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Experiences of Care and Compassion

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This thesis is submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

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List of abbreviations

BPS	British Psychological Society
CDSR	Cochrane Database of Systematic Reviews
CFT	Compassion Focused Therapy
DARE	Centre for Reviews and Dissemination
DoH	Department of Health
LCCP	Leadership in Compassionate Care Programme
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
UK	United Kingdom
US	United States

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Declaration

This thesis was conducted under the supervision of Jo Kucharska (Clinical Psychologist, Coventry University) and Dr Tony Colombo (Senior Lecturer, Coventry University). The original idea for this research was my own and followed discussion with my supervision team. The validity of the coding was undertaken by a colleague and a member of the supervision team, both of whom were familiar with Interpretative Phenomenological Analysis. The named supervisors also read drafts of the chapters. I confirm that the work presented in this thesis is my own work and has not been submitted for a degree at any other university. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Summary

Compassion has become a topic of interest amongst researchers and policy makers. Research has started to explore compassion from the perspectives of staff and patients. Research on compassion with carers is an under researched area. The present thesis aims to address this gap in the literature.

Chapter One: This paper presents a systematic review of compassionate care from the perspective of patient and professionals. Seventeen studies met the inclusion criteria and were critically reviewed and evaluated. Within the literature reviewed compassionate care is described as a skilled interpersonal and relational process. The review found that compassionate care needs to be more clearly defined in practice, education and training. Clinical implication of the findings and directions for future research are discussed.

Chapter Two: The second paper is a qualitative exploration of carers' lived experiences of compassion while caring for adults with severe and enduring mental health difficulties. Eight carers were recruited to the study and interviewed using semi-structured interviews. The data was analysed using Interpretative Phenomenological Analysis. Findings revealed two superordinate themes: 'Burdensome responsibility' and 'Something that holds you'. Findings are discussed in the context of clinical implication and areas for future research are considered.

Chapter Three: The final paper provides a reflective account on the research process including insights into carers' experiences of care and compassion. It offers reflections around six attributes of compassion: care for wellbeing, sensitivity, sympathy, empathy, distress tolerance and non-judgemental. This paper allows a chance to reflect on some of the outlying experiences that arose from the research that were not prevalent enough to become central themes.

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Chapter One

Literature Review

Compassionate Care: A Systematic Review of Patient and Practitioner Perspectives

In preparation for submission to *Journal of Professional Nursing* (see Appendix A for Author Instructions)

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1.1 Abstract

Background: There is increasing emphasis on compassion in healthcare through the delivery of compassionate care. Success in its delivery is based on establishing greater clarity around what compassionate care looks like and means within practice.

Aims: To conduct a systematic review of relevant literature to gain a clearer understanding of the meaning of 'compassionate care' from the perspective of patients and practitioners.

Method: PsycINFO, Medline Ovid, Scopus, Web of Science and CINAHL were searched for articles published from 2005 to April 2015. Reference and citation searches were also conducted. A total of seventeen papers met the inclusion criteria for the review.

Results: Within the literature reviewed, compassionate care is a skilled interpersonal and relational process. The review found a lack of coherence around the concept. Organisational pressures constrain the practice of compassionate care.

Conclusion: Compassionate care needs to be more clearly defined in practice, education and training. The delivery of compassionate care requires supporting environments that value, encourage and pay close attention to the nurturing of relationships. Clinical implications are considered along with directions for future research.

Keywords: compassion, healthcare, compassionate care, systematic review

1.2 Introduction

1.2.1 The problem with care in the National Health Service (NHS)

In the United Kingdom (UK) there have been a number of reports detailing patients' complaints about poor standards of nursing care and treatment provided by some hospitals and care homes (Care Quality Commissioning, 2011; Mid Staffordshire NHS Foundation Trust Inquiry, 2010; Parliamentary & Health Service Ombudsman, 2011). Specific concerns over caring dimensions in healthcare have been escalated in the UK following the publication of the Francis Report Inquiry in 2013 which drew widespread attention to failures in the most basic elements of patient care. The Francis Report (2013) documented a number of examples where compassion was absent from patient care and attributed this in part to a task-based culture that tends to prioritise the meeting of targets over providing quality of care. The organisational aspect of care for older patients has been a particular area of concern, especially with regards to their vulnerability to neglect (Patient Association, 2009). Such events are not restricted to the UK, with similar problems being reported in the United States healthcare system (Nauert, 2011).

Against the backdrop of concerns over poor standards of care and negative patient experiences, there has been an emphasis on the need to strengthen the climate for care and promoting practices that involve putting the patient and public at the centre of care (Department of Health (DoH), 2010). In 2012, the Department of Health published a three year vision and strategy aimed at developing a culture of compassionate care within the NHS (DoH, 2012). The strategy calls on all healthcare professionals to 'embrace' six key values believed to maximise high-quality patient care. Known as 'The 6Cs' these values are: care, compassion, competence, communication, courage and commitment (DoH, 2012). Delivering

high-quality patient care has been prioritised by the Department of Health agenda (2013a) and involves treating people with respect dignity and compassion. The Point of Care programme at the King's Fund in the UK has further emphasised the need for compassion in the delivery of healthcare (Firth-Cozen & Cornwell, 2009). Indeed, current healthcare policy and initiatives that aim to improve service users' experiences have focused on compassion through delivering compassionate care.

1.2.2 Defining compassionate care

Despite the increasing emphasis on compassion in healthcare, its meaning as it applies to practice has not been clearly defined. Healthcare policies and reports do not go as far as to help make explicit behaviours or practice that exemplifies compassionate care. Nonetheless, making compassionate care explicit is said to be challenging due to the largely 'invisible' nature of this work (Dewar, 2012). The term compassion has been described in slightly different ways in the literature. Chochinov (2007) refers to compassion as "a deep awareness of the suffering of another coupled with a wish to relieve it" (p.184). According to Gilbert (2009) it includes attributes such as empathy, sensitivity and sympathy and encompasses open attention, awareness of suffering, motivation and action.

The NHS Constitution also suggests what compassion might mean in practice: "We respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find the time for those we serve and work alongside" (DoH, 2013b, p. 5).

Following the recent interest in compassion, the Leadership in Compassionate Care Programme (LCCP) (Edinburgh Napier University & NHS Lothian, 2012) was set

up as a three year action research initiative (2007-2011) that aimed to capture what compassionate care means within nursing practice and to translate learning into practice and education. In line with this, further empirical research has emerged to articulate compassion and compassionate care across different healthcare settings (Badger & Royse, 2012; Lloyd & Carson, 2011). This has included observational and descriptive accounts derived from the perspectives and experiences of patients and professionals (Fry et al., 2013; Van der Cingel, 2011).

1.2.3 Rationale

There is increasing emphasis on improving caring dimensions in healthcare services. Compassionate care intuitively seems a way forward to improving patient and service user experiences. Success in its delivery is based on establishing an understanding of what compassionate care looks like and means within practice. Identifying patient and practitioner perspectives and experiences are important in shaping an understanding of compassionate care. Developing such knowledge would greatly assist in the provision of compassionate care across a range of healthcare settings. It also allows for the development of metrics and practice initiatives that can help to enhance compassionate care. To date, no published systematic review has been conducted on the meaning of compassionate care from the perspective of patients and practitioners.

1.2.4 Aims

The paper aims to gain clearer understanding of the meaning of compassionate care through a review of the empirical literature from the perspective of patients and professionals. The review will consider the following key questions:

- i. What are the various patient and practitioner perspectives on the meaning of compassionate care and compassion in healthcare?
- ii. What are the similarities and differences between patient and practitioner accounts?
- iii. How might the various patient and practitioner perspectives help improve our understanding of the meaning of compassionate care and in turn the delivery of compassionate healthcare services?

1.3 Method

1.3.1 Search strategy

An initial search was carried out on the Cochrane Database of Systematic Reviews (CDSR) and the Centre for Reviews and Dissemination (DARE) to ensure that this review is an original contribution to the literature relating to compassionate care. No similar reviews were identified in the current area.

A comprehensive search was undertaken to systematically identify literature relating to patient and practitioner perspectives of compassionate care. The search strategy involved two main elements: (1) searching electronic databases (PsycINFO, Medline Ovid, Scopus, Web of Science and CINAHL); and (2) scanning references and retrieving papers. Searches were carried out in between December 2014 and April 2015 using the identified search terms (Table 1.1). An additional search was carried out in the new Journal of Compassionate Health Care. References were collected using a reference management database and duplicate papers were removed.

Table 1.1 Highlights the search terms used in the systematic review

Search terms	Search location
Compassion *	Title (all databases)
AND practitioner* or staff or patient* or nurse* or nursing or care	Anywhere (PsycINFO, Medline Ovid, CINAHL) Topic (Web of Science)
AND perspective* or experience* or perception* or practice	Title, Abstract & Keyword (Scopus)
* represents word truncation to capture variations in terminology.	

The term compassion* was used to capture literature relating to compassion and compassionate care. The search was restricted to the title in order to manage the high volume of literature using a broader search.

1.3.2 Study selection

In the first instance, study titles and abstracts were examined to determine their relevance for inclusion in the present review (see Table 1.2). The full manuscripts of citations that appeared to be relevant were further assessed to determine inclusion. The study considered papers from 2005 onwards due to attention on compassionate care created by the Francis Report inquiry (2013). An inquiry into standards of care took place between 2005 and 2009 (Mid Staffordshire NHS Foundation Trust Inquiry, 2010). The review considered papers outside the UK and across physical and mental health practice due to the paucity of literature available.

Table 1.2 Highlights the inclusion and exclusion criteria for the systematic review

Inclusion Criteria	Exclusion Criteria
Primary research	The paper was a review paper, commentary paper, conference proceeding, letter or book chapter
Printed in English language	Case study
Published from 2005 onwards	Not printed in English language
Focused directly on compassionate care or compassion in healthcare	Printed prior to 2005
	The primary focus was not on compassionate care or compassion in healthcare

1.3.3 Systematic search results

The process of study selection was recorded on a ‘Preferred Reporting Items for Systematic Reviews and Meta-analyses’ (PRISMA: Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) flow diagram below (Figure 1). In total 1084 articles were identified, of which 569 were duplicates, resulting in 515 to be considered in line with the inclusion and exclusion criteria. Of these, 472 records were excluded for non-relevance and a further 27 were excluded as non-primary research or case studies. A total of 17 studies remained and met the inclusion criteria for the present review.

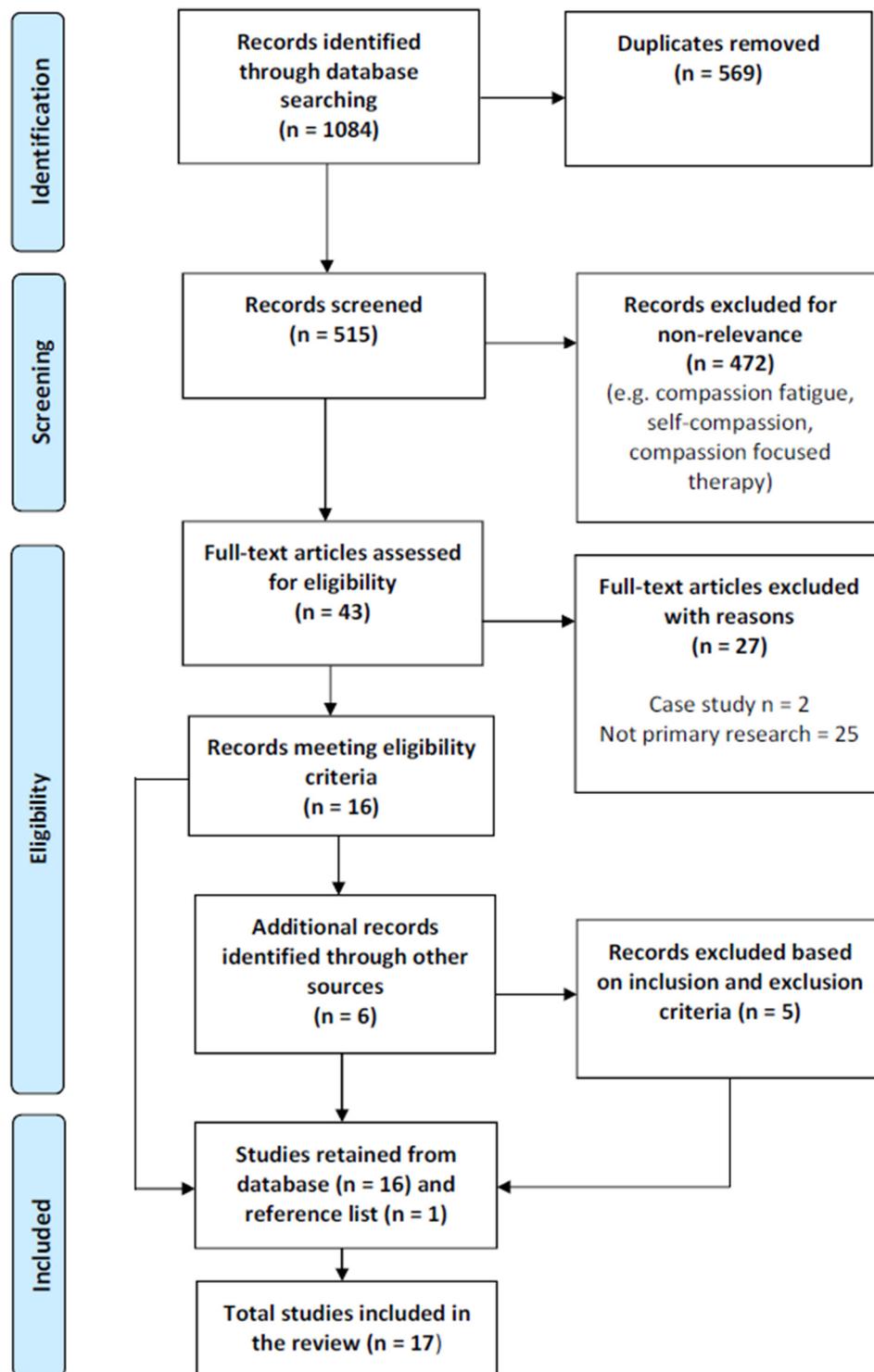


Figure 1 A PRISMA flow diagram of the study selection process (Moher et al., 2009)

1.3.4 Assessment of quality

The quality assessment framework by Caldwell, Henshaw and Taylor (2005) was utilised to critically evaluate and compare the quality of the 17 studies obtained from the review. It is recognised that there is no ‘gold standard’ critical appraisal tool for allied health research and there is also little consensus with regards to appropriate items that should be included within a quality framework (Katrak, Bialocerkowski, Massy-Westropp, Kumar & Grimmer, 2004). Caldwell et al’s., (2005) framework was considered suitable for the current review because it was designed for health studies and can be applied to quantitative and qualitative research methodologies. The assessment tool includes 18 quality criteria for both qualitative and quantitative research. A scoring system was devised wherein two points were awarded if the criterion was met in full, one point if it was partially met and zero points if it was not met or discussed. Each study could receive a score between 0 and 36. Cut off points were used to classify papers as high (25-36), medium (13-24) and low (0-12) for the purpose of the review.

1.3.5 Reliability of quality

To examine inter-rater reliability of the assessment of quality, kappa coefficients were computed for three papers: Badger and Royse (2012) $k = .878$, $p < .001$; Dewar and Nolan (2013) $k = 1.00$, $p < .001$; and Brown, Crawford, Gilbert, Gilbert and Gale (2014) $k = .870$, $p < .001$. Thus there was either very high or perfect agreement between the two raters. As presented by Landis and Koch (1977) values of kappa from 0.40 to 0.59 indicate moderate, from 0.60 to 0.79 substantial and 0.80 outstanding.

1.3.6 Summary of quality assessment

All of the papers were included in the review as they scored over 25 and were rated as high quality. The studies scored high on the quality appraisal due to consistently clear aims, rigorously defined context and concepts and clear analysis and reporting. The quality review of studies is presented in Appendix B.

The quality review process revealed a number of potential biases that are important to acknowledge when considering the findings in the review. Firstly there was an emphasis on females' perspectives which could suggest a bias in the findings. Most of the studies reviewed did not provide ethnic background demographic information. The three studies that did report this information noted a predominant Caucasian sample (Badger & Royse, 2012; Bramley & Matiti, 2014; Vivino, Thompson, Hill & Ladany, 2009) and cultural differences may have been missed. A number of the studies used groups to collect their data. It is important to consider the influence of 'groupthink' and social desirability bias that emerge from the group dynamic (Stewart & Shamdasani, 2014) and their potential impact on eliciting a full range of participant accounts (Carey, 1995).

1.4 Results

The purpose of this review is to gain a clearer understanding of the meaning of compassionate care through reviewing patient and practitioner perspectives of compassionate care or compassion in healthcare.

1.4.1 Findings overview

The systematic search strategy resulted in 17 research papers that met the inclusion criteria for the present review. The findings from these papers will be reviewed in

relation to main themes that emerged from the papers with patient and practitioner perspectives in compassionate care or compassion in healthcare. These themes include:

1. Understanding compassion in healthcare
2. Attitudes towards compassion and compassionate care
3. Compassion in practice
4. Constraints to compassionate care

When citations fall into more than one theme, then the findings are reported separately under each theme. Compassionate care was considered from different angles including observations, perspectives, experiences and language.

The study characteristics are presented in Table 1.3, including the study aims, sample, research design and findings.

As shown in Table 1.3, 11 studies focused on practitioners, 4 studies focused on patients and 2 focused on both patients and practitioners. Out of these studies 11 were conducted in the UK, 2 in the US, 1 in Australia, 1 in the Netherlands, 1 in Norway and 1 Sweden. 10 of these centred on nursing care, 3 focused on mental health care and 1 on therapy, 1 related to older adult care and 1 to end of life dementia care and 1 involved a mixture of disciplines. Of these, 15 adopted a qualitative methodology and 2 utilise a mixed methods design.

