing. I also had to be particularly mindful of not leading the interviews into areas I was hoping for, and for many interviews I said very little.

Having the structure of the interview questions was very useful in ensuring each participant was given similar opportunities to reflect on their experiences. The interview questions had been discussed with service users, the local Macmillan Survivorship group, at the planning stage in early 2013, and wording had been adapted following their suggestions. The research certainly benefitted from this input, and I was bowled over by how many people at the group were interested and enthusiastic about the research.

The interviewees who participated in the final study were so open and honest with me, and shared such valuable insights into their struggles. I was struck by their hopefulness for the future. I only hoped I could do their words justice in the writing up of their stories.

### ***Transcription & coding***

I was really excited to start the transcriptions. This was a familiar process for me, as I had spent several years in various secretarial positions and was experienced in audio typing. I found it helpful to transcribe an interview within two weeks of recording it. That way, I was able to immerse myself in the interview, without becoming overwhelmed with a backlog of tapes needing transcription. Each tape took around four to six hours to transcribe, which could be done in one sitting. Again, I found it helpful to

immerse myself in the process. Listening and concentrating on each sentence as I heard it, and typed it, illuminated ideas and meanings that I had missed during the actual interview. This continued into the coding process, where again, meaning opened before me. I had toyed with the idea of using software to assist with coding, however, having installed and trialled it, I decided that I felt more at home with a back to basics approach. Pens, paper and lots of typing into a word processing package ensued, until at last I reached themes that made sense conceptually. I discussed the themes with Chris, Emma and an independent reviewer who was experienced in IPA. These conversations helped to tighten the themes, and gave me confidence that I was on to the right track with my interpretations.

### ***Systematic literature review (SLR)***

Initially I was completely daunted by the scale of this piece of work. Reading other SLRs, and having the teaching on SLRs at the University, I could not imagine ever completing one. Again though, the starting place was in reading the literature to find a gap. This process took a long time, and at several points I feared I would never find a question. Chris was extremely patient, and guided me back constantly to the literature. After many, many searches of the databases, and lots of reading, I eventually settled on investigating predictors of coping strategies in cancer pain in early 2014. Once the question was found, the rest followed. Finalising the pool of papers for the review was, again, a lengthy task and involved lots of reading and discussion with Chris. I was eager to run before I could walk though, and had to take the process a step at a time. Ensuring the basics were well thought out, especially the inclusion and exclusion criteria for reviewed studies, was vital. Our final pool of papers was agreed by late March 2014. Other aspects of the SLR took me by surprise. Initially I had thought the quality assessment tool appeared a straightforward exercise. However, I soon found out that

because I wanted to include mixed methodologies within the review, and tailor the quality assessment directly to my question, this would take much more work than initially planned. Hours and hours were spent reading other SLRs and critiquing how they had conducted quality assessments, and looking at the pros and cons of the many existing quality tools. I eventually decided to create my own, using a combination of two other existing tools whilst adding several of my own questions. This also required a scoring guideline to be created, to ensure that both I and the independent rater understood the questions being asked. After discussions with Chris and two pilot versions, the final checklist was ready and the review could begin.

## **The End**

### ***Writing up***

The writing up process alternated between really enjoyable, and quite arduous. I found writing the method and results sections of both papers, the empirical and the literature review, really engaging and thoroughly enjoyed thinking about what the research had actually found. I lost hours and hours doing this work, and found it hard to tear myself away from the computer. However, the more difficult aspects were the introduction and discussion sections. These did not flow in the same way, and involved lots of stop and start sessions where I wrestled with what I was trying to say. Ensuring I wound in previous research and literature, concepts and ideas, and tying it all together, was a much slower process and often quite difficult. I had booked writing-up leave in late March and early April 2014, with strict deadlines for first and second drafts in early and mid April. I was determined to have enough time in April and May to really polish my writing, along with Chris's suggested amendments, and I think that sticking to these deadlines made the final production a considered, rather than a rushed or stressful, process. Having spent two and a half years planning and conducting this research,

which meant so much to me personally, I wanted to enjoy the final writing-up and give the work the time it deserved.

