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Lancaster University Doctorate in Clinical Psychology

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**Doctoral Thesis:**

**Exploring experiences of compassion and resilience in clinical psychologists working in  
palliative care**

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### Statement of Total Word Count

<b>Section</b>	<b>Text</b>	<b>Appendices (including abstracts, tables, figures, &amp; references)</b>	<b>Total</b>
<b>Abstract</b>	248	-	248
<b>Literature Review</b>	7,891	8,793	16,684
<b>Research Paper</b>	7,997	9,752	17,749
<b>Critical Appraisal</b>	3,857	996	4,853
<b>Ethics Section</b>	2,566	7,596	10,162
<b>Total</b>	22,559	27,137	49,696

## **Thesis Abstract**

The quality of palliative care can have a profound impact upon patients' and families' lives. Furthermore, the well-being of professionals within palliative care has serious implications for patients and families, professionals, and organisations. Therefore, this thesis explored issues within palliative care from both the patients' and professionals' perspective.

Firstly, a meta-synthesis of literature was conducted in order to answer the following questions: "What do palliative care patients value in their care?" and "What enhances palliative care patients' experience of feeling cared for?" The meta-synthesis of 14 papers revealed five themes: The Holistic Nature of Care, Being With People who Have a Shared Understanding, Talking and Being Listened to, Oscillating Between Living and Dying, and Psychological Well-being. The findings suggested aspects of care that services could focus on in order to meet patients' needs.

Secondly, experiences of 12 clinical psychologists working in palliative care were explored using Interpretative Phenomenological Analysis in order to gain an understanding of the impact this work has on their levels of compassion and resilience. Six themes were identified: Being Part of Something Special, The Therapeutic Relationship, Doing More With Less, Being Changed as a Result of Involvement, The Consummate Professional, and Practicing What you Preach. Experiences were characterised by the impact of the therapeutic relationship, organisational change, and effects on the self.

Finally, the process of conducting research within palliative care was critically appraised. Methodological issues, as well as the effects of conducting research in palliative care on the researcher were discussed.

## Declaration

This thesis records research undertaken for the Doctorate in Clinical Psychology Course at the Division of Health Research at Lancaster University, from June 2014 to May 2015. The work presented is my own except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

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## **Acknowledgements**

Firstly, I would like to thank the professionals that participated in this project and shared their experiences with me. In addition, thanks goes to the professionals that helped to distribute recruitment materials.

I am also grateful to my supervisors, Dr. Ian Fletcher and Dr. Claire Rehan, who both provided invaluable advice, encouragement, and support throughout. Thank you also to the loved ones in my life for your support throughout the thesis and course.

Finally, I would like to dedicate this thesis to those who inspired me during this work, including those who did not live to see the fruition of the project. The experience of this project helped me to contemplate some existential issues of my own and to learn several life lessons along the way which will stay with me forever and for which I will be eternally grateful.

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**Section One: Literature Review**

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**The value patients place in palliative care: A meta-synthesis of qualitative research**

**Word Count:**

**7,891 (excluding abstract, references, tables, figures, and appendices)**

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Prepared for *Palliative Medicine* (see Appendix 1-A)



**Abstract**

**Background:** More people than ever now require palliative care, with the figure currently estimated at over 19 million. The quality of palliative care received can have a profound impact upon people's lives. Despite this, relatively little is known about how palliative care is experienced by patients.

**Aim:** In recent years a growing amount of qualitative research has emerged examining patients' first-hand experiences of palliative care that would benefit from a qualitative meta-synthesis approach. This meta-synthesis set out to answer the following questions: "What do palliative care patients value in their care?" and "What enhances palliative care patients' experience of feeling cared for?"

**Data sources:** A systematic search of literature was conducted in the following databases: Academic Search Complete, AMED, CINAHL, MEDLINE, and PsycINFO.

**Design:** A meta-synthesis of pertinent qualitative research was conducted. Papers were critiqued using a framework developed to appraise qualitative research.

**Results:** A meta-synthesis of 14 identified papers revealed five over-arching themes: The Holistic Nature of Care, Being With People Who Have a Shared Understanding, Talking and Being Listened to, Oscillating Between Living and Dying, and Psychological Well-being.

**Conclusions:** Findings suggest aspects of palliative care that serve to enhance patients' experiences that are not traditionally medical. These include emotional support and talking therapies, as well as creative and social activities that enhance patients' sense of purpose, connection to life, and achievement. As such, services could focus upon these aspects in service development and delivery in order to meet patients' wishes and needs.

**Keywords**

Palliative care, patient care, patient satisfaction, qualitative research, literature review

**Key statements:****What is already known about the topic?**

- More people than ever now require palliative care, with the figure currently estimated at over 19 million.
- Guidance on palliative care for adults recommends the provision of psychological, social, and spiritual support for patients and families.
- Relatively little is known about how palliative care is experienced by patients, how patients experience the concept of care, and how it helps them.

**What this paper adds?**

- In recent years a growing amount of qualitative research has emerged examining patients' first-hand experiences of palliative care that would benefit from a qualitative meta-synthesis approach.
- This meta-synthesis set out to answer the following questions: "What do palliative care patients value in their care?" and "What enhances palliative care patients' experience of feeling cared for?"
- A meta-synthesis of 14 identified papers revealed five over-arching themes: The Holistic Nature of Care, Being With People Who Have a Shared Understanding, Talking and Being Listened to, Oscillating Between Living and Dying, and Psychological Well-being.

**Implications for practice, theory or policy?**

- Findings suggest aspects of palliative care that serve to enhance patients' experiences that are not traditionally medical.

- To develop palliative care that incorporates emotional support and talking therapies to ensure this is available should patients want it.
- To develop palliative care that enhances patients' sense of purpose, connection to life, and achievement via inclusion in creative and social activities.

**The value patients place in palliative care: A meta-synthesis of qualitative research**

The World Health Organization<sup>1</sup> (p.15) defines palliative care as “an approach that improves the quality of life of individuals and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering...and other problems, physical, psychosocial, and spiritual”. The majority of deaths in the United Kingdom (UK) occur in hospitals (53%), followed by a smaller proportion occurring at home (21%), in care homes (18%), in hospices (5%), and elsewhere (3%).<sup>2</sup> Whilst palliative care comes in many guises, it has been argued that it has the potential to make a profound impact upon people’s lives.<sup>3</sup>

The modern hospice movement was pioneered by Dame Cicely Saunders in the UK during the 1960s.<sup>4</sup> Saunders placed an emphasis on the views and needs of patients, and the meeting of those via a holistic approach. Now hospice and palliative care is available in over 40 countries worldwide, including North America, Australia, Asia, and Europe.<sup>5</sup> Whilst provision of services has increased, relatively little is known about how palliative care is experienced by patients.<sup>6</sup> The term patient(s) will be used in place of service users or clients as this research is focused on care within a medical setting where the term patient is traditionally used.

Due to an aging population and improvement in survivorship with terminal illnesses more people than ever will require palliative care.<sup>7</sup> Given this increase in demand, services will need to change the way they deliver care in order to continue to meet the needs and wishes of patients.<sup>3,7-11</sup>

Despite a focus on quality and performance in healthcare, compassion is often cited as lacking around the globe.<sup>12</sup> Several key UK reviews and policies have been published in recent years<sup>13-15</sup> regarding the quality of care generally in the National Health Service (NHS). This is also the case internationally.<sup>16-21</sup> Reports make reference to service failings,

stretched resources, and patients feeling devalued and uncared for. Across the globe, it has been suggested that this compassion deficit is due to economic climates, resulting health policies, and organisational cultures that are target driven and pressured, making it more difficult for professionals to deliver care in a compassionate manner.<sup>12,16,22-24</sup> It has been suggested that care pathways and best practice outcomes contribute to a move away from personalised care where compassion was paramount to an era where technical fixes to care problems are highly valued.<sup>24</sup>

The quality across palliative care services is questionable.<sup>3,6</sup> In 2004 the National Institute for Health and Clinical Excellence<sup>25</sup> developed guidance on palliative care for adults with cancer which recommended the provision of psychological, social, and spiritual support for patients. However, a recent NHS Ombudsman report<sup>26</sup> cited failings in end-of-life care in the UK.

Whilst many definitions of compassion exist,<sup>27</sup> it is commonly defined as an awareness of the suffering of others with a longing to relieve it.<sup>28</sup> However, it is unclear how patients actually experience the concept of compassion, of feeling cared about, and how this ultimately improves their well-being. Despite numerous studies exploring the quality of life for palliative care patients and several definitions being devised internationally, there is still no clear idea of what quality of life for palliative patients actually means<sup>29</sup> or how care can contribute towards their quality of life.

Current recommended research priorities in palliative care,<sup>3</sup> include determining what adequate care is and what people's care needs are. Recently the British Psychological Society<sup>30</sup> published standards regarding the demonstration of quality and outcomes in psycho-oncology. This consists of six domains of quality regarding how safe, equitable, responsive, patient-centred, effective, and efficient services are.

Heyland et al.<sup>31</sup> emphasised how various professional societies have attempted to define quality end-of-life care, with few societies consulting families and even fewer asking patients for their views on the subject.<sup>32-36</sup>

Contrary to healthcare developers' and policy makers' statements that the views of patients are vital when developing services,<sup>37,38</sup> only a small proportion of palliative care research has been conducted with patients.<sup>39-41</sup> Instead, much research has used families and professionals to measure the experiences of patients by proxy.<sup>42</sup> Whilst the voices of such individuals are important, it has been argued that they cannot provide an accurate portrayal of patients' experiences and needs.<sup>43,44</sup>

Several barriers have been identified when attempting to include palliative care patients in research.<sup>45</sup> These include, professionals wishing to 'protect' patients<sup>46</sup> and researchers worrying about upsetting patients.<sup>47,48</sup> In addition, there may be a shorter window in which to obtain the views of palliative care patients before they die. However, research shows that palliative care patients are able to take part in research,<sup>49</sup> and potentially benefit from doing so, in terms of gaining a sense of contributing to society, benefiting others, and having an opportunity to discuss experiences.<sup>50,51</sup> Relatively recently, in a move away from proxy feedback, studies have begun to ask patients about their beliefs and experiences regarding palliative care.<sup>52</sup>

In terms of quantitative reviews of the literature on experiences of palliative care, El-Jawahri et al.<sup>53</sup> reviewed 22 randomised control trials of palliative care interventions aimed at increasing the quality of patients' end-of-life. Interventions were found to generally improve quality of life, however data was said to be lacking regarding patients' psychological outcomes. A large proportion of these studies explored families' experiences rather than patients.

With regards to reviews of qualitative literature on experiences of palliative care, previous reviews have focused on literature only pertaining to specific aspects of patient experience rather than the overall experience of being cared for in palliative services. For example, Edwards et al.<sup>54</sup> conducted a meta-study and Sinclair et al.<sup>55</sup> conducted a thematic descriptive review of spiritual needs in palliative care. Furthermore, Murray et al.<sup>56</sup> conducted a meta-synthesis of literature relating to patients' communication needs. Boston et al.<sup>39</sup> reviewed literature relating to patients' existential suffering at the end-of-life, as did Krikorian, Limonero, and Mate.<sup>57</sup> Several reviews<sup>39,54, 55,57</sup> did not provide details of inclusion criteria or reviewed literature. In addition, such papers reviewed commentary and reflective pieces rather than empirical studies.<sup>39,55,57</sup>

Where reviews of experiences in palliative care have been systematic in nature they have focused on specific service types, such as day centres<sup>58</sup> and acute hospitals.<sup>41</sup> Furthermore, these reviews have included the views of families and professionals, rather than solely patients and they have not distinguished between the views of these groups in findings. For example, of the 34 studies included in an integrative review of quantitative and qualitative studies by Robinson et al.<sup>41</sup> only 14 included patients' views. Bradley et al.<sup>58</sup> also included the views of families and professionals in a thematic synthesis of literature.

### **The current review**

It is possible that the reviews discussed contribute towards an understanding of patients' experiences in palliative services however they also have limitations. Previous reviews have often included the views of families and professionals rather than those of patients.<sup>41,58</sup> In addition, individual studies and reviews have focused on palliative care in particular locations,<sup>41,58</sup> type of service received, a diagnostic specific service, or have drawn out themes related to a particular domain of well-being, for example

spirituality,<sup>54,55</sup> existential suffering,<sup>39,57</sup> or communication needs.<sup>56</sup> This review aims to synthesise data on which aspects of care patients value and what enhances their feelings of being cared for well. Furthermore, the review will help to identify key implications for palliative care services in meeting the needs of patients and enhancing their well-being. Aside from the well documented physical aspects of care,<sup>59</sup> the relational aspects, such as interactions and relationships with professionals and other patients, and how patients feel this impacts upon their psychological well-being has yet to be fully explored.

In recent years a growing body of qualitative research has emerged examining patients' first-hand experiences of palliative care that would benefit from a qualitative meta-synthesis approach. To date no reviews have been identified that produced a meta-synthesis of the themes reported in individual qualitative studies regarding the literature relating to what patients value in palliative care and how this enhances their experience of feeling cared for.

This review aimed to answer the following research questions: "What do palliative care patients value in their care?" and "What enhances palliative care patients' experience of feeling cared for?" A meta-synthesis of existing studies would allow a deeper understanding of the needs and wishes of patients that have been identified in the qualitative literature thus far permitting the development of new insights, which would help to develop future clinical practice and policy.

## **Method**

### *Search strategy*

To define the research question, inclusion and exclusion criteria, and appropriate search strategy a Context, How, Issues, and Population (CHIP) analysis was used<sup>60</sup> (See Appendix 1-B), as well as a mind map of related words and synonyms<sup>61</sup> (See Appendix 1-C).



A systematic search of literature was conducted in five major publication databases of relevance to the research question. These databases were considered pertinent as they comprised peer-reviewed international research in the areas of science, medicine, mental health, nursing, and allied health professions, and as such would include research in palliative care across multiple health related disciplines. The databases and their years of coverage were as follows: Academic Search Complete (1961-2015), The Allied and Complementary Medicine Database (AMED) (1995-2015), Cumulative Index to Nursing and Allied Health (CINAHL) (1937-2015), MEDLINE (1906-2015), and PsycINFO (1887- 2015). Searches were conducted from each database's earliest date of coverage, up to, and including the date of the final search, which was 19.02.15.

Terms were used to identify papers relating to patients, in palliative care settings, and that used qualitative methodology. Terms were searched for in any field within the record. Boolean operators such as 'OR' and 'AND' were used when appropriate, as were wildcard asterisks (\*). The literature search was limited to peer-reviewed articles published in the English language.

The searches used a combination of subject heading and free text searching in order to ensure a comprehensive literature search, details of which are displayed in Table 1. The inclusion and exclusion criteria for the review are illustrated in Table 2.

Table 1. Description of database search strategies

<b>Academic Search Complete</b>	
(DE "Patients") OR (DE "Clients")	AND
(DE "HOSPICE care") OR (DE "PALLIATIVE treatment" ) OR (DE "TERMINAL care" OR DE "TERMINALLY ill" )	AND
(DE "Qualitative Research") OR ( interview* OR "focus group*" OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR interpret* OR perspective )	
= 75	
<b>MEDLINE</b>	
(MH "Patients")	AND
(MH "Hospices") OR (MH "Terminal Care") OR (MH "Hospice and Palliative Care Nursing") OR (MH "Palliative Medicine") OR (MH "Palliative Care")	AND
(MH "Qualitative Research") OR ( interview* OR "focus group*" OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR interpret* OR perspective )	
= 291	
<b>CINAHL</b>	
( "Terminally Ill Patients" OR DE "Hospice" OR DE "Palliative Care" )	AND
((interview* OR "focus group*" OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR interpret* OR perspective) OR (DE "Qualitative Research"))	AND
((DE "Patients") OR (DE "Clients"))	
= 57	
<b>AMED</b>	
(DE "PATIENTS")	AND
((DE "TERMINAL CARE") OR (DE "TERMINAL ILLNESS") OR (DE "HOSPICE CARE") OR (DE "HOSPICES") OR (DE "PALLIATIVE CARE") OR (DE "PALLIATIVE TREATMENT"))	AND
((INTERVIEW* OR "FOCUS GROUP*" OR "GROUNDED THEORY" OR NARRATIVE OR THEMATIC OR EXPERIENC* OR "CONTENT ANALYSIS" OR ETHNOLOG* OR INTERPRET* OR PERSPECTIVE) OR (DE "QUALITATIVE RESEARCH"))	
= 3	
<b>PsychInfo</b>	
(DE "Patients") OR (DE "Clients")	AND
"Terminally Ill Patients" OR DE "Hospice" OR DE "Palliative Care"	AND
((interview* OR "focus group*" OR "grounded theory" OR narrative OR thematic OR experienc* OR "content analysis" OR ethnolog* OR interpret* OR perspective) OR (DE "Qualitative Research"))	
= 184	
<b>Total = 610</b>	

Table 2. Inclusion and exclusion criteria of studies

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Patients' accounts of palliative care	Relatives' or professionals' accounts of palliative care
Made specific reference to issues related to the value of care to patients within the findings	Did not make reference to issues related to the value of care to patients within the findings
Used qualitative methods of analysis	Used quantitative analysis only
	Used case studies only
Patients experiencing terminal illness	
Adult (18 years & above) participants	

The abstracts and titles of all identified papers were reviewed. To be included in the review, articles required a research aim or a significant proportion of the findings to focus on the current review's objectives and contain reported themes that were extractable. Where it was not clear whether a paper was suitable for inclusion, the full text was read and the inclusion and exclusion criteria applied. Additional studies were also identified via reference lists of included papers and by checking papers' citations since publication. The process of searching for and identifying papers in detail is illustrated in Figure 1.

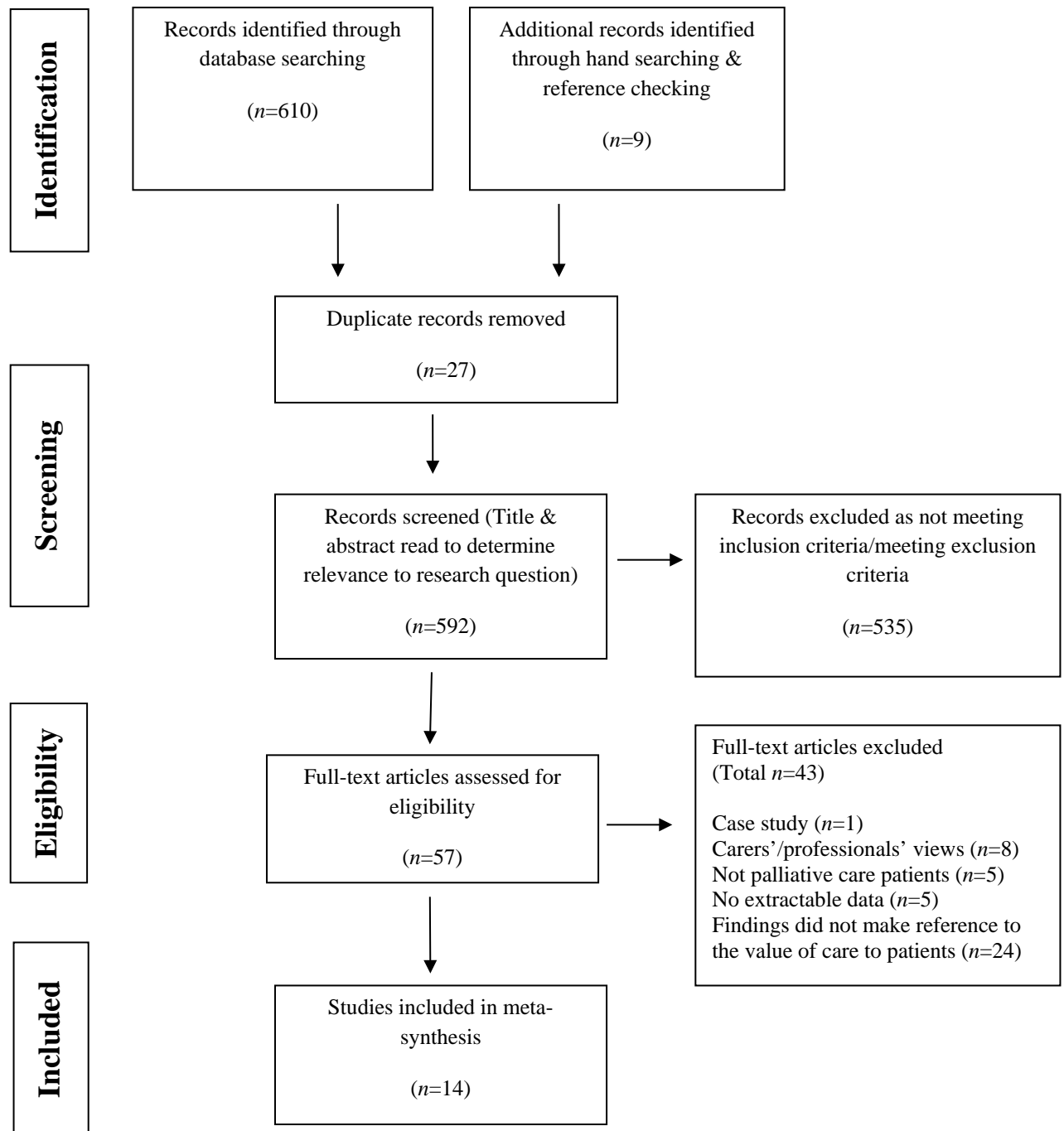


Figure 1. Flowchart of paper selection based on Moher et al's.<sup>62</sup> four phase flow diagram

*Search results*

A total of 14 papers were identified following the process illustrated in Figure 1. A summary of the main characteristics of the reviewed papers can be found in Table 3. Papers are presented in alphabetical order and numbered for ease of reference in the text.

*General study characteristics*

To gain an overview of the included papers the following details were extracted: publication date, country of study, participant information, setting, research aims, method of data collection, and method of data analysis. Data details can be found in Table 3. Papers were published between 2000 and 2014. Eight studies recruited European participants (seven in UK & one in Sweden), whilst three used American, two used Canadian, and one used a sample in New Zealand. Sample size ranged from six to 60.

All but two studies used one-to-one interviews with participants. S10 used a facilitated group discussion exercise to collect data, whilst S7 used a focus group. Studies used the following data analysis methods: content analysis (S1, S4, & S13), variants of phenomenological analyses (S7, S9, S11, & S14), a combination of qualitative approaches (S3 & S12), interpretative phenomenological analysis (IPA) (S2), and thematic analysis (S5, S6, S8, & S10). Single studies often took place across a combination of palliative care settings such as inpatient and outpatient hospices and hospitals, care homes, and patients' homes.

Table 3. Summary of main characteristics of studies included in review.

Study code	Paper	Country	Participants	Setting	Method of data collection	Method of data analysis	Research aims
S1	Bolmsjo, 2000 <sup>63</sup>	Sweden	n=10	Hospital ward & cancer rehabilitation centre	Interview	Content analysis	Clarify existential concerns & how patients want them to be managed
S2	Bradley, Frizelle, & Johnson, 2010 <sup>64</sup>	UK	n=11	Specialist palliative day care	Interview	IPA	Explore patients' experiences of attending service
S3	Chapple, Ziebland, & McPherson, 2006 <sup>43</sup>	UK	n=25	Community & hospice palliative care	Interview	Qualitative interpretive approach, combining thematic analysis with modified grounded theory & constant comparison	Examine patients' perceptions of the work of specialist palliative care nurses
S4	Cohen & Leis, 2002 <sup>65</sup>	Canada	n=60	Hospice & care home palliative care	Interview	Systematic content analysis	Explore the quality of life of patients
S5	Conner, Allport, Dixon, & Somerville, 2008 <sup>66</sup>	UK	n=10	Palliative care in hospital & at home	Interview	Thematic content analysis	Gain patients' views of their care
S6	Dzul-Church, Cimino, Adler, Wong, & Anderson, 2010 <sup>67</sup>	North America	n=20	Public hospital	Interview	Thematic analysis	Explore inpatients' perspectives on improving end-of-life care
S7	Fincham, Copp, Caldwell, Jones, & Tookman, 2005 <sup>68</sup>	UK	n=8	Hospice day unit	Focus group	Huberman & Miles' qualitative analysis framework	Explore how patients experience supportive care

S8	Gourdji, McVey, & Purden, 2009 <sup>69</sup>	Canada	n=10	Palliative care unit of a hospital	Interview	Thematic analysis	Explore the meaning of quality of life in a caring environment
S9	Hayle, Coventry, Gomm, & Caress, 2013 <sup>70</sup>	UK	n=8	Specialist palliative care	Interview	Van Manen's hermeneutic phenomenology	Gain experiences of patients accessing specialist palliative care
S10	Kennet & Payne, 2005 <sup>71</sup>	UK	n=34	Palliative care day centre	Facilitated group discussion	Thematic analysis	Explore patients' experience of palliative day care
S11	McKinlay, 2001 <sup>72</sup>	New Zealand	n=6	Inpatient palliative care	Interview	Van Manen's hermeneutic-philosophical phenomenology	Explore the care experiences of patients
S12	Nebel Pederson & Emmers-Sommer, 2012 <sup>42</sup>	North America	n=10	Hospice care at home	Interview	Interpretative content analysis using a constant comparison analysis	Explore patients' perceptions of holistic hospice care
S13	Noh, 2014 <sup>73</sup>	North America	n=28	Hospice	Interview	Content analysis	Explore patients' experiences of hospice care
S14	Richardson, 2002 <sup>74</sup>	UK	n=12	Community palliative care	Interview	Hycner's phenomenological analysis	Identify patients' perceptions of factors that promote well-being in interactions with staff

*Assessment of quality*

Papers were critiqued using the Critical Appraisal Skills Programme tool (CASP).<sup>75</sup> The tool was used to evaluate the quality of the reporting of research and identify potential methodological flaws, however this was not used to determine the papers' inclusion in the review. It has been suggested that papers should not be rejected from inclusion in reviews because of their quality.<sup>76</sup>

A score was calculated based on the fulfilment of CASP criteria. A scoring system was used to rate papers, as has previously been conducted in health based meta-syntheses.<sup>77</sup> A score of three was given for totally meeting a criterion, two for partially meeting it, one for not meeting it at all, and zero where the criterion was not applicable. The minimum and maximum scores attainable were 10 and 30 respectively. Studies' scores ranged from 20 (S1) to 28 (S14). A summary of the papers' CASP scores can be found in Table 4, whilst full details of the CASP criteria and papers' scores can be found in Appendix 1-D.

Some studies were confounded by potentially poor methodology, or simply poor reporting of processes. Typical omissions included failing to adequately discuss the credibility of findings, for example the use of triangulation and respondent validation. Others included a lack of in-depth description of data analysis meaning that the rigour of this was not clear or replicable. Strengths of the reviewed studies, included clear statements regarding aims of the research, appropriate use of qualitative methodology for research objectives, and explicit statements of findings.

A total of five studies scored 25 or above on the checklist (S2, S4, S8, S10, & S14). These studies generally achieved higher scores on areas including, detail given in the justification of research design and data collection methods, and discussion of the relationship between the researcher and participants compared to the other studies.



Table 4. Summary table of the quality assessment of studies, using the CASP

Study code	Study	Total score (out of maximum of 30)	Attained % of available score
S1	Bolmsjo, 2000	20	66.67%
S2	Bradley et al. 2010	25	83.33%
S3	Chapple et al. 2006	24	80%
S4	Cohen & Leis, 2002	26	86.67%
S5	Conner et al. 2008	23	76.67%
S6	Dzul-Church et al. 2010	23	76.67%
S7	Fincham et al. 2005	23	76.67%
S8	Gourdji et al. 2009	27	90%
S9	Hayle et al. 2013	24	80%
S10	Kennet & Payne, 2005	25	83.33%
S11	McKinlay, 2001	23	76.67%
S12	Nebel Pederson & Emmers-Sommer, 2012	24	80%
S13	Noh, 2014	23	76.67%
S14	Richardson, 2002	28	93.33%

*Synthesis method*

The meta-synthesis of the reviewed studies followed the meta-ethnography method of Noblit and Hare,<sup>78</sup> as adapted for health research by Britten et al.<sup>79</sup> and Atkins et al.<sup>80</sup> The steps of this method are outlined in Table 5.

Table 5. Meta-ethnography method.

Seven steps of Noblit and Hare's <sup>78</sup> meta-ethnography
1. Getting started- CHIP scoping exercise completed to decide upon area of topic.
2. Deciding what is relevant to the initial interest- Search strategy was developed & relevant papers identified.
3. Reading the studies- Each of the included papers was read & re-read in order to become as familiar as possible with the research.
4. Determining how the studies are related- Themes & related supporting details deemed relevant to the research question, such as participant quotes (first order constructs) & author interpretations (second order constructs) were extracted into a table.
5. Translating the studies into one another- Data were compared & contrasted, in order to discover how they were related & to create groups of data.
6. Synthesising the translations- These categories were then integrated, merged, & collapsed into one another to create third order constructs & new interpretations of the data.
7. Expressing the synthesis- A line of argument synthesis was developed in order to determine how data were related to one another & to build up an overarching representation of patients' experiences.

A table detailing extracted themes and supporting details, such as participant quotes (first order constructs) and author interpretations (second order constructs) can be found, along with the resulting final meta-synthesis themes in Appendix 1-E. Figure 2 represents how the final meta-synthesis themes are related. An original theme diagram candidate map can be found in Appendix 1-F.

**Findings**

Five over-arching themes were identified reflecting the value patients experience in the palliative care they receive and what enhances their experiences of feeling cared for. This comprised of: The Holistic Nature of Care, Being With People Who Have a Shared Understanding, Talking and Being Listened to, Oscillating Between Living and Dying, and Psychological Well-being. These areas are all important parts of palliative care that patients value. The themes are illustrated in Figure 2.

