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A Concept Analysis of Compassion in Healthcare Practice

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**UNIVERSITY OF
PLYMOUTH**

**A CONCEPT ANALYSIS OF COMPASSION IN
HEALTHCARE PRACTICE**

by

Sarah Anne Tobin

A thesis submitted to the University of Plymouth in partial
fulfilment for the degree of

DOCTOR OF PHILOSOPHY

School of Nursing and Midwifery

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Dedication

For my friend Jill Bruley who always believed that I could do this and made me believe that I could too. I hope she knows that I have.

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Author's Declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee. Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

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Signed

Date ...27th March 2019.....

Abstract

Sarah Anne Tobin

A Concept Analysis of Compassion in Healthcare Practice

The subject of compassion is frequently discussed in healthcare literature but despite this, is potentially poorly understood and lacks consensus in definition. This study sought to clarify what exactly is meant by the term compassion in a healthcare context and how this is defined in both the literature and, crucially, by the behaviour and experience of healthcare staff and the experience of service users.

In order to establish a definition of compassion the hybrid approach to concept analysis based on the method described by Schwartz-Barcott and Kim (2000) was adopted, this model combines comprehensive literature review with a fieldwork element – in this study stories of compassionate care from the perspective of healthcare workers and from that of service users have been adopted.

The literature review was carried out following searches of relevant health related databases and once relevant inclusion and exclusion criteria had been met, the resultant literature (n = 160) was analysed using the evolutionary method detailed by Rodgers (2000).

Healthcare staff (n = 23) were recruited and asked to recount a story of when either they or a colleague had behaved in a compassionate way within a healthcare setting. Service users (n = 14) were also recruited and asked to tell their story of when they had experienced compassionate care. The data from both cohorts of study participants was then analysed using a phenomenological approach based on a modified version of the methodology described by Moustakas (1994).

The final concept is based on a synthesis of the findings from the literature review with those of the fieldwork elements of the study. Analysis of this data has demonstrated that compassion can be defined, that much that is written about allied subjects can be seen as synonymous and that the antecedent conditions needed to enable compassion can be described. Importantly, for future practice, education and research, compassionate behaviours and attributes have been identified.

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Chapter One

Introduction and background

'Respect, dignity, compassion and care should be at the core of how patients and staff are treated not only because that is the right thing to do but because patient safety, experience and outcomes are all improved when staff are valued, empowered and supported'.

Department of Health, 2015.

'Love and compassion are necessities, not luxuries. Without them, humanity cannot survive'. Dalai Lama XIV, 1998

1.0 Summary of Content Chapter 1

This Chapter explains the background to and relevance of the research and presents a justification for the approach taken. The philosophical underpinning of the study are described. The aim of the study and the overall implications of the findings have been outlined. The motivation and position of the researcher has also been described.

1.1 Introduction to the study

The dictionary would have us know compassion as 'sympathetic consciousness of others' distress together with a desire to alleviate it' (Merriam-Webster.com. 2019). From such a definition it might seem obvious and unquestionable that healthcare professionals are, and need to be, compassionate. However, the almost relentless tide of negative

newspaper headlines that have appeared in recent years would appear to suggest otherwise (Adams 2011, Campbell and Meikle 2011, Birland and Groves 2012, Patterson 2012, Lakhani 2012, Chapman and Martin 2013, Bomford 2013) and the references included here as examples really only represent the tip of a disturbing iceberg.

Hewison and Sawbridge (2016, p1) outline the popular media's 'strident tenor' in describing failings in care but also point out that little is suggested in terms of cause or in remediation. Much of the initial popular media reporting and the subsequent exponential growth in these reports was as the result of a number of significant inquiries following apparently catastrophic lapses in care (Kennedy 2001, Healthcare Commission 2009, Francis 2010 and 2013, The Patients Association 2010, Care Quality Commission 2011, the Parliamentary and Health Service Ombudsman 2011, Brindle 2011). These only served to confirm an increasing perception that kindness, consideration, respect and understanding – in short perhaps, compassion – may no longer be a guiding principle for healthcare professionals.

A wealth of information including research findings but predominately opinion pieces are available to support the idea that healthcare workers should be caring (Watson 2008', Tschudin 2003, Brilowski and Wendler 2005) and compassionate (Chambers and Ryder 2009, Paterson 2011, Gelhaus 2011, Peat 2012, Saunders 2015, Sinclair et al 2016, Taylor et al 2017, Nijboer and Van der Cingel 2019). Indeed, Peters (2006) goes as far as to state that 'consumers of health care identify compassion as the cornerstone of quality nursing care...' The overwhelming weight of evidence and opinion that is available both presently and

from some of the earliest writings on the subject leave one in no doubt that those who provide health care are expected to do so in a compassionate manner.

Bradshaw (2011) describes that, for nurses, there is a long association with the idea of compassion as both indivisible from the job description and as a basic characteristic required of those who enter the profession. Bradshaw (2011, p 13) cites Eva Lúckes (1886) the then Matron of the London Hospital who argued,

'the personal qualities of the nurse were the absolute basis for nursing. Above all, the "character" of the nurse made the "real" nurse. She believed the indispensable qualities of this vocation were: self-discipline, personal responsibility for learning, truthfulness, obedience, punctuality, loyalty and the kindness of genuine compassion'

However, despite the significant volume of literature, both in the media and in relevant professional journals and books, readers could still be forgiven for a degree of confusion. The volume of description and discussion is not yet matched by an equal or meaningful level of enquiry and research to enable a common definition of what exactly defines compassion in healthcare. Without such a body of evidence it would seem challenging to compel healthcare staff to practice more compassionately. Recent emphasis in government and regulatory policy would appear to begin to address the concept of compassion (Department of Health (DoH) 2010, 2012, 2013a and 2015, Royal College of Nursing (RCN) 2010, National Institute for Health and Care Excellence (NICE) 2011, Nursing and Midwifery Council (NMC) 2009 and 2018, National Health Service (NHS) Confederation 2012) but still falls short of practical suggestions or definitions.

To try and understand what is meant by the term 'compassion' is necessarily complex due to the interchangeability of such terms as

empathy, sympathy, caring, altruism, kindness and so on. Sinclair et al (2017a) explored the meaning of the constructs of compassion, empathy and sympathy recognising how frequently these terms were used as surrogates for each other. Their review of current literature revealed that much 'scholarly activity' was devoted to distinguishing between these characteristics but that there remained a lack of empirical evidence to inform the discussion. Furthermore, such clarity in definition was seen to be important to help inform research to guide clinical practice. Strauss et al (2016, p15) highlighted the lack of any agreed definition of compassion and suggest that without such a definition it is not possible to '*study compassion, measure compassion or evaluate whether interventions designed to enhance compassion are effective*'.

Gilbert (2017) suggests that the challenge of defining compassion is confounded further by the passage of time, translation of terminology across different languages, different religious and philosophical ideologies and on the context of the definition. Papadopoulos and Ali (2016) conducted a literature review as they hypothesised that definitions of compassion would vary between different cultures and found that compassion is a complex concept dependent upon the values and context of care and is impacted upon by cultural interpretation. Gilbert (2017, p4) also concurs with the idea that there is a lack of common understanding about compassion stating that, '*although there are many general ideas around what compassion is, currently there is no clear agreement about what the specific attributes of compassion are*'.

Providing a definition is challenging as, whilst dictionary entries are undoubtedly etymologically correct they are neither subtle nor comprehensive enough to explain the quality that is expected of healthcare workers. Linguistically, the term 'compassion' is derived from the Latin roots 'com', which means 'together with' and 'pati', which is 'to bear or suffer'. Such a definition – in essence to suffer with – is equally contentious in healthcare professions where the body of evidence to support the increasing level of 'burn-out' and compassion fatigue is overwhelming (Melvin 2012, Michalec et al 2013, Pereira et al 2015, Peters 2018, Cross 2019).

Much of the literature concerning compassion appears to have been written by authors who assume an understanding of the term, or at least their perception of it. Frequently cited, Nouwen et al (1982, p 4) eloquently suggests that:

'...compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish. Compassion challenges us to cry out with those in misery, mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable and powerless with the powerless. Compassion means in the condition of being human'

Such a description falls short of defining compassion and, whilst it may inspire some healthcare practitioners' understanding, others could see this as overly sentimental, unrealistic – a way of undermining a necessary professional distance – and may even argue that there is a need to be more dispassionate to enable them to carry out their role. This was a concept explored in the work of the ethicist Anna Smajdor (2013) who suggested it can be damaging for healthcare professionals to feel too much compassion – because they may become deeply

distressed by some of the things they see and do. They are at risk of suffering burn-out, fatigue, becoming de-sensitised and damaged. Smajdor (2013, p3) suggests that compassion may not be a necessary component of healthcare provision and that

‘...one can remove an appendix without caring about the person from whose body it is taken, empty a bedpan without caring about the patient who has filled it, or provide food without caring about the person who will eat it’.

Such an opinion is compelling in its logic and needs consideration in terms of the impact upon care staff, however – hers’ is a rather lone voice in the overwhelming volume of concern and evidence about the impact of failures in compassion (Francis 2013, Reid 2012, Care Quality Commission 2011 and Youngson 2011).

1.2 Background to the study

Clearly, however compassionate an individual, they will be ineffective as a healthcare professional if they do not have sound knowledge and an effective skills base. It is a premise of the author, however, that current education for healthcare professionals may be too heavily weighted in favour of teaching theoretical knowledge and technical skills. *‘Wisdom as an outcome of education is often overlooked and drowned out by the demands of concept attainment, skills mastery and high-stakes assessment’*, so asserts Miller (2005, preface); for wisdom one could seemingly equally state compassion. If compassion, as an indispensable component of healthcare practice, is to feature in and underpin healthcare education this will undoubtedly be hampered by a lack of a widely held definition or agreed set of attributes.

Canadian physician Jeff Nisker has developed a programme linking the concept of compassion to the continuing education of medical students. Using patient stories, film, poetry, theatre and music he ensures that a relevant and timely reminder of not just what has to be learnt but why it should be learnt is brought to the student's attention (Nisker, 2001). Whilst the impact of this curriculum has not been assessed, the need to include humanities in medical education is gaining credibility within the United Kingdom (UK). The General Medical Council in its publication 'Tomorrow's Doctors' (GMC, 2009) encourage the inclusion of humanities in the medical curriculum. Giordano (2010, p 447) details a medical humanities programme delivered in Manchester which, whilst designed to teach ethics, also aims to provide 'humane professionals' who view medicine not just as a clinical subject but also as a 'science of the human'.

Latterly, not only has there been an increase in reports of educational provision to foster compassionate care (Brown and Bright 2017, Jack and Tetley 2016, Waugh and Donaldson 2016, Adamson and Dewar 2014, Jack 2015) but a significant number now emanate from a body of UK research and development. More importantly, these studies represent a move away from rhetoric and discussion to action and analysis. There is increasing evidence that the inclusion of humanities and even compassion in educational initiatives is taking root and beginning to increase in incidence (Meyer 2009, Kern 2011, Smith 2012, Curtis 2013, Dewar & Nolan 2013, Richardson et al 2015). Yet, it is still evident that these initiatives rely on participants to either agree that compassion is as described by the originators of the study or initiative or is a tacit

understanding of those who will read the views of the author(s) or review the findings of the studies.

As with Nisker's programme, the recognition that compassion cannot be taught as a 'one-off' lecture prompted the development of a 'Cultivating Compassion' programme for health professionals and support staff using a 'multi-modal compassion toolkit' in the South East of England (Curtis et al, 2017). In Scotland the Edinburgh Napier University's School of Nursing Midwifery and Social Care in conjunction with NHS Lothian, collaborated on a programme of action research entitled, the Leadership in Compassionate Care Programme (Adamson et al, 2012). One strand of this research focused on learning and teaching about compassionate care within the undergraduate curriculum (Smith, 2012). Yet, welcome as these initiatives are, definition and a common understanding of compassion was not always implicit even within these programmes.

Developments such as these are both timely and necessary as, also predominately from America, comes evidence that despite these individual initiatives, compassion has not been widely taught in healthcare education. For example, two decades ago an observational study (Burack et al, 1999) concluded that physicians did not address a perceived lack of compassion and respect in medical students. There is evidence that this situation has not changed, medical schools may actually cause a decline in empathy in students, so asserts Neumann et al (2011) a finding which echoed that of Hojat et al (2009) and Stratton et al (2008). Evidence from a UK study by Johnson et al (2007) appears to suggest that not only does nurse education actively disengage nurses from a sense of altruism but also that such a concept is becoming increasingly less important to nurses

commencing undergraduate training than had previously been the case. This finding was replicated in the study by Maben et al (2007) who suggest that those who enter nurse training do so with a clear and espoused view of their wish to deliver patient-centred, high-quality holistic care. Maben's study found that within 2 years of practice the frustration and disaffection caused by the thwarting of these ideals led to burn-out and attrition. Murphy et al (2009) studied nursing students from a Higher Education Institution in Wales and discovered that there was a significant decrease in caring behaviours between first and third year students concluding that this reduction was the result of the education process they underwent. This is not simply a UK phenomenon as a very similar study in Singapore returned the same findings (Loke et al 2015).

Straughair (2012, p 243) states '*nurse educators must be mindful about implementing appropriate recruitment and selection strategies, involving service users and embedding the concept of compassion into nursing curricula. Additionally, further research needs to be undertaken to explore the concept in greater detail*'. Bleakley (2015, p 959) also cautions that,

'...despite the widespread interest in the medical humanities in North American medical schools by the 1990s, and their introduction into the UK, New Zealand and Canada during the same period, the medical humanities in medical education have failed to gain adequate traction. Few medical schools internationally have formally designed the medical humanities into the undergraduate curriculum as core (compulsory), integrated and assessed provision'.

The wealth of literature highlighted concerning the importance of compassionate practice is evident and difficult to dispute. The failure of some healthcare professionals to demonstrate compassion in their dealings with patients is equally apparent. In the last few years it would appear that there is a will to try and

measure compassion – to develop metrics aimed at quantifying and evaluating this quality in those who care for patients (Griffiths et al 2008, Davison and Williams 2009, Ford 2012, DOH, 2013b). However, it seems almost absurd to try and measure a concept that is both ill-defined and variously understood or to assess that which may not to be taught in any formal or concerted way. From all of the perspectives described above it seemed evident that a comprehensive, focussed and relevant definition of compassion was needed and that this then might help inform future practice, education and research.

As this research progressed it was evident that there was a growing body of interested researchers who identified that defining compassion was important. The reasons for this were varied, Richardson et al (2015, p2) felt that it was challenging to establish a definition that everyone can ‘sign up to’ and that the interrelatedness of similar concepts and the nebulous nature of compassion meant that it was difficult to ensure that everyone was discussing the same thing. This is echoed by Bray et al (2014) who suggest that the concept of compassion is filled with ambiguity and contradictions. Sinclair et al (2016b, p2) sum this up as:

‘Despite centuries-old dialogue from scholars in philosophy and religion, the language of compassion has functioned largely as a superlative embedded in a corpus of interchangeable and often conflated care terms within the healthcare literature. As a result, the evidence base for compassion in healthcare remains underexplored’

They continue by suggesting that without clarity it would be difficult to ‘*inform future research in nursing theory, education, research and clinical practice*’. Ali and Terry (2017, p77) add to this by stating that ‘*understanding the concept of compassion has significant implications for its recognition, promotion and assessment in practice*’ whilst Durkin et al (2018) propose that poor definition and

the interchangeability of terminology may hamper organisations and educators from both teaching and measuring compassion.

However, is definition an important ambition? Smith and Wolf (2018) state that bringing clarity to the definition of the concept under investigation enables the construction of effective research instruments in terms of scale items or questions. This would suggest that without such clarity it would be challenging to investigate and research the concept of compassion. And, in their seminal work on theory construction in nursing, Walker and Avant (2005, p28) state that *'theoretical and operational definitions are critical in theory building. Without them there is no way to test and thus validate the theory in the 'real world''*. Whilst no study can or should claim to be 'definitive' it does appear that there is a need for a consensus as to what is meant by the concept of 'compassion' and that such a consensus may help to ensure accuracy in future research, in education, in practice and in recruitment. Francis (2013) suggested that there should be a values-based approach to future recruitment of healthcare staff but it is implicit that such values, which include compassion, need to be defined and agreed to enable such focussed recruitment.

Many of the authors whose work has underpinned this study described compassion yet still there remains a lack of agreement as to the exact determination of the concept. Importantly, Sinclair et al (2016b) suggest that there is disconnect between what clinicians believe patients and their families want and prioritise and what patients actually do value and that this is exacerbated by a lack of shared understanding. Defining compassion in a way that promotes a consensus will not alter nor improve compassion as a concept however, it may

help to improve a shared understanding and it is this greater clarity of understanding which will hopefully enhance future care for patients.

1.3 The author and their relationship to the study

This thesis will be written in the usual academic convention of the third person, however, this section will be a reflective account of the personal motivation and background of the Author and, as such, will be written in the first person. Such an account will serve not only to explain motivation but also to inform the background to the philosophical and methodological approach to the study.

This research study follows on from previous research I undertook to inform a Master's (MSc) in Education. Focus groups comprising of healthcare professionals and educators were used to identify whether compassion was seen as an important element of healthcare provision and consequently whether it could and should be taught to pre-registration healthcare professionals. The results of this research indicated that the healthcare professionals not only believed that compassion is a vital component of their practice but that it should be taught to students of healthcare.

The reason that I carried out this study to complete my MSc was also the reason and motivation for expanding the research into this current project. As a Registered Nurse predominately working in oncology I have been privileged to witness inspirational, dedicated and tirelessly compassionate care delivered to patients, relatives and colleagues. There have also been

occasions when I have also seen care that has fallen significantly short of this (see Appendix I) and these experiences have left me both bewildered and distressed. I have always found that the way to address a problem is to explore it and learn from it and so my initial response to the event described in Appendix I was to reflect upon it, the result is the account included here. It then occurred to me that any failure in technical care would result in some form of clinical incident report which could be reviewed, analysed and, if needed, appropriate remedial action could then be instigated. However, what was the response when the failure was not one of practical care provision but was a failure of simple kindness, of compassion? This did not seem to be addressed in any formal mechanism so I decided to start from the basis of trying to discover what colleagues thought about compassion and whether they felt it to be important. In short, was my response and were my concerns common? Was my understanding of what was meant by kind, compassionate care the same as that of my colleagues? As much as anything, I had to do something to assuage my sense of impotence and anger at what I saw happening to a profession I love and respect.

The MSc study convinced me that the subject was important, that others shared this view and also that compassion was, at this point, both under-researched and ill-defined and that a clear definition was needed as a starting point to inform future initiatives.

At the outset of this research project in 2012 the aim had been to define compassion with the ambition to help inform curricula development in healthcare education. As the study progressed it became apparent that to

provide a meaningful definition would take more than simply reviewing the literature and culling the common referents. In order to teach compassion, if that were to be possible, not only would a definition be required but so too would perspective, context and the identification of discernible behaviours and attributes. It became apparent that a comprehensive exploration of the concept of compassion was required and that this would need to be the focus of the research. Without such clarity the ambition to inform curricula was just that – ambitious.

1.4 Philosophical Underpinnings – the researcher and the study.

In any research study it is important to establish the position of the researcher and the approach that the research should therefore adopt. As the study was being undertaken by a relatively novice researcher this was a key starting point for the exploration, without clearly understanding what is already known and what it is possible to discover the research will not have clear aims. Guba and Lincoln (1994, p108) explain that epistemology asks the question '*what is the nature of the relationship between the would-be knower and what can be known*'? The need to address the ontological beliefs of the researcher and how this would influence the epistemological approach of the study was evident.

Compassion is a complex and subjective concept and the challenge was to establish how knowledge can be established in the face of such ambiguity. Denzin and Lincoln (2005, p183) suggest that ontology addresses the nature of reality and the nature of human beings in the world. The underpinning assumptions of the researcher were debated with the supervisory team and it was acknowledged that the researcher

believed compassion to be abstract and that the awareness and experience of compassion would be from the perspectives of multiple truths and would be shaped by context. Such awareness and the added requirement to appreciate that the knowledge of how compassion is viewed may change and evolve resulted in a relativist approach to the study. Levers' (2013, p2) description, '*the purpose of science from a relativist ontology is to understand the subjective experience of reality and multiple truths*' suggests that such an approach accords with the underlying beliefs of the researcher.

Once the ontological position is accepted, that reality is not distinguishable from the subjective experience of it, it is possible to consider the research design and how this would be informed by the need to acquire the most relevant and meaningful data to answer the research question. The epistemological approach – how compassion is understood and experienced and how this can be known – will then underpin the methodology that is selected. The subjective approach, the idea that knowledge is influenced by the characteristics of those who hold it, is a natural response to a relativist ontology, Denzin and Lincoln (2005, p21) suggest that information is '*always filtered through the lenses of language, gender, social class, race and ethnicity*'.

The methodology that was decided upon reflected these approaches, a concept analysis of compassion as experienced within healthcare was adopted (and will be discussed more fully in Chapter 2). However, how best to undertake such a study was further influenced by the acknowledgement by the researcher of their own beliefs. Within the

framework of subjective epistemology an interpretivist approach suggests '*knowledge is relative to particular circumstances – historical, temporal, cultural, subjective – and exist in multiple forms as representations of reality (interpretations by individuals)*' (Benoliel 1996, p407) and Fossey et al (2002, p720) state that the '*interpretivist paradigm focuses primarily on recognizing and narrating the meaning of human experiences and actions*'. It was evident that the concept analysis should if possible reflect these ideas and therefore the hybrid method of concept analysis as proposed by Schwartz-Barcott and Kim (2000) was identified as most closely aligning with such ideas.

The hybrid method combines a literature review with a fieldwork element, the findings of both elements are then synthesised to produce the final analysis of the concept under consideration. The literature will help elucidate the 'multiple truths' that are presented in relevant health related journals but may not capture the entirety of what the researcher was seeking. '*Reality is human experience and human experience is reality*' (Levers, 2013, p2) and the fieldwork element of the hybrid method will enable this 'human experience' to be addressed. The method is more fully explained in Chapter 2 but the use of stories as the way to capture healthcare staff and patient's experience of compassion will also try and limit what Levers (2103, p3) describes as '*observations are influenced by the observer and the observer is influenced by the observed*'.

The ontological and epistemological approach of the researcher has influenced the method of carrying out the study but also the methodological approach to the data that is uncovered. This will be more

thoroughly described in Chapter 2 but the relativist idea that concepts will change and evolve led the researcher to the evolutionary method of analysis of the data from the literature review as described by Rodgers (2000). The data that was generated from the stories shared by healthcare staff and patients was analysed using a phenomenological approach adapted from that described by Moustakas (1994). Phenomenology sits well with the interpretivist paradigm although such a contention is not without controversy. Phenomenology is not a unified doctrine and the main proponents, Husserl, Heidegger, Sartre and Merleau-Ponty all have different interpretations of a common theme – that of studying the conscious experience from a subjective, first person point of view. Heidegger challenged Husserl’s view that phenomenology was a purely descriptive philosophy countering with the view that it is impossible for any description not to be interpreted via the way it is told, recorded or represented (Mackey, 2005). Whilst the approach that has been adopted does reflect a Husserlian, transcendental perspective the adaptation and the method of data collection have insured that interpretation is allied as closely as possible to the original experience and description of the research participants.

1.5 Significance of the research

This research has potential significance for theory, practice and for future research and policy. This study provides a unique perspective to inform a definition of compassion that also encompasses the determination of

attributes and behaviours that demonstrate compassionate care. Such a definition would be beneficial to help inform healthcare practice and leadership, educational developments and future research and, as such, is a valuable and meaningful addition to the current evidence base concerning compassion in healthcare.

A number of other studies have been identified that have attempted to define compassion (Schantz 2007, Dewar et al 2014, Bramley and Matiti 2014, Bray et al 2014, McConnell and McCaffery 2015, Strauss et al 2016, Schofield in Hewison and Strawbridge 2016, Sinclair et al 2016, Kneafsey et al 2016, Taylor et al 2017, Durkin et al 2018). All of the studies highlighted that compassion was a key component of healthcare provision and that it was a complex and poorly defined concept within healthcare. Summed up by Sinclair et al (2016b, p 10) who state, '*despite its centrality to quality care and its ubiquitous usage, an empirical understanding of the nature of compassion is not well developed*'.

The majority of the studies constructed a definition based on a review of literature and no other data sources were involved (Schantz 2007, McConnell and McCaffery 2015, Strauss et al 2016, Sinclair et al 2016b, Taylor et al 2017 and Durkin et al 2018). Only three of the studies reviewed attempted to determine the views of healthcare staff, Bray et al (2014) conducted surveys and interviews of both healthcare professionals and pre-registration healthcare students whilst Kneafsey et al (2016) conducted 9 focus groups, 7 of which were for healthcare staff. Crucially, Kneafsey et al (2016) also included 2 focus groups comprised of members of the

general public, a total of 9 non-healthcare professionals took part. Dewar and Nolan (2013, p1247) describe a study which involved older people, their relatives and staff in agreeing a definition of '*compassionate relationship-centered care*'.

Involving staff is seemingly rare but studies where patients or the public are involved is rarer still, along with Kneafsey et al (2016) and Dewar and Nolan (2013), only 2 other studies drew data from patient input. Bramley and Matiti (2014) conducted 10 in-depth, semi-structured interviews with in-patients at a large, UK teaching hospital. Schofield (in Hewison and Sawbridge, 2016) describes a concept analysis comprising a review of literature but also interviews with patients, however, the only publication of this study that has been found is a chapter within the book edited by Hewison and Sawbridge (2016) and in this chapter Schofield only describes the findings of a single interview. Such a relative paucity of patient involvement is also described in the 2016 (p,14) scoping review of literature by Sinclair et al who highlight the lack of patient engagement in the majority of the research they reviewed. This finding was reflected in the final concluding statement of their study;

'Above all, future research on the nature of compassion and its application in clinical practice needs to incorporate the perspective of patients, who desperately desire and increasingly expect compassion to be a core component of their healthcare experience'.

The majority of the studies cited above concluded that despite the increasing interest and research into compassion, a clearly defined and widely acknowledged definition remains elusive (Schantz 2007, McCaffery and McConnell 2015, Sinclair et al 2016a, Schofield (in Hewison and Sawbridge) 2016, Taylor et al 2017, Durkin et al 2018).

In summary, it is evident that a responsive and meaningful definition of the concept of compassion in healthcare is missing and that the lack of such a definition may hamper the development of compassionate healthcare. No study was identified that has included a synthesis of the perspectives of literature, healthcare staff and patient and therefore the method employed and the resultant findings of this study will provide a unique and relevant contribution to the understanding of compassion in healthcare. A definition of compassion and the identification of behaviours that demonstrate compassion should enable clear expectations of staff in practice, can be modelled by compassionate organisations and leaders and can inform how healthcare staff may be educated.

1.6 The aim of the study

The theory of concept analysis will be explored in Chapter 2; however, the aim of the study has informed the choice of methodology. It was important that the concept analysis was not confined to the exploration of professional literature and, as such, the extrication of the purely theoretical. The concept analysis has encompassed relevant literature but also the lived experience of both healthcare professionals and those who use healthcare services in order to better reflect the idea that theory that is 'directly linked with clinical experience has far greater relevance for nursing practice' (Schwartz-Barcott et al, 2002, p. 281).

The overall aim of this research is:-

1. To establish whether perceptions of compassion described in relevant professional literature and held and experienced by healthcare professionals and healthcare service users are in accordance.
2. To develop a comprehensive definition of compassion and of compassionate behaviours in contemporary healthcare based on the synthesis of the intersubjective experience of the fieldwork participants with information demonstrated by the literature.
3. To use the resultant definitions to make recommendations to inform healthcare organisations, healthcare practice and future educational development and research.

Chapter Two

Methods and Methodology

'It is common sense to take a method and try it. If it fails, admit it frankly and try another. But above all, try something'.

Franklin D. Roosevelt (1933, pg. 33)

2.0 Summary of Content Chapter 2.

Chapter 2 describes the methods used to carry out the research and examines the rationale for the choice of approach. Concept Analysis is explored and the philosophical position adopted for data analysis is presented. The rationale for the use of two different approaches to data analysis is explored as is the ethical considerations that underpin the study.

2.1 Introduction

In Chapter 1 the background, justification and underpinning philosophical assumptions of the study were described, this Chapter will explain the methods and further illuminate the theoretical approach that has been adopted to explore the concept of compassion in healthcare. The research has been carried out using two different methods (research instruments) and methodologies (theoretical positions) to try and establish a meaningful and responsive definition of compassion in healthcare. These approaches have been conducted under the umbrella of a hybrid concept analysis

framework and the rationale for this approach will be examined and the methods and methodologies described.

The concept analysis of compassion within healthcare has been carried out with the aim of establishing how this idea is viewed in current professional literature and how it is experienced by both healthcare workers and users of healthcare services. Delves-Yates et al (2018) suggest that one of the main aims of concept analysis is to identify the attributes of a concept. Definition but, crucially, the identification of compassionate attributes is a key aim of this study. To justify the choice of methodology it will be helpful to examine some of the theory and development of this approach and to defend the relevance of the definition of concepts which Bergdahl and Berterö (2016, p, 2559) describe as commonly held to be '*the essential components from which theory is built*'.

2.2 Approaches to concept analysis

2.2.1 Traditional approaches

Wilson (1963), the author of a widely acknowledged seminal work on concept analysis, suggested in the preface of the book that those who professed an interest in a subject should '*spend less time in simply accepting the concepts of others uncritically and more time in learning how to analyse concepts in general*'. Wilson, as an educationalist, developed his method of concept analysis based on his need to educate school children and to encourage enquiry and understanding in that arena. His

work has subsequently formed the foundations of a number of methodologies developed by and for nurse researchers. '*Concepts are the backbone of theory in practice (that is, concepts help nurses to organise meaning to understand complex human experiences and behaviours in ways that influence the practice of nursing)*', so asserts Hupcey and Penrod (2005, p 201) who have written extensively about this method of research. Risjord (2009) states that concept analysis does not necessarily need to occur prior to theory development but that it must be part of the development of subsequent theory and that by making a concept explicit, future nursing theory can be applied and tested. The current context of compassion in healthcare as outlined in Chapter 1 indicates that there may be no concept more frequently mentioned, less understood or contextualised or more vital to patient care than that of compassion.

In order to address the aim of this study it was necessary to establish a concept of compassion that was firmly rooted in practice i.e. not simply a theoretical construct but a definable set of behaviours and common characteristics. Some models for concept analysis are based entirely on the exploration of discipline-specific literature. Two frameworks for concept analysis are frequently used within nursing research – that of Walker and Avant (1983, 1988, 1995, 2010) and, to a lesser extent, that of Rodgers (1989, 1993, 2000). Other methods are mentioned and used in the literature (Chin and Jacobs 1987, Chinn and Kramer 1991, Paley 1996, Morse 1995) but the two frameworks, in respective order, are by far the most consistently applied. Of the two, Rodgers appeared to fit the aim of this study more appropriately as she describes concepts as '*continually subject to change, and as developing through significance, use, and*

application' as detailed by Knafl and Deatrlick (in Rodgers and Knafl, 2000, p. 47). This 'evolutionary' view resonates with the concept of compassion in the current climate of healthcare – for something that is clearly not new but which has, in recent history, become embroiled in the politics, opinion and policy that informs healthcare - there must surely have been a genesis of the concept that has the potential to change and develop over time.

Rodgers' approach facilitates the inclusion of data from sources that are relevant to the concept being explored but does not restrict this to discipline specific information, as such all areas of healthcare practice can justifiably be included. Rodgers also allows for the inclusion of interview or other forms of verbalised language and is essentially a heuristic methodology generally leading to further research and enquiry.

However, as with Walker and Avant (1983, 1988, 1995, 2010) and the other, less well used, models the emphasis concerning data collection remains reliant on literature reviews. This did not seem to fulfill the ambition of this study – to try and also understand the possibility of compassion as a 'lived' aspect of healthcare professionals and healthcare users.

So, whilst Rodgers' methodology appealed to the aim of this study in terms of the wide inclusion criteria for theory, the relativist perspective of concepts as evolutionary and the heuristic nature of the analysis it still did not feel as if it could capture all that compassion may mean in current nursing practice. The reliance within most methods on the review of literature can appear to be almost reductionist in that the concept becomes a linguistic, perhaps semantic, construct rather than a dynamic

and active phenomenon. Walker and Avant's model case for the concept of coping (1995) is a case in point, striving so hard to encompass all possible attributes of the meaning of coping (even including a type of saw), to be a 'paradigmatic example', it can seem almost entirely abstract

2.2.2 The hybrid model of concept analysis

Schwartz-Barcott and Kim (2000) have formulated what they term a 'hybrid' model of concept analysis in nursing which incorporates the essential literature analysis but also a fieldwork element along with a third analytical phase which produces a synthesis of the fieldwork findings, re-examined and integrated with the theoretical component. Schwartz-Barcott and Kim felt that 'there seemed to be a rather universal assumption that simply having knowledge of a particular theory was sufficient for its unending application' (2000, p130). As a result of this position they developed a model that aims to ensure:

- Analysed concepts are integral to nursing practice (and, by extension – wider practice of healthcare professionals)
- Reviewed literature is broad enough to capture commonalities and extremes across disciplines
- There is a focus on the essential aspects of definition and measurement
- Literature analysis is integrated with empirical data gathered from practice.

The majority of studies that have adopted the hybrid model have used either participant observation or, more commonly, interviews as their fieldwork methodology (Sayer and de Vries 2008, Unger and Buelow 2009, Aghajar et al 2018, Hanifi et al 2018, Neda et al 2019 and Wells and Kartozi 2019).

As a structure for analysing the data from the literature review, the methodology as suggested by Rodgers (2000) has been used. This has ensured that concepts are presented as evolving, having defined characteristics and as resulting in consequences. Rodgers suggests that concepts are dynamic and context-dependent which challenges the previously accepted essentialist position which suggests concepts are universal and unchanging. Such an approach also accords with the researchers' contention that 'compassion' may well need to be defined by analysing multiple perspectives, in different contexts and as developing over time. Although Rodgers' approach has been categorised as 'Wilsonian', Rodgers describes this as erroneous as there are subtle but distinct differences in her approach. An emphasis on inductive inquiry and subsequent analysis without starting with the researcher's own preconceived ideas combined with the need to contextualise mark the departure from other methods.

Rodgers suggests that a lack of a common understanding concerning the attributes of a concept will impede discussion, and development concerning the concept will be restricted – as an example she suggests that several people discussing 'professionalism' will have great difficulty if each has a differing concept of professionalism. Without such common

ground there is the potential for confusion and miscommunication and whilst concept analysis is not an 'end point' it is an important process which leads to the development of knowledge. Concept analysis is essentially heuristic, as Rodgers suggests, such work forms the basis for further development and, as such, matches the ambitions of this study. This combination of the hybrid model and Rodgers' evolutionary model has been used by other researches (Shin and White-Traut 2007, Hutchfield, K 1999) with success.

The first element of the concept analysis is the selection of the concept to be studied. This had already been established as a result of the previous MSc project as described in Chapter 1, but also as a result of the growing level of focus on this concept in the media, in policy and in recent literature. Schwartz-Barcott and Kim (2000) suggest that the most 'productive' use of the concept analysis model has been when the researcher has used an encounter drawn directly from practice and when this has been unexpected and has led to frustration, horror, anger, embarrassment or bewilderment. This would seem to adequately express some of the emotions reported in relation to the researcher's own experience and much of the media coverage concerning the level of compassion within healthcare at present.

2.2.3 The trouble with concept analysis!

The idea that familiarity can breed contempt is perhaps apposite when considering the use of concept analysis as a research approach. There

has been a noticeable increase in the use of concept analysis in nursing research in recent years (Beckwith et al 2008, Cronin et al 2010, Rodgers et al 2018, Beecher et al 2018). Such an increase is evident from even a simple literature search using the Primo search tool, 'concept analysis nursing' confined to one year, 2018. This returned 6,784 results including concept analyses of moral courage in nursing, integrity in nursing students, professional nursing values and compassion fatigue in nursing amongst a very large number of others. There is, however, some disquiet about the value and benefit of this increase in the use of concept analyses to the state of nursing science and knowledge (Duncan et al 2007, Beckwith et al 2018, Rodgers et al 2018).

Beckwith et al (2008) in their controversially titled article '*The 'con' of concept analysis*' warn that frameworks for concept analysis rely too heavily on adaptations of too small a body of work. Further, they suggest that these frameworks may not provide the '*necessary depth, rigor or replicability to enable development in nursing theory*' (p,1831). However, as Baldwin and Rose (2009) point out, a dissertation may be as much an experiential method of learning about research as it is a method for discovering new evidence. Schiller (2018) feels that there are benefits to completing a concept analysis from both the intellectual exercise required but also from the level of critical thought that is needed but highlights that there is a '*distinct paucity of literature to assist educators to guide students through this challenging behaviour*' (p, 248). This does seem borne out by the researcher's own experience exploring concept analyses where they are frequently reported but, certainly more recently, much less described in terms of theory and method. Beecher et al (2018) were motivated to

review concept development methodology and felt that the literature relating to the subject was complex and that this may serve to exacerbate the challenges of exploring any given concept and agree that there is a '*dearth of knowledge evolution of the seminal methods of concept development since their inception*' (p, 6). However, they conclude that concept development is a vital element to support and advance the knowledge base that nursing and midwifery require.

The adoption of the hybrid model of concept analysis to explore compassion from both the perspective of professional literature but also from the lived experience of healthcare professionals and patients, does seem to address some of the concerns about the method. The synthesis of the two approaches to exploring the concept will naturally provide a degree of triangulation and, as long as the process is both transparent and rigorous, is a valid approach. As Baldwin (2008) suggests, the examination of a concept may not necessarily produce new empirical facts but '*rational enquiry into the meaning of concepts is a necessary first step that should precede the development of hypotheses*' (p. 56).

The method determined in this study has developed, been interrogated and adapted to fulfil the aims of the research and is therefore also a 'rational' approach. Rodgers et al (2018 p, 455) succinctly conclude that concept analysis does not need to be an '*intellectual dead end*' but as long as the process adheres to the requisites of competent research such as '*sample selection, analytic process, presentation of findings and discussion tied to a conceptual problem that promotes further enquiry*' (p, 456) then the method is an important addition to nursing science. This

study has approached all aspects of the concept analysis with openness and clarity and has provided a rationale for each stage of the method adopted.

2.3 Literature Review

2.3.1 Background information informing search strategy

The aim of conducting the literature review was to establish the current state of the concept of compassion in relevant, contemporary professional literature. *'Ultimately, the goal is to gain comprehensive command of the literature dealing with the concept and to acquire a deep grasp and understanding of it as it has been used across disciplines and over time'* (Schwartz-Barcott and Kim 2000, p. 135). The literature review has been approached with the aim of analysis using the method suggested by Rodgers (2000) and she proposes a broad review of available literature to include such sources as dictionaries, thesauri and popular press. This inclusive approach is not shared by all with Penrod and Hupcey (2015) clear that only scientific literature should be included to ensure an evidence-based definition and that sampling should be conceptually driven. Beecher et al (2018) suggest that Rodgers' approach, originally described in the 1980's, may be reflective of the volume of literature available to researchers at that time. When searching for literature related to compassion the volume returned was significant and, if including material from sources other than that relating to healthcare-specific literature, would pose a potentially unmanageable volume in terms of the

remit of this study. Rodgers does suggest that a stratified sampling technique can be employed to produce a final cohort of material for analysis. Again, Penrod and Hupcey (2005) contest this believing that a random sample may lead to significant omissions and Beckwith et al (2008) worry that this may also prevent the identification of the evolving nature of the concept.

Once all factors were considered it was decided to do a systematic review of all relevant professional literature during a defined period and that, for this study, so called 'grey' literature would not be included. In terms of the heuristic nature of this research the exploration of the relationship between professional and non-professional literature will be explored in recommendations for future research. The inclusion of the fieldwork element of the concept analysis also allows for the views of 'non-professional' healthcare experience to be included which further supports the validity of not including grey literature.

2.3.2 Literature review search strategy

The initial literature search was carried out in 2014 using an internet search engine – NHS Evidence Healthcare Databases (formerly National Library for Health) was used concentrating on the BNI, AMED, HMIC, Medline and CINAHL databases. These databases were selected to give the widest choice of relevant journals and policy literature relating to not just nursing, but also medicine and allied health professions. The word 'compassion' was used to start the literature search, the simple choice of

the key word 'compassion' was made to try to reduce the possibility of any ambiguity in what could be seen as an already somewhat nebulous concept.

2.3.3. Time frame

The literature review was the first stage of the research that was undertaken, the time frame for the literature search was set as January 1st 2004 – May 2014 when the initial literature review was conducted. This was a pragmatic approach for reducing what was a significant volume of material but was also encompassing a time-frame which was felt to reflect contemporary healthcare in a very fast changing environment to ensure that this remained recognisable and relevant. This time period was also felt to be long enough to capture the 'evolutionary' aspect of the concept that Rodgers (2000) describes.

This time frame has subsequently been revised and updated. There has been a significant increase in the level of published material that cites 'compassion' in title or abstract – not least as a result of the publication of The Willis Report (Willis, 2012) and Compassion in Practice (Department of Health, 2012) which both became available at the end of 2012 and of the findings of both the 2010 and 2013 Francis Reports. The initial, 2010 report concluded that the failings at the Mid-Staffordshire NHS Trust demonstrated a '*lack of compassion for patients or lack of reassurance that staff cared*' (p, 14). The subsequent 2013 report resulted in 290 recommendations, many of which directly address this issue. These

reports represent both a response to a perceived lack of compassion (indeed, the Willis Commission Report is entitled 'Quality with Compassion: the future of nurse education') but also resulted in an impetus for the increase in literature concerning the subject.