Table 1.3: Selected Papers for Review in Alphabetical Order

Author, Year, Country	Study Aims	Participant information	Study Design	Findings	Quality Rating (Low/ Med/ High)
Badger & Royse (2012), US.	To explore how compassionate practice might be described by burn survivors.	n = 31 adult burn survivors attending a conference about burn survivors. Participants were aged between 23-70 years; 77% were Caucasian and 60% female.	A qualitative design using two focus groups consisting of open ended questions.	Three major themes emerged: <ul style="list-style-type: none"> ▪ Respect for the person, (subthemes include: establishing an empathic connection, restoring control through choice, providing individual care and going above and beyond). ▪ Communication (subthemes include formal and informal). ▪ Provisions of competent care; professionalism. 	High
Bramley & Matiti (2014), UK.	To understand patients' experience of compassion within nursing care and their perceptions of developing compassionate nurses within practice.	n = 10 hospital inpatients from six 6 acute wards in respiratory medicine. Participants were aged 18-91 years and had received between 4-10 days of nursing care.	A qualitative exploratory descriptive approach using individual semi-structured interviews.	Three overarching themes: <ul style="list-style-type: none"> ▪ What is compassion: knowing me and giving me your time. ▪ Understanding the impact of compassion: how it feels in my shoes. ▪ Being more compassionate: communication and the essence of nursing. 	High

<p>Bray, O'Brien, Kirton, Zubairu, & Christiansen (2014), UK.</p>	<p>To explore qualified health professionals and pre-registration students understanding of compassion and the role of professional education in promoting compassionate care.</p>	<p>n = 155 qualified health professionals and n = 197 pre-registration students. Participants were from a range of health and social care disciplines. Participants were from different branches including child, learning disability, adult mental health and a range of discipline including nursing, paramedic, midwifery and allied health professionals.</p>	<p>A sequential explanatory mixed methods study using surveys and qualitative individual semi-structured interviews.</p>	<ul style="list-style-type: none"> ▪ High level of consensus in participants understanding of compassion in healthcare. ▪ Most common features of compassionate care: acting with warmth and empathy, individualised patient care and acting how you would like others to act towards you. ▪ Ambiguity and contradictions in relation to professional education in promoting compassionate care. 	<p>High</p>
<p>Brown, Crawford, Gilbert, Gilbert & Gale (2014), UK.</p>	<p>To explore the concept of compassion in the work of mental health practitioners.</p>	<p>n = 20 mental health practitioners from an inpatient facility. Participants consisted of 2 consultant psychiatrists, 2 ward managers, 2 ward sisters, 8 staff nurses, 5 healthcare assistant and 1 student.</p>	<p>A qualitative discourse analysis using individual semi-structured interviews.</p>	<p>Two main repertoires:</p> <ul style="list-style-type: none"> ▪ Practical compassion repertoire: Involves the practice of compassion through support, practice and meaning. ▪ Organisational repertoire: involves contextual factors that constrain compassionate care (i.e. staff levels, paperwork). 	<p>High</p>

<p>Crawford, Gilbert, Gilbert, Gale & Harvey (2013), UK.</p>	<p>To explore how compassion is demonstrated in the language of mental health professionals.</p>	<p>n = 20 acute mental health practitioners from two psychiatric units. Participants consisted of 2 consultant psychiatrists, 2 ward managers, 2 ward sisters, 8 staff nurses, 1 student and 5 healthcare assistants.</p>	<p>Mixed qualitative and quantitative design using corpus-assisted discourse analysis.</p>	<ul style="list-style-type: none"> ▪ Most common attributes of a compassionate mentality: helpful, giving, supportive and understanding. ▪ Marked depletion in compassionate language. ▪ Practitioners' language emphasised time pressures, care processes and organisational tensions that might limit best practice. 	<p>High</p>
<p>Crowther, Wilson, Horton, & Lloyd-Williams (2013), UK.</p>	<p>To explore the experiences of carers for dementia during the last year of life.</p>	<p>n = 40 bereaved carers of a close family member from dementia. Participants were between 18-86 years and recruited through third sector organisations. Participants consisted of 30 females and 10 males.</p>	<p>A qualitative study informed by grounded theory and phenomenology using individual in-depth interviews.</p>	<ul style="list-style-type: none"> ▪ Compassion, kindness and humane were frequently reported to describe care given. ▪ Small things and little acts of kindness are meaningful to people. ▪ The ability of formal carers to put themselves in the informal carer's position was valued. ▪ Knowledge not needed to deliver care that was compassionate. 	<p>High</p>

Curtis, Horton, & Smith (2012), UK.	To explore nursing students socialisation in 21 st century compassionate practice.	n = 19 student nurses at a University in the north of England, including males and females from diverse ethnic and religious backgrounds and from across each of the three years of the training programme.	A qualitative grounded theory methodology using individual in-depth interviews.	<ul style="list-style-type: none"> ▪ Students experienced dissonance between professional ideals and practice reality. ▪ Having time to communicate with patients was seen as key to compassionate practice. ▪ Students experienced vulnerability and uncertainty about future engagement in compassionate practice due to practice observed. 	High
Curtis (2013), UK.	To explore nurse teachers' experiences and concerns in their preparation of students for compassionate practice.	n = 5 nurse teachers at a University in the North of England. Participants consisted of males and females with 5-25 years in education and clinical practice backgrounds.	An aesthetic phenomenological approach using individual in-depth interviews.	<ul style="list-style-type: none"> ▪ Nurse teachers experience challenges in educating nursing students for compassionate practice. ▪ Nursing teachers experienced dissonance in the university setting ▪ Nurse tutors emphasised the importance of nurse leadership to challenge practice constrains. ▪ Nursing tutors emphasised the need to build students resilience. 	High

Curtis (2014), UK.	To explore students socialisation in compassionate practice.	n = 19 student nurses in the north of England. Participants included males and females from both mature and school leaver age groups and from across the first, second and third year of the programme.	A qualitative grounded theory methodology using individual in-depth interviews.	<ul style="list-style-type: none"> ▪Students expressed vulnerability and uncertainty around the emotional requirements for compassionate practice. ▪ Students experiences tensions around genuine intentions to engage in compassionate practice and feeling the need to ‘mask’ their feelings to cope with emotional labour. 	High
Dewar & Nolan (2013), UK.	To understand the relational knowledge that underpins compassion from the perspectives of older people, relatives and staff.	n = 35 staff including registered nurses, non-registered care staff, allied healthcare professionals and medical staff, and patients (n=10) and families (n = 12).	Appreciative inquiry using a range of methods: emotional touch points, structured observations, group discussions and discussions captured in field notes.	<p>The study identified eleven themes:</p> <ul style="list-style-type: none"> ▪Knowing who I am and what matters to me ▪Understanding how I feel ▪Working together to shape the way things are done ▪Engaging in appreciative caring conversations ▪Being courageous ▪Connecting emotionally ▪Being curious ▪Being collaborative ▪Considering others perspectives ▪Compromising ▪Being celebratory 	High

<p>Fry, MacGregor, Ruperto, Jarrett, Wheeler, Fong, & Fetchet (2013), Australia.</p>	<p>To examine the role of the 'expert nurse' as a compassionate carer through their interpersonal relationships.</p>	<p>Observations of emergency nurses with 5 to 10 years' experience in the role. Observations involved sixteen in-depth non-participant observations (4/5 hours each) across three emergency departments. Participants consisted of 13 females and 3 males.</p>	<p>Observational study using thematic analysis based on ethnographic principles.</p>	<p>Six themes were identified:</p> <ul style="list-style-type: none"> ▪Positive body language and emotions in nursing ▪Calming strategies for patients ▪Negative body language ▪Professional and personal conflict ▪The emergency department doctor and the emergency nurse ▪Nursing mentoring and teamwork 	<p>High</p>
<p>Horsburgh & Ross (2013), UK.</p>	<p>To explore newly qualified staff nurses perspectives of compassionate care including factors that facilitate or inhibit its delivery.</p>	<p>n = 42 staff nurses within one year of registration. Seven focus groups consisting of 4-11 participants.</p>	<p>A qualitative approach using symbolic interactionism consisting of focus groups.</p>	<p>Five main themes emerged:</p> <ul style="list-style-type: none"> ▪ Sink or swim: expectations vs. reality ▪ Preparation for practice ▪ Support in practice: the luck of the draw ▪ Ingrained in the woodwork ▪ conceptions of compassionate care ▪Data analysis revealed an underpinning tension between agency (individual ability to act) and structure (the environment within which staff worked). 	<p>High</p>

Kvangarsness, Torheim, Hole & Crawford (2013), Norway.	To gain insights into intensive care nurses' perspectives on compassionate care for patients with exacerbated chronic obstructive pulmonary disease.	n = 17 intensive care nurses. Three focus groups consisting of 5 or 6 participants. The participants were Norwegian women aged 41-65, with more than 10 years of experience.	A qualitative hermeneutic phenomenological approach using focus group interviews.	Three main themes emerged: <ul style="list-style-type: none"> ▪ Preparing to care for breathlessness (subthemes include: caring environment, ensuring co-operation, competence in mask treatment) ▪ Establishing a trusting relationship (subthemes include: creating a sense of safety, compassionate treatment, alleviating pain, balancing mask treatment with sleep and rest) ▪ To approach each patient as a person with unique needs (subthemes include: meeting the patient's fear, protecting patient's autonomy, sensitive-assisted personal body care) 	High
Lloyd & Carson (2011), UK.	To explore the subjective experiences of consumers in mental health care.	n = 30 service users and carers across five groups consisting of 2 -8 participants. Participants included consisted of males and females.	A qualitative study using an ethno methodological approach consisting of group interviews.	Three main themes: <ul style="list-style-type: none"> ▪ Universality in friendly, consistent and supportive relationships. Universal values of respect and being treated with dignity. ▪ Diversity in identifying and respecting individual needs alongside acknowledging individual differences and removing prejudice and stigma. ▪ Recovery involves responsibility for themselves through treatment, including information and control over their own activities. 	High

<p>Van der Cingel (2011), Netherlands.</p>	<p>To explore the nature and significance of compassion in nursing practice for older people with a chronic disease</p>	<p>n = 31 patients over the age of 65, of which 14 were males and 17 were females. n = 30 nurses of which 28 were females and 2 were males.</p>	<p>A qualitative study drawing on grounded theory of in-depth interviews in different care settings.</p>	<p>Seven dimensions illustrating the nature of compassion:</p> <ul style="list-style-type: none"> ▪ Attentiveness ▪ Listening ▪ Confronting ▪ Involvement ▪ Helping ▪ Presence ▪ Understanding 	<p>High</p>
<p>Vivino, Thompson, Hill, & Ladany (2009), US.</p>	<p>To explore how therapist conceptualise compassion and practice it in psychotherapy.</p>	<p>n = 14 licensed psychotherapists in private practice. Participants included PhD clinical psychologists (n = 7), PhD counselling psychologists (n = 3), masters-level marriage and family therapists (n = 3) and licensed social worker (n = 1). Participants included 11 females and 3 men, of which 12 were European American and 2 Asian American. Ages ranged from 35-65 years. The mean practice years were 18.</p>	<p>A consensual qualitative research design using individual interviews on two different occasions.</p>	<ul style="list-style-type: none"> ▪ Compassion seen as being broader and deeper than empathy. ▪ Compassion is understood as an innate quality that can be awakened. ▪ Compassion involves connecting with client's suffering and promoting change through action. ▪ There are facilitators and inhibitors to compassion in psychotherapy. 	<p>High</p>

<p>Wiklund-Gustin, & Wagner (2012), Sweden.</p>	<p>To explore participants understanding of compassionate caring, particularly self-compassion as a source to compassionate care.</p>	<p>Small group of nursing teachers (n = 4) involved in personal development.</p>	<p>Clinical application research drawing on phenomenological and hermeneutic interpretations of participants written and oral reflections.</p>	<p>Five themes were identified:</p> <ul style="list-style-type: none"> ▪ Being there, with self and others ▪ Respect for vulnerability ▪ Being non-judgemental ▪ Giving voice to things needed to be said and heard ▪ Being able to accept the gift of compassion from others. 	<p>High</p>
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1.4.2 Themes

1.4.2.1 Understanding compassion in healthcare

This theme relates to how patients and practitioners make sense of compassion in relation to healthcare. A survey by Bray, O'Brien, Kirton, Zubairu and Christiansen (2014) has revealed that acting with warmth and empathy, providing individualised care and acting in a way you would like others to act toward you, were identified as the three most important attributes of compassion in practice. A high level of agreement was found between a range of qualified health professionals and pre-registration students. Furthermore, the majority of students and professionals perceived that they had a good understanding of compassion and despite being hard to define they felt confident in their ability to be able to detect if it was present or absent in practice. However, Curtis (2014) in a study on student socialisation in compassionate practice, reported that student nurses found it difficult to define the professional requirements for compassionate practice. This may suggest the need to improve socialisation in compassionate care.

A study by Vivino et al., (2009) has reported on practitioners' understanding of compassion in psychotherapy. Compassion was understood as being connected to suffering but in a way that is broader and deeper than empathy. It involves a willingness to take action to promote change so that clients do not remain in their own suffering. Compassion was described as an attitude or way of being and includes feelings of loving kindness, being accepting and non-judgemental, as well as being open and genuine. Compassionate care seems to involve actively engaging with suffering to facilitate change. Limitations noted including a predominant sample of experienced European American therapists nominated to be

compassionate. Therapists were predominantly female, from a psychodynamic or humanistic orientation and practising long-term therapy.

A study by Crawford, Gilbert, Gilbert, Gale and Harvey (2013) explored how compassion is demonstrated in the language of mental health professionals. They identified common attributes to include ‘caring’, ‘helpful’, ‘giving’, ‘supportive’ and ‘understanding’, although a marked depletion in compassionate language was noted in practitioners’ talk. In the same context, Brown et al., (2014) revealed a distinct practical theme in practitioners’ definitions of compassion such as ‘dealing’ with people, ‘giving’ support, ‘helping’ and improving the experience of hospitalisation. For them, compassionate care was understood as formulating patients in terms of needs that can be actioned. Practical compassion involved being with patients, playing games, social activities and pre-empting disruptive behaviour. Practical activities were seen to help create circumstances for patients to open up and engage in therapeutic work and helped in managing the hospital environment. Compassion was conveyed by professionals as more than an attitude of mind; rather it is highly practical and allows practitioners to act upon their social environment. This would suggest that compassionate care shapes and is shaped by its environmental context. The findings from these two studies were drawn from in-patient settings and it is possible that compassionate care and the language of compassion might manifest differently within these contexts or within residential settings.

1.4.2.2 Attitudes towards compassion and compassionate care

This theme explores people’s views and beliefs of compassion. In the Bray et al., (2014) study, most of the students and professionals perceived compassion as something that cannot be learnt and taught or measured, albeit many were unsure

about these areas. Fifty-eight percent of professionals felt that training was necessary to provide compassionate care and this compared to thirty-nine percent of students, although again there was uncertainty in their responses. Compassion is perceived as an innate quality and that certain skills could be developed or improved if the ability to be compassionate already exists. Some felt that it would be easier to learn or develop specific skills such as communication and active listening skills rather than the broader concept of being compassionate. Furthermore, a large proportion of participants in the study, particularly pre-registration students, felt that being knowledgeable, safe and experienced was of higher importance than compassion. These findings seem to indicate a range of attitudes towards compassion and compassionate care with a lack of coherence around the concepts. The ambiguity in practitioners' opinions suggests the need to define the components of compassionate care.

A study by Bramley and Matiti (2014) explored patients' experiences of compassion in nursing care. Some participants held the view that being compassionate is integral to who nurses are and could not be changed, whereas others perceived that compassionate caring can be taught and developed. Some participants felt that practitioners were responsible for their own behaviours, while others believed it formed part of wider culture. This highlights that patients hold mixed views in relation to compassionate care and may indicate the need to convey to patients and the public that practitioners' attitudes and behaviours can be changed or improved.

1.4.2.3 Compassion in practice

There are 10 studies that define the elements of compassionate care. Of these 4 studies focus on patients, 4 focus on practitioners and 2 on both patients and practitioners. The findings are broken down into five smaller themes.

1.4.2.3.1 Individualised care for the person

A prominent theme across a number of studies on compassionate care involved respect for the person as an individual (Badger & Royse, 2012; Bramley & Matiti, 2014; Dewar & Nolan, 2013; Lloyd & Carson, 2011). This involves professionals recognising and valuing the person as more than a consumer, disease, injury or procedure (Badger & Royse, 2012; Lloyd & Carson, 2011). Patients in the Badger and Royse (2012) study conveyed the importance of an empathic connection, feeling empowered through choice and patient-focused care. Patients remembered small considerations including practitioners taking time to acknowledge the person, involving them in activities or conversations and providing encouragement or reassurance. In line with these findings, compassionate care seems to be about creating a positive environment that creates a sense of hope in the person and their recovery. Limitations reported include that participants were recruited from a conference and were self-selecting which may have impacted the result; the sample may therefore not be representative of all burn survivors. The potential for group dynamics within the focus group also need to be taken into account when interpreting the results.

Bramley and Matiti (2014) reported that compassion within nursing care was understood by patients as caring for people as individual human beings, providing encouragement in adversity and making time to be with individuals. Patients saw

compassion as a personalised experience according to the individual's subjective needs. Time was deemed instrumental in compassionate care and patients expected nurses to have time and to listen to patients. Some participants felt that the element of time only needs to be brief to establish a compassionate connection. Patients recognised that nurses were busy and they were happy to adapt to smaller gestures of compassion. Of note, all of the participants in the study described themselves as white British. Limitations reported include a small sample size and the exclusion of very sick patients and dementia patients, which limits the transferability of the results. The acute nature of illness and the participants' vulnerability and dependency on nursing care needs to be considered when interpreting their accounts.

Lloyd and Carson (2011) found that mental health consumers understood compassion to be about professionals valuing them as an individual person. They identified three concepts relevant to compassionate care: universality, diversity and recovery. They emphasise the importance of recognised individual differences (diversity) through universal values of compassion, dignity and respect (universality). Recovery involves giving equal recognition to the consumer and building a collaborative relationship that supports recovery. Indeed, they reported that compassionate care was instrumental to individuals becoming more involved in their own healthcare. The study did not provide information in relation to mental health characteristics such as severity, duration, psychological symptoms or diagnosis. It is possible that these factors may influence perspectives of compassionate care as well as involvement in one's own healthcare. The potential for group dynamics within the focus group also needs to be taken into account when interpreting the results.

1.4.2.3.2 Caring conversations and dimensions

This theme relates to the interpersonal skills that contribute to compassionate care. Dewar and Nolan (2013) have reported on a three year action research initiative (LCCP) which has highlighted the importance of developing caring dialogues between patients, staff and relatives in the delivery of compassionate care. They identified that engaging in appreciative caring conversations enables insights into ‘who people are and what matters to them’ and ‘how people feel about their experiences’. Establishing this knowledge can help all parties to ‘work together and shape the way things are done’ and develop trusting relationships. Engaging in caring conversations requires practitioners to be curious, collaborative, consider others perspectives, compromising and celebrating. These findings convey the significant relational nature of compassionate care and the importance of good interpersonal and relational skills for its delivery. On the basis of their findings Dewar and Nolan (2013) have put forward a model to implement compassionate relationship centred care in an older people care setting.