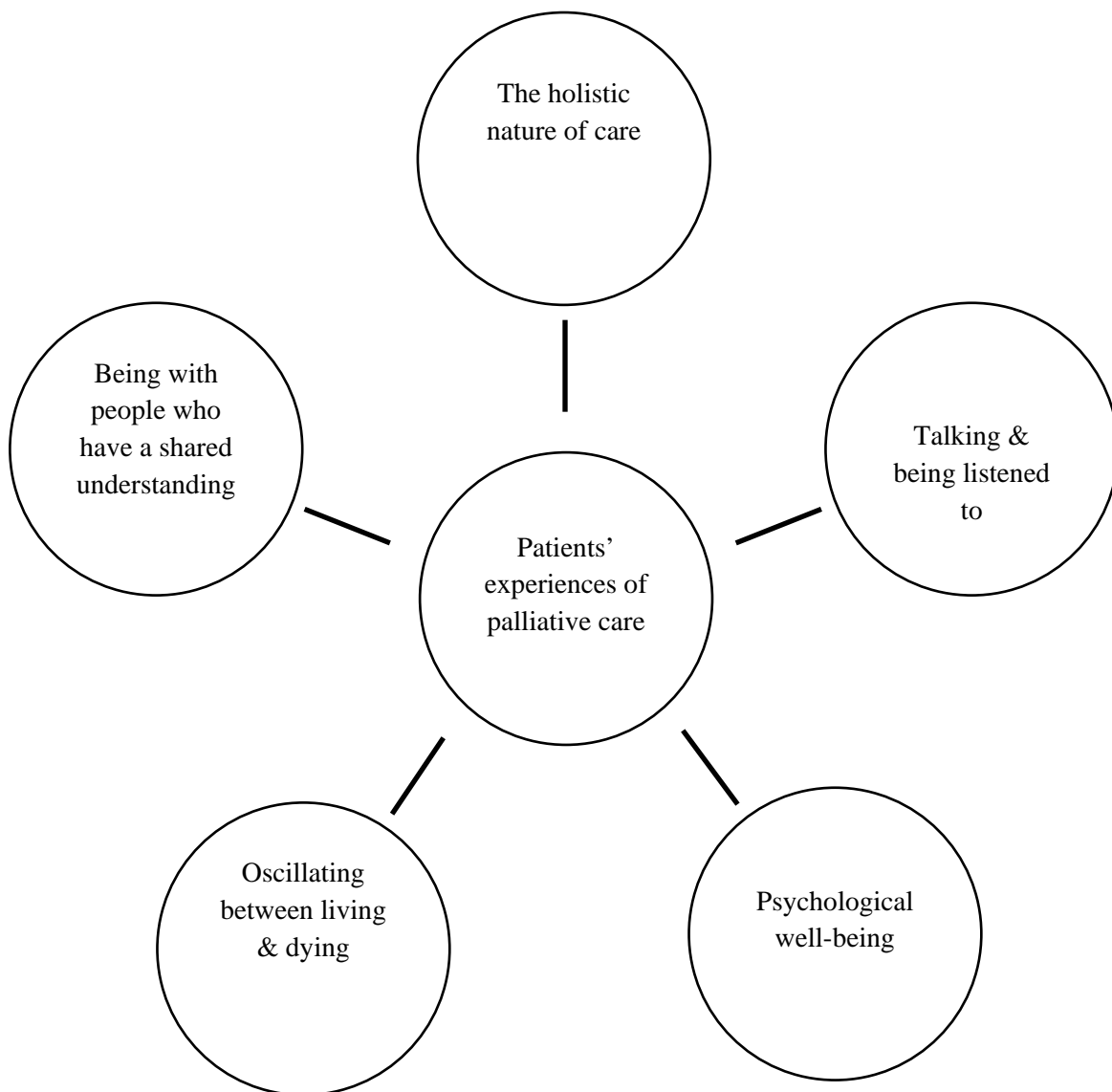


Figure 2. Thematic diagram

*The holistic nature of care*

This theme captured a sense that patients felt their palliative care service could help them with anything and everything, offering a comprehensive wraparound service. This theme exemplified how palliative care encompassed many aspects including physical, psychosocial, and spiritual care.

A total of nine studies' findings (S2, S4, S5, S7, S8, S9, S10, S11, & S14) contributed to this theme.

The majority of patients felt reassured that all aspects of this care were coordinated by the palliative care service professionals. However, for some patients this was not the case and they felt disappointment, a sense of uncertainty, and as if they had missed out on care. Patients in S5 valued having a named contact within their palliative services and a sense that a professional was coordinating their care.

An important matter to patients was access to medical care and alleviation of physical symptoms when required. Patients implied that they felt safe, secure, and cared for well within services with experienced and knowledgeable professionals to keep an eye on them. A minority felt that this was not always the case and as a result felt let down and vulnerable. It seemed that palliative care gave the patients an opportunity to focus on themselves by relieving them of their usual routines or duties, and by tending to their needs and wishes, as illustrated by the following, "I'm forced to think about myself and only myself and not 10,000 other things around. And I'm helped by professionals who know how to help me to help myself". (S8).

Patients compared palliative care services with other healthcare they or their loved ones had previously received and thought of it as much better quality and special. Patients gave a sense of palliative care services as compassionate, referred to the specialness of the atmosphere, the care shown by professionals, and of a general feeling of positivity within

services despite the nature of palliative care and the deaths of patients. A quote from S11 sums this up:

The atmosphere, the whole thing... I've had in my lifetime various friends in hospital, in and out, and ah long spells too. But oh, but I am enormously impressed. As I say there's obviously a lot of deaths. It could be a very sad place but it isn't. They create an as happy as can be situation, ah, and the compassion is clear and evident all the time. (S11).

### *Being with people who have a shared understanding*

This theme illustrated how patients valued being with people, including palliative care professionals that cared about them, and other patients who they felt had a shared understanding of illness and receiving care. A total of 13 studies' findings (S1, S2, S4, S5, S6, S7, S8, S9, S10, S11, S12, S13, & S14) contributed to this theme overall. The theme is divided into two sub-themes: staff and volunteers, and fellow patients.

*Sub-theme: Staff and volunteers.* A total of 12 studies' findings (S1, S2, S4, S5, S6, S7, S8, S9, S10, S11, S12, & S13) contributed to this sub-theme.

Patients described both paid staff and volunteers using terms such as "genuine", "dedicated", and "compassionate". As shown by this quote from S2: "The benefits of human nature I feel here, they're such nice people in here . . . makes you feel quite warm inside just thinking about it".

There was a sense that the people working in palliative care services were especially caring, more so than other healthcare professionals that the patients had encountered. This did not seem to be a slur on other healthcare staff, rather that palliative care staff were extra special. As shown in S11: "I found the people that work there, dear, were not just the

ordinary brand of nursing people. I'd call it a vision. After that, it's the attitude of the staff, everybody from the cleaner on, they're all caring".

Staff were usually believed to be doing the best they could for patients and regularly going above and beyond their duty:

I said to the woman that's generally in charge one day, I said 'if I wanted to go up Mount Everest in me wheelchair, would you push me?' and she said 'of course!' And I think they would! I think, I don't think that there's anything that they wouldn't do. (S9).

The relationships and interactions patients described having with staff felt reciprocal and more than just functional. Patients described personal interactions with professionals and saw them as more than just professionals. Patients felt that the staff were their friends and even described loving the staff. In the main, staff were described in terms of their human qualities rather than their professional functions.

Patients gave a sense of feeling that they were important, like they were the staff's only patient, and that they were known as individuals rather than patients: "They sit and listen to you and ask you questions... It makes you feel as though they're taking notice of you. You're not a number, you know you're not a, you're a person". (S9).

This was true for the majority of patients, however some groups felt that this was not the case and at times did not feel cared for, valued, or respected. The experiences of these patients are summed up by the following quotes: "I wish to be regarded and treated like a person, not like a patient" (S1), and, "In the hospital you seem to get lost in the numbers". (S5).

*Sub-theme: Fellow patients.* The sub-theme fellow patients, captured the impact of being with others having a similar experience to yourself in palliative care. A total of nine studies' findings (S2, S4, S6, S7, S8, S9, S10, S11, & S13) contributed to this sub-theme.

Patients spoke about the benefits of the social side of palliative care and of being with other patients. Patients referred to meeting others with shared experiences and understanding, whom they sought support from. Patients also spoke of doing things together and of having company, as shown below:

I watch the telly and have a read of the newspaper, and have a laugh with the lads. I say 'lads!' The other week I did a bit of modelling, which I haven't done for years, clay modelling I mean! And just sit and chat and that and what have you, you know, in general. (S9).

Patients felt that seeing others worse than themselves put their own illness into perspective:

Yeah, I mean it's never easy is it to cope with an illness? Ermm but I think because of coming here you do see other people who are much worse than yourself and that helps you...that helps them to realise you know, oh my, what have I got to worry about? You know... I'm not half as badly off as they are. (S2).

Patients described a sense of belonging that they felt within their palliative care services, which was contributed to by the staff, volunteers, and other patients. Some spoke about this feeling akin to membership of a club: "I really enjoy being with the other patients. It's like being a member of an exclusive club, nobody wants to be members but there is this bonding between patients...I don't think anybody else can experience". (S10).



For others it felt that they were part of a family or group of friends that clearly cared for each other: “I belong to the family...because of the people who are taking care, first from the volunteers, nurses, people all around, especially the doctors”. (S8).

Patients also gave a sense of being part of a team that were working together with a shared goal in mind: “It’s like a team effort. If you’re a team and they’re all together working with the patient itself, it’s going to work out really good”. (S6).

### *Talking and being listened to*

This theme illustrated patients’ feelings about having a palliative care professional talk and listen to them. The majority of the studies’ findings (S1, S3, S4, S5, S6, S7, S9, S10, S11, S12, S13, & S14) contributed to this theme.

Some patients wanted to talk about their feelings with regards to their situation but felt that the opportunity was not available to them, whilst others had been offered the opportunity to do so but had not felt ready to broach some topics yet. A portion of patients appeared reluctant to talk, feeling that emotional support was not required and that their difficulties were purely physical.

Some patients felt that illness and death was a taboo subject, even amongst professionals and other patients:

I went over to the cancer clinic and I was sitting there, getting the treatments. And there’s a chap and he looks straight in your eyes and you look into his eyes, and you know and he knows and yet you don’t talk about it. You know what you’re thinking and he knows what you’re thinking and you just look at one another and you just go. (S7).

Others simply felt that they did not have anything they wanted or needed to talk about: "I have things to say, but I don't say them...Some things are left better unsaid". (S12).

A proportion of patients made reference to having been able to talk to professionals' about their emotions and to the positive impact of this. This included a sense of feeling that they were cared about, being brought out of themselves, sharing their feelings, being listened to, and improved mood. For some it seemed that professionals offered an opportunity to talk about issues they felt they could not at home: "When I come here, I can be myself. Be ill if I want to be and I can actually express how I feel if I have a bad day. I don't like upsetting my family and friends so I keep it to myself". (S10). It also gave patients the sense of being heard:

I can say things to my Macmillan nurse and they understand and I can voice my feelings, and vent my feelings about this and there aren't any recriminations and I've been heard and I've listened to and that's the support you know, I've found it really, really helpful. (S3).

Some patients did want emotional support but felt that it was unavailable, that professionals did not have the time to talk, and that care focused on physical symptoms only. Patients that had spent time talking to professionals valued that they had taken the time to learn about their personal stories and treat them as individuals, rather than just another patient: "You know, good nurses, and doctors ...they sit and listen to you and ask you questions". (S9).

Two of the reviewed studies (S1 & S6) also made reference to participants enjoying the research interviews and wishing professionals would talk to them like the interviewer had.

*Oscillating between living and dying*

This theme represented the sense of patients oscillating between perceiving themselves as living and dying during their use of palliative care services at various points. All of the studies contributed towards this theme.

Patients spoke about their initial thoughts regarding accessing palliative care, generally hospice care. Often there was an association between the service and death which was accompanied by feelings of fear and anxiety. Patients spoke about a process of accepting that they required this type of support and of recognising that the service is not just a place to die:

If that's what you've grown up with, 'Oh she's gone in [hospice], she's about to die'. If you've grown up with that, it's there, it's in your head. So you have to educate people that that's not all they're there for. (S9).

Patients also referred to doing the things they would normally do as far as was possible as a way to stay connected to life. Alternatively, patients gave the impression of whiling away time just waiting to die within palliative care, of not knowing how palliative care could help them as the end result would be death anyway, and a perception that they were currently dying rather than living.

For some they seemed to have accepted the inevitability of their death and no chance of a cure but felt that palliative care could go some way towards soothing their suffering:

Well it's there to help you...to improve the quality of life. Well, that's what I hope it can do, you know, because I haven't got much quality of life now... if they can make the last bit more comfortable, then it would be good. (S11).

In addition to this will to live life there was an acceptance of illness and eventual death that was sometimes experienced as a positive and an enabler to continue living. At other times it seemed as though this acceptance of illness and death had halted people's living and they had transformed into a state of dying, as shown here: "There's not much needed really. I'm not trying to be cured. So there's not much he [Dr] can do for me". (S12).

In terms of living, some patients spoke about having an improved quality of life and forgetting about their health for a while. Other patients spoke about participating in outings and activities with staff and fellow patients. It seemed that this provided a focus on life as opposed to death:

It is a different life, isn't it? I mean, it gives you that life. You don't realise until you've mixed with those people, you imagine it's just a dead end. What I enjoy, here now, we're doing six weeks of drama which I've never done before and I didn't know you could have so much laughs. I never knowed I'd enjoy it so much. We laughed every day you know. (S10).

Patients also spoke about a sense of achievement and pride in participating in creative activities where they learnt and made things, often for others. Some participants specifically made reference to taking part in the studies' interviews as a way to do this. This making and doing for others was an important concept for patients who wanted to be useful, be able to give something back to people who helped them, and to give rather than just receive help:

It makes your life good. To try your best to help other people...it's very good to have the feeling that you're able to help the others...even if I am now tired and sick and stuff, I feel very happy if I can help somebody else. (S8).

*Psychological Well-being*

The final theme refers to the improvements in psychological well-being that patients associated with attending palliative care services. A total of five studies' findings (S2, S5, S9, S10, & S14) contributed to this theme.

Patients referred to feeling they had gained numerous benefits in terms of what could be referred to as their psychological well-being. These included an enhanced sense of self, improved mood and confidence, improved feelings of independence, reduced fear, feeling psychologically enabled and at ease, increased understanding and acceptance of their illness, and better coping.

Patients had felt that their diagnoses and referral to palliative care services signalled an end to their life and the quality of their life, and as such experienced many difficult emotions. For example, "I thought it was the end of everything ... then she [nurse] came and suddenly I've become more confident now". (S5).

Although patients' diagnoses still stood and they were aware of the palliative nature of the care they received, it seemed that patients felt invigorated by the care they received and more confident with the time they had left, "They've just given me a bit more confidence in myself". (S9).

Patients often felt that prior to their engagement with palliative care services their well-being and associated quality of life was poorer. More often than not, patients associated these improvements with their engagement in palliative care services, as exemplified by the following quote: "My mood, I would say, wasn't very good. It isn't easy to look out of the window and feel happy about it. Since I came here, my life has changed for the better". (S10). For some, this engagement and change had made a vast difference to their life: "I think it saved my life coming here. I was really getting into a spiral of anger and irritation and, I suppose, depression." (S7).

## Discussion

This review aimed to synthesise qualitative data regarding the needs of palliative care patients and answer the following questions: “What do palliative care patients value in their care?” and “What enhances patients’ experience of feeling cared for?” The meta-synthesis of data from 14 relevant studies revealed five over-arching themes: The Holistic Nature of Care, Being with People who Have a Shared Understanding, Talking and Being Listened to, Oscillating Between Living and Dying, and Psychological Well-being. The findings contribute to the understanding of patients’ perceptions of palliative care services.

The quality of palliative care received can have a profound impact upon people’s lives.<sup>3</sup> Despite this, relatively little is known about how palliative care is experienced by patients and how it helps them. Ultimately, the findings of this review can help services to understand how best to support patients, focus training for professionals, and develop services in a way that meets patients’ wishes and needs.

Several key reviews, policies, and guidelines have been published in recent years<sup>12-16,21</sup> regarding compassion in care. The patients in the reviewed studies gave a sense of compassion in their services. Patients described professionals in terms of their human qualities, which echoes previous research.<sup>55,56</sup> An integrative review of patients’ and families’ experiences of palliative care in acute hospitals also found that patients’ interpersonal relationships with professionals were an important part of the care experience.<sup>41</sup> Furthermore, the relationships and interactions described in the current review between patients and staff felt reciprocal rather than simply functional. Ultimately, this led patients to care about staff and to feel cared for by staff. As such, it seems that focusing on these basic elements of compassionate practice in terms of staff development and service delivery could improve how patients experience care.

The review found that patients placed much value in being with people who have a shared understanding, including fellow patients. This is in keeping with a review of literature on spiritual needs in palliative care,<sup>39</sup> which found that themes of existential loneliness, the need to be with others, and a sense of connection were predominant. This resonates with the theory of existential loneliness,<sup>81</sup> that is the sense that no one else understands what it is like to be you. Furthermore, similar to the findings of this review, Yalom<sup>81</sup> suggests that being connected with others in a similar situation can help you to deal with this loneliness and fear of death. In addition, the ability to socialise, learn from fellow patients, and simply to just be with others in a similar situation can have striking effects on the well-being of patients. Previous research has suggested that communication with other palliative care patients can offer distinct support from that provided by staff.<sup>56</sup> The opportunity to make social comparisons with other patients has also been suggested as beneficial for oncology patients.<sup>82</sup> In keeping with social learning theory this opportunity enables individuals to learn about themselves through comparisons to others,<sup>83</sup> and via the modelling of other patients' actions, attitudes, and emotions.<sup>84</sup> However, whilst this aspect of care may be an intrinsic part of services such as hospices and hospitals, those who receive care in their own home or as part of a more isolated service may miss out on the benefits of being with other patients.

Patients also valued the holistic nature of palliative care. This review highlights the importance of potential patients being aware of what palliative care means, what is on offer, and from whom. This would increase the sense of wraparound care that the patients spoke of and the feeling of knowing where their various needs can be met. In keeping with this, is the significance of palliative care services<sup>39</sup> consisting of a multi-disciplinary team that is able to pool knowledge, skills, and perspectives in order to meet patients' physical, psychosocial, and spiritual needs.<sup>85</sup>

A proportion of patients in the studies reviewed wanted to talk to professionals about their difficulties but this support was unfortunately not available. Patients sometimes felt that this was because professionals did not have the time to talk. Patients that did access such support valued how professionals had taken the time to learn about their personal stories and treat them as individuals. However, some patients did not want to talk to professionals about their emotions. The implications from the theme, talking and being listened to, suggest that more should be done to ensure that patients are able to discuss concerns with professionals should they wish to. For some patients this may simply be having access to a listening ear, whilst for others this may be more structured psychological intervention. The sparse research to date in the area suggests that palliative patients often do not request intensive psychological support with a psychologist.<sup>86</sup> Instead they utilise emotional support from other staff, such as chaplains and complementary therapists. In keeping with guidelines that recommend the provision of psychological care in palliative services,<sup>7,25,87</sup> staff at various levels should be able to provide this, in addition to clinical psychologists for those with more complex needs.<sup>88-91</sup>

As well as having access to medical care and alleviation of physical symptoms, many patients felt that they gained an improvement in their psychological well-being as a result of engagement in palliative care services. The reviewed studies found that patients experienced improved sense of self, mood, confidence, acceptance of their illness, and feelings of independence, as well as reduced fear.

Finally, patients seemed to oscillate between states of living and dying. At times, patients spoke about a sense of achievement and pride when participating in activities, and at other times of sitting around waiting to die within palliative care. This is in keeping with suggestions that a loss of identity, role, and independence at the end-of-life can contribute towards a feeling of 'social death' before actual death.<sup>92</sup> Having a sense of purpose and



meaning through engagement in activities and connections with others could help to prevent this. It seems that this could contribute to an awakening experience whereby patients gain an appreciation of the life they have left and a healthy acceptance of forthcoming death.<sup>81</sup>

Bradley et al.<sup>64</sup> found that patients at specialist palliative day centres, their families, and the professionals working at such centres also felt that engagement with others and in activities at day centres benefited patients.

### *Strengths and limitations of current review*

The current meta-synthesis provides new insights and interpretations regarding the experiences of palliative care patients that had previously not been gained. Much research on patients' experiences of palliative care has focused on symptom prevalence as an indicator of quality, and large scale satisfaction surveys using limiting and closed questions.<sup>41</sup> Such data has been integrated in quantitative reviews.<sup>53</sup> However, the current review adds to the research base by focusing on qualitative data.

The current review is valuable in that it explores the experiences of patients in a range of palliative care services, rather than within particular settings as previous reviews had,<sup>58,41</sup> thereby truly reflecting the diversity of settings in which patients receive palliative care. In addition, studies sampling palliative patients with a variety of conditions deemed to be terminal, such as chronic obstructive pulmonary disease and heart disease were included, rather than only oncology studies. Again, this variety is a strength of the review in that it moves away from a focus on the needs of only oncology patients and recognises the nature of palliative care services that often cater for patients with varying illnesses rather than solely cancer.<sup>7</sup>

Contrary to this, the points regarding the inclusion of studies sampling from a range of palliative care settings and using patients with a range of conditions could be viewed as a

limitation. The varied experiences associated with particular illnesses may have an impact on the experiences of palliative care services and needs of patients. Furthermore, it is possible that the inclusion of varied settings and services within the review gives a view of care that is too generalised and not useful for particular types of services.

Another strength of the review is that it synthesised data regarding patients' experiences rather than the opinions of families and professionals. Although proxies' opinions are valuable, the current review gives a more accurate reflection of patients' experience rather than hearing about their experiences by proxy. However, given the time and resource limited nature of this research only English language and peer-reviewed studies were included, thereby possibly missing relevant literature in other languages as well as 'grey' literature.

Whilst conducting the literature search the author noticed that an inclusion criteria of much research within palliative care is that patients with a diagnosis of dementia or delirium are excluded, as are those that cannot verbally communicate. This is a criticism of both the current review and the wider research on palliative care patients' needs. Future research should endeavour to develop methods in which to enable the opinions of these patients to be gained.

Finally, critique of the included studies using the CASP<sup>75</sup> adds to the rigour of this review and identified that the quality of the included studies is of a relatively high standard. Furthermore, the systematic nature of the review and clarity of the methodology used adds to its level of rigour and credibility.

#### *Recommendations for future research*

Guidelines' suggestions<sup>3,93</sup> for future research priorities in palliative care include developing methods to determine patients' care needs, understanding what constitutes

adequate care, exploring the non-medical aspects of palliative care, and considering the care of patients with illness other than cancer. It could be argued that the current review and the body of included studies goes some way to contributing to these objectives. It is imperative that future research continues to include the opinions of patients themselves rather than only families and professionals. Furthermore, it is important that individuals' experiences and their implications are not lost in research that utilises only large-scale quantitative methodology.

As this review was not diagnosis specific it contributes towards the discovery of which core aspects of palliative care services should be provided to patients, irrespective of their diagnosis. Further research in this area would help services to focus their resources on these essential elements of care.

Given the aging population of the world and the associated increase in the need for palliative care, services may need to alter their care pathways in order to meet demand.<sup>7</sup> In countries, such as the UK, with stretched healthcare services and reduced resources,<sup>22,94</sup> research could explore the extent that such issues impact upon care, including effects on the interactional elements of care provided by staff.<sup>12,23,24</sup>

Whilst this review may highlight aspects of care that palliative patients value, further research that measures whether this is actually translated into service delivery is now required. This would help to identify areas of service delivery that could be improved or altered.

One of the themes from the review, talking and being listened to, suggests the need for research into the nature of communication between staff and patients, including what staff and patients feel comfortable talking about, who they feel should be talking about certain issues, and whether staff require further training to be able to initiate dialogue concerning

particular aspects of emotional support with patients. This would help to ensure that support is available to patients should they want it and that patients are aware of this.

An additional theme of this review highlights the improvements in psychological well-being that patients attribute to receiving palliative care. There is a relative lack of data regarding the psychological outcomes of care compared to the physical. Therefore further research could explore these potential benefits in more depth.

### *Implications for clinical practice*

Several clinical implications can be drawn from the findings of this review. The findings highlighted that being with fellow patients provided valuable benefits to patients, including a sense of belonging and shared understanding, which could not be gained elsewhere. In addition to simply being with others, patients often engaged in group activities within services. This served to enhance patients' feelings of meaning and purpose. Therefore, services could strive to provide such opportunities for all palliative care patients, particularly those that are receiving care in their own home and are more isolated.

In addition, patients described developing personal and reciprocal relationships with palliative care staff and volunteers. Patients appreciated staff that were compassionate and personable. This human element to the relationships led patients to feel cared for. As such, services could focus on staff and volunteer development and service delivery that incorporate these basic elements of compassionate practice. In doing so, it is possible that this would improve patients' experience of care.

Finally, the findings suggest that palliative care services could do more to ensure that patients are able to discuss emotional concerns with professionals when needed. This is despite global recommendations that psychological support should be an integral part of palliative care.<sup>7</sup> For the patients in the review, when this support is provided and by whom is

an important issue. It is imperative that services enable staff to develop the skills and confidence, as well as ensuring they have the time, to be able to provide emotional support to patients if and when they want it. In addition to this, staff should also receive support and supervision to increase their confidence to discuss various issues that may arise with palliative patients. This may seem an expensive addition, however it is clear from this review's findings that the availability of such emotional support goes a long way to increasing patients' sense of being cared for at the end-of-life.

### *Conclusions*

The aim of this review was to synthesise the qualitative data regarding the needs of palliative care patients and answer the following questions: "What do palliative care patients value in their care?" and "What enhances patients' experience of feeling cared for?" An extensive search of journal databases identified 14 relevant papers.

In general findings showed that patients valued the holistic nature of palliative care and felt that all aspects of their professional care would be in safe hands. Patients valued being with others who had an understanding of them, whether that be staff or fellow patients. Linked to this was being able to talk to professionals and receive emotional support at a time that was right for the patients. At various points during their palliative care experiences patients oscillated between seeing themselves as living and making the most of their remaining life, or seeing themselves as dying and simply waiting for death. Patients felt that as a result of the palliative care they received they experienced many improvements in their psychological well-being such as increased confidence, self-esteem, and acceptance.

These findings have clinical implications in terms of the development and delivery of palliative care services, as well as for the training and support of staff and volunteers.

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*Appendix I-A*

Author guidelines for the submission of manuscripts to Palliative Medicine

**1. Article types**

*Palliative Medicine* publishes original research and review articles on all aspects of palliative care.

1. Review Articles – 5,000 words. The reviews we publish are usually systematically constructed reviews, clearly following the relevant publication guidelines (such as PRISMA) for the particular review style chosen. We are happy to consider a range of review types (systematic reviews, meta- analysis, meta-ethnography, realist review for example) for publication, but they must be methodologically clear and rigorously conducted.

NB: word count excludes references, tables and figures references

**1.1 Structured abstracts**

Reviews, original articles, short reports, case reports, audits and service evaluations should be accompanied by a structured abstract. Full details are given below of the format we expect for these:

**Review Paper**

These should generally follow the structure below, with reference to relevant review reporting guidelines such as PRISMA.

**Background:** Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.

**Aim:** A clear statement of the review aim(s).

**Design:** A statement about the review strategy/methods adopted

**Data sources:** State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal

**Results:** Report the main outcomes(s) /findings of the review.

**Conclusions:** Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

## **1.2 General instructions to authors relevant to all paper types**

We wish papers published by *Palliative Medicine* to adhere to the highest publishing standards possible. We want to ensure that the key messages for our readers are explicitly articulated. We also want you to consider the following issues: authorship; multiple publications; ethical approvals; research design; and presentation of discussion.

### **Key Statements**

Palliative Medicine has a system where all papers are required to clearly state what is already known about the topic, what their paper adds, and implications for practice, theory, or policy. You are required to give these at the start of the manuscript. Please use these three specific headings (see below), with 1-3 separate bullet points for each heading. Please use clear, succinct, separate bullet points rather than complex or multiple sentences. Each bullet point should be one sentence only.

### **What is already known about the topic?**

- Short statement(s) here about state of knowledge in this area.
- You may highlight both what is known and what is not known.



- Be specific rather than broad or sweeping statements. Avoid statements such as 'Little is known about ... x or y' in favour of statements specifying exactly what is known.

**What this paper adds?**

- Short specific statement(s) here about what this paper adds.
- These should be styled in terms of outcomes where possible (This study demonstrates that x intervention has a (specific) impact on y outcome) rather than study aims or process. (This study considers whether x intervention has an impact of y outcome).
- Be as specific as possible please here. Avoid broad statements such as 'New Knowledge is added about ... ' but rather be specific about exactly what this knowledge is. So for example rather than 'We add to the knowledge base on x' we would prefer the specific such as 'x variable was found to increase the experience of y outcome (by z amount)'.
- Ensure that these statements clearly relate to the findings of the study.

**Implications for practice, theory or policy?**

- Short specific statement(s) here on the implications of this paper for practice, theory or policy. These should clearly draw from the findings of the study, without overstating their importance.
- Where possible please make these internationally relevant.

**Study discussion**

Although Palliative Medicine does not require structured discussions, we would like you to bear in mind the typical content for a structured discussion when writing your paper. This would typically be a statement of the principal findings of the study, a discussion of the

strengths and weaknesses of the study/review with reference to other studies or reviews in the area, a discussion of what is already known about this topic and what this research/review adds, and a discussion of the implications of the research/review for clinical practice, theory or methods in this area. You may wish to raise further research or review questions.

## **2. Manuscript style**

### **2.1 Journal Style**

*Palliative Medicine* conforms to the SAGE house style [Click here to review guidelines on SAGE UK House Style](#).

### **2.2 Reference Style**

*Palliative Medicine* operates a SAGE Vancouver reference style. [Click here to review the guidelines on SAGE Vancouver to ensure your manuscript conforms to this reference style](#)

### **2.3. Manuscript Preparation**

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

#### **2.3.1 Your Title, Keywords and Abstracts: Helping readers find your article online**

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's [Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online](#).

*Palliative Medicine* requires authors to list between 4 and 6 key words that are also Medical Subject Headings (MESH headings). These key words should be closely related to the papers subject, purpose, method and focus. Details of MESH headings can be found

here <http://www.nlm.nih.gov/mesh/>. If authors submit keywords that are not MESH headings *Palliative Medicine* reserves the right to submit alternative keywords.

Abstracts for Palliative Medicine should be structured and no more than 250 words. They should not include references or abbreviations. Please refer to section 2 above.