A second and discreet literature review was therefore conducted from 2014 up to and including November 2018 and used the same databases and the same search strategy. A very significant volume of literature was identified and, in terms of the resource available for this study, it was not going to be feasible to analyse this data to the same level as the original review. However, it was also felt that not including this literature would be a significant omission that would impact on the credibility of the final conclusions. The evolutionary aspect of the concept would also be diminished if this body of opinion and research were not to be included. Therefore, a modification was employed, the literature was categorised in terms of opinion pieces and those that described research studies and the process was then clearly recorded to enable inferences to be made as to how the literature has developed over time. The research studies were then collated and reviewed using a modification of the Rodgers (2000) approach adopted for the original review. The 2 separate sections of data were then combined to form the overall literature review and this is described in Chapter 3.

2.3.4 Inclusion and exclusion criteria

All databases were initially searched with the word 'compassion' – where possible, the terms 'compassion-fatigue', 'compassion-focused therapy' and 'mindfulness based compassion' were excluded. These are specific terms for well-explored and detailed concepts and will not add to the aims of the study. The time frames detailed above were established, the search term was limited to title and abstract and in all databases the search could be limited to human subjects and publications in English.

In terms of refining the data, the inclusion criteria were clarified to include the following; that the word 'compassion' had to be in the title or abstract in the context of healthcare and that the article subsequently explored the idea of compassion. This was to exclude those articles where the word featured in the title or abstract but where compassion was not a significant feature of the work i.e. the article did not contextualise, define or examine the concept of compassion in healthcare

Further exclusion criteria were developed to exclude articles not originating from Western Europe, Scandinavia, North America, Canada, Australia or New Zealand. Both the researcher and the study supervisors felt that this would reflect opinion or research that related to health systems that were comparable in terms of sophistication and service provision if not always in structure. Further, these countries also represent those with a background culture that would ensure that a degree of similarity in terms of societal norms and understanding would allow for reasonable comparison in terms of opinions expressed. Literature not

initially published in English was also, where obvious, excluded. Whilst this will inevitably exclude relevant material, it was felt that when dealing with such a nuanced concept as compassion it was possible that definition and understanding of this may be compromised by translation.

Literature was also excluded if it was not relating to human subjects i.e. from veterinary science journals or if it was not exploring issues relating to healthcare.

The search strategy was documented for each database including which inclusion/exclusion filters could be applied to ensure clarity and to aid replication. The searches were, however, replicated as closely as possible within each database.

2.3.5 Initial search of each database

The researcher completed the initial selection process. The search term used produced articles simply because the word 'compassion' had occurred in the title or abstract, where it was apparent that this was not the focus of the article, the researcher excluded that article. Where there was any doubt about the focus of the article, the full text was obtained.

Many articles that featured the word 'compassion' prominently in the title did not, in fact, subsequently discuss compassion as a clearly identified or significant subject. As an example, Howard (2012) wrote a report entitled, 'Compassion in practice nursing' however, once retrieved and read in full, the article was about the donation of blankets by a local chaplaincy

department for patients receiving end of life care. The word 'compassion' is mentioned only three times in the article and that in relation to the fact the blankets had been named 'compassion blankets'. One could argue that the whole 'tone' of the article was about compassionate care but the link to compassion, the definition of compassion and, ultimately, compassion as the focus of the article was missing. Parry's (2013) article 'Communication and compassion need time and support: Insights from end of life care' was about the Liverpool Care Pathway whilst Hill (2010) wrote about compassion fatigue and the possibility of measuring compassion in her article 'Compassion, quality and standards of care' but, not about compassion as a concept.

In many ways, such literature, and there were significant numbers of articles with 'compassion' in the title or abstract that were not then focussed on compassion, demonstrated the assumption of a tacit understanding in the professional readership. Such an assumption reinforced the premise for the study and the need to determine an acceptable definition of compassion.

All papers identified by the above process were retrieved for further scrutiny as electronic copies where possible and paper copies if not available electronically

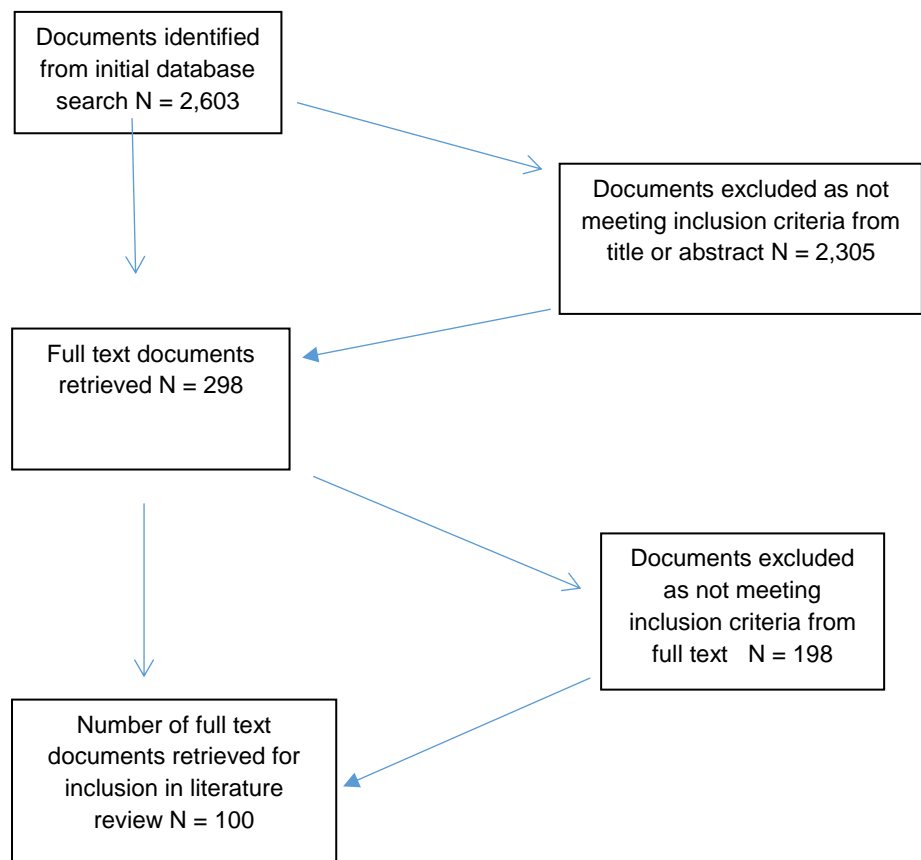
2.3.6 Review the papers for content:

The researcher then reviewed all of the full text articles to insure that these articles met the inclusion/exclusion criteria. The articles were then categorised as:-

- Meets criteria
- Possibly meets criteria
- Does not meet criteria

The supervisory team then reviewed a selection of these articles independently of the researcher to ensure that there was overall agreement that the inclusion/exclusion criteria had been met. This then resulted in the final number of studies that were analysed to complete the literature review. The 100 papers that were identified via the method described are listed and included as Appendix II. The process of determining papers for inclusion is demonstrated in the diagram that follows:

Process map of search protocol



2.3.7 Rigour and elimination of bias in the literature review

Each step outlined above has been clearly and comprehensively documented to ensure both clarity and replicability. The inclusion and exclusion criteria were discussed with and subsequently agreed by the supervisory team and the researcher and were adhered to. The supervisory team independently of each other and the researcher, reviewed a selection of the papers arrived at in section 2.3.7 above. The supervisory team and the researcher then agreed upon the final selection of papers that were included in the literature review.

2.3.8 Analysis of the Literature Review: Rodgers' approach

Schwartz-Barcott and Kim (2000) suggest that there is a need to look for the intersubjectivity of the meanings of the concept within the literature and suggest a simple format to help organise and analyse the included papers. The format suggests placing the data under one of four headings; Explicit, Implicit, Examples and Comments. However, as Schwartz-Barcott and Kim state – it is also important to examine the concept over time as well as within context and therefore the evolutionary emphasis in Rodgers' method (2000) suited this ambition more closely and has been adopted. Rodgers (1988 p, 332) stated that,

'In the evolutionary view, a concept is considered to be an abstraction that is expressed in some form, either discursive or non-discursive. Through socialization and repeated public interaction, a concept becomes associated with a particular set of attributes that constitute the definition of the concept. Concepts are publicly manifested through certain behaviours, with linguistic behaviours being one significant form of manifestation. Concepts, therefore, are generally expressed in statements that indicate what are considered to be the attributes.'

It was the aim of the literature analysis to examine the linguistic representation of the concept, to determine definition and attributes and to assess whether that representation changes over time and within disciplines and contexts.

All documents retrieved based on the process described were therefore subsequently analysed using the methodology adapted from Rodgers (2000) i.e. the content was analysed and relevant exemplars were placed within one of the five following categories:-

- **Surrogate terms**

Do other words say the same thing as the chosen concept?

Do other words have something in common with the concept?

- **Antecedents**

Which events or phenomena have been associated with the concept in the past?

- **Attributes**

What are the concept's characteristics?

- **Examples**

Are concrete examples of the concept described in the data material?

- **Consequences**

What happens after or as a result of the concept?

Rodgers (2000) instructs the researcher to read each of the included articles at least once to gain an understanding of the author's tone and of their use of the concept – to immerse themselves in the work. From this position of immersion, the researcher can then identify the data relevant to the major categories (as above). A framework to capture the data was created which allowed the relevant elements of the article to be sited within the appropriate category; the framework also included the title of the work, author and date of publication and the nature of the article – i.e. opinion piece, editorial, research study etc.

As Rodgers (2000) points out, the use of this device ensures that at the conclusion of data collection the data will already be organised by category to facilitate analyses relevant to each aspect of the concept. Based on Rodgers' suggestion for analysing the data (Rodgers in Rodgers and Knafl, 2000 p94) the following process was followed.

Each article was examined for examples of the five categories via a process of '*organizing and reorganizing similar points in the literature until a cohesive, comprehensive, and relevant system of descriptors is generated*' (Rodgers, 2000 p95). The category of related 'Concepts/Surrogate terms' was not subject to the same process as these 'typically need no further reduction, as they are recorded in simple one or two-word units of data' (2000, p95). Rodgers does suggest that these surrogate terms are viewed further in terms of the frequency of occurrence and to establish if any difference across disciplines is evident. The relevant elements of each article were then included – usually verbatim –

within the appropriate heading in the framework. '*Through such means, researchers...attempt to uncover patterns in the data analysis and allow main themes to emerge from the data material*' (Toftthagen and Fagerstrøm 2010, p24).

Where possible 'exemplars' were identified – Rodgers (2000) points out that the evolutionary method is inductive and therefore exemplars should be identified rather than constructed by the researcher. The purpose of the exemplar is to provide a practical demonstration of the concept within a relevant context. Such a device would also enable more relevant comparison with the findings from the fieldwork and assist with the aim of providing definable attributes to inform subsequent recommendations. Rogers states that the ideal exemplar is '*generic or universal enough to illustrate the concept clearly as it might appear in a variety of instances*' (2000, p96). More than one exemplar is provided where there was a need to provide clarity or to demonstrate different aspects of the concept.

2.4 Fieldwork

2.4.1. Introduction

Penrod and Hupcey (2005, p404) suggest that the 'everyday meaning' of concepts contribute to scientific *understanding* but are inadequate for scientific *enquiry* and that there should be scientific enquiry into the empirical derivation of the concept rather than '*simply accepting and integrating the contextual everyday meaning*'. However, this '*everyday meaning*' is exactly what this study is also trying to capture and so a

fieldwork element exploring the concept of compassion as experienced by those who work in healthcare and those who receive healthcare has been undertaken.

The aim of this phase of the research is to provide '*concept clarification and theoretical congruence through fieldwork in clinical settings*' (Schwartz –Barcott et al, 2002, p281). Such an approach is not unique, as early as 1982, Norris described a pioneering approach combining observing a concept through fieldwork combined with a systematic literature review. Although Beecher et al (2018) believe that this method has become somewhat redundant in contemporary approaches to concept analysis due to the volume of available literature now available to researchers and this may be why the majority of approaches do rely on literature review alone. However, it has been the ambition of this study from inception not to simply provide theoretical understanding but to explore the experience of healthcare professionals who are currently practicing and of patients who are receiving compassionate care, to place the theory in the reality of the clinical setting. This is the reason the hybrid model was selected, the aim being to use a fieldwork element as a means of '*corroborating and refining a concept by extending and integrating the analysis begun in phase one with on-going empirical observations initiated in this phase.*' (Schwartz-Barcott and Kim in Rodgers and Knafelz, 2000 p137).

In the hybrid model one fieldwork methodology that is frequently adopted is that of participant observation however, the nature of the research question in this study made this an impractical approach – what would the researcher observe? Furthermore, the concept of bracketing (which is

discussed more thoroughly in due course), highlights the need to ensure the researcher's own experience and preconceptions were acknowledged and removed as far as possible from the fieldwork. Participant observation would make this a challenging task; as far back as Benner's (1975) research as a participant observer in Intensive Care Units, it was observed that there were difficulties for both the researcher and the subject when the researcher is familiar to the subjects and with the research environment. The other, equally if not more frequently adopted methodology is that of interviews, either structured or not, as already described. However, the need to exert as little influence over the findings led the researcher to explore another option.

The use of storytelling as a research methodology has become more prevalent in recent years (Lewis 2011, Haigh and Hardy 2011, Banks 2012, Scott et al 2013, Wang and Geale 2015, Lee 2015, Nurser et al 2018) and presented a practical way to collect data. Such a method should reflect the experience of participants but enable the researcher to exert minimal influence on them. Put simply – the aim was to ask people to recount stories detailing their experience of compassion with as little input from the researcher as possible.

2.4.2 Phenomenology: the theoretical position of the fieldwork analysis

Creswell (2012) suggests that researchers should have some understanding of the philosophy that underpins the methodology they chose in order to carry out their study. Phenomenology is a qualitative

research methodology that enables the description of the meaning of the lived experience of a concept or phenomenon. Phenomenology comes from the academic disciplines of philosophy and psychology, and draws heavily upon the work of the 20th century philosopher Edmund Husserl (1859-1938), which was then later developed and expanded by, amongst others, Heidegger, Sartre and Merleau-Ponty (Spiegelberg, 1982 in Cresswell, 2012). Husserl's central tenet is the fundamental recognition that experience is the foundation and meaning of knowledge. Moustakas (1994, p26) suggests that 'phenomena are the building blocks of human science and the basis for all knowledge'. Such a position succinctly echoes the suggestion that concepts are the 'backbone of theory in practice' (Hupcey and Penrod, 2005).

Christensen et al (2010 p) suggest that the objective of a phenomenological study is to explicate the meaning, structure and essence of the lived experience of a person, or a group of people, around a specific phenomenon. The phenomenologist tries to illuminate human behaviour through the eyes of the participants and from a perspective free from hypotheses or preconceptions (Husserl, 1970). Importantly, Giorgi and Giorgi (2003 p27) emphasise the importance of capturing as accurately as possible not only how the phenomena is experienced but also the context in which the phenomena is experienced.

Two types of phenomenological approach are commonly described – hermeneutic phenomenology (Heidegger 1927, van Manen, 1990) and empirical (also known as transcendental or psychological) phenomenology (Husserl 1970, Moustakas, 1994). Hermeneutic phenomenology involves

interrogating the lived experience through the 'texts' of life and is seen as an interpretative methodology. Moustakas (1994) felt that it was important to focus less on the interpretation of the researcher and more on the description of the experiences of the participants. Heidegger (1982), however, argues that description is already interpretation and this idea will affect the approach to the chosen method, the study participants who tell their story have already therefore interpreted the experience they describe.

The data provided by the fieldwork participants has been analysed using an empirical phenomenological perspective based on the methodology of Moustakas (1994). Creswell (2012, p80) describes this methodology succinctly stating that it consists of...

*'... identifying a phenomenon to study, bracketing out one's experiences, and collecting data from several persons who have experienced the phenomenon. The researcher then analyses the data by reducing the information to significant statements or quotes and combines the statements into themes. Following that, the researcher develops a **textural description** of the experiences of the persons (what participants experienced), a **structural description** of their experiences (how they experienced it in terms of the conditions, situations, or context), and a combination of the textural and structural descriptions to convey an overall **essence** of the experience.'*

Moustakas' approach has been adopted by the researcher for this study because of the systematic way in which data can be analysed. It is important to understand a number of individual's common experience of a phenomenon in order to gain a deeper understanding of that phenomenon and such a systematic analysis supports the management of data from a number of sources. Despite the controversy relating to whether interpretation is required within analysis or whether description alone

(Giorgi 1992) will suffice the approach by Moustakas provides a clear and transparent framework. Creswell (2012 p54) states that phenomenological data analysis steps are generally similar in all approaches and both Moustakas (1994) and Polkinghorne (1989) concur. However, Moustakas (1994) also incorporates the personal meaning of the experience which resonated with the aim of this study.

Ultimately, the result of phenomenological analysis is to enable the definition of a 'single, unifying meaning of the experience' (Cresswell, 2012, p55) being examined. The idea that all experiences have an underlying and discernible structure, Cresswell gives the example of grief and that the underlying structure would be the same experience by someone who lost a child, a puppy or a parakeet! Perhaps less challengingly, Polkinghorne (1989) suggest that any reader of the research findings should be left with the feeling that they have a greater understanding of what it is like for someone to experience the phenomena – in this case compassion.

2.4.3 The researcher and the research method

An important consideration in the epistemological assumptions inherent in transcendental phenomenology is the requirement of the researcher to separate themselves from the research by suspending their own attitudes and beliefs. This is a requirement in both the collection of data and the subsequent analysis. It would also be disingenuous not to acknowledge that the researcher had opinions about the subject of compassion such that they motivated the will to carry out this study.

The choice of Moustakas' (1994) method appealed to the researcher not just because of the systematic structure. The concept of bracketing or *epoch* will be discussed more fully in Chapter 4 in relation to the findings of the fieldwork however it is a challenging concept for all researchers let alone the novice. Applebaum (2013) suggests that Moustakas is seen as a transcendental phenomenologist informed by the philosophical approach of Husserl, however, he believes this to be a problematic assumption. The very fact that Moustakas views his method as heuristic suggests that Husserl is more an inspiration than an actual epistemological foundation. Moustakas also implies that to become transcendental merely requires reflecting and setting aside bias and Applebaum feels this sets him apart from Husserl's position on bracketing. However, whilst Applebaum clearly sees this as a flaw in Moustakas' interpretation he also states that this can appear a more '*easily understandable, humanistically rendered version*' (2013, [blog]) of phenomenology.

Moustakas describes the researcher as remaining present as the person they are, that the researcher has or adds a transcendental consciousness to their personal presence by setting aside bias. That epoch and reduction is '*nothing more than the setting aside of personal prejudices*' (Moustakas 1994, p 87). It is this very 'tempering' of the Husserlian ideal that appealed to the researcher and informed the methods subsequently adopted. The beliefs and import accorded to the concept of compassion by the researcher will be acknowledged by being transparent about their experience of compassion (see Chapter 4). The data collection and

subsequent analysis will be carried out, as described, to both acknowledge and limit the inevitable experience and any bias of the researcher.

2.5 Fieldwork Phase 1 – Healthcare Staff

2.5.1 Sample strategy for healthcare staff inclusion

Sampling strategies and the size of the resultant sample in qualitative research is the subject of debate (Polit and Beck 2010, Burmeister and Aitken 2012, Trotter 2012). Curtis et al (2000) suggest that this element of the research process still, however receives less attention in methodological discussion than either data collection or subsequent analysis. There does appear to be discussion about what qualitative sampling methodology is **not** but less about what it should be (Boddy 2016, Vasileiou et al 2018, Sim et al 2018). In quantitative research, the 'gold standard' is to conduct a power analysis taking into account the theoretical framework, population size and characteristics and the subsequent statistical analysis. In contrast, qualitative researchers aim to interview to either redundancy or saturation so quantitative researchers will sample a specific number whereas qualitative research produces a process (Trotter, 2012). Adler and Adler (in Baker and Edwards, 2012 p 8) suggest a number of considerations concerning qualitative research samples and highlight that '*numerous well-respected and even classic studies have been produced using the single case study*'. However, they also describe that '*hypothetico-deductice epistemological factors*' such as the representativeness, objectivity and validity of the study need also be

considered. Reflecting the ontological stance of the researcher, that compassion is abstract, context dependent and experienced from the perspective of multiple truths it was clear that more than one participant would be required to reflect this.

Curtis et al (2000, p1003) suggest a solution to ensure adequacy in sampling is to consider the 'checklist' for qualitative sampling described by Miles and Huberman (1994). This suggests that sampling strategies should possess the following 6 attributes:-

1. The strategy should be relevant to the conceptual framework and research question.
2. The sample should generate rich information on the type of phenomena that is being studied.
3. The sample should enhance the generalisability of the findings (Curtis and colleagues qualify this by defining this generalisation as analytical rather than statistical –as in quantitative research - thus dealing with another potential criticism concerning the validity of qualitative research).
4. The sample should produce believable description/explanation.
5. The strategy should be ethical – this is explained in terms of informed consent, the transparency of risks and benefits and of the relationship between researcher and participant.
6. The method should be feasible in terms of available resources.

The sampling method employed in the study is both convenient and purposive and whilst this does not initially seem to be the basis for unbiased selection (Lucas, 2012) it represents utility and practicality.

The researcher approached colleagues based in a District General Hospital and invited them to take part in the study. Care was taken to try to ensure a range of disciplines; levels of seniority and qualification were encompassed within the sample group. The initial plan was for 20 stories from healthcare staff to be collected, a relatively arbitrary figure but one that would seem to be large enough to try to address any analytical bias and to result in enough data to allow for relevant themes to emerge as common referents. Polkinghorne (1989) recommends between 5 and 25 individuals who have experienced the phenomena but this represents a rare numerical figure in the writings on the subject of sample size.

This sampling method did seem to adhere to the principles laid down by Miles and Huberman (1994) – the sample was relevant to the research aims, all participants agreed that they had what they believed to be a relevant story, themes became apparent and repeated which would suggest the likelihood of generalisability, there was no reason to doubt the content of the stories, ethical concerns were addressed in the pre-interview information and consent was sought and the feasibility of such a methodology was apparent. In all, 22 peoples' stories were collected, this represents the number of people who agreed to participate, some of whom returned some time after the initial approach – the researcher felt that if they agreed to participate then their story should be collected even though the required number had already been reached.

To ensure that the sample was large enough to achieve the research aims the concept of data saturation was applied. The resulting stories demonstrated common themes and repetition of phraseology and content and it was decided that the number collected represented saturation and was therefore sufficient. The concept of 'saturation' is, as with all qualitative concepts of rigor and validity, the subject of debate; although Morse (2015, p587) states that it is '*the most frequently touted guarantee of qualitative rigor offered by authors*'. The very apparent commonality of experience and terminology did, however, seem to fit with the concept, one of four types of saturation, which Saunders et al (2018) describe as data saturation.

2.5.2 Data collection – healthcare staff

2.5.2.1 Method of data collection – Storytelling

Data can be collected in a variety of different ways, this often takes the form of in-depth interviews (as is common in hybrid concept analysis) but other forms of data have also been collected such as observations, poetry, music and other forms of art (Creswell, 2012, p81). van Manen (1990) also suggests poetry and novels as well as taped conversations, people's accounts of films and drama – this would seem to embrace the idea that stories could be a legitimate method of data collection.

The adoption of the hybrid model of Concept Analysis validated the inclusion of a fieldwork element of the study. Schwartz-Barcott and Kim (2000) generally advocate either participant observation or in-depth

interviews singularly or in combination as the method of data collection. However, the researcher contacted Professor Schwartz-Barcott to discuss the possibility of using stories as a data collection method within the model. Following discussion about this there was agreement that this method would be acceptable within the hybrid model and would facilitate the aim of the study.

By utilising stories where the researcher plays a very minor role the issue of *epoch* or bracketing is acknowledged and this is further supported by Mishler's (1986) contention that the question and answer method of interviewing has a tendency to suppress respondent's stories. The simple invitation to 'tell me a story' allows participants to recount the event they have selected as an exemplar of compassion in their own way, using their own words with almost no direction from the researcher.

According to Rice and Ezzy (1999, cited by Hunter 2010, p44) 'telling a story about oneself involves telling a story about choice and action, which have integrally moral and ethical dimensions'. The hope was that telling a story about oneself or others would illuminate and help define the very personal interpretation of compassion.

Participants were asked to recount a 'story' of when either they or a colleague had behaved in a compassionate way within a healthcare context. No other referents were given – the story could relate to who or whatever they wanted, they were simply asked to try and make the story last no more than 10 minutes with the expectation that most would be substantially shorter than this. This very simple format replicates that which was designed by Moustakas (1994) who suggests that research

participants are asked two broad questions – ‘what have you experienced in terms of the phenomenon?’ (Tell me a story about compassion) and ‘What contexts or situations have influenced or affected your experience of the phenomenon?’ (The story must relate to a healthcare context). The aim was to produce data that would lead to both a textural and structural description of the experience with the ultimate goal of providing an understanding of the common experience of the participants. The stories were recorded and subsequently transcribed verbatim.

2.5.2.2 Process of data collection

A Participant Information Sheet was devised (Appendix III) and given to all potential study participants to read. If they chose to take part they were asked to read and sign a consent form – both of these documents formed part of the ethics application for the study.

Those participants who agreed to take part in the study were approached and a mutually convenient time was agreed. Various locations were used to ensure a practical arrangement but all were private and steps were taken to ensure the ‘interview’ would not be interrupted.

Each recording was conducted by the same person, the researcher, and was audio recorded with a simple digital voice recorder. The same brief introduction preceded each person’s invitation to share their story – a simple run through of the basic requirements as detailed in the Participant Information Sheet and an opportunity for the participant to ask any questions – this was always also captured in the digital recording to ensure consistency. Once the participant had acknowledged that they understood and agreed to the terms of involvement the researcher simply

asked them ‘...in your own time please tell me the story that came to your mind when I asked you for an example of compassion in healthcare’

Each story was stored digitally within the memory of the voice recorder and subsequently transcribed verbatim by an audio typist. The transcriptions were then saved as word documents and these were stored securely on a password-protected computer by the researcher. It is these transcripts that represent the data for the healthcare staff focused fieldwork element of the concept analysis.

2.5.3 Data analysis – healthcare staff

The initial plan was for the stories to be analysed using the same methodology as that of the literature – the Rodgers (2000) evolutionary method. However, as the researcher became more familiar with the emerging data it became apparent that this structure was more suited to analysing literature rather than narratives. The emphasis on identifying exemplars, for instance, the purpose of which ‘*is to provide a practical demonstration of the concept in a relevant context*’ (Rodgers 2000, p96) is redundant when each individual story represents an exemplar.

As outlined previously, Moustakas (1994) developed a methodology for analysis, which fitted the aims of the fieldwork, to focus less on interpretation (as Rodgers would have it) and more on ‘*a description of the experiences of the participants*’ (Creswell 2012, p150). Moustakas modified an earlier methodology by van Kaam (1966) to form the following

structure to analyse transcribed 'interviews' and this has been adopted as the method to analyse the transcription of the stories collected.

The Moustakas modification of van Kaam's method is outlined below:-

1. Listing and preliminary grouping:

Every expression that is relevant to the experience is listed. Significant statements, sentences or quotes that provide an understanding of how the participants experienced the phenomenon are highlighted. Moustakas calls this step 'horizontalization'.

2. Reduction and elimination:

This step determines the 'invariant constituents' by testing each expression for 2 requirements –

- Does it contain a moment of the experience that is both necessary and sufficient to understand it? and
- Is it possible to identify and label it?

If so then it is a 'horizon' of the experience.

Expressions that do not meet the requirements are eliminated.

Overlapping, repetitive or vague expressions are either eliminated or presented in more exact descriptive terms. The horizons that remain are the invariant constituents of the participant's experience.

3. Clustering and thematising the invariant constituents:

'cluster' or group the identified invariant constituents that are related into a thematic label – these then represent the core themes of the experience.

4. Final identification of the invariant constituents and themes by application (validation):

Check the invariant constituents and themes throughout the entire transcript of each participant to ensure that they are expressed explicitly or are at least compatible. If they are not then they are not relevant and should be discarded.

5. Individual textural description:

Using the established, validated invariant constituents and themes for each participant construct an individual textural description of the experience, **what** the participants experienced - this should contain verbatim examples from the transcript.

6. Individual structural description:

How the context or setting influenced how the participants experienced the phenomenon.

7. Textural-structural description:

The meaning and essence of the experience that incorporates the invariant constituents and themes.

Finally, from each of the individual textural-structural descriptions a composite description of the meanings and essences of the experiences of all of the participants can be developed. An example of one story (#5) has been included as Appendix IV with the horizons highlighted to demonstrate the initial process.

Individual textural description involves the researcher reflecting on the phenomenon and ensuring they exercise the concept of 'Epoche' or bracketing (setting aside pre-judgements and being both receptive and unbiased). Moustakas (1994, p96) states that what is required to construct the textural description begins '*with Epoche and going through a process of returning to the thing itself, in a state of openness and freedom, facilitates clear seeing, makes possible identity, and encourages the looking again and again that leads to deeper layers of meaning*'. The researcher attempted to ensure their own preconceptions and *a priori* understanding of compassion did not impact on those telling their story or on the subsequent analysis. However, it would be both disingenuous and lacking in rigor and transparency to ignore the possibility of researcher impact and bias. This will be discussed further in section 2.8 and in the analysis of the findings of the fieldwork research.

Whereas the textural description of the account focusses on **what** the participant experienced, the structural experience is concerned with the **context** in which the participant had the experience (Moerer-Urdhal and Creswell, 2004). Structural description focusses on '*the underlying and precipitating factors that account for what is being experienced; in other words the 'how' that speaks to the conditions that illuminate the 'what' experience*' (Moustakas, 1994, p98).

Moustakas (1994, p98) discusses the use of what he calls 'Imaginative variation' as a means to 'arrive at a structural description of an experience'. This process is designed to help capture what Husserl described as the 'essence' of the experience (Giorgi, 2009). Giorgi

describes imaginative variation as a way of changing the qualities of the object being analysed to establish which qualities are essential and which incidental. van Manen (1990) suggests removing a theme and then asking if the essence of the phenomenon withstands. Merriam (2009, p26) suggests it is a way of viewing the data from varying perspectives to see 'all angles as if one is viewing a 3-dimensional work of art'. An example might be that cited earlier when Creswell (2012) suggested that there was an underlying structure of grief no matter what the underlying cause.

Within the structure of many of the 23 stories that were collected the use of this device was problematic – it appeared that the story was so explicit that the individual experience did not require further imagination to explicate the essence of the phenomenon. In fact, following discussion within the supervisory team, it was felt that the use of this element of the methodology may in fact serve to lose or impede clarity – it felt as if the data was being manipulated to fit the method rather than the method highlighting the findings within the data. Moustakas's methodology was therefore modified (a precedent already set by Moustakas himself) to simply ask the question, as per van Manen (1990), i.e. what elements of the story would remain when any one of the themes were removed? - this then helped to exemplify the essence of the phenomenon. This modification also served to acknowledge Heidegger's premise that 'all description inevitably involves interpretation' (Davidsen 2013, p322) – the storytellers recounting of their experience of compassion **was their** interpretation, to reduce that or 're-imagine' it could only risk changing the essential essence that the fieldwork study was trying to capture.

Moerer-Urdahl and Cresswell (2004) describe this overall process and argue that there needs to be a 'thread' to connect the significant statements, units of meaning and finally the essence and that this then results in a 'composite description of increasingly general meaning'(p. 24). The concept of epoch is also important when analysing the data from the stories, the need for detachment free from bias or assumptions (Gill, 2014) also informed analysis. Each story was summarised by clustering the invariant constituents in to thematic labels which were then combined to form the composite description of the meaning and essence of the participants' experience. The simple expediency of citing the number of times a descriptor was mentioned by participants served to both provide the thread to connect the experience of the participants but also strengthened the 'interpretation' of the relevance of the descriptor as unaffected by any preconceptions of the researcher.

Once again, care needed to be taken to ensure the voice of the storyteller remained clear and that the 'increasingly general meaning' was identifiable in the texts and not as a construct of the researcher. Some of the stories were very short and the identified themes were so evident that the textural and structural descriptions were essentially redundant in terms of helping to explore the concept – no further reduction was necessary.

Once each story had been analysed using the methodology outlined above all of the individual textural-structural descriptions were combined to form a composite description of the meanings and essences of the experience which will represent the group of study participants as a whole. When using stories as the data collection method it became apparent that

it was in this final step that the representation of the textural and structural elements could be of greater use. Whilst it was challenging to take a short account and assess the impact of context or experience on the phenomena without the risk of becoming overly interpretative, the body of data as a whole, lent itself much more to such exploration.

2.6 Fieldwork Phase 2 – Healthcare (Patients and Carers)

2.6.1 Background

An explanation of the need for a further fieldwork element is presented in Chapter 5 of this study. The initial plan to include healthcare workers' experiences reflected the work completed as part of the researcher's MSc which explored the attitudes and opinions of healthcare staff. However, the inclusion of only professional literature and then the collecting of stories from healthcare staff felt as if the evidence being uncovered was at risk of becoming one dimensional. Qualitative research should be both a reflective and reflexive process (Finlay and Gough 2003, Attia and Edge 2017, Reid et al 2018) and the possibility of a bias in the research caused disquiet in the researcher and was the subject of discussion with the supervisory team. As a result it was decided that balance and further insight would be important and possible if stories were also collected from patients. Once the stories from healthcare staff had been collected and analysed the next phase of fieldwork was undertaken.

2.6.2 Method for Phase 2

The aim was to follow the same methodological framework as that employed in the collection and analysis of the stories of Healthcare staff. However, as the participants were to be health service users there were obviously some differences in the sampling approach. Ethics approval was sought and granted for this next phase of the study from the academic institution supporting the research but not from the National Health Service (NHS), which was a departure from the previous field research. Rather than restrict recruitment for the study to patients cared for within the NHS it was felt that any care setting would be relevant to the aim of the study.

2.6.3 Sample strategy for healthcare patients and carers

As described in the previous section, sampling is a contentious subject in qualitative research. In 2015, Gentles et al described the ambiguity and inconsistency relating to sampling in qualitative research studies. Indeed, they cite van Manen (2014) who suggests that the commonly held concept of sampling is not compatible with phenomenological enquiry. Further defending the position van Manen states, "*the term sample should not refer to an empirical sample as a subset of a population. This use of the notion of sampling presupposes that one aims at empirical generalization, and that is impossible within a phenomenological methodology*" (p352).

van Manen (2014) preferred the term 'examples', however, whether an example or a sample, a selection of patients was required to provide data for analysis and comparison so a sampling strategy was required.

Once again, the 'checklist' for qualitative sampling described by Miles and Huberman (1994) was employed to try to confer as much rigour as possible to the sample selection process. Access to patients who had received healthcare was the key challenge and would need to ensure relevance to the research question, the generation of rich information related to the phenomena that was believable and was both ethical and feasible (Miles and Huberman, 1994).

The proposal was to identify service users by approaching local patient support groups and asking volunteers to agree to recount a story of their experience. Patient support groups within a defined geographical location (within the West, South and East of the county where the researcher resided – incorporating three large urban areas as well as a large rural component) were identified via an internet search. The internet search simply stated 'Patient support groups' followed by the defined area. The support groups were selected based on geographical utility as it was anticipated that the researcher would have to travel to the support group venue in order to record the stories. The search was iterative as some support groups were identified but these were national organisations without a 'local' branch, however, the specific health need that the group represented was added to the search term and this often generated a local 'version' of a group. As an example, there is a national charitable support web site for those who have Multiple Sclerosis but a specific search

subsequently identified a local (within 10 miles) support group for those diagnosed with the disease.

The volunteers needed to have been the recipient of either in-patient or outpatient health care – no time limit was specified as it was evident from the health professionals' stories that a number related to events that had happened many years previously. No restrictions were placed on the location of the care environment either – National Health Service or private health care establishments would be acceptable. The requirement was to identify an episode of interaction with healthcare staff that defined compassionate care for the storyteller whenever or wherever that occurred.

By sending an invitation letter to the identified contact for each group for them to disseminate amongst group members the researcher would exert no influence over who would be included in the study – participants would volunteer and would subsequently then be sent further details. In anticipation that the 'general public' may not be clear as to what constitutes 'compassionate' practice the initial invitation letter (see Appendix V) also gives the surrogate terms of 'care' and 'kindness' as these had been identified as such in the stories of the healthcare professionals.

The support groups were identified and an email was sent inviting participation. Initial responses were limited to requests for further information, which was then sent in the form of the Participant Information Sheet (PIS) (Appendix VI). The groups identified included 'general' support organisations i.e. Age Concern and the Carers Association where

there was a local branch as well as support groups for more specific conditions i.e. Ileostomy Association, Cardiac support group, Stroke Association, Bereavement support, Baby Loss support group among others.

Not all respondents who asked for further information subsequently took part in the study – once sent the requested information no further direct follow-up was carried out

It is to be noted that not all patients included in the sample volunteered via the initial contact with the support groups. There was an element of snowball sampling whereby early participants subsequently contacted the researcher and suggested that they had friends or family members that would be willing to share a story of their experience within healthcare. Snowball sampling may be defined as *'any type of sample recruitment strategy, whereby all or a portion of participants who are asked to provide data are not directly recruited by the researcher but through other persons who connect them to other persons as participants'* (Marcus et al 2017, p636). Discussion within the supervisory team about the validity of such participation did not identify any conditions or concerns that were felt to affect validity. Marcus et al (2017) suggest that there could be issues in snowball sampling with such confounding elements as data fabrication or lack of generalisability, however, as patients are recounting stories of their experience as they recall it these concerns were felt to be unfounded in this study. Therefore, those stories (3 in total) collected via this method were recorded and included.

2.6.4 Data collection for healthcare patients and carers

Once a service user chose to take part, an individual contact, mode of their choosing (telephone, e-mail etc.), was undertaken to arrange a convenient time and location for the story to be recounted. Each story was again audio-recorded by the researcher and stored digitally within the memory of the voice recorder; an audio typist subsequently transcribed these verbatim. The transcriptions were saved as word documents and stored securely on a password-protected computer by the researcher. These transcripts represent the data for the patient focused fieldwork element of the overall concept analysis.

2.6.5 Data analysis for healthcare patients and carers

Each story was transcribed and the transcriptions were subjected to the same analysis methodology as that used for the Healthcare staff's stories – see above. Clearly, in order to collate the fieldwork the methodology and analysis had to be carried in as similar way as was possible. The resulting data analysis and findings are detailed in Chapter 5 of this study.

2.7 Ethical considerations relating to the Concept Analysis

The principles of biomedical ethics proposed by Beauchamp and Childress (2013) will be used to give structure to the description of the ethical concerns that were apparent when designing and carrying out this research. The principles, based on a distillation of deontological and utilitarian philosophical ideas are autonomy (to respect the individual), beneficence, non-maleficence (to do good and not to cause harm) and

justice. Guillemin and Gillam (2004) make the distinction between procedural ethics (gaining approval) and process ethics that underpin the conduct of the study. Therefore, the 4 principles as ascribed to Beauchamp and Childress (2013) will be applied to these 2 distinct phases and will be addressed to each element of the study.

2.7.1 Ethical considerations within the literature review:

The first consideration for ethical research is to establish how it will build upon that which has already been done, that it will add something to what is already known. Procedural ethical approval was granted for the research (see 2.7.2) based on the submitted proposal. Vergnes et al (2010) suggest that ethical considerations when reviewing literature are rarely touched upon. Ensuring that the literature reviewed is as exhaustive as possible and the process is transparent will result in any reader being able to follow that process and determine for themselves if it is valid, it would also ensure replicability. Thomas et al (2015) describe a single example of a research assistant and a specialist librarian both doing a similar literature search and producing very different outcomes and suggest that this means that variance is possible and all relevant literature may not be captured. The literature review undertaken for this study does not claim to be exhaustive but does include a significant volume of literature and generated data sufficient to enable repeated and obvious themes to emerge. As such, this approach responds to the concept of justice, ethically the process is as fair, open and transparent as possible.

There is some debate about including research studies in a literature review when clearly the review is not part of the consent process for the original study participants (Vergenes et al 2011) but all studies included were in the public or professional domain. No results of the studies have been reinterpreted or used in such a way as to invalidate or discredit the findings. Wagner and Wiffen (2011) also describe the need to ensure that the literature included is clearly attributed to the original authors and that replication of very similar evidence should be avoided. These authors also describe the need to ensure any competing interests and sources of funding are clearly identified.

2.7.2. Ethical considerations within the Fieldwork

The first phase of the fieldwork element of the study gained ethical approval from both the Higher Education Institute under whose auspices the research is being conducted and the National Health Service Trust who employed the staff members who volunteered to recount their stories of compassion. It was demonstrated to the satisfaction of the research ethics committees of both organisations that the study has the potential to add to current understanding of the research question and that this could subsequently be of benefit to healthcare providers and patients. As the same methodology and analysis was adopted for the proposed next phase of the study, the same ethical considerations and principles to establish rigour and validity were replicated. Ethical approval was again sought and granted by the Ethics Committee of the Higher Education Institute. As such, procedural ethical considerations were agreed based on the rigorous standards of 2 separate organisations.

This study represents a minimal level of ethical concern, this can be equated to the idea of 'minimal risk' which is defined as that which represents the likelihood of any harm or discomfort being no greater than that usually associated with daily life (Wada and Nisker, 2015). However, no study can or should be undertaken without considering what challenges may be present.

2.7.2.1 Justice and Autonomy

Although no influence from the researcher was exercised in terms of participant selection, it is acknowledged that healthcare staff were recruited from the same organisation where the researcher also worked. In order to address any possible power imbalance that might influence recruitment, the researcher approached a significant number of staff and supplied relevant information. Karnieli-Miller et al (2009) suggest that ensuring any possible participants are in possession of all relevant information will redress potential power imbalance between researcher and recruit. The researcher did not follow-up any of the healthcare staff who took information sheets and relied upon those who wished to take part contacting the researcher. This ensured that no coercion or undue pressure was applied to any possible recruit to the study.