Similarly, in a study with older adults and nurses, Van der Cingel (2011) identified seven dimensions of compassionate care: attentiveness, listening, confronting, involvement, helping, presence and understanding. This study and the Dewar and Nolan (2013) study both emphasise the importance of showing an interest in the person and listening to the things that matter to them, rather than making assumptions about patient care. There is also an emphasis on using banter and humour (Dewar & Nolan, 2013) and sharing personal information or experiences to connect to the patient and develop a bond (Dewar & Nolan, 2013; Van der Cingel, 2011). Importantly, there was an emphasis on emotional aspects of care such as recognising and exploring what is going on for the person and helping them to face

their difficulties or distress. These findings support compassionate care as a relational and interpersonal process. Here compassionate care appears to be an instrument that brings patient and professional together, thereby supporting the professional process.

1.4.2.3.3 Self-compassion

A study by Wiklund-Gustin and Wagner (2012) with clinical nursing teachers, explored the role of self-compassion as a source of compassionate care.

Compassionate care was illustrated through five themes: 'being there', 'with self and others', 'respect for vulnerability', 'being non-judgemental', 'giving voice to things that need to be said and heard' and 'being able to accept the gift of compassion from others'. They suggested that a compassionate approach towards oneself makes it easier to understand and adopt a compassionate approach towards others. Their findings suggest that compassionate care is not an intervention from practitioner to patient; rather it is a mutual interpersonal phenomenon which involves connecting to the patient's unique experiences, while acknowledging self and others vulnerability and dignity. From this perspective, compassionate care can be understood as an intrapersonal and interpersonal process and requires focusing on the needs of the practitioners as well as those of the patients. Taken to an organisational level, it requires a supportive compassionate culture to promote it. Limitations of this study included a small group of nursing teachers; the potential for group dynamics need to be taken into account when interpreting the results.

1.4.2.3.4 Interpersonal and informational communication

A prominent theme running throughout the studies on the delivery of compassionate care is communication. Fry et al., (2013) carried out an observational study with

experienced emergency nurses. They observed that the practice of compassionate caring relies on a mixture of core communication and interpersonal skills. They emphasised the importance of positive body language and conversations which appeared to have calming effects for patients and alleviated their stress. They demonstrated that eye contact, empathy, humour, small talk and use of touch to offer comfort are important aspects of compassionate care. Limitations here included a predominant female sample. The study focused on experienced nurses who may hold different views or practise differently to less experienced staff. Nonetheless, more experienced staff would have the skills and experience to convey compassionate care.

The study by Badger and Royse (2012) with burn survivors has reported on the importance of both interpersonal and informational communication in the delivery of compassionate care. Interpersonal communication involves verbal and non-verbal exchanges including interpersonal greetings, smiling, making eye contacts and talking through care activities and actively listening. Communication was particularly powerful when it validated the individual as a person. Patients emphasised a need for good communication from healthcare providers and wanted to be informed about care procedures and medical terminology. They also emphasised the significance of communication between healthcare providers to avoid mistakes and promote continuity in care. This was described as 'demonstrating competence'. These findings suggest that compassionate care involves communication at different levels including interactions between individuals, staff teams and healthcare providers.

1.4.2.3.5 Competent care

Kvangarsnes, Torheim, Hole and Crawford (2013) carried out a study with patients with exacerbated chronic obstructive pulmonary disease. They identified three themes related to the delivery of compassionate care: preparing to care for breathlessness, establishing a trusting relationship and to approach each patient as a person with unique needs. The study reports on the importance of careful preparation for care as well as co-operation and collaboration across different disciplines. They report that both theoretical and practical competences are central to the delivery of compassionate care. Indeed, Badger and Royse (2012) found that providing competent care inspired a sense of trust, safety and wellbeing which allowed patients to relax. Competence was reported when professionals were seen as accountable and they had completed practice correctly, and with confidence. The study reports that competent care is necessary to achieve the delivery of compassionate care. From this perspective, compassionate care can be seen to entail a complex mix of clinical skills, communication skills and interpersonal relationships. Both studies reported a predominant female sample and use of focus groups which need to be taken into account when interpreting these results.

Contrary to findings above, a study by Crowther, Wilson, Horton and Lloyd-Williams (2013) on bereaved carers for dementia, has reported that individuals do not require in-depth knowledge about a disease and its nature in order to deliver acts of kindness and care in a humane and compassionate way. They suggested that it is the small acts of kindness that are often most meaningful to individuals. Limitations include not interviewing a sequential sample of carers of people dying with dementia and a biased sample of females who self-selected into the study. These may have impacted the outcome of study findings.

1.4.2.4 Constraints to compassionate care

A number of studies have reported on constraints to compassionate care. The study (Crawford et al., 2013) in acute mental health care identified marked limits to the compassionate language by practitioners. Where compassionate language did appear, it was divorced from affect or related more to a service product, process or system rather than emotional engagement with patients. Their language placed high emphasis on time pressures, care procedures and delivering problem-focused care, as opposed to person-focused care. Crawford et al., (2013) noted a small sample size which limits the transferability of the findings.

Similarly, Brown et al., (2014) explored the discourse of compassion in acute mental health care. Practitioners mentioned staff shortages, record keeping and internal processes which took time away from patients. They reported feeling unable to engage in compassionate work in a way they would like. These findings seem to suggest that organisational pressures that focus on task rather than process can create emotional distance between patients and practitioners which has implications for delivering compassionate care.

The observational study (Fry et al., 2013) with emergency nurses revealed that stressful or challenging circumstances including a busy waiting room, can negatively impact on nurses' body language. This in turn can affect nurses' ability to provide compassionate care due to increased difficulties connecting to patients at an interpersonal level. This shows how organisational pressures can influence the practitioner's capacity to practise compassionate care.

A study by Horsburgh and Ross (2013) with newly qualified staff nurses, found that practitioners were highly motivated to provide compassionate care but experienced

difficulties due to the attitudes of other staff who were perceived to be ‘ingrained in the woodwork’ and the environment from which they worked in. Their experiences included feeling ‘flung in at the deep end’ and ‘left to sink or swim’. They experienced tensions between individual agency and organisational structure and felt that more emphasis should be placed on the reality of being a nurse instead of an idealistic view. The potential for peer pressure in group settings needs to be considered when interpreting the results of the study.

Curtis, Horton and Smith (2012) explored student socialisation in compassionate practice. Students considered time to communicate with patients as central to compassionate practice but found it difficult to observe organisational pressures having an impact on nursing practice activities. Students believed that the reality of nursing practice was very different to the professional ideal of compassionate practice. This left students feeling vulnerable and uncertain due to constraints which they viewed outside of their control. Students identified the potential for future disillusionment in the profession and were at risk of abandoning their compassionate ideals and behaviours if they could not overcome these and engage in compassionate practice. Limitations noted the sample size and use of a single centre study, although saturation was reported to be reached. Curtis (2013) reports that nursing faculty staff also experience challenges in teaching compassionate practice. This is due to pressures in managing large student groups, limiting the time and opportunity to engage in smaller group discussions which are central to developing the student’s skills in compassionate care. A limitation worthy of note was the small sample size utilised in study.

Curtis (2014) found that students expressed vulnerability and uncertainties in relation to the emotional requirements for compassionate practice. Particular

concerns centred on the 'compassionate practice boundary' including the degree of emotional engagement with patients and getting 'the balance right' for their patient and their own emotional wellbeing. Students expressed tensions around striving to be genuine, open and honest in their intentions to engage in compassionate practice whilst at the same time feeling the need to 'mask' their feelings or use a 'coat hanger smile' to cope with the emotional labour of compassionate practice, whilst receiving limited formal support.

1.5 Discussion

1.5.1 Review of the findings

Although there is a lack of clarity around compassionate care or compassion in healthcare, the findings show that a range of professionals and pre-registration students have a clear perception of compassion in practice and feel confident to detect its presence or absence in healthcare interactions (Bray et al., 2014).

However, Curtis (2014) reported that student nurses found the requirements for compassionate care difficult to define showing some inconsistency in practitioners' understanding of compassionate care. The review identified a range of attitudes towards compassion and compassionate care, illustrating a lack of coherence around the concept. This may be due to the possible differences between conceptions of compassion and notions of compassionate care, suggesting the need to tease out and promote the components that make up compassionate care in the workplace. The findings from the review suggests the need to improve socialisation in compassionate care.

The findings from the review demonstrate that compassionate care is a skilled interpersonal and relational process. The findings indicate that compassion is an important instrument that brings together patient and practitioner and supports the professional process. Compassionate care is about showing respect for the person as an individual human being (Badger & Royse, 2012; Bramley & Matiti, 2014; Dewar & Nolan, 2013; Lloyd & Carson, 2011). It goes beyond feelings of empathy and requires taking the time to communicate and understand the patient's unique needs and providing individualised care. Patients and practitioners saw time as being instrumental to compassionate care (Bramley & Matiti, 2014; Curtis, 2012).

However, this element of time only needs to be brief to establish a connection and small actions by practitioners can convey compassion to patients (Bramley & Matiti, 2014). This is important for practitioners to bear in mind when faced with challenging circumstances and experiencing time pressures in the workplace. Nevertheless, the review findings would suggest that there needs to be a certain amount of resources to maintain good levels of compassionate care.

The review highlights that caring conversations are central to demonstrating compassionate care and need to be supported and promoted in practice (Dewar & Nolan, 2013). A number of dimensions have been identified to support compassionate practice including attentiveness, listening, confronting, involvement, helping, presence and understanding (Van der Cingel, 2011). Positive body language and communication such as eye contact, empathy, humour, small talk and touch are also important aspects of compassionate care (Fry et al., 2013; Badger & Royse, 2012). The importance of interpersonal and informational communication have been reported in the delivery of compassionate care and include co-operation and collaboration across different disciplines and healthcare providers (Badger &

Royse, 2012; Kvangarsnes et al., 2013). Findings from the review have also suggest that competent care is necessary to achieve the delivery of compassionate care (Badger & Royse, 2012; Kvangarsnes et al., 2013), albeit how this is perceived or understood may depend on the healthcare context (Crowther et al., 2013).

Findings from the review suggest that organisational pressures constrain the practice of compassionate care (Brown et al., 2014; Crawford et al., 2013; Fry et al., 2013).

The findings suggest that practitioners aspire to the professional ideals for compassionate practice but feel their agency as compassionate professionals is stifled by organisational structures (Horsburgh & Ross, 2013). Curtis et al., (2012) and Curtis (2013, 2014) have demonstrated that student socialisation in compassionate practice is negatively affected by dissonance between professional ideals and practice reality. This review highlights the need for more supportive frameworks and strong leadership to challenge practice constraints and to prevent burnout, dissatisfaction or cynicism. The findings suggest that the delivery of compassionate care requires supporting environments that value, encourage and pay close attention to the nurturing of relationships. This would require a 'compassionate design' in order to implement changes to the physical environment, language and culture of the healthcare system (Crawford, Brown, Kvangarsnes & Gilbert, 2014).

1.5.2 Clinical implications

The review findings suggest that self-compassion is important to compassionate care. This suggests that it might be important for healthcare professionals and nursing students to receive training and/or engage in reflective learning to facilitate a compassionate self. Some student nurses found it hard to describe the professional requirements for compassionate practice suggesting that this may need to be more

clearly defined in practice, education and training. The findings suggest that student nurses may experience difficulties upholding the professional expectations for compassionate practice without future support, particularly emotional support. There are implications for education programmes which could help to prepare students for the reality of professional practice and help to develop resilience for maintaining compassionate practice. Newly qualified staff may also require support in their practice environments in order to facilitate the delivery of compassionate care. Although individual accountability is an important factor in providing care, NHS managers need to ensure that environments for compassionate care are supported in relation to staff, resources and culture. Furthermore, the practice environment and university setting could work to ensure that clinical mentors and academic tutors are effectively prepared and supported.

1.5.3 Limitations of the review

The literature was reviewed to gain clearer understanding of compassionate care through examining patient and practitioner perspectives. There was an emphasis on practitioner perspectives within the literature. It is important that both practitioners and patients' perspectives are considered in understanding the practice of compassionate care. In particular, understanding patients' perspectives are crucial for ensuring that care initiatives are informed by those who will benefit from them and thus improving compassionate care. Furthermore, a number of the studies reviewed were from outside of the UK, potentially limiting the utility of the findings for a UK audience. Moreover, the review was based on studies from different patient groups and contexts and the findings should be understood within the specific context they occurred. However, these studies are still meaningful for understanding the practice of compassionate care in general.

1.5.4 Future directions

Future research could expand on patient perspectives of compassionate care which could assist in its provision in clinical practice. There is no research reporting on patient perspectives of compassionate care within acute mental health care settings which would be valuable to our understanding and to address equality in mental health. Further research is needed to understand if different approaches and supportive structures might be needed according to patient groups or contexts including acute or primary care settings. Research could look to demonstrate if Dewar and Nolan's (2013) model of compassionate relationship centred care is applicable across a range of care settings. Future research is needed from a cultural perspective to explore if compassionate care is understood differently within other cultures. This would assist in delivering high quality care. Research could also benefit from observing gender differences in the delivery of compassionate care. Additional research could also expand on the work by Crawford et al., (2013) to explore the language of compassion across healthcare settings and interactions to include academic training.

1.6 Conclusion

Compassionate care in the NHS has been advocated by the Department of Health (DoH, 2013b). Despite this there remains a lack of clarity about what compassionate care means in practice. This review has highlighted that compassionate care is a skilled interpersonal and relational process that involves 'caring conversations' to understand the person's unique needs and to provide individualised care. It requires good interpersonal and informational communication between individuals, families and healthcare teams and providers. However, compassionate care needs to be more

clearly defined in practice, education and training. Organisational structures affect the delivery of compassionate care and supportive structures are required to support practitioners to deliver compassionate care in accordance with their beliefs and values. The implications for clinical practice have been outlined and areas for future research have been suggested.

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*Denotes studies reviewed in the current paper.

Chapter Two

Empirical Paper

Carers' Lived Experiences of Compassion while Caring for Adults with Severe and Enduring Mental Health Difficulties

In preparation for submission to *Issues in Mental Health Nursing* (see Appendix C for Author Instructions)

Tables are presented within the thesis chapter to provide clarity and help with understanding. Tables will be moved to the end of the paper prior to journal submission as per the author's instructions.

Chapter Word Count (excluding tables, figures, footnotes and references): 7853 words

2.1 Abstract

Objective: Compassion is associated with health and wellbeing and has been linked to mental health recovery. Compassion has been explored in mental health settings from the perspectives of staff and patients. Research on compassion with carers is an under researched area. This study aims to explore carers' lived experiences of compassion while caring for an adult with severe and enduring mental health difficulties.

Method: This study was organised around the principles of Interpretative Phenomenological Analysis (IPA). Qualitative information was collected from eight carers using semi-structured interviews.

Results: Two superordinate themes emerged from the data: 'Burdenome responsibility' and 'Something that holds you'. Caring for an adult with severe and enduring mental health difficulties is an all-consuming task that places heavy demands on the carers. Carers experienced a lack of support and compassion from services. Carers placed high value in carers' support systems and supportive networks which helped them to cope.

Conclusion: Whilst the study looked at compassion, what appeared to emerge were experiences of caring. Carers reported a lack of support from services which could serve to create a sense of threat for carers. This can inhibit caring mental states including compassion for self and others. Clinical implications consider compassion based interventions for carers.

Keywords: Compassion, carers, mental health, Interpretative Phenomenological Analysis

2.2 Introduction

2.2.1 Emergence of compassion

Compassion is a complex but valuable phenomenon which unites people in times of suffering (Van der Cingel, 2009). It is now recognised that compassion is central to building healthy human development and can promote both physical and mental health (Gilbert, 2009). Although the concept of compassion has been written about for decades, the evidence base into the nature and function of compassion has only recently emerged and has grown substantially over the last ten years (Davidson & Harrington, 2002; Gilbert 2000, 2005, 2009; Neff, 2003). Compassion has started to receive attention worldwide amongst researchers and policy makers. As a result, there is a growing emphasis on compassion as a core value in healthcare relationships (Rider et al., 2014).

2.2.2 Understanding compassion

Compassion is described in slightly different ways in the literature. Many definitions of compassion are firmly rooted in religious and spiritual traditions whereby suffering is considered to be the trigger for compassion. The Dalai Lama (1995) describes compassion as ‘an openness to the suffering of others with a commitment to relieve it’. It involves feelings of kindness, gentleness and warmth (Fehr, Sprecher & Underwood, 2009). Gilbert (2009) and Gilbert and Choden (2013) have emphasized two different psychological approaches that underpin compassion. One is the psychology of engagement and focuses on the ability to approach, understand and engage with suffering. The second is the psychology of alleviation and includes a motivation and commitment to take steps to alleviate or prevent suffering. Gilbert (2009) refers to compassion as a social mentality because it integrates motivational, cognitive, emotional and behavioural elements to achieve

goals. Compassion is also described as requiring commitment, courage and wisdom (Cole-King & Gilbert, 2011). Gilbert (2005, 2009) has identified and begun to explore the key attributes of compassion: motivation to be caring, sensitivity, sympathy, empathy, distress tolerance and being non-judgemental.

Gilbert and Choden (2013) have written about 'compassion as flows' to describe the direction of compassion including compassion for others, compassion from others and self-compassion. They suggest that building a capacity for compassion requires an understanding of compassion flows, recognizing that individuals can accord with it or resist and fear it (Gilbert, McEwan, Matos & Ravis, 2011). There is increasing research to suggest that being compassionate towards oneself and others is associated with resilience and positive wellbeing (Lutz, Greischar, Rawlings, Richard & Davidson, 2004; Smeets, Neff, Alberts & Peters, 2014). However, there is also evidence to suggest that helping others can diminish health and wellbeing (Amirkhanyan & Wolf, 2003; Schulz & Sherwood, 2008). This is reported to be particularly true for people who feel obligated to provide care and have few resources to cope (Vitaliani, Zhang & Scalan, 2003) or attend to others needs to the exclusion of their own (Hegelson & Fritz, 1999).