### **3. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

Debbie Ashby

Editorial Manager

[debbie.ashby@bristol.ac.uk](mailto:debbie.ashby@bristol.ac.uk)

### **SAGE UK House Style Guide**

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## 2. Article opening material

### 2.1 Headings

1. Headings should have an initial capital with everything else lowercase, unless proper names.

2. Italics can be included in A heads (H1) if needed, e.g. mathematical symbol or genus name.

3. Headings are unnumbered and formatted as below.

4. Where headings are referred to in the text use section names, as headings are not numbered.

A head (H1) (bold with initial cap, all the rest lowercase)

B head (H2) (italic with initial cap, all the rest lowercase)

C head (H3) (same as B head, but set as first line of paragraph, full out; italic with initial cap, all the rest lowercase, followed by a full stop. Following text runs on)

Headings for Abstract, Keywords, Funding, Acknowledgements, Conflict of interest (in that order), References, Appendices are same as A head but smaller font size

(CEs: where a template is being used there is no need to format these. Where no template is being used, please format as bold/italic, but there is no need to mark the font sizes, TS will format.)

## 2.2 Article types

Where a journal displays article types, these should appear on the first page of each article, left aligned above the horizontal rule, and in italics.

General technical or research papers should be classified as Original Article (with uppercase initial caps) for STM.

Other usual paper types are as follows: Review Article, Case Study, Technical Note, Case Report. Individual journals may also have other paper types, as agreed with the Editor. Where no particular convention has been agreed, Original Article should be followed for STM.

## 2.3 Article title

Please format with an initial capital only and remaining words lower case, unless proper names. Italics can be included where necessary (e.g. genus name). Run on subtitle after colon, with initial capital after colon.

## 2.5 Abstract and keywords

Abstract should appear in bold without a colon, text should start on the next line, with no indent.

Keywords (all one word) should appear in bold without a colon. The keywords should start on the next line, separated by commas only, not semi-colons. The first keyword should have an initial cap.

In some journals, Abstracts have sub-headings, e.g. Methods, Conclusion etc. These should be formatted in bold with a colon in bold and each sub-heading should start a new paragraph. The text should run on after each heading with an initial capital.

Submitted/accepted dates

For journals that publish received/revised/accepted dates (applies to specific journals, if unsure please check with the PE), this should appear after the Keywords and be formatted thus:

Date received 29 July 2010; reviewed 30 August 2010; accepted 5 November 2010

## 2.6 Running heads

Recto: should be author surname(s), e.g. Smith, or Smith and Jones, or Smith et al. (for three or more authors, and et al. is also in italic).

Verso: full journal title in italic, followed by 0(0).

For IMechE journals: e.g. J. Automobile Engineering 0(0), without the Proc. IMechE or journal letter).

## 3. General style and layout

### 3.2 Figures

1. STM: All figures should have a key line (i.e. be enclosed in a box).
2. Figures should be appropriately sized (done by the TS). They do not need to be a full column width or page width.
5. Any abbreviations needing to be spelled out should be listed after the caption, starting on the next line, in the following format: IC: internal combustion; PID: proportional–integral–derivative).
6. Captions are positioned below the figures and left aligned. 7. Captions should start, for example, Figure 1. (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but should be aligned left. 8.

Where figures have multiple parts, these should be labelled as (a), (b), (c), etc. (not A, B, C).

Captions should contain subheadings for all parts if not present in the figure itself. 9. All

figures should be numbered consecutively and cited in the text as Figure 1, Figure 2 etc.

(Figure should be spelled out in full, not abbreviated). 10. Text citations: figures should be

referenced in the text as follows: Figure 1, or Figures 1 and 2, or Figures 2 to 4, or Figure

1(a) and (b), or Figure 2(a) to (c). Where the figure citation is not part of the sentence it

should be placed in parentheses. Examples:

### 3.3 Tables

1. Tables do not need to be a full column width or page width, but should be the appropriate width for the content. They will be laid out by the TS so no work is required by CEs on table layout, only on content.

2. Table headings should be left aligned, even when they relate to multiple columns, unless this creates confusion.

3. Tables should only have minimal horizontal rules for clarity, and no vertical rules.

4. All tables should be numbered consecutively and cited in the text as Table 1, Table 2 etc. (Table should be spelled out in full, not abbreviated).

7. Any abbreviations needing to be spelled out should be listed under the table (smaller font, TS will format), in the following format: IC: internal combustion; PID: proportional–integral–derivative. 8. General notes to the Table should be positioned below the Table, typeset in a smaller font and should start ‘Note:’, and end in a full stop. Do not add the word ‘Note:’ unless needed for clarity.



9. Footnotes should be represented in the table by superscript letters a, b, c, etc., and appear below the Table (smaller font, TS will format). Each footnote should start a new line and end with a full stop. These notes should precede the source for the table, if included.

10. Captions are positioned above the table and left aligned.

11. Captions should start, for example, Table 1. (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but aligned left.

13. Normal text in columns should always be left aligned. Data in tables should be aligned on units if all the data in that column take the same units. Otherwise, the data should be left aligned. Units in table headings should be enclosed by parentheses, not square brackets (if any brackets are required at all).

### 3.6 Appendices

#### Maths notation list

1. Where present, notation should appear as Appendix 1, following the references. The heading Notation should be a B-head (not Notations; it is not plural).

2. Abbreviations list should be separated from mathematical notation under a separate B-head Abbreviations.

3. Notation should be listed in alphabetical order, English letters first, followed by Greek, followed by numbers, followed by symbols.

4. Subscripts and superscript should come under a separate C-head (italic and smaller font), and symbols should follow the same order as in point 2 above.

5. The Notation section does not need to be cited in the text, like other Appendices.

6. Notation list should be left aligned. Text in the notation section should be left aligned in general, not justified.

7. Please note that a notation list is not compulsory in mathematical papers, as long as all symbols are defined in the text.

#### Other appendices

1. Numbering of figures/tables/equations in Appendices should follow on from the numbering in the text.

2. All tables/figures should have captions.

3. All appendices should be cited in the text, e.g. (see Appendix 1). If they are not cited, authors need to be queried for a citation position.

#### 3.7 Notes and footnotes

##### Textual notes

Any other textual notes: are indicated by a superscript Arabic numeral placed after the punctuation. All textual notes should be collected and placed after the text and before the reference section with the heading Notes.

##### STM

References: Vancouver style reference citations are represented as textual notes, as a superscript Arabic numeral. Harvard style references are as follows (Smith, 1999).

Any other textual notes (whether references are Harvard or Vancouver) are indicated by a superscript Arabic letter and the corresponding footnote appears at the bottom of the relevant column.

In STM journals, footnotes should be edited into the text if appropriately and easily incorporated. However, please leave footnotes if this is not possible.

#### 4. Spelling, punctuation and formatting

##### 4.1 Author style/voice

We will endeavour to keep the author's voice as much as possible:

1. Some authors write in the first person. CEs please note that we will not be taking articles out of the first person into the third person.
2. Where American authors have used American spellings, we should also endeavour to keep the author's grammar/punctuation, e.g. closed em-dashes instead of spaced en-dashes, single quotation marks within double, series comma etc.
3. Where UK authors have used –ise spellings throughout their papers in a consistent fashion, please do not change. Where there is inconsistency, use -ize.

##### 4.2 General spelling rules

The general rules are as follows:

- UK spellings should be followed for European articles (-ise is acceptable)
- US spellings should be followed for North American articles
- Rest of the world – follow author style but make it consistent
- Canadian spellings should be standardized to UK or US, depending on author preference
- The following list shows some common exceptions to the '-ize' rule:

Samples:



6. Last Names containing de, van, von, De, Van, Von, de la, etc. should be listed under D and V respectively. List them as: De Roux DP and not Roux DP, de. When cited in the main text without the first name, use capitals for De, Van, Von, De la, etc. (Van Dijk, year)

7. Names containing Jr or II should be listed as follows:

- Author Last Name Initial Jr (year)
- Author Last Name Initial II (year)

## 2. Text citations

Please use superscript numerals after the punctuation (STM) and check that it corresponds to the correct number in the reference list.

## 3. Reference styles

### Book

1. Huff D. How to lie with statistics. 4th ed. London: Penguin, 1991, p.51.

### Chapter in book

1. Huff D and Black TL. Comprehensive statistics. In: Miller C and Smith H (eds) How to lie with statistics. 4th ed. London: Penguin, 1991, pp.51–55.

### Journal article

1. Ludbrook J, Miller T and Russel A. Musculo-venous pumps in the human lower limb. *Am Heart J* 1966; 71: 635–641.

2. Araki C, Black TL, Patberg FT, et al. Significance of calf muscle pump function in venous ulceration. *J Vasc Surg* 1994; 20: 872–879.

## Journal article published ahead of print

1. Ludbrook J. Musculo-venous pumps in the human lower limb. *Am Heart J*. Epub ahead of print 12 June 2011. DOI: 10.1177/095443271167940.

## Website

1. Smith JR. Choosing your reference style. *Online Referencing* 2(3), <http://orj.sagepub.com> (2003, accessed 12 October 2008).

2. National Center for Professional Certification. Factors affecting organizational climate and retention, [www.cwla.org./programmes/triechmann/2002fbwfiles](http://www.cwla.org./programmes/triechmann/2002fbwfiles) (2002, accessed 10 July 2010).

## Conference paper

1. Peters J. Musculo-venous pumps in the human lower limb. In: ASME conference on automatic transmissions (ed A O'Brien), Pisa, Italy, 29 May–2 June 2003, paper no. GE1234, pp.4–10. New York: ASME.

## Thesis/dissertation

1. Clark JM. Referencing style for journals. PhD Thesis, University of Leicester, UK, 2002.

## Patent and patent applications

1. Smith ST. Referencing styles for journals – a new method. Patent 12346-ZH, USA, 2011.

2. Jones P. Referencing styles for journals – a new method. Patent application 12346-ZHA, USA, 2011.

## Report (published/unpublished)

1. MacDonald S. The state of social welfare in the UK. Report, University of Durham, UK, June 2011.

2. Citigroup Ltd. How to make your money work for you. Report for the Department of Finance. Report no. 123345, 13 June 2011. Oxford: OUP.

SAE/JSAE etc. papers

1. Clark JM. A new exhaust gasket manifold for powertrains. SAE paper 2002-0101234, 2002.

Newspaper/magazine

1. Clark JM. Referencing style for journals. The Independent, 21 May 2006, p.10.

Package insert (medical etc.)

1. Eisai Inc. Aloxi (package insert). New York: Esai Inc, 2008.

Manual (automotive etc.)

1. Fiat. Driver's manual, Fiat Uno 4-litre diesel model, December 2010.

Standard

1. ISO 27799:2008. Information security management in health.

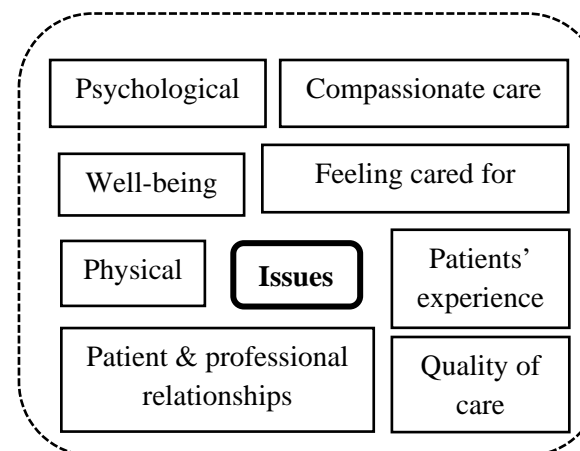
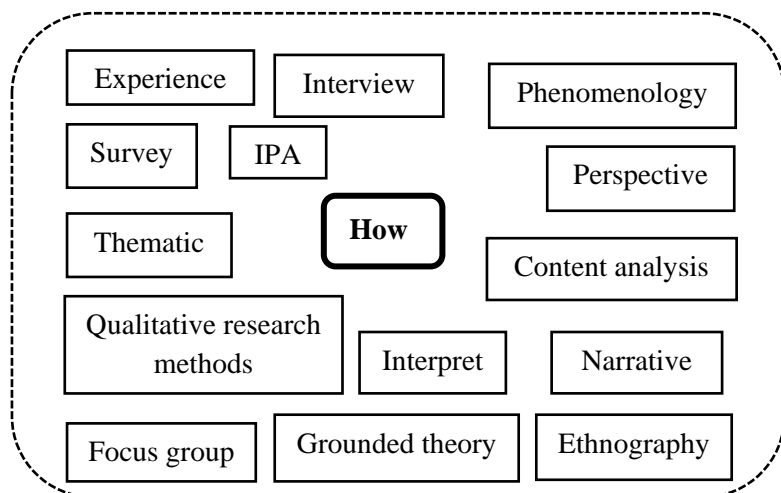
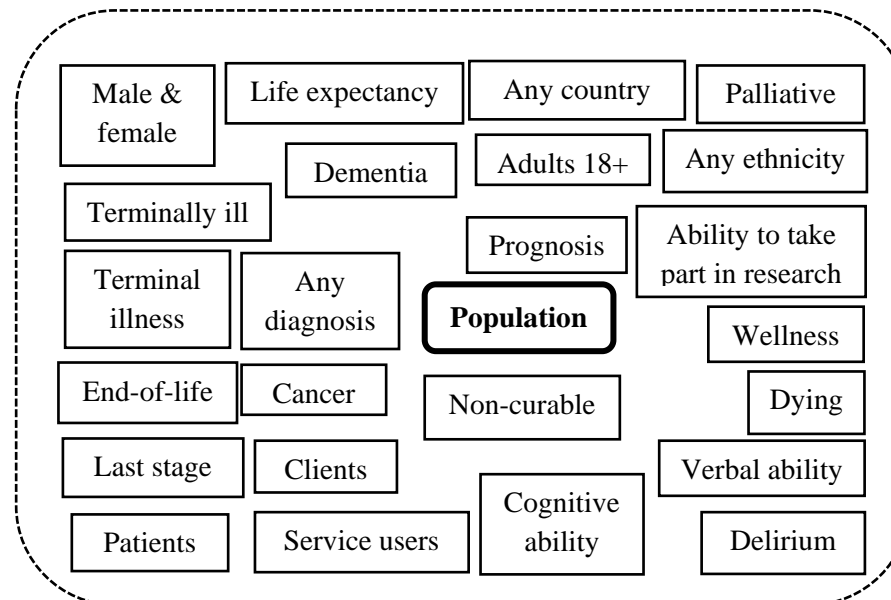
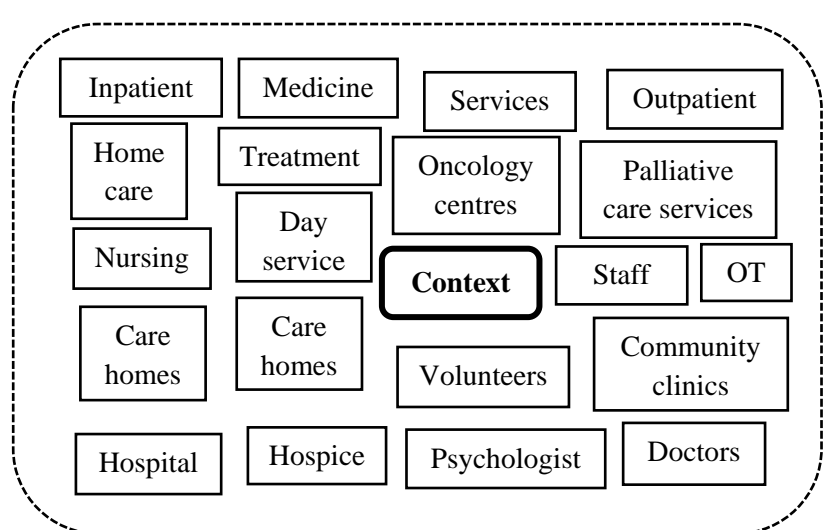
*Appendix I-B*

CHIP analysis

<b>Context</b>	<p><b>In what context are experiences of care important?</b></p> <p>Patients accessing palliative care/end-of-life care/hospice care/terminal care services</p>
<b>How</b>	<p><b>What research methods are of interest?</b></p> <p>Qualitative research methods</p>
<b>Issues</b>	<p><b>What issues related to care are important?</b></p> <p>Patients' experiences of care</p> <p>The aspects of care patients value</p> <p>The components of feeling cared for</p>
<b>Population</b>	<p><b>Which groups are of interest?</b></p> <p>Patients who are accessing palliative care services, such as hospices, hospitals, care homes, community care, oncology centres etc.</p> <p>Patients who are classed as dying, terminally ill, have less than set amount of time to live etc.</p>
	<p><b>Process led to following research questions:</b></p> <p>What do palliative care patients value in their care?</p> <p>What enhances palliative care patients' experience of feeling cared for?</p>



Appendix I-C  
CHIP mind-map



*Appendix 1–D*

## Full table of the quality assessment of studies, using the CASP

Study code	Aims	Qualitative methodology	Research design	Recruitment strategy	Data collection	Relationship between research & participants	Ethical issues	Data analysis	Findings	Value of research	Total score	Attained % of available score
S1	Bolmsjo, 2000	2	3	2	2	2	3	1	1	2	20	66.67%
S2	Bradley et al., 2010	3	3	3	2	2	2	3	3	2	25	83.33%
S3	Chapple et al., 2006	3	3	1	3	2	3	3	3	2	24	80%
S4	Cohen & Leis, 2002	2	3	3	2	3	2	3	2	3	26	86.67%
S5	Conner et al., 2008	3	3	3	2	2	2	2	3	2	23	76.67%
S6	Dzul-Church et al., 2010	3	3	1	3	2	2	2	3	3	23	76.67%
S7	Fincham et al., 2005	3	3	2	2	3	3	2	2	2	23	76.67%
S8	Gourdji et al., 2009	3	3	3	2	3	2	3	3	3	27	90%
S9	Hayle et al., 2013	3	3	1	2	2	2	3	3	3	24	80%
S10	Kennet & Payne, 2005	3	3	2	2	3	3	2	2	3	25	83.33%
S11	McKinlay, 2001	2	3	3	2	2	3	2	2	2	23	76.67%
S12	Nebel Pederson & Emmers-Sommer, 2012	3	3	3	3	3	1	2	3	2	24	80%
S13	Noh, 2014	3	3	1	3	2	3	2	3	2	23	76.67%
S14	Richardson, 2002	3	3	3	3	3	3	3	2	3	28	93.33%

Key: Fully met (3), partially met (2), not met at all (1)

*Appendix I-E*  
Final meta-synthesis table

Relevant Studies	Examples of Supporting Quotes (first order constructs)	Examples of Author Interpretations (second order constructs)	Over-arching Theme (third order constructs)
S2 Bradley et al., 2010 S4 Cohen & Leis, 2002 S5 Conner et al., 2008 S7 Fincham et al., 2005 S8 Gourjdi et al., 2009 S9 Hayle et al., 2013 S10 Kennet & Payne, 2005 S11 McKinlay, 2001 S14 Richardson, 2002	Cohen, 2002- What is important for me? ...calm, serenity, tranquillity. I cannot put up with a turbulent atmosphere. Can't put up with people coming and going all the time, no. I need a serene atmosphere. Tranquillity is very important.  Gourjdi et al., 2009- I'm forced to think about myself and only myself and not 10,000 other things around. And I'm helped by professionals who know how to help me to help myself.  McKinlay, 2001- And they just watch and see if I'm relaxing and things like that. Just a case of watching and seeing how I was and how I was feeling.	Cohen, 2002- Feeling secure/vulnerable.  Gourjdi et al., 2009- Feeling secure. Living in a caring environment.  McKinlay, 2001- The circle of care. Being safe. Being watched.	<b>The holistic nature of care</b> Help with anything & everything. Relaxed, tranquil, peaceful, spiritual therapeutic environment. Feeling safe & secure (or not). Staff to keep a watchful eye on you. Experience & knowledge of staff. Access to medical care & alleviation of physical symptoms. Staff coordinating care well (or not).
S1 Bolmsjo, 2000 S3 Chapple et al., 2006 S4 Cohen & Leis, 2002 S5 Conner et al., 2008 S6 Dzul-Church et al., 2010 S7 Fincham et al., 2005 S9 Hayle et al., 2013	Chapple et al., 2006-	Bolmsjo, 2000- Communication. Information received. Truth with tenderness.  Chapple et al., 2006-	<b>Talking and being listened to</b> Emotional support seen as 'alternative care'. Reluctance to talk. Focus on physical. Taboo subjects. Timing of talking to professionals.

<p>S10 Kennet &amp; Payne, 2005                  S11 McKinlay, 2001                  S12 Nebel Pederson &amp; Emmers-Sommer, 2012                  S13 Noh, 2014                  S14 Richardson, 2002</p>	<p>I can say things to my Macmillan nurse and they understand and I can voice my feelings, and vent my feelings about this and there aren't any recriminations and I've been heard and I've listened to and that's the support you know, I've found it really, really helpful.</p>	<p>Talking &amp; listening to people's feelings.</p>	<p>Unavailability of support.                  Patients enjoyed interviews.                  Benefitting from talking.                  Share feelings &amp; be listened to.                  Improvements in mood.                  Communication style of staff</p>
	<p>Dzul-Church, 2010-                  One participant said to the interviewer: Talk to me like you're doing. That makes me happy.</p>	<p>Dzul-Church, 2010-                  Interpersonal relationships.</p>	
	<p>Fincham et al., 2005-                  I went over to the cancer clinic and I was sitting there, getting the treatments. And there's a chap and he looks straight in your eyes and you look into his eyes, and you know and he knows and yet you don't talk about it.</p>	<p>Fincham et al., 2005-                  Wanted access to therapy.</p>	
	<p>Nebel Pederson &amp; Emmers-Sommer, 2012-                  Psychological, huh? Okay, so now this is my mind. Well, sometimes I think I'm losing my mind, but that's beside the point I guess.</p>	<p>Nebel Pederson &amp; Emmers-Sommer, 2012-                  Lack of psychological &amp; emotional needs.</p>	
<p>S1 Bolmsjo, 2000                  S2 Bradley et al., 2010                  S4 Cohen &amp; Leis, 2002</p>	<p>Bolmsjo, 2000-                  I wish to be regarded and treated like a person- not like a patient.</p>		<p><b>Being with people who understand</b>  <b>Sub-theme: Staff and volunteers</b>                  Caring qualities</p>

<p>S5 Conner et al., 2008                  S6 Dzul-Church et al., 2010                  S8 Gourjdi et al., 2009                  S9 Hayle et al., 2013                  S10 Kennet &amp; Payne, 2005                  S11 McKinlay, 2001                  S12 Nebel Pederson &amp; Emmers-Sommer, 2012                  S13 Noh, 2014                  S14 Richardson, 2002</p>	<p>McKinlay, 2001-                  I found the people that work there, dear, were not just the ordinary brand of nursing people- I'd call it a vision. After that, it's the attitude of the staff, everybody from the cleaner on, they're all caring. Everybody's caring and you only have to make a request and it's there. I think it's the people that work in the hospice that make it so, because they're all dedicated people.</p>	<p>McKinlay, 2001-                  Caring qualities.                  Recognition of patient identity.</p>	<p>Genuine, dedicated &amp; compassionate.                  Feeling cared for &amp; valued (or not).                  Feeling loved &amp; respected (or not).                  Personal interactions.                  Connections with staff.                  Human qualities.                  Going above &amp; beyond.                  Specialness &amp; difference of staff.                  Feeling important.</p>
	<p>Noh, 2014-                  They pay attention to the little tiniest thing. I knew nothing about hospice, but I can tell you this, I have never been treated so well [as I am] in hospice. I love all of 'em. I love 'em to death.</p>	<p>Noh, 2014-                  Caring &amp; friendly attitude.                  Dependability.</p>	
	<p>Richardson, 2002-                  That's the difference, the real difference – we get the feeling that they really care.</p>	<p>Richardson, 2002-                  Nurse as a person.                  Integrity.                  Caring.                  Personal interaction.                  Connecting.</p>	
<p>S2 Bradley et al., 2010                  S4 Cohen &amp; Leis, 2002                  S6 Dzul-Church et al., 2010                  S7 Fincham et al., 2005                  S8 Gourdjji et al., 2009</p>	<p>Bradley et al., 2010-                  And they're all doing in much the same sort of way or the net result is in the same way. I can't tell what's going on their minds but I mean the</p>	<p>Bradley et al., 2010-                  Belonging.                  Companionship.</p>	<p><b>Being with people who understand</b>  <b>Sub-theme: Fellow patients</b>                  Social side.                  Being with other patients.</p>

<p>S9 Hayle et al., 2013                  S10 Kennet &amp; Payne, 2005                  S11McKinlay, 2001                  S13 Noh, 2014</p>	<p>net result seems to be the same way which is good which makes you feel more ok, maybe I'm doing something right.</p>		<p>Shared experiences &amp; understanding.                  Humour.                  Doing things together                  Having company.                  Making comparisons with others.                  Sense of belonging.</p>
	<p>Hayle et al., 2013-                  Well I watch the telly and have a read of the newspaper, and have a laugh with the lads. I say 'lads'! The other week I did a bit of modelling, which I haven't done for years – clay modelling I mean! And just sit and chat and that and what have you – you know, in general. Have a laugh if you can.</p>		
	<p>Kennet &amp; Payne, 2005-                  I really enjoy being with the other patients. It's like being a member of an exclusive club, nobody wants to be members but there is this bonding between patients why I don't think anybody else can experience.</p>	<p>Kennet &amp; Payne, 2005-                  Sense of belonging.</p>	
<p>S1 Bolmsjo, 2000                  S2 Bradley et al., 2010                  S3 Chapple et al., 2006                  S4 Cohen &amp; Leis, 2002                  S5 Conner et al., 2008                  S6 Dzul-Church et al., 2010                  S7 Fincham et al., 2005                  S8 Gourjdi et al., 2009                  S9 Hayle et al., 2013                  S10 Kennet &amp; Payne, 2005</p>	<p>Fincham et al., 2005-                  Don't say I've come to terms with it, yes, but I think I've got to the stage of recognising the difference between healing and a cure. I know there's no cure, but the healing is a process that's going on right up to the last minute and I can live with that.</p>	<p>Fincham et al., 2005-                  Patients' acceptance of cancer &amp; adjustment.</p>	<p><b>Oscillating between living and dying</b>                   Remaining time.                  Living or dying in services.                  Making use of time.                  Participating in activities.                  Focus on life as opposed to death.                  Improved quality of life.                  Forgetting about their health.</p>

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<p>S11 McKinlay, 2001  S12 Nebel Pederson &amp; Emmers-Sommer, 2012  S13 Noh, 2014  S14 Richardson, 2002</p>	<p>Hayle et al., 2013-  If that's what you've grown up with, 'Oh she's gone in [name of local hospice], she's about to die'.  If you've grown up with that, it's there, it's in your head. So you have to educate people that that's not all they're there for.</p>	<p>Hayle et al., 2013-  Perceptions of specialist palliative care services.</p>	<p>Achievement &amp; pride.  Creativity.  Doing for others.  Being useful.  Staying connected to normal life.  Acceptance of illness &amp; eventual death.  Relinquishing care to others.  Sense of lost time.  Worries about what palliative care meant.  Association with palliative care &amp; death.</p>
<p>McKinlay, 2001-  You don't feel as if you're in there to die. And I hope to die there, but as I say, as far as the hospice is concerned, they've done all they can for me dear. They cant possibly do anymore. And in the environment at the hospice, what a better way to die, I don't know, dear. I hope to be there when it happens.</p>	<p>McKinlay, 2001-  Keeping control.  Relinquishment &amp; relaxation.  Awareness of mortality.</p>	<p>McKinlay, 2001-  Keeping control.  Relinquishment &amp; relaxation.  Awareness of mortality.</p>	
<p>Nebel Pederson &amp; Emmers-Sommer, 2012-  There's not much, I should say, there's not much needed really. I'm not trying to be cured. So there's not much he can do for me.</p>	<p>Nebel Pederson &amp; Emmers-Sommer, 2012-  Hospice as representative of mortality.</p>	<p>Nebel Pederson &amp; Emmers-Sommer, 2012-  Hospice as representative of mortality.</p>	
<p>Richardson, 2002-  I'm not dead yet, there's still a bit left in me.</p>	<p>Richardson, 2002-  I'm not dead yet, there's still a bit left in me.</p>		

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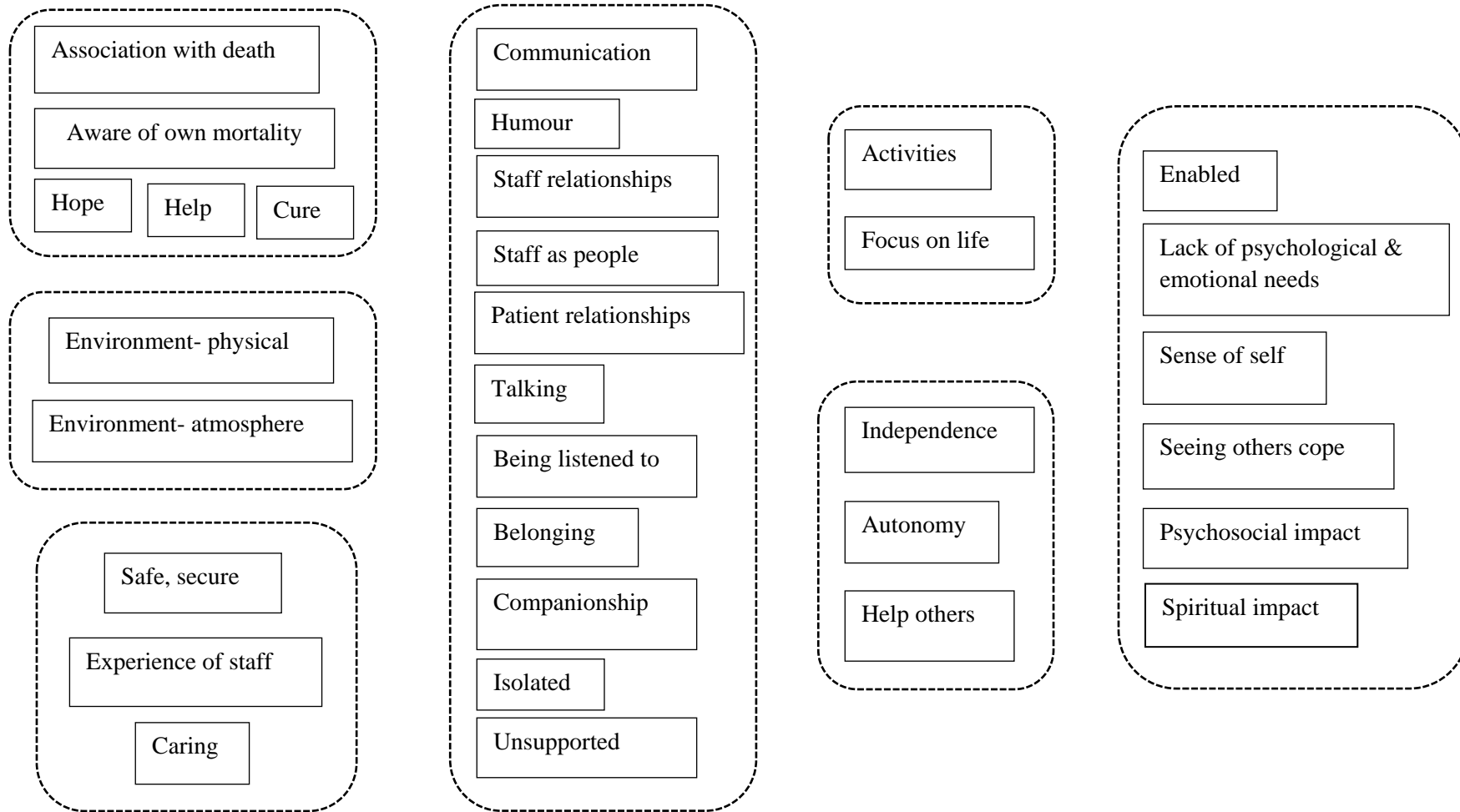
<p>S2 Bradley et al., 2010                  S5 Conner et al., 2008                  S9 Hayle et al., 2013                  S10 Kennet &amp; Payne, 2005                  S14 Richardson, 2002</p>	<p>Conner, 2008-                  I thought it was the end of everything ... then she came and suddenly I've become more confident now.</p> <p>Hayle et al, 2013-                  They've just given me a bit more confidence in myself.</p> <p>Kennet &amp; Payne, 2005-                  My mood, I would say, wasn't very good. It isn't easy to look out of the window and feel happy about it. Since I came here, my life has changed for the better.</p>	<p>Bradley et al., 2010-                  Sense of self.</p> <p>Conner, 2008-                  Independence.                  Hope/enablement/adjustment.</p> <p>Hayle et al, 2013-                  Psychosocial impact.</p> <p>Kennet &amp; Payne, 2005-                  Mood change.                  Sense of achievement.</p> <p>Richardson, 2002-                  Confident.                  Coping.                  Encouraged.                  Psychological ease.</p>	<p><b>Psychological well-being</b>                  Numerous benefits in psychological well-being.                  Enhanced sense of self.                  Improved mood.                  Improved confidence.                  Feelings of independence.                  Less fear.                  Feeling psychologically enabled &amp; at ease.                  Increased understanding &amp; acceptance of their illness.                  Better coping.</p>
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*Appendix 1-F*

Original theme diagram candidate



**Section Two: Research Paper**

Laura Cramond

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Division of Health Research, Lancaster University

**Exploring experiences of compassion and resilience in clinical psychologists working in  
palliative care**

**Word Count:**

**7,997 (excluding abstract, tables, figures, references, and appendices)**

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Prepared for *Palliative Medicine* (see Appendix 2-A)

**Abstract**

**Background:** The well-being of professionals within palliative care has serious implications for patients and families, professionals, and organisations. Levels of compassion have been found to be inconsistent in palliative care professionals. Research to date has largely excluded the exploration of compassion in clinical psychologists, despite guidelines suggesting that their roles in palliative care may have a marked effect on their physical and mental well-being.