Whilst the researcher did not influence the selection of the patients, the geographic area of contact for the patient support groups selected and, indeed, potentially the use of such groups will influence the demographic of the respondents.

The presence of the researcher during data gathering can affect participant's response and issues of confidentiality and anonymity can be

problematic (Anderson 2010). The use of the storytelling method has tried, as far as possible, to reduce the effect of the researcher on the participants. The transcribed stories were stored securely and, whilst some stories and a significant number of examples from the texts are cited to support the findings of the study, this has been done with caution to ensure no identifying features of participants are revealed. Any identifying details contained within them would not be available to any but the researcher, audio typist and the supervisory team therefore the anonymity and confidentiality of the participants has been maintained.

2.7.2.2 Beneficence and non-maleficence

When recounting stories, some healthcare professionals did become emotional however, this was proportionate to the story being recounted and often seen as a positive reflection of how moved they were by the memory. If any participants became distressed and requested it or the researcher felt it expedient, the recording was suspended and this consideration was made clear to all prior to the commencement of the recording. The researcher is a registered health professional and therefore bound by their professional Code of Conduct (NMC, 2018) and this informed their interaction with the study participants. In relation to the patient group, the facility for onward referral to either the participant's own General Practitioner or back to the support group as appropriate was available. The Participant Information Sheet explained the study and included the rights of the participants to withdraw at any time, to have their contribution removed where possible and to receive appropriate support if needed.

Following the completion of the recording of the story the researcher offered time for the participant to ask any questions about how their story will be used or, indeed, any other aspect of the study. The aim of the study was reiterated and the participant was offered the opportunity to receive a copy of any subsequent published material that results from the study. All participants had the researcher's contact details and those of the Director of Studies and were informed that they could make contact with either of these people to discuss any concerns that may arise.

2.8 Rigour

2.8.1 Within the fieldwork phase

Qualitative research is 'heavily dependent on the individual skills of the researcher and more easily influenced by the researcher's personal biases and idiosyncrasies' (Anderson 2010, p2). The researcher in this study is undeniably a novice and this can obviously be seen as a limitation, however, regular and structured support from expert supervisors has ensured rigour in process and validation of results. As with the literature review, transcripts from the stories from both healthcare staff and from patients (1 from each) were independently reviewed by a member of the supervisory team. The same transcripts were also reviewed by the researcher and both they and the Supervisor carried out horizonization (see section 2.5.3) of the content and identified the invariant constituents. Discussion subsequently highlighted areas of agreement and the, few, areas where similarities had not been identified. Sandelowski (1993)

suggests that such peer checking may not be the best way to ensure reliability but this was within a critique of the concept of reliability and she further states that neither peers nor participants (member checks) could be expected to arrive at the same themes and categories as the researcher. Sandelowski (1993) felt that the aim should be trustworthiness and that this was a theoretical construct based on each individual study. However, for pragmatic reasons of resource member checking was not an option and therefore the expedient choice of peer (or expert) checking was employed. This provided some measure to mediate personal bias and ensure a degree of trustworthiness within the data analysis.

No time limit was imposed on the stories recounted and this means consideration must be given to the possibility of recall bias if stories are remembered from a time distant to the recoding of that recollection. Hassan (2006) suggests that to avoid such bias consideration should be given to the data collection method and suggests a well-structured questionnaire or blinding subject and interviewer – but this was clearly not appropriate in this instance. Recall bias can be a limitation in any retrospective study that relies on self-reported data (Althubaiti, 2016) however when utilising stories as the methodology such bias, whether intentional or unintentional, may not be a limitation but a validation of the participant's perspective. As Richardson et al (2009, p3) suggest '*that accuracy of recall is less important in qualitative research than the meaning of the story*'. The phenomenon under investigation is the lived experience of the participant and however they choose to recall this it is their story and therefore valid.

2.8.2 Rigour and reflexivity within the study

Mortari (2015) describes how researchers who aim to be reflective in their approach do not merely report the findings of the research but they also question and explain how the findings are constructed. The idea of reflexivity requires a '*process whereby researchers place themselves and their practice under scrutiny*' (McGraw, Zunkovic and Walker, 2000).

Dowling (2006) suggests that self-reflexivity is not an introspective process based on an isolated and private contemplation but always involves an intersubjective process considering the tension within the researcher as both subject and object. Dowling (2006) believes that this tension needs to be addressed within a supervisory relationship.

Dowling (2006) further describes a number of different types of reflexivity – the first being that which is aimed at ensuring objectivity. Dowling cites Koch and Harrington (1998) who describe Husserlian bracketing as a version of such reflexivity. The nature of compassion and the researcher's own views and experience of compassion were discussed within the supervisory meetings. The idea suggested by Creswell (2012) of describing the researcher's own story of compassion was discussed and it was felt that including the account along with that of the experience that motivated the research might add to the idea of transparency.

Rolfe (2006) describe the use of an audit trail and Sandelowski (1986) a decision trail so that any reader might be able to track and verify the research process. The researcher was supervised by both a Director of Studies (DoS) and a 2nd Supervisor throughout the research process

detailed within this thesis. Each meeting between the researcher and the supervisory team was documented with notes made within the meeting. Subsequently, a record and action plans based on these contemporaneous notes were completed by the supervisor and sent to the researcher and DoS with agreed time spans and dates for future meetings. In between these meetings email and Skype conferences were also held to address questions and to provide supervision and direction. Skype meetings were followed up with email confirmation of content and all emails were retained and filed.

Wall et al (2004) propose 3 phases of bracketing, pre-action, in action and on action. The aim of the regular meeting was to enable consideration of how the researcher would approach, conduct and then reflect on each element of the research process. Van Manen (1984) describes the need to resist personal judgement and that to achieve such 'indifference' the researcher needs to address and record their own beliefs and biases. Significant discussion was given to the search strategy for the literature review which without pretension to be exhaustive did meet the criteria of transparency and replicability. Perhaps the most notable impact of the reflexive and iterative nature of the research based on supervision and subsequent reflection was that which resulted in the second phase of the fieldwork element of the study.

The growing acknowledgement that the researcher had pre-judged the utility of collecting stories to provide the necessary fieldwork element of the hybrid concept analysis (Schwartz-Barcott and Kim, 2000) was addressed within the supervisory meetings. Dowling (2006) suggests that

epistemological reflexivity requires the researcher to ask how the research question might have been investigated differently and encourages the researcher to reflect upon their assumptions and how these may impact on the study and the findings. It became apparent that the researcher had believed that stories from healthcare staff would provide enough data to demonstrate the lived experience of compassion in healthcare. During the collection of these stories the researcher and the supervisory team identified an emergent theme and that was a disquiet at the absence of the patient voice in the fieldwork. Further discussion ensued and it was during these sessions that the idea of adding a further fieldwork element to the study arose. This example acts as an exemplar for the iterative and reflective nature of the decision trail that was recorded and highlights the need to identify and acknowledge what Manias and Street (2001) describe as a researchers' own 'taken-for-granted' values and judgements.

Whiteley (2012, p219) describe an audit trail as comprising of '*evidential accounts of contacts, procedures, problems and decisions*'. These can take the form of written accounts and emails but also iterations of the thesis with comments and track changes. Throughout the period of the study a number of different iterations of the thesis have been reviewed, commented upon and subsequently amended. Whiteley (2012) also highlights that an audit trail can provide a '*continuous stream of records of activities, decisions, dilemmas and seemingly mundane accounts of successful and unsuccessful communication with target organisations and respondents*'. All correspondence and emails between those who participated in the fieldwork at both organisational and participant level

have been retained and marked with appropriate versions where content changed in any way.

Finally, self-reflection such as that described above was fully supported with critical discussion and debate within the supervisory meetings. Always having 2 supervisors meant that any difference in approach or opinion could be moderated and, whilst the researcher takes ultimate responsibility for the conduct of the study this process provided both balance and expertise.

Chapter Three

Literature Review

‘I would rather feel compassion than know the meaning of it...’

Thomas Aquinas (1225-1274)

3.0 Summary of Content Chapter 3

Chapter 3 presents the first element of the Concept Analysis, a comprehensive review of relevant, professional literature. This review has been updated to include an examination of how the literature has evolved over the period of this study. Compassion, as described in the literature is presented following analysis using the framework described by Rodgers (2000).

3.1 Introduction

The premise behind this research study is that, contrary to Aquinas’s compelling thought, it may be necessary to know the meaning of compassion in order to be able to better understand and, even, teach it. According to Lingard (2018), the purpose of a literature review is not to report what is known about a topic; the purpose is to identify what remains unknown - thereby establishing the need for further research. Hart (2018, p31) suggests at least 12 criteria to demonstrate the purpose of a literature review with perhaps the most relevant to the aims of this study being *‘synthesising and gaining a new perspective’*, *‘enhancing and gaining the subject vocabulary’* and *‘having a body of knowledge to which you can relate your own research findings’*, although all 12 criteria have a degree of relevance. Schwartz-Barcott and Kim (2000, p135) state that

'ultimately, the goal is to gain comprehensive command of the literature dealing with the concept and to acquire a deep grasp and understanding of it as it has been used across disciplines and over time' The literature review was conducted to enable an exploration of how compassion in healthcare is described and analysed within contemporary, professional literature and, to establish if what Giltrow et al (2014) describes as a knowledge deficit exists in relation to compassion in healthcare. The method used has been described in Chapter 2, this Chapter will therefore present and explore the findings of the literature review. The main body of the chapter comprises the findings of the initial literature review that was conducted in the early stages of the study, the latter part of the chapter details the rationale and findings of an update to this review.

3.2 Findings

When describing the method for interpreting the results of a literature review Rodgers (2000, pg 97) states that the findings *'may be viewed as a powerful heuristic, promoting and giving direction to additional enquiry'*. The purpose is not so much to provide a definitive notion of the concept but rather to provide a foundation and greater clarity for continued development of the concept. The suggestion is that interpretation takes two approaches; to shed insight on the current status of the concept and to identify any gaps in knowledge – as Lingard acknowledges, the justification for any research is not simply to confirm what is known but to determine what is not (2018).

The findings are presented here in 5 sections corresponding to the associated categories within the data framework with a concluding section to both act as a cohesive overview but also to identify implications for the subsequent elements of the study.

3.2.1 Introduction to the findings:

Following the method outlined in Chapter 2, 100 articles were identified and included in the review; these are classified as follows:

Place of publication	N =	Type of article	N =	Year of publication	N =		N =	Discipline	N =
UK	54	Editorial	6	2004	5	2010	3	Nursing	49
N America	30	Opinion/Article	48	2005	3	2011	13	Medicine	11
Australia/New Zealand	5	Qualitative study	24	2006	5	2012	13	Healthcare generally	34
Western Europe	6	Quantitative study	5	2007	7	2013	24	Allied Healthcare Professionals	3
Canada	3	Review/Report (of e.g. new guideline)	12	2008	6	2014 (incomplete)	8	Mental Health	2
Other	2	Other	5	2009	13			Other	1

Table #1 Breakdown of articles included in the literature review 2004-14.

Over 50% of the included literature was from the United Kingdom followed somewhat behind by the United States – together these two countries account for over 80% of the included material. It is to be acknowledged therefore that this literature review will demonstrate an understanding of compassion from a distinct perspective – such a predominance of data from two areas will influence the findings. The search criteria stated that work had to have been published in English, this obviously resulted in the

distribution of articles with a bias toward the USA and UK; the relative paucity of literature from Australia, and New Zealand is perhaps not fully accounted for by smaller population numbers.

Nearly half of the included papers were either editorial, discussion or opinion pieces whilst 29 were research articles. Such bias towards opinion as opposed to research findings is likely a reflection of the lack of clear definition as to what constitutes compassion – it would seem a pre-requisite to any research about compassion that there is a clear understanding of the research topic. The research base for compassion in the reviewed literature is discussed further in section 3.1.2.

The literature has been included from a search encompassing 10 years from 2004 until the first half of 2014 however the papers are predominately from the latter half of this period, 26 from 2004-2008 and 73 from 2008-2014. This rise in numbers is perhaps reflective of significant events in the UK that resulted in a contemporary increase in literature concerning compassion. In 2008 the public became aware of significant failings at the Mid-Staffordshire NHS Trust, concerns highlighted the previous year but which only gained publicity following the publication of the Healthcare Commission (2008) report on the concerns. The subsequent reports by barrister Robert Francis in 2010 and 2013 attracted widespread coverage in the national media but also within healthcare related literature. As a result, at least in part, due to the increased concern about the perceived failings in compassion highlighted by these reports, the Department of Health responded with 'Compassion in Practice' (2012). In the same year,

the way nurses were educated was also scrutinised; the impact of Francis resonated here too – the Willis Commission’s report is entitled ‘Quality with Compassion’ (2012).

The noticeable increase in journal articles seemingly about compassion reflects the timing of the publication of these reports. This also influences the type and the relevance of the literature as, somewhat ironically, the increase in search findings based on ‘compassion’ being highlighted in title or abstract was not reflected in the subsequent inclusion in the review. Many articles that had ‘compassion’ in the title were concerned with the reason for or impact of these reports and discussed this rather than the concept of compassion as a subject. The inclusion of the word ‘compassion’ in the title of these reports was the driver for the large numbers of articles returned in the search. Once again, the expectations of the authors of these articles was clearly that compassion was known and understood as a concept as little space within articles was dedicated to explanation or exploration of the concept.

The publication of these reports and guidelines may also account for the prevalence of literature relating to nursing in the review with half of those included being specifically identified as having a nursing focus. A third related to healthcare, including nursing in general, 11 were medicine specific articles. This would also seem to reflect the response to Francis (2010, 2013) which appeared to result in a significant impact on nursing in terms of policy and guidelines but not to the same extent on medicine or the allied health professions.

3.2.2 The research base

Aveyard (2014) describes the need to ensure that all literature included in a review is critically appraised and that inclusion is therefore justified. This study seeks to establish a definition of compassion as a concept; the assumption and preliminary research that drove the study and the subsequent research question is that compassion is not widely studied and that those studies that do exist do not seek to specifically define compassion. It was therefore anticipated that a significant amount of literature would be based on opinion, commentary or would be reports or reviews of policy initiatives and this has proved to be the case. The inclusion and exclusion criteria and transparency in the process followed in order to establish which literature qualified for inclusion hopefully ensures the validity of that inclusion.

However, 29 of the papers included in the literature review were research studies. It is significant to note that whilst 22 of the included research studies specifically mention compassion in the study title or specific research aims, the remaining 7 included studies did not. Whilst these, as with all 29, still obviously met the inclusion/exclusion criteria, all of them also identified compassion as a relevant, significant and meaningful element of the research findings. For instance, the study by Greenfield et al (2008) looked at the meaning of 'caring' to 7 novice physical therapists. Not only did this study find that compassion was a key component of caring and healthcare practice as a whole but the words 'compassion' and

'caring' appeared to be used synonymously throughout large sections of the study.

Two studies are also worthy of specific note in terms of this research, firstly Schantz (2007) carried out a concept analysis looking at compassion and this work should be acknowledged as having a similar title and intent to this study. However, the analysis is now 12 years old and used the Walker and Avant (1995) methodology for concept analysis with subsequent clarification via Rodgers's evolutionary paradigm (Rodgers and Knafl, 1993). Schantz's analysis was based on a literature review of a single year's publications, in this case 2004-2005. It was somewhat unclear from the published findings of the analysis how the literature had informed the findings, however a very well described model case was presented. Despite any possible methodological flaws with the work, subsequent authors have cited it frequently and this alone would seem to justify inclusion in this study, which seeks to establish how literature has influenced definition and understanding of the concept of compassion.

Secondly, the 2011 study by van Der Cingel, '*Compassion in care: a qualitative study of older people with chronic disease and nurses*' did present a definition of characteristics which defined compassionate practice following analysis of interview transcripts from 30 nurses and 32 patients. van Der Cingel's study, more than any other included, contains similar outcome measures to this research project however, there are also enough differences in methodology and certainly in scope to justify the

continuance of this research as an allied and complementary addition to the research body.

The opinion-based literature included in the review represents the 'zeitgeist' of the published view of compassion during the review period. By definition, whether valid or not the opinions were expressed in professional journals and therefore affect the views and understanding prevalent at the time. However, research studies represent a different criterion – these present the findings of the research and therefore claim to demonstrate verifiable facts. Research studies therefore do need to be valid and need to stand up to critique.

Smith and Noble (2016) suggest that the need to evaluate research is best achieved by the use of a quality appraisal tool as this provides structure for the evaluation. The Critical Appraisal Skills Programme (CASP) is widely described (e.g. Smith and Noble 2016, Aveyard 2014, Harrison et al 2017) as a credible checklist to determine the validity of a study and has a number of different editions based on the specific study approach (Critical Appraisal Skills Programme, 2018). The qualitative checklist has 3 sections - are the results of the study valid, what are the results and will the results add to the research being undertaken? These 3 sections take the form of 10 questions, the first 2 are screening questions and if both can be answered 'yes' then it is worth continuing with the remaining questions in the list. A checklist such as that designed by CASP is especially helpful to the novice researcher; Aveyard (2014) suggests that those new to research may accept any literature, especially if published in

a reputable journal, without the necessary critique. Such an uncritical approach would obviously reduce the impact and utility of the research included to support the subsequent findings of the literature review. When combined, as in this review, with opinion and editorial articles there could be a tendency to be less rigorous in interrogating the research, however this would seem short-sighted and an acceptance of poor review standards.

The 29 studies predominately utilised qualitative research methods including grounded theory, focus groups, observational and concept analysis approaches – this accounted for 24 of the studies, a further 5 used quantitative approaches. The quantitative methods used were 3 surveys, 1 rating scale and a study which researched the physiological impact of a compassion intervention (on heart rate and blood pressure). All of the qualitative research studies included in the literature review passed the first 2 questions in the relevant CASP checklist and were therefore deemed worthy of further consideration. These 2 questions could also be applied to the studies that were not qualitative as a measure of potential validity and all of the remaining 5 studies also met these criteria. Utilising the CASP checklist the qualitative studies were reviewed for adherence to the remaining 8 questions and related prompts to establish whether they subsequently met the criterion for inclusion. All, with the exception of the Schantz study as discussed above, did meet the standard within the checklist.

Heal and Twycross (2015) advise that quantitative research needs to demonstrate not only meaningful results but also rigour in methodology and that this can be measured in terms of validity and reliability. The 4 quantitative studies that used either survey or rating scale as the research instrument described the development of that instrument, strategies to reduce bias, clarity in recruitment strategy and could demonstrate significance in findings. All 4 described the approach to developing the instrument to ensure that it measured what they intended to measure – so called face validity – and to measure the whole extent of the aims of the study – content validity. Finally, construct validity appeared to have been addressed in all 4 studies by the justification and explanation of the results obtained by using the described research instrument. Little was included in any of the studies about the reliability of the instruments but neither did they record any failings or concerns in consistency, stability or equivalence. None of the 4 studies appeared to represent concerns in validity based on the information included in the reports, there was not enough concern about reliability to warrant exclusion.

The final quantitative study, by Kemper et al (2012) assessed volunteers' responses to 4 different non-verbal compassionate interventions – either 10 or 20 minutes of either tactile contact or no contact but presence – for all participants the practitioner meditated on loving kindness towards the subject. The subjects were randomized to one of the groups and blinded to the meditative intent, having been told that the study was testing the effect of time and touch on the autonomic nervous system. All interventions resulted in significantly decreased heartrate and blood

pressure ($p < 0.01$) 'with generally greater effects for the tactile than non-tactile strategies and for 20 minute than 10 minute doses'.

All of the included research articles were scrutinised to a reasonable level in terms of the nature of the concept under examination (compassion, arguably, does not require the level of scrutiny of a medication trial for instance) and the aims of the literature review. None of the 29 studies were excluded as a result of concerns about the credibility or value of the research presented.

3.2.3 Findings from the literature analysis:

All of the literature included in this study was analysed using the framework described in Chapter 2, a section of this framework has been included here as Appendix VII to enable scrutiny of the process. The findings of the analysis will be presented in 5 sections which correspond to the 5 sections of the framework. Schwartz- Barcott and Kim (2000) describe the notion of 'intersubjectivity' and Rodgers (2000, p41) cites the idea that concepts can be publicly manifest and that linguistic behaviours are '*one significant form of manifestation*'. Rodgers (2000, p41) also suggests that '*the intent of the analysis is to identify a consensus, failure to incorporate occasional extraneous bits of information along with predominate themes is not a cause for great concern*'. In order to ensure that this shared understanding and consensus is achieved the data framework was reviewed for what Vaismoradi et al (2013, p 400) describe as '*trends and patterns of words used, their frequency, their relationship*'.

The use of verbatim quotes within the framework and in the analysis serves to add context and relevance.

3.2.3.1 Surrogate terms/allied concepts

As suggested by Rodgers (2000), the surrogate terms and allied concept units of data were often represented by single or very small numbers of words. It became apparent that 2 themes emerged from this element of the data, firstly, the terms that were often used synonymously with the word compassion and, secondly, the concepts that were most often seen as similar or complimentary. The confounding factor was that the same term could be used in either or both ways in different articles. It is an important distinction and deliberation, as Faust (2009) states, *'How we use terms influences how we act, how we think about situations, and how we set expectations'*.

As an approach to manage and order the data the frequency that a term was cited will be used. The ambition to demonstrate the shared understanding and the consensus presented by the literature made this a logical and simple way to present the findings within the five categories. This is reflective of Rodgers' (2000, p97) idea that concept analysis is an inductive process and a means of identifying *'a consensus or the 'state of the art' of the concept'*. Such a simple approach also ensures that the findings are as free as possible from the risk of manipulation or misinterpretation by the researcher.

To this end, the term most often cited as either synonymous with or in place of compassion was that of **'care'** or **'caring'**. Of the 100 articles reviewed the term was present in 56 and in no article was there any dispute or discussion about the similarity of the 2 concepts. A common citation which can serve as an exemplar was provided by Hadridge and Pow (2008, p10), *'Caring for the whole of the human being is what true compassion is'*. Indeed, Dunn (2012, p38) stated that *'Compassion becomes the energy of caring'*.

The concept of 'care' is so deeply ingrained and intertwined with the idea of compassion that it also featured in other descriptors such as 'person-centred care' or 'humanistic care'. The importance of this for future work and research is clear – research and commentary about the concepts of 'care' and of 'compassion' may well be looking at the same subject, rather than separate bodies of research. The information such work provides may well need to be viewed as, if not synonymous, at least symbiotic.

This is in contrast to the next most commonly cited surrogate – that of **'empathy'**, which was used in 37 of the reviewed articles. Whilst empathy was seen by some as synonymous (Kayser-Jones et al 2005, MacCulloch 2007, Maxwell 2008, Paterson 2011, Scott 2013, Crawford et al 2013 as examples) several authors were at pains to discuss why the terms may well be allied but that they were not synonymous. Both Schantz (2007) and Ekstrom (2012) make the point that empathy may be related to compassion but that it is also different. As Schantz (2007, p51) writes *'...what distinguishes compassion from all these related words is its intrinsic motion-generated effect. That is to say, only compassion impels*

and empowers people to not only acknowledge, but also act toward alleviating or removing another's suffering or pain'.

A perhaps more nuanced view is that of van Der Cingel (2009) who coins the term '*compathy*' which highlights the inter-connectedness of compassion and empathy, she states that empathy is a pre-condition for compassion but by describing it thus she also highlights that it is not synonymous. Warmington (2011), describes empathy as both complimentary and related to compassion but presumably therefore different and Kret (2011) states that compassion is a reaction to empathy, thereby also reflecting the distinction.

The next most frequently cited surrogate was that of '**kindness/kind/kind-hearted**' which were mentioned on 21 occasions in the reviewed articles. Closely followed by '**humane/humanistic/human**' input and these terms were used 17 times. The human/humane quality of providing health care was also often linked to the idea of compassion demonstrating or requiring **love, affection** or the involvement of the '**heart**' in the relationship between care-giver and patient, occurring in 13 articles. Dewar and Nolan (2012, p1251) cite a participant in their study who stated that, '*Compassionate care is about caring. It's about loving, treating others like you would want to be treated yourself, going the extra mile*'. Dewar and Nolan (2012) also clarify this, as their research progressed it was evident that with greater attention to patient's needs it was more important to determine what the patient wanted and what was important to them. Graber and Mitcham (2004, p92) state that '*caring is also enlivened by the heart – the spontaneous expression of love, feeling and altruism*'. And in the 2012 study by Kemper et al compassion was demonstrated by

meditating with 'loving kindness' towards the subject. Allied synonyms related to love/affection for compassion but which appeared only once or twice included '**intimacy**', '**tenderness**', '**nurturing**' and '**sustaining**'.

The relationship between compassion, caregiver and the patient was also reflected in the terms of **person-centred/patient-centred/relationship-centred** care and this was cited as a surrogate or allied term for compassion in 9 of the articles reviewed (Black 2008, Greenfield et al 2008, Maben, Cornwell and Sweeney 2010, Trueland 2012, Dewar and Nolan 2012, Curtis, Horton and Smith 2012, Horsburgh and Ross 2013, Dewar 2013, Kagan 2014).

Terms that received more than one or two mentions were those of **sympathy** and **pity** in 10 and 4 articles respectively and these, like empathy were divisive in their usage. Authors either cited them as synonymous with compassion (Warmington 2011, Gelhaus 2011, Straughair 2012, Davison and Williams 2009) or distinctly different although related (Buchanan-Barker and Barker 2004 and Schantz 2007). Ekstrom (2012) agreed with the theory described by Aristotle (Nussbaum 2001 p. 315), proposing that pity was different from compassion as it suggests a position of superiority and power for the person who pities in relation to those who are pitied and this may be incompatible with the concept of compassion. However, Gelhaus (2011) argues that this very asymmetry is necessary, an essential element in the relationship and is due to the patient's vulnerability rather than the carer's moral superiority.

Nevertheless, she still cautions against condescension thus acknowledging the risk of power imbalance suggested by Ekstrom (2012).

The final categories of allied terms mentioned enough times to be of significance was that of **dignity** in 5 papers and **respect** and **benevolence/beneficence** in 3. It was clear that the authors of these articles felt that the provision of care that promoted dignity and provided respect was a pre-requisite for compassion in a healthcare setting. Indeed, Mickel (2008, p14) stated that '*it (compassion) is treated as near-synonymous with dignity and respect*'. Although perhaps less definitive, Foster (2013) agreed that both elements were synonymous with compassion, while Cornwell and Goodrich (2009, p15) stated '*It (compassion) can be equated with providing both dignity and respect*'. The idea of beneficence or benevolence – the intention to benefit or do good to the patient - was exemplified by Greenfield et al (2008, p1155) who stated '*... compassionate caring, or benevolence, is often viewed as a virtue that implies doing good (promoting health and well-being versus rightful action, which involves avoiding basic harms, such as pain, injury, loss of freedom, and loss of pleasure) out of genuine care or concern.*'

Finally, the list of surrogate terms that appeared only once or twice have been included as Rodgers (2000, p95) suggests that whilst it is no cause for concern if the research fails to incorporate 'extraneous' information it would be inappropriate to ignore data that may seem to represent 'outlying' ideas. Such terms may provide added insight or even indicate emergent trends or the direction of future research. These terms are included as follows:-

Humility	Altruism	Identification	Professionalism	Resilience
Healing	Clemency	Consideration	Communication	Comfort
Decency	Commiseration	Understanding	Encouragement	Competence
Sincerity	Acceptance	Commitment	Value/virtue	Sensitivity
Warmth	Emotional intelligence/attention	Concern	Conscience	Safety
Mercy				

Table #2 Single use surrogate terms for compassion

The difference between related terms will be further explored in the 'attributes' section of the analysis.

3.2.3.2 Antecedents

Toftthagen and Fagerström in their 2010 critique of Rodger's methodology suggest that the idea of 'antecedent' concerns events or phenomena that may have been previously related to the concept. Sadler (in Rodgers and Knaf, 2000 p 257/8) in their discussion about caring describes 'antecedents' as those elements that caring was founded upon, such as an adequate knowledge base, attitude, relevant skills and so on. For the purpose of this study, the literature was analysed within the 'antecedent' category for those conditions or behaviours that would be needed for compassion to be possible. As an example, a number of authors suggest that without compassion for themselves, healthcare workers could not then be compassionate to their patients – it was a prerequisite for compassion to exist. Indeed, this was a frequently cited requirement with 14 articles explicitly making the link; Nyatanga (2013, p299) succinctly sums this up as '*compassion breeds compassion*'. Greenberg (2011, p106) expands on this idea, '*Develop compassion that is self-focussed and directed – failure to take care of your needs or have compassion for*

your own human behaviour puts an obstacle in the way of caring'. Allied to this is the idea that there is a direct relationship between the ability to provide compassionate care and subsequent personal satisfaction for healthcare staff (Adamson, 2013).

The single most frequently occurring theme concerning what was required before compassion could flourish was that of the **culture and priority** of the organisation in which care is delivered, 29 authors definitively suggested that this was antecedent to compassionate care. Compassion *'depends on the environmental and cultural conditions in the workplace'* asserts Trenchard (2013, p15) and *'...what it comes down to is culture'* Hehir (2013, p111) and in the same year, Dewar (p51) suggested *'.... one needs to work in a compassionate care environment to be able to deliver compassionate care'*.

Whilst 'only' 29 authors made this link implicit in their work, they and others also described the environment and resources that needed to exist for compassion to occur so, could equally be seen to be commenting upon culture and organisation. For instance, 11 (although only 3 were not included in the 29) authors felt that staff needed adequate **time** in order to provide compassionate care and 6 felt that without adequate **resources** it would be difficult, even impossible to provide for compassion in care. However, of the 6 only 2 were not also included in the group citing the relevance of culture, which seems to highlight that culture is not solely to do with attitude. This is further confirmed as authors within this group also suggested that too much stress or pressure could also militate against

compassion (Mickel 2008, Horsburgh and Ross 2013 and Trenchard 2013), which would seem to reaffirm the importance of resource and culture.

Many of the authors cited specific characteristics that were needed by staff as essential for compassion to occur – this is closely linked with the ‘attributes’ section of the analysis but was differentiated by the premise that these elements were needed **for** compassion **to** occur. Qualities that are desirable in healthcare staff include **patience, trust, humility** and an **absence of arrogance, imagination and interest** as well as **wisdom** and **individual will**, with Graber and Mitcham (2004, p87) stating that ‘*the ability to provide compassionate care clearly has its source in individual motivation and wisdom*’.

The idea that compassion was **innate** in healthcare staff and intrinsic to the role also featured in Larkin’s 2011 editorial, which suggested that compassion was ‘*intrinsic to the core of what it means to be a palliative care nurse*’ (p107) and Vivino et al (2014, p162) who felt that compassion was ‘inborn’. Whether innate or intrinsic it was felt that an understanding of the nature of compassion was necessary as described by Spandler and Stickley (2011, p555), ‘*...an understanding of compassion is necessary to appreciate what actually stimulates hope-inspiring practices*’ also suggesting that providing **hope** is synonymous with compassionate care. Crawford and colleagues (2013) went even further stating that their study demonstrated that for compassion to develop their needed to be

considerably more research to determine the psychological nature of compassion and what can facilitate and what inhibit compassionate practice.

Allied to the idea that to practice compassionately one must understand what compassion is, was the belief that there needed to be the **presence of suffering** as an antecedent, as a requirement (Vivino et al 2014, Peters 2006) and that there needed to be recognition and respect for the nature of that suffering. Ekstrom (2012, p162) eloquently described this as

'...the recognition, appraisal, or acknowledgement that another person (or sentient being) is indeed suffering' and that there needed to be *'respect for the sufferer.....one cannot experience compassion for another if one does not believe that the other is suffering'*.

The notion of suffering also ties in with the Aristotelian idea that for compassion to be felt the compassionate must believe that the sufferer is experiencing significant suffering, that the suffering is underserved and that the sufferer is both worthy of compassion and not culpable for their suffering (Paterson 2011, Gelhaus 2011, van Der Cingel 2009 and Vivino et al 2014). However, such a belief was more a discussion point rather than a significant argument for an approach to fostering compassion. This is demonstrated by the number of authors who cited **tolerance**, **universality or unconditionality**, and **acceptance** as being prerequisites and these qualities were mentioned far more frequently than any attitude reflecting blame or judgement related to the patient. Spandler and Stickley (2011) going so far as to reflect the Rogerian (Rogers, 1902-1987) concept of unconditional positive regard.

One consideration that perhaps reflects both positions – that compassion is based on the relationship between the carer and the cared for but also

can be conditional was highlighted by a number of writers. Eight authors suggested that there needed to be a level of **identification** rather than simply forming a respectful or caring relationship. Spandler and Stickley 2011, Kim and Flaskerud 2007, Greenberg 2011 and Roberts et al 2011 all suggested that this identification of shared experience or understanding was helpful in informing compassionate practice. Indeed, Curtis (2014, p214) stated that '*...associating their own personal experiences with a patient's situation enabled them to 'connect' with individual patients and empathise, enhancing compassionate practice.*' Gelhaus (2011), van Der Cingel (2009) and Vivino et al (2014) however all go so far as to suggest that it is easier to be compassionate to those for whom we feel a sense of similarity or when we imbue the sufferer with positive attributes. It is important to note that these authors also described the need to see the situation from the patient's perspective with understanding.

Following on from the idea of both tolerance and acceptance is that of **empathy** – a term that was offered frequently as a surrogate term and was also described as an antecedent by 9 authors specifically, Kret in her 2011 study described compassion as a reaction to empathy, and by a number of others who used allied but related terms. A number of associated terms emerged from the data, firstly that healthcare staff needed to understand or identify the patient as an individual was cited by 11 authors. Warmington (2011) described this as needing the patient's perspective to make sense of the situation, whilst Kim and Flaskerud (2007) suggest that a connection needs to be formed between the 'sufferer and helper', Chochinov (2007) describes this as identification with

the ill and suffering. Poll (2013) states that healthcare staff must think about care from the patient's perspective, see the patient and not the disease or condition and ensure that the patient's 'voice' is heard.

Equally prevalent as an antecedent was the allied concept of the need to foster and **create positive relationships** and engagement between carer and the cared for as described by 8 writers, to have **person-centred skills** and values by 3 and **emotional engagement** by another 2. It was evident that the relationship between the patient and those who care for them is an integral component of the ability to provide compassion. Straughair (2012b, p243) sums this up by stating that staff need to *'strengthen the humanistic approach to care and disregard the notion that professionalism requires detachment from patients'*.

Whilst specific **qualities** were necessary so too were specific **skills**, as an example a number of writers felt that staff needed to be **courageous** and able to stand up for their beliefs and values, to be able to **challenge** when necessary. Dewar and Christley (2013, p48) wrote *'courage is about standing up for one's innermost values and is essential to the delivery of compassionate, relationship centred care'*. Mickel (2008) identified this courage as that required to give meaningful feedback and coaching to the minority of healthcare staff that do not demonstrate compassion whilst Curtis (2014) in her study looking at the skills nursing students need to practise compassionately clearly felt courage to be a requirement as did Maben, Cornwell and Sweeney (2010) as a skill needed by all health professionals.

Perhaps linked to the idea of culture but with enough examples to warrant discussion as a discreet concept was that of the need for compassion as both **a quality and emphasis of leadership** and the associated need for **compassionate role models**. Five authors explicitly described the need for focussed compassionate leadership, '*Nurse Leaders informed by a compassionate leadership model would be able to expand their horizons of understanding to place a premium value on the compassion perceived by patients and nurses*' asserts Georges (2011 p134). Forrest (2011, p38) felt that it was '*vital that bright, dynamic leaders and practitioners within nursing re-assert the importance of kindness and compassion to enable the highest quality patient care to be delivered*'.

Modelling compassionate behaviour was seen as a significant antecedent behaviour being described by 13 authors and was clearly viewed as a way of fostering and enabling compassion. Gelhaus (2011, p407) suggests that '*compassion can succeed only in a climate of confidence and respect where good role models are willing to invest in personal contact...to learn compassion we need examples*', Cornwell and Goodrich (2009, p15) go further and state '*without systematic modelling and explicit endorsement and support for striving to be compassionate towards every patient, every time, it will be eroded and more difficult to practice*'.

Newton (2010) suggests that role modelling is key to developing compassionate nurses and Curtis (2014) highlights the importance of role modelling as a part of nurse education programmes. This also links to the

idea that compassion, as an underpinning expectation of healthcare professional's education, was **a requirement for training future staff** and was highlighted by 5 authors. Once trained however, a further 5 authors also suggested that compassion was **an expectation** of all professionals and should be viewed as part of what it means to be a healthcare professional – both antecedent and expected. Two authors felt that such was the importance of compassion in educating healthcare staff that it should be a prerequisite for recruitment – quite how this would be determined was less evident.

As an interesting counterpoint and to be considered when educating professionals was the view that too much emphasis on academic skills could hamper compassion (Davison and Williams, 2009) and that too much knowledge and technology could have the same effect with Kearsley (2011, p215) positing that *'the more facts we learn about disease, the more complex technologies and treatments we develop and embrace, the more we risk marginalizing compassion'*.

A final group of antecedent skills and qualities needed for compassion was that of the **relationship between the patient and carer** and was another area where some authors felt that the issue was not clear-cut. The majority of those writing on the subject felt that there was a need to foster a specific relationship with patients whereby their needs were always put first (van Der Cingel 2009 described this as a need to 'de-self oneself') and that healthcare professionals needed to be **selfless** (Bradshaw 2014), demonstrate **humility** (Ekstrom 2012 and Maben, Cornwell and Sweeney

2010) and a **lack of arrogance** (Ekstrom 2012). Healthcare staff needed to **listen** to patients (Graber and Mitcham 2004) and welcome their views (Grumbling Appendix 2013) and ensure that they are at **the centre of their care** (Hughes 2013). Such an environment was created by having **good communication skills** (Graber and Mitcham 2004, Wollenburg 2004, Greenfield et al 2008, Black 2008, Straughair 2012 and Dewar 2013), **imagination** (van Der Cingel 2009 and Georges 2013), **respect** (Warmington 2011, Reid 2012 and Ekstrom 2012), **intimacy** (Smajdor 2014), **experience** (Chochinov 2007, Davison and Williams 2009, Roberts et al 2011 and Curtis 2014) and **interest** (Wright and Sayre-Adams 2006).

An interesting discussion was put forward by Gelhaus (2011) who suggested that there needed to be an '**asymmetry**' between the patient and those who cared for them. Gelhaus qualifies this by stating that the '*asymmetry in the situation is due to the patient's vulnerable situation, rather than one's own moral superiority*' (p404). This does, however, result in the need for caution to prevent condescending attitudes towards those who suffer and it is compassion that Gelhaus seems to suggest may act as the mediator in this circumstance.

Less frequently cited but still significant was the antithesis of this requirement to form a close relationship with patients, was the need to actually ensure that there was a '**boundary**' between patient and staff (Peters 2006, Roberts et al 2011, Kearsley 2011 and Curtis 2014), that a professional distance was necessary (van Der Cingel 2009) and that care should be provided without attachment (Wright and Sayre-Adams 2006) or

too much emotional engagement (Bradshaw 2009). This was often couched in terms of staff protecting themselves from becoming too engaged and involved with patients as this could result in subsequent distress and emotional strain (Smajdor 2014). The link was made with the **need for self-compassion** and that staff needed to protect themselves in order to prevent 'burn-out' as this serves neither staff member nor patient, Curtis in 2014 described this as the need to preserve one's own emotional wellbeing. The literature review did not include the body of work relating to compassion fatigue and burn-out in healthcare and this evidence would undoubtedly provide greater clarity and context relating to this idea of boundaries as an antecedent. The relational nature of the concept will be explored more fully in the light of the fieldwork findings in Chapter 7.

Finally, in order to provide the resource and skills for staff to be compassionate there needed to be a climate of **reflective behaviour** and an awareness of self. A number of authors noted this including Hughes (2013, p307) who suggests that workplaces need to '*Invest in compassion - enable continuous high-quality learning and reflection, build internal capacity for reflection on compassion*'. Dewar (2013), Greenfield et al (2008) and Curtis (2014) describe the need for self-reflection as well as reflecting on experience and van Der Cingel (2009) calls for 'continuous reflection' as a necessary antecedent for compassionate care.

3.2.3.3 Attributes

Understandably, this category resulted in a significant amount of data generating over 250 different, named attributes that either demonstrate or

are required in order to demonstrate compassion. Two considerations were clearly a common referent and can be said to be a definitive finding of this literature review. Firstly, nearly half of the authors (46) suggested that compassion was an **expectation of healthcare staff** – in effect, a basic requirement of practice. It was described as a virtue or a moral obligation that all staff should possess as an imperative component of healthcare. Indeed, Ekstrom (2012, p162) quotes the work of Rousseau (1712-1778) going as far as to say that compassion ‘...*by moderating the violence of love of self in each individual, contributes to the preservation of the whole species*’. Leget and Olthius (2006, p618) echo the sentiment that compassion is ‘*useful for the survival of the species*’.

More commonly, authors stated that compassion was a basic requirement for healthcare staff or was an expectation of both patient and staff alike.

Fry et al carried out an observational study in 2013 and stated that ‘*compassionate caring is central to nursing praxis*’ (p38), whilst Dewar and Nolan (2012) suggest that compassion is identified as a ‘core value’ within the National Health Service. Davison and Williams (2009a) describe it as ‘*nurse’s most precious asset*’. Whilst relating to nursing, the statement by Curtis, Horton and Smith (2012, p790) following their study of student nurse socialisation could be an exemplar for much of the literature within the review,

‘Compassionate practice is an explicit expectation and a key quality indicator for nursing in the UK according to standards set within the Department of Health and the Nursing and Midwifery Council, the Canadian Nurses Association and the American Nurses Association. Compassion is also an expectation of those accessing healthcare’.