Catarino, Gilbert, McEwan and Baião (2014) have recently begun to explore the motivations associated with compassion and have differentiated between genuine compassion and submissive compassion. Submissive compassion has been described as a form of caring behaviour which is motivated by the desire to be liked, valued or to avoid rejection. This may be a form of appeasing submissive behaviour developed in childhood (see Gilbert & Allen, 1994). They found submissive compassion to be linked to depression, anxiety and stress, unlike genuine

compassion, illustrating that not all forms of compassionate behaviour are associated with wellbeing.

2.2.3 Compassion and mental health

A range of applications of compassion have been shown to be particularly helpful for people with mental health difficulties (Gilbert & Proctor, 2006; Braehler et al., 2013). Spandler and Stickley (2011) have argued that compassion enables us to develop a sense of purpose, meaning and hope which is vital to mental health recovery. Indeed, there is now increasing emphasis on the role of compassion and kindness in mental health recovery (Johnson et al., 2009; Laithwaite et al., 2009). Initiatives at the King's Fund in the UK have recently emphasised the need to develop and nurture compassion, particularly in acute hospital settings (Firth-Cozens & Cornwell, 2009). There have been reports in the UK about the quality of care standards in these areas (Care Quality Commission, 2009). Research has also started to emerge looking at compassion in mental health settings, especially from the perspectives of staff and patients (Crawford, Gilbert, Gilbert, Gale & Harvey, 2013; Lloyd & Carson, 2011). There is currently no research exploring informal carers' perspectives or experiences of compassion.

2.2.4 Compassion and carers

Since the move towards community care in the UK, more responsibility has been placed upon family carers to provide psychosocial care (Rowe, 2012). Over the last ten years there has been an increasing emphasis on family caregivers' involvement in mental health services (Department of Health, 1999; Hervey & Ramsay, 2004). The involvement of carers and family members in research is also recognised as vitally important (Repper, Simpson & Grimshaw, 2011). There is rich literature looking at

the experiences of family carers in severe mental illness. For example, research has included exploring carers' needs and burden (Bailey & Grenyer, 2013, for a review) as well as expectations, relationships and engagement between family carers and professionals (Rowe, 2012, for a review). To date, little attention has been paid towards compassion within the family caregiving literature. Moreover, there has been limited emphasis on carers in the broader literature on compassion. Research that does exist, has mainly focused on the concept of compassion fatigue from formal caregivers' perspectives (Adams, Figley & Boscarino, 2008; Joinson, 1992). More recently, Day and Anderson (2011) have suggested that the concept can be applied to family caregivers. Schulz et al., (2007) have put forward a discussion paper on patient suffering and caregiver compassion. They have presented a preliminary conceptual model linking these constructs based on descriptive and research literature in the field. Schulz et al., (2007) also highlights the need for more research in order to gain a better understanding of carers' experiences of compassion.

2.2.5 Aims

This research aims to extend current research and focuses on carers' lived experiences of compassion. It aims to address the following question:

What are carers' lived experiences of compassion while caring for an adult with severe and enduring mental health difficulties?

2.3 Method

2.3.1 Design

The epistemological and methodological framework for this study was greatly influenced by interpretive phenomenological analysis (IPA). IPA endorses social constructivism which sees reality as dynamic and socially constructed (Smith, Flowers & Larkin, 2009). IPA is concerned with how people understand their experiences with phenomena, in a particular context, rather than making general claims (Chapman & Smith, 2002). Its primary aim is to explore in detail the meaning that participants attach to their subjective experiences and therefore does not look to test hypotheses. Participants are acknowledged to be experts on their own experiences, and IPA invites them to tell their story, in their own words (Smith et al., 2009).

IPA is increasingly recognised as a valuable tool in healthcare research and is one of the most commonly used qualitative methods in psychology (Smith, 2011). IPA has the potential to look beyond the first person experience and to develop a rich understanding of the lived experiences of significant others including formal carers (Thomson, Powis, & Carradice, 2008) and informal carers (Hunt & Smith, 2004). It is particularly appropriate for understanding new and under researched topics and allows the voices of under researched groups to be heard. IPA was considered to be a suitable method for use within the present study due to recognition that carers are often described as hidden, undervalued and excluded from research despite their valuable contribution (Repper, et al., 2011; Pinfold & Corry, 2003).

2.3.2 Participants

A purposeful sample of informal carers providing support to adults with mental health problems were recruited from two carers support services in the West Midlands region of the UK. A set of inclusion and exclusion criteria were developed in order to establish a relatively homogeneous sample and are presented in Table 2.1. The criterion of carers for mental health difficulties was set to extend on compassion in mental health research (Crawford et al., 2013)

Table 2.1 Participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Adult carers aged 18 years and over	Participants who are unable to speak the English language
Participants are able to communicate in English	Young carers under the age of 18 years
Provide informal care to adults with severe and enduring mental health diagnosis who:	Carers for individuals due to physical illness, disability or dementia
Live with or visit/meet their partner, friend or relative at least three times a week; and	
Has a role in the care of their partner, friend or relative	
(N.B. Informal carers definition obtained from Jankovic et al., 2011)	

Eight participants were recruited for the study and consisted of four males and four females. This number is in line with Smith et al., (2009) who advise that four to ten participant interviews are sufficient to gain richness of data and allow for similarities and differences to be examined. A summary of participant characteristics is presented in Table 2.2.

Table 2.2 Participant characteristics

Category	Demographic information
Caregivers gender	Males (4), Females (4)
Caregivers age	55-64 years (1), 65-74 years (6), 75-84 (1)
Caregivers race	White British (6), White Irish (1), White Other (1)
Caregivers relationship	Parents (5), Partner/Spouse (2), Adult Child (1)
Living together	Yes (3), No (5)
Number of hours caring a week	0-10 hours (1), 11-30 hours (4), 31-50 hours (2), Missing (1)
Number of care recipients*	1 person (6), 2 people (1), 3 people (1)
Care recipients diagnosis	Schizophrenia (5), Bipolar (1), Borderline Personality Disorder (1), Schizophrenia and another with Bipolar (1)

* Number of care recipients with a mental health diagnosis

2.3.3 Procedure

2.3.3.1 Materials

In IPA research, a semi-structured interview is considered to be the most appropriate form of data collection (Smith et al., 2009). A semi-structured interview guide was developed by the research team in line with the epistemological underpinnings of IPA and by drawing on existing compassion literature in line with the study aims. The interview guide was piloted on a carer known to the researcher. Feedback informed the final interview guide in terms of the content and wording of questions and their capacity to draw out individual experiences (Appendix D). The interview guide draws on Gilbert's (2009) key attributes of compassion as a way of providing a structure to the interview. The questions were open ended to generate rich and detailed descriptions of carers' experiences.

A demographic information sheet was developed in order to obtain participant characteristics (Appendix E).

2.3.3.2 Recruitment

Potential participants were identified and contacted via carer support workers within the carer support services. Potential participants attending a carer support group were provided with a participant information pack. This included a letter from the lead researcher with a reply slip to express an interest in participating (Appendix F) and a participant information sheet outlining the nature of the study (Appendix G). The information packs were also electronically distributed from one carer support service. Participants were encouraged to contact the researcher if they wished to take part. Fifteen carers expressed an interest in the study and were subsequently contacted. Five carers did not meet the criteria and an additional two carers expressed an interest but did not respond to contact from the researcher.

2.3.3.3 Interview procedure

One-off in-depth interviews were conducted by the lead researcher between November 2014 and March 2015. Two of the participants were interviewed in a private meeting room at a carer support service which was familiar to participants. Six participants were interviewed at their own home for their convenience. The mean interview length was 78 minutes (ranging between 61 to 117 minutes).

At the start of the interview session, participants were given time to review the participant information sheet and ask the researcher any questions. Participants were informed about confidentiality and then were asked to sign a consent form (Appendix H) and complete the demographic information sheet. Interviews were recorded on a digital audio recorder and the interview guide was used in a flexible

manner in accordance with IPA guidance (Smith et al., 2009). At the end of the interview, participants were given the opportunity to ask further questions and were provided with de-briefing information (Appendix I).

2.3.3.4 Ethical approval

The research was approved by Coventry University Ethics Committee (Appendix J). The research was conducted in accordance with the codes of ethics and conduct set out by Coventry University (based on guidance published by the UK Research Integrity Office August, 2009 and the Research Councils UK, 2013) and the British Psychological Society (BPS, Code of Human Research Ethics, 2010). Informed written consent was obtained from participants prior to interviews commencing. Participation in the study was voluntary and the participants were aware of their right to withdraw. The researcher ensured time at the end of the interview to debrief regarding feelings that might have been evoked during the interview. Information of support was also provided, should participants have a need following the interview. There was no evidence of the participants becoming distressed during the research.

2.3.4 Analysis

The recorded interviews were transferred onto a password protected computer and transcribed verbatim by the same researcher who conducted them. Participants were assigned a pseudonym and personally identifiable information was removed to maintain anonymity. Each transcript was analysed using IPA, following the steps outlined by Smith et al., (2009) (Appendix K). An extract of a participant transcript is presented in Appendix L alongside an example of themes developed and clustered for one participant in Appendix M.

2.3.4.1 Validity of the study

A number of guidelines have been produced to facilitate the assessment of quality and rigour in qualitative research (i.e. Spencer, Ritchie, Lewis & Dillon, 2003; Yardley, 2000). Smith et al., (2009) suggest the ‘four principles’ approach by Yardley (2000) which was used to guide and enhance the validity of the study. These included: sensitivity to context, commitment and rigour, transparency and coherence, impact and importance. The hermeneutic underpinning of IPA requires the researcher to evaluate their own pre-conceptions and to be aware of their influence when engaging with the data. A bracketing interview was employed regarding the researcher’s assumptions around compassion which was used to enhance researcher reflexivity and transparency (Husserl & Welton, 1999).

Transcripts, initial coding, emergent and final themes were discussed within the supervision team and with colleagues who are experienced in IPA methodology. Additionally, one transcript was partially coded by a colleague familiar with IPA. This was then used to compare similarities and differences in coding. A peer IPA group was established with three trainee clinical psychologists who were also involved in IPA for their own research. These groups met on three occasions and involved presenting examples of data from the study and suggested themes and clarifying whether themes were grounded in the data.

2.3.4.2 Position of the researcher

The researcher is a trainee clinical psychologist who has no association with the carer support services or mental health carers involved in the study. The researcher takes the view that experiences and their meaning derive from social interactions which continuously evolve. This is akin to symbolic interactionist and social

constructionist underpinnings of IPA (Smith et al., 2009). The influence of the researcher is recognised to be important in IPA and relies on the researcher adopting a reflective stance towards the research. A reflective journal was kept throughout the research process, whereby the researcher reflected her own pre-conceptions, thoughts, feelings and impressions generated by the research and acknowledged their potential impact on engagement with the data. A reflective peer group session was also held by the peer IPA group and included reflection on the subjective position of the researcher and is considered further in Chapter 3.

2.4 Results

Two superordinate themes were identified in the data, reflecting the lived experiences of compassion while caring for an adult with severe and enduring mental health difficulties: 1) ‘Burdening responsibility’ and 2) ‘Something that holds you’. These are presented in Table 2.3 along with their subordinate themes. Extracts from participant transcripts are presented to illustrate the themes. Three dots (...) in the quotations represent omitted text.

Table 2.3 Superordinate themes and subordinate themes

Superordinate themes	Subordinate themes
Theme 1: Burdening responsibility	We can't get any help It's all down to me Thankless task
Theme 2: Something that holds you	Somewhere to turn Me time

2.4.1 'Burdensome responsibility'

The burdensome responsibility of caregiving was evident across all participant accounts. As James said "*I don't know how they would function if I escaped*" (James, 474)¹. There was a strong sense of duty and obligation in carers' narratives to take on the caring responsibility which resulted in heavy demands being placed on the carers. This theme is discussed under subordinate themes 'We can't get any help', 'It's all down to me' and 'Thankless task'.

2.4.1.1: *We can't get any help*

The majority of carers expressed 'we can't get any help'. The carers' experiences indicated feeling ignored and disregarded by services through professionals not acknowledging or acting on the carer's concerns. Carers expressed a lack of trust and confidence in professional services which contributed to burdensome responsibility.

"See I find this, you pick up early warning signs and it doesn't do any good I don't think, I have heard carers mention it err, you can pick up these early warning signs but nothing is done until it is fully blown and something happens. They could save the country a lot of money if they listened to you"
(John, 336)

A number of carers made reference to the monetary cost that could be saved and a perceived lack of investment in mental health care. For some, these concerns may be experienced due to stigma of mental illness.

"It's so, it's quite hard, it's very hard because there is just nothing and nowhere and if (name) had got learning difficulties as well that opens an

¹The number denotes the line number in the participant's transcript.

avenue of doors but because she hasn't they're all closed and as I say to my knowledge there isn't anything, err, and I think it's a shame" (Pauline, 460)

However, behind the issue of money there was a sense that emotional suffering could also be spared through service provision. As a result of the burdensome responsibility, carers expressed feeling emotionally overwhelmed through times of worry and fighting for help.

"It made me severely ill which I had to go to the doctors and I have never felt like that before and completely overwhelmed by it because we wasn't being listened to, (name) wasn't getting any help. He wasn't getting any help and we felt that we were fighting at a time when we needed all of our energy to look after him" (Victoria, 130)

Wendy summarises her experiences of feeling dismissed and shut out by services and being confronted by confidentiality when seeking information.

"We had legitimate fears because he was afraid he was going to be assaulted and we wanted to know how are they dealing with it and that kind of stuff... They actually said to me that they were following their confidentiality protocol so I thought don't get involved" (Wendy, 263)

Wendy's language conveys a sense of feeling rejected or defeated by services.

Feelings of anger and frustration were noted across many of the carers' narratives in relation to feeling ignored or disregarded.

"It, it is, it is, umm frustrating and it makes you very angry when people don't listen to you" (Pauline, 300)

2.4.1.2 *It's all down to me*

Evident across all of the carers' narratives was their experience of carrying the burden of responsibility through 'it's all down to me'. The carers described holding sole responsibility for caregiving and for many there was a sense that without me there is no one else to provide care. The carers conveyed that their relative was almost totally dependent on their help and that they needed to be accessible for them.

As Victoria states:

"he needs your support 100%, that he needs it whatever" (Victoria, 127).

There are three themes within 'it's all down to me' that contribute to burdensome responsibility:

1. Cuts to services
2. All-consuming task
3. Unpredictability

2.4.1.2.1 *Cuts to services*

For some carers, cuts to mental health and support services fuel the burden of responsibility and contributed to feelings of vulnerability and uncertainty about the future.

"I think that we will be looking after (name) for as long as we are able to, but then what happens I don't really know, It doesn't bear thinking about it really, does it? It's very hard to think about it. Because you just don't know do you?"
(Pauline, 463)

Pauline experiences distress in not knowing that there will be future support available. Perhaps there is an underlying fear that her daughter will not survive without her. The prospect of this is too unbearable for her to contemplate.

Chris describes:

“the continual cut back cut back cut back of the beds is very very dangerous and if the carers were not able to do their job then god only knows what would happen; it would be a dreadful situation” (Chris, 596)

Chris emphasises considerable concern in his choice of language. The repetition of ‘cut back’ and ‘very’ with the choice of the word ‘dangerous’ has an angry and aggressive feel to it. There was a sense that carers were expressing fears that cuts to services were cutting a lifeline.

2.4.1.2.2 All-consuming task

Most of the carers spoke about the caring task as an all-consuming experience which often left carers feeling overwhelmed and worn through caring. The carers conveyed a strong sense of their role as *“having to act really as a mental health advocate”* (Wendy, 314), closely monitoring mental states, behaviour and wellbeing and protecting their best interests as well as being the link to professional support.

“It’s like all day you are trying to sort things out and do things and be help and err so sometimes you feel you are drowning in the whole situation, yeah”
(Victoria, 309)

John’s narrative also conveys the intense and relentless nature of the caring role.

“you have heard of a dripping tap haven’t you, it’s that kind of thing, it’s like that with my daughter. Its constant and I don’t know (sigh/laugh) that does get to me sometimes” (John, 287)

It seemed that many carers sacrificed their own needs and desires in order to provide care to their family member.

“Yeah I get sad at times that I am missing out” (James, 390)

For some carers, caregiving is an isolating experience that contributes to burdensome responsibility.

“it’s got worse, you don’t think it can get any worse, gradually it’s got worse and worse and probably since there have not been very much contact with the clinic and we have had to do it on our own it has been absolute hell” (Pauline, 215)

For Mary there is a financial burden associated with caring.

“I have had a year off so I am looking for some part time work so I have been here to stabilise him” (Mary, 85)

2.4.1.2.3 Unpredictability

The majority of carers, at some point in their experience, spoke about the unpredictable nature of mental health difficulties which places heavy demands on the carers and adds to burdensome responsibility. They described experiencing feelings of *“apprehension...because you don’t know what you are going to be dealing with”* (Wendy, 525)

“I suppose it is responsibility and just you have to plan each day knowing they might be a phone call or some problem in hand and how to cope with that and respond and deal with the unexpected really, it’s a bit stressful not knowing what will come up next” (Mary, 414)

Victoria's narrative conveys a sense of needing to be strong and to cope with the demands of caring which may serve to increase the burden of caring.

“you just have to deal with it as it comes but you are always waiting for something to come and know that you got to deal with it, you've got to cope with it” (Victoria, 330)

For some, caring can be frightening experiences as there are times that the care recipient becomes verbally or physically aggressive towards the carer.

“to try and stop him from bashing up something and he broke my ribs” (Chris, 117)

“err (pause) yeah and to take all the knocks as well when they turn on you (laughs)” (John, 81)

Additionally, the frightening and unpredictable nature of mental health difficulties was also experienced by some carers in relation to risk. There seemed to be pressure and discomfort in holding the responsibility which is expressed in Chris's laugh.

“I could see that he was very very disturbed and so it was very difficult as we had to hide all the knives and forks. All the knives and sharp things were in the boot of my car and every time I made dinner for him I had to go to the boot open it up and take it out [laugh]” (Chris, 91)

2.4.1.3 Thankless task

This theme indicated that several carers felt undervalued for their caring efforts which were seen as a thankless task in relation to the government, services and the person cared for. As Victoria claims *“this is where I feel there has been no compassion, there has been no help for us”* (Victoria, 180). They described feeling

left to provide care with little respect, consideration or help for the carers, the effect of which seems to increase the burden placed on the carers.