**Aim:** This study explored the experiences of clinical psychologists working in palliative care to gain an understanding of the impact this type of work has on their compassion, resilience, and the self-care practices they use.

**Design:** Experiences were explored using one-to-one semi-structured interviews and analysed using Interpretative Phenomenological Analysis.

**Participants:** Twelve clinical psychologists working in palliative care were recruited via national special interest groups and ehospice.

**Results:** Six overarching themes were identified: Being Part of Something Special, The Therapeutic Relationship, Doing More With Less, Being Changed as a Result of Involvement, The Consummate Professional, and Practicing What you Preach. Clinical psychologists' experiences were characterised by the meaning they attributed to being part of palliative care services, the nature of the therapeutic relationship, and the lasting impact of the work on the self. The importance of self-care and the use of a range of coping strategies was identified.

**Conclusions:** Further research is required to explore clinical psychologists' experiences, particularly regarding the impact of the therapeutic relationship and organisational change on levels of compassion and resilience, and feelings of shame and stigma related to such experiences.

**Key words:** Qualitative research, palliative care, staff, self-care, resilience

**Key statements:**

**What is already known about the topic?**

- Levels of compassion have been found to be inconsistent in palliative care professionals.
- The well-being of palliative care professionals has implications for patients and families, professionals, and organisations.
- Research to date has largely excluded the exploration of compassion in clinical psychologists, despite guidelines suggesting that clinical psychologists' roles in palliative care may have a marked effect on their physical and mental well-being.

**What this paper adds?**

- Six overarching themes were identified: Being Part of Something Special, The Therapeutic Relationship, Doing More With Less, Being Changed as a Result of Involvement, The Consummate Professional, and Practicing What you Preach.
- Interviews revealed the challenges and rewards for clinical psychologists working in palliative care and how this impacts upon compassion and resilience.
- Clinical psychologists' experiences were characterised by the meaning they attributed to being part of palliative care, the nature of the therapeutic relationship, and the lasting impact of the work on the self.

**Implications for practice, theory or policy?**

- To develop training to enable clinical psychologists to prepare for working in palliative care settings and develop self-care methods.

- To create systems that enable clinical psychologists to identify, discuss, and seek support around experiences of compassion fatigue.
- To explore the specific nature of clinical psychologists' and patients' therapeutic relationships in palliative care, and how this contributes to levels of compassion and resilience.

## **Exploring experiences of compassion and resilience in clinical psychologists working in palliative care**

Palliative care as defined by the World Health Organization<sup>1</sup> is an approach aimed at improving the quality of life of patients and families facing physical, psychosocial, and spiritual difficulties associated with life-threatening illness. More people than ever now require palliative care.<sup>2-7</sup> The term patient(s) will be used in place of service users or clients as this research is focused on care within a medical setting where the term patient is traditionally used.

### **Psychological provision in palliative care**

Current guidelines for palliative services recommend the provision of psychological care.<sup>4,6,8,9</sup> Psychological distress in patients with life-limiting conditions has been found to interfere with quality of life and treatment engagement.<sup>6,8</sup> Whilst some patients can rely on their existing coping mechanisms others require additional psychological intervention.<sup>8</sup> As such, clinical psychologists (CPs) are now viewed as a vital part of palliative care teams.<sup>8,10-12</sup> As well as delivering intervention to patients and families, CPs also conduct supervision, training, and consultation with professionals working in palliative care.

The well-being of CPs within palliative care has implications for patients and families, professionals, and organisations.<sup>13,14</sup> Research concerning the emotional resilience of professionals working in palliative care has predominantly been conducted with nurses,<sup>15,16</sup> with relatively few studies sampling CPs. However, guidelines<sup>8,17</sup> have emphasised that whilst it is recognised that many healthcare professionals may require support to cope with the impact of their work, the level of support required for CPs is currently unknown due to a lack of data.

### **Compassion fatigue and satisfaction**

Compassion has been described as “a basic kindness with a deep awareness of the suffering of oneself and of other living things, coupled with the wish and effort to relieve it” (p. xiii).<sup>18</sup> Compassion fatigue refers to a profound emotional and physical exhaustion felt by professionals in caring professions.<sup>19</sup> This can lead to an erosion of professionals’ empathy, hope, and compassion. Research has suggested that compassion fatigue is mediated by professionals’ use of empathy with patients.<sup>20,21</sup> Whilst some have called empathy a ‘channel of vulnerability’,<sup>22</sup> others have suggested that it can leave professionals feeling invigorated and sustained by their work rather than depleted by it.<sup>23</sup>

The way professionals deal with trauma and loss shapes their capacity to be psychologically available to hear patients and sit with their distress, or ‘be present’.<sup>24</sup> It is proposed that an accumulation of listening to patients’ stories of suffering can lead professionals to experience compassion fatigue.<sup>19</sup> Although, research into compassion fatigue has largely focused on the well-being of nurses,<sup>20</sup> given that sitting with patients’ distress is a large part of a CP’s role one would expect to see high levels of compassion fatigue in CPs.

Inversely, compassion satisfaction encompasses the positive aspects of helping those who experience trauma, such as the pleasure of providing care, being able to do it well, and beliefs about the self.<sup>25</sup> It has been suggested that compassion satisfaction may counterbalance the risks of compassion fatigue and increase levels of resilience.<sup>26,27</sup> As such, research has found that higher levels of compassion satisfaction are associated with lower levels of compassion fatigue.<sup>21,28</sup>

Compassion fatigue in professionals can lead to increased absenteeism and staff turnover, as well as decreased productivity<sup>29</sup>. Furthermore, a literature review<sup>30</sup> found that work-related stress in oncologists presented as depression, anxiety, fatigue, and even suicidal ideation. It has been suggested that most professionals in a caring role develop compassion

fatigue in varying degrees at some point in their career.<sup>19</sup> Quantitative research indicates that between 40-85% of caring professionals experience compassion fatigue.<sup>24</sup> However, the prevalence of compassion fatigue, and related concepts such as burnout, distress, and secondary traumatic stress,<sup>31</sup> have been found to be inconsistent in professionals working in palliative care. Sabo et al.<sup>32</sup> found that compassion fatigue was actually lower in palliative care professionals than those working in other specialities. A systematic review found that levels of burnout in oncology professionals were no higher in palliative care than in other areas of health.<sup>33</sup> Another study carried out among hospice nurses found that 79% had moderate to high rates of compassion fatigue.<sup>24</sup> Very little is known about the factors that influence levels of compassion and resilience.<sup>28</sup> Research with palliative care nurses has suggested that interpersonal factors, including a sense of purpose, autonomy, and challenge, were related to coping in this area of work.<sup>34</sup>

### **Vicarious personal growth**

It has been suggested that professionals who are constantly confronted with the suffering of patients and their potential death can be vicariously affected by this exposure.<sup>35-</sup><sup>37</sup> However, these effects are not necessarily negative.<sup>38</sup>

Contrary to compassion fatigue, vicarious posttraumatic growth is a positive psychological change after indirect exposure to trauma.<sup>39</sup> Palliative care professionals often describe their work as meaningful and rewarding.<sup>40,41</sup> The literature cites numerous positive effects of working with death, such as increased well-being,<sup>42</sup> a heightened awareness of one's good fortune,<sup>39</sup> and an ability to live in the present.<sup>37</sup>



### **Coping with the emotional impact of work**

Psychological strategies can be utilised by professionals in order to protect themselves from the emotional impact of their work. Strategies such as positioning oneself as an observer and having a task orientation can be employed to act as an emotional buffer.<sup>43-46</sup> Junger and Payne<sup>13</sup> suggest that creating an emotional distance in this way can hinder professionals' abilities to empathise.

Zapf<sup>47</sup> suggests that professionals who feel distress but do not acknowledge this can experience an emotional dissonance which can negatively affect them. A lack of supervision and reflective spaces can increase levels of stress in cancer nurses.<sup>48</sup> Where such space is provided, self-presentational concerns can lead to professionals keeping certain issues private and not effectively using supervision.<sup>49,50</sup>

### **Organisational pressure**

A quantitative survey of CPs in Japan found that organisational pressures contributed to their experiences of compassion fatigue.<sup>51</sup> Professionals feeling an inability to provide effective care, for instance due to time pressures, has also been linked to experiences of compassion fatigue.<sup>32</sup> When organisations have increased demands and reduced resources, it has been suggested that this can contribute to levels of compassion fatigue.<sup>52-55</sup> Demands on time could also lead to professionals not prioritising self-care. Bober and Regehr<sup>56</sup> found in a sample of Canadian therapists that although they believed several coping strategies would be useful in improving their well-being, they actually did not devote time to practice these.

### **Prevention, self-care, and resilience**

Resilience has been defined as “a relative resistance to environmental risk experiences, or the overcoming of stress or adversity” (p. 1).<sup>57</sup> In order for professionals to

remain resilient working in end-of-life care services, self-care is important. It has been argued that to date, minimal attention has been given to the support and training required to enable palliative care professionals to address compassion fatigue.<sup>58</sup>

Self-care and improved work-life balance have been suggested to reverse compassion fatigue and increase compassion.<sup>59</sup> The issue of self-care amongst the caring professionals is not a new idea with many emphasising its importance for several decades.<sup>60-67</sup> However, as discussed, when other pressures are placed on professionals it is unclear whether they actually adhere to self-care practices.

Factors that increase compassion satisfaction include building resilience, acquiring increased work skills, resolving internal conflicts, and having a connection with others.<sup>59</sup> Swetz et al.<sup>68</sup> found that a diverse range of self-care practices were utilised by palliative care physicians and concluded that further research was needed to help future professionals develop their own strategies. Furthermore, healthcare professionals themselves have also suggested that there is a need for further exploration of self-care in staff.<sup>69</sup>

### **The current study**

The field of compassion research is still in its infancy.<sup>24</sup> Whilst there has been an increase in quantitative research around compassion fatigue and satisfaction,<sup>31</sup> there is a lack of qualitative research that includes the narratives of professionals regarding their actual experiences.<sup>20,33</sup>

Research to date has largely excluded the exploration of compassion fatigue in CPs, despite guidance<sup>8,13,17,70</sup> suggesting that psychologists' roles in palliative care are likely to impact on their physical and mental health. It is unknown how CPs maintain their well-being despite working in services that potentially affect their ability to deliver effective care.

It has been said that professionals working in palliative care “have a duty to educate those entering the field to anticipate how the work will affect them and to prepare them to address these effects” (p.3).<sup>71</sup> Therefore, this study explored the experiences of CPs working in palliative care settings to gain an understanding of the impact this type of work has on their levels of compassion, resilience, and the self-care practices they use.

## **Method**

### *Design*

Given that research into professionals’ compassion and self-care research has largely been of a quantitative nature, using pre-determined hypotheses and questionnaires,<sup>20,31,33</sup> it was felt that a qualitative and more reflexive approach was required. The study’s aims of exploring the experiences of CPs naturally leant towards a qualitative design, in order to allow participants to describe their experiences in their own words. Experiences were explored using semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA) following the approach outlined by Smith, Flowers, and Larkin.<sup>72</sup>

### *Ethics*

The study was approved by Lancaster University’s Faculty of Health and Medicine Research Ethics Committee prior to commencing (See Section Four for details).

### *Recruitment and consent*

Recruitment materials were distributed in September 2014. Participants were recruited via a national special interest group for psychologists working in oncology and palliative care (SIGOPAC), cancer network psychology groups, and via ehospice.

Coordinators of SIGOPAC and cancer network groups forwarded a communication via their e-mailing list which introduced the project and attached a participant information sheet. A recruitment advert which gave details of the project and contact details of the researcher was placed in the United Kingdom (UK) edition of ehospice, a website publishing commentary on end-of-life care.

### *Materials*

Materials (see Section Four) included a communication to potential participants from the researcher (Appendix 4-B), recruitment advert (Appendix 4-C), participant information sheet (Appendix 4-D), consent form (Appendix 4-E), interview schedule (Appendix 4-F), and debrief sheet (Appendix 4-G).

### *Participants*

A purposive sampling method was used whereby CPs currently working in palliative care services were recruited. There are no set rules about the size of an IPA sample.<sup>73</sup> It was anticipated that between a minimum of eight and a maximum of 12 participants would be recruited. Given the aims of this project, the relatively small number of CPs working in palliative care in the UK, and the time and resource limited nature of the study, it was thought that this range would be both adequate enough to strive for theoretical sufficiency and appropriate to analyse in the available time.<sup>74,75</sup> A total of 23 professionals contacted the researcher requesting to take part. Priority was granted to those who requested to take part first and met the recruitment criteria. The final sample comprised 12 CPs.

Brief details of participants are presented in Table 1. All participants' names have been anonymised.

Table 1. Details of participants

Pseudonym	Description
Steve	Steve works predominantly with patients with cancer & other life limiting conditions. He currently spends around 50% of his time in direct patient contact.
Richard	Richard works predominantly with patients with cancer & occasionally with patients with other life limiting conditions. Richard spends approximately 75-80% of his time in direct patient contact.
Lisa	Lisa works with patients with any palliative life limiting condition. She estimated that approximately 70% of her time is in direct patient contact.
Peter	Peter works with patients with cancer & other palliative conditions. Peter spends 40% of his time directly with patients.
April	April works mainly with patients with cancer, but also with patients with other life limiting conditions. April spends around 90% of her time directly with patients.
Jane	Jane works mainly with patients with cancer. Jane spends around 15% of her time directly with patients.
Rose	Rose works across cancer & palliative care. The vast majority of Rose's patients have cancer but occasionally she will work with patients with other life limiting conditions. Rose spends about 30-40% of her work time directly with patients.
Sarah	Sarah works in cancer & palliative care. Sarah spends approximately 30-40% of her time directly with patients.
Nick	Nick works with patients with cancer. Nick described spending between 13-40% of his time in direct patient contact per week.
Pam	Pam works with patients with cancer & spends nearly all of her time directly with patients.
Belinda	Belinda works with patients with cancer. She spends between 45-64% of her time directly with patients.
June	June works with patients with cancer & spends approximately 60% of her time directly with patients.

*Data collection*

Interviews were conducted between September-December 2014 by the researcher. Eight interviews were conducted face-to-face at participants' workplaces, whilst four were conducted over the telephone due to it being inconvenient for the researcher and participant to meet in person. Face-to-face interviews lasted between 49-71 minutes, whilst telephone interviews lasted between 51-71 minutes.

An interview schedule was designed by the researcher and reviewed by the project supervisors (see Section Four). In keeping with IPA, the topic guide was informed by existing literature in the area<sup>76</sup> of compassion fatigue and satisfaction, for example the Professional Quality of Life Scale.<sup>77</sup> The schedule explored participants' experiences of work, including the feelings this induced, the impact upon them, and their coping strategies.

*Data analysis*

Data was analysed by the researcher. Interview transcripts were explored using IPA to extract themes around the experiences of participants within each interview transcript and across all of the interview transcripts. IPA allowed for the detailed exploration of how participants make sense of and apply meaning to their personal experiences.<sup>78</sup> IPA attempts to capture the participants' outlook on the world, in order to gain, as much as is possible, an insider's view.<sup>79</sup> IPA also acknowledges and allows for the role of the researcher interpreting that experience through their own lens therefore having an active and reflective role within the research.<sup>80</sup>

The use of IPA also fits well with the researcher's epistemological stance of critical realism.<sup>81</sup> Critical realism proposes that whilst an objective truth may exist, individuals' subjective experiences are real and valid from their perspective.<sup>82</sup> Given that individuals

occupy and possess different positions and perceptions in the world, subjective differences ascribed to experiences and meaning are to be expected.<sup>83</sup>

Given the researcher's critical realist approach to research and the aim of this study being to explore the subjective experiences of CPs working in palliative care, IPA was deemed highly appropriate for the study.

A six stage process, described in Table 2, was used to analyse data.<sup>72</sup>

Table 2. Stages of IPA

1	Reading & re-reading the first participant's transcript
2	Making initial annotations in the transcript in the right hand margin
3	Identifying & developing emergent themes in the transcript in the left hand margin
4	Compiling a list of emergent themes. Searching for connections across these emergent themes & clustering connected themes together to form superordinate & subordinate themes
5	Moving on to each of the remaining participant's transcripts & conducting the previous four steps for each of them
6	Finally looking for patterns across all of the cases, connecting the themes as a group & identifying superordinate themes across the group

An extract of annotated transcript can be found in Appendix 2-B. As part of the analysis, a table (see Appendix 2-C for an excerpt) was created which included an explanation of the superordinate theme, details of emergent themes, initial notations, and quotations that exemplified this theme. Furthermore, several candidate thematic maps were produced before being finalised (see Appendix 2-D for an example).

*Reflexivity*

As recommended,<sup>84</sup> a brief statement regarding the researcher's position is presented in order to acknowledge and bracket their stance in relation to this research. It is hoped that transparency about this will help readers to interpret the researcher's understanding of the data.

At the time of the study I was a trainee CP on the Doctorate in Clinical Psychology programme. Prior to commencing training I had volunteered at a hospice with patients at the end of their lives. During training I undertook a placement within a physical health setting working with individuals with cancer, some of whom were receiving palliative treatment. I was beginning to consider a future career as a CP within a palliative care setting.

At the beginning of the study I expected to find that participants would find their work rewarding but challenging. I also expected that the participants would have developed ways of coping with this that meant they were able to continue to fulfil their role well.

To facilitate reflection and bracketing, and to enhance the credibility of the interviews and subsequent data analysis, the researcher used a field diary (see Appendix 2-E for extracts).<sup>85,86</sup> The academic supervisor read several interview transcripts, reflected upon interview style and richness of emerging data, and was consulted during analysis.

In order to enhance the transparency, credibility, and coherence of the data several resources relating to the analysis are provided. These include, details of participants, portions of data and analysis at all stages demonstrating how a participant's direct quote progressed into the development of a theme, and the use of participants' direct quotes to illustrate themes.<sup>87</sup> Overall, guidelines for examining the quality of qualitative research<sup>84,87</sup> were utilised to ensure a high level of quality.



**Findings**

During data analysis six overarching themes were identified (see theme table for details of emergent and final themes in Appendix 2-F). The themes were: Being Part of Something Special, The Therapeutic Relationship, Doing More With Less, Being Changed as a Result of Involvement, The Consummate Professional, and Practicing What you Preach. The findings are illustrated in the final thematic map presented in Figure 1.

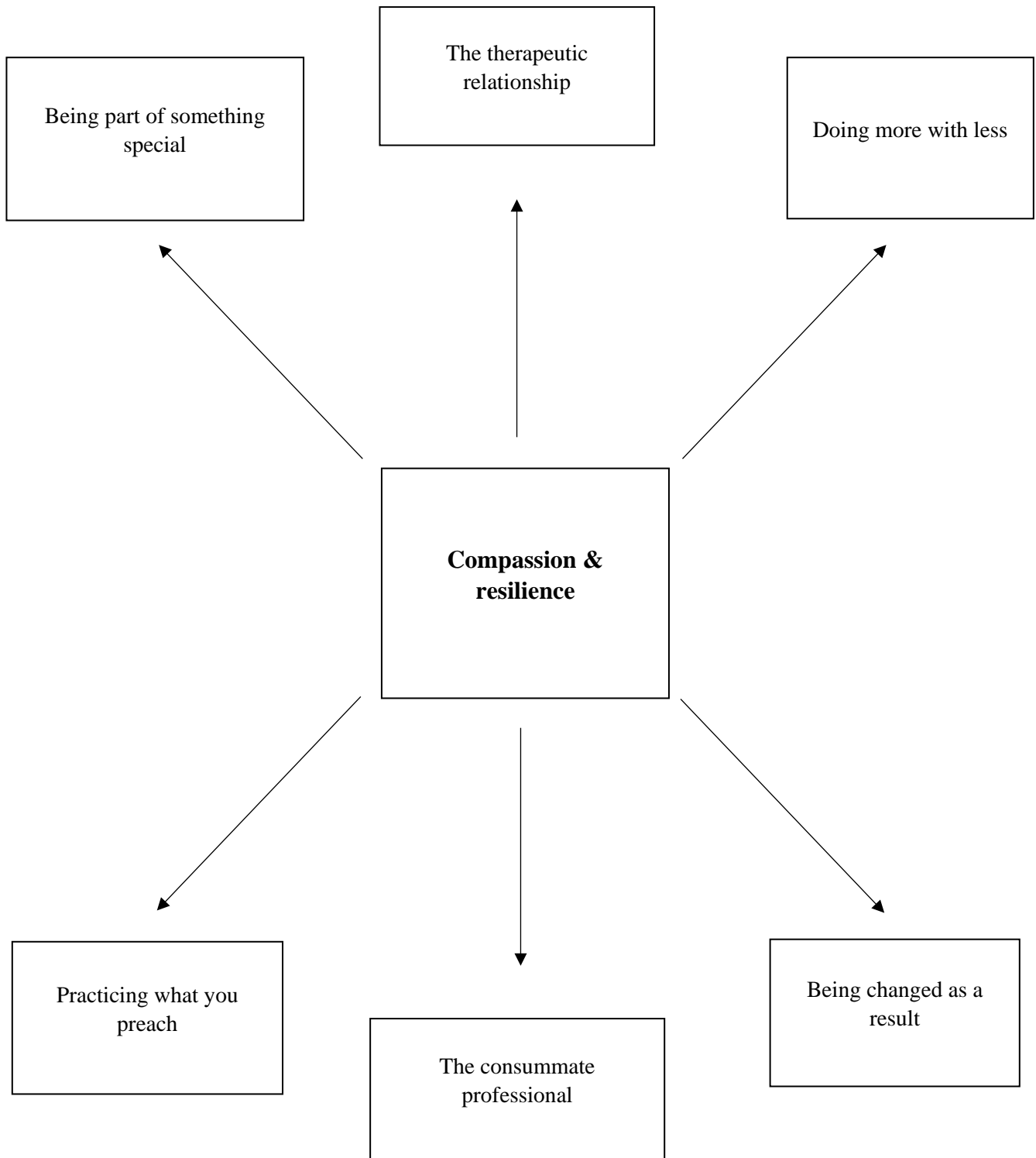


Figure 1. Final thematic diagram

*Being part of something special*

This theme captured the sense that palliative care was special compared to other areas that the participants had worked in. As well as being part of a field that felt special to the participants, they described how as CPs they uniquely influenced and added to that specialness.

Many of the participants described their experience of working in palliative care positively, referring to it as “a privilege” (April, Rose, & Belinda) and “rewarding” (Peter & Jane). Some participants referred to a feeling of the work being “heavier but it doesn’t feel hard” (Pam) and “more draining but also more rewarding” (June).

Several participants made comparisons between palliative care and mental health work. Participants described patients in palliative care as easier to work with because they had more psychological resources to draw upon compared to patients in mental health settings.

You can make a big difference very quickly... You get some of those real kind of umm buzzing moments I think in this job that there were maybe fewer of in, in sort of more community working in chronic long term mental health conditions. (Belinda).

Several participants stated that they worked with irreversible difficulties, such as death, and as such were not expected to bring about change. This was reflected by Richard, “Knowing that I don’t have to fix things for people, that isn’t an expectation that that person has of me. They don’t come in and go ‘find me the miracle cure’”.

It seemed that this gave the participants a sense of liberation and lack of responsibility, and somewhat set them apart from CPs working in other settings and from medical professionals working within palliative care, adding to their sense of providing something different.

Finally, the participants felt that their ways of thinking and working psychologically provided something different and valuable in a traditionally medical setting. June differentiated herself from her medical colleagues by stating, “The compassion that I feel isn’t directed to sitting with people and commiserating with them necessarily or making everything better, it’s about sitting with difficulties and allowing them to, to express those difficulties”. (June).

This theme captured the essence of working in a special area. As well as the work with patients seeming rewarding and manageable, the participants felt that as CPs they too were special and unique within the traditionally medical field.

#### *The therapeutic relationship*

This theme illustrated aspects of the therapeutic relationship between the CPs and patients. It seemed that a sense of uncertainty existed in the therapeutic relationship given the chance of patients dying. Finally, participants spoke about their experiences of the deaths of their patients.

Participants described how they identified and empathised with their patients, often feeling moved by their stories, as exemplified by Belinda.

You’ll meet somebody that has an effect on you in a particular way and if that person’s treatment isn’t going to plan or they’re getting bad news or umm you know eventually they die, you need to think about ways of keeping yourself well because there are moments where you, you can feel that kind of chest crushing sadness.  
(Belinda).

It seemed that the type of work meant that the CPs easily identified and empathised with patients. Several participants made reference to the fact that everybody will die and

therefore there was no distinction between patients and themselves. This seemed to make it easier to relate to patients by thinking “you’re just like me” (Sarah).

Several participants discussed uncertainty in the therapeutic relationship due to working with the threat of patient death. It seemed that this led to an intensity and quickening of the therapeutic relationship. The CPs felt that palliative care patients entered the therapeutic relationship willing to give it their all, “That process is speeded up because you know you’ve only got six months”. (Pam).

Patient death often led to abrupt therapeutic endings. Participants spoke about a sense of “unfinished business” (Peter) and said “it’s hard to get a proper goodbye” (Richard). The emotional aspect of processing patients’ deaths often involved taking a short time to reflect upon, remember, and say goodbye to patients which provided closure for the CPs. It seemed that the frequency with which patients died meant the CPs had come to expect it and as such had developed methods for processing this that allowed them to move on relatively quickly: “I can’t give too much time to kind of grieving because in a way it would stop you being able to do the job”. (Peter).

This theme captured the nature of the therapeutic relationship, including the ease at which participants identified and empathised with patients. A sense of uncertainty, intensity, and acceleration existed in the therapeutic relationship. When patients died the CPs were often left with a sense of unfinished business and used various methods to process this.

### *Doing more with less*

This theme described issues associated with the systems that participants worked in. Due to the current economic climate in the UK, aging population, and increasing survivorships, several participants spoke about the change within their organisations with

uncertainty: “There’s change afoot ... we know it’s necessary but it doesn’t have a kind of firm shape to it yet”. (Belinda).

Most participants felt that organisational issues were the most stressful part of their role. Participants gave the sense of their patient work being “pure” (Pam) and strengthening: “Sometimes I can hide in the clinical work if some of the managerial tasks are a pain in the ass. I just book a few more patients and kind of strengthen me”. (Nick).

Although participants spoke about the pressures of reduced funding and increased referrals there was a sense that they were not as affected as other areas of healthcare, as illustrated by Richard.

Many of us feel that pressure of trying to do more for less. I think there’s a little bit of a difference in that when I think about some of my colleagues working in mental health ... I feel somewhat better off. (Richard).