The second most significant attribute described in the literature was that of compassion being a **response to suffering** and that suffering needed to be present, acknowledged and addressed. Forty-four authors directly referenced suffering and the response to it, Crowther et al (2013, p496) was common of many by stating that *'we search for the things we can do, however small, to give comfort and relieve suffering'* which is a direct quote from the 2015 NHS Constitution (Department of Health). Straughair (2012b, p239) acknowledges this by stating, *'This value statement represents compassion as expressed by patients, public and staff... and demonstrates a commitment to recognizing people's suffering and actively engaging in action to alleviate it'*.

Many also mentioned suffering as it features in the most common dictionary definitions of compassion; the Oxford English Dictionary (2018) for instance defines compassion as *'Sympathetic pity and concern for the sufferings or misfortunes of others'*. Whether a reaction to Government policy or simply a commonly held definition, suffering was still so frequently described and discussed as to be significant and echoes the relevance given by many writers as an antecedent to compassion – suffering and compassion appear to go hand-in-hand.

Broadly speaking, attributes could be categorised as either relating to a characteristic, such as **kindness** or **warmth** or as behaviours such as **listening, giving time** or **promoting independence**. In order of frequency, the following characteristic of compassionate staff or environments was as follows:-

Characteristic	Caring	Empathetic	Respectful	Kind/ Kindness	Non- judgemental/ unbiased/ Impartial/non- discriminatory	Sensitive
Frequency	36	31	25	21	17	15
Characteristic	Sympathetic	Concerned	Love/loving	Gentle Gentleness	Open Approachable	Attentive
Frequency	13	11	11	10	10	9
Characteristic	Warm	Intuitive	Genuine Authentic Spontaneous	Honest Truthful	Humility Lacking arrogance Self- absorption	Expert Competent Confident
Frequency	9	8	7	7	7	7
Characteristic	Courageous	Friendly/ Companiona ble	Polite/ courteous	Trustwort hy	Supportive	Accepting
Frequency	6	6	6	6	5	4
Characteristic	Tolerant	Benevolent	Realistic	Calm	Encouragin g	Validating/ valuing
Frequency	4	4	4	3	3	3
Characteristic	Equanimeou s	Generous	Curious	Nurturing	Pitiful	Interested
Frequency	3	3	3	3	3	3
Characteristic	Being female	Helpful	Reassuring	Merciful	Committed	Tactful
Frequency	3	2	2	2	2	2
Characteristic	Responsible	Objective/ detached	Appreciativ e/ approving	Patient		
Frequency	2	2	2	2		
All of these characteristics were mentioned once only	adaptable affectionate solicitous sustaining,	Empowering creative accountable imaginative professional	Affirming thoughtful resilient tender, self- controlled	dedicated forbearing pleasant optimistic hospitable	giving soothing wise altruistic stable	smiling integrity engaged healing notices

Table #3 Compassionate attributes of staff and of environments

Understandably, the frequency of attribution mirrored in many ways the frequency of those terms listed previously as those seen as surrogate terms, as being synonymous with compassion. However, to be included as an attribute, the author(s) needed to have made it apparent that the quality was required for compassionate practice – it could not simply, as with surrogacy, be mentioned in the article. A number of characteristics were very similar and when this was obvious, they have been grouped together – as with non-judgemental and non-discriminatory. However, one could also argue that ‘tolerance’ and even ‘respect’ are related terms and could be listed together. The groupings may therefore seem arbitrary but, by including all attributed characteristics, the overall trend can be seen in the table above and similar characteristics can be acknowledged.

Some characteristics bare further consideration because of the number of times that they were cited by authors and, over a third of authors (36) felt that to be compassionate one had to demonstrate **caring** or that caring was inherent within compassion. ‘*Compassion is the essence of caring*’ assert Chambers and Ryder (2009, p2) whilst Badger and Royse (2012, p772) stated that the ‘*delivery of compassionate care can be construed as a professional duty and responsibility transcending the boundaries of any specific profession*’ both highlighting the care component, the expectation of compassion as a core requirement and that this is so for all healthcare staff.

Being **empathetic** was the next most significant attribute and was described by almost as many authors (31) as those detailing caring.

Moreover, many of those who had suggested it was a surrogate term for compassion often qualified or tempered this. However, it was clear from the use of the term in the articles that the characteristic of being empathetic was less contentious when demonstrating compassion. Kret (2011) saw compassion as a reaction to empathy and Kayser-Jones et al (2005, p19) suggest that '*compassion comes through a multiphase process known as empathy*'. Coulehan (2009, p595) cited empathy as a component of compassion but also described compassion thus, '*characteristically involving imaginative dwelling on the condition of the other person, an active regard for his good*' which is very similar to many definitions of empathy. Perhaps this is most prosaically described by Peters (2006, p38) as, '*Compassion may begin with the cognitive experience of empathy or "walking in another's moccasins"*.' As a final exemplar of the many mentions, Chambers and Ryder (2009, p12) suggested that '*Compassion is a strong emotion or sentiment stimulated by the presence of suffering that evokes recognition and mutual sharing of the despair or pain of the sufferer*' which both reinforces the presence of empathy (which is also directly cited) but also the previously discussed awareness of suffering.

Behaviours that demonstrate compassion were then identified, more nuanced than simply describing characteristics; the descriptions within the literature that defined behaviour were clustered into similar themes. The initial number of behaviours identified resulted in 65 different categories but these were then organised into allied and complimentary groupings. As an example, a frequently described behaviour was that of responding

with humanity or of being humane in one's dealings with patients. However, there was also the recognition within the various author's discussion of the notion of shared humanity and of reciprocity and so, these behaviours were listed together and could be found in 22 of the included articles. Staren (2006, p413) stated that '*....acting with compassion is the sine qua non for a physician to demonstrate humanistic behavior towards their patient*' whilst Cornwall and Goodrich (2009, p15) described this as '*communication that is human to human rather than clinician to patient*'. This also serves to introduce another commonly cited behaviour of the compassionate – that of effective and skilled communication.

Nine authors simply stated that good **communication skills** were essential for compassionate care whilst others suggested the need to engage and connect (Trueland 2012 and Dewar 2013) or that there was a need to be informative and accurately so in a further 4 articles. More significant was the emphasis on **listening**, both to the words spoken but also to the body language of patients and to do so without interrupting or speaking over the other and nearly a quarter (24) of the authors described this listening in some form or other as a required behaviour. Being **attentive** and/or paying attention was an allied behaviour described by 10 authors with Warmington (2011, p333) making the link between the 2 attributes, '*...asking the right questions and then listening precisely in a manner that is unselfconscious, non-judgemental and open fully to the other's perspective.....with an attentive mind....check the accuracy of understanding through respectful dialogue*'. Dewar and Nolan (2012) and

2 others describe '*caring conversations*' whilst 6 authors list '*interpersonal skills*' as a component of compassionate behaviour. Fry et al (2013, p39) describe interpersonal skills as, '*practice closely related to their ability to interpersonally relate to patients and engage in compassionate caring – especially through the use of eye contact, empathy, humour, small talk and touch*'. Communication as a key theme was a significant presence in the literature and could be said to also encompass other described behaviours such as being open and welcoming questions (Apker et al 2006) and willingness to negotiate (Dewar, 2013). Practical demonstrations of communication were mentioned and, as with Fry et al highlighted touch (Kim and Flaskerud 2007, Reid 2012, Bradshaw 2014) and the use of humour (Dewar and Nolan 2013 and Apker et al 2006) as well as small talk or banter (Kagan 2014). The relevance of good communication is perhaps best illustrated by Staren (2006, p414),

'If compassion is such an integral aspect of humanistic patient care, what practical approach might be used to optimize such care? I would suggest that the single most important essential to such care may be summed up in one word, communication'.

In terms of being attentive, several authors suggest the need to pay attention to emotions and this link between emotion and compassion was a frequently occurring theme. This was described variously as compassion being an **emotional response**, an emotional presence and that this emotion could, at times, be painful to experience. In all, 23 articles highlight this idea, examples being '*the painful emotion caused by the awareness of another person's undeserved misfortune*' (Paterson 2011, p20) whilst Torjuul, Elstad and Sorlie (2007, p526) stated that '*...nurses allowed themselves to become emotionally involved in such a way that*

they were moved by what the patients were undergoing'. To compliment this, 2 authors felt that compassion was '*thinking as well as feeling*' (van Der Cingel 2009, p135) and '*affective as well as cognitive*' (Peters 2006, p39).

Another theme that emerged linked to compassionate behaviour was that of being '**present**' with the patient and that this presence was, importantly, with full understanding of the patient's situation. Larkin (2011, p107) exemplified this, '*The compassionate practitioner is one that has the courage to be present without delusion*'. This idea of 'presence' was mentioned by 12 authors and was therefore significant, so too was the idea of needing to be able to comprehend and face pain, grief and loss to enable this presence. Healthcare staff needed to be able to be with those who suffer without fear themselves and be confident to stay close, Kearsley (2011, p216) suggested that compassion is '*an unnatural passion*' because of this ability to be with hurt and to '*enter into places of pain, to share in brokenness, fear, confusion and anguish*'. Not only would healthcare staff be present with suffering they also would never abandon or leave a patient feeling they are alone (Perry 2009).

The experience of patients often presents challenges for those caring for them and it is how healthcare staff respond to this distress and suffering that was highlighted by a number (13) of authors. This was described as either '**distress as a stimulus** to act or that care was based on an understanding of distress and suffering. Kearsley (2011) defined why this was a behaviour as it required a '*preparedness*' to develop this

understanding and Forrest (2011, p38) suggested that compassion *'requires us to be vulnerable ourselves whilst acknowledging distress and vulnerability in others'*. Spandler and Stickley (2011) describe the need to be **tolerant of distress** and that this tolerance needs to be coupled with warmth and kindness. The link between suffering and distress therefore is not simply an antecedent to compassion but also a response and an action.

Whatever the patient was experiencing, the need for a **'person-centred'** approach was mentioned a number of times, allied to this was the notion of identifying with the patient – including to the extent of treating them as you would your own family and loved ones or in the way you would wish to be treated. Within this category were the need to be able to recognise the patient's need, take their feelings into account and involve the patient in decision-making and in their care. It was seen as important to believe the patient (Ekstrom 2012) and to accord their views the significance that the patient saw as relevant; van Der Cingel (2011, p677) described this as the *'verbalization of suffering and the accompanying emotions, according to participants'*. Treating patients as you would like your own family and loved ones to be treated was also linked to 'practice what you preach' and the idea that staff need to have an awareness that it might be them needing care one day. Horsburgh and Ross (2013) quoted nurses who suggested that they tried to put themselves in the patient's position and that this helped them to treat the patient as they would like to be treated if ever in the same circumstances.

This theme continued within the idea that healthcare staff needed to **cultivate relationships** with patients that were receptive to their needs and that fostered a connection between the cared for and the carer.

Despite her caution concerning the need for compassion based relationships, Smajdor (2014, p6) described them as '*I/thou rather than I/thee*' and further suggested that compassion requires that nurses '*respond to all patients as individuals, form intimate, loving relationships with them and allow themselves to become vulnerable to suffering in forming these relationships*'. Paterson (2011) and Buchanan-Barker and Barker (2004) both described it as 'fellow-feeling' and Maben, Cornwell and Sweeney (2010, p10) emphasised that staff '*structured their work deliberately to promote caring, intimacy, partnership and reciprocity in relationships with individual patients*'.

Leading on from this was a further category and this was the **way** in which healthcare staff '**related**' to those within their care in a way that demonstrated their compassion and at least 21 authors made mention of this aspect of care provision. This could be seen in the description offered by Trueland (2009, p19) who simply stated '*It is about the relationship that we have with someone else. It is something to which we respond, human to human*'. And Perry (2009, p14) added to this by describing the importance of the interaction, '*In other words, it is in the social relationship between two people that compassion is experienced, conveyed and received*'.

Perhaps more contentious was the suggestion that healthcare staff not only needed to have insight in to the needs of others (e.g. Kayser-Jones, Chan and Kris, 2005) but that this also leads to the need to put others first, to be **selfless** and to give of oneself. Graber and Mitcham (2004) go so far as to describe this as 'self-abnegation' and van Der Cingel (2011, p679) as the '*setting aside of one's own interests*'. Such an expectation was commonly cited and could be seen in over a fifth of the reviewed articles. Dossey (2007, p1) prosaically sums this up as,

'Compassion doesn't mean feeling sorry or pity for people but feeling with the other, learning to dethrone yourself from the centre of your world and put another there. Compassion, therefore, now as then, involves radical surgery of the notions of I, me, mine'.

In a similar vein, the idea that the compassionate practitioner is prepared to go beyond what is expected or '**above and beyond**' was suggested a number of times. Hudacek (2007, p124) describes this as '*going the extra distance*' and Dewar and Nolan (2012, p1251) as '*going the extra mile*'. Greenfield et al (2008, p1160) stated that compassion led staff to care in such a way that '*in most cases, this ethic of care went beyond rules-based beneficence*' and this idea of being prepared to bend or even break rules in order to be compassionate was also cited by Vivino et al (2014, p161), '*...taking action by going beyond traditional boundaries when necessary*'. Maxwell (2008, p221) echoes this but also highlights the active element of compassion (discussed below), compassion '*...is an action incentive that is liable to diverge from standards of moral impartiality*'. Finally, both Adamson (2013) and Dewar and Nolan (2012) suggest that there may be a need to take risks in order to provide person-centred care.

Of course, there will always be counterpoints to this view, even from those authors who suggest it is a desirable trait of the compassionate practitioner. Less common than the description of selflessness but still cited enough times to be meaningful was the idea that there also need to be **boundaries** as such intimate and giving relationships risk taking their toll. Curtis (2014, p219) who clearly states the necessity of emotional engagement and altruism also cautions, stating the '*...importance of nurses learning to manage the emotion or feeling of fear so that it does them no harm*' and that '*a balance was required in order to engage in compassionate practice for the benefit of their patients, which was a professional expectation and ideal, alongside avoiding detrimental effects on their own emotional well-being*' (p216). Peters (2006), who investigated the experience of nurse educators, highlighted their recognition of the need for boundaries to enable both the nurse and the patient to take responsibility for themselves. Larkin et al (2009, p54) eloquently suggest that '*compassion is the mean between indifference and involvement to the point of ineffectiveness*'.

The need to '**act**' in order to be compassionate was a regularly occurring motif in the literature and one that was often highlighted as being the distinguishing feature between compassion and empathy. Vivino et al (2014, p161) studied the views of psychotherapists who had been nominated for inclusion in the research because they were seen as compassionate, they said that this '*action component of compassion was described by one participant as a sword that cuts through slothful ignorance*'. Amongst others, Larkin (2010, p338) describes compassion as

a *'deep internal feeling that moves us to action... something felt within the gut'* and Wright and Sayre-Adams (2006, p22) suggest that compassion *'combines feelings with action to alleviate suffering'* whilst Georges (2011, p133) includes the oft-cited quote from the Buddhist commentator Thich Nhat Hanh that *'compassion is a verb'*. Davison and Williams (2009, p36) make this implicit by writing, *'... compassion impels and empowers people to not only acknowledge, but also act...it involves focusing on another person's needs and channeling the emotion generated by their predicament into an active response'*. Coulehan (2009, p597) described and perhaps summed up this theme as, *'the objective and subjective steps or components of compassion find their fulfilment in action'*.

The importance of **'witnessing'** was highlighted and this was also linked to the idea of **'seeing'** the person and not simply a patient, exemplified by Kapitan (2011, p154) thus, *'...preoccupation with seeing came from a desire for compassionate witness, to recognize the human face in the other, in each of the others'*. Also, *'Compassion and dignified care are about seeing the person in the patient (the other), and responding accordingly'* (Reid, 2012, p218). Examples of how this can be achieved included *'asking patients about their concerns and what matters to them'* (Adamson 2013, p64) whilst Reid (2012) suggests the need to address patients by their preferred name and to give them time to share their story. Curtis (2014, p219) neatly summarises this by stating, *'... bearing witness to' or 'having presence with' another person's suffering, and through being human, wilfully connecting to that person emotionally in a way that says "I am here for you"*. Such a statement was common of much of the literature

when one, articulate statement could encompass a number of the key themes linked to behavioural attributes. Allied to the idea of ensuring patients received care that recognised their needs was the requirement to assess these needs and then pay attention to the details of the assessment, Perry (2009, p18) states that this results in a '*process that turns compassionate urges into practical, effective nursing actions*'. Simply put, Gelhaus (2011, p400) describes the need to '*identify a bad situation*' as the motivation to go beyond benevolence and to act with compassion to assist the patient.

Naturally leading on from the need to be aware of the needs of the patient was the need to be **self-aware** and this was represented in a number of ways. Adamson (2013a, p61) simply described it as '*knowing me, knowing you*' whilst Warmington (2011, p335) states that staff need to be '*attentive to the patient as well as his or her own responses*'. van Der Cingel (2011) illustrates this as the need to set aside one's own interests and to withhold judgements and Greenberg (2011) advises staff to be aware enough to send patients elsewhere if they know someone else can provide better care or input. This idea of knowing one's own limitations also links to the idea that compassionate clinicians can give but also take feedback (Dewar and Nolan 2012 and Adamson 2013a) and reflect (Georges, 2013) and then react as appropriate. Coulehan (2009, p600) describes this as the need for '*reflexivity and self-understanding*' and Dunn (2012, p38) as '*intentionally knowing the nursed and self*'.

Giving time was another theme and has been linked with giving space and making oneself available, Crowther et al (2013) studied end of life care for people with dementia and determined that compassionate care was demonstrated by finding time for those who are cared for and also for those who care. This study along with several others used a direct quote from the original 2010 NHS Constitution (p14), *'We search for the things we can do, however small, to give comfort and relieve suffering. We find time for those we serve and work alongside. We do not wait to be asked, because we care.* Castledine (2005, p1001) developed this idea and stated that, *'It is misleading to understand patience simply in terms of time, for we give the patient space as well'*. Staren (2006) highlighted the need for patients to feel that the physician was available to them whilst Straughair (2012, p243) stated the need to *'reinforce compassionate practice by advocating that staff take time to care and acknowledge the positive impact this has on patients' care'*.

Some of the more practical behaviours cited included the need to provide **comfort** and to be comforting by 11 authors, to provide and promote a patient's **dignity** by a significant 21 and to maintain **privacy** and **confidentiality** by 7. The role of carers to demonstrate compassion by promoting the patient's **independence**, preserving their **integrity** and respecting their **individuality and autonomy** also featured heavily, being highlighted by 18 writers. Paterson (2011, p21) describes several aspects thus, *'the right to have services provided in a manner that respects the dignity and independence of the individual'*. Dewar in 2013 (p49) describes

all of these behaviours highlighting that compassion is about *'human experience and preserving the integrity of the individual'*.

Whilst a number of behaviours were about behaving in a certain way there was also discussion about compassion being demonstrated by the provision of essential and **'basic care'**, practical help and necessary and skilled clinical input. It was recognised that to be compassionate would be impossible if the basic needs of the patient were not adequately addressed. Perry (2009, p14) stated that *'compassion that is not matched by appropriate practical action is empty'* and Hadridge and Pow (2008, p10) that *'clinical excellence'* was needed. Indeed, Perry in her 2009 study recorded that nurses felt that it was through the provision of 'basic' care such as assisting patients to eat, sleep or stay clean they were able to communicate compassion. Cornwell and Goodrich (2009, p15) in their exploration of how to improve compassionate care in hospitals state that *'compassion starts with good basic care and can be demonstrated in very practical ways – for example, making sure that a patient's feeding needs are addressed, that pain is managed and that the patient is helped to the toilet as needed'*.

Such an approach was mirrored by the idea that compassion could be demonstrated by **'small acts'** (again, a term used in the NHS Constitution, 2012) and that it could be found in the simple and small acts or those that paid attention to the 'essential ordinary' (Perry, 2009, p17). Flynn and Mercer (2013, p13) describe this as, *'nurses are able to talk and listen to their patients and attend to the small details that may not be medically*

important but are of concern to patients and their families'. Curtis, Horton and Smith (2012, p791) echo this, *'and through moral choice doing the small things that matter to the patient so they feel cared for and cared about'*. Wollenburg (2004, p1785) quotes Mother Theresa who said *"There are no great acts; only small acts, done with great love."* Dewar (2013, p49) also quotes the work of another to illustrate this, Pearson (2006), who concluded that small acts of compassion were *'simple not clever; basic not exquisite; peripheral not central'*.

However care was demonstrated there was an expectation that this was done by staff who would be **unconditional** in their compassion and that they would be **inclusive**, just and treat everyone equally. Schantz (2007, p50) suggested compassion entailed *'making justice and doing works of mercy'* and Curtis (2014) highlighted that compassion needs to be available to all including strangers and acquaintances. Straughair (2012) cites the Royal College of Nursing (2010) standard that nurses provide care and compassion to all people equally whilst Ross (2010) describes the need for inclusivity and Bradshaw (2014) that help is provided for the *'stranger in need'*. Gelhaus (2011, p403) portrays the reality of such behaviour in the following,

'... as a general attitude of a healthcare professional to feel the inclination to help suffering people... even extremely unsympathetic, disgusting or vicious patients can be treated with compassion...one must even be able to act in a compassionate way if there is a deep antipathy towards the patient'.

The need to be **culturally and diversity aware** was highlighted by Chambers and Ryder (2009) and would seem to link to the ability to

provide inclusivity and equality as Wollenburg (2004) highlights that compassion can be challenged by cultural barriers.

The need for healthcare staff to ensure patients are **kept safe** (Kapitan 2011), avoid harming them (Kagan 2014 and Jormsri et al 2005) or causing suffering (Peters 2006) whilst Badger and Royce (2012) describe the need to avoid making mistakes. The responsibility to **protect** patients was highlighted by a number of authors (Hudacek 2007 and Kagan 2014) with Maxwell (2008, p221) stating that compassion meant the '*protection and promotion of fundamental human needs*'. Allied to this is the need to take responsibility and to be answerable for actions that are taken, Torjuul et al (2007, p530) describe this as '*... being answerable for the patients' condition, pain and vulnerability*'. Gelhaus (2011) suggests that it is because of compassion that physicians feel responsible to respond emotionally to suffering.

The need for healthcare staff to act as **advocates** for the patient was evident in the writing of a number of authors, Hudacek (2007, p129) felt that being an advocate resulted in '*great connections and relationships*' with patients and Greenfield et al (2008), Chambers and Ryder (2009) and Apker et al (2006) all make the link between advocacy for patients and the provision of compassionate care. Similarly, 3 authors identified that compassion motivated healthcare professionals to make changes when these were needed to benefit patients and, where necessary, challenge the status quo if it was unhelpful to patient care. Maxwell (2008, p221) goes so far as to say that '*compassion and justice enjoin healthcare professionals to endorse, maintain and - when institutional arrangements*

impede the capacity to provide this level of care - advocate appropriate institutional change'.

A really positive behaviour that was felt to demonstrate compassion was that of being willing to **feel joyful** and **happy** with a patient, to celebrate with them when that was possible. van Der Cingel (2009) highlights the need to be joyful and (2011, p680) to '*cherish happy and joyful moments in life....as a counterweight to troubles for patients*'. Dewar (2013) describes the need to celebrate with patients and Dunn (2012, p38) sums these two ideas up as '*the nurse answers the call of the patient with the intent to alleviate suffering or celebrating joy*'.

Lastly, in terms of compassionate behaviour, authors suggested that there was a need to provide **hope** (Castledine 2005), **anticipate anxiety** (Perry 2009 and Horsburgh and Ross 2013) **compromise** where necessary (Dewar and Nolan 2012) and **encourage** the patient to flourish (Hughes 2013). That compassion cannot be a false emotion was described by Forrest (2011) who writes that intention needs to be **genuine** and that to pretend that you are being kind would actually be unkind. Peters (2006, p39) sums this up as '*genuine compassion cannot be forced or imposed; it must be felt to be known*'.

Finally, in terms of attributes were the themes that emerged that were neither characteristics nor behaviours of compassionate healthcare staff but were attributes of compassion itself.

The most significant attribute of compassion was that it was **subjective, unquantifiable, lacking definition, complex and contested**. A rather long list of attributes that add up to the idea that compassion is little

understood in terms of a common definition but as Foster (2013) points out, is in danger of becoming ubiquitous. In terms of this study, such a notion is of both concern and reassuring in equal measure – concerning that much is written about a subject that is ill-defined but possibly over-used and reassuring that there is therefore a need for the research that this study has undertaken.

Dewar (2013) suggested compassion is subjective whilst Perry (2009) described it as ‘a vague and largely unquantifiable and immeasurable phenomenon’. Dewar and Nolan (2013, p1248) conceptualised the idea of compassionate, relationship-centered care by using appreciative caring conversations but cited an earlier narrative synthesis by Dewar (2011) of over 500 items which they state revealed ‘*that consensus as to a definition of compassion was lacking and that there was no comprehensive model indicating how it could be achieved in practice*’. Peters (2006) and Dunn (2012) concur, with Dunn stating ‘*the review of literature for compassion revealed there is little known in the professional literature that addresses the essences of compassion*’ (p38). Curtis, Horton and Smith (2012, p790) expand on this and suggest that compassion is a ‘*complex and contested concept*’, the idea of complexity being identified also by Foster (2013), Curtis (2014) Grumbling Appendix (2013) and Coulehan (2009). Leget and Olthius (2006, p618) highlight that ‘*compassion is an ordinary experience that remains a mystery in our thinking*’. Finally, several authors described the **difficulty in measuring compassion** (Horsburgh and Ross 2013, Harrison, 2009 and Martins et al 2013), the need to measure compassion being a frequent topic of the initial literature search (much of which was excluded as it did not actually discuss or describe compassion). Generally,

such articles were opinion pieces or editorials in response to political speeches or the publication of reports criticising healthcare professionals or highlighting failings in compassionate care.

Interestingly, again in the light of the ultimate aim of this study, some authors felt that compassion was an **innate or inherent** quality (Hudacek 2007, Hadridge and Pow 2008, Curtis 2013 and 2014 and Maben, Cornwell and Sweeney 2010) but also that it **could be taught** (Curtis 2013 and 2014 and Gelhaus 2011). Only Schantz (2007, p51) put forward an opposing view stating, *'it is important to note that compassion is not an inherent quality human beings possess'*.

Compassion was often 'labelled' and ironically, in quite definitive ways such as *'a radical concept'* (Buchanan-Barker and Barker 2004, p19) and as *'a whole praxis'* by Bradshaw (2014, p466), Fry et al (2013) and Georges (2013). Curtis, Horton and Smith (2012, p793) found that student nurses could feel it was an *'unachievable Utopia'* whilst Kearsley (2011, p219) prosaically described compassion as acting *'like rain upon dry ground'*.

'Compassion' had some admirable characteristics attributed to it including that it was **courageous** (Schantz 2007), **admired** (Gelhaus 2011) **is restorative** (Larkin 2010) **an achievement** (Kapitan 2011) and a **'visceral, physical response'** (Peters 2006, p38). In fact, so affective is the receipt of compassion that a study by Kemper et al in 2012 demonstrated that it could actually affect a person's autonomic nervous system.

Some authors did moderate their descriptions taking a more cautious approach; compassion was '*how feelings shape care*' (Chochinov 2007, p186) and '*the mean between indifference and involvement*' (Adams et al 1996 quoted by Gelhaus 2011, p405 and also included by Larkin et al 2009, p54). Perhaps a contributory factor as to why compassion is complex and difficult to define, Dewar and Nolan (2012, p1248) suggest that it is often '*invisible in nature*' and is '*meaningful, unsettling, even disturbing*' (Buchanan-Barker and Barker 2004, p18).

The literature suggested that compassion is seen as part of that element of service that defines it as a **privilege** (Greenberg 2011) and exemplified the element of care provision that was a **duty** (Graber and Mitcham 2004 and Peters 2006) or an element of **service** (Larkin 2010). Compassion was seen as a key element of medical training (Roberts et al 2011) and was part of the goals and duties of the physician (Gelhaus 2011).

There was also some cautionary suggestions in the idea that compassion may be context dependent (Reid 2012), cannot be shown to all to the same extent (Gelhaus 2011) may not be possible or appropriate all of the time (Graber and Mitcham 2004) and can '*rise and disappear like burning straw*' (Leget and Olthius 2006, p618).

Bradshaw's 2011 powerful entreaty that '*compassion is not strained by pressure nor displaced by stress*' (p14) whilst supported by Mickel (2008, p15) who writes that compassion should '*shine through regardless of working conditions*' is tempered by Georges (2011) who states that to be compassionate takes energy and by Larkin (2010) as causing fatigue. Hughes (2013), meanwhile, describes compassion as the element of care

provision that means people can rely on those who are paid to care for them. Perhaps this reliance is also part of why Mickel (2008, p15) states that compassion is a *'dimension of care beyond the routine expectations of competency.'*

Finally, several authors, perhaps as a result of the frequent press reports that seemed to suggest that nurses might be 'too posh to wash' (e.g. Hall, 2004, Gill 2004, Chapman and Martin 2013) presented the argument that academic ability and compassion were not exclusive (Buchanan-Barker and Barker 2004) any more than *'advanced clinical skills and compassionate care are not mutually exclusive'* (Davison and Williams 2009a) and that compassion *'seeks to regain the balance between the humanistic and technical skills necessary for effective healthcare'* (Sykes and Durham 2014, p35). Although Newton (2010) does suggest that compassion is often even more important to patients than technical procedures and treatments.

3.2.3.4 Examples of compassion

Rodgers (2000, p96) advises that the evolutionary method for concept analysis that she developed is inductive and that any exemplars of the concept under investigation should be identified rather than constructed. This idea is one of the key differences between this method and that of many other forms of concept analysis, such as Wilson (1963), who suggest that the development of a model case is iterative and requires the investigator to create the definitive model based on an amalgam of the key elements of the concept.

The literature reviewed in this study presented a large number of examples of compassion in healthcare and these could, broadly speaking be divided into actual stories of compassionate practice and care from healthcare staff and authors own opinions or research findings as to what constitutes compassionate care. As an example of the 2 categories, Adamson (2013b, p64) suggested that '*simple acts such as smiling and making introductions*' were found to be helpful but also related the story of a student nurse who was caring for a confused patient. The patient kept saying that she could not see, others had attributed this to her state of mind but the student nurse found her glasses and so reduced the patient's fear and distress. Both of these examples were added to the data framework as examples of compassion. Any such descriptions in all of the 100 articles reviewed were included in the data collection, thus reducing the risk of what Rodgers (2000) describes as the researcher failing to exercise neutrality and selecting exemplars that represent personal interests.

Forty-nine authors included examples or stories of behaviours that demonstrated compassion and, understandably, these often reflect the antecedents and attributes already presented. It is helpful, however, to understand these attributes in the context of healthcare and the examples given do serve to enhance the understanding of how the behaviours were able to demonstrate compassionate care. Wherever possible, the example has been supported by a specific story that the author has included to act as an exemplar.

A theme that was evident in the examples cited was that of the physical **presence** of the healthcare staff and a number of authors described the need to maintain or give eye contact (van Der Cingel 2011, Badger and Royse 2012, Forrest 2011) or a 'meaningful look' (Buchanan-Barker and Barker 2004) an 'understanding look' (Chochinov 2007) a glance (Warmington, 2011). Clearly, how healthcare staff looked at a patient mattered, and this was also evident in the examples of the need to smile (Curtis 2014, Badger and Royse 2012, Adamson 2013 and Perry 2009). *'They remember the nurse who adjusted their pillow, who explained the test results in everyday language, who gave their medication with a smile instead of a frown, these small actions convey something more; they convey compassion'* (Perry, 2009, p19).

Allied to this was the need to provide **appropriate body language** (Forrest 2011, Dunn 2012), gestures (Warmington 2011) and to touch the patient (Warmington 2011, Fry et al 2013, Buchanan-Barker and Barker 2004) a 'light touch' (Mooney 2009) or 'gentle touch' (Chochinov 2007).

Peters (2006, p43) further explored touch in the following example,

'...another stayed at the bedside of a patient dying of cancer. She said: I spent a fair amount of time really just holding his hand and being there for him. I couldn't do anything. His pain was relieved. I couldn't do anything about his O₂ level. The only [thing] I could really do for him was to sit with him and hold his hand'.

Dossey (2007, p1) described the impact of this seemingly simple interaction, *'The nurse simply held my hand. Her lingering touch conveyed to me – silently, powerfully, unequivocally – that everything was going to be all right'*. The importance of holding a person's hand was also

mentioned by Wright and Sayre-Adams (2006) and Fry et al (2013).

Hudacek (2007, p128) movingly recounts the following story from a study participant,

'I sat there beside him and reached for his hand. He looked me deeply in the eye; there was no place to hide. His eyes were so trusting as he asked, "Is it time?" "Yes, Frank, it is time." He died peacefully, the epitome of dignity and self-directed care.'

Frank's story also served to exemplify the idea that care staff need to be 'present' and to be so even in the face of death and suffering and when there is nothing they can do to affect the patient's condition. Indeed, the idea of 'presence' became the therapeutic endeavour, especially in the face of seemingly no therapeutic options (Vivino et al 2014), Peters (2006) describes this as the wish to do something and even if unable to make the patient better staff could make the experience better. Kearsley (2011, p216) reiterates this need to be not only present but to reassure the patient that you would stay and would not abandon them, *'...it is sometimes simply enough for our patients to perceive that we are with them in their struggles, and that we are on their side'*. Forrest (2011) adds to this with *'...nursing someone who is dying may sometimes mean simply being present and offering companionship, while accepting the inevitability of the patient's death'*.

Touch was also highlighted in the examples of carers who would provide a pat on the back (Graber and Mitcham 2004) or a hug (Apker et al 2006) and Kayser-Jones et al (2005, p19) included the following, *'...the nurse said, "You can't go to sleep without giving me a hug. He gave me the most wonderful hug; it was so reassuring'*. Badger and Royse (2012, p775)

describe the care of a burn survivor, who said, “*everything was wrapped*” except for the toes on her right foot. She remembered a care provider who touched her toes while talking to her and “*that meant more than anything to me*”.

Expanding on the idea of touch, appropriate communication in all forms was also highlighted by a number of authors. Several mentioned the importance of ensuring patients were welcomed by staff and that staff introduced themselves (Adamson 2013a and 2013b, Graber and Mitcham 2004, Badger and Royse 2012) and of always using the patients preferred name (Warmington 2011, Dewar 2013). The importance of both introducing yourself and using names was highlighted by Kate Granger in the ‘Hello, my name is’ campaign which she started in August 2013 (NHS Employers, 2018) after becoming frustrated with the number of staff who failed to introduce themselves to her when she was an inpatient with post-operative sepsis. This campaign quickly gained momentum with over 400,000 staff signing up to the values and action promoted by the initiative within the first 2 years (Kmietowicz, 2015). Kate, in an interview, said that introducing oneself to patients is ‘the first rung on the ladder to providing compassionate care’ (BMJ Confidential 2014, p7697) and it would appear that the findings from this literature review support this belief and also suggest that the success of the campaign may have been because it was ‘sowing a seed’ in very fertile ground.

The importance of effective communication was seen as a way of recognising the patient and is allied to the idea that patients are individuals

and this needs to be recognised in order for care to be compassionate. Spandler and Stickley (2011, p559) recognised the importance of validating a patient's suicidal feelings as '*legitimate, genuine and authentic*' whilst Ekstrom (2012) also described the need to validate, in this case the severity of a patient's pain. Ekstrom uses stories of different patients who had significant dental pain; one patient who described severe, debilitating and distressing pain was disbelieved by a number of doctors (more than 20) until a specialist made the correct and confirmatory diagnoses and both treated the pain but, crucially, believed her account. Forrest (2011) also describes the need to validate what the patient says even when the clinician may not share the same opinion. To ensure that the patient's perspective could be appreciated there is a need to have a '*genuine interest*' in the patient (Kearlsley 2011 and Forrest 2011), commit to them (Warmington 2011), pay attention to details and to follow through on what has been agreed (Badger and Royse, 2012).

Understanding and recognition of the needs and preferences of the patient was described by Dewar and Nolan (2012), Badger and Royse (2012), Curtis (2014) and Vivino et al (2014). This recognition was also related to seeing the patient and not simply the illness or disease they suffered with – this was very evident in the study findings of Badger and Royse (2012) and was similarly and evocatively described by 2 separate authors, in an account of a patient who said '*I'd like my doctor to scan me, to grope for my spirit as well as my prostate*' (Chochinov 2007, p186) and by Paterson (2011, p22) as '*be bonded with me for a brief space, survey my soul as well as my flesh*'.

This idea was demonstrated in a story included in the article by Kearsley (2011) who describes seeing a patient, Wal, in a clinic appointment having treated him for prostate cancer 8 years earlier. Kearsley thinks he is cured and the medical students that are with him are clearly not interested in the consultation and keen to go for a meal break but Kearsley, as his clinician acknowledges the patient and chats with him.

'We finish – I thank Wal for his stories and for coming. "Your prostate cancer is under good control Wal, and your PSA is normal." "See you in another 6 months' time." Wal stands; we shake hands, he turns to leave – and dissolves in tears. "All I wanted was someone to listen." No one speaks. He hugs me. None of us can speak. Wal left. We were no longer hungry. There was silence' (p219).

The recognition of the encounter clearly affecting all concerned is something that will be explored further in the next section, which analyses the consequences of compassionate care.

The idea of patient **awareness** and focus continued in the literature and the word '**attentiveness**' and the allied 'attention' were mentioned a number of times (Warmington 2011, van Der Cingel 2011, Greenberg 2011, Dewar and Nolan 2012, Badger and Royse 2012) and indicated the need to listen to the patient and hear what they were saying. Greenfield et al (2008, p1160) agree, *'I really try to understand what the patients are saying. I really, truly think there are a lot of people who need that. . . letting them talk'*. To do this staff need to be comfortable with and able to promote silence (van Der Cingel 2011, Mooney 2009, Buchanan-Barker and Barker 2004) with Kearsley (2011, p216) describing this as, *'accepting stillness, engaging with the silence. Silences can often penetrate those places where words cannot go'*. Warmington (2011) also noted the idea of 'stillness' and van Der Cingel (2011, p676) acknowledges the need

sometimes to '*slow the pace*' to enable connection with the patient and '*pulling up a chair to sit next to the bed*'. Clearly there was also the need to listen and this was highlighted in a number of the articles and demonstrated by the story by Peters (2006, p42) in her exploration of the experience of nurse educators:

'I could hear that her need to go home was more important than her need to be in clinical and be a good student and meet expectations and not be absent and all of those other things. I could support her in that. Sometimes, you do those things and you're just very happy that you listen to what's going on'.

The need for patients to be able to **talk and to be heard** was expanded upon by authors who also highlighted the need for them to be able to tell their story (van Der Cingel 2011, Dewar and Nolan 2012, Kearsley 2011) and this served 2 purposes, to ensure their individual needs might be met but also to acknowledge the individuality and uniqueness of each person. This possibility and the idea of person-centred care could be achieved by open communication (Dewar 2013), listening carefully and also communicating regularly between staff to ensure patients' needs and preferences were known (Black, 2008). Meaningful communication is a skill and authors gave practical advice as to how this should be approached. Being honest and using realistic language (Perry 2009, Adamson 2013 and Forrest 2011), the appropriate use of 'small-talk', banter and humour (Fry et al 2013, Apker 2006 and Dewar and Nolan 2012) and even 'scripting' key words and phrases. Gould (2008, p430) described the following, '*...a simple initiative of proactive 'scripting' key words and at key times, ending with: 'Is there anything else I can do for you at this moment I have the time?'*' Explaining things clearly (Wenrich et

al, 2004) and instilling hope without compromising truth and reality was also identified as compassionate (Forrest, 2011).

The idea of ensuring **enough time** was also highlighted and in the case of examples was linked to giving enough time to effectively relate to and hear the patient, allow them to tell their story (Adamson 2013a, Gould 2008, Kearsley 2011, Forrest 2014, Wenrich et al 2004). Forrest (2014, p38) described this as follows, *'even if you are short of time, convey a sense of having time for the patient by facing them and listening to them, giving them the opportunity to respond, reflect and react to your questions'*. Gelhaus (2011) describes the importance both allegorically and in reality of not looking at your watch when a patient needs help and Dewar and Nolan (2012, p1251) recount a very patient-focussed way one nurse spent their time.

'A lady had been in for a couple of weeks when she began to deteriorate. She was quite a proud woman . . . She would always brush her hair and would put her makeup on. She got quite poorly . . . and eventually she lost consciousness. Her husband was coming in every day – they had been married for over 50 years. One day, when I was giving her a bed bath. I found her makeup...so I thought I would put it on. I don't know if she was aware that I was doing this. A few members of staff went in afterwards and kind of laughed and said, what is the point, I think they thought I was a bit daft and slightly time wasting. When her husband came in, he came out of the room and said 'who put her makeup on? She looks lovely, she looks like herself'.

This idea of doing things for people which acknowledged their specific preferences and recognises them as individuals was highlighted by Crowther et al (2013, p494) in a story concerning an elderly gentleman with dementia who had been admitted to hospital. A secretary who was talking to his wife said *'I believe your husband likes nice coffee, he can*

have a nice cup of coffee with me', and so she brought special cups in, biscuits and 'nice' coffee for him. Snell (2013) describes the actions of a ward cleaner who helped someone's father by finding him extra pillows and a fan when he was hot and Hehir (2013, p111) included this story.

'When asked what she would like to eat or drink, Lily reminisced about holidays at the seaside and said she would really like a soft ice cream. The hospital ice cream machine had broken down and Owen agreed with Sarah that he would drive to McDonalds at the end of his shift. He returned with the ice cream and Lily's friend helped her to have this. Lily died some hours later'.