“So the frightening thing is that the government is stupid they tacitly accept that carers look after the people but will not provide resources so that the carers the subject of the carers, in other words the one for whom they are looking after can have some help” (Chris, 146)

Pauline described feeling left to get on with it until breaking point, conveying the psychological impact of care.

“But I often do wonder whether because she lives at home and they do know that we are responsible parents for (name) we do everything we possibly can for her, I do think that they just let you get on with it until you virtually break and that’s been my umm, well that’s just how it’s been” (Pauline, 304)

A number of carers expressed feeling unappreciated and undervalued by their care recipient which had a personal impact on them as a care, particularly self-esteem.

“What I get very niggled at is when (name) does not accept what I do as being all right. ‘You’ve done that wrong’ now once upon a time my tolerance levels would take that, now I am likely to snap back” (Robert, 450)

Wendy stated:

“and unfortunately I agreed to take him in and he always said that I betrayed him you see so that was another nail in my coffin” (Wendy, 143)

Mary appeared to be the exception in relation to being thanked for her caring efforts with a noted increase in the level of support.

“He probably isn’t aware of how much I am doing for him, although he does thank me for things” (Mary, 382)

2.4.1.4 Summary: ‘Burdensome responsibility’

This theme reflects the carers’ overwhelming sense of feeling ignored and disregarded by services (we can’t get any help) which contributes to feeling isolated and alone in their caring role (it’s all down to me) and without any appreciation or support from the government, services or the care recipient (thankless task). Consequently, physical, emotional and financial demands are placed on the carers and contribute to burdensome responsibility.

2.4.2 ‘Something that holds you’

The theme ‘something that holds you’ was present across all participant accounts. Carers indicated the importance of support for the carer and finding ways to cope with burdensome responsibility. This theme is discussed under subordinate themes ‘somewhere to turn’ and ‘me time’.

2.4.2.1: Somewhere to turn

Evident throughout the carers’ narratives was the importance of having somewhere to turn. The carers placed high value in carers’ support systems and other supportive networks which appeared to help carers to cope with the burden of responsibility. As Chris states *“there are very few resources and the carers centre is an incredible valuable resource”* (Chris, 165). Most of the carers had spoken about feeling ignored and disregarded by professionals as well as feeling undervalued for their caring role. Consequently, there was a sense of relief and personal acknowledgement in finding support.

“Until I actually got a carer’s assessment and met a sympathetic person who was concerned about how I functioned as a person. I described it; it was like coming in from the cold” (Wendy, 516)

For Victoria and Chris there was a strong sense of comfort in carers’ shared experiences which may mitigate feeling alone and isolated.

“the carers and they have been a fantastic support because there are other, like other people in a similar situation...to know that someone understands and that somebody is listening to your problems” (Victoria, 144)

“For a start I realised that I wasn’t the only one with a problem” (Chris, 540)

For many, there was a sense of value in a supportive community whereby the carer could ask for help and provide support to others, potentially increasing self-esteem.

“Sometimes when they have their meetings you can ask some other parents have clever ideas and one of the ladies err I told her how I manage to get the doctor to do something” (Chris, 540)

John stated:

“You hear younger carers coming in to it and you can help them” (John, 190)

For James knowing that there was somewhere to turn appeared enough to hold him. Perhaps for James it is important to find solace outside of caring and a need to separate from his caring role.

“As people know this place exists and there is help there...There are all sorts of things that go on here [carers’ organisation] that I have never bothered with. I could benefit but as I said I have got my hobby” (James, 324)

A number of carers also turned to their church community for support.

“I know that going to church helps me to cope...you can offload at church and that and meeting people, that helps me a lot” (John, 60)

2.4.2.2 Me time

This theme reflects all the participants’ (carers’) attempts to cope with the burden of responsibility through needing time away or to ‘escape’ from their caring role. They described the importance of having an outlet and finding solace outside of caring.

As Pauline notes

“I go to (name) Club once a fortnight...I say that is my world there you see, so I’ve got some good friends there” (Pauline, 398)

Mary spoke about feeling tired through responsibilities and needing to plan time for herself, suggesting it is not easy to take time for herself.

“I know from a carer’s point of view that you have to look after yourself, your own health else you won’t be able to look after anybody” (Mary, 228)

Mary was the only carer who directly expressed the importance of self-care. Other carers expressed the need for ‘me time’ in other ways. James emphasises the importance of his hobby which keep him going.

“I have got my hobby...I am that involved I can escape from one thing to the other. So that is my saviour shall we say” (James, 329)

The other male carers, Chris, Robert and John, all expressed how they have retired but continued to work as a form of outlet and escape.

“Well I am still working, I am retired...I find I can relax, I can talk to people who understand, and it’s an outlet as well” (John, 52)

For some carers there was a sense of guilt and conflict around taking time for themselves.

“I asked her is it selfish of me to want to have a break just to get away and she said no it is not. So I did go but then I had to come back again [laughter]”

(Chris, 552)

2.4.2.3 Summary: ‘Something that holds you’

This theme indicates the importance of finding support that acknowledges the carer and their experiences (somewhere to turn) and finding an escape or outlet from their caring role (me time) in order to cope with the burden of responsibility (something that holds you).

2.5 Discussion

The aim of the present study was to explore carers’ lived experiences of compassion while caring for an adult with severe and enduring mental health difficulties. The intention of the study was to provide a rich understanding of compassion with carers due to this being an under researched area. Although the study aimed to explore compassion, what appeared to come through the data were experiences of caring. The results present two themes that emerged from the interview data and depict the carers’ experiences: ‘Burdensome responsibility’ and ‘Something that holds you’. The two superordinate themes will be discussed within the context of previous research. The clinical implications, limitations and recommendation for future research will also be discussed.

The study findings are discussed in relation to Gilbert's (2005, 2009) understanding of compassion. Gilbert (2005, 2009) proposed six attributes of compassion: care for wellbeing (motivation to be caring to alleviate distress), sensitivity (the ability to notice the other's distress), sympathy (an emotional response to another's distress), empathy (working to understand another's point of view) distress tolerance (ability to manage difficult emotions) and non-judgmental (to not condemn, criticise, shame or reject). Although some carers demonstrate aspects of these attributes, they were not prevalent enough to become central themes. This may reflect the carers' attention being largely focused on services. A reflective account around the carers' experiences of these attributes will follow in Chapter 3.

Gilbert's (2005, 2009) work on compassion describes three types of emotional regulation systems: the threat (protection) system, the drive (resource-seeking) system and the soothing-contentment system. Gilbert (2005) suggests that distress is caused by an imbalance between the three systems, often associated with an under-development of the soothing-contentment system. These factors are considered in the discussion.

2.5.1 Exploration of themes

2.5.1.1 Superordinate theme 1: 'Burdensome responsibility' captures the physical, emotional and financial burden of taking on the caring role. The carers' narratives depicted caring as a difficult, demanding and often unpredictable experience that can have a negative impact on the carer. These findings are consistent with a wealth of research that shows the significant risks of being a carer on physical, psychological and social health and wellbeing (Butterworth, Pymont, Rodgers, Windsor & Anstey, 2010; Pinquart & Sörensen, 2003). There is also an extensive body of research on

psychological distress in carers of people with mental health difficulties (Shah, Wadoo & Latoo, 2010, for a review).

The carers in this study felt a great obligation or duty to provide care for their relative which appeared to increase the burden of care. The carers indicated that 'it's all down to me' and for some there was a sense that 'without me there is no one else'. Carers' narratives indicated they acted like a mental health advocate for their relative, closely monitoring their wellbeing, acting in their best interest and being the link to professional support. Their accounts appear to be more in line with Gilbert's (2009) and Gilbert and Choden (2013) second psychology of compassion, namely alleviation and prevention. Although some carers demonstrated a wish to alleviate their relatives suffering they did not always understand it. Research shows that carers typically identify obligation or lack of alternatives as a reason for undertaking the caring role (Cash, Hodgkins & Warburton, 2013). Research also indicates that caring can have a negative impact on an individual's health and wellbeing when they feel obligated to provide care with few resources to cope (Vitaliani et al., 2003). Additionally, research shows that not all compassionate motivations and behaviours appear to be associated with wellbeing (Catarino et al., 2014). These study findings appear to suggest that carers are predominantly in the 'threat protection system' whereby they are attuned to signals of danger and a drive based system where they are motivated towards action and finding resources. The distress linked to burdensome responsibility may be caused by an imbalance between systems, associated with the underuse of the soothing-contentment system (Gilbert, 2005).

In the present study, burdensome responsibility appeared to be exacerbated by 'we can't get any help'. The carers' narratives indicated feeling ignored and disregarded by services and demonstrated a lack of confidence in obtaining professional support

for their relative. Some expressed feeling angry and let down by the health care system. The findings of the present study are consistent with literature which shows that carers of adults with mental health difficulties experience feelings of isolation, frustrations of not being listened to or taken seriously and feel ignored with nowhere to go, particularly in crisis situation (Lyons, Hopley, Burton & Horrocks, 2009). This can create a sense of threat and low morale in carers. The present findings suggest that carers are at risk of becoming overwhelmed by burdensome responsibility. Carers' narratives demonstrated feeling cut off from professional support for their relative which left them in a vulnerable position and increased the burden of caring. In considering Gilbert and Choden's (2013) 'compassion as flows' these findings appear to suggest an absence of compassion or compassionate care towards the carer. It is interesting to observe that when carers were asked about compassion, their focus was drawn to experiences of caring and services. It could be hypothesised that carers are too overburdened to think about compassion. It is possible that carers' attention towards difficulties with services may serve to preoccupy the carer and detract from the concept of compassion.

The carers in the study conveyed their caring efforts as something of a thankless task. They demonstrated feeling criticised, unappreciated and undervalued in relation to the government, services and the person cared for. Previous research shows that carers do not feel recognised or valued by mental health professionals (Wilkinson & MacAndrew, 2008). The majority of carers had been caring for a significant number of years and it is possible that they have habituated to feeling ignored, criticised and undervalued by services and their relative and may have adopted a position of learned helplessness (Seligman, 1975). Nonetheless, the carers in the study indicated a lack of support and compassion for the carer. Gilbert's

(2005) work would suggest that for carers there is a perception of threat towards the self and social wellbeing such as rejection, humiliation and defeat. He further suggests that the experience of personal threat can lead to the development of defensive emotional states which in turn makes it more difficult for an individual to access caring mental states (i.e. soothing-contentment system) and to express compassion for self and others. The experience of threat can also lead to compassion fatigue and/or deterioration in care (Collins & Long, 2003; Gilbert, 2009). It was interesting to observe that some carers spoke of positive feelings but these seemed to be overshadowed by difficult aspects of caring.

2.5.1.2 Superordinate theme 2: 'Something that holds you' indicates the importance of emotional support for carers and finding ways to cope with burdensome responsibility. Having 'somewhere to turn' that was supportive was highly meaningful and significant to carers. Indeed, there is research emphasising the significance of social support in reducing caregiver burden (Rodakowski, Skidmore, Rogers, & Schulz, 2012). Most of the carers had spoken about feeling ignored, disregarded and undervalued in their caring role and conveyed a sense of comfort and relief in carers' support or church community. Research shows that religion plays a significant role in coping with the stress of caring for a relative with mental health difficulties (Rammohan, Rao & Subbakrishna, 2002). The findings of the present study may be related to the importance of compassion for the carer and the need for carers and their experiences to be listened to and validated in order to generate feelings of value and self-worth. According to transactional analysis theory (Berne, 1968), recognition is a basic biological need that all individuals have a drive for. It is similar to the need for love and belongingness and self-esteem in Maslow's (1970) hierarchical theory of needs. The supportive structures described by carers

can be described as a form of holding environment (Winnicott, 1945) or psychological containment (Bion, 1962) in psychodynamic theory. Gilbert's (2005) model would suggest that feelings of connectedness can help to deactivate the threat system and help individuals to cope with adversity.

Carers in the study indicated the significance of 'me time' which was demonstrated as needing time away and to find an escape or outlet from the caring role.

Interestingly, the male carers continued to work in employment or projects as a form of outlet and escape. Gilbert (2005) understands 'escape' as being associated with the threat system and self-protection system. Specifically, he distinguished between safety-seeking and safeness. Safety-seeking is understood as a defensive behaviour linked to fight, flight and avoidance strategies with the aim of fleeing to a 'safe base'. It contrasts to a state of safeness and contentment where there is a relative absence of threat which is linked to the soothing-contentment system and associated with compassion. The present study indicates that some carers are utilising safety seeking strategies to cope with burdensome responsibility. One of the carers in the study emphasised the importance of self-care in order to care for others. Indeed, Gilbert's (2005, 2009) work on compassion demonstrates the need to be compassionate with ourselves in order to be compassionate with others. The present findings raise the question: who is caring for the carer and helping them with compassionate care?

2.5.2 Clinical implications

A lack of support for carers of adults with severe and enduring mental health difficulties was evident in the present study, along with distress in taking on the caring role. These findings highlight the need to improve the provision of support

for this group of carers. The findings that carers felt ignored, disregarded and undervalued in their role have significant implications for compassion. Gilbert's (2005, 2009) work highlights that threat perception such as rejection can affect an individual's ability to access caring mental states and hence compassion for self and others. Additionally, high activation or arousal from the threat system can have longer-term consequences for wellbeing and result in compassion fatigue (Gilbert, 2009).

The findings suggest that carers are predominantly operating in a drive based system and threat protection system. Consequently, carers may require support or intervention to increase their soothing-contentment system which would help to regulate these systems and increase compassion for themselves. Moreover, the finding that some carers are engaging in safety seeking strategies may suggest that carers may require more coping skills and self-care strategies to manage the demands associated with the caring role. Cultivating a compassionate mind through compassion focused therapy (CFT) is one particular intervention that has a growing evidence base (Leaviss & Uttley, 2014, for a review). This intervention could be offered in a group setting with carers and help to alleviate and prevent distress. It could also help them to develop resilience in their caring role. Clinical psychologists are in a prime position to hold in mind the impact on compassion for carers who might present to services, in order to deliver these types of interventions.

The present study highlights that the interactions between carer and services can have a negative impact on carers. It is recognised that carers are entitled to be treated with dignity, respect and compassion (DoH, 2013) and should be highly recognised and valued for the job they do (DoH, 2010). Professionals may also require training to engage with carers in a supportive, empathic and compassionate

way. Clinical psychologists working within teams are in an ideal position to be able to deliver staff training on compassionate interventions. Furthermore, the wider healthcare system needs to be aware of the negative impact that service cuts and lack of services provision can have on the carer and their need to feel supported in their role.

2.5.3 Methodological implications

The present study provides qualitative accounts of a small and purposeful sample of carers from a specific area in the UK. This makes it difficult to determine the extent to which the findings might reflect the experiences of carers nationwide. All of the participants in the study were over the age of 55, with 75% (n = 6) of the sample falling between 65-74 years of age. Therefore the findings from this study may not reflect the experiences of younger carers. Furthermore, the sample was predominantly parental carers (63%, n = 5) for an adult with schizophrenia (63%, n = 5) which may have biased the data. It is possible that the findings may not accurately represent the experiences of spousal carers or adult carers for a parent with mental illness. The sample consisted of equal male and female carers who were of Caucasian ethnicity. A limitation of the study is the absence of Black and Minority Ethnic participants. It is possible that compassion is experienced differently across cultures and different religious backgrounds.

Participants were recruited through two carer support services which may have introduced a bias to the sample and the data. For example, recruiting carers through support workers may have resulted in an atypical sample of engaged carers. There may be differing characteristics between carers who decide to access and engage with carers support services compared to those that do not.

A final limitation of the study includes the absence of carer feedback following the stages of data analysis. Whilst participant validation is not considered standard practice in IPA research (Smith et al., 2009), it would have offered further validity checks to the findings.

2.5.4 Areas for future research

There are a number of potential areas that could be explored in future research. The current sample was a sample of engaged carers from a support service and more research may be needed to characterise the experiences of compassion with carers who are not engaged with support services or recruited through NHS settings. It would also be useful to expand this research across different groups and settings such as young carers, dementia carers, physical health and learning disabilities. It would also be valuable to explore carers of different ethnic backgrounds. Research shows that individuals from Black and Minority Ethnic (BME) backgrounds appraise the caregiving situation differently to their white counterparts (Janevic & Connell, 2001) and therefore it would be interesting to explore their experiences of compassion. Based on findings from the present study, further research could explore different gender experiences of compassion. Future research could also evaluate the effectiveness of a CFT intervention in reducing the burden of care.

2.6 Conclusion

The present study aimed to explore carers' lived experiences of compassion while caring for an adult with severe and enduring mental health difficulties. The findings suggest that caring is a burdensome responsibility that is associated with physical and emotional suffering. Carers' experiences indicate a lack of support and compassion from services and feeling undervalued in their role. This can create a

sense of threat which may inhibit caring mental states including compassion for self and others. The present findings have suggested more support provisions for carers including compassion based interventions (i.e. CFT) which may help to alleviate and prevent suffering and to develop resilience in caring roles. More research is needed to explore compassion with carers across different groups including carers of different ethnic backgrounds.

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Chapter Three

Reflective Paper

The Voice of Carers: A Researcher's Experience and Reflections on Qualitative Analysis and Compassion

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words

3.1 Introduction

Compassion is a topic that has long caught my interest both personally and professionally. It is only through clinical training that I have found the opportunity to explore this area in more depth. This thesis has investigated the lived experiences of compassion while caring for an adult with severe and enduring mental health difficulties using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). This paper provides an opportunity to reflect on the research process including insights into carers' experiences of care and compassion. It offers a reflective account around Gilbert's (2005, 2009) six attributes of compassion: care for wellbeing, sensitivity, sympathy, empathy, distress tolerance and being non-judgemental. Whilst the research was focused on compassion, what appeared to come out from the findings were experiences of caring. This reflective account allows the chance to reflect on some of the outlying experiences that arose from the research that were not prevalent enough to become central themes. In writing this paper I have considered my position as a researcher and psychologist.

3.2 The researchers position on care and compassion

I did not originally plan to carry out research with carers for adults with mental health difficulties but this is where my project naturally progressed. My research interest was in compassion and I had intended to explore nurse managers' experiences of compassion within secondary care mental health services in line with recent attention on compassion in healthcare (Care Quality Commission, 2009). This was my initial plan, however, when looking at the feasibility of the project I was aware of a number of contextual issues that would make it a difficult area to

research at this time. Key issues revolved around organisational changes and uncertainty within the local NHS trust.