Several participants spoke about the demands that came with seniority forcing them into becoming more business-like and less compassionate: “You’ve got to be more disconnected from patient experience in a way, ironically because you are trying to improve patient services...it’s probably all just a great defence mechanism”. (Jane).

The increase on the demands of the CPs to do more with less often led to a personal striving to do well by their patients, as illustrated by Richard, “There are some months where I get inundated with referrals, where I think I just can’t keep going...I don’t want to create a waiting list. I’ve avoided it so far but sometimes by giving up lunch breaks”.

This theme captured a sense of the CPs feeling the need to do more for their patients but often with less resources. In terms of compassion, the CPs appeared to be striving to do the very best that they could for their patients, however it is possible that in doing this their self-care practices may be affected which could lead to a reduction in resilience.

*Being changed as a result of involvement*

This theme illustrated how the CPs were affected and even changed as a result of their work. This impact included levels of compassion, vicarious growth, and experiences of feeling vulnerable.

Many participants spoke about experiences that could be inferred as being representative of compassion fatigue. The impact of such experiences included not listening to patients, rumination, and insomnia. Whilst most of the participants spoke about these experiences, only four of them (Lisa, Jane, Peter, & Sarah) referred to “compassion fatigue”. There seemed to be an accumulative effect of hearing patients’ stories around death that depleted the CPs’ resources. In an example below, Lisa recalls a time she identified with compassion fatigue:

I was seeing a patient who was really really distressed ... I just didn't want to hear it, any more bad stuff. I just felt like I was full up with it and I didn't want to kind of hear about people's bad stories and miserable lives. (Lisa).

It is possible that the experiences described above acted as defence mechanisms. Although Nick did not refer to his experiences as compassion fatigue, he could recall a time he had used defensive practice to protect himself:

I would avoid a patient. So I would go on the ward...I would see one patient instead of the other because I saw the one that I could manage, that emotionally I found less challenging. And the other, I would find ways of being busier and having very brief contacts with. Running away basically. (Nick).

In addition to experiences of feeling depleted, participants also referred to periods of feeling invigorated. In particular, many participants spoke about the confrontation with death

leading to them reprioritising their life, as shown by Steve: “I’m very fond of saying, that on their death bed nobody says I wish I spent more time at work, so that potentially is a way of getting your priorities straight”.

However, a couple of participants spoke about feeling that they were wasting life, as illustrated by Jane: “The mismatch between what you see your patients go through, their life is ebbing away, you’re alive but you wish things were different, and the sort of mismatch between those two things caused a crisis within me”.

Perhaps linked to this sense of dissonance between the patients and the CPs’ lives, June referred to subconsciously trying to match this up:

I’ve started smoking again... I’m thinking why, why are you doing that?... Maybe its guilt and the privilege of being healthy when so many people are not...like kind of survivor guilt almost. (June).

Several participants spoke about having an increased awareness of their own mortality and a sense of the fragility of life that could not be restored, such as April: “A sharp reminder of how things can suddenly be fine one minute and next, you know, you could be in hospital for whatever reason and it, yeah, it definitely highlights how fragile humanity can be”. (April).

This theme captured the impact the work has on the CPs. Participants spoke about the impact upon their levels of compassion, including experiences indicative of compassion fatigue. Participants also described existential learning through their patients and although this left them with a sense of fragility, overall it had positive effects on them, such as feeling an appreciation for life.



*The consummate professional*

This theme exemplified the CPs' expectations about a requirement to remain professional at work. There was also a perception about others' expectations of CPs. The theme also illustrates the feelings of the CPs regarding their own reactions, including shame and eventual acceptance and normalisation.

Participants very much felt an emotional response to their work however for the most part they managed this in a way that they believed was contained and professional: "As a psychologist you get very well at managing your stuff in front of other people... I think we have to but that doesn't mean we don't experience that stuff". (Peter).

Some participants spoke about either choosing to process their feelings at home or them inadvertently spilling over into home life. It seemed that some participants chose what to show others about how they felt, whilst they contained the rest of it, "I'd be really surprised if it was noticeable... at times I choose to say look this is what's going on inside my head rather than it being something that is hugely apparent to the outside world". (Rose).

However for others their feelings seemed to leak out, "It sort of was an acknowledgment to my manager and to my family that actually I couldn't carry on doing what I was doing and something had to change". (Jane).

Several participants spoke about feeling expected to act as a container for others' emotions without any acknowledgement that they too could be affected: "There's this sort of expectation a bit, I think cos you're a psychologist, you'll be able to deal with everything... [The team] see me as some kind of emotional robot". (Sarah)

This seemed to be at odds with how participants actually felt with several acknowledging sentiments along the lines of, "It's ok to find things upsetting...that's very much the sort of human element of what we do". (Belinda).

This sense of acceptance seemed to have developed over time for the participants and was contrary to how some of them described initially feeling about their emotional responses to work: “shocked” (Lisa), “embarrassed”, “shamed”, and “stigmatised” (Jane & Sarah). The participants now felt that their experiences were a normal and acceptable reaction to their work:

There’s kind of like, you know, clinical psychologist off sick with exhaustion, depression, really? You know it was a bit of an extra stigma...it’s something that you know a lot about and therefore ergo shouldn’t suffer from but of course we’re human aren’t we? (Jane).

Furthermore, Jane went on to discuss how these feelings had initially acted as a barrier to her seeking help. Some participants recounted how learning about others’ experiences of compassion fatigue had helped to normalise it:

To see them [peers] go through that human experience and then to come through the other side and be able to re-engage with work and do their job to the same level as before, it’s been a huge relief for me. (Nick).

This theme captured the expectations of the participants themselves and the perceived expectations of others about how CPs should react to their work. Participants largely described an attempt at impression management, but at times this was difficult to maintain. Participants valued sharing and hearing about others’ experiences which led to a normalisation and acceptance of the impact of their work upon them.

*Practicing what you preach*

In this final theme participants commented on the importance of self-care, their ability as CPs to heed their own advice, and various methods of looking after themselves.

Several participants spoke about the importance of self-care and ensuring that they were in an emotionally well place in order to be able to provide the best service to patients and professionals.

In order to practice your vocation you've got to look after yourself, look after your family, you've got to get things at home right first, and then you're in a much better position to put yourself on the line for people. (Steve).

Participants seemed to fall into one of two groups. For some it seemed that being a CP meant by virtue that you should "practice what you preach" (April, Steve, & Peter). However, this was often suffixed with "or try to", acknowledging that although the participants knew this in theory, in practice it was more difficult. Others described how it was not until they had experienced a period of not coping that they realised they did not practice self-care, and that this experience spurred them into taking action, such as Lisa:

You know generally on training people like talking away about self-care and you kind of think 'yeah, yeah, yeah, I know all that stuff' but actually being faced with the fact that I was feeling, literally I'm not sure if I can actually be a clinical psychologist anymore. That was a real wake up call for me. (Lisa).

Several of the participants spoke about inner resources positively influencing their resilience, such as Rose:

I'm pretty much as tough as old boots, highly resilient, and have a lot of experience being with people who are really distressed, all those kind of things, so I've got a lot

in store, so that when I then have an experience that's about it being knocked I've got plenty to draw on. (Rose).

All participants referred to their particular methods of self-care, such as eating well, exercise, time with family and friends, and personal use of psychological intervention. Participants spoke about strategies they used in work, including supervision, monitoring their emotional and physical responses, using grounding techniques, and turning off from patients' stories after sessions, "I kind of download it on to paper by writing the letter and then it's out of my head". (Steve).

However, several participants also mentioned potentially negative practices such as not taking breaks, a reluctance to take annual leave, and regularly working over their hours. This seemed to be related to a sense of busyness and needing to fit more into their time at work.

This theme captured a sense of the qualities that a CP may possess that makes them suitable for working in palliative care. For some this was about an inner resilience combined with their psychological knowledge regarding self-care methods. For others, it was about having an ability to reflect upon and acknowledge when their self-care had slipped and then being able to take action on this. For all participants though the importance of self-care was apparent.

## **Discussion**

This study aimed to explore the experiences of CPs working in palliative care settings to gain an understanding of the impact this type of work has on their levels of compassion, resilience, and the self-care practices they use. The analysis identified six superordinate themes: Being Part of Something Special, The Therapeutic Relationship, Doing More With

Less, Being Changed as a Result of Involvement, the Consummate Professional, and Practice What you Preach, which are discussed in light of the research aims, and existing research and theory.

Since the publication of documents<sup>4,6,8,12,17,70</sup> related to the provision of psychological care at the end-of-life there has been relatively little research on the impact upon those delivering this, including CPs. The current study addresses this. The findings revealed some similarities to previous research conducted with other professional groups however several differences were also apparent, that may be specific to CPs working in this area.

Whilst there were draining elements of the role it seemed that most participants felt the positives outweighed the negatives. This rings true with Pereira et al's<sup>33</sup> finding that burnout in palliative care professionals is no higher than in other areas of healthcare and Vachon's<sup>88</sup> finding that burnout is lower for palliative care professionals. The sense of the role being a source of satisfaction resonates with previous literature in this area.<sup>38,40,41,89</sup> Furthermore, similar to nurses in Ablett and Jones'<sup>34</sup> study, the CPs valued the challenges in their role and felt equipped to deal with them. This contributed towards a sense of achievement, mastery, and compassion satisfaction.

It seemed that the process by which the therapeutic relationship between patient and CP in palliative care developed was accelerated due to the sense of impending death. This provided a heightened intensity and intimacy in the relationship. The majority of participants discussed the ease at which they identified with, empathised with, and ultimately felt compassion towards palliative care patients. The feeling of 'this could be me' served to heighten their compassion. In keeping with compassion literature, participants described feeling sorrow for their patients and of wanting to alleviate that suffering,<sup>27</sup> but also recognised that this could not mean preventing them from dying.

Participants felt that organisational issues had a negative effect on their resilience, whilst clinical work served to strengthen them. These views are similar to those of CPs working in end-of-life care in Japan<sup>51</sup> who felt that organisational pressures contributed to their experiences of compassion fatigue. This links to suggestions that compassion within healthcare systems can be enhanced via organisational design.<sup>90,91</sup> The participants in the current study felt less affected by organisational pressures than CPs in mental healthcare, and seemed to have a sense of control and autonomy over their workload. Previous research<sup>34</sup> suggested that these factors also contributed to the resilience of palliative care nurses.

The work of palliative care is said to offer professionals an opportunity to learn from their patients.<sup>37,38</sup> Professionals that work with death reflect on their own mortality, live in the present, and gain an appreciation of life.<sup>37</sup> It seemed that the current participants' work impacted upon them in various ways which generally had a positive effect on their resilience.

In keeping with the idea of vicarious traumatisation,<sup>92</sup> participants experienced potentially negative effects, such as increased health anxiety, vulnerability, and a sense of unfairness between the disparity in their own and patients' health. Participants interpreted these as warning signs that they were finding work difficult and needed to take time to self-care.

Similar to existing literature in the area, participants spoke about their emotional responses to patients dying. However, whilst participants felt sad when a patient died, there was also a sense that this was not a feeling of grief similar to that felt for a loved one. Some participants also spoke about there not being time to grieve which resonates with the research of Aycock and Boyle<sup>93</sup>.

Several participants spoke about a cumulative effect of listening to patients' stories leading to a feeling of depletion which was similar to that described by Figley<sup>19</sup> and

Vachon<sup>94</sup>. Some participants spoke about tuning out to patients' distress or even avoiding patients altogether. In this sense, the CPs were similar to professionals in previous research who were found to employ such strategies to create distance between themselves and patients' experiences.<sup>13,43,44</sup> The CPs seemed to be aware of when this happened and took it as a sign that they needed to take action. However, for the majority of time the nature of patients' distress seemed to make it easier for the CPs to provide empathic support. Furthermore, this feeling of empathy was believed to strengthen participants' feelings of purpose and reward, and add to levels of compassion satisfaction. This contradicts suggestions that individuals feeling higher levels of empathy are more likely to experience compassion fatigue.<sup>95</sup> Alternatively, this may reflect the concept of 'exquisite empathy' which is defined as professionals demonstrating "highly present, sensitively attuned, well-boundaried, heartfelt empathic engagement" (p.213).<sup>23</sup> As well as invigorating professionals, this connection with patients is thought to act as a protective factor against compassion fatigue.<sup>24</sup>

Nevertheless, it seemed that at various points in their career and in varying degrees participants felt effects that resonated with the concept of compassion fatigue. Participants seemed to occupy different positions: those that identified as having experienced compassion fatigue, those that described experiences that could be considered to be compassion fatigue but did not explicitly name it, and those that did not describe such experiences and instead painted a picture of continually being able to manage. The heightened levels of depression, suicidality, and substance use found in oncologists<sup>30</sup>, were not disclosed by the current study's participants. It is possible that participants did not disclose such effects due to a desire to convey a professional self-image. However, it is also possible that the CPs did not feel this way due to the resilience building effects of their work and self-care methods. When participants did have experiences that could be thought of as compassion fatigue they were

initially shocked, ashamed, and embarrassed. However, all participants felt that compassion fatigue was an acceptable experience, something to monitor for, and that they could take action to decrease the effects of it via self-care.

Participants' experiences of compassion satisfaction were also apparent, including the pleasure of helping patients, being able to do their role well, and feeling valued in the workplace. This fits with the idea that compassion satisfaction reduces risks of compassion fatigue and increases resiliency.<sup>27,28</sup>

Some participants described becoming hardened to the impact of their work and feeling that this was maladaptive. Previous research has suggested that this can create an emotional dissonance for professionals which can contribute to a negative effect upon levels of resilience.<sup>47,49,50</sup> The participants felt that others, and sometimes themselves, held perceptions about their ability to contain emotions. These perceptions often led to a sense that they should not feel a particular way about issues and they certainly should not show it at work, similar to research with palliative care nurses.<sup>96</sup> An effect of this impression management led to some participants feeling and showing the impact of their work at home. For some participants, these self-presentational concerns were verbalised, and for those where it was not, it is possible that they also felt this way during the interview and were in fact not sharing how they truly felt in an attempt to remain professional during the interview.

The participants generally described feeling compassionate towards their patients. This was demonstrated by participants feeling empathy for the patients and their situations, as well as striving to do their best to attempt to relieve patients' suffering. In addition, the participants described feeling self-compassion, in that they acknowledged the impact of their work on them and took action to self-care in order to build and maintain their resilience. It seemed that generally, when the participants felt that compassion for their patients had slipped this indicated that they needed to take time to replenish their own resilience so that they could



reconnect with patients' suffering. This replenishment was achieved by practicing self-compassion and engaging in self-care.

Participants gave a sense of being aware of their emotional states, of spending time to reflect upon these, and putting actions into place to self-care, with the hope that this would lead to sustainability in the role. It seemed that being equipped with the knowledge and experience to help patients maintain their well-being was vital to the CPs' own ability to remain compassionate and resilient. Previous research with palliative care professionals has found the use of a diverse range of self-care practices.<sup>68</sup> In keeping with this, participants' coping strategies were not limited to work based strategies.<sup>97</sup> Strategies could be organised into the three areas of personal, professional, and organisational as suggested by Pearlman and Saaktvine.<sup>98</sup> Participants used several self-care practices that have been suggested to reduce compassion fatigue in other palliative care professionals,<sup>99</sup> including mindfulness, supervision, caring for their physical health,<sup>68,100</sup> and using peer support.<sup>101</sup> It seemed that the suggestion that self-care and a good work-life balance can reverse compassion fatigue and increase compassion satisfaction<sup>59</sup> was true for the participants.

#### *Future research suggestions*

There are several future research suggestions from this study. Given the importance of the therapeutic relationship for participants, research exploring the nature of this in more depth could elicit which facets of the relationship are most protective and help to invigorate rather than deplete professionals. It is perhaps through exploration of the specific nature of the CPs' and patients' therapeutic relationship in palliative care that differences between CPs and other palliative care professionals' abilities to remain compassionate and resilient may lie.

Furthermore, it is important that the impact of organisational changes are measured from the professionals' perspective. Whilst this study gives an insight into a somewhat protected corner of the healthcare service, it is clear that the impact of stretched resources not only directly affects patients' care but could also indirectly impact this by negatively affecting the professionals that treat them.

Additionally, the idea of CPs being the consummate professionals and experiencing feelings of shame, embarrassment, and stigma in relation to compassion fatigue suggests that wider research into the emotional needs of CPs, not only in palliative care, is required in order to help professionals feel that they can speak out about their needs.

Finally, several participants described experiences indicative of compassion fatigue, such as feeling emotionally exhausted and avoiding emotionally charged stimuli, but did not identify as having experienced compassion fatigue per se. Future research and training is needed to help professionals recognise instances of compassion fatigue and develop their own package of self-care.

### *Strengths and limitations*

The study researched an area which has received relatively little coverage to date, and in which more detailed research is needed. Previous research has been related to other palliative care professionals. Understanding CPs is valuable given that they are often supporting other healthcare professionals working in palliative care services.

The use of IPA to explore the experiences of CPs allowed the participants' stories to be heard without the inflexibility of pre-determined hypotheses. Whilst the findings relate to the experiences of this particular group of staff, it is likely that the meanings could be transferable to other CPs working in palliative care. Furthermore, the findings could be

transferable to psychologists working in other areas where they experience patients' deaths frequently, such as those working in other physical health areas and with elderly patients.

A strength of the study included talking to CPs who worked with a variety of end-of-life conditions rather than specifically oncology. This recognises the changing nature of palliative care, given that only 34% of adult palliative care needs are accounted for by cancer.<sup>6</sup> However, it is also possible that there may be differences in experiences between CPs working in oncology as opposed to purely palliative care. CPs working in oncology across the trajectory of patients' illnesses could have different experiences given that their patients may at some point have been receiving curative treatment and perhaps were not expected to die, compared to CPs working with patients in a hospice where it is apparent that their condition is palliative.

A possible limitation of the study, given that all of the participants were still working in palliative care, is that those most severely affected by the impact of their work had perhaps chosen to leave the area already. Furthermore, the participants were self-selecting and potentially chose to take part in the study because they felt they had good self-care practices that they wanted to share. In addition, the participants that took part may have considered themselves as having the time to take to reflect on their practice and perhaps those that were experiencing compassion fatigue and felt they were too busy did not take part.

Given the findings related to the idea of CPs as consummate professionals it is possible that participants were guarded during the interview process and reticent in talking about their experiences. However, the participants' accounts can only be taken at face value. Some of the participants commented on how the interview felt indulgent in that it provided them with time to reflect on themselves. This study shed light on the experiences of CPs as a group of professionals who are usually the listeners and containers rather than the talkers.

Finally, this study only offers a single researcher's interpretations. However, steps were taken to ensure high standards by adhering to guidelines and criteria for the quality of qualitative research.<sup>84,87</sup>

#### *Clinical and theoretical implications*

The findings of this project have a number of implications. The findings highlight and contribute towards an awareness of risk factors that could affect levels of compassion and resilience, as well as methods to cope with such experiences and build resilience for the future. Furthermore, the research highlights factors that contribute towards a sense of compassion satisfaction for CPs working in palliative care.

The study's findings could have implications for the training of CPs as well as the development of support systems around them during their career. The role of the CP in palliative care is very different to the more traditional mental health roles that training will have typically prepared them for.<sup>11</sup> Guidelines have made several suggestions for the training of palliative care psychologists, including reflecting on the impact of work, the containing of emotions, and the ability to recognise ones' own limitations.<sup>13</sup>

Finally, the sharing of experiences of compassion fatigue amongst CPs helps to normalise and reduce stigma attached to these experiences. It also potentially encourages more practitioners to identify, discuss, and seek support around these issues.

#### *Conclusions*

This study explored the experiences of 12 CPs working in palliative care. The study highlighted factors that may contribute to enabling CPs in palliative care to remain compassionate and resilient, and therefore act as protective factors. The study also indicated which factors could negatively affect compassion and resilience, such as organisational

issues, and a propensity to be seen to be professional at all times which could potentially act as a barrier to discussing the emotional impact of work and seeking help when required. The CPs' experiences were characterised by the meaning they found in being part of a special area, the nature of the therapeutic relationship between them and their patients, and the lasting impact on the self. In addition, the CPs recognised the importance of self-care and utilised a range of strategies to cope.

Given the lack of research in the area, further studies are required to explore CPs' experiences, particularly regarding the impact of the therapeutic relationship and organisational change on levels of compassion and resilience, and feelings of shame and stigma related to such experiences.

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*Appendix 2-A*

Author guidelines for the submission of manuscripts to Palliative Medicine

**1. Article types**

**Palliative Medicine** publishes original research and review articles on all aspects of palliative care.

2. Original Articles – 3,000 words with up to six tables or figures. For papers reporting qualitative methods participants' quotations may be excluded from the word count. We still prefer, however, that these quotations are succinct and carefully chosen – it is rare that more than one quote is required to illustrate the point being made. All research papers should follow relevant reporting guidelines such as CONSORT for trials, COREQ for qualitative research etc. Please see <http://www.equator-network.org/resource-centre/library-of-health-research-reporting/> for up to date information on reporting guidelines, and fuller instructions below on constructing different aspects of the paper.

NB: word count excludes references, tables and figures references

**1.1 Structured abstracts**

Reviews, original articles, short reports, case reports, audits and service evaluations should be accompanied by a structured abstract. Full details are given below of the format we expect for these:

**Research Paper/Short Report/Audit/Service Evaluation:**

Abstracts should have clear headings, which should generally follow the structure below when reporting research, but may vary depending on the requirements of the reporting guidelines followed. There is some flexibility for audit/service evaluation as it is important that these are not presented as research.

**Background:** Identify the issue to be addressed, current knowledge on the topic and some

indication of its relevance and importance to clinical practice, theory or research methodology.

**Aim:** A clear statement of the main research aim(s), research question (s) or hypotheses to be tested.

**Design:** A statement about the research strategy adopted. For intervention studies, a clear statement of the intervention is required. For clinical trials, the trial number should be given.

**Setting/participants:** Indicate the type of setting(s) the research was conducted in (i.e. primary/secondary care), the number of centres, and who participated including brief indication of inclusion/exclusion criteria, numbers of participants and any relevant characteristics.

**Results:** Report the main outcomes(s) findings of the study. If appropriate, report levels of statistical significance and confidence intervals.

**Conclusions:** Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology. Suggestions for further research.

## **1.2 General instructions to authors relevant to all paper types**

We wish papers published by **Palliative Medicine** to adhere to the highest publishing standards possible. We want to ensure that the key messages for our readers are explicitly articulated. We also want you to consider the following issues: authorship; multiple publications; ethical approvals; research design; and presentation of discussion.

### **Key Statements**

Palliative Medicine has a system where all papers are required to clearly state what is already known about the topic, what their paper adds, and implications for practice, theory, or policy. You are required to give these at the start of the manuscript. Please use these three specific headings (see below), with 1-3 separate bullet points for each heading. Please use clear,



succinct, separate bullet points rather than complex or multiple sentences. Each bullet point should be one sentence only.

**What is already known about the topic?**

- Short statement(s) here about state of knowledge in this area.
- You may highlight both what is known and what is not known.
- Be specific rather than broad or sweeping statements. Avoid statements such as 'Little is known about ... x or y' in favour of statements specifying exactly what is known.

**What this paper adds?**

- Short specific statement(s) here about what this paper adds.
- These should be styled in terms of outcomes where possible (This study demonstrates that x intervention has a (specific) impact on y outcome) rather than study aims or process. (This study considers whether x intervention has an impact of y outcome).
- Be as specific as possible please here. Avoid broad statements such as 'New Knowledge is added about ... ' but rather be specific about exactly what this knowledge is. So for example rather than 'We add to the knowledge base on x' we would prefer the specific such as 'x variable was found to increase the experience of y outcome (by z amount)'.
- Ensure that these statements clearly relate to the findings of the study.

**Implications for practice, theory or policy?**

- Short specific statement(s) here on the implications of this paper for practice, theory or policy. These should clearly draw from the findings of the study, without over stating their importance.
- Where possible please make these internationally relevant.

**Study discussion**

Although Palliative Medicine does not require structured discussions, we would like you to bear in mind the typical content for a structured discussion when writing your paper. This would typically be a statement of the principal findings of the study, a discussion of the strengths and weaknesses of the study/review with reference to other studies or reviews in the area, a discussion of what is already known about this topic and what this research/review adds, and a discussion of the implications of the research/review for clinical practice, theory or methods in this area. You may wish to raise further research or review questions.

## **2. Manuscript style**

### **2.1 Journal Style**

**Palliative Medicine** conforms to the SAGE house style [Click here to review guidelines on SAGE UK House Style](#).

### **2.2 Reference Style**

**Palliative Medicine** operates a SAGE Vancouver reference style. [Click here to review the guidelines on SAGE Vancouver to ensure your manuscript conforms to this reference style](#)

### **2.3. Manuscript Preparation**

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

#### **2.3.1 Your Title, Keywords and Abstracts: Helping readers find your article online**

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's [Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online](#).

**Palliative Medicine** requires authors to list between 4 and 6 key words that are also Medical Subject Headings (MESH headings). These key words should be closely related to the papers

subject, purpose, method and focus. Details of MESH headings can be found here <http://www.nlm.nih.gov/mesh/>. If authors submit keywords that are not MESH headings **Palliative Medicine** reserves the right to submit alternative keywords. Abstracts for Palliative Medicine should be structured and no more than 250 words. They should not include references or abbreviations. Please refer to section 2 above.

### **3. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

Debbie Ashby

Editorial Manager

[debbie.ashby@bristol.ac.uk](mailto:debbie.ashby@bristol.ac.uk)

### **SAGE UK House Style Guide**

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## 2. Article opening material

### 2.1 Headings

1. Headings should have an initial capital with everything else lowercase, unless proper names.

2. Italics can be included in A heads (H1) if needed, e.g. mathematical symbol or genus name.

3. Headings are unnumbered and formatted as below.

4. Where headings are referred to in the text use section names, as headings are not numbered.

A head (H1) (bold with initial cap, all the rest lowercase)

B head (H2) (italic with initial cap, all the rest lowercase)

C head (H3) (same as B head, but set as first line of paragraph, full out; italic with initial cap, all the rest lowercase, followed by a full stop. Following text runs on)

Headings for Abstract, Keywords, Funding, Acknowledgements, Conflict of interest (in that order), References, Appendices are same as A head but smaller font size

(CEs: where a template is being used there is no need to format these. Where no template is being used, please format as bold/italic, but there is no need to mark the font sizes, TS will format.)

## 2.2 Article types

Where a journal displays article types, these should appear on the first page of each article, left aligned above the horizontal rule, and in italics.

General technical or research papers should be classified as Original Article (with uppercase initial caps) for STM.

Other usual paper types are as follows: Review Article, Case Study, Technical Note, Case Report. Individual journals may also have other paper types, as agreed with the Editor. Where no particular convention has been agreed, Original Article should be followed for STM.

## 2.3 Article title

Please format with an initial capital only and remaining words lower case, unless proper names. Italics can be included where necessary (e.g. genus name). Run on subtitle after colon, with initial capital after colon.

## 2.5 Abstract and keywords

Abstract should appear in bold without a colon, text should start on the next line, with no indent.

Keywords (all one word) should appear in bold without a colon. The keywords should start on the next line, separated by commas only, not semi-colons. The first keyword should have an initial cap.

In some journals, Abstracts have sub-headings, e.g. Methods, Conclusion etc. These should be formatted in bold with a colon in bold and each sub-heading should start a new paragraph. The text should run on after each heading with an initial capital.

## Submitted/accepted dates

For journals that publish received/revised/accepted dates (applies to specific journals, if unsure please check with the PE), this should appear after the Keywords and be formatted thus:

Date received 29 July 2010; reviewed 30 August 2010; accepted 5 November 2010

## 2.6 Running heads

Recto: should be author surname(s), e.g. Smith, or Smith and Jones, or Smith et al. (for three or more authors, and et al. is also in italic).

Verso: full journal title in italic, followed by 0(0).

For IMechE journals: e.g. J. Automobile Engineering 0(0), without the Proc. IMechE or journal letter).

## 3. General style and layout

### 3.2 Figures

1. STM: All figures should have a key line (i.e. be enclosed in a box).
2. Figures should be appropriately sized (done by the TS). They do not need to be a full column width or page width.
5. Any abbreviations needing to be spelled out should be listed after the caption, starting on the next line, in the following format: IC: internal combustion; PID: proportional–integral–derivative).
6. Captions are positioned below the figures and left aligned. 7. Captions should start, for example, **Figure 1.** (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but should be aligned left. 8. Where figures have multiple parts, these should be labelled as (a), (b), (c), etc. (not A, B, C). Captions should contain subheadings for all parts if not present in the figure itself. 9. All figures should be numbered consecutively and cited in the text as Figure 1, Figure 2 etc. (Figure should be spelled out in full, not abbreviated). 10. Text citations: figures should be referenced in the text as follows: Figure 1, or Figures 1 and 2, or Figures 2 to 4, or Figure 1(a) and (b), or Figure 2(a) to (c). Where the figure citation is not part of the sentence it should be placed in parentheses. Examples:

### 3.3 Tables

1. Tables do not need to be a full column width or page width, but should be the appropriate width for the content. They will be laid out by the TS so no work is required by CEs on table layout, only on content.
2. Table headings should be left aligned, even when they relate to multiple columns, unless this creates confusion.
3. Tables should only have minimal horizontal rules for clarity, and no vertical rules.
4. All tables should be numbered consecutively and cited in the text as Table 1, Table 2 etc. (Table should be spelled out in full, not abbreviated).

7. Any abbreviations needing to be spelled out should be listed under the table (smaller font, TS will format), in the following format: IC: internal combustion; PID: proportional–integral–derivative.
8. General notes to the Table should be positioned below the Table, typeset in a smaller font and should start ‘Note:’, and end in a full stop. Do not add the word ‘Note:’ unless needed for clarity.
9. Footnotes should be represented in the table by superscript letters a, b, c, etc., and appear below the Table (smaller font, TS will format). Each footnote should start a new line and end with a full stop. These notes should precede the source for the table, if included.
10. Captions are positioned above the table and left aligned.
11. Captions should start, for example, Table 1. (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but aligned left.
13. Normal text in columns should always be left aligned. Data in tables should be aligned on units if all the data in that column take the same units. Otherwise, the data should be left aligned. Units in table headings should be enclosed by parentheses, not square brackets (if any brackets are required at all).