Perry (2009, p18) describes an exquisite and gentle tale of focussed care,

'Helen was bathing a lady with dementia who was afraid to have a bath. So, carefully, Helen prepared the room, laying out all of the items she would need to perform the bath smoothly and without interruption. Towels were warmed in the dryer, shampoo and fresh nightwear were at the ready. The water was poured so the room was quiet when she brought the lady for her bath. As the lady began to protest Helen quietly talked in a soothing voice saying, "It's okay, I've got you", "This is going to feel good" and so on. As Helen washed the woman gently she hummed softly and the client began to relax and enjoy her bath experience. Nothing was rushed but everything was done in reasonable time and in the end the lady, towelled and pyjama clad, smiled and hummed too.'

In the pressured environment characterised by many modern healthcare facilities such a seeming luxury may seem implausible however, Perry (2009, p19) describes several other interactions with patients and that by focussing on their preferences and needs,

'I don't actually spend more time doing things the way he prefers. I follow his lead and the care gets done and we are both a lot less stressed. I think the key is I asked and I listened and I proved I cared by remembering his preferences'.

Greenfield et al (2008) found that it was important to ensure decisions about a patient's goals were 'mutually agreeable'.

Practicing and demonstrating **self-awareness** was an example given by some authors; Ekstrom (2012) describing the need for physicians to

acknowledge that if they could not help the patient then they must work 'diligently' to find someone who can. Greenberg (2011) echoed the attribute described in the previous section of focussing on the patient as if they were a member of your own family but explains the process that enables him to do this and the language he might use. Both Greenberg (2011) and Forrest (2011) suggest that there is a need to apologise if you make a mistake or keep people waiting however unavoidable this might be.

Giving of yourself was a theme that was evident in a number of examples and stories and does seem to suggest that staff are more willing to let down 'professional barriers' that some writers suggested were a necessary part of self-protection for healthcare staff (see discussion in previous section). Dewar and Nolan (2012) describe sharing personal information and Curtis (2014, p214) included a testimonial from a student nurse who said that 'you give a piece of yourself'. Vivino et al (2014, p160) wrote, *'It's simply for me the openness to be present to another's difficulties and suffering ...the willingness to be there and open oneself to receiving and connecting with the person'*. Graber and Mitcham (2004, p92) illustrate this in the following example,

'...she described her interactions with a young female patient whose first 2 childbirths were unsuccessful. This nurse even attended the funeral of one of the patient's infants. Somewhat later, there was a third pregnancy and the nurse allowed the woman to attend free childbirth classes (as she did not have insurance coverage or funds to pay for the classes). The third pregnancy was successful and the nurse who was present during the delivery said of this. "... it was a celebration of our spirits—of our very beings" '.

It is to be noted that the nurse recounted it as a celebration of 'our' spirits – it was implicit that compassionate care required that they share the

experience. Spandler and Stickley (2011, p558) echo this in the idea that there is a need to '*draw attention to the common humanity*' underlying the patient experience.

As with the attributes highlighted by the literature, caring for a patient's 'basic needs' was seen as an example of behaving compassionately (Perry, 2009) and to do so whilst preserving dignity (Badger and Royse, 2012).

Finally, recognising that compassionate behaviour is **equally important when working with colleagues**, several authors highlighted specific behaviours that represented examples of this. Dewar (2013, p52) described the need to give '*positive, specific feedback*' and to consider the perspective of all of the team rather than simply believing that the individuals' belief is right. Encouraging people to find their own solutions to problems rather than simply telling them what to do and to be brave when there was a need to challenge behaviours that have a negative impact were also highlighted by Dewar (2013) which reiterated findings from a study the previous year investigating a model to implement compassionate care for older people (Dewar and Nolan 2012). This study also highlighted the importance of thanking staff at the completion of demanding shifts and to make a point of commending people when they did well. The need to challenge on behalf of patients was again mentioned,

'one of the patients was blind and agitated, we asked what was important to her, she replied 'Being read a chapter from the Bible, John 14' . . . there were no longer any Bibles. . . they had been removed because of equality and diversity issues and infection control. Staff went to the Chaplaincy Centre and managed to retrieve one, following discussions with the chaplain, copies of

Bibles and Korans were reinstated in all wards. It would have been easy for staff to give up but they persevered demonstrating that the organisation could be challenged' (p1252).

Wright and Sayre-Adams (2006, p21) reinforce this idea and suggest that it takes '*love to argue the case for services someone needs*'. Finally, Apker et al (2006) described the attributes of compassionate leadership as a willingness to listen, engaging staff in stories about them and their lives, being positive, funny, warm and friendly. Feeling that staff could trust this person and that if they approached her with a problem, she would listen and then deal with it. It would appear that the needs of staff to feel compassion are very similar to the needs of patients, again reinforcing the common humanity of patient and carer.

3.1.3.5 Consequences

Toftagen and Fagerstrom (2010, p27) describe this element of Rodgers's method as '*the result of the use of the concept in a practical situation*', and Sadler (2000, in Rodgers and Knafli) describe the idea of consequences as being either what happens after an instance of the concept or what results from it. Exactly three quarters of the included literature cited statements or examples that described the consequences of compassion or, crucially, a lack of it. In terms of positive consequences, examples and descriptors were clear; when considering the negative consequences it seemed as if there were two separate elements. Negative consequences could result because of a lack of compassion when caring for patients but also, could occur because healthcare staff were compassionate.

Firstly, the positive consequences and a number of authors suggested that compassion was, of itself, a **therapeutic entity** and promoted healing. Warmington (2011, p328) stated that compassion could '*promote healing*' whilst Perry (2009, p18) suggested, '*when the nurse addresses basic care needs in a compassionate way, patients are left psychologically intact. Individuals are placed in a state that may allow optimum physical healing or improvement in physical conditions to occur*'. Healing as an outcome of compassionate care was also mentioned by Schantz (2007), Kret (2011), Dossey (2007), Coulehan(2009), Kearsley (2011) Larkin et al (2009), Cornwell and Goodrich (2009), Larkin (2010), Gelhaus (2011) and Vivino et al (2014). Others who did not specifically mention the word 'healing' did, however, describe the benefit to patient's physical wellbeing when in receipt of compassionate care. For instance, Keogh (2014) feels that compassion results in better engagement and therefore better compliance with medical advice and van Der Cingel (2011) describes compassion as helpful in ensuring the right information is forthcoming and that this leads to the right care outcomes and that compassion is therefore 'an instrument of care'. Cornwell and Goodrich (2009) agree and write, '*... compassion affects the effectiveness of treatment. For example, patients who are treated by a compassionate caregiver tend to share more information about their symptoms and concerns, which in turn yields more accurate understanding and diagnoses.*'

A further consequence was the manifest benefit to the employee, employer or organisation if there was a culture of compassionate care.

The introduction to this study (Chapter 1) described the poor publicity that

healthcare professionals had received because of various reports and circumstances that identified poor care, Cornwell and Goodrich (2009) state that a *'lack of compassion fuels media outrage'*. Compassionate care, in contrast was seen as a way of ensuring a high level of patient satisfaction. Badger and Royse (2012, p772) suggest that *'compassionate health care is...valued by patients and can financially affect institutions'*, a concept echoed by Georges (2011, p134) who describes compassion as *'a premium that could, in time, become a powerful marketing tool for their institutions'*. Newton (2010, p10) describes compassion as one of the *'three top answers of what patients valued'* and this idea that compassion was a vital component affecting patient perception of their care was also endorsed by Mickel (2008), Dunn (2012) and Peters (2006).

Beneficial to employee or patient alike, compassion was seen as having mutually beneficial consequences. Nyatanga (2013, p299) suggested that *'compassion breeds compassion'* and Greenberg (2011, p105) that compassion *'connects us deeply with our patients, offering us both a greater sense of satisfaction in the interaction'*. Dewar (2013) states that giving compassionate care provides both pleasure and can positively affect a person's mental wellbeing and Kret (2011) felt that compassion *'empowered'* nurses. Kagan (2014, p69) also highlights the reciprocity of benefit, *'compassion is a mutually beneficial emotion that promotes health and well-being for those who feel it and those who benefit from its expression'*. This mutual and positive response felt by those providing compassionate care was a theme in a significant number of articles, an

important consideration when subsequently looking at the 'cost' of providing compassionate care.

One consequence could result in good or in ill, dependent upon whether a person was treated with compassion or, alternatively, if this was lacking. Authors highlighted the lasting impact of care in a patient's memory. Crowther et al (2013) cite an example of a daughter who was still experiencing negative effects 9 years after her father's death who was perceived to have been treated without compassion. Cornwell and Goodrich (2009) describe this as, '*it is the presence or absence of compassion that often marks the lasting and vivid memories patients and family members retain about the overall experience of care in hospital and other settings*'. Kearsley (2011) and Graber and Mitcham (2004) describe the positive impact on patient experience and Forrest (2011) reinforce the idea that, '*the kindness of nurses has transformative powers in these situations and may be remembered and valued for ever*'.

Crucially, in an era where health care provision has likely never been under such intense and sustained pressure, a significant number (10) of authors felt that to be compassionate resulted **in efficient care**. From specific examples such as, '*...you can see that when patients experience compassion that the effect is that they do not ring the bell anymore . . . simply because they get their share of genuine attention*' (van Der Cingel 2011, p683) and '*What we know is that if people feel cared for, then it is actually time-saving because you head off problems before they start*' (Trueland 2009, p21). In the study by Perry (2009, p19), a nurse stated

that, *'In the end I don't actually spend more time doing things the way he prefers. I follow his lead and the care gets done and we are both a lot less stressed'* and Dossey (2007) cited a study which demonstrated that when homeless people were treated with compassion the number of repeat visits to ED diminishes. To the practical benefits of being compassionate, *'... the expression of compassion sustained and supported them rather than tiring or weakening them. There is an important link between staff wellbeing and the quality and safety of care delivered'* (Dewar 2013, p50) an idea echoed by Graber and Mitcham (2004). Hughes (2013, p307) succinctly describes this as *'the win win—a focus on compassion is more efficient, as staff feel happier and more fulfilled. Patients/residents are safe and families rest assured the best care is on offer'*.

Compassion was seen as such an indispensable aspect of **humane care** (van Der Cingel 2009 and 2011, Schantz 2007, Straughair 2012, Kapitan 2011 and Peters 2006) that it was felt that this quality should therefore be integral to any new initiatives and guidelines. *'Compassion...a quality which must surely underpin all new innovations, policies and practices'* (Spandler and Stickley 2011, p563). Both a consequence and an antecedent, compassion was seen as a fundamental element of care provision (Dossey 2007, Newton 2010, Murinson et al 2013) with Georges (2013, p7) so convinced by this that the consequences of compassionless care would be that, *'when compassion disappears, we are no longer nurses'*.

Compassion was seen as a **vital component of patient care**, as important, if not more, than clinical expertise (Graber and Mitcham, 2004) to the extent that even when technical care was accomplished the overall patient experience could still be unsatisfactory (Larkin et al, 2009). Fry et al (2013, p43) describe this as, '*It is the connection between these 2 skill sets – clinical and compassionate care – that can create optimum care for patients*'. Kagan (2014, p70) concurs, stating '*compassion frames the knowledge we possess as geriatric specialists and enables us to individualise the care that uses theoretical knowledge and scientific evidence for each patient*'.

Finally, in terms of the positive consequences of compassion, a number of authors cited the specific consequence with such specificity that they can simply be 'listed' as a consequence. For instance, 6 authors stated that to be compassionate reduced the patient's suffering and 5 that it helped the formation of therapeutic relationships. In addition, either 1 or only a small number of authors mentioned other, distinct consequences but, these consequences remain valid indications of what the literature demonstrates and should, therefore be included. These consequences of compassionate care have, therefore, been included in the following table:

Consequence	Reduces suffering	Provides dignity	Enhances the quality of care	Improves communication skills	Recognition and acceptance	Increases trust	Empathy
Number of times cited	6	5	4	4	4	4	4
Consequence	Provides comfort	Helps build therapeutic relationships	Provides safety	Empowers	Pain and/or anxiety vanishes	Compassion breeds compassion	Understanding
Number of times cited	3	3	3	3	3	2	2
The remaining consequences, listed here, were all mentioned once		<p>Promotes independence, autonomy, results in kindness, gives purpose, meaning and hope, unites people, offers consolation, enables understanding of 'difficult' patients, makes people perform to their best, supports professional practice, makes the intolerable bearable, provides justice, promotes knowledge and awareness, a sense of inclusion, protects, maximises evidence based care, increases cultural and spiritual sensitivity, creates partnership, gentleness, invisible balm, peace and ensures patients are heard.</p> <p>In addition – for staff, potentially more pay, validation by the relevant regulatory body and the creation of a better learning environment. .</p>					

Table #4 The consequences of compassionate care

Compassion, whilst seen as fundamental to care, could also have **negative consequences**, for patient and caregiver alike. The first, and by far away the most frequently cited, was the consequences that resulted when care was delivered without any compassion. The previous 4 categories of data analysis (surrogate, antecedent, attributes and examples) were noticeable for the predominance of positive examples. The idea of less favourable consequences clearly excited the interest of the authors and 25 authors described the impact of compassionless care.

These consequences include becoming '*desensitised to things that matter to patients*' (Adamson, 2013a, p61) and service users describing themselves as '*survivors of services*' (Spandler and Stickley 2011) who also described care without compassion as 'iatrogenic'. Hehir (2013) believed such care could result in '*cruelty*', '*rudeness*' and a '*lack of finesse*', Ramesh (2013, p69) as '*disenchantment, a loss of empathy and emotional withdrawal*' and as '*alienating*' by Hawkes (2012). Wenrich et al (2004, p239) describes compassionless care as '*cold, rude, inhuman, distant*' and of giving a sense of abandoning the patient'. Paterson (2011, p22) reminds the reader that '*without some recognition, I am nothing but my illness*'. In addition, Ekstrom (2012, p168) highlighted the very real and significant seriousness of failings in compassion by describing '*...individuals who have committed suicide over lack of validation and help from the medical profession*'.

As well as the emotional toll of care without compassion there were also practical implications, Warmington (2011, p330) states, '*...when a lack of a sense of connectedness limits the exchange of important information, data which are critical to good diagnosis or treatment may fail to be communicated*'. Gould (2008, p430) suggested that '*... lack of compassion equates to inferior, dangerous maternity care*' and Maben, Cornwell and Sweeney (2010, p10) write that without compassion, patients were, '*certainly not seen as partners in the care process and were often kept in ignorance of their diagnosis and plan of care*'. Ekstrom (2012) described the consequence of the failure of compassion as resulting in poor medical decision making.

Finally, there were negative consequences for staff because of compassionate practice - as counter-intuitive as that may sound. Keogh (2014, p7) cited a study by Kinman and Leggetter (2014) which found that *"...those required to display higher levels of compassion were more likely to feel drained because of the need to manage their feelings in front of patients"*. van Der Cingel (2009, p128) suggested that *'reactions to suffering encompass different kinds of emotions. These emotions can evoke and obstruct compassion' and that 'too much compassion can end up in self-sacrifice'*. In the study undertaken by Torjuul, Elstad and Sorlie (2007, p526) the findings suggested that *'nurses declared that their sensitivity to patients' suffering had increased, and that perceiving suffering had become more difficult to endure as they became more experienced'* and research by Greenfield et al (2008, p1163) found that *'over involvement as a caregiver is, in fact, antithetical to an ethic of caring, reflecting instead a need to control and dominate a situation'*. This rather unsettling idea was also alluded to by Gelhaus (2011, p402) who wrote *'...there remain three doubts about its desirability as a professional attitude: the fear of overstraining, of condescension and of injustice'* and that *'concentration on one patient who has aroused a caregiver's compassion at the expense of all others might be a problem for the concept of compassion'*. Gelhaus (2011) cites the stoic philosophers who promote the idea that compassion promotes sorrow and that this sorrow is a hindrance to providing effective care. Larkin (2010, p107) gives a more contemporary but similar view; *'there is a suggestion that compassion*

blurs professionalism and impinges on the objective stance of rational science’.

In her 2013 article, Smajdor (who has written widely about the negative impact of compassion on the effectiveness of health care staff) reinforces this idea, suggesting that the frequency with which nurses witness suffering results in a lack of resources to respond to everyone’s needs. Buchanan-Barker and Barker (2004, p19) go so far as to suggest that *‘for many of us, the reflection of our own suffering and frailty is too hard to bear. Compassion even carries a health warning – the risk of secondary traumatic stress disorder’*. Curtis (2014, p219) studied student nurses and observed that they had *‘concerns about the emotional requirements for compassionate practice that left them feeling vulnerable and uncertain. This in turn left students at risk of abandoning their compassionate practice ideals and behaviours’*. Importantly, Murinson et al (2013, p348) highlight that such an idea may not be supported by research,

‘..in the absence of substantive evidence, it is not infrequently asserted in the popular press that compassion is unhealthy for physicians, interfering with clinical decision making and contributing to burn out. To date, studies of other allied health professions suggest that compassion may actually be a source of satisfaction for providers’.

3.3. Summary of Section 3.1

This literature review represents a substantial body of work; Hart (2018, p) identifies 7 pillars of such a review:

- Identifying information needs
- Scoping information available
- Planning a logical search
- Gathering relevant information
- Evaluating information sources
- Managing process
- Presenting findings.

The rationale for the review, the material included and the process and method have been clearly explained to ensure all 7 pillars have been addressed. The findings have been presented under 5 headings and demonstrate that the concept of compassion is a complex and multi-faceted one. However, in each of the 5 categories there were descriptors that occurred more frequently than others and thus would seem to be more significant. The implications of this review and any subsequent recommendations will be discussed in the final chapter of this study as the literature review has been carried out as one part of the concept analysis and the intention is to combine the findings with those of the fieldwork element of the study to provide the final, definitive concept analysis.

It was clear that authors do use terms interchangeably and as surrogates when writing about compassion and those writing about care and caring were often describing very similar ideas. Empathy was also described frequently although this was a more divisive term, less frequently cited but also less controversial were the synonymous terms of kindness, humane, loving, person-centred and sympathetic care.

Such care, to be compassionate, needs to be delivered within an organisation that values and promotes compassion as a priority for patients and staff alike. The working environment needs to be resourced effectively to ensure that staff have the time, the practical means required to care for patients and that they are not themselves suffering levels of pressure and stress that prevent compassionate practice. Whilst seemingly an oxymoron, suffering is required for compassion to be present but, crucially, that suffering needs to be recognised and there needs to be a definite will to alleviate it.

Compassionate staff need to have certain attributes for compassion to flourish and these are both pre-requisites and elements of compassionate care delivery. This is crucial as compassion is seen as an expectation, a basic requirement of care provision. Key to ensuring this is the relationship between the patient and the care provider and this relationship needs to be that of human-to-human, without judgement where the patient is seen as an individual and where their needs and preferences are prioritised. Care staff need to both see the patient and to listen to their story attentively as this will enable them to accurately inform the patient whilst also protecting and keeping them safe.

Compassion is an active element of care; this is what differentiates it from empathy, and it is the impact of suffering that mobilises the compassionate caregiver to action. Care that is compassionate does not need to be technically complex; 'basic' care provided by respectful, sensitive, concerned and loving staff is as compassionate as any specialised or 'expert' engagement. Whilst being overly technical or academically qualified was viewed with caution, compassion is the mediator that ensures such attributes of staff translate into meaningful care.

It was seen as important to be kind, empathetic, sympathetic - all those attributes listed within the review but actions were also important. Body language, facial expression, eye contact and touch are vital components of compassionate care. To hold a patient's hand, if that is their need, was mentioned too many times to be anything other than a vital component of compassionate care. To be welcoming and respectful, using the patients preferred term of address and being present and to act as a witness are defining examples of compassionate behaviour.

In order to be a compassionate clinician it can be necessary and desirable to give of oneself, to share in the common humanity that binds patient and caregiver in the shared experience, sometimes going above and beyond what might be expected. However, such an emotional and impactful relationship can have consequences for both patient and staff.

Staff need to be self-aware and ensure that their own care and resilience is prioritised along with that of their colleagues. Without this, it becomes almost impossible to provide compassionate care for others. The balance between selflessness and self-preservation is important and an awareness

of this need and the resources (both external and internal) to serve this need are necessary. Compassionate care must be prioritised in this way as, when patients are not treated with compassion; the consequences can be devastating and long lasting.

As long as there can be an element of dispassion – when decisions need such perspective, but that this can be balanced with compassion when required, both staff and patient will benefit. Far from being excessively demanding on resource, compassionate care is efficient, can save time and be healing as an instrument of care in its own right. The evidence from this review overwhelmingly supports the idea that compassionate care is beneficial for the patient, for staff and for the overall organisation that manages the care delivery. Patients view compassionate care as being as important as technical excellence and this must be recognised. Compassion must be the driving force behind new developments and service improvements, guidelines and policies.

Rodgers (2000) suggests that a review of the literature should enable an exemplar case to be identified, as with Schantz (2007) who used the story from the drama 'Wit' (Edson, 1999) as the exemplar of compassion based on her concept analysis. All of the stories included in the 'Examples' section of this review could be seen as exemplars but, based on the evidence described within this study a story of compassion did seem to stand out as exemplifying the findings. Reid (2012, p218) suggested that compassionate care '*went a long way to making intolerable or distressing situations bearable*' and this echoed the experience of Kenneth Schwartz, an American lawyer who succumbed to lung cancer in 1995. His 10 month

experience from his diagnosis until his death led him to believe that compassion was the vital component of his healthcare and that it was this, and not technical expertise, that had rendered ‘the unbearable bearable’ (Schwartz, 1995). Days prior to his death, a substantial legacy from him enabled the development of the ‘Schwartz Centre for Compassionate Healthcare’ in Boston, Massachusetts. An initiative from the Centre, Schwartz Rounds, were trialled in the UK from 2009-2013 by the Kings

Fund, now being supported by the Point of Care Foundation the Rounds run in over 100 NHS Trusts and healthcare organisations (Point of Care Foundation, 2018). The Rounds are designed to support staff, to be compassionate and recognise the emotional and psychological impact that caring can cause and ‘*improve well-being, increase empathy for patients and colleagues and change practice*’ (Maben et al 2018, pvi).

Kenneth Schwartz’s story was reproduced in the Boston Globe (1995) and many experiences that he recounts highlight the impact and importance of compassion but the story that completes this conclusion perhaps most succinctly aligns to the findings of this review.

‘During the period between my two chemotherapies, when I also received high- dose radiation twice a day, I came to know a most exceptional caregiver, the outpatient oncology nurse Mimi Bartholomay. An eight-year veteran who had experienced cancer in her own family, she was smart, upbeat, and compassionate. I had to receive fluids intravenously every day at the clinic, and while there we talked regularly about life, cancer, marriage, and children. She, too, was willing to cross that professional Rubicon -- to reach out and talk about my fear of dying or, even worse, my fear of not living out my life, of not biking through the hills of Concord and Weston on summer weekends with my brother, of not seeing my child grow up, of not holding my wife in my arms. And she took the risk of talking about her own father’s recent bout with cancer. I cannot emphasize enough how meaningful it was to me when caregivers revealed something

about themselves that made a personal connection to my plight. It made me feel much less lonely. The rule books, I'm sure, frown on such intimate engagement between caregiver and patient. But maybe it's time to rewrite them'.

3.4 Literature review revisited

3.4.1 Introduction

As mentioned in Chapter 2, the initial literature review for this study formed the basis for the work and, as such, was the first element of the data collection to be carried out and, whilst the process has to a certain degree, been ongoing was a discreet section of research. The original search encompassed the dates January 2004 through to and including May 2014. As the study progressed and the fieldwork elements were undertaken, the contemporary literature, since 2014, was used to inform and support the continuing work. In terms of ensuring a comprehensive and meaningful literature review, it was clear that this now needed to be updated to include literature published since this date.

The new search provided an opportunity to see if there had been any change following the publication of the key policy documents and review findings mentioned in Chapter 2. The analysis of the 2004-2014 material did demonstrate increasing coverage of compassion in professional literature and that this was predominately opinion pieces or reports with only 29 studies included in the 100 articles reviewed.

The assumption, which would need to be tested, was that opinion-based articles would show little change in terms of surrogate terms, antecedents

or attributes. New examples would be cited and consequences described, but again it would seem unlikely that these would be significantly different in how they demonstrate the concept. The next phase of the literature review was therefore carried out as a separate and discreet element of the study with 3 aims. Firstly, to see if the increasing volume of relevant literature was a continuing trend, secondly to see if there was increasing levels of research directed at the concept of compassion in healthcare and thirdly, to review this research to see if there was any change in how compassion was viewed pre and post the apparently impactful documents of 2009-2013. This approach would ensure that the Literature Review was updated and that the evolutionary nature of the concept (Rodgers, 2000) continued to be addressed. Importantly, bringing the data up-to-date would ensure that the rigour of the study was not detrimentally affected, nor the validity and relevance of the conclusions. In fact, as an added dimension to the study, the inclusion of this second review augments and strengthens the findings and impact of the research.

3.4.2 Search strategy

The search strategy mirrored as closely as possible the original that had been conducted and this was via the databases that were found within NHS Evidence Healthcare Databases including Medline, BNI, AMED, HMIC and CINAHL. The same search term was used, 'compassion' and this had to be found in either title or abstract and both 'compassion fatigue' and 'compassion-focused therapy' were excluded. The search period covered the whole of 2014 (even though this represented an overlap, it

proved too complex to filter out January to May which had been included in the initial review) until November 2018.

This search of just less than 4 years returned 3,589 results which compares with 2,603 in the original search of the 10 years and 5 months. Already a striking result and a very clear indication that there had been a significant increase in the amount of literature concerning compassion since the first review. The increasing trend in the volume of literature was also highlighted by the scoping review of compassion by Sinclair et al in 2016b who nevertheless describe compassion as '*still a nascent area of study within healthcare*' (p 10)

3.4.3 The nature of the literature

As already described, there was neither the resource nor need to completely replicate the analysis of the data but it did seem important to assess whether some of the other trends seen in the original review were changing or not. Therefore a random sample of 10% of the literature identified was selected (by selecting sections of 25 titles at random points in each database) n = 350. The numbers from each database reflected the volume returned in each database i.e. CINAHL returned the greatest number of results therefore 160 articles from this database were included, 100 from Medline, 80 from BNI, 6 from HMIC and 4 from AMED. The search results were based on 'compassion' appearing in abstract and title alone and the 350 selected were from these results and was not therefore comparable to the final literature included in the initial review which was based on scrutiny and subsequent relevant exclusions of the abstracts

(see process map, Chapter 2). However, this exercise is to look at trends in certain demographic information so would still be relevant and of interest. The information was added to the same table format as for the original review and is included below:

Place of publication	N =	Type of article	N =	Year of publication	N =	Discipline	N =
UK	76	Editorial	27	2014	46	Nursing	93
USA	149	Opinion/article	105	2015	68	Medicine	14
Australia/ New Zealand	1	Qualitative Research	99	2016	88	Healthcare Generally	34
Western Europe	3	Quantitative Research	59	2017	92	Allied Health Professions	13
Canada	3	Review/ Report (of e.g. new guideline)	33	2018 (incomplete)	52	Mental Health	35
Other	5	Other	27			Other	161

Table #5 Breakdown of the sample of literature from the database search 2014-18

It is obviously lacking in rigour to compare 2 differing sets of figures and certainly not to draw definitive conclusions from such a comparison. The original table of the first review only includes the 100 final articles whereas this table is the result of 350 random articles selected from title and abstract alone. So, no statistically defensible nor definitive conclusions can or will be forthcoming. This exercise does, however, provide some interesting possibilities and does also provide some illumination as to the evolution of the literature relating to compassion.

The original 100 articles were predominately from the UK and the USA (54 and 30 respectively). The new sample suggests that the dominance of these two countries continues. However, the search strategy only included articles in English so that would clearly influence the origins of the literature. This would not account for the apparent and continuing lack of material from other English-speaking areas such as Canada, Australia or New Zealand nor the fact that many published articles are published in English even though this may not be the native language of the author(s) (Baethge, 2008).

The number of published articles relating to compassion increased each year from 2014-17 (2018 is an incomplete year) and it is therefore clear that there is an increasing interest in the subject. Although this has not been examined specifically, a large number of articles reviewed do cite the policy documents and reports previously mentioned so it would appear evident that these have had an impact on increasing interest and investigation in to the subject.

Nursing remains the healthcare discipline most represented within the literature although a large number of 'other' has been recorded as it was often not possible to determine the target audience nor background of the author(s) from the abstract alone.

Perhaps the most striking trend demonstrated by this sample is the increase in the amount of research studies being reported in the literature – nearly 50% of the sample were either quantitative or qualitative research studies. This finding seemed to be relevant and possibly indicative of an increasing evidence base relating to compassion that was in it's infancy in

the original review. As a result of these findings the original 3,589 responses in the 2014-2018 search were further refined, this time to exclude all literature that was not a report of research studies.

3.4.4 The emerging research base

3.4.4.1 Search Strategy

Further inclusion and exclusion criteria were applied to all databases to identify research i.e. dependent upon the database terms such as *Clinical Study, Clinical Trial, Comparative Study, Conference Paper, Controlled Clinical Trial, Evaluation Studies, Meta-analysis, Multicentre study, Observational Study, Randomized Controlled Trial* etc. were applied – in fact any search term within the database that has a relationship to research was used. Once the same exclusion criteria were applied (compassion fatigue, mindfulness, non-human etc.) 225 studies were identified for further consideration from title and abstract. All of the abstracts were then reviewed by the researcher for relevance, where any doubt was evident the full text document was reviewed. This resulted in 60 studies reported between mid-2014 and November 2018 that detailed research relevant to compassion within a healthcare context, see Appendix VIII for titles. Such a finding is significant, 60 relevant studies in under 4 years in contrast to 29 relevant studies in over 10 years in the original review. It would seem clear that interest in the subject of compassion is not simply increasing but also changing to include the need to examine the concept.

3.4.4.2 Review process

Each of the 60 studies was read by the researcher and the key findings were identified; these were then linked together to identify any consensus or themes. The rigour of the research was not appraised and the content of the articles was not coded and themed as with the original review. The aim of the exercise was to augment and update the main literature review, look for trends and to ascertain whether there were any clear differences in the volume of research, approach or in definitive findings.

3.4.4.3 Findings and implications

The methods employed by the studies are still predominately qualitative; 29 studies were definitely qualitative, a further 12 were literature reviews, 3 utilised mixed methods, 3 were concept analysis of which 2 relied only on literature and 1 was an evaluation. Only 12 of the 60 employed quantitative methods and this was highlighted as an issue by Blomberg et al (2016) who analysed research studies aimed at evaluating interventions to improve compassionate nursing care. Their analysis of 24 studies demonstrated a lack of methodological quality overall and a dearth of randomised controlled trials. Further, in terms of the research base for compassion interventions, they suggest that the weakness of the methodological approaches identified may result in overly positive reporting of findings and that those studies they identified as more vigorous were more likely to present negative effect. They conclude that the need for research into the subject of compassion remains compelling but that this needs to be addressed with more robust research design.

The amount of studies based on reviews of available literature was significant, both in volume but also because this study also utilises a literature review as a significant component of the research.

Unsurprisingly, much of the literature included in the original review in this Chapter and even some within this second update also appear in some or all of the 12 reviews and 3 concept analyses. Whilst this then requires consideration in terms of what new or different information can be discovered from the review within this study, there is also a degree of triangulation within the findings of the 15 literature-based studies discussed here and the one that is described within this Chapter. Such levels of similarity, as well as widening the scope for understanding a body of even broader literature also infer greater credibility on the findings by acting as a body of confirmatory evidence. This will be discussed further in Chapter 6 of the thesis.

Whilst the research is still dominated by the USA and the UK, other countries are also increasingly interested in how compassion affects healthcare. Interestingly, the emergence of research from Canada appears to be attributable to one specific author and team with 6 of the 8 articles being authored by them. This does then pose an interesting question; whether a significant amount of research from one person or group in one area could possibly influence perceptions of the subject in a way that could be biased. Little research on the specifics of this question could be found in amongst the significant literature about bias in research methods but it did seem compelling that such an evident volume of research was being authored by the same person or group of people and that the background of the researcher, palliative care, had informed a

number of those studies. It is difficult to offer such a perception when, overall, the literature published by this author will undoubtedly raise the profile of compassion as a subject of interest. However, as an example of concern, a 2016 study investigated 53 patients with advanced cancer to discover how they understood and experienced compassion in clinical care (Sinclair et al 2016a, p193). The study concluded that the results, 7 categories with distinct themes constituted a model, '*the first empirically based clinical model of compassion*'. They further suggest that such a model could then be used to inform future '*research, measures, training and clinical care based on this vital feature of quality care*'. It could be argued that patients facing end of life care may view compassion quite differently from someone experiencing a very disparate element of healthcare – planned surgery, maternity care, mental health support and so on. The issue of how the research base impacts on the perception of compassion will be discussed more fully in Chapter 7.

Nursing was the most common discipline within the 60 research studies; 26 detailed research specifically concerned with nursing whilst a further 22 looked at compassion within a wider healthcare environment which included nursing. Patients were included in 8 of the studies and medicine provided the background to a further 7. Mental Health practitioners (both nursing and physicians) were studied in 2 and there were single studies that also included members of the public, carers and healthcare providers. The predominance of nursing in researching compassion appears to be consistent and the lack of patient involvement in research continues and this was an issue highlighted as concerning by some researchers (Bramley and Matiti 2014 and Sinclair et al 2016b).

Perhaps the most significant finding from a review of the 60 studies is the frequency of discussion concerning the responsibility and impact of the healthcare organisation on the provision of compassionate care for patients. Twenty-four of the studies definitively conclude that the culture and emphasis of the healthcare organisation is key in enabling or blocking compassionate care and, whilst this was a major theme in the original review, this represents an increasing level of relevance (29% of studies cite organisational responsibility in the first review and 40% in the later studies). Crawford et al (2014, p725) suggest that '*reducing the threat posed by production-line mentality, with its instrumentality and time obsession, may rehumanise care*'. Henshall et al in 2017 agree stating, '*that compassion is a systemic issue, to be tackled at all levels of the NHS and not just within individual employees*' (p248). Whilst there was evidence that this was a common finding, Bray et al (2014) uniquely found that workplace and institutional pressures did not erode levels of individual compassion and this idea of individual as well as corporate responsibility was endorsed by Jones et al (2016) and Singh et al (2018).

An emerging theme in the literature is that of research which either informs or evaluates frameworks designed to promote compassionate practice. Curtis et al (2017) presented findings following an appreciative inquiry into the implementation and evaluation of the Cultivating Compassion programme which was also the subject of a study by Ramage et al (2017). Hewison et al (2018) evaluated a scheme aimed at promoting compassionate organisations, Bridges et al (2017) reviewed a programme aimed at developing compassionate leadership whilst Adamson and Dewar (2015) investigated student nurses experience of the Leadership in

Compassionate Care Programme which sought to capture what compassion meant in practice and how this could inform education. Sinclair et al (2018, p11) conducted a grounded theory study into the utility of the Healthcare Provider Compassion Model and determined that it, *'...provides a foundation that defines compassion in healthcare and its provision at the bedside. It may lead to the development of clinical tools to cultivate the requisite knowledge, skills, behaviours and qualities to enhance compassionate care to others'*.

Moore et al (2017) describe a study to assess the success of implementing The Compassion Intervention model to enhance care for patients with dementia towards the end of life and finally Kneafsey et al (2015) suggest a 'Framework for Compassionate Inter-Personal Relations' which highlights a cycle of interventions required to demonstrate compassion. The developments of programmes and frameworks such as these is less evident in the initial review and where these were described they are now being evaluated in the updated literature. The findings from all of the studies that described these initiatives are of a positive impact on the promotion of compassion in healthcare and this was confirmed by a meta-analysis of compassion-based interventions conducted by Kirby et al in 2017.

Evidently there remains confusion around the definition of compassion in healthcare with a number of studies still suggesting this is an issue. As examples, Richardson et al (2015), Perv-Bret et al (2016), Mills et al (2017) and even Durkin et al as recently as 2018 still suggested that compassion was ill-defined. However, definitions of compassion have

been both cited and also proposed within the literature reviewed e.g. Dewar (in Dewar et al 2014 and Valizadeh 2018) and by Perez-Bret et al (2016). Dewar et al (2014 p1740) state that despite compassion being a defining value of the NHS what compassion actually means in practice has not been clearly defined. They suggest that compassion is frequently defined based on philosophical and conceptual ideas and that this, combined with interchangeability of terminology presents a challenge when defining compassion. Dewar et al (2014) include a definition based on Dewar's 2011 research relating to the implementation of the Leadership in Compassionate Care Programme which used stories, observation and interviews to gather the views relating to compassion of staff, patients and families in an acute, elderly care environment.

Despite this study and definition, in 2018 (p2) Sinclair et al stated that *'earlier research largely used a priori definitions of compassion' or 'definitions based on factors or situations HCPs associate with compassion'*. And, in the same year, Ledoux et al (2018) suggested that compassion is not well studied in nursing (despite citing Dewar and colleagues work). Bloomberg et al (2016, p138) suggest that *'definitions of compassion abound and the literature is both confused and confusing in the way the term is used and often conflated'*. Such an idea is confirmed as Perez-Bret et al (2016) defined compassion based on a literature review that included the search terms 'compassion' and 'empathy' as empathy was a MESH term.

The volume of literature related to compassion is also significant although arguably nascent so perhaps Jack and Tetley's description of compassion

as complex (2016) and Bray et al's (2014) notion of ambiguity confirm Blomberg et al's idea (2016) that there is a lack of consensus and therefore it is this rather than a lack of definition that is the issue. This lack of consensus appeared to motivate Perez-Bret et al (2016) who felt there was a need for specificity in definition and Sinclair et al (2016, 2018) who carried out 2 different studies, one involving patients and one involving HCPs to try and further clarify the implications for compassion in practice. It would seem evident that definition remains a contested and complex notion and consensus an ambition yet to be fulfilled.

The attributes and characteristics of compassion remain a feature of the research and the results continue to highlight those described within the initial review. Empathy remains controversial with authors citing it as synonymous with compassion (Richardson et al 2015) and different to compassion (Sinclair et al 2016a, Leffel et al 2018). However, it was the single attribute most commonly associated with compassion along with caring and kindness.

Other factors that feature in the studies include the need to involve patients in their care, with Dewar et al (2014, p1741) providing an exemplar, *'It is not so much about what we choose to do for other people, but what we choose to do together with them. It thus implies a level of reciprocity and interdependence'*. This notion was also described by those authors who chose to describe it as 'person-centred care' and this was another common theme in a number of studies. The importance of small acts is highlighted by more than 1 author with Bramley and Matiti (2014) describing these as *'fleeting'* yet still impactful. And the need for

compassion to be an 'active' response was a feature of the literature reviewed with Cameron et al (2014) citing the need to address recognised suffering as one of the 3 key components of compassion. The importance of effective communication was another recurrent theme but all of the studies, especially those based on reviews of the literature, highlighted frequently recurring themes. Importantly, no obviously new or disparate themes relating to the attributes of compassion were apparent from the examination of the recent literature.

This recognition of suffering as an antecedent to compassionate care was highlighted in the initial review 2004-14 and this theme continues to be prominent in the second review. At least 11 of the studies highlight this as an implicit element of or antecedent to compassionate care with Dunn and Rivas (2014, p48) stating that compassion included that healthcare staff have the '*motivation to reduce or alleviate suffering*' and Leffel et al (2018, p311) describing compassion as the '*feeling that arises in witnessing suffering which results in the desire to help*'. Papadopoulos and Ali (2015) suggest that despite the conceptual complexity of compassion it is the recognition and ending of suffering. Other studies, whilst not as implicit do describe similar mechanisms but may not describe 'suffering' instead using words such as 'distress' or 'vulnerability'. The idea remains compelling – compassion is an active component of care predicated on the recognition of suffering or distress and the motivation to reduce or end this.

An interesting theme that appeared to be growing in prominence in the literature was that compassion was a way of improving job satisfaction and possibly therefore even retention,

'...compassionate feelings produced a positive effect, activating regions of the brain associated with reward, love, and affiliation. Taken together, these findings suggest that compassion may not only be better for patients but also for their healthcare providers, requiring a reconceptualization of the notion of compassion fatigue as empathetic distress' Sinclair et al (2017, p445).

Tierney et al (2017) agree that staff who were supported to provide compassionate care had greater job-satisfaction and Leffel et al (2018) cited better student well-being in those who were more compassionate. Sacco and Copel (2018) felt that this was also the case and that this job-satisfaction was an important factor in retaining nurses in the workforce. More of the authors in this review seem to be highlighting that the provision of compassion for others, far from causing stress and 'compassion-fatigue' can actually be a source of job satisfaction and wellbeing for healthcare staff. Mills et al (2017) describing the positive impact for health professionals of compassion and self-compassion in terms of improved sleep and resilience.

Compassion for oneself was a theme in the initial review and this continues to be seen as both a pre-requisite and an enabling component of compassion. The positive correlation between levels of self-compassion and the ability to provide compassionate care was equally, if not more prevalent in the second review (Henshall et al 2017, Jakimowicz et al 2017, Barron et al 2017, Sacco and Copel (2018). This was also allied to the idea that compassion needed to be 'bi-directional' (Tierney et al 2017) and was a vicarious emotion (Perev-Bret et al 2016 and Leffel et al 2018) and this idea of reciprocity and shared benefit was highlighted as impacting the patient, health professional and organisation.

Educating staff to be more compassionate featured in a number of the studies with the majority who highlight education suggesting that it could be taught and in a variety of ways, and this idea was present in at least 14 of the studies. In fact Mills et al (2017) went as far as to suggest it must be taught and Bray et al (2014) state that care and compassion need to be at the core of nurse education. However, Mills et al (2018) felt it could be cultivated rather than taught and Sinclair et al (2016a) suggested that, as a virtue, compassion may be difficult to teach. And Durkin et al in 2018 carried out a systematic review that found there was little consideration of how compassion could be taught to students of nursing and this was possibly due to the belief that compassion was not something that could be taught, furthermore, '*a clearly defined theoretical base in nursing is missing*' (p56). In contrast, Papadopoulos et al (2016) describe the development of tools to promote and teach, amongst other values, compassionate practice and these tools subsequently evaluated positively across 6 European countries. One educational strength which was mentioned more than once and which also resonated with the initial literature review was that of the importance of role models (Leffel et al 2018, Ali and Terry 2017 and Valizadeh et al 2018).