### ***Journal selection***

The journal selected for submission was *Psychology & Health*. This was selected as the journal's aims of publishing papers within health psychology fitted well with my research topic of coping in cancer. This journal has previously published good quality IPA research studies and has a good national and international reputation, with a 2012 impact factor of 1.950.

### ***Reflections***

I started this research process knowing very little about qualitative research, nothing about IPA, with no knowledge of NHS ethics panels or R&D procedures, and very little about systematic review papers. The opportunity to explore all of these methods, procedures and systems, with a sensitive and knowledgeable supervisor, has enabled my research knowledge and confidence to grow in many ways.

No longer daunted by the research process, I hope to continue to undertake research in my future career, and can certainly foresee that I will undertake further IPA analysis in the years ahead. This method, enabling participants to have a voice, felt empowering and real, and after all, our work as clinical psychologists is so often focused upon listening to people's stories. I certainly felt privileged to hear the stories, in this research study, of courage and coping.

It certainly felt vital to research a topic that I was so interested in. A passion for a topic can get you through the tough days, and so my advice for future researchers would be to

select a research topic that you are really, really interested in. I would also advise that making good alliances with field supervisors and referring clinicians is essential, and time must be set aside to network and get to know people. You will be relying on people for their time, energy and enthusiasm for your research.

I feel that my main strength in regard to conducting research has been utilising my organisational and planning skills. Deadlines were, as much as possible, adhered to, and my passion for the research meant that I never felt it an ordeal. I often felt the research gave me a focus and direction, and whilst the workload fluctuated, I remembered why I was doing this. My family, my memories of loved and lost ones, and the achievement of a doctorate spurred me on.

Cancer leaves many of us feeling helpless and powerless. The process of conducting this research, choosing my research topic, producing an empirical paper and a systematic literature review paper, and writing for publication, gave me a sense of regaining power. For the chance to be proactive within the context of a disease that affected me profoundly, I give thanks.

### **Appendix Q. Epistemological statement.**

Knowledge can be gained through various methods, however, in psychology three main philosophies of science dominate: post-positivism, social constructionism and critical realism. This statement will explain the epistemology (theory of knowledge) that underpins the study. In addition, the statement aims to explain the methodological approach to the empirical research question and the reason that method was selected.

Positivism and post-positivism, includes what is commonly termed as the ‘scientific method’, which involves quantitative research. This method is objective, deterministic and reductionist, in that it aims to reduce ideas into hypotheses and allow the scientific measurement of human experience through testable items. These can then be empirically investigated through numeric measure to establish causal relationships (Creswell, 2003).

In contrast, social constructionism acknowledges that human experience is subjective and rather than starting with a testable theory, constructivists generate data from questioning, which then leads to meaning or theory development (Creswell, 2003). Undertaking qualitative methods of investigation (e.g. interviews, diaries, transcripts etc.) allows researchers to investigate the inner worlds and meanings generated by their participants.

Critical realism posits that whilst there is a real world with external events that take place in it, as human beings our interpretations of the world are imperfect (Robinson & Smith, 2010). As such, science has to be interpretative rather than realist. Whilst social constructionism would suggest that individuals can only understand the world through

their lens of experience, and post-positivism would suggest that there is an objective reality that can be accessed only through accurate measurement, critical realism would suggest that there is a middle ground between realism and constructionism that can be accessed (Bhaskar, 2008). Therefore, whilst post-positivism is concerned with quantitative investigation, and social constructionism is (predominantly) interested in qualitative methodology, critical realism encompasses both quantitative and qualitative studies, and critical realists can undertake either method dependent on the research question (Alvesson & Skoldberg, 2010).

The experience of pain, the main topic of this research portfolio, is understood to be a uniquely subjective experience (Katz & Melzack, 1999). Cancer pain in particular is understood to be sensitive to psychological influences and individual interpretations (Raphael et al., 2010). In addition, the paucity of research in the field of coping strategies for cancer pain management suggested that an exploratory stance, rather than theory testing, would be most appropriate.

Therefore a qualitative methodology as opposed to a quantitative approach seemed most appropriate to explore this research question.