### 3.6 Appendices

#### Maths notation list

1. Where present, notation should appear as Appendix 1, following the references. The heading Notation should be a B-head (not Notations; it is not plural).
2. Abbreviations list should be separated from mathematical notation under a separate B-head Abbreviations.
3. Notation should be listed in alphabetical order, English letters first, followed by Greek, followed by numbers, followed by symbols.



4. Subscripts and superscript should come under a separate C-head (italic and smaller font), and symbols should follow the same order as in point 2 above.

5. The Notation section does not need to be cited in the text, like other Appendices.

6. Notation list should be left aligned. Text in the notation section should be left aligned in general, not justified.

7. Please note that a notation list is not compulsory in mathematical papers, as long as all symbols are defined in the text.

#### Other appendices

1. Numbering of figures/tables/equations in Appendices should follow on from the numbering in the text.

2. All tables/figures should have captions.

3. All appendices should be cited in the text, e.g. (see Appendix 1). If they are not cited, authors need to be queried for a citation position.

#### 3.7 Notes and footnotes

##### Textual notes

Any other textual notes: are indicated by a superscript Arabic numeral placed after the punctuation. All textual notes should be collected and placed after the text and before the reference section with the heading Notes.

##### STM

References: Vancouver style reference citations are represented as textual notes, as a superscript Arabic numeral. Harvard style references are as follows (Smith, 1999).

Any other textual notes (whether references are Harvard or Vancouver) are indicated by a superscript Arabic letter and the corresponding footnote appears at the bottom of the relevant column.

In STM journals, footnotes should be edited into the text if appropriately and easily incorporated. However, please leave footnotes if this is not possible.

#### 4. Spelling, punctuation and formatting

##### 4.1 Author style/voice

We will endeavour to keep the author's voice as much as possible:

1. Some authors write in the first person. CEs please note that we will not be taking articles out of the first person into the third person.
2. Where American authors have used American spellings, we should also endeavour to keep the author's grammar/punctuation, e.g. closed em-dashes instead of spaced en-dashes, single quotation marks within double, series comma etc.
3. Where UK authors have used –ise spellings throughout their papers in a consistent fashion, please do not change. Where there is inconsistency, use -ize.

##### 4.2 General spelling rules

The general rules are as follows:

- UK spellings should be followed for European articles (-ise is acceptable)
- US spellings should be followed for North American articles
- Rest of the world – follow author style but make it consistent
- Canadian spellings should be standardized to UK or US, depending on author preference
- The following list shows some common exceptions to the ‘-ize’ rule:

Samples:

advertise      arise      devise      enfranchise      expertise      merchandise      promise

surmise

advise      chastise      disenfranchise      enterprise      franchise      misadvise

reprise      surprise

affranchise    circumcise    disguise    exercise    improvise    premise  
                   revise    televise  
 apprise        comprise    emprise    excise    incise    prise    supervise    treatise

### **SAGE Vancouver referencing style**

#### 1. General

1. Reference numbers have full points in the reference list.
2. Please ensure that publications are referenced in the order in which they appear in the text.
3. Journal titles should be abbreviated according to the standard in the Index Medicus. If unsure, please check for any inconsistencies within reference lists. For STM journals, please refer also to the following: <http://scieng.library.ubc.ca/coden/>.
4. Do not separate initials with spaces or full points, but add a full point after last initial before the title.
5. Up to three authors may be listed. If more, then list the first three authors and represent the rest by et al. Fewer author names followed by et al. is also acceptable. Where et al. is used, it should always be upright, not italic in both references and textual citations.
6. Last Names containing de, van, von, De, Van, Von, de la, etc. should be listed under D and V respectively. List them as: De Roux DP and not Roux DP, de. When cited in the main text without the first name, use capitals for De, Van, Von, De la, etc. (Van Dijk, year)
7. Names containing Jr or II should be listed as follows:
  - Author Last Name Initial Jr (year)
  - Author Last Name Initial II (year)

#### 2. Text citations

Please use superscript numerals after the punctuation (STM) and check that it corresponds to the correct number in the reference list.

### 3. Reference styles

#### Book

1. Huff D. How to lie with statistics. 4th ed. London: Penguin, 1991, p.51.

#### Chapter in book

1. Huff D and Black TL. Comprehensive statistics. In: Miller C and Smith H (eds) How to lie with statistics. 4th ed. London: Penguin, 1991, pp.51–55.

#### Journal article

1. Ludbrook J, Miller T and Russel A. Musculoavenous pumps in the human lower limb. *Am Heart J* 1966; 71: 635–641.
2. Araki C, Black TL, Patberg FT, et al. Significance of calf muscle pump function in venous ulceration. *J Vasc Surg* 1994; 20: 872–879.

#### Journal article published ahead of print

1. Ludbrook J. Musculoavenous pumps in the human lower limb. *Am Heart J*. Epub ahead of print 12 June 2011. DOI: 10.1177/095443271167940.

#### Website

1. Smith JR. Choosing your reference style. *Online Referencing* 2(3), <http://orj.sagepub.com> (2003, accessed 12 October 2008).
2. National Center for Professional Certification. Factors affecting organizational climate and retention, [www.cwla.org/programmes/triechmann/2002fbwfiles](http://www.cwla.org/programmes/triechmann/2002fbwfiles) (2002, accessed 10 July 2010).

#### Conference paper

1. Peters J. Musculovenous pumps in the human lower limb. In: ASME conference on automatic transmissions (ed A O'Brien), Pisa, Italy, 29 May–2 June 2003, paper no. GE1234, pp.4–10. New York: ASME.

#### Thesis/dissertation

1. Clark JM. Referencing style for journals. PhD Thesis, University of Leicester, UK, 2002.

#### Patent and patent applications

1. Smith ST. Referencing styles for journals – a new method. Patent 12346-ZH, USA, 2011.
2. Jones P. Referencing styles for journals – a new method. Patent application 12346-ZHA, USA, 2011.

#### Report (published/unpublished)

1. MacDonald S. The state of social welfare in the UK. Report, University of Durham, UK, June 2011.
2. Citigroup Ltd. How to make your money work for you. Report for the Department of Finance. Report no. 123345, 13 June 2011. Oxford: OUP.

#### SAE/JSAE etc. papers

1. Clark JM. A new exhaust gasket manifold for powertrains. SAE paper 2002-0101234, 2002.

#### Newspaper/magazine

1. Clark JM. Referencing style for journals. The Independent, 21 May 2006, p.10.

#### Package insert (medical etc.)

1. Eisai Inc. Aloxi (package insert). New York: Esai Inc, 2008.

#### Manual (automotive etc.)

1. Fiat. Driver's manual, Fiat Uno 4-litre diesel model, December 2010.

#### Standard

1. ISO 27799:2008. Information security management in health.

Appendix 2-B  
Extract of annotated transcript (Belinda's interview)

Initial notations	Line no	Transcript text I= interviewer, B= Belinda	Emergent themes	Final theme
<b>Branch brings a lot of interests together</b>	114	B: So it's just I think it's just a branch of psychology that just brings so many things	<b>Holistic care combines m&amp;p.health</b>	<b>Being part of something special</b>
	115	together. I really enjoy systemic working cos I really, you know I, get the opportunity with		
<b>Systemic working with medical teams, couples</b>	116	my inpatient work to work with the ward teams I don't do so much family work really here	<b>Variation in role</b>	
	117	but we're a small service so we are really commissioned for patients only. But we'll do		
<b>Variety in role- interesting, responsive</b>	118	some couples work sometimes if that's indicated so so much scope, so much variety. Ermm	<b>Variation in role</b>	
	119	you know and each day is as different, you know one day's very different from the next. So	<b>Responsivity of role</b>	<b>The therapeutic relationship</b>
<b>Rewarding- Patients are resourceful</b>	120	it's just really interesting I think. Very very rewarding. People can bring a lot to their work	<b>Patients as resourceful</b>	
<b>Make a big difference quickly</b>	121	which as a clinician can be really rewarding. You can make a big difference very quickly.	<b>Making big changes quickly</b>	<b>Being part of something special</b>
	122	Ermm you know quite often we might be working with people who may have had lots of		
<b>Comparison to m.health or variety of patients in her role now?</b>	123	lifelong experiences, trauma, mental health difficulties or they may not and they may have		
	124	been very psychological psychologically well before physical illness umm comes into their	<b>Comparison to m.health</b>	<b>Being part of something special</b>
<b>Patients: resourceful, motivated</b>	125	life. And it might be an accumulation of events, that they're very well resourced to work	<b>Patients as resourceful</b>	
	126	with you so you can get quick results very effectively with people cos they're often very		
<b>Comparison to m.health- buzzing</b>	127	motivated. So that's a really nice little aspect of the work. You get some of those real kind		
	128	of umm (pause) buzzing moments I think in this job that there were maybe fewer of in in	<b>Comparison to m.health (different)</b>	<b>Being part of something special</b>
	129	sort of more community working in chronic long term mental health conditions. You it's a		
<b>In it for the long term- p or m.health?</b>	130	very different type of work, you're often in it for the long term with people. Umm so it's		
	131	yeah, it brings its challenges umm and and it's just something that I think fits well with me.		
	132	Hopefully I bring something to it as well.		
	133	I: So it sounds like there's quite a few rewarding aspects of the job?		

	134	B: Definitely		
	135	I: What about the more difficult aspects of the job?	Emotions attached to role	
Appropriate sadness but not depressing	136	B: Umm there's a lot of sadness sometimes. You know people have occasionally said to me	Other people's expectations of role (unfounded)	The consummate professional
Other people expect it to be	137	ooh is that not depressing? Well I don't find it so. There is sadness but umm that's	Own expectations of psychs	
Psychs are trained to manage the sadness	138	appropriate for what we're doing umm you you know we have as you know we have lots of		
	139	training in how to sort of manage things, how to use supervision and all of those things. But	Empathising with patients	The therapeutic relationship
BUT	140	occasionally you know you'll meet somebody that has an effect on you in a particular	Emotions attached to role	
There are times when it does affect you	141	way and if that person's treatment isn't going to plan or they're getting bad news or	Plan to manage own well-being	Practice what you preach
Chest crushing sadness	142	umm you know eventually they die you need to think about ways of keeping yourself	Identifying with patients	The therapeutic relationship
	143	well because there are moments where you you can feel that kind of chest crushing	Projecting on to patients	
Identify with particular patients- young reminds you of someone	144	sadness* and often it's with younger people but not always sometimes it's just there's	Acceptance & normalisation of effect of role	Being part of something special
	145	something might push your button, you know there's someone who just triggers something	Use of humour	The therapeutic relationship
Can happen in any role & to anyone	146	about you, they look like Mum or remind you of Grandad, those kinds of things that we all	Acceptance & normalisation of effect of role	The consummate professional
	147	get, but yeah anybody can get that in any aspect of our work. Umm I knew that I was	Questioning own usefulness	Being part of something special
Supportive, friendly, similar team	148	coming in to a really supportive and friendly team. We all take a quite a similar approach to	Just being with patients	
	149	our work in that we're flexible about it umm it it pays to have some humour about yourself		
Humour- lighten atmosphere	150	and with your colleagues in terms of umm you know just sometimes you need to just		
Support from colleagues	151	lighten the atmosphere a little bit. Umm and and I think just to accept its ok to find things		
	152	upsetting because it is. Umm and that's very much the the sort of human element of what		
Acceptance of sadness- its human	153	we do. Umm and and knowing that sometimes you can't do anything but what you can do is		
	154	be with somebody and just sit alongside or sit with. Umm which I think one of the		
What am I actually doing vs. just being with	155	challenges there can be am I doing anything here. What what am I doing?		

\* The development of this quote is illustrated throughout the appendices, starting here from the original transcript.

*Appendix 2-C*  
Excerpt from theme table

<b>Theme title and description</b>		
The Therapeutic Relationship		
<p>This theme captured the nature of the therapeutic relationship between the psychologists and patients in a palliative care setting, including the ease at which participants identified and empathised with palliative care patients. It seemed the fact that we will all die knocked down any ‘them and us’ distinctions between the psychologists and patients. Particular types of patients resonated with participants and at times made it easier to find compassion for them. A sense of uncertainty existed in the therapeutic relationship given the chance of patients dying. This uncertainty and the intensity of the time period, aided a quickening in the development of the therapeutic relationship and a sense of urgency in the psychologists’ work. When patients did die the psychologists were often left with a sense of unfinished business and used various methods to process patients’ deaths.</p>		
<b>Examples of emergent themes</b>	<b>Examples of initial notations</b>	<b>Examples of quotations</b>
Quickened rapport due to sense of impending death	Therapeutic relationship speeded up. (Pam). Working in the moment on current difficulties. Sense of urgency but not pressure, just being responsive. (Rose).	Maybe that process is speeded up because you know you’ve only got six months so you then don’t, you don’t relax and think well I won’t take the risk. (Pam). People are in are in the midst of something, so whereas I might have been doing a lot of work on helping people process something that was a long time ago, people might be quite quickly post-treatment or just having had some difficult news last week or that I might pop on to the day unit just to check out what’s happening, so it feels very kind of in sometimes in the moment of. (Rose).
Intimacy & intensity of conversations	Privilege, people allow you in at important time. Quickly develop rapport. (Belinda). Relationship with patients- very strong. Poignancy of time period. (Sarah).	People let you into their lives at their most vulnerable and distressing times and you know welcome you with open arms and and very quickly share their, you know they’re most intimate thoughts. (Belinda). I think meeting people and supporting them through a really really grim time of their life you do feel like there’s quite a strong connection. (Sarah).
Empathising with patients	Easier to understand & be compassionate with p.health clients- we know what cancer is. (Nick).	One of the benefits of working in cancer, there’s always, for me at least, a bit easier to find my compassion whereas I think in mental health it’s more difficult because we don’t understand really borderline personality disorder. (Nick).

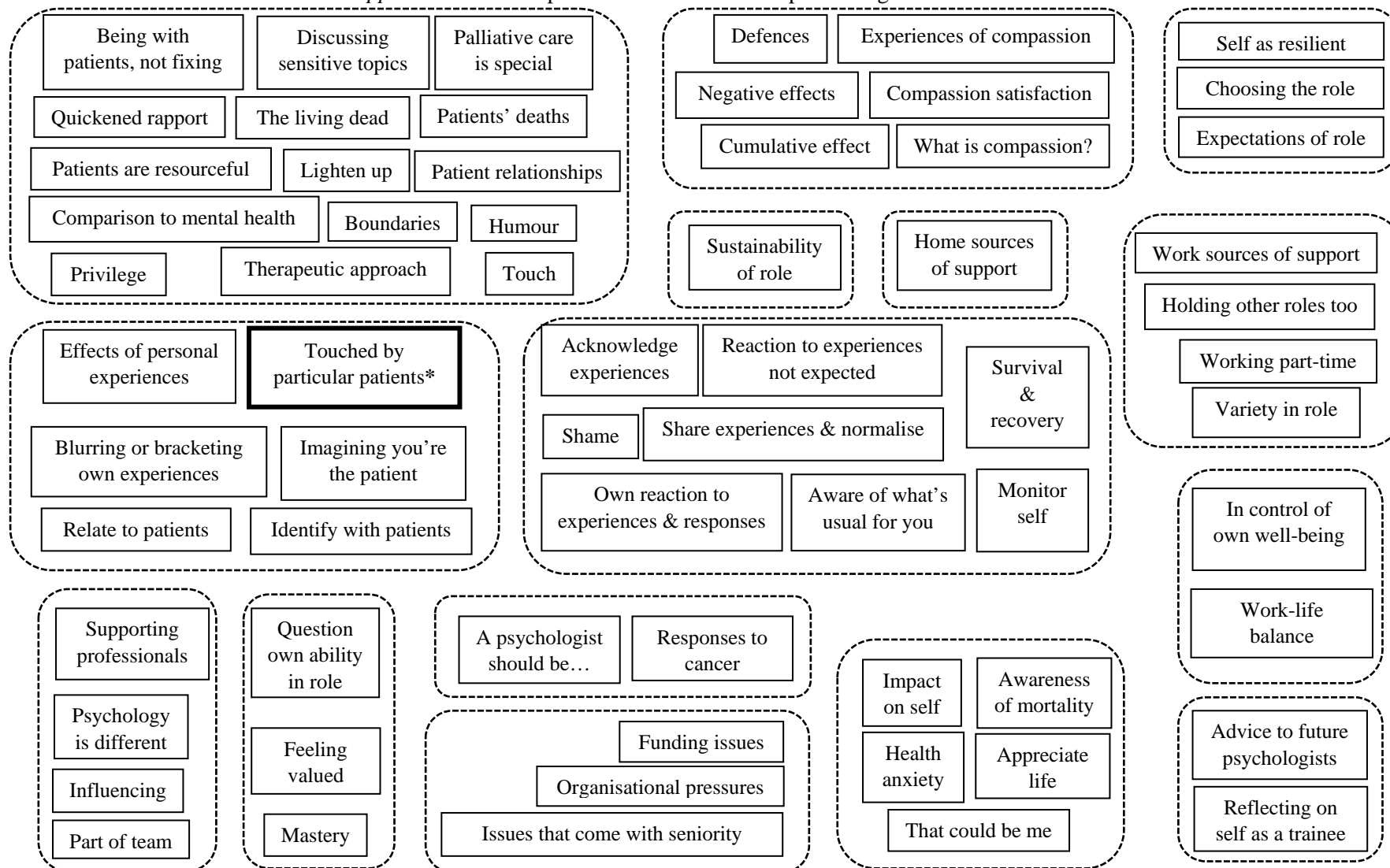


	Emotional impact- you're comparable to the patient (perhaps unlike m.health) - you will die too. (Pam).	It's emotionally more thought provoking because we may not suffer from depression or bipolar but we're all going to die. (Pam).
Identifying with patients	Distant- not using as much of self, not identifying as much compared to other roles +ve, more energy. (June).	Maybe I'm a bit more distant as well because of, I know that I've been in settings where there's so much of me present and I don't feel like I'm using as much of myself umm in this setting which is a good thing. (June).
	Different to m.health? Comparison of physical & mental health patients. Relates better with physical health patients. (Peter).	A lot of the people I encounter in palliative care are psychologically intact as it were. You know they're not psychologically damaged or disturbed in anyway, they're normal people like you or I but dealing with the most horrendous of situations. (Peter).
Touched by particular patients*	There are times when it does affect you. Chest crushing sadness. Empathising with patients. Plan to manage own well-being. (Belinda).	You'll meet somebody that has an effect on you in a particular way and if that person's treatment isn't going to plan or they're getting bad news or umm you know eventually they die, you need to think about ways of keeping yourself well because there are moments where you, you can feel that kind of chest crushing sadness. (Belinda).
	Having children of my own- young Sus. Transference & counter-transference with particular clients. Effect of being a mother. (April).	Working with someone of a teenage age, that would, I'd be drawn in a bit more, someone of a younger age group cos that's, I guess that just tugs at certain heartstrings about how you see youth and having children of my own, that sort of thing. (April).
Uncertainty & unfinished endings	Unfinished endings with clients. Hard to not be able to finish, say goodbye or acknowledge you may not see them again. (Richard).	It's hard to get a proper goodbye. (Richard).  I find it much harder to contract with people when it comes to end-of-life stuff, I feel that that's something we just have to accept may not have a very neat ending. (Richard).
	No tidy endings- feel cheated. Sense of impending death- working on a session by session basis. Interrupted therapeutic relationship & endings. (Sarah).	Sometimes I feel a bit cheated of an ending sometimes, umm because we, you know there isn't, there's often not a sense of any kind of tidy ending... I mean it's the ultimate ending isn't it, when I say we haven't had a particular ending, the person dying is the ultimate ending. (Sarah).

Acts to process patients' deaths	Initially shocked, now harsh, cut-off. Noticing difference between self & trainees' reactions. Harden self to the emotional impact. (Lisa).	Even that sense of, of a kind of relief that 'oh, right I've got a space in my diary then' because someone's in hospital or someone's died. Which seems really callous but I think it's just what can happen over time when you can kind of harden yourself up. (Lisa).
	Can't grieve too much- it would stop you being able to do job- why? Cos of time limits, being emotional, psychologists need to manage their stuff? (Peter).	I can't give too much time to kind of grieving because in a way it would stop you being able to do the job. (Peter).
Discovering patients' deaths	Sadness hit me. Honeymoon period at first. Response to patients dying. Emotions evolve during role. (Jane).	There was kind of two or three years into the job there became more bereavements of patients that I'd got to know really well. And I think that's when the sadness of it started to hit me. Whereas the first bit was a bit like a honeymoon period. (Jane).
	Carrying patients with you in your mind. Unsure whether to check- confirm if she is dead or not. (June).	I haven't heard from her, and I keep, I can, she's there...She's there, she's there in my mind... you kind of have to live with that kind of unsatisfied curiosity about where people are and what they're up to. Umm so do I remain that way? Do I keep her alive in my head or do I, do I kind of look on you know the the the database and see if she's still around? (June).
Impact of patients' deaths	Attachment to some patients. Sad when patients die. Rightly so- It's ok to be sad. (Steve).	So it's sad, yeah, and rightly so it's sad when they die. (Steve).
	Realism & compassion hand in hand. Death is sometimes welcomed by clients- that feels better for him. (Richard).	To prepare for that and I know that they, that death is in sometimes very welcome because they are in a lot of pain and suffering by the end as well. So I think I have a very compassionate view that death is sometimes the best possible outcome. And I think that's a very realistic way of thinking about it. (Richard).

\* The development of this quote 'Belinda, Line 140-144' is illustrated throughout the appendices. How it forms part of a theme can be seen here.

Appendix 2-D. Example of initial candidate map of emergent themes



\*The sub-theme containing the quote 'Belinda, Line 140-144' is asterisked in order to illustrate the development of the quote into a theme.

*Appendix 2-E*  
Extracts from field diary

My thoughts after arranging an interview with Jane:

“Just finished arranging an interview time with Jane. Although she seemed very keen to take part in the interview and spoke about the research’s importance, she also said she could only spare 30 minutes due to being very busy. Is this the first part of data she’s given me? That she wants to talk about compassion fatigue and self-care, that she thinks it’s important but hasn’t got the time to prioritise it? It seems ironic. I’m wondering what will emerge during the interview and whether that’s how self-care in general is for her. Maybe this is a thread that’s run through a few of my interviews so far actually- people being very busy and wanting to take time to self-care but not being able to and perhaps not even realising the irony in it?”

(Extract from reflexive diary- 03/10/14)

My immediate thoughts following Richard’s interview:

“The general themes I picked up during this interview are about how the person’s early experiences made them feel that they were used to being in a challenging environment. It felt like they’d always been in battles, were used to it, and now expected things would always be a battle but they could deal with it. Like they’d become hard.

There was a massive sense of being busy, so much so that I was worried about taking up his time but he also seemed really happy to take time out for the interview, almost like it gave him a bit of a reprieve and a chance to stop and reflect on how busy he is.

He seemed so busy, he even spoke really fast as if he needed to get as many words out as possible, to get as much done as possible all of the time. When I arrived he commented on how he had been hoping to get some admin done before the interview but time had crept up on him. After the interview he was hoping to get the admin done so he could leave on time. He didn’t seem to resent this busyness but just presented it as ‘well that’s how it is here, it’s just part of the job’, and he’s happy to do it for his patients.”

(Extract from reflexive diary- 14/10/14)

My thoughts following the first two interviews:

“I’m finding it difficult not to be in therapy mode during interviews and having to catch myself when I go to sum up or reflect back what the participant has said. I’m worried that this could have the potential to contaminate the data in some way but it also feels weird to not have this sort of interaction with the individual. Thankfully it seems like the psychologists would talk a lot even without me asking any questions. But there could have been times where, if the group was less articulate and verbose, that I might have missed out on information because I didn’t follow up with necessary prompts. I’ve just gone through a transcript, outlining where I could have added more prompts or follow up questions, and hopefully this will lead to more in-depth data about participants’ feelings and thoughts in the

following interviews. It seems like in this first couple of interviews I'm getting a lot of 'its ok, I'm fine, I'm a psychologist I'm supposed to be able to cope'. This could be how they really feel but I was expecting to get some deeper reflections. Hopefully it'll get deeper as time goes on".

(Extract from reflexive diary- 20/10/14)

A particularly difficult interview to transcribe:

"Just finished transcribing June's interview. That was so hard. There was so much background noise from construction work down the corridor even though I'd reduced it as much as I could on the software I have. My pedal gave up working too so I had to use the keyboard to rewind and pause which is much slower. This has been the longest one to transcribe so far. This was the final interview to transcribe. In total it's taken 10 hours 45 minutes to transcribe compared to just 3 hours 30 minutes for some. But this was the last interview!"

(Extract from reflexive diary- 20/12/14)

*Appendix 2-F*  
Theme Table

<b>Emergent themes</b>	<b>Final themes</b>
Longing for a role in palliative care	<b>Being part of something special</b>
Palliative care is an easier area than mental health	
Feeling valued as a psychologist in palliative care	
Psychology providing something unique & special	
Spreading psychological thinking	
Being part of a team	
Palliative care teams as special	
Palliative care patients as more resourceful	
Quicker to make progress with palliative care patients	
Working with irreversible difficulties	
No sense of responsibility	
Acceptance vs. change in therapeutic work	
Own expectations of & response to palliative care	
Others' response to palliative care & your role	
Balance between draining & rewarding	<b>The therapeutic relationship*</b>
Patients as living dead	
Seeing patients' trajectory of illness	
Impact of patients deaths	
Discovering patients' deaths	
Acts to processing patients' deaths	
Uncertainty & unfinished endings	
Transference & countertransference	
Touched by particular patients*	
Identifying with patients	
Empathising with patients	
Loosening of boundaries	
Effects of personal experiences related to death	
Intimacy & intensity of conversations	
Sense of impending death	
Quickened rapport	<b>Doing more with less</b>
Stress of organisational issues	
Protected as a psychologist	
Protected within palliative care	
Sense of busyness	
Impact on patient care	
Expectation to do more	
Battling against pressures	
Targets	
Changing NHS/services	
Evolving roles	
Effect of seniority	
Stretched resources	
Uncompassionate environment	
Awareness of own mortality	
Awareness of human fragility	
Health anxiety	
Cumulative effect	
Depletion	
Insomnia	

Rumination		
Compassion fatigue		
Compassion satisfaction		
Mechanisms as defence strategies		
Outlook on life & death		
This could be me		
Reprioritisation in life		
Disparity between psychologist & patient		
Appreciation of life		
Adversarial growth or damage		
Direction of compassion		
Learn from patients		
Own responses to experiences of compassion fatigue		<b>The consummate professional</b>
Shame & stigma		
Acknowledging impact		
Sharing, accepting & normalising compassion fatigue		
Surviving & recovering		
Not expecting it		
Awareness of own usual & unusual responses		
Use of the self		
Monitoring self		
Providing & receiving support		
Own expectations of a psychologist		
Others' expectations of a psychologist		
Impression management		
Psychologists are human too		
Psychologists as containers	<b>Practice what you preach</b>	
Self as resilient		
Inner resources		
Suitability of role for some rather than others		
Sense of mastery		
In control of own well-being		
Work-life balance		
Support from colleagues		
Sustainability of role		
Recommendations for future trainees		
Reflecting upon self prior to role		
Support from people outside of work		
Boundaries between work & home		
Transitioning between work & home		
Strategies to self-care outside of work		
Escapism		
Distraction		
Personal therapy		
Respite from palliative care		
Supervision		
Strategies to self-care in work		

\*The theme (the therapeutic relationship) and sub-theme (touched by particular patients) containing the quote 'Belinda, Line 140-144' are asterisked in order to illustrate the development of the quote into a theme.

### **Section Three: Critical Appraisal**

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**Critical reflections on the process of conducting research within palliative care**

**Word Count:**

**3, 857 (excluding references and appendix)**

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**Critical reflections on the process of conducting research within palliative care**

Critical reflections on the process of conducting research within palliative care will be discussed within this paper. Firstly, a summary of the current research study's findings will be given, followed by discussion of the development of the project idea, recruitment process, data collection and analysis, and planned dissemination. This paper will conclude with a consideration of the effects on the researcher of conducting research in palliative care. The use of the first person within this paper is intentional to allow the researcher to reflect on their experience of the project.

**Summary of research**

The research project explored 12 clinical psychologists' (CPs) experiences of compassion and resilience when working in palliative care, using one-to-one interviews. Interpretative Phenomenological Analysis (IPA) identified six superordinate themes: Being Part of Something Special, The Therapeutic Relationship, Doing More With Less, Being Changed as a Result of Involvement, The Consummate Professional, and Practicing What you Preach.

The study emphasised implications regarding the training and support offered to CPs working in palliative care in order to maintain their levels of compassion and resilience. In addition, the project goes some way to highlighting, sharing, and normalising experiences of compassion fatigue in CPs. I hope that this enables individuals to acknowledge the impact of their work without experiencing the feelings of shame, stigma, and embarrassment that participants spoke about, and facilitates them to access the support they want.

**Development of the project idea**

Prior to clinical psychology training I volunteered in a hospice and during my training I worked with patients with a diagnosis of cancer. As a result, I came to appreciate the value of clinical psychology to patients and families at the end-of-life. Furthermore, specific guidance<sup>1,2</sup> stipulates the role of CPs within palliative care in supporting patients, families, and colleagues. I was also increasingly aware through my development as a trainee clinical psychologist that my supervisors and I were expected to support many people within the systems we worked in and to take care of ourselves too. It was then that I began to wonder who or what takes care of us, and what are the effects if this does not happen?

I attended a conference where an individual gave a presentation on their own experiences of compassion fatigue.<sup>3</sup> I then began to explore the field of compassion and self-care research. After speaking with a colleague during my health placement I decided that this was an area I wanted to conduct further research into and this person became my thesis supervisor. As part of this piece of research I was also interested in the experiences of feeling cared for from the patients' perspective in palliative care and so my literature review idea developed.