Finally, a subject which seemed only in infancy in the first review appears to have gained momentum and that is the need to have acceptable, validated tools with which to measure compassion (Papadopoulos and Ali 2015). Lown et al (2017), Lee and Seomun (2016) and McSherry and Pearce (2018) all describe either the use of existing scales and instruments or the development and evaluation of a new tool. All felt the use of the scale in their study to be beneficial although Sinclair et al

(2017b) reviewed all available such tools found in a 'comprehensive and critical review'. They concluded that the findings demonstrated '*an unmet need for a psychometrically validated instrument that comprehensively measures the construct of compassion in healthcare settings*' (p389).

3.4.5 Summary of the updated literature review

This second, additional review of literature and, specifically, the available research generated since the conclusion of the initial literature review must be viewed with a note of caution. It does not seek to replicate the level of scrutiny present in the original review nor to demonstrate the same level of impact or outcomes as is intended with the original. The aim has been to augment the literature review by adding a necessary update and by looking at 3 specific aspects, has there been an increase in literature and research since the original review, can that be attributed to the publication of some key documents between 2010-2013 and has there been any change in the way compassion is described or viewed?

It is clear that there has been an increase in the volume of literature relating to compassion and this is also acknowledged within that literature. It is also evident that there has been a shift from discussion and rhetoric to a more evidence-based examination of compassion in healthcare. It has not been possible to say definitively that, for instance, the Francis Reports (2010 and 2013), The Ombudsman's report (2011) or the publication of Compassion in Practice (DoH 2012) has provided the impetus for this increase but these documents, and others, are frequently cited and they most certainly have had a significant impact on the literature.

The overall approach to compassion did not seem to have altered with very familiar themes relating to attributes, behaviours, examples and consequences being mentioned repeatedly and very much in accord with the findings of the first literature review. However, it was possible to see emerging trends in the research reviewed since 2014 including the development of frameworks and programmes to promote compassion and even the evaluation of some that had been running for long enough to demonstrate effect. The idea that compassionate practice, far from causing compassion-fatigue may actually provide job-satisfaction and the link between carer wellbeing and self-compassion and the ability to be compassionate was more apparent. There was a similar level of literature as in the original review relating to the role of the organisation in supporting and promoting a compassionate culture but now this idea was more firmly rooted in research findings as is the efficacy (or not) of instruments with which to measure compassion. The approach to teaching compassion, whilst undoubtedly more widely researched, remains controversial with apparently contradictory views reported. It is this level of ambiguity and inconsistency that does rather seem to characterise research relating to a number of aspects of compassion as identified in the second review and this may well be the cause of the continued debate about definition and a lack of consensus.

3.5 Conclusions

Foley and Davis (2017, p71) suggests that the researcher who uses Rodgers' (2000) method will need to '*dissect the concept into several descriptors*' to enable the transformation of '*an abstract idea into a more*

tangible concept'. The researcher in this study has tried to ensure that the literature has been analysed in a transparent and logical manner and that the resultant descriptors are valid. Delves-Yates et al (2017) propose that such clarity both inspires confidence and ensures integrity in the research and the findings. That the abstract idea of compassion has become more tangible is apparent as has the complexity and multifaceted nature of the concept.

The literature has demonstrated that there is a significant level of interest in the subject of compassion and that the approach to examining compassion has evolved over the period reviewed. The evolution of the concept (Rodgers, 2000) will be examined more fully once all elements of the research have been synthesised. Importantly, this exploration of compassion will have a role in informing future research and in further development of the concept (Rodgers et al 2018). The literature review has ensured that the perspective of appropriate, professional authors will inform the findings of this study and, in combination with the fieldwork analysis, add understanding and relevance to the definition of compassion in healthcare.

Literature that has been published over the period of time that the study has been conducted was also reviewed and findings updated accordingly. This subsequent exploration also ensured that the evolutionary development of the concept was addressed and the changes in nature of literature and in the priorities for practice could be identified and presented.

Chapter 4

Fieldwork Phase I.

Health Care Staff - Stories of Compassion.

'An anecdote reflects an entire era as much as the substance of a political constitution'

(Sartre, 1965)

4.0 Summary of Content Chapter 4

Chapter 4 describes the first of the fieldwork elements of the Concept Analysis where practicing healthcare professionals were asked to provide a story of compassionate practice. The data from the stories is analysed using a modification of the method described by Moustakas (1994) and the definition of compassion as experienced by healthcare professionals is then presented.

4.1 Introduction

Creswell and Poth (2018, p21) describe the importance of conducting studies in the 'field', '*where the participants live and work – these are the important contexts for understanding what the participants are saying*'.

Rodgers (2000) suggests that fieldwork can serve to evaluate the concept being explored within the context of nursing situations but also acknowledges the role that the data gathered provides to further clarify existing knowledge. This was an important consideration for this study; the literature review demonstrated the state of the concept of compassion based on what is already known but the next phase of the study aimed to

be theory-generating thereby providing original data. The premise is that the combination of what is already known and which underpins current thinking can be both tested and strengthened by the addition of a fieldwork element.

The views of how compassion is experienced by those who work within that profession are what will be captured in the first phase of the fieldwork. There has been examination and criticism of phenomenology as a research approach both from those who develop the method and who have differing approaches, Husserlian versus Heideggerian for instance (Lowe and Prowse, 2001) and from those who feel phenomenology can be incompatible with nursing research (Paley, 2017). However, Moran (2006, p4) suggests that phenomenology is best understood as an approach which, '*emphasises the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever happens in the manner in which it appears, that is as it manifests itself to the consciousness, to the experienter*'. This reflects the aim of this element of the study – to reflect how compassion becomes manifest in the experience of those who work in health care.

Chinn and Kramer (2011, p217) highlight an issue with qualitative research, many phenomena cannot easily be observed directly. Using a phenomenological approach responds to this problem, the acceptability of more indirect methods aimed at gathering data and the choice of transcendental phenomenology further attempts to ensure the mitigation of any *a priori* understanding of the researcher. This is important when the

initial research process had resulted in the researcher being immersed in the theory of compassion during the literature search and review process. As Zahavi and Martiny (2019, p161) explain, not only can phenomenology *'make a difference in the handling, analysis and interpretation of the available data, but also in how the data are obtained in the first place'*.

The use of stories as a means of giving *'testimony to past events and experiences'* (Crowther et al 2017, p827) was chosen specifically to ensure as little influence from the researcher as possible. The method used for the fieldwork has been described in Chapter 2 but it is interesting to note that the use of storytelling as a method of research seems to be gaining in popularity. In the second literature review undertaken for this thesis for example, 3 studies describe the use of storytelling as an explicit element of the research (Adamson and Dewar 2015, Waugh and Donaldson 2016 and Ramage et al 2017).

4.2 The findings from the Fieldwork involving Health Care Staff

4.2.1 The healthcare staff participants

Following the sampling strategy described in Chapter 2 a total of 23 stories were recorded told by 22 health care staff who were recruited to the study. One participant, an Foundation level, Year 1 (F1) Medical Doctor told an initial story but as he was leaving following the recording he stated that this story was not the one that he had thought of when asked what first came to mind when recalling an example of compassion. He felt that he might become overly emotional if he recounted his first thoughts so

had elected to tell a 'safer' and less emotionally impactful story, one that nevertheless epitomised compassion for him. The researcher reiterated that this was absolutely fine but that he could always tell the first story if he subsequently felt that he wanted to. Within an hour the F1 Doctor returned and asked if he could tell the story, this was then recorded and during the recounting he did get visibly upset but he made it clear that he wanted the story to be captured and included. All of the storytellers appeared to be invested in the stories that they shared, what Newman (2003, p1424) describes as the 'power of stories', but this example was the most compelling in terms of the obvious impact that sharing the story had on the participant.

The demographic information of all of the health care staff who participated is presented here:

Story	Discipline	Qualified (Q) or Unqualified (UQ)	Age (decade)	Gender
#1	Senior Nurse	Q	50's	F
#2	Midwife	Q	40's	F
#3	Senior Pharmacist	Q	40's	F
#4	Staff Nurse	Q	30's	F
#5	Nurse – Unit Manager	Q	40's	F
#6	Staff Nurse	Q	50's	F
#7 + #8	F1 Doctor	Q	20's	M
#9	Operating Department Practitioner	Q	40's	M
#10	Radiology Support Worker	UQ	40's	F
#11	Consultant Doctor	Q	40's	F
#12	Senior Psychologist	Q	60's	M
#13	Chaplain	Q	50's	M
#14	Senior Physiotherapist	Q	40's	F
#15	Dietician	Q	30's	F
#16	Clinical Nurse Specialist	Q	40's	F
#17	Health Care Assistant	UQ	20's	F
#18	Occupational Therapist	Q	30's	M
#19	Physiotherapist	Q	30's	F
#20	Physiotherapist	Q	20'S	M
#21	Patient Experience Lead (Nurse)	Q	40's	F
#22	Consultant Surgeon	Q	40'S	M
#23	Matron	Q	40'S	F

Table # 6 Demographic details of healthcare staff participants

Although care was taken to try and ensure that there was a variety of disciplines, ages and seniority represented in the sample, it is evident that some themes emerged. Of the staff who volunteered their story, 20 were qualified health professionals and only 2 were unqualified clinical support workers. This is in contrast to the way healthcare is staffed in the NHS where, according to the NHS Confederation in 2017, 54.06% of employees were professionally qualified whilst 29.89% provided support to clinical staff in roles such as Nursing Assistant Practitioners and Health Care Assistants as examples. This breakdown of staffing is clearly not reflected by the participants in this study and this will, inevitably, impact on the findings. All staff who shared their stories were clinically active and involved in face-to-face patient care, the predominance of qualified staff in the sample needs to be considered in terms of the subsequent transferability of the findings.

The age profile of the participants is also unevenly distributed with 50% of those who took part in their 40's. However, this is more reflective of current NHS staff where, according to NHS Employers 2017, 23% of staff are aged 25-34, 24% 34-44 and 29% 45-55, although these figures do not give the results for those only in their 40s the same source states that the average age of those working in the NHS is 43. The age range of participants is also reflective of the roles represented as, NHS Employers (2017) also demonstrate that the average age of those who are professionally qualified (i.e. pay scale Band 5 and above) is higher than the age range of those in an unqualified role.

A variety of disciplines feature, however nurses are the largest group with 8 of the participants coming from a nursing background whilst 3 are doctors and 3 physiotherapists, all other disciplines involved are represented by a single participant. This demographic is also loosely reflective of NHS staffing as figures indicate there are over 285,000 nurses in contrast to just over 106,000 doctors and nearly 133,000 scientific, therapeutic and technical staff (NHS Confederation, 2017).

None of the participants came from black or obviously minority ethnic backgrounds, none were obviously from the European Union (EU) as far as the researcher was aware although this data was not captured specifically by the research. The important consideration is that, no matter what the background, the cohort did not obviously represent a cross-section of current NHS staff where, according to NHS Digital (2018), whilst 80.2% of staff are white (including white ethnic minorities), 19.8% are from other ethnic groups. And, according to the NHS Confederation (2017) 5.51% of staff, approximately 62,000 people, are from the EU. The implications of the demographics will be discussed in Chapter 7 when considering recommendations based on this study.

4.2.2 The invariant constituents, core themes and essence of the stories:

The method of data analysis has been described in Chapter 2. The transcripts of the stories were read by the researcher, and each 'horizon' or statement relevant to the topic was identified with each seen as having equal value. From the 'horizontalized' statements the 'meaning units' are

listed and then clustered into common themes removing overlapping or repetitive statements. Once these themes have been used to inform the textural and structural descriptions of the experience, the '*essence of the phenomena are constructed*' (Moustakas, 1994 p118)

The invariant constituents, core themes and 'distilled' essence of each story is presented in table #7 that follows.

STORY	INVARIANT CONSTITUENTS	THEMES	ESSENCE
#1	<ul style="list-style-type: none"> Compassion requires time Systems that militate against compassion need to be overridden or bypassed The need to walk alongside those who suffer To take responsibility for them but not control To be their advocate To hear their story To be non-judgemental To make them feel safe To be kind To treat people with tenderness 	<ul style="list-style-type: none"> To give time, to walk alongside, to hear their story, to make them feel safe, to take responsibility, to be kind and to be tender. Non-judgemental, advocacy, non-controlling Override systems that prevent compassionate care 	<ol style="list-style-type: none"> Openness (to walk alongside, to hear, to not judge). To be an active participant in the relationship (take responsibility but not control, to advocate and override systems, to create safety and be kind and tender). To give time.
#2	<ul style="list-style-type: none"> Took opportunity which was a choice Compassion is powerful Risk – entering the unknown Time – had to be made and own was given Actively create appropriate environment Enable the person to tell their story and then listen and validate Above and beyond accepted job role Be informed Be kind Openness – despite others judgements Take responsibility – keep the patient safe Stay with the patient until resolution 	<ul style="list-style-type: none"> make time, enable the person by listening and getting information, keep them safe, be kind Openness in spite of previous action/judgements Take responsibility despite not necessarily your job to do so. 	<ol style="list-style-type: none"> Go beyond what is expected – even if not your job, make time, make the choice Be open and enable – listen, hear the story, get information, do not judge Be kind – take some responsibility, keep the patient safe and stay with them until resolution.
#3	<ul style="list-style-type: none"> Looked and immediately saw e.gs of compassion No need for recognition, without fuss Took some of the pressure off of someone perceived as needing support (?reward) Opportunity – chose to do it, not told Used own time 	<ul style="list-style-type: none"> Choice/opportunity- not normally expected, gave own time. No need for recognition/fuss Support for people identified as in need Not just empathy but action taken 	<ol style="list-style-type: none"> To go beyond expectations – own choice, not part of job, gave own time and worked extra Recognition – of the impact on another but not the need for personal recognition

	<ul style="list-style-type: none"> Beyond what would be expected/job role Not only empathised but acted 		3. Not just emotion (empathy) but proactive.
#4	<ul style="list-style-type: none"> Consistently kind and gentle – infamously so, unique Non judgemental Respectful – looked people in the eye and spoke to them like they were someone Compassion hindered by worn out staff with no time Took personal approach to compassion – gave own time and possessions Little things make a difference Rules are needed but need to be flexible – if applied strictly can lack compassion and be thoughtless Being compassionate can pay-off for staff Easier to be compassionate to some more than others 	<ul style="list-style-type: none"> Consistent – always compassionate and non-judgemental Took responsibility for own actions Behaved beyond expectations – own time and resources Gentleness There needs to be rules but these should be applied flexibly lest they become a barrier to compassion Compassion can pay-off for staff 	<ol style="list-style-type: none"> Going beyond expectations and regulations Non-judgemental, consistent with all people Gentleness and kindness Compassion can be beneficial for both pt and staff`
#5	<ul style="list-style-type: none"> Memorable Already worked long shift but still stayed on in own time – several hours Patient at end of life Made the Storyteller emotional to recount the episode What the patient wanted was frowned on by others Above and beyond what was expected Shared the experience with the patient Did what the patient wanted despite it being against received practice Didn't ask for recompense Storyteller was proud of her colleague's actions Used own initiative Treated someone society would cast aside Non-judgemental 	<ul style="list-style-type: none"> Effect on the Storyteller – lump in throat, goosebumps, long-remembered act, proud Time – already worked over but stayed even longer Did what she perceived was needed despite other's opinions and prejudices Went beyond what was expected Was present with the patient Non-judgemental 	<ol style="list-style-type: none"> Above and beyond expectations A need was identified Non-judgemental Took risks, responsibility and used initiative
#6	<ul style="list-style-type: none"> End of life Reassured – took responsibility, patient was in 'good hands' Physical care ('basic') 	<ul style="list-style-type: none"> Identification and recognition of both patient and daughter Would have done same for any patient Took responsibility and provided reassurance 	<ol style="list-style-type: none"> This is nursing Universal provision of 'basic' care provides dignity To hold and to listen Common humanity

	<ul style="list-style-type: none"> Recognised patient – spoke to them even though unconscious Identified with daughter (similar relationship with own mother) Would have done the same for any patient (didn't know daughter could hear – not motivating factor) What nursing is Enjoyed doing it, found it humbling 'Held' daughter – arm around, listened, held hand, touched Peaceful and dignified death Care given to mother helped daughter too Daughter recognised care as compassionate 	<ul style="list-style-type: none"> Touch/hold/listen Peaceful and dignified death 	5. Took responsibility
#7	<ul style="list-style-type: none"> Significant but unexpected diagnosis Had seen the patient every day but was a junior member of the medical team Patient had been given some information but was still worried The Storyteller was looking after 'everybody' Difficult to be open and honest but recognition that was what was needed However, the patient needed all of the available information. Despite other demands responding immediately and gave time Recognised the individual and their needs Needed to demonstrate empathy and consideration Surrogacy – provided what friends and family might provide if the patient had had any Did what the patient wanted despite initial reservations 	<ul style="list-style-type: none"> Recognition – what the patient needed and what they lacked Prioritising despite competing demands Honesty and accuracy Giving time Taking on the role of friends and family when none were present Empathy and consideration 	<ol style="list-style-type: none"> To provide what a person needs no matter what your role or reservations and this can entail being surrogate family/friend. Empathy, honesty and consideration Recognition and time
#8	<ul style="list-style-type: none"> Communication barriers – isolation The Storyteller could communicate with effort – created a rapport/connection Patient dying Struggling for breath but still has a sparkle in his eye Looked very sad 	<ul style="list-style-type: none"> End of life Isolated and alone Rapport/connection between patient and doctor Both sad Impact on the doctor 	<ol style="list-style-type: none"> No-one should die alone Connectedness affects both carer and patient Presence in and of itself is care provision

	<ul style="list-style-type: none"> • Storyteller was very sad despite only recently met the person • Sat with him while he died • Really bothered by the patient's situation • Gave support and reassurance he was not alone 	<ul style="list-style-type: none"> • Stayed with the patient so he did not die alone 	
#9	<ul style="list-style-type: none"> • Critically ill child – mother died in childbirth • Storyteller involved with their care • Took on a role not usual for him as he felt it would not be right to do otherwise • Identification and empathy with the Father • Recognition – that for the Father this was the 'most sincerely bad thing' • Responsibility – need to reassure the Father that he would do his best for the child • Not sure if his actions were right or wrong but felt he was compassionate • Found it difficult • Father 'opened up' and cried • Honesty – others were compassionate but 'contrived' 	<ul style="list-style-type: none"> • Intimately involved in care of mother and child resulted in a connectedness to the Father. • This both compelled and enabled the Storyteller to go beyond usual role • Recognition and empathy • Responsibility – to respond with his best and to go beyond his usual role • Honesty and realism - real and not 'contrived' compassion • Father's gratitude 	<ol style="list-style-type: none"> 1. Responsibility, empathy and identification as motivation to act compassionately. 2. Above results in the ability to step outside your usual role 3. Compassion needs to be 'real' and not 'contrived' so requires honesty and realism 4. Is difficult and upsetting but results in gratitude.
#10	<ul style="list-style-type: none"> • Patient ill, distressed and alone • Unasked but responded to witnessed distress • Practical help as well as reassurance • Recognition of positive attributes of the patient – 'lovely lady', 'wasn't very old' • Personal recognition – patient subsequently always remembered her and she gets letters stating that she does a good job and is 'kind' • Identified this (kindness) as part of her job role and not out of the ordinary • Treat everyone the same and how you would want to be treated if in the same situation 	<ul style="list-style-type: none"> • Recognition of distress • To respond to distress is 'just' doing your job properly • Simple interventions – 'not a big thing' but these demonstrate kindness • Such kindness is remembered • That everyone should be treated the same and as she would want to be treated in the same circumstance 	As per themes
#11	<ul style="list-style-type: none"> • Difficult to select one story – 'hundreds' of examples • Lots of suffering and grief results in lots of compassion • Compassion means to suffer alongside 	<ul style="list-style-type: none"> • Difficult to define compassion but it is different from empathy • Means to suffer along side 	<ol style="list-style-type: none"> 1. Compassion means to suffer with and is a frequent response to suffering and

	<ul style="list-style-type: none"> • Different to empathy which is feeling what the other is feeling • Difficult to define ‘ don’t know’ • Young woman with incurable disease • Consultant gave the bad news and he managed their expectations, acknowledged their grief and was sensitive • Accepted their grief, gave space and time, was open, allowed them to vent all of their emotions • Didn’t get ‘caught up’, didn’t cut them off but worked with the time available – allowed them to work through it. • Demonstrated that you can treat but not always cure but it is important to still treat the patient as a whole person • The compassion he displayed inspired the storyteller to the career she now has 	<ul style="list-style-type: none"> • Many examples – linked to levels of grief and suffering witnessed • Despite no cure you still need to treat the whole person • Giving information in a way that was sensitive and responded to the needs of the patient • Openness, acceptance and acknowledgement. 	<p style="text-align: center;">grief which is also a common occurrence.</p> <ol style="list-style-type: none"> 2. Being with a patient but being able to keep yourself separate 3. Providing support, space, time, acknowledgement and acceptance
#12	<ul style="list-style-type: none"> • Immediately thought of the story as identifying compassionate care • Isolated patient – dying in ICU • Newly qualified F1 doctor – found the experience difficult, more experienced staff were less affected • Families are reassured that their loved one will not die alone – usually a nurse will be present • F1 felt compelled to spend time with patient – wanted to be with him when he died so he wasn’t alone • Not expected or part of role – beyond expectation • Initially told not appropriate but senior staff relented as impact on F1 was evident • Never spoken to patient (unconscious since admission) – not a friend or family member • Own time – sat and held his hand – behaved as if a close relative • Ensured did not die alone – fulfilled duty/responsibility as undertaken to pts absent daughter • First experience of ‘confronting death’ – was ‘all over the place’ 	<ul style="list-style-type: none"> • Isolated patient who was dying • 1st encounter with death as a Dr • Responsibility – reassured relative that the patient would not die alone • Compelled to stay with the pt • Was significantly affected by the situation • Beyond expectation, faced opposition, beyond remit of role • Pt was a stranger • F1 stayed with him, touched him – acted like a relative rather than a Dr • Own time • Will be a better Dr for it 	<ol style="list-style-type: none"> 1. No-one should die alone 2. Obligation and responsibility 3. Beyond expectations – acted as a ‘carer’ and not a Dr 4. Own time 5. Impact on the ‘carer’ – still determined to stay with patient 6. Will be a better Dr for it

	<ul style="list-style-type: none"> Some colleagues = if you can't deal with this then you need to leave, Storyteller = she will be a better doctor for the experience 		
#13	<ul style="list-style-type: none"> Concerned an experienced Chaplaincy volunteer Patient had no religious belief Terminal illness – had unresolved issues to discuss Rapport with patient who requested continued input Beyond normal provision – gave own time Despite reservations – continued Support was significant to both pt and their family Family said volunteer had been 'so kind' and wanted input from volunteer at subsequent funeral Not usual, going the extra mile Not unusual – had many examples of staff doing more than expected 	<ul style="list-style-type: none"> Non-judgemental (no religious belief) What the patient wanted – given despite reservations Not normally done – beyond expectations Kindness To patient and family alike Volunteer also benefitted and 'got something' from the encounter 	<ol style="list-style-type: none"> Non-judgemental Went above and beyond to do what the patient wanted Gave own time Kindness The 'kindness' affected the whole family and continued after the pts death The volunteer benefitted from the encounter
#14	<ul style="list-style-type: none"> Hard to give one example – so much that is done is compassionate Colleague was unwell – significant illness = increased work burden on remaining colleagues Immediate response = 'great sadness' Team 'selfless' – offered 100% support, concern for their colleague and never for their increased workload Didn't crowd, offered space, showed they were concerned and cared Transparency but took care to protect her, never overstepped boundaries No resentment – care, love and passion for their colleague Obligation to provide service despite less staff She was 'the most important' – supported without complaining about the impact on them Not individual but a whole team demonstration of compassion 	<ul style="list-style-type: none"> Sadness and recognition of colleagues predicament Concern for colleague despite impact on team 100% support, care, love, acceptance, passion and NO resentment Still ensured service for patients continued Team felt concern, sadness, anxiety and worry Team acted selflessly, respectfully and without complaint 	<ol style="list-style-type: none"> Recognition of another's plight and selfless concern for this despite negative impact on the team Compassion identified as concern resulting in support, care, love, acceptance and passion provided without resentment

<p>#15</p>	<ul style="list-style-type: none"> • Patient well known to storyteller – had a lot of clinical input over a protracted period • Patient very unwell • Isolated due to nature of condition and lack of family input • Built relationship – ‘bonded’ • Spent time that was not part of clinical role – social, over and above job role • ‘Just’ needed to talk – had a lot to deal with and process • Identification – common ground (motherhood – actual and hoped for) • Felt it was ‘necessary’ as the patient was ‘crying out’ for a friend 	<ul style="list-style-type: none"> • Well-known patient – needed more than clinical input • Recognition of her predicament = response • Isolated and lonely but had a lot to deal with • Above and beyond job role – provided friendship • Was necessary 	<ol style="list-style-type: none"> 1. Recognition of isolated and lonely person who was having a very difficult time 2. Crying out for friendship so went above and beyond job role to provide what was ‘necessary’
<p>#16</p>	<ul style="list-style-type: none"> • Incident happened yesterday • Noticed couple who were upset – nothing to do with storytellers job • Initial inquiry rebuffed – couldn’t leave them as so obviously distressed so persisted • Explained recent and devastating (terminal) diagnosis of one of the couple • Needed ‘space’ – they ‘didn’t know what to do’ • Storyteller felt awful for them – touched by their situation • Took them somewhere private, got tea, spent time, talked it through, got specialist support as well • ‘Repairing’ earlier input from other professional re: breaking the initial news • Enabled them to gather their thoughts and make a plan • Still awful but they had made a plan instead of believing ‘the world was ending’ • Self-deprecating – ‘didn’t make a difference’....however ‘sorted it’ 	<ul style="list-style-type: none"> • Couldn’t ignore obvious distress • Not storytellers patients • Gave space, time, talked it through, tea • Got specialist support and therefore follow-up • Planning instead of believing the world was ending • It was still awful but they had a strategy and had gathered their thoughts • Significant time was given to the couple – ?impact on the storytellers own work (only touched upon very lightly) 	<ol style="list-style-type: none"> 1. Obvious distress cannot be ignored whether ‘your’ patient’s or not 2. Time, space and the ability to talk 3. Support – above and beyond job role
<p>#17</p>	<ul style="list-style-type: none"> • 45 year old lady, severe stroke • Identified with the patient – reminded Storyteller of her own mother and patient had 2 sons the same age as Storyteller • Story concerns patient’s husband 	<ul style="list-style-type: none"> • Identification with the patient • Husband also ‘lost’ but cared despite this • Never got angry despite lack of response 	<ol style="list-style-type: none"> 1. Selfless care in the face of limited chance of response – no anger or resentment 2. Constant input – both time and encouragement

	<ul style="list-style-type: none"> • Visited every day, sat with patient for long periods and encouraged his wife – put ‘so much effort in’ • This despite limited chance of recovery/significant improvement • Distressing to see – even when little response he kept trying • Day in, day out – small acts • Never got angry with his wife despite it being ‘the most frustrating thing in the world’ • He had also lost so much – world turned upside down but ‘still’ there every day • Touched, brought a tear to her eye, still remembered ‘to this day’ • Incredible the amount of care one person can have for another 	<ul style="list-style-type: none"> • Long hours, constant input, many small acts • Always encouraging in the face of unlikely recovery • Incredible care • Touched and stayed with the Storyteller 	<ol style="list-style-type: none"> 3. Incredible amount of care from one person to another – touching and long remembered
#18	<ul style="list-style-type: none"> • 35 year old man – severe spinal injury = paraplegia • Storyteller closely involved in his care • Life changing and devastating injury • Identification – similar age • Team work • ‘Compassion’ got him through including ‘dark days’ when he did not want to live • Storyteller acknowledged the input of the nurses who were with the patient over long periods of time – a constant presence through the ‘hard times’ • ‘Amazing’ to deal with his distress day to day • Practical solutions to help him achieve things – key element of compassion was to get him ‘back on track’ • Patient felt safe • Goal setting and how to overcome limitations and barriers, how to compensate 	<ul style="list-style-type: none"> • Identification and recognition of the devastating nature of the injury • Compassion was the element that made the difference • The difference between wanting to die and to carry on • Team work • ‘Amazing’ to provide constant support day after day through difficult times • Practical help • Goal setting and the subsequent ability therefore to compensate for the injury • Ultimately to get on with his life 	<ol style="list-style-type: none"> 1. Compassion is what makes the difference and got the patient through 2. The sense of the team going through the journey with the patient – day in/day out 3. The Storyteller’s role was also practical and this too is compassionate – helped the patient achieve
#19	<ul style="list-style-type: none"> • Elderly lady in out-patients had urgent message to go home as husband had had a heart attack • Receptionist tried to get transport but none immediately available 	<ul style="list-style-type: none"> • Recognition of distress • No ‘official’ help immediately available • Practical solution to the problem 	<ol style="list-style-type: none"> 1. Recognised distress and need to respond

	<ul style="list-style-type: none"> • Storyteller advised patient they would have to wait • Patient upset, felt guilty for leaving her husband to attend appointment • Thought no more about it until few weeks later when the patient returned to thank the lady who had given her a lift • The receptionist had got her car and driven the lady home – didn't tell anyone • Shocked the storyteller – done what she did without telling anyone • 'Really amazed' 	<ul style="list-style-type: none"> • Not her role and potentially against 'the rules' • Didn't tell anyone – didn't want or need recognition • This element 'shocked' the storyteller 	<ol style="list-style-type: none"> 2. No 'official' help so went beyond job role and 'rules' and provided help 3. No need for recognition
#20	<ul style="list-style-type: none"> • Felt that compassion was generic and happens with every patient • Compassion is associated with giving time and listening • Storyteller sees this as part of his role • Story involves terminally ill lady who was upset and tearful – lots of thoughts going around her head • Seeing the patient to carry out an assessment but instead prioritised looking after and listening to the patient • 'just' to listen and be 'compassionate towards her' • Rather than 'getting the job done' or 'noting points on bits of paper' • Discussed the future – reassured the patient 'we' would be there for her, make her life easier • Honesty – no false hopes • Goal setting – practical support to enable patient to look forward • Patient wanted to go home – reassured could have care at home • Reassurance – 'take each day as it comes' • Did complete the assessment • At end of meeting patient less upset due to having time to talk and having a plan to look forward • 'Despite' prognosis would be given as much help as anyone else • He provided a 'service of care' 	<ul style="list-style-type: none"> • Compassion means responding to what the patient needs rather than your agenda • It means to listen and give time • Practical support is also important • Giving people reassurance and hope • Realistic – no false hope but to also provide support to achieve the patient's goals • Enable people to look forward and have hope 	<ol style="list-style-type: none"> 1. More important to be compassionate than to 'get the job done' 2. Compassion is part of the job 3. Listen and give time and reassurance 4. Give the patient reason to look forward and the confidence to do so

	<ul style="list-style-type: none"> • By helping her look forward and have something to achieve she did not give up 		
#21	<ul style="list-style-type: none"> • Compassion is ‘the way you do things’ • Numerous examples – especially when caring for the dying and even more so when at night or when the patient is alone • Experience is that Storyteller and colleagues would spend ‘hours’ with such patients • Selected story was 25 years ago when Storyteller worked in A + E and involves a homeless man who was ‘sad, dirty, unkempt, non-compliant’ • Self-neglect – specifically dreadful feet • Broke rules – gave him shelter, a bed, warmth and food • Soaked and cared for his feet – ‘people’ thought they were ‘bonkers’ • Stuck with her – was about ‘doing the right thing’ despite the rules – not letting bureaucracy stop them • Didn’t let the ‘patient’ know they were breaking rules • Looked after him as well as he would allow – were fond of him..even his feet! • Showed him care and compassion • No judgement – acceptance • Made him part of the community – ensured he was looked out for • Even though he was ‘grim’ they did their best for him • He needed care – they gave him care 	<ul style="list-style-type: none"> • Compassion is common – it is how you do things • Certain situations inspire greater levels • Marginalised patient – unpleasant presentation and non-compliant • Practical care as well as acceptance • The right thing to do despite the rules • Provided non-judgemental acceptance and therefore inclusion • Kept him safe • Cared for him 	<ol style="list-style-type: none"> 1. As per themes 2. Became his ‘family’
#22	<ul style="list-style-type: none"> • Young woman with terminal illness • Same age as Storyteller, same age children so he identified with her • Felt empathy • Unusual condition for someone so young – physical presentation unpleasant, ‘really horrible’ • Storyteller intimately involved in her care, felt she was incredibly brave, stoic and realistic – found that admirable 	<ul style="list-style-type: none"> • Identification resulted in empathy • Recognition of the severity and impact of the illness • Admiration for the patient • Compassion was a combination of factors – listening, doing all he could, understanding, openness and honesty • She was compassionate too 	<ol style="list-style-type: none"> 1. Identification results in empathy 2. Admiration for the patient 3. Compassion can be mutual 4. Compassion identified as listening, understanding, doing all possible and being open and honest

	<ul style="list-style-type: none"> • Compassion demonstrated by 'dealing' with her in a way that suited her best • She called him her 'little angel' • He was very affected by her situation – she knew she was dying and treatment was only to prolong life, that she would not see her kids grow up • Patient showed compassion to the Storyteller – he hoped it was reciprocal • They understood each other, he listened to her, did everything he could for her and was open and honest 		
#23	<ul style="list-style-type: none"> • Compassion not about technical skill but about recognising when to provide the 'human thing' • To be with, to hold, to be alongside – to see the patient and not just the illness • Patients need medicine but also emotional care • Even in the face of exemplary technical care a lack of compassion leaves patients distressed • Learnt to listen more – to be self-aware and listen to your own emotions so you become more skilled at recognising the feelings of others • To feel with another is to care and caring can hurt • Patient – long-term in-patient, depressed, isolated with limited family input – increasingly angry with the team caring for her • Complaints not the 'real issue' – was to do with 'the hand she had been dealt', the impact of her illness and possible mortality • Time, companionship and presence that was required – sit alongside, listen and hear. • Not 'mere handholding' but to see her as the person she was, her sense of self • Didn't want Storyteller to 'fix' her but to hear her and see her – to see her perspective • Recognition of her anxiety, anger, sadness and fear • May have looked like a 'luxury' to spend this time and was difficult to quantify but complaints subsided • Patient sadly died – storyteller attended funeral – humbled that she was allowed to get to know the patient • Son said patient had been grateful and that it made a difference to her final weeks 	<ul style="list-style-type: none"> • Compassion = human thing...to be with, to hold, to see the patient as more than their illness • Lack of compassion can cause distress as can lack of recognition • Can impact on those who give compassion • Need to look past presenting behaviour to see cause • Emotional care = time, companionship, listening and hearing, recognition • Difficult to quantify such input but it does make a difference 	<ol style="list-style-type: none"> 1. Compassion is not about technical skill but human input 2. Compassion = to be with, to hold, to recognise the patient, to give time, companionship, to listen and hear 3. Such care is difficult to quantify but it does make a difference 4. Lack of compassion caused distress but to feel for/care for others can hurt so has a cost

4.2.3 Data saturation:

As explained in Chapter 2, the concept of data saturation is that which is most frequently suggested as a measure of qualitative rigour (Morse, 2015) and is used as a '*criterion for discontinuing data collection and/or analysis*' (Saunders et al 2017, p1894). The decision to seek 20 , participants for this element of the fieldwork was, as already described, an arbitrary number, the aim was to achieve saturation of the data such that '*additional data do not lead to any new emergent themes*' (Given, 2016 p135). It became clear that themes were being repeated and that this was also frequent enough for them to be seen as commonly occurring. Not just repetition, but the richness of the stories was also an important component of the data. As all of the stories and the subsequent analysis was carried out by the same researcher it is inevitable that they become immersed in the data. Morse (2015, p588) describes this as the researcher becoming '*competent about the topic*' and cites this as a requirement that ensures '*indices of richness become evident*'.

Saunders et al (2017) highlight the idea that the concept of saturation is less clear-cut in certain qualitative approaches and describes interpretative phenomenological analysis as an example. They suggest that continuous strands rather than recurrent themes might be a better approach and can occur across the range of data collected. However, the concept of a certain number has become somewhat redundant when some commentators suggest that data from a single participant can be justifiable (Baker and Edwards, 2012). It would seem that richness, quality and not quantity, is just as important in determining sample size adequacy.

As previously described, the aim within this study was to determine the shared understanding of the experience of compassion and this meant that a single source of data was not appropriate. However, the need for relevant and meaningful data which was vibrant and dynamic was just as important whatever number of participants contributed. Certainly, the data provided by the participants in this phase of the research was rich, detailed the individual experience and provided a number of repetitive themes.

4.2.2 Data Analysis

As previously described, the use of stories as a data collection method posed some difficulties when attempting to 'reduce' the data using structure and texture combined using the concept of 'imaginative variation' (Moustakas, 1994 p 97). However, when viewing the data in their entirety the concepts of structure and texture have a greater level of applicability. Notwithstanding the idea that the 'imaginative variation' is in fact provided by each storyteller the individual situations and experiences do enable common features to be identified. Imaginative variation functions to eliminate that which is irrelevant (Lin, 2013) – the storytellers had done that by identifying their story to exemplify compassion, to conclude that any element of that story is irrelevant would do both the storytellers and the integrity of the research a disservice.

4.2.5 Textural description of the data:

What did the Storytellers experience when asked to describe compassion? This is derived from the invariant constituents and themes and illustrated with examples from the transcripts, each example when taken verbatim from the stories will be identified by the participant's number as they appear in the demographic list (Table #6).

From the recordings of the stories it is apparent that a number of the storytellers were still affected by the memory they were recounting. Several people shed tears, it was audible that their voices were strained or broke whilst others described themselves as having a 'lump in their throat' or that they could feel themselves near to tears (#5, #8, #17). A number of the Storytellers recounted how the memory had stayed with them over a long period of time, for instance, '*.....well this incident happened about 7 years ago so it must have been quite memorable to still remember it today*' (#5). Another Storyteller said that, '*....he stuck with me, the thought of 27 years ago*' (#21), all but 2 of the stories were about events that had happened months or years earlier. However, 1 person specifically spent the morning observing practice around her and came to the meeting with 2 examples of compassionate care she witnessed. It had appeared important to her to find a contemporary example rather than recalling an event – by looking for examples on that day she was confirming that compassion continued and was part of everyday practice. Compassion was identified as **hard to define** or even so **commonplace** as to result in difficulty in isolating one, specific example – at least 5

people stated that it was integral to their job. *'Initially it was actually quite difficult to think of a story. Working in a profession where we see a lot of grief, suffering and compassion is I suppose, I think, something that I would feel we see a lot of'* (#11) and *'I found it quite difficult to pick out a story and I'm sure I have got hundreds of examples of nurses and doctors who have exhibited compassion'*(#11). Another person said *'I could replicate that type of thing several times over really with both volunteers and hospital staff just doing more than what is expected'* (#13) and *'I struggled a little bit to think of a story immediately because I think a lot of the work we do is compassionate'* (#14) further supported by yet another storyteller who said *'it's something you seem to think that is generic and happens with every patient which made it difficult to think of a story'* (#20).

Finding and giving time to the patient was a key component, *'because I felt the first thing they needed was time'* (#1) and *'that we spend time listening to what they're saying'* (#1). One Storyteller stated, *'I ended up starting to spend more time with her just in a more social way and we just used to talk through like life things, not just necessarily about health care'* (#15) This also acted as an example of the value staff placed on relating to the patient on a human, non-medical level.

Often the time given was outside of the normal shift that the staff member was rostered to complete, *'using her own time, on her own initiative'* (#5) and *'in her own time continued to visit this lady'* (#13). Very powerfully, *'she had done a really, really long shift already, already done a double shift because we were really short staffed at the time.....She asked him what his dying wish would be, you know because we all understood that*

this man was going to die.... and proceeded to sit with him for 2 or 3 hours' (#5). And....'so compassion was displayed I think by the fact that we made some time in our working time and actually my colleague came in on her day off' (#2).

Such statements also resonated with the idea that staff often acted **outside of their job or role remit** and that this was a necessary element to demonstrate or prevent the impedance of compassionate care. *'We were aware that it was not necessarily within our direct job roles to do this so it was a little bit of flexibility that we had to provide to do this but we listened to her story' (#2).* Another Storyteller told of how a junior doctor ended her shift and then sat with a man through the night to ensure he would not die alone, *'I think she went beyond what was required of her.....I think that she will be a better doctor for it... and I have a suspicion that this event will be with her until she retires and hangs up her coat' (#12).*

A number of the participants described **recognising need** and responding to the individual patient and this was allied to the need to listen and really hear what a person was saying, *'it was just his entire approach. It was just the acceptance of her grief, it was giving them space and time to come to terms with it. It was his openness to them to allow them to vent anger and frustration and upset and all of that without cutting them off' (#11)* and from another storyteller *'I felt it was necessary, that day, just to listen and try to be compassionate towards her, rather than getting my job done and noting points on bits of paper' (#20).*

It was apparent that there is an **emotional cost** in engaging with patients that inspire compassion and in then providing this to them. When a colleague had had a busy night and had to then come in to do the day shift as well, a member of staff, despite their busy workload, went and covered some of their work for them, *'they took the action to do it, they didn't make any fuss about it they just got on with it and did it for the person who was on call. So I thought that was very compassionate'* (#3). Often the compelling nature of the patient's predicament affected the staff member, the doctor who sat through the night with the patient explained why she could not leave and go home, *'she said "I wouldn't be able to do that, I would go home, I wouldn't sleep and would just sit in a chair waiting to come back to be told how he died"'* (#12). In addition, this meant that the Storyteller would have an added requirement as they *'dealt not with only supporting this particular person but also their own selfless feelings about the impact'* (#14). One participant said, *'...responding often takes courage as it may mean risk taking - as you can't be sure if you open the door emotionally what will unfold for you and or the patient. To feel with another is to care and caring can hurt'* (#23).