Starting out the research, I was aware that I had relatively little experience with severe and enduring mental health difficulties as well as little contact with carers for mental health. I saw this as an advantage and considered that I would be able to maintain an objective stance during the research. However, in the IPA tradition it is important for the researchers to be aware of their subjective position and how it might influence interpretation of the data (Smith et al., 2009). This encouraged me to reflect on myself as an individual, researcher and psychologist and to engage in reflective practice throughout the research process. This was achieved through a reflective diary and IPA peer group. I started to consider my own experiences in relation to care and compassion and identified that I may have more in common with carers than originally thought. I considered my own role of 'helping' as a psychologist including my experience that drew me into the profession of clinical psychology. I recognised that I developed a 'helping' mentality whilst growing up and thus have a range of thoughts, feelings, memories and motivations in relation to providing care. These reflections helped me to connect to caring experiences but also to 'bracket off' these reflections in order to be open to the full range of carers' experiences.

I reflected on my interest in compassion and my recognition that I have not always been compassionate towards myself; albeit I consider this part of the human condition that can be nurtured. There were times during the project that I found compassion a hard concept to grasp, possibly due to its complex nature, different skills and attributes and underlying theory (i.e. Gilbert, 2005, 2009). I had considered that people are not either 'compassionate' or 'not compassionate',

although I believe that the capacity for compassion depends on learning environments and present context. In an attempt to ‘bracket off’ any preconceptions I engaged in reflective writing around the interview guide. Additionally, I came across literature by Marr (2009) on personal reflections of compassion. She described that compassion is not a static state but manifests itself in each moment. This provides greater clarity to my current understanding of compassion and helped me to be open to carers’ present experiences.

3.3 Care for wellbeing

Care for wellbeing involves the motivation to be caring for the purpose of alleviating distress and to promote development and wellbeing (Gilbert, 2005, 2009). Within the carers’ narratives, I noticed a strong responsibility and motivation to provide help, care and support. I recalled one particular carer who stated ‘*people don’t understand how much you want to help*’ (Victoria, 324). Carers wanted the best possible life for the cared-for person and the whole family. They were committed in their efforts to help and lead as ‘normal’ a life as possible. I was curious about the use and meaning of ‘normal’ across some of the carers’ narratives. I wondered if carers were conveying to me their sense of feeling different from others or wanted to be acknowledged as people trying to live ‘ordinary’ lives. I found myself thinking about carers for mental health and how it would be interesting to explore how these carers construct their identities from a critical discursive approach (i.e. Potter & Wetherell, 1987).

I distinctly remembered one participant who described caring for her father as a ‘return of love’. Mary illustrated ‘*for me there is compassion and feeling kind and finding the time to be with him and making the time deliberately*’ (Mary, 397). I was

struck and touched by the participant's strong sense of family connection and her caring efforts to keep her parents and family together. I noted that Mary was an outlier in the way that she described her caring. Interestingly, she had a supportive structure around her and did not express current difficulties with services. I wonder if this allowed her to connect more to her relationship. For me there was something that appeared altruistic in her accounts and I found myself being curious about her earlier experiences growing up with a parent with mental health difficulties. I found myself wondering if caring can be purely altruistic; a topic that has been debated in the literature (Cialdini et al., 1987; Maner et al., 2002). I would have liked to have heard more of these experiences.

Reflecting on the above, I found myself trying to make sense of Mary's experiences or otherwise formulate them as a psychologist. I noted in my reflective diary submissive compassion versus genuine compassion in terms of compassion motivations (i.e. Catarino, Gilbert, McEwan & Baião, 2014) and subjugation in terms of schema theory (i.e. Young, Klosko & Weishaar, 2003). For example, evolutionary models of compassion suggest that one motive to help may be linked to a form of appeasing or submissive behaviour which individuals might have learned in their early histories in order to avoid rejection or be valued or liked (Gilbert, 2009).

However, I wonder if these reflected my own preconceptions around underlying motives to help, related to my personal experience and hence why I may have been struck by her accounts. These reflections have highlighted how judgements and clinical formulations can move us away from others' lived experiences which could hold positive meaning to them.

A few of the carers mentioned positive or loving feelings towards the person cared for but there was a sense that more positive feelings were overshadowed by difficult

experiences of caring. For example, a carer would mention love for their relative and then proceed to another avenue not allowing for the creation of richer data. Many carers expressed anger towards services which detracted away from their relationship. It was so prevalent throughout the narratives that I wondered whether carers were preoccupied. For some carers it felt there was little choice and they were bound by their strong duty and responsibility. This suggests that carers' motives to help may be complex and included learning histories as well as current circumstances. Indeed, each carer's experience was unique and for many there seemed to be a shared anxiety around separation and loss which appeared beneath the carers' motivations and behaviours. It could be suggested that caregivers are trying to manage their environment to avoid becoming overwhelmed by 'hidden feelings' of grief in psychodynamic thinking (Malan, 1999). Gilbert (2005) would describe this as safety-seeking which is an attempt to cope with a threat based emotional regulation system.

For Engel (1961) grief is "the characteristic response to the loss of a valued object, be it a loved person, a cherished possession, a job status, home, country, an ideal, a part of the body, etc" (p.18). Across some carers' accounts there was a sense of lives blighted by mental health difficulties. Some carers made expressions towards the loss of the person or their relationship due to mental health difficulties or effects of medication. I was particularly touched by the narrative of one carer who had lost emotional connection with his wife whom he cared for, and felt the need to invest in hobbies and other relationships to gain a sense of appreciation. There was a strong sense of sadness in relation to missed opportunities due to caring and his need to try to make sense of himself and his role in life. I felt his strong desire for care and affection. Through connecting to feelings of being isolated and alone I started to

reflect on who looks after the carers and their emotional wellbeing, and the importance of care and compassion for them. It was evident that many carers placed high value in the support delivered by the carer organisations and carers' groups.

3.4 Sympathy, sensitivity and empathy

Central to care and compassion is being in tune with the other person which requires sensitivity, sympathy and empathy on behalf of the caregiver. Sympathy is an emotional response to another's distress and is linked closely to sensitivity which is the ability to notice the others need for help (Gilbert, 2005, 2009). Early into the interviews I remember being emotionally moved by the carers' experiences. My second interview made a particular impression on me and I felt I had connected to the carer's experience and to my research at a more profound level. The carer's narrative conveyed a strong sense of fighting for help for her son but not feeling heard or listened to. I remembered clearly her expressive language as she described 'the complete disregard' by services for the people who know the person well. This portrayed to me a feeling of 'total rejection'. The carer's narrative conveyed a range of emotions including sadness, frustration and anger. I was left reflecting on vulnerabilities to the sense of self. For example, feeling disregarded is recognised to be a core hurt which is capable of causing considerable emotional pain (Stosny, 1995).

Up to this point in the research I had been thinking about my study in terms of theoretical and clinical justifications. However, my experience of being with the first two carers and listening to their experiences put my research into a different context. I felt that I saw the person behind the caring role and could empathise, respect and acknowledge the difficulties faced by the individual. I noted a

particularly strong desire for my research to be credible, meaningful and to benefit the carers. I felt a high sense of responsibility to 'voice' their experiences.

Reflecting on this, I wonder if this feeling of responsibility was a countertransference reaction (Freud, 1910, 1959) and was a reflection of the carers desire to be heard, acknowledged and rescued from their emotional suffering. It was evident that carers were looking after their relative's best interests but I wondered who was advocating on behalf of the carers. I experienced a desire to help but recalled feeling insignificant in the face of such complex difficulties.

The carers' narratives conveyed being in tune with the person being cared for and being sensitive to signs of distress. Carers demonstrated trying to understand the person's situation or perspective but found it difficult at times to understand their relative's logical reasoning or mental health difficulty. Gilbert (2005, 2009) describes empathy as working to understand another person's inner world so you can see it from their point of view. I noted in my reflective diary that 'it is hard to empathise with what you don't understand' to illustrate that carers may want to alleviate their relative's suffering but without always understanding it. I recognised the potential complexity of the two psychological approaches that underpin compassion, namely 'understanding and engagement' and 'alleviation and prevention' (see Gilbert, 2009; Gilbert & Choden, 2013). Reflecting on carers' experiences highlighted to me the emotional intensity of caring for a relative. Some carers indicated feeling upset by their relative's distress which was generated by not knowing the cause of distress or finding it hard to observe or think about them in their suffering. I distinctly recalled the experience of one lady where there was a strong emotional resonance with her daughter and who stated that she is 'alright' when her daughter is 'alright'. I was curious if this reflected a strong emotional

attachment which may prohibit the carer from separating or detaching from their emotions in the same way that they could for others, as indicated by another carer. Additionally, I could see that there were times that carers experienced discomfort in not being able to help, access professional support or influence their relative's behaviour. Therefore, I wondered if some of their distress was related to feeling powerless or helpless to affect change, in a similar way to what I had experienced. A lack of control is a central feature of learned helplessness theory (Seligman, 1975). Day and Anderson (2011) have argued that 'helplessness' increases the risk of compassion fatigue in family caregivers. I found myself being curious about the quality of the interaction and the relationship between the carer and the cared for. For example, Day and Anderson (2011) have suggested that a good bond between the care recipient and caregiver can protect family caregivers from compassion fatigue.

3.5 Distress tolerance

Distress tolerance means to bear complex or high levels of emotion both within ourselves and in others (Gilbert, 2005, 2009). I found it somewhat hard to pull together my reflections around this concept largely because of carers' broad and complex range of experiences and the spectrum of feelings these generate. It became clear from the narratives that caring for mental health difficulties is associated with high emotional discomfort in carers. I noted in my reflective diary that some carers had to bear unpleasant habits, behaviours and experiences related to symptoms of mental health difficulties including 'negative symptoms' in schizophrenia. This included struggling with the other's basic hygiene. Some of the examples in the carers' narratives were more overt than others but nevertheless many have remained

prominent in my mind. Although this is likely given that IPA involves immersing yourself in the participant's data, I reflected on the carers' position and the layers of emotional memories that they potentially carry. I recalled one male carer's narrative which spoke about how he used to keep a diary but then found this depressing and would sooner forget. He spoke about the benefits of having a 'faulty memory' where things disappear from his mind and which meant he was not storing 'all this stuff'. Gilbert (2005) has suggested that individuals may be motivated to escape or turn away from suffering because it is too upsetting or threatening. Indeed, there was a sense across carers' narratives that they were trying to protect themselves from feeling overwhelmed by distress. Carers' language conveyed 'it doesn't bear thinking about' and 'don't go where he is thinking'. Although carers seem to indicate some emotional avoidance, I wondered if this reflected feeling uncontained as opposed to difficulties with distress tolerance skills.

During the stage of IPA analysis, I observed strong feelings and reactions in myself. The further I immersed myself into the analytic process, the more I noticed feeling overwhelmed. Although I considered that this may be related to managing and interpreting a large amount of data, I did allow time and space to remove any pressure. I reflect that my feelings provided insights into the carers' experiences and that my reactions reflected a parallel process. Interestingly, I noted in my diary feeling tired, burnt out and feeling that I can't take anything in, which is not a common experience for me. I reflected that I felt all consumed by my data, noticing becoming angry at feeling alone and knowing that it was only down to me to work it all out. I used this experience to guide the themes. Reflecting on the analytical process at some distance, I can see how emotionally connected I was to the carers' experiences. It conveys how caring can feel emotionally intense and the potential

difficulty gaining some emotional distance. As a psychologist I am becoming increasingly trained to think about my emotional reactions in order to guide an understanding of the client's experience through the therapeutic use of self (Wosket, 1999). I have experienced the importance of supervision to aid this process and to separate out one's own feelings. This left me reflecting on 'emotional boundaries' in caring and the potential difficulties in defining where one person ends and the other person begins.

I noticed occasions where the carers' narratives had an impact on me. For example, as I was reading a few of the carers' narratives I found that my mind digressed into therapy mode at specific points in the text. I was engaging with some really difficult and uncontained experiences that occurred in the carer's past and involved a new-born baby and a separate instance of violence towards the carer. It felt hard to code and process these experiences and I reflected on them as the 'extremities of distress'. This led me to think about containment and the potential difficulties that carers face in trying to contain the other's and their own distress. There were times when something was 'felt' but not 'spoken'. Specifically, there appeared to be an underlying fear of loss in the carers' narratives which for some included loss to suicide. I particularly felt for one carer who had made previous attempts on their own life through reaching limits in caring and desperately needing help. This brought up many reflections including duty of care for the carers and ethical issues and responsibility around managing risk as a researcher. In this case it was discussed within the research team and deemed low risk, but it highlighted tensions around confidentiality, sitting with uncertainty and trusting that the carer will access support if needed.

3.6 Non-judgemental

Gilbert (2005, 2009) describes non-judgemental as not condemning, criticising, shaming or rejecting. Soon after deciding to explore the lived experiences of compassion with carers, I became aware of concerns about not wanting to portray carers and their experiences in a negative light. Through reflecting on my concerns, I could see that perhaps I was making some assumptions about what the research findings might potentially reveal, instead of adopting an open curiosity about what might come up and seeing it as an opportunity to understand carers' experiences. I wonder if this process related to how I was trying to make sense of compassion.

During an IPA peer group, I became aware of occasions whereby I defended the carer's position. This occurred when a peer made comments to suggest that a carer was being critical of their situation or the person they cared for. We were able to reflect on this process and consider if I was defending carers and potentially my research from criticism, or if I was trying to make sense of the situation in terms of their wider context. It was helpful to reflect and be aware of these issues for further analysis and checking coding. We reflected more generally on how individuals can quickly make judgements and assumptions about people and their situations, particularly when unfamiliar to us. As psychologists and researchers, we considered the importance of 'seeing the moment as it is' to allow a more compassionate understanding of behaviour in the present context.

Through peer group reflections, I started to think about carers' experiences of feeling judged and whether my sensitivity paralleled something of their experience. I clearly remember one male carer's narrative whereby he made reference to feeling that he and his wife were being judged by a professional for their son's mental illness:

“he thought my wife was trying to poison him...this psychologist or whatever she was, was totally loopy and said to him the reason he said that is because we were bad parents and we didn’t have a colour TV...I knew she wasn’t very good and of course said to my wife it’s your fault because you haven’t brought him up properly and so it’s a very old view it’s not the correct view” (Chris, 104).

This small extract of Chris’s narrative generated a number of reflections. Firstly as a psychologist, I was curious about the interactions that occurred and found myself thinking about objective and subjective realities in a way that could be gently challenged. However, I considered that perhaps I was making assumptions that Chris had interpreted information in this way, rather than staying close to his lived experiences and the personal meaning he attaches to them. While the latter is important, I wonder if a compassionate approach is a way that integrates the two. Vivino, Thomson, Hill and Ladany (2009) have shown that compassion is understood as a willingness to take action and to promote change so that individuals do not remain in their own suffering. It was clear that Chris was impacted by others’ negative judgements or attributions. Furthermore, the narrative shows Chris expressing judgement towards a professional which was also noted in few of the carers’ accounts. Specifically, Chris’s narrative indicates a reciprocal interaction such as feeling judged and being judgemental. This led me to think about the reciprocal nature of compassion and the potential feedback circle for carers. For example, Gilbert and Choden (2013) have spoken about ‘compassion as flows’ to illustrate how compassion can be experienced in different ways, namely compassion to others, compassion from others and self-compassion.

Through reflecting on carers' experiences, I started to think about various examples in carers' narratives that either related to stigma, shame or embarrassment around mental health difficulties, some of which were more overt than others. Stories involved feeling judged, looked down upon and rejected by wider family and services. There was a sense of exclusion and discrimination in carers' narratives. I particularly recalled one carer who spoke about how the government has money to go to war and kill people but will not put a person in hospital and make people well. I was left feeling angry that the government does not invest in saving people's lives which illustrated to me the carer's strong feelings on the subject. Additionally, the carer was concerned that the media would 'headline it' when a person with mental health difficulties does something wrong, rather than looking at the system and the wider government. I was left reflecting on how mental health difficulties are portrayed in the media and how they are stigmatising for carers, their family and exacerbate negative social judgements. In this way, mental health can be seen as a collective as well as an individual responsibility.

3.7 Conclusion

Carrying out my research project has illustrated to me the complex nature of care and compassion. I feel that I have developed a better understanding of compassion through the project. I am glad that I completed my research with carers and have allowed their 'voice' to be heard and listened to. I enjoyed each interview and gaining a greater understanding of carers' lives. I have felt emotionally moved by the carers' experiences and believe the research has increased my empathy and compassion for carers. I feel that I have developed better skills in focusing on people's lived experiences and being open and non-judgemental to their present

experiences. I intend to use the findings from the study and my reflections to improve my clinical practice. I also aim to disseminate my findings to the carer organisations that I recruited from and publish the findings to help others in clinical practice.

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Appendix A

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Reference style

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered from  <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Examples:

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style*. (4th ed.). New York: Longman, (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.