**Recruitment process**

There are no set rules about the size of an IPA sample.<sup>4</sup> I was initially apprehensive about being able to recruit an adequate number of participants to take part in this study, due to there being a relatively small number of CPs working in palliative care in the United Kingdom (UK) compared to those working in more traditional fields of mental health. I planned to recruit between eight to 12 participants given the research aims and objectives, the size of the available sample, and the time limited nature of the project. However, nearly double the upper limit of participants I had planned to recruit responded to the emails and

adverts I placed. A total of 23 CPs responded. Such was the interest in the project, that when I informed subsequent respondents that I had reached my capacity of participants and therefore they could not take part, several suggested that I could contact them if any of my scheduled interviews fell through and expressed their interest and pleasure that such a project was taking place. To say I was relieved that I had obtained my required participants was an understatement. However, I was also aware that having 12 participants as opposed to eight meant I had considerably more work to do in terms of conducting interviews, transcribing, and analysing data within my time scale. Nonetheless, I felt hugely satisfied and believed that this response rate demonstrated the importance of the project topic and highlighted that it is an area that CPs are concerned with and want to discuss.

### **Data collection**

As I recruited via national groups this meant that many of my participants were based outside of the North West of England, where I am based. Where possible I endeavoured to travel by car and train to conduct interviews face-to-face with participants. However, where this was not possible due to time constraints and convenience for participants, interviews were conducted over the telephone.

Prior to clinical psychology training I worked for a charity that provided support to clients over the telephone and so I felt I had transferable skills that I would be able to use in the process of conducting research interviews over the telephone. In preparation for the interviews I also spent time reading literature about conducting research interviews over the telephone. More and more researchers are suggesting that with improvements in technology, data collection no longer needs to rely only on face-to-face interviews.<sup>5</sup> Telephone interviews have been suggested to be able to provide data that is as equally valuable as face-to-face interviews.<sup>5,6</sup> I also discovered via the use of an IPA discussion

group that Jonathan Smith himself, the developer of IPA, is currently involved in a study using telephone as well as face-to-face interviews.<sup>7</sup>

I was initially apprehensive about the ability to develop rapport over the telephone and about the richness of data that could be gathered. I wondered about potentially losing data due to not getting a sense of the participant and their story from 'being in the room' with them, and not being able to see their facial expressions and body language. It has been suggested that telephone interviews can result in a lack of rapport developing between interviewee and researcher, and a loss of non-verbal cues which can aid communication.<sup>8,9</sup> To counter the unavailability of non-verbal cues in telephone interviews, an alternative that I could have used was Skype video-conferencing. It has been suggested that using this method allows researchers to access both verbal and non-verbal cues in a manner that is equal to face-to-face interviews.<sup>10-12</sup> However, it has been noted that the suggestion that telephone interviews lead to difficulties in rapport and communication has been made despite there being a lack of evidence regarding telephone interviews.<sup>8,9</sup> To investigate this, Irvine<sup>8</sup> used conversation analysis techniques to examine whether actual differences existed between face-to-face and telephone interviews, and concluded that concerns about rapport, and impaired communication and understanding were unsupported. Irvine<sup>8</sup> felt that telephone interviews could involve a different type of interaction but that this did not necessarily result in a disadvantage for a study, and that decisions about data collection methods should be particular to each study and its objectives. It is clear that further research is needed to establish an evidence base regarding the advantages and disadvantages of using telephone interviews, as well as other technological communication methods, in qualitative research.<sup>8,9</sup>

During my preparatory reading regarding telephone interviews, I collected several useful tips from researchers that had used this method, such as researching the various types of equipment available to record interviews and practicing with the equipment.<sup>13</sup> To record

the interviews I used a pick up microphone that plugged into the Dictaphone and had an earpiece that I placed between my ear and the telephone. Despite practicing with the equipment with willing friends, several issues during the research interviews did arise. At times the quality of the sound that the microphone picked up was poor which resulted in lengthy transcribing times and on one occasion an interview was interrupted due to the telephone battery running out in a participant's handset.

Research has also suggested that telephone interviews lead to researchers having reduced insight into participants' physical surroundings during the interview.<sup>8</sup> This was certainly true for me, where for example, an interview was interrupted by knocks on the door at the participants' interview site. At other times I wondered about the amount of concentration participants were giving during the interviews. For example, during one interview I could hear the participant making themselves a drink in their kitchen at home. In hindsight I could have asked participants beforehand whether they wanted to plan a break at a particular time so that this could be worked around and the flow of the interview would not be interrupted. My advice for future researchers using telephone interviews would be to explain to participants that a quiet environment where they are unlikely to be disturbed is required and to check whether the participant expects any interruptions.

The four telephone interviews were on average two and a half minutes shorter than the eight face-to-face interviews. However, caution has been advised when drawing conclusions about the quality of data based on the length of interview time.<sup>8</sup> Research questions were covered in both telephone and face-to-face interviews and it may be that the telephone interviews were simply more focused. What sometimes felt like the preliminary general questions and answers, and required pleasantries in order to build rapport before getting to the crux of the matter were rebuffed by the telephone participants and they simply got straight to their experiences of compassion fatigue and the like much quicker. Irvine<sup>8</sup>

also suggested that telephone interviews have a more formal and less social feel because of less time being spent on these preliminaries. In my study it seemed that telephone participants had an extra layer of anonymity, given that I had never met them face-to-face, which may have allowed them to speak more freely, which has also been proposed in existing literature.<sup>8</sup>

Aside from some technological difficulties, it did not seem that my initial apprehensions about using telephone interviews were borne out and I found their use to be convenient and efficient.

### **Data analysis**

I decided to use IPA to research CPs' experiences as this is a method that does not attempt to establish an objective truth but simply to explore the meaning and subjective experiences of individuals. I felt that the field of compassion and self-care in professionals required a more qualitative and reflexive approach to counter balance some of the quantitative research that uses pre-determined hypotheses, surveys, and questionnaires. In essence I wanted to hear directly from participants about what matters to them.

IPA views individuals as active contributors to their reality, who are embedded, intertwined, and immersed in the world they inhabit.<sup>14</sup> Furthermore, it questions whether a reality could ever exist that is separate from us and proposes the framework of symbolic interactionism suggesting that our meanings are constructed within a personal and social world.<sup>15</sup>

Whilst the findings relate to the experiences of this particular group of professionals, it is likely that the meanings could be transferable to other CPs working in end-of-life care. Furthermore, it is possible that the findings could be transferable to psychologists working in

other areas where they experience patients' deaths frequently, such as those working in other physical health areas and with elderly patients.

Due to the time limited nature of the project I decided to follow the IPA suggestions of Smith, Flowers and Larkin<sup>16</sup> who state that when working with a larger body of data, emphasis is on identifying key emergent themes for the whole group whilst still exploring individuals' experience. This entailed conducting a complete detailed analysis of each of the first four participants' data. That is for each transcript I followed these steps: 1) reading and re-reading the transcript, 2) making initial annotations in the transcript's right hand margin, 3) identifying and developing emergent themes in the transcript's left hand margin, and 4) compiling a list of emergent themes, searching for connections across these emergent themes, and clustering connected themes together to form superordinate and subordinate themes.

For each of the remaining eight participants' data I conducted steps one to three. Only once this was complete for all eight transcripts did I then move on to step four where I compiled a list of the eight transcripts' emergent themes, searched for connections across these, and clustered them to create a set of superordinate and subordinate themes for this group of data. This is in keeping with Smith et al's<sup>16</sup> suggestion that when working with a larger body of data, emergent themes be identified at case level but the search for patterns and connections amongst themes is only done once on a group level when examining all of the cases' emergent themes together. Prior to examining the eight cases as a whole, I chose to do the complete analysis of the initial four cases in order to allow me to experience and immerse myself in the detail and process of completing analysis from start to finish. After completing this I was satisfied that I would be able to interpret and demonstrate the group level themes and still illustrate the idiographic nature of individuals' data by using quotes as examples of how themes applied to the individuals. Furthermore, final themes were representative of the

majority of participants therefore exemplifying how both the group and individuals' stories had been captured.

### **Plans for dissemination**

I plan to disseminate the findings of this research via publication in a peer reviewed journal and presentations at appropriate conferences. One such potential conference is that held by the national special interest group for psychologists working in oncology and palliative care (SIGOPAC). The SIGOPAC was one of the groups I used to recruit my sample and therefore would provide an opportunity to provide feedback to some of the study's participants. Feeding back directly to participants has been suggested to reduce participants' potential feelings of exploitation by the researcher and enhance trust in the research process, emphasise participants' role in furthering knowledge, and demonstrate that their contribution is being used to raise awareness of issues.<sup>17</sup> However, it is also possible that presenting findings to participants can have negative consequences, such as the distress of revisiting a potentially difficult experience<sup>17</sup> and re-encountering their own narrative but in the presence of others.<sup>18</sup> It has been suggested that this can lead to a feeling of exposure, as well as worries about how they are being represented in public and perceived by others even when quotes have been anonymised.<sup>18</sup>

A further difficulty in disseminating the findings is related to the relatively small number of CPs working in palliative care in the UK, particularly where many members of the field know one another. This potentially raises the chance of people being able to identify participants. This issue led to me deciding to significantly pare down the pen portraits of participants to reduce the possibility of identification.

The 'consummate professional' conclusion I drew from the findings, whereby CPs are invested in a level of impression management regarding their coping, is potentially sensitive.



There is the possibility that CPs may feel exposed by this and may even adopt the position of impression management when hearing the findings and in turn may refute the proposal that their work has a greater impact on them than they allow others to see. Nevertheless, the research findings are valuable and should be disseminated. Therefore, it is imperative that when I come to disseminate my findings I do so in a sensitive manner. I will need to balance my commitment to making use of the participants' investment of time and sharing of stories, with my wanting to contribute to the evidence base, whilst protecting participants' well-being and identity.

### **Effects of conducting research within palliative care**

Whilst undertaking this project my Granddad was diagnosed with a chronic physical condition and began to access palliative care within a hospice setting. This cross over between my professional and personal life was at times difficult to navigate. As I was reading studies for my literature review regarding palliative care I found myself questioning, is this how my Granddad feels and is this how he experiences care? Furthermore, research sampling palliative care patients has a tendency to report the number of patients that die during the study and this was a stark reminder that my Granddad had begun this trajectory. Whilst I was spending time reading about the types of experience he may be having I was spending less time actually with him whilst he was alive. It was at these points that I regretted my choice of thesis topic. At other times I felt a passion about this research, perhaps because of my Granddad's predicament and a sense of wanting to complete the research for him, ultimately to add to the field in order to improve services for palliative care patients, him now being one of them.

At times it felt extremely intense and as if I was immersed in death. I was either reading about death for my thesis or I was talking about it with my family. I felt like I

wanted to avoid doing thesis work or even avoid conversations with loved ones knowing what the topic would be. During this experience I identified with the CPs participating in my research who had described similar reactions in their work, such as avoiding a patient or not listening to a story which they found particularly emotive. I wondered then, was I experiencing compassion fatigue too and was this response in me signalling that I too needed to take action to improve my self-care and seek support?

In addition to my own reflections on how I was experiencing the research process, two of the participants actually asked me this question at the end of their interviews. The two participants both made reference to themselves feeling that they had been changed as a result of working in palliative care. The participants felt they had lost a sense of naivety that they wished they could get back, but knew they could not. The participants also spoke about having gained a sense of vulnerability regarding the fragility of life. The participants directly questioning me about this brought into the forefront of my mind a need to further reflect on the process, the idea that the research was potentially changing me, and that I should be prioritising self-care. As part of the research process I kept a field diary, of which extracts relating to the impact of the research upon me can be found in Appendix 3-A.

In order to help me reflect on the research process, I negotiated additional supervision from my supervisors, both of whom were supportive. Using supervision in this way felt vital and was a positive and helpful space. However, somewhat mirroring my participants' experiences, practicing self-care seemed easy to do in theory but, when balancing this with thesis, other training commitments such as placements and teaching, as well as home life, was actually more difficult in practice. Nevertheless, similar to how the research participants described utilising practices they would suggest to patients, I too began to use some of the strategies I recommend in my clinical work, such as mindfulness and producing a self-soothe box.

I spent time reflecting on how the research had changed me. I had read about, listened to, and considered other people's experiences of working with death and the existential matters this brought up for them. In doing so I too had begun to consider these issues for myself and I realised my view on life and death had changed. When participants spoke about gaining a new appreciation for life and reprioritising aspects as a result, it felt like I too was beginning to feel this. I appreciated the shortness of life and accordingly wanted to reprioritise life according to my values, spend time with the people I love, and do the things I enjoy. However, at the same time I was partly constrained in doing this because of the time and effort the thesis demanded. Accordingly, for now whilst it seems that my outlook has been changed I have so far been unable to put this into action.

There seems to be relatively little literature about the effects on researchers of working with end-of-life issues.<sup>19</sup> However, listening to respondents' accounts of stories about death can evoke emotions within the researcher<sup>20,21</sup> and therefore it is important for researchers to consider their emotional responses and practice self-care.<sup>22</sup> Although strategies such as using a reflective journal and supervision have been suggested<sup>22</sup>, it is possible that further research is needed in the area of developing resilience within researchers and embedding this as part of their training.<sup>19</sup>

One reflective paper I found<sup>23</sup> commented on the emotional effect of conducting research relating to the end-of-life and how it can be a positive experience. Briggs<sup>23</sup> talks about experiencing a period of adjustment following involvement in end-of-life research, which left him with a newfound focus on end-of-life issues, confronting his own mortality, and seeing life and death differently. I felt that the process of conducting research within palliative care, added to the simultaneous potential loss of loved ones in my personal life, had changed me and taught me some important life lessons.

Similarly, I wondered how having the opportunity to discuss their experiences and feelings about working in palliative care had affected the participants. Some of the participants commented on how it had felt for them to reflect on their experiences, for example noticing the difference they were feeling in being the talker rather than the listener, and feeling it was self-indulgent. I felt that this research gave the CPs the opportunity to be on the receiving end of being asked to reflect on their experiences and perform some sort of introspection that perhaps they do not usually do. In addition, I wondered whether the interview served to reconnect the participants with the reasons why they chose and continue to work in this area, as well as taking stock of the works' effects on them, and potentially highlighting the need for increased self-care.

## **Conclusions**

Overall this project has highlighted the emotions that palliative care can evoke and the importance of self-care for all involved, including the CPs that work in palliative care and researchers exploring the area. The themes that emerged from the research highlighted that, although CPs are a group of professionals who are used to being the listeners and containers of others' emotions, we are also affected and require strategies to help us process our responses. This is required in order to maintain our well-being but also to continue to care for others. Whilst CPs may have the knowledge around how to do this, it may not actually happen in practice which suggests that further work is required to encourage practitioners to prioritise self-care and to acknowledge the impact their work has on them. Furthermore, developments are needed within organisations in order to recognise that all professionals can be impacted by the work they do and to support them with this. I hope that this research gave the CPs the opportunity to drop the consummate professional image they use if only for a

short while in order to truly reflect upon the impact of their work on them and how they manage this.

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*Appendix 3-A*

## Extracts from field diary

My thoughts following Rose's interview:

“Yesterday Rose was the second participant to ask me after the interview how I was finding the immersion in palliative care during my project and how I was managing to self-care. Jane asked me something similar too. Jane said had I been her trainee she may not have told me as much as she has done because she would have wanted to protect me. There was something from both Rose and Jane about reflecting on themselves before they worked in palliative care and a kind of luxury of being naive, feeling strong, and not having had to confront certain existential issues yet. It almost seemed like there was a bit of regret in there or happily remembering what they used to have but had now lost, and a sense of sorrow that they were perhaps witnessing or even contributing to that happening to me. It felt as though they had wanted to protect me and that made me wonder that despite them both speaking about experiences of feeling impacted upon by their work, how much did they hold back? It's also reinforcing the feeling that I am going to be changed by this research, which I think I had expected but only in the same way any research would change you. Now this feels like there's going to be a bigger shift in my outlook in general, on life and death. I'm not sure how I feel about it”.

(Extract from reflexive diary- 14/11/14)

My considerations about personal and professional lives mirroring each other:

“Today I noticed that I’m making jokes about my research and the fact that I’m always thinking about death. For example, I’ll finish reading an article about professionals’ grief over patients’ deaths and I’ll get up to make a cup of tea and say ‘on that cheery note’. But it’s not cheery and it’s not funny. I think this is some sort of defence thing, and that if I didn’t laugh and joke about it, actually I would cry. It feels like I’m living and breathing, excuse the pun (another example of a non-funny joke defence thingy), death and dying. I’m either reading literature about patients’ experiences in palliative care, or I’m writing about my participants’ experiences when patients die, or I’m trying to make links in their data about how their experiences have changed their outlook on death. All the while I’m thinking about my outlook on death and my Granddad who’s in a hospice at the moment. I read an article about the experiences of patients with COPD, like him, and I keep wondering is this how he feels? And then the article talks about how many of the patients died before the end of the study. This weekend I’m going to visit him in the hospice. Maybe there’s an opportunity to do some impromptu field research whilst I’m there! (I know, it’s not funny)”.

(Extract from reflexive diary- 13/02/15)

**Section Four: Ethics Section**

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**Word Count: 2, 566 (excluding appendices)**

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**Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University**

**Application for Ethical Approval for Research**

1. Apply to the committee by submitting
  - ✓ The University's Stage 1 Self-Assessment Form (standard form or student form) **and** the Project Information & Ethics questionnaire. These are available on the Research Support Office website: [LU Ethics](http://www.lancs.ac.uk/shm/research/ethics/)
  - ✓ The completed FHMREC application form
  - ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)
  - ✓ All accompanying research materials such as, but not limited to,
    - 1) Advertising materials (posters, e-mails)
    - 2) Letters of invitation to participate
    - 3) Participant information sheets
    - 4) Consent forms
    - 5) Questionnaires, surveys, demographic sheets
    - 6) Interview schedules, interview question guides, focus group scripts
    - 7) Debriefing sheets, resource lists
2. Submit all the materials electronically as a **SINGLE** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (<http://www.lancs.ac.uk/shm/research/ethics/>).
3. Submit one collated and signed paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website <http://www.lancs.ac.uk/shm/research/ethics/>. Applications must be submitted by the deadline stated on the website, to:
 

OMITTED  
Faculty of Health & Medicine  
B03, Furness College Lancaster  
University,  
LA1 4YG  
OMITTED
5. Attend the committee meeting on the day that the application is considered.

1. Title of Project: Exploring experiences of compassion and resilience in clinical psychologists working in palliative care	
2. If this is a student project, please indicate what type of project by ticking the relevant box:	
PG Diploma	<input type="checkbox"/> Masters dissertation <input type="checkbox"/> MRes <input type="checkbox"/> MSc <input type="checkbox"/> DClInPsy SRP
PhD Thesis	<input type="checkbox"/> PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being <input type="checkbox"/> MD
<input checked="" type="checkbox"/> <u>DClInPsy Thesis</u>	
<input type="checkbox"/> Special Study Module (2 <sup>nd</sup> year medical student)	

3. Type of study  
 Involves direct involvement by human subjects

Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

**Applicant information**

4. Name of applicant/researcher:  
 Laura Cramond

5. Appointment/position held by applicant and Division within FHM  
 Trainee Clinical Psychologist

6. Contact information for applicant:

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7. Project supervisor(s), if different from applicant:

Name(s): Ian Fletcher  
 Claire Rehan

E-mail(s): i.j.fletcher@lancaster.ac.uk  
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8. Appointment held by supervisor(s) and institution(s) where based (if applicable): Ian

Fletcher- Senior Lecturer, Division of Health Research, Lancaster University

Claire Rehan- Clinical Psychologist, Clinical Health Psychology, Royal Bolton Hospital

9. Names and appointments of all members of the research team (including degree where applicable)

Laura Cramond- Trainee Clinical Psychologist, Lancaster University & Lancashire Care NHS Trust Ian

Fletcher- Senior Lecturer, Division of Health Research, Lancaster University

Claire Rehan- Clinical Psychologist, Clinical Health Psychology, Royal Bolton Hospital

**The Project**

**NOTE:** In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

This project will explore experiences of compassion (fatigue & satisfaction) and resilience in clinical psychologists working in palliative care using one to one interviews. Interpretive phenomenological analysis (IPA) will be used to interpret the data. It is hoped that the knowledge gained in this study will include how to prepare for such experiences and how to cope with them. Knowledge will also be gained regarding circumstances that led up to the experience. It is hoped that findings could be influential in highlighting how practitioners new to the area can prepare for working in palliative care and be aware of risk factors, triggers and signs that affect and indicate their levels of compassion and resilience, as well as methods to help cope with such experiences, and build resilience for the future.

11. Anticipated project dates

Start date: September 2014      End date: May 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

Between 10-12 Clinical Psychologists working in palliative care settings (e.g. hospices, hospitals)

13. How will participants be recruited and from where? Be as specific as possible.

Clinical Psychologists will be recruited via a national special interest group for oncology and palliative care psychologists (SIGOPAC), cancer network psychology groups, and via the UK edition of ehospice. The groups' mailing list coordinators will forward a communication from the principal investigator to group members via their current mailing list (post or email). This communication will introduce the project and attach a participant information sheet. The participant information sheet attached to the communication for the groups' mailing lists will include details of how potential participants can contact the principal investigator via email, telephone or post to declare their interest in the project.

A recruitment advert will also be placed in the UK edition of ehospice, a free app and website publishing news, commentary and analysis on hospice, palliative and end of life care. The advert will introduce the project and contain details of how potential participants can contact the principal investigator in order to find out more about the project.

In addition to the above recruitment methods, snowball sampling will be used to recruit further participants. The communication to members of the groups' mailing lists will also ask recipients to forward the communication to others who they believe could take part in the study. Furthermore, the advert in ehospice will ask individuals to forward details to others who they believe could take part in the study.

14. What procedure is proposed for obtaining consent?

Once the principal investigator has been contacted by a potential participant they will arrange a detailed discussion about the project with the participant, ensure that they have read the information sheet and receive their informed consent. Participants will sign a consent form.

This discussion will take place in person usually, however where this is not possible it may be done over the telephone, and then signed consent forms will be posted by the participant to the principal investigator using their freepost address. The principal investigator will ensure the potential participant has had at least one week to consider the participant information sheet before receiving their consent and conducting the interview if they are willing.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

It is unlikely that the project will cause discomfort, inconvenience or danger to the participant. The interview length (approximately one hour) could be considered an inconvenience however if potential participants feel that taking part would be an inconvenience it is unlikely that they will choose to participate. Furthermore, the interview will be arranged to take place at a time and place, and using a method of communication (e.g. face to face or telephone) that is convenient for the participant.

It is unlikely that the material discussed during interview will be distressing to the participant. However, if a participant were to become distressed and require further support they will be provided with contact details for sources of support, such as Samaritans and Mind, and advised to contact their GP for further support should they think it necessary.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

It is not expected that the principal investigator will encounter any risks beyond that of a typical day working in a clinical service. Furthermore, the principal investigator has several

years of experience of working in a clinical setting and is experienced in containing and assessing distress and risk. The principal investigator is trained in communication, de-escalation and breakaway techniques. Should anything be disclosed during interview which causes the principal investigator concern, the principal investigator would seek advice from their field or academic supervisor as appropriate depending on the nature of the concern. Similarly, all participants will also be informed that any disclosure of information relating to risk or harm to themselves or someone else will result in the principal investigator following appropriate risk assessment procedures. Where possible and where this does not create any further risk or harm these procedures will be discussed with the participant before they are taken. This would include the principal investigator discussing concerns with their supervisor and with other individuals/agencies where necessary, for example Safeguarding Leads, Social Services and Police etc. The principal investigator will ensure they have a mobile telephone with them during the interview with the telephone numbers of the field supervisor, Safeguarding Leads, Social Services and Police etc stored should they need to contact them urgently.

Interviews will take place at participants' place of work, home or over the telephone. If interviews take place at work places it will be in venues where other clinical staff are present and are aware of the principal investigator's presence. Where interviews take place at participants' homes Lancaster University & Lancashire Care NHS Foundation Trust's lone working policies will be adhered to by implementing a buddy system whereby a colleague will have details of the principal investigator's movements, contact details, and agreed escalation procedures if the principal investigator fails to contact the buddy with the agreed timescales.

Where possible interviews will take place during normal working hours (Mon- Fri 8am-6pm), however where this is not possible due to participants' commitments interviews will take place during early evenings.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits to participants as a result of this research, although some participants may find taking part interesting, and it will provide them with a space for reflection and an opportunity to voice their opinion which may be valued.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

No incentives or payments will be made.

19. Briefly describe your data collection and analysis methods, and the rationale for their use



Qualitative interviews with participants will be conducted by the principal investigator face-to-face with an individual either at their place of work or their home. Alternatively, interviews will take place over the telephone where it is inconvenient to meet in person, for example the participant lives outside of the North West of England.

A semi-structured interview topic guide has been developed with the aim of addressing the stated aims and research questions. The guide was designed by the principal investigator and revised with the help of the project supervisors to achieve a comprehensive and reliable framework to allow exploration of the subject matter. Broad, open questions will be used to guide and prompt dialogue but participants will be encouraged to take the lead on the direction of discussions. Interviews (whether in person or over the telephone) will last approximately one hour and will be digitally audio-recorded. The principal investigator will then transcribe interviews with all identifiable information removed.

Data will be analysed by the principal investigator with support from the academic supervisor. Interview transcripts will be explored using IPA to extract themes around the experiences of participants. IPA will allow the detailed exploration of how participants make sense of and apply meaning to their personal experiences. IPA will also allow the researcher to have an active and reflective role within the research. The following IPA process will be used to analyse data (Smith, Flowers & Larkin, 2009): identify themes within the first participant's interview, connect these themes, continue the analysis within the other participants' interviews, connect the themes as a group and identify super-ordinate themes across the group.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

The project received input into its development at an early stage from a service user advisory panel and a peer-review process at Lancaster University. The findings of the project will be presented to tutors, students and the service user advisory panel at the Clinical Psychology department, Lancaster University.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Interviews will be audio-recorded. Recordings will be transferred from the non-encrypted digital recorder to the principal investigator's password protected H drive on Lancaster University's computer network as soon as possible following the end of the interview. Interviews will then be

Interviews will then be transcribed with all identifiable information removed. Audio-recordings will be deleted after the award of the Doctorate in Clinical Psychology. Each participant will be given a pseudonym, therefore personal details will not be included on research documents, such as transcripts. Anonymised transcripts will be stored in password protected file space on the Lancaster University computer server. Hard copies of consent forms will be stored securely in locked storage cabinets in lockable offices at Lancaster University.

After the study has ended, data (interview transcripts and consent forms) will be encrypted in order that it can be transferred securely to the Doctorate in Clinical Psychology Research Coordinator, who will store the data in password-protected file space on the university server. Data will then be destroyed 10 years after submission.

22. Will audio or video recording take place?  no  audio  video  
 If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Interviews (whether in person or over the telephone) will be audio-recorded with the consent of participants. Recordings will be transferred from a non-encrypted digital recorder to the principal investigator's password protected H drive on Lancaster University's computer network as soon as possible following the end of the interview. The reason for transferring these files as soon as possible is because it is not possible to encrypt the portable digital recorder. Interviews will then be transcribed with all identifiable information, such as names and place of work, removed. Audio-recordings will be deleted after the award of the Doctorate in Clinical Psychology. Each participant will be given a unique identity code, therefore personal details will not be included on research documents, such as transcripts.

23. What are the plans for dissemination of findings from the research?

The project findings will be disseminated via publication of a paper in an appropriate journal and presentation at appropriate conferences and seminars. The findings will also be presented to tutors, students and the service user advisory panel at Lancaster University.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice from the FHMREC?

No

Signatures:                      Applicant: .....

Date: 10.06.2014

Project Supervisor\* (if applicable): .....

Date: 10.06.2014

\*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

LANCASTER  
UNIVERSITY



Applicant: Laura Cramond  
Supervisor: Dr Ian Fletcher  
Department: DHR

22 September 2014

Dear Laura and Ian,

**Re: Exploring experiences of compassion and resilience in clinical psychologists working in palliative care**

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, [REDACTED], [ethics@lancaster.ac.uk](mailto:ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

[REDACTED]

Secretary, University Research Ethics Committee

Cc: [REDACTED]

Enterprise

Lancaster University  
Bowland Main  
Lancaster LA1 4YT  
United Kingdom

\*Please note the new address of the RSO is Research Support Office, 858 Bowland Main, Lancaster University, LA1 4YT

Phone: +44 (0) 1524 593229  
Web: <http://www.lancs.ac.uk>

*Appendix 4-A*

Thesis Protocol

**Exploring experiences of compassion and resilience in clinical psychologists working in palliative care.**

Version 1, 10.06.2014

**Title**

Exploring experiences of compassion and resilience in clinical psychologists working in palliative care

**Research team**

The research team consists of the following members:

Principal Investigator- Laura Cramond, Trainee Clinical Psychologist, Doctorate in Clinical Psychology, Lancaster University

Academic Supervisor- Dr. Ian Fletcher, Senior Lecturer, Doctorate in Health Research, Lancaster University

Field Supervisor- Dr. Claire Rehan, Clinical Psychologist, Bolton NHS Foundation Trust

**Summary**

This project will explore experiences of compassion (fatigue & satisfaction) and resilience in clinical psychologists working in palliative care using one to one interviews.

Interpretive phenomenological analysis (IPA) will be used with data.

Research findings will increase knowledge regarding the experiences of working in

palliative care and how this affects compassion, and provide insight for individuals, teams and employers in how to build resilience in staff working in palliative care, thereby enhancing compassion satisfaction and reducing compassion fatigue.

### **Background**

Palliative care was defined by the World Health Organization (WHO, 2002) as an approach that improves the quality of life of patients and families facing problems associated with life-threatening illness. It refers to the prevention and relief of suffering via early identification, and assessment and treatment of pain and other physical, psychosocial and spiritual difficulties. More people than ever now require palliative care (WHO, 2004) and the quality of that care is a global public health issue (Foley, 2003). Clinical psychologists are now an important part of palliative care teams (Nice, 2004) which goes some way to addressing the psychological needs of patients at the end of their life. If professionals are not supported their ability to offer effective care to patients at the end of their life is implicated.

In palliative care especially, professionals are confronted with the suffering and potentially the death of patients. Such confrontation with death is said to influence all of our experiences and conduct (Yalom, 1980). The way professionals deal with trauma and loss in work shapes their capacity to be present and provide effective care to patients (Mathieu, 2012), this is particularly true in palliative care where professionals may regularly experience loss and bereavement.