However, a significant number of stories also highlighted the **benefit to staff** of being compassionate i.e. gratitude and recognition, personal awareness, development and so on. *'It was lovely to have the time to do that as a staff nurse, I enjoyed that, even though it was a very sad situation'* (#4). The Storyteller describing the junior doctor who sat all night with a dying patient felt that she would *'be a better doctor for it'* (#12) and *'I have had several letters from patients like that which makes me think I'm doing my job properly. That means a lot to me...'* (#10).

There were also a significant number of statements about behaviour and characteristics that demonstrated compassion, from, ‘.....*how **gentle** she would be. Her gentleness is unique*’ (#6), and, ‘*I was trying to be **honest** with her and not to give her any false hope*’ (#20). Several noted that a lack of judgement and acceptance was important, thus ‘*my job in trying to be compassionate was to be **non-judgemental**, to be able to make sure that whatever they told me I didn’t respond to with an opinion if you like but that I constantly reassured them that they were safe*’(#1) and ‘.....*just the whole, you know, way she treated a man that society would kind of cast aside*’(#5) whilst another stated that the colleague in their story, ‘*at no point felt resentful and at every point showed that **care, love and passion** for what this particular person was going through*’ (#14).

Actions that demonstrated compassion were mentioned with the following as just a small number of examples, ‘.....***listening** to her and **holding her hand** and keeping **eye contact** and if not holding her hand the whole time, I would be touching, listening, looking..*’ (#4) and, ‘.....*but I’m just quietly there to offer them even a drink..... a touch on the arm shows I’m here for them*’ (#10). ‘*I think about my ability to recognise when a patient or their loved one needs me to provide the ‘human thing’ – just to be with them, to hold them, to be alongside them when they are facing a difficulty – seeing the person not just their illness.*’ (#23). **Selflessness and focus** on the patient is described in the following two excerpts, ‘*how their first thought was always for her*’ (#14) and, ‘.....*she wanted to be at his bedside not in scrubs holding his hand so when he died he wasn’t alone*’ (#12).

Taking **responsibility** but not control was seen as key, *'but basically although I am taking responsibility for what is about to happen you have the control to be able to say how you want it to be'* (#1). This was also reflected in the idea of **accompanying** patients on their journey and being their **advocate**, *'meant that I could walk alongside those young people.....that they felt that they had somebody who was an advocate for them'* (#1) and, *'protected her from things that may not have been helpful but without hiding any content'* (#2).

Confusion also existed about how people had behaved – they were unsure if the story they recounted was indeed indicative of compassion. Frequently people understated their role in the story or were self-deprecating – **'it's just my job'**, one participant described helping a distressed couple in a way that would seem clearly compassionate but ended the story with, *'although I felt I hadn't made any difference, I felt that they were discussing plans and talking instead of thinking 'my world is ending''* (#16). Equally, people described their actions as inevitable in the circumstance described – they were **compelled** to behave as they did, they felt they had to do so. Several stories highlighted the difficulty in quantifying compassion or the benefits of providing it but that this did not reduce the compulsion to do so.

Compassionate care produced outcomes for patient and staff alike and these are listed in the table below. If specific terms were mentioned more than once as a descriptor for compassion then they too are listed below – this could be seen as synonymous with Rodgers' surrogate terms as applied to the literature search data analysis (2000). In terms of

behaviours (Rodgers 'examples') and characteristics the following were identified and are also included in the table below:

Results of compassionate care	Behaviours of compassionate staff	Characteristics of those providing compassionate care	Terms used to describe compassion
Reassurance	Identify and recognise suffering/need	Openness	Kindness
Acceptance	Give time	Honesty	Empathy
Acknowledgement	Listen/hear	Lack of resentment	Care
Encouragement	Provide support	Selflessness	Concern
Feel safe/protected	Take responsibility	Non-judgemental	Love
Provides dignity	Offer friendship	No need for recognition	Common humanity
Enables peace	Do your job	Kind	To suffer with
Feel seen/recognised	Override systems/rules if they impeded compassion	Tender	
Companionship or connectedness	Walk alongside	Accepting	
No one dies alone	Touch/hold the patient	Gentle	
Space to 'be'	Advocate	Take initiative	
Hope	Go above and beyond if necessary	Considerate	
	Consistency	Real	
	Practical care	Sensitive	
	'Do as you would be done by'	Passionate	
		Concerned	
		Understanding	
		Courage	

Table #8 Textural description of healthcare staff stories.

4.2.6 Structural description of the data

In what **context** was the phenomenon experienced?

A significant number of the stories involved patients who were terminally ill or dying – 12 of the 23 stories were directly related to this scenario and indirect reference was made in several of the others too. Even when the story was about a patient who was not at the end of their life, it was identified that they had suffered a significant or ‘devastating’ illness or situation (spinal cord injury, loss of a child/spouse, sexual assault and severe stroke). This may well link to the textural description where participants often stated that compassion was an ‘everyday’ experience and ‘part of the job’ so, struggling to find a significant example, they ‘default’ to situations where compassion is ‘easy’ to identify. The dying are, clearly, a compelling and ‘worthy’ group of patients and compassion could be seen as more readily associated with their circumstance. It was emphasised by a number of the Storytellers that no one should ever die alone and therefore a number of the stories related to people who stayed with those who were at the end of their lives, even in one case when they did not know the person who had been unconscious since admission.

A number of the Storytellers highlighted that they **identified** with the subject of their story in some way. This was either as a direct comparison to do with age, family or social situation of the patient – *‘it came to me that she reminded me of my mum a bit, you know similar sort of age and things like that’* (#17) - or more obliquely by stating that they shared some common ideas or had a ‘rapport’. In one story the teller ‘admired’ (#22) the

patient; in another the Storyteller said they were 'fond' (#21) of the patient. It appeared to be important to 'humanise' the patient or subject with biographical and character description – to place the person in the situation.

Another theme that was described in a number of the stories was that the demonstration of compassion was at **variance with the participant's job role** and that which was expected of them and even, on occasions, against the received rules and policies of the workplace. Frequently, the descriptions were of people giving up their own time or flouting convention to provide what the patient needed. Examples include giving a man with end-stage liver disease his dying wish of a bottle of beer (#5), giving a (hospital) bed and food to a homeless man (#21), driving a desperate lady home in the staff member's own car to her sick husband (#19), bringing in a husband's clothes for homeless patients (#6), sitting with dying patients long after a shift has ended (#8 and #12). One Storyteller who said, 'it was sense of - we must do the right thing we must not be stopped by bureaucracy' (#21), summed this up. Allied to this, several Storytellers highlighted that they had decided to step outside of the professional role expected of them and provide their definition of compassion. 'So even when I didn't need to review her, I would still pop in and say 'Hi' and sit down and have a little chat' (#15) and '...we don't get involved with talking to the relatives, that's usually left to the nurses in A+E but I didn't think I could do that...' (#9). Examples such as these also leads on to the final context.

Many of the participants (10 stories with direct reference to lack of family/friends) identified that they fulfilled the role of absent 'friend' or 'family' member in circumstances where these roles were unfulfilled. Such isolation in a patient was seen as very compelling and led to a feeling of obligation from the professional to step in to the role. Several people identified the difference between their professional function and this '**ex loco familia**' role and that they often tried to provide both. One participant recalled, *'he never had any visitors and she realised that the staff, well she said to me the staff are spending more time with this man than his family' (#12)*. *'He was just quite, quite unsupported emotionally outside of the hospital environment...I think I needed to sit down with him that took half an hour to speak to him and kind of give that social support that maybe friends and family may have done if they were available...'* (#7).

4.2.7 The overall composite description

Moustakas (1994, p 100) suggests that the concluding part of the research process is *'the intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essences of the experience of the phenomenon as a whole'*. Moustakas cites the theory of Husserl (1931) and Sartre (1965) when defining 'essence' as common or universal and an 'infinite series of individual manifestations' respectively. So, quite simply, the aim of this final section is to exemplify what each individual manifestation of the concept of compassion had in common. The result is *'the essential, invariant structure of ultimate 'essence' which*

captures the meaning ascribed to the experience' (Moerer-Urdahl and Creswell, 2004 p 22). As Creswell (2012) explained using the notion of grief, no matter what the source of that grief or how it is viewed by others there will be common, underlying structures that have common features – the feeling of grief would be understood by all.

The structural and textural elements of each story resulted in an essential essence – what was recognisably the manifestation of compassion for each of the Storytellers. Inevitably, this synthesis will be impacted upon by the researcher no matter how hard the attempt to bracket their own experience and belief. Moustakas seems to not only acknowledge but embrace this – he states '*One learns to see naïvely and freshly again, to value conscious experience, to respect the evidence of one's senses, and to move toward an intersubjective knowing of things, people, and everyday experiences'* (1994 p 101). In addition, Wertz et al (2011, p2) state that '*interpretation presupposes some shared understandings; and interpretation requires involvement in a dialogical relationship of the interpreter and the interpreted'*. It is with this in mind that the researcher has interpreted the textural and structural descriptions of the Storytellers to arrive at the composite description whilst trying to stay as true to the transcripts as possible. See section 4.3.

By grouping together the common essence of each story, the composite and therefore definitive, intersubjective experience of the cohort of Storytellers is achieved. This final component of the analysis benefits from being broken down into sections reflecting allied themes, which results in a

final, definitive description of the phenomenon as experienced by health care staff.

The most common thread through a number of the stories is that of time and the need to provide this in order to both demonstrate compassion and to enable the possibility of compassion. Giving time also facilitated the next theme which is that of connectedness between health care staff and the person for whom they are caring and this was described as walking alongside and being present, holding, providing space and listening/hearing. Such a connected relationship requires the staff member to be consistent, to remain with the patient as long as is needed even if this were to be to their cost and to do so selflessly without the need for personal recognition. The relationship could be that akin to family and friends if they were absent and needs to be based on acceptance and be without judgement. Importantly for this cohort of participants, no patient should suffer or die alone and health care staff will stay with them in this circumstance if possible.

Secondly, the staff member needs to recognise the patient as an individual thereby be an active participant in the relationship, an advocate who enables but does not control and, to facilitate this, they need to get and give information. This recognition extends to understanding the person's needs and this then inspires the staff member to be proactive in meeting these needs. Whilst not controlling, healthcare staff need to accept responsibility for the patient and provide what is needed even if this requires them to challenge rules or override systems. Indeed, the very

expectation of staff is that they are required when necessary to go beyond what is accepted as the remit of job or role and even take risks if they believe the patient's need dictates such action. Many of these aspects were captured by participant #23 who said, *'It was my companionship and my presence that was required – my time, my ability to be able to visit daily and sit alongside her, to listen to hear her story and ask questions. Not mere handholding – but to see her as the person she was'*.

If the elements of compassion identified were present then the result for the patient would be that they would be safe, supported, and provided with hope and reassurance. In order for this to happen the healthcare staff would need to be open, realistic and honest, kind, gentle and loving, caring and concerned. They need to demonstrate empathy but not at the expense of action and do so with passion and without resentment.

Finally, compassion was seen as commonplace and 'merely' part of the job, a requirement to recognise distress, take the initiative and act upon it, to act as you would want others to act toward you or your family.

Compassion was seen to be integral to a staff member's role, a commonplace and 'basic' requirement of the job, although practical care was highlighted to be of equal relevance and import and could be a way to demonstrate compassion to a patient. Ultimately, there would also be impact upon staff of such necessary connectedness and it was recognised that whilst it was gratifying, mutually beneficial and made for 'better' staff who would be remembered and who made a difference there were also costs. It was acknowledged that compassion did require staff to suffer with

patients and that this common humanity could be difficult and upsetting and that this distress meant that staff had to be mindful and even cultivate a level of separateness within the relationship.

4.3 Epoch or Bracketing and the role of the researcher:

The choice of transcendental phenomenology was an acknowledgement that the subject of this study, compassion, was one that the researcher felt to be important and that such a motivating interest was likely to have some effect on the subsequent research. Being aware of this and working out how this could be accommodated in a way that was open, honest and meaningful is key to the idea of phenomenology. Moustakas (1994, p 84) describes the idea of *epoch* (described by others using the term 'bracketing') as '*I know that I see what I see, feel what I feel, think what I think. What appears before me and in my consciousness is something I know is present regardless of how many others perceive the phenomenon differently*'. Creswell and Poth (2018, p81) suggest that to bracket personal experience is difficult as researchers cannot help but make assumptions based on their prior experience. They suggest that by discussing their own understanding the researcher does not try and remove themselves from the study but that by doing this they can '*serve to identify personal experiences with the phenomenon and to partly set them aside so that the researcher can focus on the experiences of the participants in the study*' (2018 p77). They feel that by being this transparent the reader can then see for themselves whether the researcher was able to focus solely on the evidence from the participants without bringing their preconceptions into the work. Giorgi (2009) sees

bracketing not so much as a need to forget but rather a need to ensure that any past knowledge does not impede the clarity of the experience of others. Giorgi uses the example of a judge in a trial instructing jurors to discount some evidence that they have heard or seen as inadmissible or of a scientist who hopes to prove a pet-hypothesis but is able to acknowledge the reality if the results do not favour their position.

In order to provide clarity and to ensure that the researcher's own experience is demonstrated as fully as is possible within this study, this seemed an appropriate point to share the story that they would have told had they been a participant in the study. The researcher is, after all, a health care worker and meets the criteria for participation. Such a sharing of experience is not without precedent, Creswell and Poth (2018) cite studies where the researchers describe their own experience with the phenomenon under investigation and then bracket out their views prior to then investigating the experience of others.

4.3.1 Reflections of the Researcher:

As this will be a reflective account, this section will be written in the first person.

The story that follows has been one of the motivations that has led me along the path that brought me to this research. It has always existed in my mind as my defining example of compassion in healthcare and this had been so prior to both my MSc studies and this current research. This story also relates to the episode recounted as Appendix I and referred to in Chapter 1, an example of the antithesis of compassion and the final jolt

that was needed to get me thinking about researching the meaning of compassion – see the comments at the end of the following story.

Some years ago – 16 at least, I was working as a staff nurse on an oncology ward, the shift was busy as they pretty much always were and I was responsible for the patients on one side of the ward whilst another staff nurse, 'Cathy' (pseudonym) was covering the other. Whilst my focus was on those patients I was looking after you have an awareness of the remaining patients on the ward and I and my colleagues knew that a relatively young patient who had breast cancer was approaching the end of her life and was in a side room on Cathy's side of the ward. We all knew her as she had been a patient for some time and throughout her treatment as both in and out-patient. Her husband was with her, they had no children and no obvious other close family, and his grief and distress were palpable. It was clear that Cathy would need to spend as much time as she could with both the patient and her husband – we all tried to take pressure off of her to free her up to do this. It was also very evident that this man had rather 'latched' on to Cathy – it was Cathy that he needed and she was able and willing to be his support. It was a hard and demanding job, although we tried to do as much as we could for the patients, Cathy was pulled in many directions throughout the shift.

We were both present when the patient died, near the end of a long and tiring shift, near the end of a very emotionally draining shift. The patient's husband sobbed and held his wife, rocking and crying out – he appeared broken and inconsolable but Cathy stayed with him. Following hand-over

to the newly arrived night staff I returned to the side room to see if Cathy was in a position to leave – she had a family to get home to, young children, and was back the next day to undertake another shift which would start early in the morning. I am unsure if he realised the time or that Cathy’s shift was at an end but the patient’s husband asked Cathy if he could stay with his wife, if he could help prepare her body – Cathy said of course he could, that there was no rush, that there would be people to help him. He responded by asking her if she would stay with him and help him care for his wife. Without hesitation Cathy simply agreed that ‘of course’ she would stay with him, as far as I could tell there was no hesitation, no sense of tiredness or unwillingness. I went home and next saw Cathy the following morning at 7.30 as our new shift began – she had not left the patient or her husband until well into the early hours of that morning and then only when sure that others were available and could provide for them.

Cathy simply did what she saw was needed, without apparent thought to the cost to herself and certainly without any evidence or demonstration of that cost to the patient’s husband. Cathy responded in a way that I have never forgotten, she responded in a way that has epitomised compassionate care to me ever since.

The link with the story alluded to in Chapter 1 (Appendix I)? The shift after the events recounted here fell on a weekend day and was relatively quiet, by mid-afternoon it was clear that the team were pretty well on top of the work and the patients were all safe, the late shift would be arriving in a

couple of hours. We asked the nurse in charge if Cathy could go home early in light of her late finish the night before, Cathy didn't ask but we did and we made it clear that we would happily cover her work once she left. The nurse in charge said that this was not possible, the rules forbade anyone leaving early and the ward could not be left 'short-staffed' in this way. She was adamant and unmoved by our explanation or justification for the request – her intransigence felt petty and without consideration nor, certainly, compassion. The nurse in charge was the same nurse who had refused to help 'S', the patient in the story in Appendix I. In this single encounter I was able to identify that which I believed exemplified compassion and behaviour which I believed, equally clearly, did not.

These experiences, as I have explained, pre-date this research by some years but the impact of these incidents remain as relevant as when they occurred. To not acknowledge them would seem disingenuous at best and dishonest at worst – the key, of course, is do my experiences impact on the analysis of the participants' stories? The details of my story clearly resonate with many of the findings from the analysis of the participants' stories but whether that would be inevitable or the result of preconceptions is always difficult to fully understand. The best approach to try and ensure that this is not so is to be as thorough as possible in following the described method but also, to be as transparent as possible and this reflection has, hopefully, contributed to that transparency. Moustakas (1994, p33) describes epoch as the need to set aside understandings, judgements and 'knowings' and to approach the phenomena '*freshly, naively, in a wide open sense*' and that has been my intent.

4.4 Summary of Phase 1 of the Fieldwork

This first phase of the fieldwork element of the research has provided a defined set of examples of health care workers' experiences of compassionate health care. The common experience of the participants has been distilled to enable the overall essence of the collective understanding to be presented. Vagle (2016 p 54) describes how *'important it is to go to the source of the phenomena under examination in order to discover the complexities of it'*, this sample does represent a meaningful source of data and the complexities of compassion and of practice have resulted in information that is both rich and relevant to the aims of the study. The overall composite description can be seen as the definition of compassion based on the experience of healthcare staff.

The findings from this phase of the research, this definition, will be viewed in relation to the findings from the literature review and from the next phase of the fieldwork. The synthesis and re-analysis of all of the data once combined will inform the overall concept of compassion and this will be described in Chapter 6.

Chapter 5

Fieldwork Phase II

Patient – Stories of compassion

'Storytelling reveals meaning without committing the error of defining it'

Arendt, 1968, p 105

5.0 Summary of Content Chapter 5

Chapter 5 outlines the second element of the fieldwork, stories of patients and carers who recounted their experience of being in receipt of compassionate care. Data is analysed using the same method as the healthcare workers' stories and the definition of compassion that results is then described.

5.1 Introduction

Arendt (1968) suggests that stories can reveal meaning without the 'error' of defining that meaning, however, this phase of the study seeks to discover how the lived experience of healthcare users results in both the subjective experience of compassion and an objective experience of compassion that shares something in common with other people (Creswell and Poth 2018, p 76). The use of storytelling as a device to ensure that the impact of the researcher on the data is minimised also allows for the Storyteller to define their own, subjective, sphere of reference, perhaps not *defining* compassion but describing it and placing the phenomena in the shared context of healthcare. Scott et al (2013) highlight the benefits of

storytelling, 'one of the oldest forms of communication', in terms of its effectiveness in conveying information, adding clarity to personal experience and even increasing memory retentiveness.

Moerer-Urdahl and Creswell (2004) point out that transcendental phenomenology as described by Moustakas (1994) analyses lived experience by 'allowing researchers to develop an objective "essence" through aggregating subjective experiences of a number of individuals'. Once stories of compassionate practice from healthcare staff had been collected and analysed the next step was to establish whether the aggregation of their subjective experience could be enhanced by collecting stories from a different perspective. The healthcare staff stories demonstrated distinct and recurring themes that exemplified what they saw as compassionate care delivery. However, it is important to see if the opinion of those for whom they care – the patient, matched the perception of healthcare staff. Important clearly because if there was a mismatch in perceptions then care provision may be compromised.

Not only would studying the views of healthcare users ensure that there was increased rigour in defining the experience of compassion in healthcare but this would also resonate with an emergent trend in current healthcare. Snyder and Engstrom (2015) suggest that there is a 'paradigmatic' shift in Western healthcare whereby the patient is no longer a passive recipient of healthcare but 'an autonomous, active and involved participant'. This is echoed by Garfield et al (2015) who specifically concentrate on patient and public involvement in health research, believing that not only should patients be involved in a meaningful way but that there is both an increased awareness of the benefit of patient

involvement and in funding bodies asking researchers to demonstrate patient involvement in research bids. The views of patients are to be valued not just in relation to their own healthcare but also how evidence is generated to inform future healthcare provision.

The Health and Social Care Act (Great Britain, 2012) aimed to put the patient first and laid down the requirement that healthcare provision must be grounded in 'systematic patient involvement'. The success of the initial fieldwork method, the need to engage patients and the need to provide consistent and therefore comparable data meant that repeating the method used to collect healthcare workers' to collect patient stories was both appropriate and practical.

Rigour in qualitative research is the subject of much discussion (Golafshani, 2003, Cypress, 2017) but Carter et al (2014, p545) suggest that it may be '*a qualitative research strategy to test validity through the convergence of information from different sources*' and Noble and Smith (2015) maintain that data triangulation can be sought whereby different perspectives produce a more comprehensive body of data. To augment the healthcare workers' stories of compassion by recording stories from patients aims to provide a more comprehensive and valid definition and this then forms Phase II of the fieldwork element of the concept analysis.

5.2 Findings

5.2.1. Study Participants

Recruitment to the study followed the method described in Chapter 2 and resulted in 16 stories from 14 different people who had been the recipients of healthcare, in this case all but 1 described care as patients within the National Health Service in England. The participant who shared 3 stories came prepared with one already written out so that she could read it to the Researcher and not forget any details, but once she had done so said she had many more stories that she could share but that there were 2 that were particularly affecting and she would like to share them as well. There had been no limit stipulated when asking for volunteers for the study and so these stories were also recorded and were examples of 2, discreet episodes of care thus the patient's stories were treated as 3 separate examples.

The demographic details and the site where the researcher met the participant are detailed in the table below:-

#	Age	Gender	Health Condition	Site of story collection
1	70's	F	Breast Cancer	Patient's home
2	40's	M	Brain Tumour	Support Centre
3	70'S	F	Oral Cancer	University office
4	50'S	F	Ovarian Cancer	University office
5	80's	F	Urological surgery	Patient's home
6	70's	M	Multiple Sclerosis	Patient's home
7	60's	M	Chronic pain/amputee	Patient's home
8	20's	F	Stillborn child	Patient's home
9	40's	F	Inflammatory Bowel Disease	Hospital Clinic
10	50's	F	Inflammatory Bowel Disease	Hospital Clinic
11	40's	M	Organ donation family member	Patient's home
12	60's	F	Breast Cancer	Patient's home
13	60's	F	Breast Cancer	Patient's home
14	60's	F	Lung Cancer patient's carer	Patient's home

Table #9 Demographic Details of the Patient and Carer Participants.

It is important to note that there was a difference in the stories that the patients told when compared to those told by the healthcare professionals. This was a practical issue rather than one of content – in every case with the healthcare staff the stories were short and focused and the researcher approached the initial patient meetings with the same expectation. It became apparent that a number of the patients, either from preference or as a result of their health, told quite protracted stories or recounted very

general events rather than focusing on what they had found to be compassionate care. This resulted in a modified approach as the story collection progressed, with the researcher identifying that spending time with the patients prior to starting the recording to allow them to become comfortable and to share some of the general points that they wanted to make first was of benefit. It had been naïve to assume that people who had been through challenging and often distressing experiences would be able to simply recount a story about one element of their journey. This had implications for both time and for the concept of epoch or bracketing as discussed in the previous chapter. It had been relatively simple to ensure as little influence from the researcher as possible when collecting the healthcare staff's stories – busy staff generally spent only a few minutes prior to recording their stories, needed little if any prompting and then simply left on completion. Polkinghorne (1989, p57) challenges the researcher to ask themselves relevant questions to try and establish that their methods are valid: he suggests '*did the interviewer influence the content of the subject's descriptions in such a way that the descriptions do not truly reflect the subject's actual experience?*' In allowing the patients time and space to 'chat' with the researcher there did not seem to be any reason to believe that the story that they already had in their mind to tell would be altered or changed in any way. The researcher was mindful not to discuss the study but to allow the patient to tell their wider story until they were comfortable that context and background had been covered. It could be argued that the added time and the establishment of a relaxed atmosphere ensured that the patients told their story with greater detail and clarity. There was also the simple need to be kind! The participants

often needed to share their whole stories and not simply the element that the researcher wanted to capture – giving them the opportunity to tell their story was both politic but also polite and respectful of the participant's contribution. Ashton (2014) emphasises the importance of the relationship between researcher and patient and that this can impact on the patient's feeling that their contribution is both valued and valuable.

Of the 14 participant patients who shared their story the researcher asked for clarification or prompted the patient in 7 of the encounters and said nothing in the 7 others. Of the 7 where prompting was required to keep the patient focused on the idea of compassion 2 of the patients were also accompanied by family or friends (these were the only 2 of the 14) and in both instances the family members also prompted the patient with questions that further encouraged them to recall elements of their story. It was evident that they had discussed their story prior to the meeting and that the family member was keen that they did not forget any relevant points.

None of the 14 participant patients showed any evidence of being distressed or upset when recounting their stories – quite the opposite in fact with most being very positive and even enthusiastic about the process. Even those who recounted stories that clearly moved them in terms of their recollection were adamant that they found the experiences they were sharing to be a positive in what had been a very trying or otherwise distressing circumstance. This was in contrast to the healthcare staff who, on a number of occasions, were visibly moved to tears by their

recollections and the circumstances that had led to the story they chose to recount. The researcher was not subsequently contacted by any of the participants of either group, although this possibility was reiterated to each participant, to express any concerns or report any distress.

The participants demonstrate a range of backgrounds, ages and diagnoses although 6 had a diagnosis of cancer and 1 was the carer of a cancer patient. 10 of the participants were female and 4 male and this is not representative of the current patient population, no current gender divide figures for NHS patients could be found but the Office for National Statistics (2018) states that the current population in England and Wales is 51% female and 49% male. This element of the demographic along with the illness trajectory of the participants will be explored more in Chapter 7 of this thesis.

5.2.2 Data Analysis:

Each story was transcribed and the transcriptions were subjected to the same analysis methodology as that used for the healthcare workers' stories – see Chapter 2 for the analysis methods. Each story was reviewed and any significant statements that provide an understanding of the participants understanding are highlighted and then these 'horizons' (Moustakas, 1994) are clustered into themes of similar meaning. These themes are then used to describe what was experienced (textural description) and in what context (structural description) and, finally, from these a composite description of the experience is presented as the final 'essence'.

Following horizonization and clustering, as with the healthcare staff stories, the invariant constituents, core themes and 'distilled' essence of each story are presented in the following table.

STORY #	INVARIANT CONSTITUENTS	THEMES	ESSENCE
#1	<ul style="list-style-type: none"> • Fear (of anaesthetic/not waking up) • Sitting on the bed and smiling • Asking are you alright • Passing on messages from loved ones • Confirmed that she was alright • In control • Listening and concentrating • Reassuring and smiling 	<ul style="list-style-type: none"> ○ Storyteller was vulnerable due to fear ○ Nurse sat with the Storyteller ○ Reassurance ○ Smiled, listened and concentrated 	<ol style="list-style-type: none"> 1. Reassurance 2. Presence – listening, proximity, concentration
#2	<ul style="list-style-type: none"> • Significant illness • A lot of treatment • Finds it useful to share with others who have had a similar experience and understands • Complimentary therapies help • Frightened and confused – staff reassured him • Reassurance = known condition which they had treated before • His condition was ‘treatable’ • <u>Guaranteed</u> that help was available and he would be ‘fine’ • Reassured – preserve his life • Ensured his wife was present when results given • Taught him neurology – understanding the process decreased worries • Given choices/options gave back control • Referrals to experts • Nice attitude of nurses – did everything possible for the ‘unsolvable’ problem • Aware of his preferences • General Practitioner (GP) acknowledged serious nature of diagnosis and was more understanding • GP practice provided more practical and responsive help • ‘Adapted to his needs’ 	<ul style="list-style-type: none"> ○ Significant diagnosis – resultant fear and confusion ○ Immediate reassurance – they were experienced, ‘guaranteed’ him help, would keep him alive and make expert referrals ○ Responded to his needs – ensured his wife was present, GP now responsive to him, aware of his preferences, aware he wanted to be informed ○ Gave him choices and information – thereby giving him back control ○ Practical help ○ Understanding ○ Didn’t give up – when problem ‘unsolvable’ or when he got things wrong 	<ol style="list-style-type: none"> 1. Reassurance 2. Individualised care and recognition 3. Gave hope 4. Understanding 5. Empowerment

	<ul style="list-style-type: none"> • Clinical Nurse Specialist (CNS) managed the 'system' for him – practical help • CNS listened to him and recognised him • CNS acted as liaison with consultant and gave information • CNS does not lecture him if he gets muddled • Main thing was understanding what he was going through • That there are solutions and others had had their problem 'solved' • Hope that it would get better 		
Story #3a	<ul style="list-style-type: none"> • The story demonstrates compassion, empathy and agape love • 18 years ago – serious illness, cancer of jaw/tongue • Not coping well psychologically, very frightened, anxious, distressed, loss of self-esteem and value • Had a soft toy as a comfort • Frightened in spite of calm reassurance • Night – wound broke down, oozing, smelling • Had unpleasant and frightening investigations, illness left her feeling dirty and smelly • Didn't want any of the complications, didn't want to be as she was – wanted to be well and 'normal' • Medics were superb – calm, reassuring, informal, empathetic, purposeful, kind, professional • Reassured cancer had not recurred and infection could be treated • On return to ward Health Care Assistants (HCA) had remade 'dirty' bed and insisted she get in and sleep despite protests that she would soil the bed again – sight made her cry • Registered Nurse (RN) then helped her bathe, wash hair and redress wounds – she no longer smelled, she knew her illness had not returned • Returned to bed – it had been remade and her soft toy was on it and flowers were on the locker • HCA's made her comfortable and stayed to chat 	<ul style="list-style-type: none"> ○ Compassion = empathy and love ○ Was frightened, distressed, loss of self-esteem and value ○ Frequent reassurance which was done with calmness, informality, purpose, kindness and professionalism ○ Practical help plus extra personal touches ○ Gave time and both understood and met her needs ○ Brought beauty and order ○ Were welcoming, kind, empathetic and compassionate ○ Turned a nightmare into a beautiful and therapeutic experience – a treasured memory 	<ol style="list-style-type: none"> 1. Compassion = empathy, love, kindness 2. Reassurance 3. Being calm but purposeful and kind but professional 4. Identified and responded to need 5. Gave time

	<ul style="list-style-type: none"> • Turned ‘the nightmare of the night into the beauty and order of daytime’ • Loved her, understood her needs and met them • Welcomed her, were kind, empathetic and compassionate • Created an unforgettable, beautiful and therapeutic experience – now a treasured memory 		
Story #3b	<ul style="list-style-type: none"> • 3rd serious diagnosis • Angry, cross with everyone, resentful and ‘scared absolutely silly’ and frightened • Scared the radiographer would know the diagnosis and she would not be told • Utterly devastated and finished – wished she had her cat or her ‘comfort’ soft toy with her • Radiographer made a substitute with towels for her to hold • Kindness, love, empathy, compassion ‘absolutely broke down all of the anger...hate...resentment’ • Still felt sad but felt understood and not thought to be stupid • Understanding and caring made such a difference – felt if the ‘hospital’ was like this then she would be supported and that influenced the way she approached her future ‘journey’ 	<ul style="list-style-type: none"> ○ Angry, cross, scared, frightened, devastated, finished ○ Understood a need without making her feel silly – provided a substitute for what she could not have ○ Demonstrated kindness, love, empathy and compassion ○ This then broke down the anger and hate and positively affected how she viewed her future journey 	<ol style="list-style-type: none"> 1. Kindness, love and empathy 2. Understanding without judgement 3. Thoughtfulness 4. Positive influence on future care
Story #3c	<ul style="list-style-type: none"> • Not in a good place ‘cancer lurked in every corner’ • Frightened and not coping – panic attacks which were irrational but real and debilitating • Simply went to hospital and asked to see Consultant – burst in to tears • Staff arranged for this to happen and without delay • Can’t manage, don’t know what to do – frightened • Consultant examined her, told her what he could see and reassured her all was ‘honestly ok’ • Relieved – went to leave but Consultant asked her to stay – thought she was going to be told off for being ‘stupid, over-emotional, menopausal, hormonal idiot’ 	<ul style="list-style-type: none"> ○ Frightened, panic, irrational, debilitated ○ Responded to her cry for help promptly and without censure or criticism ○ Reassured her she was ok ○ Clinician shared a personal story – their vulnerability meant that she could deal with her vulnerability ○ Recognised her as a whole person ○ Empathy, compassion and professionalism 	<ol style="list-style-type: none"> 1. Reassurance 2. Lack of criticism 3. Shared vulnerability/humanity 4. Recognition of the whole person 5. Empathy, compassion and professionalism

	<ul style="list-style-type: none"> • Told her a story of when he had a cancer diagnosis and had an acute reaction to a fear or recurrence – went to pieces, felt sick and faint • If he – Consultant Surgeon – could feel like that then so can you • Cried – lovely man shared his story of vulnerability to help her manage hers • Strengthened her – he would be there for her as a ‘whole person’ – not just a cancer case but a human being with normal natural human reactions • Special experience – hugely privileged, treasured memory of compassionate, empathetic, professional care. 		
Story #4	<ul style="list-style-type: none"> • Had surgery – was in hospital • One nurse to look after her – very concerned to provide pain relief post-op – went out of her way • Nice to know you had someone gentle and kind at your bedside to keep an eye on you • Feeling of relief that it was all over and somebody nice looking out for you – really appreciated • On ward – nurse identified herself and was very caring – found a lost bag, kept answering the bell when busy but behaving as if it was no trouble, got her food – thought she was very nice • Others had been nice but this nurse was very professional, happy to help and make things as nice as possible, encouraging and friendly • Important to introduce who you are – confusing with so many coming and going, nice to know who people are and what their role is – reassuring in a bewildering situation • The particular nurse on the ward introduced herself and seemed ‘really, really good and kind’ • CNS who told her the diagnosis was ‘really lovely’ – gave her information and contact details immediately • Had worries so phoned CNS – just hearing her voice, her soothing voice, nothing was a drama and all was well – put her mind at rest 	<ul style="list-style-type: none"> ○ Individual nurse relationship - gentle and kind and went out of way to ensure pain free ○ Relief that she was looked out for ○ Practical help but without feeling she was being any trouble even when staff busy ○ Encouraging, friendly, happy to help, kind, concerned for wellbeing ○ Introduced themselves and what they did – reassuring when confused and bewildered ○ Was accessible, reassuring in voice and by giving information with a lack of drama ○ Recognised patient – even after time passed ○ Gave time – even when outside of plan/remit – still not rushed, quiet and calm ○ Recognised patients need and preferred style of relationship – related to her 	<ol style="list-style-type: none"> 1. Relationship between patient and healthcare staff 2. Based on understanding need and preference 3. Gentle, kind, quiet, calm and informative 4. Time 5. Reassurance 6. Recognition as a person

	<ul style="list-style-type: none"> • Always remembered who she (patient) was, said Hello • CNS saw her unexpectedly and gave her significant amount of time to explain in detail the situation – possibly in her lunch break – realised patient was unsure and responded • Didn't have to spend all of the time, not rushed – reassuring person. Was outside of her remit for that attendance. • Patient needed quiet, calm and reassurance and this nurse recognised this where others didn't – felt she was genuine • Radiographer – was friendly, chatted about normal things, personal info – wanted to know how she was, really caring • Recognised patient over a year later and said Hello - 'it's nice to have people that see you' • Personal contact helps – makes you feel like you are not just a cog in the wheel, just another patient • Person-focussed care – that's important • Took more time, fitted with her, related well to her 	<ul style="list-style-type: none"> ○ Person-focussed – 'normal' chatting and sharing personal details, made her feel like she was not simply another patient/cog in the wheel 	
Story #5	<ul style="list-style-type: none"> • Frequent visits to hospital for surgery • Nurses are absolutely wonderful • Anaesthetist helpful and kindly • Checked how previous visits/treatment had affected her • Improved on previous problems she had experienced • Worked long hours but weren't obviously in a hurry • Always had time to talk to everyone even when you knew they didn't have time • Kept her in hospital as long as her condition required • Told her they were proud of her and she could be discharged • Checked that she was ok – 'really ok' 	<ul style="list-style-type: none"> ○ Kindly and helpful ○ Reviewed previous care to see if improvements could be made ○ Staff appeared unhurried even when they were and always made time to talk ○ Responded to her needs ○ Gave positive feedback 	<ol style="list-style-type: none"> 1. Kind and helpful 2. Responsive to need based on assessment 3. Made time 4. Talked to her and gave positive feedback
Story #6	<ul style="list-style-type: none"> • Giving smiles • Want to help people get better – that's the big answer, what's needed • Doctor (Dr) visited him at home just before Christmas – twice in one day and rang the next day – was very kind, didn't rush even though they thought she'd want to be at home 	<ul style="list-style-type: none"> ○ Various staff visited him at home as his disability restricts mobility ○ Kindness ○ Unhurried even when busy ○ Above and beyond what was expected 	<ol style="list-style-type: none"> 1. Responsive to his individual need – helped him 2. Kindness and good humour

	<ul style="list-style-type: none"> • Over and above what was expected • Made a point of coming to chat when he was in hospital, nice just talking to the nurse – over and above what he had to do • CNS – came to his house and helped fill out forms – very prompt help – ‘over the top’ for him • Physio came to his home as he had been unwell at an appointment – helped him into house, called ambulance and made tea while they waited – doing more than was asked • Dr took time with him and wanted future feedback about his progress • Nurses busy, put him at ease and carry out unpleasant jobs – laughed about things • Member of staff saw they needed help and prioritised them when already engaged in other work – was not her patient but saw their need. Got a blanket, helped with a wheelchair and to get him in to a car – was kind • When ‘lost’ someone will always help, take trouble and be nice • Offered help – didn’t assume he was able to do things • Hospital staff always kind and helpful, never grumpy or cross 	<ul style="list-style-type: none"> ○ Unpleasant tasks with good humour ○ Gave time ○ Recognised need ○ Never grumpy or cross ○ Need recognised and help always given 	<ol style="list-style-type: none"> 3. Often people go above and beyond what is expected 4. Gave time and were unhurried
Story #7	<ul style="list-style-type: none"> • In hospital for rehabilitation after an accident • Felt desperate, grief, extremely upset • End of the day – no one about, just had to return to the ward • Didn’t feel he could hold his grief, crying, upset • Member of staff going home – saw his distress and stayed to sit with him • Made him tea, let him cry • Kind and compassionate • Could have just gone home but didn’t • When finished crying talked things through • Gave him her time • Above and beyond what was expected • Compassion was the ‘true word for it’ – saw someone in need and reacted to it • Kind and unscheduled 	<ul style="list-style-type: none"> ○ Loss, grief, distress, crying ○ Alone ○ Recognised and stayed to sit with him ○ Gave him time – above and beyond shift, was unscheduled ○ Made tea, listened, talked it through ○ Kindness ○ Saw need and met it with subsequent benefit 	<ol style="list-style-type: none"> 1. Recognition of need – which was met 2. Above and beyond 3. Gave time and listened 4. Kindness

	<ul style="list-style-type: none"> • Did him good – was able to start processing what had happened to him – hated to think what state he would have been in if she had not stopped 		
Story #8	<ul style="list-style-type: none"> • On own, in hospital, couldn't find baby's heartbeat • Moved to side room, prompt attention from senior staff – confirmed baby had died • Helped her phone her parents • Midwife who also had husband in the military arranged contact with patients husband who was in navy and away on ship – knew how to do this • Midwife sat on bed, stayed with her – 'just didn't leave' • Spoke calmly, didn't bombard, speaking softly, kind, very warm and lovely • Devastated • Midwife explained what would happen and that she would be on duty during next admission • Offered her the chance to visit the labour ward and see where she would be returning to – enable her to prepare • Physical touch once checked that was ok • Gauging and reading what 'I gave back to her' • Real skill – took patient's behaviour and 'mirrored' it back • Same midwife when she phoned - calm, gave options, calmed her down • Made recommendations which were 'quite right' • Listened to what patient said and responded • Next admission – 'so relieved' to see same midwife • Smiled at patient – 'bounced' off of them • Wanted to be 'us', have conversations, even laugh – read their need and 'behaved exactly as we hoped she would' • Encouraged them, on the journey with them, so comfortable with her • Terrified how the baby would look, guilt ridden she had ruined/trashed the baby – asked midwife to look and give them a warning if needed 	<ul style="list-style-type: none"> ○ Staff stayed with her/them – even after discharge were available and interested ○ Used personal knowledge/experience to give specific help ○ Calm, softly spoken, kind, warm, lovely ○ Explanations, options and choices ○ Frequent checking/gauging need – then appropriate response ○ Constantly mirrored the pt/husband – reflected them in how they cared ○ Listened ○ Shared the journey – relieved at the familiar and understanding ○ Smiled, encouraged, gentle recommendations and delicate follow-up ○ Openness – didn't force their knowledge/experience – did what the patient/husband wanted ○ Gave them hope for the future ○ Made the experience what they wanted – normalised it ○ Made them feel comfortable and very safe 	<ol style="list-style-type: none"> 1. Care reflective of the individuals 2. Attentive, present, listening and responsive 3. Gentle, calm, kind and warm 4. Open and informative but gave them control 5. Hope 6. Safety