Appendix B Quality Assessment Results

Quality Framework (based on Caldwell et al., 2011)		Badger et al. (2012)	Bramley et al. (2014)	Bray et al. (2014)		Brown et al. (2014)	Crawford et al. (2013)	
1. Does the title reflect the content?		Yes	Yes	Yes		Yes	Yes	
2. Are the authors credible?		Yes	Yes	Yes		Yes	Yes	
3. Does the abstract summarise the key components?		Yes	Yes	Yes		Yes	Yes	
4. Is the rationale for undertaking the research clearly outlined?		Yes	Yes	Yes		Yes	Yes	
5. Is the literature review comprehensive and up to date?		Partial	Yes	Partial		Yes	Yes	
6. Is the aim of the research clearly stated?		Yes	Yes	Yes		Yes	Yes	
7. Are all ethical issues identified and addressed?		Yes	Yes	Yes		Partial	Yes	
8. Is the methodology identified and justified?		Partial	Yes	Yes		Partial	Yes	
Quantitative	Qualitative	Qualitative	Qualitative	Mixed Method		Qualitative	Mixed Method	
9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?	Partial	Yes	Partial	Partial	Yes	Partial	Partial
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	Yes	Yes	Yes	Yes	Yes	Partial	Yes
11. Is the population identified?	11. Is the context of the study outlined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	Partial	Yes	Partial	Partial	Partial	Partial	Partial
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	Yes	Yes	Yes	Yes	Partial	Yes	Partial
15. Are the results presented in a way that is appropriate and clear?		Yes	Yes	Yes	Yes	Yes	Yes	
16. Is the discussion comprehensive?		Yes	No	Yes		Yes	Yes	
Quantitative	Qualitative	Qualitative	Qualitative	Mixed Method		Qualitative	Mixed Method	
17. Are the results generalisable?	17. Are the results transferable?	Partial	Partial	Partial		Partial	Partial	Partial
18. Is the conclusion comprehensive?		No	Yes	Yes		Yes	Yes	
Score		29	33	32		31	32	

Quality Framework (based on Caldwell et al., 2011)		Crowther et al. (2013)	Curtis et al. (2012)	Curtis (2013)	Curtis (2014)	Dewar et al. (2013)
1. Does the title reflect the content?		Yes	Yes	Yes	Yes	Yes
2. Are the authors credible?		Yes	Yes	Yes	Yes	Yes
3. Does the abstract summarise the key components?		Yes	Yes	Yes	Yes	Yes
4. Is the rationale for undertaking the research clearly outlined?		Yes	Yes	Yes	Yes	Yes
5. Is the literature review comprehensive and up to date?		Partial	Yes	Yes	Yes	Yes
6. Is the aim of the research clearly stated?		Partial	Yes	Yes	Yes	Yes
7. Are all ethical issues identified and addressed?		Partial	Yes	Yes	Yes	Yes
8. Is the methodology identified and justified?		Partial	Yes	Yes	Yes	Yes
Quantitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative
9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?	Partial	Yes	Yes	Yes	Yes
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	Partial	Yes	Yes	Yes	Yes
11. Is the population identified?	11. Is the context of the study outlined?	Yes	Yes	Yes	Yes	Yes
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	Partial	Yes	Partial	Yes	Yes
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	Yes	Yes	Partial	Yes	Yes
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	Partial	Yes	Yes	Yes	Yes
15. Are the results presented in a way that is appropriate and clear?		Yes	Yes	Partial	Yes	Yes
16. Is the discussion comprehensive?		Yes	Yes	Yes	Yes	Yes
Quantitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative
17. Are the results generalisable?	17. Are the results transferable?	Partial	Partial	Partial	Partial	Partial
18. Is the conclusion comprehensive?		Yes	Yes	Yes	Yes	No
Score		27	35	32	35	33

Quality Framework (based on Caldwell et al., 2011)		Fry et al. (2013)	Horsburgh et al. (2013)	Kvangarsnes et al. (2013)	Lloyd et al. (2011)	Van der Cingel et al. (2011)
1. Does the title reflect the content?		Yes	Yes	Yes	Yes	Yes
2. Are the authors credible?		Yes	Yes	Yes	Yes	Yes
3. Does the abstract summarise the key components?		Yes	Yes	Yes	Yes	Yes
4. Is the rationale for undertaking the research clearly outlined?		Yes	Yes	Yes	Partial	Yes
5. Is the literature review comprehensive and up to date?		Partial	Yes	Yes	Yes	Partial
6. Is the aim of the research clearly stated?		Partial	Yes	Yes	Partial	Yes
7. Are all ethical issues identified and addressed?		Yes	Yes	Yes	Partial	Yes
8. Is the methodology identified and justified?		Partial	Partial	Partial	Partial	Yes
Quantitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative
9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?	Partial	Partial	Yes	Partial	Partial
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	Yes	Yes	Yes	Yes	Yes
11. Is the population identified?	11. Is the context of the study outlined?	Yes	Yes	Yes	Yes	Yes
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	Yes	Partial	Yes	Yes	Partial
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	Yes	Yes	Yes	No	Yes
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	Partial	Partial	Yes	No	Partial
15. Are the results presented in a way that is appropriate and clear?		Yes	Yes	Yes	Yes	Yes
16. Is the discussion comprehensive?		Yes	Yes	Yes	Yes	Partial
Quantitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative	Qualitative
17. Are the results generalisable?	17. Are the results transferable?	Partial	Partial	Partial	Partial	Partial
18. Is the conclusion comprehensive?		Yes	Yes	Yes	Yes	Yes
Score		30	31	34	26	30

Quality Framework (based on Caldwell et al., 2011)		Vivino et al. (2009)	Wiklund-Gustin et al. (2012)
1. Does the title reflect the content?		Yes	Yes
2. Are the authors credible?		Yes	Yes
3. Does the abstract summarise the key components?		Yes	Yes
4. Is the rationale for undertaking the research clearly outlined?		Yes	Yes
5. Is the literature review comprehensive and up to date?		Yes	Yes
6. Is the aim of the research clearly stated?		Yes	Yes
7. Are all ethical issues identified and addressed?		No	Yes
8. Is the methodology identified and justified?		Partial	Partial
Quantitative	Qualitative	Qualitative	Qualitative
9. Is the study design clearly identified, and is the rationale for choice of design evident?	Partial	Partial	Partial
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	Yes	Yes	Yes
11. Is the population identified?	Yes	Yes	Yes
12. Is the sample adequately described and reflective of the population?	Partial	Partial	Partial
13. Is the method of data collection valid and reliable?	Yes	Yes	Yes
14. Is the method of data analysis valid and reliable?	Partial	Yes	Partial
15. Are the results presented in a way that is appropriate and clear?		Yes	Yes
16. Is the discussion comprehensive?		Yes	Yes
Quantitative	Qualitative	Qualitative	Qualitative
17. Are the results generalisable?	Partial	Partial	Partial
18. Is the conclusion comprehensive?		Yes	Yes
Score		30	31

Appendix C

Author Instructions for Issues in Mental Health Nursing

Issues in Mental Health Nursing conforms to the guidelines of the Publication Manual of the American Psychological Association (2010) regarding plagiarism and self-plagiarism. To wit, "Just as researchers do not present the work of others as their own (plagiarism), they do not present their own previously published work as new scholarship (self-plagiarism) (American Psychological Association, 2010, p. 16). The potential for self-plagiarism is greatest when several aspects of a study are reported in different articles. To avoid this ethical violation, make sure that each article makes a unique contribution to the science. Clearly delineate where other articles about the study have been reported. Extensive duplication of one's own words (for example, in a methods section) requires a citation of the previously published work.

IMHN also conforms to the criteria for authorship specified by the American Psychological Association (2010, p. 18): "Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed." Please specify, in your cover letter, the role played by each author on the project (for example, formulated the hypothesis, collected data, participated in data analysis, wrote part of the paper). Individuals who did not play a major role (e.g., recruiting subjects, data entry) should be listed in "Acknowledgments," but not credited with authorship.

All papers should be submitted via the journal's online Manuscript Central site <http://mc.manuscriptcentral.com/umhn>. Microsoft Word files are best for the text of the document. Tables and figures should be submitted as separate individual files. Manuscript and other requirements conform to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" established by the International Committee of Medical Journal Editors (N Engl J Med 1991;324:424-8).

Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher. All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text. Declaration of interest. It is the policy of all Informa Healthcare, to adhere in principle to the Conflict of Interest policy recommended by the International Committee of Medical Journal Editors (ICMJE). (<http://www.icmje.org/index.html#conflict>)

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. It is the sole responsibility of authors to disclose any affiliation with any organization with a financial interest, direct or indirect, in the subject matter or materials discussed in the manuscript (such as consultancies, employment, paid expert testimony, honoraria, speakers bureaus, retainers, stock options or ownership, patents or patent applications or travel grants) that may affect the conduct or reporting of the work submitted. All sources of funding for research are to be explicitly stated. If uncertain as to what might be considered a potential conflict of interest, authors should err on the side of full disclosure.

All submissions to the journal must include full disclosure of all relationships that could be viewed as presenting a potential conflict of interest. If there are no conflicts of interest, authors should state that there are none. This must be stated at the point of submission (within the manuscript after the main text under a subheading "Declaration of interest" and where available within the appropriate field on the journal's Manuscript Central site). This may be made available to reviewers and will appear in the published article at the discretion of the Editors or Publisher.

If no conflict is declared, the following statement will be attached to all articles:

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

The intent of this policy is not to prevent authors with these relationships from publishing work, but rather to adopt transparency such that readers can make objective judgments on conclusions drawn.

References. Cite in the text by author and date (Smith, 1983). Prepare reference list in accordance with the APA Publication Manual, 6th ed. Examples:

Journal: Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. *Archives of Sexual Behaviour*, 7(6), 417-427.

Book: Millman, M. (1980). *Such a pretty face*. New York: W. W. Norton.

Contribution to a Book: Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), *Ageing in the 1980s* (pp. 239–252). Washington, DC: American Psychological Association.

Illustrations. Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be digital files for highest quality reproduction and should follow these guidelines:

300 dpi or higher

Sized to fit on journal page

Submitted as separate files, not embedded in text files

EPS, TIFF, or PSD format only

Tables and Figures. Tables and figures (illustrations) should not be embedded in the text, but should be included as separate files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double spaced, in a separate file.

Proofs. Page proofs are sent electronically to the designated author. They must be carefully checked and returned within 48 hours of receipt.

Offprints. Free access to a pdf which can be sent or printed up to 50 times.

Appendix D

Interview Guide

Interview Guide

Introduction and setting the tone.

Researcher: Thank you for agreeing to take part in the interview. This research is about understanding carers' experiences of compassion. As I have mentioned my name is Caroline Garner and I am a Trainee Clinical Psychologist. I will be recording the interview and making notes as we go along. This is so that our conversation can be transcribed, allowing me to look at the different themes that might emerge. The interview will take about an hour, but if you would like to stop at any time then please let me know. Please remember that you are free to withdraw your consent to take part in this research up to 1st March 2015 and without giving a reason. Please do comment on whatever you feel is relevant. There are no right or wrong answers; this interview is about your experiences as a carer. I would like to remind you that you do not have to answer any questions that you do not feel comfortable with. Are you ok to start?

Note: use general prompts and probes throughout the interview to elicit rich and detailed accounts. Bullet points represent questions that the researcher may ask to elicit further information to meet the aims of the study. They are not intended to be an exhaustive list.

General prompts/probes

Why?

How?

What do you mean by X?

Can you tell me more about X?

What happened?

What did/do you think about that?

What did/do you feel about that?

Can you think of / give me an example of that?

Interview Questions

Empathy

Could you tell me something about the person that you are a carer for?

What do you think are the main difficulties that they face?

What feelings/emotions do you think they experience?

Care for wellbeing

How do you get up in the morning and do what you need to do as a carer?

- What drives you?
- What do you do?
- Do you get tired?; what keeps you going?

Sensitivity

How would you know if the person you care for is distressed?

How do you make sense of the needs of the person you care for?

How do you make sense of the distress of the persons you care for?

- What are the persons needs?

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- What are their complaints
 - How do they communicate their needs?
 - How do they communicate their distress?
 - How do you deal with that?

Sympathy

When caring, what make you upset?

- What situations or behaviours upset you?
- How do you deal with that?

Non-judgemental

Does being a carer make a difference to how you see the person you care for?

What thoughts and feelings do you notice towards the person when you are caring?

Distress tolerance

How do you manage difficult situations/emotions?

How do you respond to difficulties?

Concluding question

Do you have any other thoughts or comments that we have not covered about your experience or anything else that you would like to add?

Complete the debrief form.

Appendix E

Demographic Information Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Demographic Information

Please provide us with some additional information about you. All responses will be confidential and will be used solely for the purposes of the research study.

Participant identifier number:.....

1. Gender – are you: (please circle)

- Male
- Female

2. Age - which age group do you belong to? (please circle)

- 18-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65-74 years
- 75-84 years
- 85 or over
- Prefer not to say

3. Ethnic group – which best describes your ethnic group or background? (please circle)

A. White

- British
- Irish
- Other White background

B. Mixed/multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Other Mixed/multiple ethnic background

C. Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Other Asian background

D. Black/African/Caribbean/Black British

- African
- Caribbean
- Other Black/African/Caribbean background

E. Other ethnic group

- Arab
- Other, please specify:.....

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Dean of Faculty of Health and Life Sciences
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Trosilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Appendix F

Participant Invitation Letter

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Kraigt
BSc Clin.Psy.D, CPsychol

THE UNIVERSITY OF
WARWICK



Research Invitation Letter

30th October 2014

Dear Carer

Re: Research on Carers' Lived Experiences of Compassion

My name is Caroline Garner. I am currently training to be a Clinical Psychologist at Coventry University and the University of Warwick. I would like to inform you about a carers based research project that you might be interested in.

I would like to talk to carers about their lived experiences of compassion. You may be aware of discussions and media reports during the last couple of years on the importance of compassion in healthcare. Although little research exists in this area, researchers have started to explore staff and patient perspectives of compassion. There is currently no research on carers' experiences of compassion. I am interested to understanding carers' lived experiences of compassion in caring for adults with severe and enduring mental health problems.

Taking part in the study would involve us meeting for about an hour. During this meeting I would ask you to share some of your experiences of caring for somebody with severe and enduring mental health problems. Participation is voluntary and it is up to you to decide whether you would like to join the study. All information will remain confidential.

Enclosed with this letter is a participant information sheet which explains more about this particular research project and what it will involve if you decide to take part.

If you are interested in participating, and would like to discuss this further, please contact me by email at garnerc3@uni.coventry.ac.uk. Alternatively, please complete and return the reply slip overleaf and I will be in contact with you.

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Dean of Faculty of Health and Life Sciences
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Thistle BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7007 3008

www.coventry.ac.uk

I look forward to hearing from you.

Yours sincerely,



Caroline Garner
Trainee Clinical Psychologist
Coventry University and the University of Warwick

Enc: Participant information sheet, stamped addressed envelope



Consent Slip for Research Study

I give my consent to be contacted by the Principal Researcher (Caroline Garner) about participating in the research study. I understand that taking part in the study is voluntary and that I am free to withdraw without giving a reason. This will not affect my support or the person I care for's support in any way.

Name:.....

Contact details (phone number):.....

Best days/times to contact you by telephone:.....

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Appendix G

Participant Information Sheet

Coventry University

Priority Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.PsyD, CPsychol

THE UNIVERSITY OF
WARWICK



Participant Information Sheet

Title of study: Carers' Lived Experiences of Compassion
Researcher: Caroline Garner, Trainee Clinical Psychologist

Part 1: Essential Information

Invitation to take part:

I would like to invite you to take part in the above research study. Before you decide if you would like to be involved, this information sheet gives an explanation of why the research is being done and what will be required of you. Please take the time to read this information carefully and discuss it with others if you wish. If there is anything that you would like explained further then please feel free to ask me.

What is the purpose of the study?

The purpose of the study is to explore carers' lived experiences of compassion.

Compassion has recently become a topic of great interest with researchers and policy makers, with a growing movement towards compassion as the basics of care and delivery. While compassion is at the forefront of current healthcare policy, there has been little research conducted around this topic. Research that has started to emerge has mainly looked at compassion in mental health settings from staff and patient perspectives. There is currently no research exploring carers' experiences of compassion. I am interested to understand carers' experiences of compassion in caring for adults with severe and enduring mental health problems.

Why have I been chosen?

You have been invited to take part because the research is keen to involve informal carers in research and to learn about their experiences of compassion. I would like to talk to informal carers who care for an adult with severe and enduring mental health problems.

An informal carer can be described as someone who:

- 1) Lives with or visits/meets their partner, friend or relative at least three times a week; and
- 2) Has a role in the care of their partner, friend or relative

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Dean of Faculty of Health and Life Sciences

Professor Guy Daly Coventry University Priority Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Do I have to take part?

No. Participation in the research is voluntary and it is up to you to choose whether you would like to join the study. I will go through this information about the study with you. If you agree to take part I will ask you to sign a consent form for you to take part in the study. You will be provided with a copy of the consent form to keep. After signing the consent form, you can still change your mind about taking part in the research. You are free to withdraw from the study and you do not have to provide a reason as to why. This would not affect any care or support that you or the person you care for receives. It is important for you to know that you can withdraw your information after the interview up until 1st March 2015 by informing a member of the research team using the contact details provided at the end of this information sheet.

What will happen if I decide to take part?

I will contact you to arrange a convenient time to meet with you at the carer support service. I will conduct a one of interview with you about your experiences which is estimated to last approximately one hour, but may take up to 90 minutes. The discussion will be guided by open questions already identified for the research. There are no right or wrong answers. You will be encouraged to be as honest as you can but you will not be asked to discuss anything that you do not feel comfortable sharing.

Before the interview, there will be an opportunity to discuss the research project and ask any questions. If you are happy for the interview to go ahead then I will ask you to sign the consent form for your participation in the study. I will ask you to complete a brief form asking about demographic details. The interview will be audio recorded on a digital voice recorder so that I have an accurate record of what we spoke about. This will be transcribed verbatim for later analysis. The interview and all information generated will be confidential, and you will be given a participant information number in order to ensure your responses remain anonymous. The original audio recording will be destroyed after transcription to protect confidentiality. At the end of the interview you will be given the opportunity to ask any questions that you may have.

What will happen next?

If you decide at the end of this information sheet that you are interested in participating in the study, I ask you to contact me directly. You can contact me by email at garnerc3@uni.coventry.ac.uk or by completing the slip below and returning it to Coventry University in the pre-paid envelope provided.

What are the possible disadvantages and risks of taking part?

When discussing your experiences it is possible that sensitive or emotive topics might be touched upon. You have the choice to only disclose information that you feel comfortable sharing. If you become distressed then we may decide to stop the interview. If you do take part and feel distressed then let me know. I will ask you if you wish to continue or not. You will have the opportunity to talk about the interview at the end and details of suggested relevant local support services will be provided in a Participant Debrief Sheet that I will give you at the end of the interview.

What are the possible benefits of taking part?

Some people enjoy telling others about their experiences and you might too. It cannot be assured that the study will be of any help to you directly, although you might find that talking about your experiences help you to make more sense of them. It is hoped that participants will find the experience positive. By participating you will help to improve our general understanding about carers' experiences of compassion.

Will my taking part in the research be kept confidential?

All information collected during the research will remain strictly confidential, unless you share any information during the interview that I believe might put you or another person at significant risk. In this case we will have to share your information with the relevant departments within the NHS Trust. This may be without your permission, although where possible we would discuss it with you first.

Confidentiality will be protected by the following methods:

- All of your information and data will be coded and stored using a participant information number to ensure you remain anonymous. I will keep a list of names and participant numbers which will be shredded once all interviews have been completed.
- All of your data will be kept securely in a locked cabinet. Electronic data will be kept on password protected computers. Audio recordings will be destroyed securely following the transcription process.
- As the lead researcher, I will be the only person with access to participant identifiable information.
- Once the study has been completed, transcripts will be stored at Coventry University for 5 years on secure university premises in accordance with data storage policy. They will then be destroyed securely by the university.