It is suggested that the cumulative effect of psychologists' work of listening to clients' stories of pain, fear and suffering may lead therapists to also feel similar pain, fear and suffering (Figley, 1995). It is suggested that this is an occupational hazard and that it would be near impossible to do this type of work and remain unchanged (Pearlman &

Saakvitne, 1995).

In palliative care settings psychologists are often supporting patients, families and other staff members but how do psychologists themselves gain support and take care of themselves? This is an important question as in order to effectively help others psychologists need to take care of themselves.

In order to provide effective palliative care compassion is required.

Compassion has been described as feeling and acting with deep empathy and sorrow for individuals who suffer (Stamm, 2002). Working in palliative care settings can be both a highly rewarding and demanding profession, and as such there are both costs and gains associated with such experiences of caring for others.

Compassion satisfaction relates to the pleasure an individual derives from being able to do their work and do it well (Stamm, 1999). This satisfaction may be related to aspects of providing care, the organisational system worked in, colleagues, and beliefs about the self.

The flipside to compassion satisfaction is compassion fatigue. This can be thought of as the more negative aspects of helping those who experience trauma and suffering, or from a palliative care aspect, physical health difficulties.

Compassion fatigue refers to the profound emotional and physical exhaustion that helping professionals can develop over the course of their career. It is a gradual erosion of all the things that keep us connected to others in our caregiver role: empathy, hope, and compassion, not only for others but also for ourselves. Almost every helper who cares about their clients will eventually develop a certain amount of it, in varying degrees of severity. In fact, compassion fatigue has been suggested to affect those who do their work well (Figley, 1995). Related but distinct concepts to compassion fatigue include vicarious traumatization and burnout.

It has been suggested that compassion satisfaction may counterbalance the risks of compassion fatigue and increase levels of resiliency (Stamm, 2002).

Furthermore, research has found that higher levels of compassion satisfaction are associated with lower levels of compassion fatigue (Slocum-Gori et al., 2013). It has been suggested that levels of compassion satisfaction can be increased and compassion fatigue decreased by various methods within organisations, teams, and individuals, however very little is known about the factors that limit or promote positive outcomes when practicing compassion (Slocum-Gori, Hemsworth, Chan, Carson & Kazanjian, 2013).

In order for professionals to protect themselves from the negative effects of this type of work self-care and resilience is important. If self-care is neglected it can lead to an array of difficulties including but not limited to distress, ill health, increased compassion fatigue, and reduced compassion satisfaction (Jaffee & Scott, 1984).

Much quantitative data indicates that many helping professionals from various fields experience signs of compassion fatigue. Depending on the studies, between 40% and 85% of helping professionals were found to have compassion fatigue (Mathieu, 2012). Within palliative care a recent study carried out among hospice nurses found that 79% had moderate to high rates of compassion fatigue, and 83% of those who did not have debriefing or other support after a patient's death had symptoms of compassion fatigue (Mathieu, 2012).

On the other hand, it has been found that levels of burnout are no higher in palliative care than in other areas of health (Pereira, Fonseca, & Carvalho, 2011). There are numerous positive aspects of this type of work, such as undergoing personal growth, gaining a deeper connection with the human experience, and a greater awareness of all aspects of life (Pearlman, 1999). In palliative care being faced with death on a regular



basis may lead to a reassessment of priorities in life, having more compassion and a greater connection with humanness (Yalom, 1980). However, little empirical research highlights what it is about working in palliative care that is most rewarding and therefore what could help to increase levels of compassion satisfaction.

The levels of compassion fatigue and satisfaction that a helper experiences can ebb and flow from one day to the next, and even healthy helpers with optimal work/life balance and self-care strategies can experience a higher than normal level of compassion fatigue when they are overloaded, are working with a lot of traumatic content, or find their case load suddenly heavy with clients who are all chronically in crisis. (Mathieu, 2012).

The issue of self-care amongst the helping profession is not a new idea with many psychologists emphasising its importance for many years (Freudenberger, 1974; Guy, 2000; Kilburg, Nathan, & Thoreson, 1986; Mahoney, 1997; Norcross, 2000; Saakvitne & Pearlman, 1996; Schwebel, Skorina, & Schoener, 1991; Sussman, 1995) however the changing roles of psychologists and their work environment, including increased workload, reduced resources and organisational change can make it difficult to allow self-care to be a priority. In addition to this neglected self-care can lead to an increase in absenteeism and long term sickness.

Compassion fatigue can be reversed and compassion satisfaction increased by improving self-care and work/life balance. It has been suggested that the areas to focus on are building resiliency, acquiring increased work skills, self-care, resolving internal conflicts, and having a connection with others (Baranowsky & Gentry, 2011). However, it is unknown whether professionals in palliative care do employ these strategies when they themselves experience what could be considered compassion fatigue.

In order to provide an effective service to clients and teams the concept of life balance has been emphasised (Yassen, 1995). Self-care strategies that have been

recommended range from physical exercise and care for our physical bodies (Pearlman, 1999), spiritual exercise (Pearlman & Saakvitne, 1995), and peer support (Catherall, 1999). Supervision is also routinely used by psychologists however it has been suggested that self-presentational concerns in the workplace sometimes leads to professionals not discussing some issues in supervision (Tardy & Dindia, 2006).

Alternatively, psychological strategies can be employed by professionals who may think about certain aspects of work over others in order to protect themselves. For example positioning themselves as an observer or being task orientated rather than patient orientated (Menzies-Lyth, 1960).

As well as individual coping strategies, more effective organizational changes that offer helpers better working conditions, more control over their schedule, good-quality supervision, and reduced exposure to trauma are needed.

The field of compassion research is still in its infancy but rapidly growing. Whilst more quantitative research exists around compassion fatigue and satisfaction and related concepts there is a lack of qualitative research and the stories of professionals experiencing it (Pererira et al., 2011; Sabo, 2011). There has also been a clarion call for more understanding about the factors that may increase or reduce risk (Pererira et al., 2011; Sabo, 2011).

In addition to knowing what strategies can help professionals to cope with working in palliative care whilst reducing compassion fatigue and increasing compassion satisfaction it is important to understand what triggers and warning signs professionals recognise in themselves when they are practicing compassion.

It has been said that psychologists “have a duty to educate those entering the field to anticipate how the work will affect them and to prepare them to address these effects” (Zimering, Munroe, & Gulliver, 2003). This project could help to provide the knowledge

and understanding to do this.

### **Aims and objectives**

In exploring the experiences of compassion (both fatigue & satisfaction) and resilience in clinical psychologists working in palliative care it is hoped that knowledge regarding these experiences will be gained, including how to prevent and prepare for such experiences, and how to cope with them. Knowledge will also be gained regarding circumstances that led up to such experiences. It is hoped that findings could be influential in highlighting how practitioners new to the area can prepare for working in palliative care and be aware of risk factors, triggers and signs that affect and indicate their levels of compassion and resilience, as well as methods to help cope with such experiences, and build resilience for the future.

### **Methodology**

#### **Design**

This study aims to gain qualitative accounts of compassion and resilience as experienced by clinical psychologists working in palliative care and explore how clinical psychologists working in palliative care cope with such experiences. These questions naturally lend themselves to a qualitative design using one to one semi-structured interviews and interpretative phenomenological analysis.

#### **Participants**

It is anticipated that between 10 and 12 clinical psychologists working in palliative care (e.g. hospices and hospitals) will be recruited via a national special interest group for oncology and palliative care psychologists (SIGOPAC) and via cancer network

psychology groups. In addition, a recruitment advert will be placed in the UK edition of ehospice, a free app and website publishing news, commentary and analysis on hospice, palliative and end of life care. The advert will introduce the project and contain details of how potential participants can contact the principal investigator in order to find out more about the project. Convenience sampling (Strauss, 1987), as well as snowball sampling will be used. In the event that the number of participants requesting to take part in this research exceeds 12, then priority will be granted to those who request to take part first and meet the recruitment criteria.

### **Materials**

Materials include a communication to potential participants from the principal investigator to be sent via the SIGOPAC and cancer network psychology groups' mailing list coordinators, a recruitment advert to be placed in ehospice, a participant information sheet, a consent form, interview topic guide, and a debrief sheet (see following appendices).

### **Recruitment & Consent**

The coordinators of the SIGOPAC and cancer network psychology groups' mailing list will forward a communication from the principal investigator to group members via their current mailing list (post or email) introducing the project and attaching a participant information sheet which will include details of the project and how potential participants can contact the principal investigator via email, telephone or post to declare their interest in the project.

The recruitment advert to be placed in ehospice will introduce the project and contain details of how potential participants can contact the principal investigator via email, telephone or post in order to find out more about the project.

Snowballing sampling will also be used to recruit participants. Thereby, members of the SIGOPAC and cancer network groups' mailing lists will be asked to forward the above communication through their social networks to others who they believe could take part in the study. Furthermore, the advert in ehospice will ask individuals to forward details to others who they believe could take part in the study.

Once the principal investigator has been contacted by a potential participant they will arrange a detailed discussion with the potential participant about the project and ensure that the participant has read the information sheet. In addition, the principal investigator will ensure that the potential participant meets the recruitment criteria, i.e. they are a clinical psychologist working in palliative care. This discussion will take place in person usually, however where this is not possible it may be done over the telephone, and then signed consent forms will be posted by the participant to the principal investigator using their freepost address. The principal investigator will ensure the potential participant has had at least one week to consider the participant information sheet before organizing the receiving of consent if they are willing and conducting the interview.

A mutually convenient date and time will be arranged to conduct the interview either at the participants' home or workplace or over the telephone. Interviews will usually take place outside of participants' work hours and at their home. However, if the participant chooses to take part in the interview during their work hours or at their workplace it will be their responsibility to inform their local R&D department and comply with any procedures necessary.

Participants will be given an opportunity to ask any questions they might have prior to the start of their interview. They will also be given the principal investigator's contact details should they require any further information, at any point, about the research process. Participants will be given the option to stop the interview at any time and

withdraw their consent. Participants will also be able to withdraw their consent and data after the interview has been completed. After the data has been anonymised and the process of analysis has begun it may not be possible to withdraw the data although every attempt will be made to do so.

Recruitment will begin around September 2014 or as soon as ethical approval is obtained. It is expected that data collection will begin by October 2014 and will be complete by December 2014. However, in the event that this is not successful interviews may continue up to March 2015.

### **Data collection**

Participation in the interviews will be entirely voluntary. Qualitative interviews with participants will be conducted by the principal investigator face-to-face with an individual either at their home or their place of work. Alternatively, interviews will take place over the telephone where it is inconvenient to meet in person, for example if the participant lives outside of the North West of England. Where possible interviews will take place during weekdays (Mon-Fri 8am-6pm), however where this is not possible due to participants' commitments interviews will take place during early evenings.

A semi-structured interview schedule has been developed with the aim of addressing the stated aims and research questions. The guide was designed by the principal investigator and revised with the help of the project supervisors to achieve a comprehensive and reliable framework to allow exploration of the subject matter. Literature including existing quantitative measures of compassion fatigue and satisfaction, for example the Professional Quality of Life Scale (ProQOL; Stamm, 2008), was used to develop ideas for areas to cover. Broad, open questions will be

used to guide and prompt dialogue but participants will be encouraged to take the lead on the direction of discussions.

The schedule will include questions around:

- Their role, how long they have done it
- Why and how they came into this area of work
- Atmosphere at work
- Positives/negatives of the work
- Feelings induced by work setting
- Feelings induced by the individuals worked with
- Impact of work on them as a person/their view of life/well-being/social life/home life
- Satisfaction with work
- Difference made to others in work
- Experiences of loss in work
- Examples of work that touched them in a positive way
- Challenges of work
- Warning signs
- Triggers
- Coping strategies in work
- Concrete strategies of caring for self
- Strategies to prepare for future work experiences
- Recommendations for professionals entering this area of work

Interviews (whether in person or over the telephone) will last approximately one hour and will be digitally audio-recorded.

### **Data handling and analysis**

Interviews will be audio-recorded. Recordings will be transferred from the digital recorder to Lancaster University's encrypted server as soon as possible following the end of the interview. Interviews will then be transcribed with all identifiable information, such as names and work places, removed. Each participant will be given a pseudonym, therefore personal details will not be included on research documents, such as transcripts. Audio-recordings will be deleted after transcripts have been checked for accuracy. Anonymised transcripts will be stored on the principal investigator's password protected H drive on Lancaster University's computer network. Hard copies of consent forms will be stored securely in locked storage cabinets in lockable offices at Lancaster University. Data will be kept for ten years from the end of the study. Data will then be destroyed.

Access to audio-files and transcripts will be restricted to the principal investigator and academic supervisor. The field supervisor will only have access to anonymised and analysed data within the report write up.

Data will be analysed by the principal investigator with support from the academic supervisor. Data will be analysed at Lancaster University and the principal investigator's home. Each participant will be given a pseudonym, therefore personal details will not be included on research documents. Paper files will be kept in locked cabinets whilst electronic files will be stored on the principal investigator's password protected H drive on Lancaster University's computer network.

Interview transcripts will be explored using IPA to extract themes within the



participants' experiences. IPA will allow the detailed exploration of how participants make sense of and apply meaning to their personal experiences. IPA will also allow the principal investigator to have an active and reflective role within the research.

The following IPA process will be used to analyse data (Smith, Flowers & Larkin, 2009): Firstly, themes will be identified within the first participant's interview. Secondly, these themes will be connected. Thirdly, the analysis will be continued throughout the remaining participants' interviews. Finally, the themes will be connected for the group of participants and super-ordinate themes will be identified across the group. At all stages of analysis, the academic supervisor will be consulted. This triangulation will help to ensure data consistency and accuracy.

Direct quotes may be reported, however care will be taken to ensure that those used do not make it possible for participants to be identified. If the principal investigator becomes aware that quotes make participants identifiable, the quotes in question will be removed.

### **Ethical Issues**

The project will be submitted for ethical review and approval by the Faculty of Health and Medicine Research Ethics Committee. The project proposal underwent a peer review process within the Doctorate in Clinical Psychology programme, which included course tutors, service user representatives and fellow trainees, during which it was granted approval.

It is not expected that the principal investigator will encounter any risks beyond that of a typical day working in a clinical service. It is unlikely that the material discussed during interview will be distressing to the principal investigator or to the participant. However, if a participant were to become distressed and require further

support they will be provided with contact details for sources of support, such as Samaritans and Mind, and advised to contact their GP for further support should they think it necessary.

Furthermore, the principal investigator has several years of experience of working in a clinical setting and is experienced in containing and assessing distress and risk. The principal investigator is trained in communication, de-escalation and breakaway techniques. Should anything be disclosed during interview which causes the principal investigator concern, the principal investigator would seek advice from their field or academic supervisor as appropriate depending on the nature of the concern. Similarly, all participants will also be informed that any disclosure of information relating to risk or harm to themselves or someone else will result in the principal investigator following appropriate risk assessment procedures. Where possible and where this does not create any further risk or harm these procedures will be discussed with the participant before they are taken. This would include the principal investigator discussing concerns with their supervisor and with other individuals/agencies where necessary, for example Safeguarding Leads, Social Services and Police etc. The principal investigator will ensure they have a mobile telephone with them during the interview with relevant telephone numbers stored should they need to contact someone urgently.

### **Practical Issues**

Costs such as the printing of participant materials, envelopes and postage will be covered by Lancaster University.

Where it is not convenient to receive consent and conduct interviews face to face, for example with participants living outside of the North West of England where travel

would incur significant financial and time costs, this will be done over the telephone and digitally audio-recorded.

### **Service user involvement**

The project received input into its development at an early stage from a service user advisory panel and a peer-review process at Lancaster University. The findings of the project will be presented to tutors, students and the service user advisory panel at Lancaster University.

### **Project management**

The principal investigator will receive supervision from the academic supervisor formally on a monthly basis however the academic and field supervisors will also be available to give support and advice as needed.

### **Dissemination**

The project findings will be disseminated via publication of a paper in an appropriate journal and presentation at appropriate conferences and seminars. The findings will also be presented to tutors, students and the service user advisory panel at Lancaster University.



Data collection																	
Data analysis & report writing																	
Submit draft																	
Submit final																	
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**Communication to potential participants to be sent via SIGOPAC and cancer network psychology groups' mailing lists, Version 2, 29.07.2014**



MESSAGE HEADER: Research in to experiences of compassion and resilience in clinical psychologists working in palliative care.

Hello,

I am sending this email to invite you to participate in a research study. I am a Trainee Clinical Psychologist at Lancaster University.

As part of my training I am conducting a research study for my doctoral thesis using one to one interviews that explore the experiences of compassion and resilience in clinical psychologists working in palliative care.

Research findings will increase knowledge regarding the experiences of compassion and provide insight into how to build resilience and cope with such experiences.

You are invited to take part in this study if you are a clinical psychologist currently working within a palliative setting.

The study will involve a face-to-face or telephone interview at a location and time convenient for you. The interview will last approximately one hour.

An information sheet is attached to help you decide whether you would like to take part.

Please feel free to forward this communication and the attached information sheet to other clinical psychologists that you feel may be interested in taking part.

The study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University and approved by Lancaster University's Research Ethics Committee.

If you would like to take part in the study or discuss any aspect of the study prior to deciding whether to participate, please contact me via the following methods:

Post:

Laura Cramond  
FREEPOST: RTAU-SYXU-YCZZ  
Clinical Psychology  
Furness College  
Bailrigg  
Lancaster  
LA1 4YG

Phone:

OMITTED

Email: [l.cramond@lancaster.ac.uk](mailto:l.cramond@lancaster.ac.uk)

Many thanks,  
Laura Cramond

Trainee Clinical Psychologist  
Lancaster University

**Recruitment advert to be placed in the UK edition of ehospice, Version 2, 29.07.2014**



**Research in to experiences of compassion and resilience in clinical psychologists working in palliative care**

I am a Trainee Clinical Psychologist at Lancaster University. As part of my training I am conducting a research study for my doctoral thesis using one to one interviews that explore the experiences of compassion and resilience in clinical psychologists working in palliative care.

Research findings will increase knowledge regarding the experiences of compassion and provide insight into how to build resilience and cope with such experiences.

The study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University and approved by Lancaster University's Research Ethics Committee.

You are invited to take part in this study if you are a clinical psychologist currently working within a palliative setting.

The study will involve a face-to-face or telephone interview at a location and time convenient for you. The interview will last approximately one hour.

Please feel free to pass the project details on to other clinical psychologists that you feel may be interested in taking part.

If you would like more information about the project or would like to discuss any aspect of the study prior to deciding whether to participate, please contact me via the following methods:

Post:

Laura Cramond  
FREEPOST: RTAU-SYXU-YCZZ  
Clinical Psychology  
Furness College  
Bailrigg  
Lancaster  
LA1 4YG

Phone:

OMITTED

Email: [l.cramond@lancaster.ac.uk](mailto:l.cramond@lancaster.ac.uk)

Many thanks,  
Laura Cramond

Trainee Clinical Psychologist  
Lancaster University

**Participant information sheet, Version 2, 29.07.2014**



**Exploring experiences of compassion and resilience in clinical psychologists working in palliative care**

You are invited to take part in a research project. Before you decide whether or not to take part it is important that you understand why the research is being conducted and what it would involve if you were to participate so please take the time to read this information sheet. Please feel free to talk to others about the project if you wish.

**What is the purpose of the study?**

I would like to interview people about experiences of compassion and resilience when working in palliative care.

**Why have I been asked to take part?**

You have been asked because you are a clinical psychologist working within a palliative care setting.

**Do I have to take part?**

No, participation in this research project is completely voluntary. If you do decide to take part in the project, you can stop the interview at any time. You can also withdraw your consent and data after the interview has been completed, providing that a request is made within two weeks. After this time data will have been pooled and the process of analysis begun so withdrawal may not be possible, although every attempt will be made to extract data concerning you, up to the point of publication.

**If I say yes, will I definitely get to take part in the research?**

You probably will, but if more than 12 people want to take part, those who responded first will be interviewed.

**What will I be asked to do if I take part?**

If you decide to take part in the research project, you would be asked to sign a consent form and be interviewed by me about your experience of working in palliative care, including compassion and resilience. The interview is anticipated

to last approximately one hour and will take place at a time and place, such as your home or workplace, that is convenient for you. The interview would be conducted face-to-face, or if this is not convenient could take place over the telephone. You can say as much or as little as you like and you do not have to answer questions if you do not want to. You can ask to stop the recording at any time and have words deleted or replaced. You can stop the interview at any time.

**Will taking part be confidential?**

Yes, if you agree to take part in the study your information will be kept private. The content of your interview will be anonymised, so any identifiable information such as your name or place of work will be removed. Your name will not appear anywhere in the research. Anonymised direct quotes may be used within the write-up of the project.

Whilst every effort will be made, it is not possible to ensure confidentiality of participation where interviews take place on work premises during the working day.

The only reason confidentiality would be breached is if you say something in the interview that makes me think that you, or someone else, is at risk of harm. If this happens I will have to speak to my supervisors about this. If possible, I will tell you if I am going to do this.

**Are there any risks?**

There are no anticipated risks involved in taking part however it is possible that you may find talking about your experiences upsetting. If you do become upset the interviewer will ask if you want to stop the interview, reschedule the interview or withdraw from the study.

The researcher will provide participants with a sheet detailing sources of further support should you feel upset after participating in the research.

**Are there any benefits to taking part?**

Although you may find taking part in the study interesting and it will provide an opportunity to voice your opinion, there are no direct benefits to taking part.

**How do I get involved or get more information?**

If after reading this information sheet you would like to take part in the research or would like more information then please contact me, Laura Cramond via one of the following methods:

Email: [l.cramond@lancaster.ac.uk](mailto:l.cramond@lancaster.ac.uk)

Telephone: OMITTED

Post:

Laura Cramond  
FREEPOST: RTAU-SYXU-YCZZ  
Clinical Psychology  
Furness College  
Bailrigg  
Lancaster  
LA1 4YG

Alternatively, you can contact my supervisors, Claire Rehan or Ian Fletcher.

Email: [Claire.Rehan@boltonft.nhs.uk](mailto:Claire.Rehan@boltonft.nhs.uk) Telephone: OMITTED  
Email: [i.j.fletcher@lancaster.ac.uk](mailto:i.j.fletcher@lancaster.ac.uk) Telephone: OMITTED

If you decide to take part in the study, I will contact you to arrange a suitable time to discuss the project further and answer any questions you may have. If after this you consent to take part in the study, a time will be arranged to conduct the interview. You will be given a copy of your signed consent form to keep. After the interview you will be given a de-briefing sheet, with helpful contacts should you wish to talk about any issues that might arise for you through participating in this interview.

#### **What will happen to the results of the research project?**

The interview will be audio-recorded and later typed up. The recordings will be deleted after they have been typed up. The results of the research will be written up into a thesis as part of the clinical psychology doctorate at Lancaster University. The report may be published in professional journals too. Your words from the interview could be used in this report but your name will be taken out. Data will be stored securely for ten years. This is the standard procedure for data used in research which forms part of an educational qualification.

#### **Who has reviewed the project?**

This project has been reviewed by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University and approved by Lancaster University's Research Ethics Committee.

#### **What if this information sheet has made me feel upset?**

If the information in this sheet has upset you, you could talk to Mind on **0300 123 3393** or the Samaritans on **08457 90 90 90** in private.

#### **What if there is a problem?**

If you wish to make a complaint or raise concerns about this project and do not want to speak to me about it, you can contact:



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Dr Jane Simpson

Research Director

Tel: (01524) 592858

Email: [j.simpson2@lancaster.ac.uk](mailto:j.simpson2@lancaster.ac.uk)

Division of Health Research

Lancaster University

Lancaster

LA1 4YT

If you wish to speak to someone outside of my course, you may also contact:

Professor Paul Bates

Associate Dean for Research

Tel: (01524) 593718

Email: [p.bates@lancaster.ac.uk](mailto:p.bates@lancaster.ac.uk)

Faculty of Health and Medicine

Division of Biomedical and Life Sciences

Lancaster University

Lancaster

LA1 4YD

If there is anything that is unclear, or if you would like more information, then please contact the researcher Laura Cramond (Trainee Clinical Psychologist) at [l.cramond@lancaster.ac.uk](mailto:l.cramond@lancaster.ac.uk)

**Thank you for taking time to read this information sheet.**

**Laura Cramond, Trainee Clinical Psychologist, University of Lancaster**

**Participant consent form, Version 2, 29.07.2014**



**Exploring experiences of compassion and resilience in clinical psychologists working in palliative care**

Please read the Participant Information Sheet and ask the researcher if there is anything you do not understand, or if you have any questions. If you would like to take part in the research please read each sentence below carefully and tick the box if you agree to it.

1. I confirm that I have read and understand the information sheet (version 2, 29.07.14) and fully understand what is expected of me within this study.
  
2. I have had the opportunity to ask any questions I want to and understand the answers given.
  
3. I understand that my participation in this study is voluntary and if I do take part that I am free to withdraw at any time without giving any reason.
  
4. I understand that I can stop the interview at any time and withdraw my consent. I can also withdraw my consent and data after the interview has been completed, providing that a request is made within two weeks. After this time data will have been pooled and the process of analysis begun so withdrawal may not be possible, although every attempt will be made to extract my data, up to the point of publication.
  
5. I understand that if I choose to be interviewed at my workplace or within my work hours it is my responsibility to seek out and adhere to my

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organisation's research and development (R&D) policies.

- 6. I understand that if I choose to be interviewed at my workplace or within my work hours, whilst every effort will be made, it is not possible to ensure confidentiality of my participation.
- 7. I understand that any information I give will remain strictly confidential unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor.
- 8. I agree to take part in an interview with the researcher, which will be audio-recorded and then typed into an anonymised transcript without my personal details in it.
- 9. I understand that anonymised direct quotations from my interview may be used in, research reports, publications, conferences and training events, once my personal details have been removed.
- 10. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be used in research reports, publications, conferences and training events, once my personal details have been removed.
- 11. I understand that data will be kept for 10 years after the study.
- 12. I agree to take part in this study.

**Name of participant:** .....

**Participant's signature:** ..... **Date:**.....

**Name of researcher:**.....

**Researcher's signature:**..... **Date:**.....

**Exploring experiences of compassion and resilience in clinical psychologists working in palliative care**

**Semi-structured interview schedule, Version 2, 29.07.2014**

**Beginning of session**

- Introductions
- Discuss information sheet and answer any questions that might arise
- Explain confidentiality and limits. Address any concerns about risk
- Explain about recording and anonymity
- Sign 2 copies of the consent form (one to be held by participant, one to be held by researcher)
- Explain that the participant can choose not to answer any questions and can stop the interview at any time. Explain that the interview will take approximately one hour and can be paused for breaks at any time should the participant require it
- Explain that the researcher is interested in their true thoughts, feelings and opinions. There are no right or wrong answers
- Explain that it is ok for silences during the interview. The researcher or participant can take time to think about their answer or question
- Explain that the participant can ask for more information or for something to be explained differently should they require it
- Explain that if the participant becomes distressed by anything discussed in the interview, there will be time at the end of the interview to discuss these issues further and explore appropriate avenues of support

**Interview**

The researcher will use this schedule as a guide to facilitate participants to discuss their experiences. The questions will be used as a guide and will be adapted depending on individuals' response. Additional prompts will be used as necessary.

Open questions will focus on the following areas, with prompt questions used as necessary:

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- Their role, how long they have done it
- Why and how they came into this area of work
- Atmosphere at work
- Positives/negatives of the work
- Feelings induced by work setting
- Feelings induced by the individuals worked with
- Impact of work on them as a person/their view of life/well-being/social life/home life
- Satisfaction with work
- Difference made to others in work
- Experiences of loss in work
- Examples of work that touched them in a positive way
- Challenges of work
- Warning signs
- Triggers
- Coping strategies in work
- Concrete strategies of caring for self
- Strategies to prepare for future work experiences
- Recommendations for professionals entering this area of work

#### **Close of session**

- Stop the recording
- Ensure participant is not distressed
- If any evidence of distress, ensure participant has been advised appropriately. Discuss further sources of support for the participant as detailed on the de-brief sheet
- If participant has disclosed risk, researcher will revisit confidentiality agreement and take appropriate action following advice from supervisors

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- Ensure participant has a copy of the information sheet, signed consent form and debrief form
- Inform participant of timescale for the research
- Thank participant for their time

**Debrief sheet, Version 2, 29.07.2014**



**Exploring experiences of compassion and resilience in clinical psychologists working in palliative care**

**Thank you for sharing your experiences with me.**

**What will happen to the interview I have just recorded?**

Your interview audio-recording will be destroyed once it is typed up and it will be kept on a secure computer system at Lancaster University. Data will be kept for up to ten years. The information will be written into a report for my course at Lancaster University. The report may be published too.

**Can I see the research when it is finished?**

Yes, if you would like to see the report please contact me on my email or phone number below.

**What if I change my mind about taking part in the study?**

You can change your mind at anytime; just contact me to let me know. You do not need to give a reason. Once data has been anonymised it might not be possible for me to remove your data but I will try.

**What if the things I have talked about have made me feel upset?**

If the interview upset you, you could talk to Mind on **0300 123 3393** or the Samaritans on **08457 90 90 90** in private.

**What if there is a problem?**

If you wish to make a complaint or raise concerns about this project, and you do not wish to speak to the researcher, you can contact:

Dr Jane Simpson  
Research Director  
Tel: (01524) 592858  
Email: [j.simpson2@lancaster.ac.uk](mailto:j.simpson2@lancaster.ac.uk)  
Division of Health Research  
Lancaster University  
Lancaster

LA1 4YT

If you wish to speak to someone outside of my course, you may also contact:

Professor Paul Bates  
Associate Dean for Research  
Tel: (01524) 593718  
Email: [p.bates@lancaster.ac.uk](mailto:p.bates@lancaster.ac.uk)  
Faculty of Health and Medicine  
Division of Biomedical and Life Sciences  
Lancaster University  
Lancaster  
LA1 4YD

**If you have any questions or you would like more information, then please contact me, Laura Cramond (Trainee Clinical Psychologist), by email [l.cramond@lancaster.ac.uk](mailto:l.cramond@lancaster.ac.uk) or on OMITTED**

**Thank you again for participating in this study**