Many of the qualitative methods have common features. Complex data, such as transcripts, narratives, diaries or field notes, are fragmented and then analysed to produce some form of themes which are synthesised and given meaning (Robinson & Smith, 2010). The main methods which dominate include grounded theory (Glaser & Strauss, 1965), the discursive approaches (e.g. thematic analysis and discourse analysis) and phenomenological approaches such as interpretative phenomenological analysis (IPA; Smith & Osborn, 2003). All of these methods were considered for the research study.

The discursive approaches, aimed to offer an alternative to mainstream quantitative approaches and deconstruct experience by focusing on textual content (Clarke, 2010). Discourse analysis examines the role of language and its involvement in a person's experience, however, this method was rejected as the role of language was not the main focus of the research question. Grounded theory (Glaser & Strauss, 1965) as a method was rejected as the paucity of research in the area suggested that rather than theory development being the main aim of the research, again, uncovering experience was a more realistic goal. Thematic analysis (coding and counting text), has limited interpretative power, and guidelines for use are varied with no clear universal method of use (Braun & Clarke, 2006). This method was rejected as it was felt that, in line with the previous qualitative methods, interpretation of meaning was a central issue.

IPA is concerned with the investigation of subjective experience (phenomenology) and aims to uncover how people experience events through interpreting their language and constructing meaning (Biggerstaff & Thompson, 2008). IPA is understood to be particularly useful within fields usually dominated by biomedical models (Brocki & Wearden, 2006), to gain perspectives and subjective meanings on bodily experiences (such as pain). IPA's epistemological stance, based upon the critical realist perspective, was consistent with the research question. In recognising that experience and making sense of that experience is subjective, IPA is connected to hermeneutics: the art and science of interpretation of verbal and written expression (Smith & Osborn, 2003). Two stages of interpretation are used (a double hermeneutic), in that the researcher interprets the participant's interpretation of their subjective experience. This goes beyond a more straight forward thematic analysis, and the exploration of meaning within a social and personal world is therefore allied to symbolic interactionism (Smith & Osborn, 2003). It is also acknowledged that the interpretive role of the researcher should be explicitly

mentioned, including perspectives, research interests, theoretical groundings and reasons why the research was undertaken (Brocki & Wearden, 2006). Transparency, internal consistency, and coherence are core elements (Robinson & Smith, 2010). It is understood that truth is subjective and IPA acknowledges both the individual participants and the researchers own experiences and subjective interpretations.

In regard to this study, the researcher acknowledges biases and assumptions in regard to familial experiences of cancer being both painful and difficult to manage, and also in regard to assumptions held regarding cohort attitudes such as stoicism in an older population. It is important to acknowledge that generational differences between the researcher and participants exists, and as such, representation of their experiences is interpreted with the researcher's experiences in the double hermeneutic. It was felt important to reflect on these factors in several ways. Supervision was used extensively, and whilst the interpretation of data was, naturally, subjective and therefore open to biased interpretation, several methods of validation were employed including discussions with an independent IPA reviewer. During the research process, it was challenging to be mindful of personal assumptions whilst also being mindful of not leading the interviews into preconceived areas. However, it is acknowledged that there may have been a compromise between the researcher's desire to not unduly influence conversations by being deliberately objective during interviews, and the truly subjective nature of the interpretative methodology which, without doubt, is influenced by prior experiences, knowledge, assumptions and biases. As a trainee clinical psychologist, psychological models and constructs naturally shape interpretations, and this study particularly makes reference to positive psychological constructs. Again, reflecting both in supervision and using a reflective diary ensured that influences were made explicit and transparent.

IPA accepts that whilst there is a real world, language limits how the reality of this is represented, and thus interpretations are needed (Robinson & Smith, 2010). It is acknowledged that the events which are interpreted are real, with real participants discussing their real lives. As such, transcripts provide a window onto their realities, and we can assume that participants are reliable witnesses to their reality (Robinson & Smith, 2010). This acceptance, along with the acceptance that interpretation, whilst subjective, has at its core a reflection of reality, we can assume that to some extent, analysis will make sense not just to the researchers, but to the participants also. In the spirit of this, this study aimed to involve participants in an analysis of the themes which were generated by the researcher, to ensure the study had, to some extent, accurately reflected their internal worlds.

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## Appendix R. Journal guidelines for authors.



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