Part 2: Additional Information**What if there is a problem?**

If you have any concerns or complaints about the study then you can contact me directly and I will do my best to address your concerns. Alternatively you can contact Professor Ian Marshall who is independent of the research team and is responsible for overseeing research reviewed by Coventry University Ethics Committee. He can be contacted in writing at the address below:

Professor Ian Marshall
AB124
Alan Berry Building
Coventry University
Priory Street
Coventry
CV1 5FB

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Telephone: 024 7679 5294
Email: i.marshall@coventry.ac.uk

If you wish to complain formally, you can contact PALS (Patient Advice and Liaison Service):

PALS (Patient Advice and Liaison Service)

Telephone: 024 7653 6804
Text message: 07826 900 926
Email: pals@covworkpt.nhs.uk

What will happen to the results of the research study?

The results of this study will be written up and presented as part the academic requirements of my Coventry and Warwick Doctoral Course in Clinical Psychology. The findings may be put forward for publication in academic journals. A copy of the results will be made available to all participants at their request following research submission in May 2015. The whole report will be accessible through Coventry University. Your personal information, including verbatim quotes from the interviews, will remain anonymous in any report or publication.

Who is organising and funding the research?

The research is organised and funded as part of the Doctorate course in Clinical Psychology and the Universities of Coventry and Warwick. This project is not externally funded.

Who has reviewed the study?

The research has been reviewed and approved by Coventry University Research Ethics Committee.

Contacts for further information:

If you would like to find out more information about the research or if you have any questions please do not hesitate to contact me or any of the research supervisors below.

Researcher and Chief Investigator

Caroline Garner
Trainee Clinical Psychologist
Coventry University
Faculty of Health and Life Sciences
Priory Street
Coventry
CV1 5FB
Telephone: 024 7688 8328
Email: garmerc3@uni.coventry.ac.uk

Academic Supervisor
Jo Kucharska
Clinical Director for Doctorate Course in Clinical Psychology
Coventry University
Faculty of Health and Life Sciences
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Telephone: 024 7688 8328
Email: jo.kucharska@coventry.ac.uk

Thank you for taking the time to read this information!



Consent Slip for Research Study

I give my consent to be contacted by the Principal Researcher (Caroline Garner) about participating in the research study. I understand that taking part in the study is voluntary and that I am free to withdraw without giving a reason. This will not affect my support or the person I care for support in any way.

Name:.....

Contact details (phone number):.....

Best days/times to contact you by telephone:.....

Appendix H

Consent Form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Consent Form

Title of study: Carers' Lived Experiences of Compassion

Researcher: Caroline Garner, Trainee Clinical Psychologist

Participant identifier number:.....

Please initial box

1. I confirm that I have read and understood the participant information sheet (version 1. 20.10.14) for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview. I can also withdraw my information after the interview by contacting the researcher up until 1st March 2015.
3. I understand that all the information I provide will be treated in confidence.
4. I agree for the interview to be audio recorded and transcribed and for anonymised quotes to be used as part of the research project.
5. I am aware that I can contact the research if I have any questions or concerns.
6. I agree to take part in the research project.
7. Would you like to receive a summary of the study findings.

YES/NO
(please circle)

.....
Name of the participant Date Signature

.....
Name of the researcher Date Signature

Version1. 20.10.14

1

Dean of Faculty of Health and Life Sciences
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Appendix I

Participant Debrief Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Participant Debrief Sheet

Title of study: Carers' Lived Experiences of Compassion
Researcher: Caroline Garner, Trainee Clinical Psychologist

Dear Carer,

Thank you for taking part in the study and for sharing your thoughts and experiences with me. Your reflections about your experiences as a carer are valuable and without your involvement this research would not have been possible.

What has happened?

You have just taken part in an interview with myself, Caroline Garner for the purpose of research. The research is looking to understand carers' experiences of compassion. You have also completed a brief questionnaire collecting demographic information about yourself.

What happens next?

There is nothing further that you need to do. The audio recording of this meeting will be transcribed and the information will be analysed and written up. Your name and other identifiable information will be removed to ensure your anonymity, and it will be treated confidentially. If you decided to withdraw your information from the research then you can do this up to 1st March 2015 by notifying a member of the research team.

What will happen to the results?

The results of the study will be written up into an academic Thesis as part of the requirements of the Clinical Psychology Doctorate at Coventry University and the University of Warwick. If you would like a summary of the research findings then please inform me of this using the form below. The whole report will be accessible through Coventry University. The results are also intended to be put forward for publication in psychology and/or mental health journals. You will not be personally identified in these reports.

What if I feel distress from taking part in the study?

The research was not intended to cause discomfort or distress, but in talking about your experiences you may have experienced uncomfortable emotions. If these persists after the interview or cause you some concern then you may wish to contact services that may be of support to you listed below.

Version 1. 20.10.14

1

Dean of Faculty of Health and Life Sciences
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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- Carers UK are a charity aimed at supporting people who look after family members or friends. You can access advice and support by calling: **0808 808 7777**.
- Further support such as counselling and other talking therapies can be accessed via your G.P. should you feel that this would be beneficial.

What if I have any questions about the study?

If you have any questions or concerns about the research then you can contact the principal researcher as detailed below or any member of the research team. Further contact details can be found on the participant information sheet including details of who to contact if you wish to make a formal complaint.

Contact details:

Caroline Garner
Trainee Clinical Psychologist
Coventry University
Faculty of Health and Life Sciences
Priory Street
Coventry
CV1 5FB
Telephone: 024 7688 8328
Email: gamerc3@uni.coventry.ac.uk

Thank you again for taking part in the study, your time is greatly appreciated.

Yours sincerely,



Caroline Garner
Trainee Clinical Psychologist
Coventry University and the University of Warwick



Are you interested in receiving a summary of the study's results?

Yes
No

If you have answered yes, please provide contact details as to where you would like the results summary to be sent:

Appendix J

Coventry University Ethical Approval

Coventry University
Priority Street
Coventry CV1 5FB
Telephone 024 7688 7688

Professor Guy Daly
Executive Dean



Prof Jane Coad
Chair of Ethics Committee
Tel: (024) 7679 5831
Email: ethics.hls@coventry.ac.uk

24 November 2014

Dear Sir/Madam

Re: Ethical Approval – P27787

I am writing to confirm that **Caroline Garner** has received ethical approval on 30 October 2014 for the research project: *Carers' lived experiences of compassion*. Project end date 8 May 2015.

The research project has addressed the main ethical issues appropriately, and has been approved by a member of the Faculty of Health & Life Sciences, Ethics and Governance Committee at Coventry University.

If you have any further queries please do not hesitate to contact me.

Yours sincerely

A handwritten signature in black ink, appearing to read "Jane Coad".

Prof Jane Coad

Faculty of Health & Life Sciences
Direct Line
Fax
www.coventry.ac.uk



Appendix K

Analytical Process used to Guide IPA (Smith et al., 2009, p. 82-101)

IPA - Six Stage Process	
Writing in reflective diary	Reflections were made about the research prior to data collection and following each interview.
Transcribing	Interviews were transcribed by the researcher immediately following each interview.
Reading	Transcripts were read and re-read and each interview was listened to again.
Commenting	Initial notes including descriptive, linguistic and conceptual comments were details on the right hand column of each interview.
Noting emergent themes	Transcripts are read with attention to the right hand codes and themes that capture the essence of what is being said is listed in the left hand margin.
Connecting themes	Emergent themes are listed chronologically and connections between them are made before moving to the next case.
Merging themes	Superordinate themes for each interview are compared and clustered together. Relevant extracts from participants were created to provide a check for internal consistency.
Taking it deeper	Superordinate themes were checked and themes at a descriptive level were re-considered at an interpretive level.

Appendix L

Participant Transcript and Themes

5

<p>Responsible for keeping him safe.</p> <p>Difficult to observe distress</p> <p>Urgent plea for help.</p> <p>Mental health is frightening for person & carer</p> <p>Feeling blamed & judged by professionals</p> <p>Feeling Safety</p> <p>Experiencing violence</p>	<p>91. stay with her sister and I could see that he was very very disturbed and so it was very</p> <p>92. difficult as we had to <u>hide all</u> the knives and forks. All the knives and sharp things were in</p> <p>93. the boot of my car and every time I made dinner for him I had to go to the boot open it up</p> <p>94. and take it out [laugh] and in the end the doctor didn't know so in the end the doctor works</p> <p>95. on Saturdays and so I went to see them and said <u>look my son is very ill</u> and needs to be</p> <p>96. admitted will you please write a letter it is really really urgent and I said I have <u>written a</u></p> <p>97. letter to my sister giving details telling that I am going to see him and if I get murdered she</p> <p>98. will open the letter and know why so will you please do that. I have always had to do things</p> <p>99. like that and it's terrible so fortunately he actually did because I said that. I said I posted it</p> <p>100. on my way in. It wasn't true but didn't tell him that obviously. So he phoned up he</p> <p>101. was admitted, this was Saturday and he was admitted on the Thursday and he was</p> <p>102. sectioned for the whole year so he really was bad.</p> <p>103. And what was that experience like?</p> <p>104. Very frightening and he thought my wife was trying to poison him and he was...this</p> <p>105. <u>psychologist or whatever</u> she was was totally loopy and said to him the reason he</p> <p>106. said that is because we were bad parents and we didn't have a colour TV. But I</p> <p>107. couldn't see the relationship but apparently it is a well-known cause of having a</p> <p>108. black and white TV. Did you know that? Well you know as well as I do that is</p> <p>109. rubbish; it doesn't affect the biological. I knew she wasn't very good and of course</p> <p>110. said to my wife it's your fault because you haven't brought him up properly and so</p> <p>111. it's a very old view it's not the correct view. It is not; you would... no-one who has a</p> <p>112. child would bring up their child well they would have to be quite awful to try and</p> <p>113. make them mad. Well think of children who have had dreadful conditions have</p> <p>114. come out and survived so no it wasn't that and... Anyway he thought my wife was</p> <p>115. trying to do this. If he was walking with her down the road the puddles turning into</p> <p>116. blood and various horrible things like that so she had to <u>disappear</u> but before she</p> <p>117. did he... I forgotten what he was doing now to try and stop him from bashing up</p> <p>118. something and he broke my ribs and then he went and got his hands around like</p> <p>119. that round my wife's ^{behind out} <u>through</u> and her eyes were sticking out and I thought what can</p> <p>120. I do. Have you ever had a broken rib?</p>	<p>← keep him safe.</p> <p>I could see he was very very distressed suggests observing extreme distress.</p> <p>Hiding knives & forks. Laughter - suggest discomfort</p> <p>Very difficult to observe distress.</p> <p>Carrying responsibility for son.</p> <p>Look - please notice. urgent plea for help</p> <p>Desperate measures to be heard.</p> <p>up the anti to be listened to. Distress / seriousness</p> <p>validation</p> <p>very frightening experience. Frightening for son & carer</p> <p>We were bad parents & didn't have TV</p> <p>Feeling blamed & judged by others</p> <p>Sarcasm - covering anger?</p> <p>Old views <u>parental blame</u>.</p> <p>Old views suggest outdated stigma. Judgemental attitudes.</p> <p>Defending position - feel judged</p> <p>Disappear - suggest alone.</p> <p>Tried to prevent bashing up</p> <p>High levels of emotion & violent behaviour</p> <p>Conveying severity / extreme behaviours.</p>
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<p>Fear danger Life threatened Threat to Safety</p> <p>Mental illness Is a frightening Condition</p> <p>Unstable without Medication</p> <p>Frightening for Carers. Fear of harm.</p> <p>Carers need Support to provide care</p> <p>Anger at the System.</p> <p>Uncertainty with future support</p>	<p>121. No ^{desperate.}</p> <p>122. Well it hurts I tell you that. It really hurts and I mean I don't joke when I say that and</p> <p>123. I thought <u>what can I do</u>. I'll have to and you can't lift your hand up and its agony but</p> <p>124. I thought if I don't do something he will kill her so I jumped and it was ever so</p> <p>125. painful. I held his arm when I came down and I thought if that doesn't work I know</p> <p>126. where there is a hammer and ill hot him on the head with a hammer but thank god</p> <p>127. that stopped him. She got scared as well which I can understand. When he has his</p> <p>128. <u>delusions</u> and he is <u>not taking medication</u> he can be very very frightening and he</p> <p>129. was...just to give an example he was in the [inpatient centre] which I am sure you</p> <p>130. have heard of and outside they have some railings and he hadn't taking his</p> <p>131. medication and he got really really bad and it was so scary he got the railings out of</p> <p>132. the ground and I've never seen anybody do it. I couldn't do it. He managed to pull</p> <p>133. them out and was running around threatening people and there was a place next</p> <p>134. door and everyone was running like mad [laughter] and the nurses called the police</p> <p>135. and they arrested him and then he stayed there half a night at the cop shop and the</p> <p>136. police psychiatrist said he had to be sectioned so he has been sectioned loads of</p> <p>137. times. Now he has taken his medication and he is reasonably <u>compliant</u> but it is a</p> <p>138. very frightening condition.</p> <p>139. <u>So that makes me think what are the main difficulties?</u></p> <p>140. Sorry I have been waffling on.</p> <p>141. <u>No, no not at all that's your experiences</u></p> <p>142. It's so frightening you realise they have so much strength. I couldn't do it, lift it and</p> <p>143. pull it out. I don't know how me managed to do it.</p> <p>144. <u>So what did that bring up for you then?</u></p> <p>145. That he badly needed the help; they wouldn't admit him but when the police</p> <p>146. psychiatrist said that he had to be admitted so the <u>frightening things is that the</u></p> <p>147. <u>government is stupid they tacitly accept that carers look after the people but will not</u></p> <p>148. <u>provide resources so that the carers the subject of the carers, in other words the</u></p> <p>149. <u>one for whom they are looking after can have some help. They are cutting back</u></p> <p>150. [service] all of the time and [service] are for people who are not compliant and he</p>	<p>It really hurts - I don't joke. <u>Schizophrenia</u>. Experience physical & emotional pain</p> <p>me - hard to comprehend. Extreme. Threat to Safety</p> <p>Delusion - <u>very very</u> frightening medication as a form of control. Mental illness is a frightening condition. Frightened by <u>what delusions can do</u>. Delusion as frightening and overwhelming. Threatens others.</p> <p>Compliant with meds. Sense of relief. Mental illness <u>frightening condition</u>.</p> <p>Frightened by their strength. I couldn't do it suggest others as powerless. <u>Fear of harm</u>.</p> <p>Government is stupid. Got it wrong Tacitly accept carers look after. Carers need resources to provide care. Will not provide support withholding. Carers need support. Government doesn't provide support to carers</p> <p>"Cutting back" Fear there will be no support in a time of need. Anxious non compliance</p>
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Appendix M

Participant Superordinate and Subordinate Themes

Chris (pseudonym)		
Superordinate theme	Subordinate theme	Examples
Feeling angry towards the system	Anger at service cuts	"The main difficulties are the government have cut cut cut the support services, the support services" (Line 28) "you have always plenty of money when you want to have a war...you find the money but as soon as it comes to spending money on making people well and not killing them you don't" (Line 160)
	Feeling unsupported	"the government is stupid they tacitly accept that carers look after the people but will not provide resources so that the carers the subject of the carers, in other words the one for whom they are looking after can have some help" (Line 146)
	Lack of trust and confidence in professionals	"the general practitioners have great deficiencies in their knowledge and understanding of mental illness and to be honest that is basically one of the problems" (Line 70)
	Feeling ignored by professionals	"the doctors don't really seem to be listening to any input from carers" (Line 36) "she saw him and saw me and said that there was nothing wrong with him" (Line 44)
	Feeling judged by professionals	"this psychologist or whatever she was ... said to my wife it's your fault because you haven't brought him up properly' and so it's a very old view, it's not the correct view." (Line 104)
Unpredictable experience	Little control over the others actions	"When he has his delusions and he is not taking medication he can be very very frightening" (Line 127)
	Fearing safety	"to try and stop him from bashing up something and he broke my ribs" (Line 117)
Carrying the weight of responsibility	Holding responsibility	"everything she touched turned into blood and all sorts of delu like that and I was left looking after him" (Line 89)
	Responsible for keeping them safe	"he was very very disturbed and so it was very difficult as we to hide all the knives and forks. All the knives and sharp thing were in the boot of my car and every time I made dinner for hi had to go to the boot open it up and take it out [laugh]" (Line 91)
	Totally reliant on me	"He is certainly vulnerable because his capacity to make judgements like that are defective. He can't really manage to organise anything on his own" (Line 433) "she can't get him to wash...err I am the only one who can [laughter]" (Line 441)
Taken for granted	My needs are not considered	"I said look I am staying in a hotel here now you have got to have a shower it's not fair I am in the car and having to put up with the smell and it's horrible and said you have got to go and have a shower" (Line 377)
	Lack of respect and consideration from others	"when he goes for a wee he splashes all over the place...and when I go to the toilet at night I sometimes walk down and it's wet and I have walked in his wee [laughter] and it's horrible and have to wipe that up and I am half asleep, wipe that up and wash my feet and go back to bed" (Line 400) "I found that he drunk the whole lot and he was drunk and sick as anything and guess who had to clear it up; it's not fair" (Line 412)

Relief in a mutual supportive community	Finding sanctuary in church and relationships	"I go to church, I find my faith helps me and people are very nice at church and that helps as well" (Line 556)
	Carers support is a valuable resource	"The carers centre here is extremely helpful and they are invaluable" (Line 535) "They are very few resources and the carers centre is an incredible valuable resource" (Line 165)
	Help from carers	"But also you can ask the people concerned for advise and places for help" (Line 546)
	Finding shared understanding	"the meetings are helpful in you meet other people with similar problems that are not your own and even if you cant do anything about it you can talk to each other" (Line 584)
Needing an escape from caring responsibilities	Needing an escape from caring	"I have retired I and working part time as I need a form of escape" (Line 185)
	Need time for self	I do need to...in the nicest way possible carers also need to have a break
Feeling connected to my son	Pleasure in activities together	"I phone him once or twice a day and on Sundays it's quite a pleasure to take him to Pizza Hut and we have something to eat together so we meet" (Line 189)
	Caring out of love	"He is my son so I love him. If he were not my son I don't think I would make so much effort [laughs] but if it is your child, he didn't ask to be born, you have a responsibly and also I love him" (Line 199)
	Reciprocal affection	"I mean he loves me and he is a very affectionate and has got good heart" (Line 451)