	<ul style="list-style-type: none"> • She knew he was probably going to look ok but didn't say, said that's fine and just agreed – knew her mind-set and said 'that's fine I'll do that for you' • After baby born put him in cot and cleaned him and said 'he looks perfect' • Husband saw him and said he was perfect and was upset – midwife commented about the size of his feet – knew it would be an acceptable joke • Made the whole birth positive, lovely • Kept complimenting the baby but gave them space and time – he's your son – do what you want • Every midwife 'very open' – treated them as parents • Thought they'd be told to leave but they weren't • Gentle recommendations, all said very delicately and followed up • All who visited complimented the baby, came ready to chat, mirrored the parents • We wanted to be treated normally - they treated them normally, mirrored them • Wanted to enjoy the 36 hours that they had with him and be normal – carried him around, cut his hair, bathe him. Stayed relaxed • Midwife said she was glad she had delivered the baby – had been 'desperate' that it was her even though sorry it was in such awful circumstance • Encouraged – look forward to meeting them again in better circumstances, sure they would be back – really nice to hear that • Some weeks later at out-patients appointment the midwife was on duty and came 'flying out' to see them – had been following their progress – 'very supportive and lovely' • They were just incredible – mirrored what we wanted, made it the best possible experience in such a horrible time – made it better by doing what we wanted, advice in exactly the right way, in small doses, calmly or at a later time 		
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	<ul style="list-style-type: none"> • Stressed they would be there to help them now and once discharged 'at the end of the phone' • Didn't rush them, gave them options • Felt safe – very safe 		
Story #9	<ul style="list-style-type: none"> • 'My nurse' – always kind and compassionate, lovely • Listens to my moans and groans • Had an investigation – wasn't very happy, miserable, started crying • Nurse always asks how she is – saw upset and pressed her to tell her how she was • Sat next to her, put her arm around her, gave her tissues • Speaks to her and tries to reassure • Acted as liaison between patient and consultant • Although busy said to leave it with her – was reassuring • Once says she will do something she will actually do it • Makes you feel reassured she will back to you, helpful 'mentally' • Feel better for the hug, the reassurance and the fact that there is a plan • Talks about other things to lighten the mood, always makes the end of the session happy, have a laugh • Less miserable at the end of the appointment than at the beginning • Did get back to her and said what she'd done, kept her in the loop – did what she said she would do • A good nurse – makes you feel reassured 	<ul style="list-style-type: none"> ○ Relationship – 'my nurse' who is good, kind and compassionate ○ Genuine concern for wellbeing, consistently ○ Listens ○ Physical and emotional reassurance ○ Even though busy takes responsibility and action to help ○ Always does what she says she will do and keeps patient informed ○ Tries to ensure patient is happy ○ Better for seeing the nurse 	<ol style="list-style-type: none"> 1. Consistent 2. Listens 3. Reliable 4. Reassurance 5. Kind and compassionate
Story #10	<ul style="list-style-type: none"> • First diagnosed 3 years ago following heavy bleeding in the night when away from home • Anxious – something is really wrong • Went to nearest hospital – felt not taking her seriously or taking any notice of her • Told them she was a specialist nurse – still did not seem concerned 	<ul style="list-style-type: none"> ○ Anxious, something really wrong, worried ○ First place sought help dismissed her even when told she was a healthcare professional ○ Contacted own place of work – immediate help 	<ol style="list-style-type: none"> 1. Quick response by people who care about what they do 2. Listened to, had an advocate 3. Protected, safe, cared for, supported 4. Reassured

	<ul style="list-style-type: none"> • Went home – phoned the hospital where she works as still worried. Phoned back by consultant almost immediately – told to come straight away • Immediate action to investigate and treat • Saw colleague who recognised something was wrong so immediately accompanied her – was lovely, felt protected and cared for • Everyone rallied around, looked after • Worried that she had cancer as her father had had it • Everyone was listening to her – immediate investigation and subsequent reassurance • Colleague chatted to her throughout investigation – made her feel comfortable in an embarrassing situation • Everyone spoke to her and told her what was happening • Felt reassured • Found out diagnosis – can cope with it • Ever since has felt supported and cared for • Treated where she works makes her feel safe, everyone was amazing • Not because she works there, all patients get that level of care – knows people and knows that even when things go wrong people always try to put it right, work as a unit, everyone does care about what they do and how they look after people • You are looked after as you’d want your relatives to be looked after • Having someone accompany you, be an advocate, look out for you and keep you safe • Go through it with you, feel involved and talk with you after 	<ul style="list-style-type: none"> ○ Felt protected, cared for, looked after, supported and safe ○ Everyone rallied around, spoke to her and kept her informed ○ Listened to ○ Reassured ○ Not because she worked there – same level of care as all patients ○ Work as a unit, care about what they do ○ Was looked after as she imagines her relatives would be looked after ○ To be accompanied, to have an advocate – to be kept safe 	
Story #11	<ul style="list-style-type: none"> • Sudden event – mother had fall – had to travel to get to hospital • Situation changed – deterioration, bleed on brain • Seemed to improve and then had another bleed and was ‘brain dead’ • Quickly and quietly mentioned that she was on donor register • Met nurse specialist – was amazing 	<ul style="list-style-type: none"> ○ Staff – calm, quiet, compassionate matter of factness, ‘held their hand’ and explained ○ Never felt ordinary – all about them and their Mum even though 	<ol style="list-style-type: none"> 1. Calm, matter of fact, honest and sensitive 2. Held – with empathy and understanding 3. Care responsive and focussed

	<ul style="list-style-type: none"> • What really helped – a calmness, a compassionate matter of factness – made the whole thing ok • Faced with reality had a lot of questions and needed someone to hold my hand through it and explain process • They never felt ordinary even though it was her ‘daily job’ • Gave time, was very honest, didn’t use euphemisms – that was very important, matter of fact but sensitive • Checked their understanding • Took them to ICU to say Goodbye – came in with them, stayed but at ‘respectful distance’ – felt like a metaphorical hand on the shoulder • Told family she would stay with their Mum through the whole procedure and would look after her – made a massive difference • Would ring them when it was complete no matter what time – rang and will never forget her words – made going to bed ok • Said it was over, she was sat with her and she was peaceful • Asked if they needed anything – arranged for them to see their Mum the next day • Mortuary assistant – made them welcome, gave them the time they needed, present but knowing what distance was needed – the empathy and understanding to know when to come forward and when to stand back • Most important thing – felt like they were circling them at a distance but felt held, not guided – they guided it • Always felt it was about them and their Mum even though there was obviously another agenda • Balance was held very effectively 	<p>other agendas and their job – effective balance</p> <ul style="list-style-type: none"> ○ Staff – honest, gave time, sensitive, checked their understanding, welcoming ○ Stayed with their Mum, looked after her and kept them informed despite late time ○ Made it ok – responded to their need, were guided by them and responded with empathy and understanding 	<p>4. Gave time</p>
<p>Story #12</p>	<ul style="list-style-type: none"> • Cancer diagnosis #1 – 19 years ago • Breast care unit from ‘home’ hospital phoned her to see if she wanted a visit or needed anything – couldn’t believe they were thinking about her • Felt cared for immediately • Member of staff shared their own, similar experience and offered availability and reassurance all would be ok 	<ul style="list-style-type: none"> ○ Significant diagnosis ○ Was considered and offered help immediately – felt cared for ○ HCP shared their experience and offered reassurance ○ People were positive – like a ‘giant hug’ 	<ol style="list-style-type: none"> 1. Noticed/recognised and then cared for, supported and never deserted 2. Shared personal experience 3. Individualised care

	<ul style="list-style-type: none"> • Horrible journey but people were really positive • Was like a giant hug, it was lovely • Weird but used to look forward to going in for treatment – felt people really cared about what was happening to you • Sister was terminally ill – staff remembered and always asked after her as well even though many patients – thought it was lovely • Made friends for life • Always there for her – even years later, on the end of the phone, never felt deserted • Staff amazing, funny – had some real laughs, remembers the laughter more than anything – was how she got through • Had to self-discharge to be with her sister, they understood and gave advice and support – made her feel secure. Was a positive • Information given in a straightforward but caring way, never kept anything back nor over-exaggerated. Given facts but in a way she could handle • Never frightened – apprehensive as never knew what the outcome would be but was always given honest facts in a kind way • Eye to eye contact, physical contact – even from unlikely people • Responded to request for help – sat on the bed and listened and answered questions – gave her time even when obviously busy • Not uncomfortable with questions • Met with kindness, care and compassion – made dealing with the 2nd diagnosis some years later much easier 	<ul style="list-style-type: none"> ○ Remembered individual details about her even with so many patients ○ Was supported, never deserted even years later ○ Knew her – that she liked a laugh, how she wanted information given, that physical contact ok ○ Answered questions kindly and in a way she could handle ○ Gave her time even when busy ○ Were kind ○ First experience was so good that it made subsequent diagnosis much easier to deal with 	<ol style="list-style-type: none"> 4. Time 5. Made future care more bearable
Story #13	<ul style="list-style-type: none"> • Treated gently • Lots of people which was horrible but reassuring not to be on your own • Respected her problem • Held her hand, reassured – knew that she needed this • Scared, shaking – gave her options • Diagnosis given by CNS – gentle and handled it well • Everyone was caring 	<ul style="list-style-type: none"> ○ Gentle treatment, caring, lovely, calming. Confidence = reassuring ○ Respected – severity of her illness and her as a person, ‘handled’ nicely, not just a number but as an individual ○ Held her hand when scared, eye contact, smiled – important 	<ol style="list-style-type: none"> 1. Gentle, caring, calm, confident staff – professional 2. Individualised care and respect as an individual 3. Reassurance 4. Normalised the abnormal

	<ul style="list-style-type: none"> • Timely – not kept waiting around • So worried at OPA became ill – nurses were lovely, joked, calmed her down, were very sweet • Consultant confirmed diagnosis but then told her what they could do to treat her - all the stress went away as she had a plan, relieved • ‘Handled’ her nicely, even the more distant doctor guided people to care for her • ‘Bent’ the rules to allow her to use a toilet in another area – ‘thank God for that’ • Nurses/everybody very nice, frightened but they calmed her and were very caring • Humour, spoke normally which made her feel relaxed – if they are on edge or speak quietly then it causes worry • Shivering – got blankets, checked on her • Gave her positive news as soon as possible – felt good about that • Put her at ease when she was embarrassed • Got her tea, biscuits, sandwiches • Cleaners – very pleasant, chatted, made her feel comfortable. • Everyone she met was very gentle, talking about normal things, checking she was ok and if she wanted anything. Reassured her constantly • Fast service, everyone knew what they were doing, everything was in order – couldn’t fault anything, was reassuring • Procedure done gently and caringly • Phone in at any time no matter what time – always someone to talk to – they would be there to help • People respected her – not just a number, felt comfortable and safe • Gave the impression they knew what they were talking about, knew what she was going through, what she was feeling • Caring and professional • Still to have ‘that’ amount of care even when under a lot of pressure, never rushed so never felt in the way 	<ul style="list-style-type: none"> ○ Given options, checked she was ok and if she wanted anything ○ Timely – procedures, results, discharge ○ Never rushed, given time she needed ○ Practical help – access to toilet, blanket when cold, tea and food, comfort ○ Normalised the situation, spoke of normal things, used humour, dismissed embarrassing situation ○ Constant reassurance, offered contact and support once discharged ○ Comfortable and safe ○ Professional – knew what they were talking about and what she was going through/feeling 	<p>5. Given time and not rushed</p>
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	<ul style="list-style-type: none"> • Always gave eye contact and smiled – this is important • Important staff don't look worried or frightened as this affects the patient • Attitude and treating patients as individuals 		
Story #14	<ul style="list-style-type: none"> • Staff had experience = resulted in intervention to prepare her for her husband's death • Sitting with doctor – comfort and seclusion • Can't remember what he said but his manner – tentative, gentle and his patience remembered well • As if he had all the time in the world • Checked on what support she had • Facilitated by staff - following the death, family, friends and staff gathered together – homely and an over-riding memory • Closeness and caring, feeling held – a good memory • Bereavement appointment with oncologist – different to previous OPAs • Appointment very much hers – space and time to speak and feel and to say thank you and goodbye to someone who had been important • Wanted to offer comfort – the words have stayed with her 	<ul style="list-style-type: none"> ○ Experience of staff prepared her and ultimately gave comfort ○ Sat with Doctors – in seclusion and comfort ○ Doctor tentative, gentle and patient – unrushed, gave time ○ Facilitated to stay with family and friends after husband's death – closeness and caring, felt held ○ Oncologist gave space and time for her to speak and feel which gave lasting comfort 	<ol style="list-style-type: none"> 1. Experienced staff 2. Comfort - lasting, felt held 3. Gentle, patient, unrushed 4. Time 5. Given space - recognised

Table # 10 Invariant constituents, themes and essences of the patient and carer participants.

5.2.3 Textural description

What did the storytellers experience when asked to describe compassion?

It was very apparent that no matter what the circumstance, common themes and experiences were emergent. It was, in fact, striking how similar the description of patients' experiences were. Time was not a factor – stories ranged from very current, to several years ago to many years ago (19 years plus) but many themes remained constant. So much so that after 14 patient participants telling 16 stories it was decided that saturation in the findings had been reached and no further stories were required. The notion of saturation has been described in Chapter 2 and further contextualised in Chapter 4. As with the healthcare workers' stories the very apparent commonality of experience and terminology did seem to fulfil the requirements of what Saunders et al (2018) describe as 'data saturation'.

Commonly cited behaviours and adjectives are included in table ##11 below based on the number of times each was mentioned by patients, however examples which add context are also an important element of the analysis method with Moustakas (1994) making it clear that verbatim examples from the transcriptions should be included. Each example included below is attributed to and identified by the number assigned the participant in Table #9.

The idea that healthcare staff treated patients as **individuals** and that they should be able to recognise and respond to specific needs was present in

9 and 7 of the 16 stories respectively – patients variously described this as being there for them *‘as a whole person’* (#3) and as *‘you don’t feel like just another cog in the wheel or just another patient’* (#4). **Recognition** was an important constituent of compassionate care and linked to the idea of being seen as an individual with individual needs. The nurse was *‘very much gauging me and reading what I gave back to her’*(#8) and this determined her response to the patient, one patient recalled that the nurse remembered details about her family and said *‘how have they remembered that with everybody that was there, being treated that day’* (#12). This individualisation and recognition was demonstrated in needs assessment, which was then responded to – the lack of feeling as if ‘one size fitted all’ was identified as important as was understanding and **lack of being judged.**

Healthcare staff recognizing what patients did or did not like – such as physical contact, humour, the amount and depth of information further exemplified this and then, importantly, informed care delivery. One patient recalled *‘staff were great and it was funny, there were some real laughs, I mean I laughed my way through my treatment, that’s how I do it’* (#12). Another said *‘she was occasionally putting her arm on my arm and gathered that I am okay with that’* (#8) and later on in her story she said *‘when we went in she came flying out of the staff room arms open, you know big cuddle, really happy to see us again’*. Of course, this individualised need could also present the very opposite reaction in a different patient,

‘...some of them I didn’t like as much, nothing to do with them I think it’s just a personality thing. They were perhaps a bit too gushy

er, you know really er, you know almost giving you a hug. I know it was all from a really nice motive er, I didn't find that as good as just somebody who would take the time and be quiet and be calm and reassuring and not so showy and not so gushy about it. So a bit more genuine perhaps.' (#4).

Clearly, one size does not fit all and the recognition of this and the tailoring of interactions to the patient's preferences was demonstrably important.

The recognition of what individual patient participants wanted was also reflected in the **need for information**, but importantly, whilst patient participants spoke of the importance of this they also spoke of how this needed to be delivered in a way that reflected their needs. One said, '*they always give everything in little stages so as not to overwhelm you*' (#4) whilst another said '*I always sort of thought the facts I was being given were honest facts but they were given to me in a kind way*' (#12). '*She stayed with me, she spoke so calmly. She didn't bombard me with things*' (#8) and '*I cannot recall much of what was said but how he was, his manner, tentative and gentle, and his patience I remember well*' (#14) both demonstrate the importance of the manner in which information is given. The skill required in very testing times, in this case discussing organ donation with a bereaved family, was both evident and clearly integral to the experience of the participant, '*...she was very honest, she didn't use any euphemisms, I think that to me that was really important. It was matter of fact in that sense but was very sensitive in the way that questions were answered and questions were asked of us as well, of our understanding*' (#11).

Perhaps unsurprisingly, being **given time** was identified by 8 patient participants and being unhurried and not rushed by a further 2 – one said it *'was as if he had all the time in the world'* (#13) and that she had *'space and time to speak and feel'* (#14). Often this feeling of being given time was accompanied by the understanding that this was achieved seemingly easily even when it was obvious that the relevant member of staff was clearly busy or had even, in this case, completed their shift, *'I must have had an extra 15, 20 minutes of her day that she just gave, you know, just out of kindness'* (#7). One patient recalled *'he went to walk away when I'd asked him something and gave me a short answer and I said, excuse me I just asked you so and so and he came back.....and sat on the bed and....he listened to what I'd got to say and answered. He was in a rush....but it was something I really needed to know and he came back and he sat with me and he gave me the time I needed.....he could have kept walking'* (#12).

The importance of the **relationship** between patient and healthcare staff was evident – demonstrated by the ideas of how the staff behaved - **calm** and **gentle** was mentioned by a third of the patients, **purposeful** and **professional** by 3. Other descriptors such as **consistent**, **reliable**, **confident** and **experienced** were also highlighted. The common denominator when describing such characteristics of staff was that this then resulted in patients feeling **reassured** (a theme identified as key by 7 participants). Reassurance was important as the stories were most commonly about times when patients were in great distress, frightened, angry, confused or in pain (see Structural Themes for further details). This

reassurance was described in various ways *'everyone just rallied round and I just felt totally protected and I knew I was going to be looked after'* (#10) and *'take the time and be quiet and be calm and reassuring'* (#4) as well as *'she said to leave it with her but it was reassuring because she's a lovely nurse and you know that once she says that she will do something that she will actually do it and that always makes you feel reassured and she will get back to you'* (#9).

The demeanour and behaviour of healthcare staff was also highlighted by several patient participants who valued either a personal experience shared or the **'normalisation'** of what was, to them, anything but normal. One participant described this as *'compassionate matter-of-factness'* (#11) and another that *'they had humour and they talked to me in an everyday sort of situation not quietly like, "oh are you all right?"....normal you know "is this OK, can you manage on that?".....that sort of attitude which, made you feel a bit more relaxed'* (#13). Another benefitted from a shared military background which resulted in the nurse understanding both how to contact the patient's husband who was away at sea but also how to respond to the couple's needs. A doctor was able to relate his own, similar experience to a patient with the following consequence;

'this lovely man had shared his story of his vulnerability with me in order to help me manage my vulnerability and that strengthened me so much because I just knew that.....I was a human being with all the natural, normal human reactions that people have and that was just so special to me and that also remains as a hugely privileged, treasured memory of compassionate, empathetic, professional care' (#3).

The allied concepts of feeling **held, supported and cared for** were common to a number of stories, one participant described this as; *'....it felt*

like they were circling us and sometimes they were circling quite closely and sometimes they were circling at more of a distance and knowing ...I felt held by that, not guided but held'(#11). Another described being accompanied by a member of staff to a distressing procedure and that that this meant that *'I just felt so actually protected and cared for'* (#10). Another stated *'if you were going to have to go through that treatment you might as well have it somewhere where you felt people really cared about what was happening to you'*(#12).

Understanding **without judgement** was also a repeated theme, *'she doesn't think I was stupid at the age of 50+ wanting to hold a soft toy'* (#3) and *'She knew I was in a mind-set and left me to it and said, "that's fine, I'll do that for you" as well as 'she can apparently tell me without a lecture about how stupid I am (laughs) because possibly I could be more organised'* (#1). One participant feared that *'this is where I get told off and this is where I am told I am stupid and over emotional and I'm a menopausal, hormonal idiot'* (#3) when the exact opposite happened.

The impact of compassionate care was also apparent – several participants whose care was or is ongoing said that a positive experience meant that they approached future care with much more confidence and empowerment; *'because I just knew that if the hospital was like her whatever happened they would be there for me and that's so much influenced the way that I went along the rest of the journey'* (#3). The same participant described the result of a compassionate intervention thus; *'her kindness, her love, her empathy, her compassion absolutely*

broke down all that anger and all that hate and all that resentment and I felt sad but I just felt, here is this wonderful person who understands me as a very frightened human being'. Another patient participant had a recurrence of her illness and said that because, *'I've had amazing treatment, I've met with kindness, care and compassion all the way through'* (#12) that the second episode of care was much less daunting.

As with the healthcare staff participants, being involved in a compassionate encounter had identified outcomes for the patient participants too and these are described here in the same table format as used in Chapter 4 to present the healthcare staff's textural descriptions. Specific terms which were used to describe compassion (surrogate terms) or to describe the characteristics and behaviours of those who are compassionate have also been included.

Results of compassionate care	Behaviours of compassionate staff	Characteristics of those providing compassionate care	Terms used to describe compassion
Improved confidence in future care	Gave time/unhurried	Matter of fact/normalise	Empathy
Empowerment	Supportive	Listen	Love
Seen as an individual	Go above and beyond if needed	Understanding	Kindness
Feeling held	Caring	Patient	Thoughtfulness
Recognition of specific needs	Understanding and non-judgmental	Concentrate	Helpfulness
Needs were acted upon	Willingness to share own experience and stories	Efficient/timely	Warmth
Informed	Reassuring	Calm	Care/caring
Lessened fear, anxiety, anger	Provide hope	Purposeful	Comfort/comforting
Safety	Advocacy	Professional	
Reassurance	Closeness, proximity, physical contact	Good humoured	
	Holding	Consistent	
		Positive	
		Reliable	
		Confident and experienced	
		Honest	

Table #11 Textural description of the patient and carer participants

5.2.4 Structural Description

In what context was the phenomenon experienced?

The practical context that underpinned the stories was that of being a hospital in-patient and in a National Health Service care environment in the majority of the stories – 11 were either partly or wholly about in-patient hospital care experience. Six patients also either wholly or in part recounted their experience of outpatient hospital care, 1 also discussed care in their own home and 1 was of care within a hospice setting. Twelve of the stories concerned the experience the participant had as a patient

whilst 2 were stories from the close relative of a patient and in this case, both patients were being cared for at the time of their death, one in an Intensive Care Unit following sudden and catastrophic illness and the other in a hospice following a period of palliative treatment for cancer.

A recurrent theme was that the recollection either highlighted or at least referenced the point of diagnosis of a significant illness and this featured in 4 stories or when there was a sudden change in condition or in need – again in 4 stories. Six of the patients were in hospital for surgery and in all cases, the operations were significant resulting in either disfigurement or prolonged procedures, however, all patients who had surgery ultimately had a positive outcome from their procedures. All of the patients who gave stories were currently experiencing quiescent or remission stages of their illness or had been told that they were ‘cured’. It is inevitable that the situation the participants found themselves in at the time that they participated will have influenced their stories and this will be discussed more fully in Chapter 7.

Timing of the interaction also featured in several stories with staff identified as giving time over and above what was expected – for instance, once their shift had finished, when the patient did not have an appointment or at Christmas. *‘...she could just have said “Oh I have to go home now, it’s half past four, my shift is done” (#7) and ‘it was the day before Christmas eve so it wasn’t like a day she’d want to be hanging around and she came in the day, she came again in the evening and she rung again on Christmas eve. Now you know she, even if she hadn’t got children or anything she*

wants to be at home I am sure' (#6) as examples. Expressly making time for the Storyteller when the person involved was obviously very busy was highlighted in seven of the stories. This was summed up by participant #5 as, *'always having time to talk to people. You'd think they had plenty of time but you know jolly well they didn't'* and participant # 14 as *'...it was as if he had all the time in the world'*.

The emotional and psychological state of the patient appeared to influence both how they experienced the interaction with healthcare staff but also, apparently, how the healthcare staff behaved. The description that predominated was of being frightened or scared and this was cited by 6 of the storytellers, *'I was scared absolutely silly. And I was called in and I was prepared for the MRI and I was so frightened because of what this scan might show and I was also very frightened that she wouldn't tell me'* (#3). Being frightened was debilitating with one participant describing how she was *'lying there almost shaking'* and that *'...I don't think I have legs, you know it was that bad'* (#13).

The allied emotions of worry by 4 and anxiety by 3 demonstrated that this emotional state was a common experience that either preceded or perhaps motivated the behaviour of the healthcare staff. Two participants spoke of interactions with staff that helped to make an embarrassing situation less awkward, *'she chatted to me the whole way through my scope, made me feel really, really comfortable in a really embarrassing situation'* (#10) and:-

'...I don't know what they pump air into you or God knows what, that I made a rude noise and we've got the porters there, not so

bad for the nurse perhaps but for the porter, oh my God. And anyway and they just kept, er and said oh not to worry about that, he said, you're not the first and not the last. Anyway I got on, so embarrassing' (#13).

Unsurprisingly, the Storytellers often remembered periods when they were very upset describing this variously as devastated and being in a nightmare (*'because it was an absolute nightmare' #12*) – both by 2 patients, and of being visibly upset or crying by three others, *'...so I just burst into tears and she finds me a tissue and comes and sits down and speaks to me and sort of tries to talk it through with me' (#9)*. Descriptors such as distressed, dread, shaking, *'on a horrible journey'* and heart-rending were used and 4 of the stories highlighted feelings of grief, loss and bereavement *'I really didn't feel I could hold, you know, my grief' (#7)* and *'...she came in with us and stood at a very respectful distance but was just there as a, it just felt like a metaphorical hand on the shoulder whilst we basically said goodbye' (#11)*.

It is important, however, to note that a number of the stories also chronicled the compassionate interaction of the 'everyday' and this was emphasised by a number of patients. Laughing together, joking, sharing seemingly mundane details (*'talking to me about daily routines' #13* and *'She'd just moved into her flat, went into lots of detail, she was just really friendly and just talking about normal things all the time' #4*) and common experience and using 'matter of fact' language to give even very impactful information was all seen as responsive and person-centered and thus compassionate. One patient (#12) explained that a radiographer used a story about her *'for after dinner entertainment for a number of years as he*

told me when I bumped into him years later' and far from being upset by this she clearly felt it forged a relationship with him and that 'there were funny things like that. You know it was, well I just sort of, I can remember the laughter more than anything else because that's how I got through'.

More challenging emotional circumstances were also described such as confused or muddled by 2 patients and stressed by another 2. Descriptors such as desperate, guilty, shocked, panicked and irrational were also used and could arguably have been more challenging for healthcare staff to manage. Specifically, anger was mentioned in several stories and in each instant was met with a positive and memorable response from staff and that spoke of compassion to the patient, *'...and I was angry. I was cross. I was very resentful. I was cross with everybody' (#3)* but after the staff member had intervened with kindness and understanding, the patient felt all of her anger fade away, she recalled feeling 'loved'.

Situations where the patient felt out of control, disempowered and in a position of facing the unknown recurred in the stories and highlighted that the response from healthcare staff enabled them to regain control or grow in confidence that their future would be more positive than they had believed. *'I felt as if I was once again, back in control of my own destiny' (#1)* and *'the fact that I had different choices gave back the control and I think that's the compassionate thing to do not to say you're going on all this medical pathway' (#2).*

Finally, practical discomforts such as pain, hunger, mobility issues and being cold were detailed by more than 1 storyteller and in each instance was met with equally practical responses. Patients almost seemed surprised that nurses would get them a snack in the middle of the night because they were hungry, *'I know they were very busy but it was no trouble at all and she came in, got me some milk and biscuits because I hadn't really eaten anything and just in the middle of the night I just thought how nice she was'* (#4) or find extra blankets to keep them warm. A physiotherapist who followed a patient home due to her concern for him was proved right in this and whilst awaiting an ambulance went to the kitchen and made him tea and got biscuits out – his exclamation at her behaviour was indication enough of his surprise that she would go to such lengths (#6).

5.3.5 The overall composite description of the participants:

Moustakas (1994, p100) suggests that *'the final step in the phenomenological research process is the intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essences of the experience of the phenomenon as a whole'*.

Essentially, this requires the researcher to identify that which is common or universal, as Husserl (1931, p 43) would have it, *'the condition or quality without which the thing would not be what it is'*.

To recap, the aim of this section is to exemplify what each individual manifestation of the concept of compassion had in common. The composite description of the patient participants' experience is the

distillation of the textural description – what was experienced – and structural description – in what context was compassion experienced. Therefore, as with the stories shared by the healthcare staff participants, the final step is to combine the elements of the data to provide the essential characteristics of compassion as experienced by those cared for by healthcare staff. This then becomes the description of compassion in healthcare as experienced by patients in this study and is as follows.

There were some common themes that recurred in a significant number of the stories and the most evident of those was that patients felt they were cared for compassionately when they were given time or were unhurried by staff who were also patient. Allied to this was a timely response to worries or problems from people who would advocate and support the patient. Feeling listened to and given space to ‘be’ ensured recognition and was linked to being understood. It was important to be seen as an individual and this could be achieved by identifying specific needs and then making a positive attempt to answer those needs as well as by recognition of each person as different with unique needs.

Patient participants needed reassurance above all else and they indicated that this was achieved when they were treated with calmness, with quiet and confident professionalism and by experienced people who were gentle, consistent, reliable and thoughtful. Such an approach made the confusion and abnormality of their circumstance appear normalised and so a ‘matter of fact’ approach when coupled with openness, information and honesty was empowering. Patient participants valued being acknowledged

as a fellow human being with similar needs and vulnerabilities as those experienced by the people who cared for them and that they did feel cared for.

The participant Storytellers felt safe and protected and this was often linked with staff who were present, attentive, responsive, focused and who appeared to be concentrating on them and their needs. The individuality of the Storyteller participant's needs was apparent in the fact that whilst some valued quiet and calm others valued the realisation that they needed positivity and humour but no matter what the approach it was important that staff were understanding and not critical or judgmental.

The patient participants identified kindness as synonymous with compassion and also described being shown empathy, understanding and even love by those who cared for them – and they did care.

The result of compassionate care was that patient participants had hope, were reassured, felt comforted and were held in situations which were truly devastating, terrifying and distressing by helpful and warm-hearted staff who often went above and beyond what the patients had expected of them. Importantly, it also meant that those patient participants who had to face successive periods of care did so with a greater level of positivity and confidence.

5.4 Conclusion

Each story demonstrated the subjective understanding of the individual participant who recounted their experience, each account was valid, equally important and of equal value. However, when reviewing the essence of each story together it was apparent that there was intersubjectivity within the experiences described. There was a thread which linked each storyteller and this '*rich contextual data*' (Crowther et al 2017, p827) enabled the meaning of compassion to emerge and to be captured.

The stories told by those who had experienced health care were as affecting and powerful as those told by the health care staff. The clarity of recall and the impact of the care received was very evident, the stories were important in their own right but also provided clear and identifiable data to help inform that which may seem anathema to Arendt (1968), a definition of compassion, and this will be detailed in the next Chapter of this thesis.

Chapter 6

The Concept of Compassion in Healthcare

The aim of science is 'not to throw open the door to infinite wisdom, but to set a limit to infinite error'. Bertolt Brecht, 1940, p71.

6.0 Summary of Content Chapter 6

Chapter 6 provides a synthesis of the 3 elements of the Concept Analysis, Including both the literature and the lived experience of the fieldwork participants. This Chapter will presents the results of the synthesis and the definition of compassion and of compassionate behaviours that resulted.

6.1 Introduction

'I maintain that compassion can, however, be talked about in a meaningful way providing we view it as more than a word, but return to it as a concept, where we examine the variables and events in which the concept of compassion is situated'

(Wynard, 2014 p19).

Having gathered all of the data from the 3 phases of this research study the aim is now to combine all of the findings to provide a synthesis of the evidence and to, as Wynard suggests, approach compassion as a defined concept. One of the discoveries of this undertaking has been the identification of a significant and increasing volume of literature relating to compassion in healthcare – from many differing perspectives. Compassion is discussed, described, alluded to and, more and more, researched and this results in a significant volume of literature. As Brecht (1939) implies, it

is unlikely any 'science' can ever provide a finite answer but the evident continuing controversy, confusion and, significantly, lack of consensus about compassion would suggest that there is still a need to try and, at least, reduce the level of 'error' or misunderstanding about it.

By combining the findings of the 3 elements of this study the aim is to provide a comprehensive and responsive definition of compassion in healthcare. This will also result in identifying both the attributes of compassionate clinicians and those behaviours that demonstrate compassion to patients and healthcare staff alike. This will enable recommendations to be made in terms of practice, organisational structures, education and future research and these are contained within Chapter 7.

It is important to justify the need for this research, if there is so much that is written about compassion what more is needed? One of the patient participants in the study asked the researcher if they wanted her to tell them about her experiences of care that had not been compassionate. It was explained that, for this study, only stories of compassionate care were required but in the subsequent discussion the participant said that whilst she had experienced many fewer instances of compassionless care the impact was both distressing and long-lasting. As described in Chapter 1, failures to provide compassionate care have devastating consequences and examples are not hard to find, often the literature alluded to in this introduction provided harrowing and disturbing examples. The stories of the 'care' provided to the patients in the Health Service Ombudsman's report (2011) are difficult to read, the Francis Reports (2010, 2013) highlight failures in Compassion and reports by The Kings Fund (2011),

the Patients Association (2009) the RCN (2008) and the Care Quality Commission (2011) amongst others all confirm that such findings were not isolated nor a rarity. There has yet to be a convincing body of literature that indicates the findings in these reports have been reversed.

Some people are able to turn their experience into positive action for change, Robin Youngson, a consultant anaesthetist, recounts his family's experience when his teenage daughter, Chloe, had a protracted stay in hospital following a spinal injury in 2004. The lack of compassion that Chloe and the family as a whole were shown by hospital staff prompted him to set up the Centre for Compassion in Healthcare at Waitakere Hospital in New Zealand (Youngson, 2008). The experience of US attorney Kenneth Schwartz in the mid-1990's already described in Chapter 3 led to the foundation of the Schwartz Centre for Compassionate Care in Boston, Massachusetts (The Schwartz Centre for Compassionate Healthcare, 2019). In the UK, the Department of Health published 'Compassion in Practice' (2012) a 'vision and strategy' for nursing, midwifery and care staff as a response to the tide of negative press and the stories of failings in compassion highlighted by Francis (2010).

However, such positive outcomes following the imposition of care without compassion are rare and not possible for the vast majority of those who suffer the experience. That positives can come from adversity are admirable but not a reason to tolerate such adversity, the better solution is to try and combat the cause of the misfortune. There has to be a way of improving the experience for patients to ensure that the ambition set out in the NHS Constitution (DoH 2010 p12), who defined compassion as:

'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 time for those we serve and work alongside. We do not wait to be asked, because we care',

...is not simply an ambition but the expectation and reality of people's experience. Compassion is important, failures can be catastrophic and there is a need to ensure that there is a limit to 'infinite error'.

6.2 Concept Analysis and data synthesis:

Schwartz-Barcott and Kim (2000, p147) describe the need to 'step back' following completion of the fieldwork and look at the findings from the perspective of the initial focus of interest. They suggest that the researcher needs to ask 3 questions:

- '1. How much is the concept applicable and important to nursing?
2. Does the initial selection of the concept seem justified?
3. To what extent do the review of the literature, theoretical analysis and empirical findings support the frequency of this concept within the population selected in the empirical study?'

The concept of compassion is demonstrably applicable to nursing and healthcare as a whole, the background information in Chapter 1 and the exploration throughout this research have both laid the foundation for this study but also demonstrated the continued relevance of compassion. The need to justify selection of the concept is equally uncontentious and the frequency of the concept in the literature and in the experience of the

study population has been established. In such a circumstance, Schwartz-Barcott and Kim (2000, p148) describe the need to compare the definitions and information from the theoretical findings with those of the empirical evidence from the fieldwork.

6.3 The Literature review and the framework for synthesis:

The literature review resulted in 5 distinct themes related to how the idea of compassion was described in the relevant, professional literature: surrogate terms, antecedents, attributes, examples and consequences. These categories form a logical structure and will be used to frame the synthesis of the literature findings with the empirical findings from the 2 fieldwork studies. In effect, the development of consensus between theory and empirical findings will enable a taxonomy of surrogates and of characteristics to be established. These, combined with the antecedents or requirements for compassionate care to be delivered, will then enable a definition of compassion in healthcare, as demonstrated by this research, to be established. Examples from the fieldwork will be referenced against those within the literature and will then act as exemplars of the definition. The consequences of poor care, of a lack of compassion, were explicitly not explored within the fieldwork as only stories of compassionate care were recorded. However, the stories did highlight the positive consequences of compassionate care and those will be combined with the theory-generated data on consequences both good and bad.

6.3.1 The synthesis explained:

The synthesis of the findings will replicate the analysis of the individual elements of the study in terms of trying to stay as true as possible to the aim of presenting the data as free from the researchers' influence as possible whilst reflecting the intersubjectivity of the three elements. Erlingsson and Brysiewicz (2017, p96) suggest that novice researchers often try and base analysis on meaning units that are too large and include many meanings that are lost in the condensation process. It would be tempting to group and reduce findings that appear allied into themes and present these. The philosophical approach is that of interpretivism but this also acknowledges an intersubjective understanding and, according to Myers (2009), that such an approach is predicated on the understanding that reality is only accessed through social constructs such as language and shared meaning. Therefore, the data from the study participants and the literature will be grouped according to the frequency that specific terms were used. When allied or synonymous terms have been included this will be clearly described and justified. The use of terms and the shared use of language will therefore represent the intersubjective experience of compassion as demonstrated within the literature and the fieldwork elements of the research.

Such a seeming 'quantification' may seem incompatible with a qualitative approach however, Banbury-jones et al (2017, p15) contend that the use of numbers is not antithetical in qualitative enquiry when used 'as a *compliment to the process*' and that it is '*the clear articulation of that orientation that is important*'. The noted research theorist John Creswell

changed the title of his much cited book from 'Qualitative Inquiry and Research Design: Choosing Among Five Traditions' in 2007 to 'Choosing Among Five Approaches' by the 4th Edition in 2016 as he felt that there was no single way to approach any methodology. The aim of this approach to presenting the data has been presented with clarity and with relevant references and verbatim quotes to ensure that the context is also apparent. It is hoped that this transparency in method will confer dependability, which can refer to the stability of data such that replication is possible (Polit & Hungler 1999, p430). The criterion against which dependability is measured is consistency (Lincoln & Guba 198, p316) and the ability to ascribe the data to identifiable sources. It is the contention of this research that replication of the data is eminently possible and that the idea of frequency is both acceptable and accessible as a way to present the data. Schwartz-Barcott et al (2002) state that the integration of the empirical data from the fieldwork with the literature corroborates and refines the concept.

Schwartz-Barcott and Kim (2000, p149) suggest the need to view how other authors have utilised concept analysis and cite Kim (1983) who moved from a discussion of definitions across '*diverse bodies of literature to differentiation of the concept from other similar concepts, to operationalization and lastly to possible relationships with other concepts*'.

The composite intersubjective experience of the two cohorts of fieldwork participants was presented as allied themes resulting in the definitive description of compassion as experienced by the participants in this study.

Graneheim and Lundman (2003, p106) describe 'meaning' units as '*constellations of words or statements that relate to the same central*

meaning' and that these can be constructed from keywords or sentences and that these can then be condensed (i.e. shortened) and then abstracted to present codes or categories. Rodgers (2000, p78) states, '*concepts are formed by the identification of characteristics common to a class of objects or phenomena and the abstraction and clustering of these characteristics, along with some means of expression (most often a word)*'.

6.3.2 How evidence was weighted

The data from the literature was not weighted in favour of research in relation to reports or opinion pieces – the aim of a literature review within a concept analysis is to establish the nature of the concept in relevant professional writing – that which affects the understanding and usage of the concept by a professional group. The literature included in the first, substantive review incorporated a number of different sources and this was partly reflective of the lack of research that was found during the 2004-14 search. The second literature review was undertaken primarily to acknowledge the need to establish the 'evolution' (Rodgers, 2000) of the concept and, as a pragmatic approach, only included research studies. In keeping with the initial approach to the literature review, no greater weight was accorded to the studies either in relation to the first review or to the various research approaches described.

In the Schwartz-Barcott and Kim (2000, p130) model of concept analysis the final integrative stage asks for 'weighing, working and writing up findings'. No specific guidance is provided as to how to weigh the evidence – the authors suggest that researchers should review how others

have utilised the method in their studies and to acknowledge the traditions of the fieldwork method employed. However, Rodgers (1993, p83) advises that the researcher diligently identifies data relevant to the concept by looking at all statements that provide a clue as to how authors have defined the concept. This seems synonymous with Moustakas' (1994) 'horizonization' of the fieldwork data. Walker and Avant (1995) suggest that these attributes can be identified by noting characteristics which frequently occur.

6.4 Compassion surrogacy and the impact on the understanding of compassion

There were a number of commonly cited terms used synonymously with that of compassion in the literature and by the participants in both elements of the fieldwork. In the literature the most frequent of these was that of **'care' or 'caring'** and this was described by 56% of the original articles and was a noticeable term in the 60 studies reviewed for the updated section. 'Care' was also present in the stories of both healthcare staff and patients, often being used to demonstrate that some positive action had been seen as very 'caring' or simply as a description of a person, 'he/she was very caring'. The importance of such a frequently cited surrogate may be in the recognition that much that is written about 'caring' can equally be applied to the understanding and development of compassion. Studies and literature that was not included in this review because they related to 'care/caring' and not compassion may well have had a great deal to contribute to the overall understanding of the concept.

For example, Chochinov (2014) writes about care and caring and makes points that could equally be applied to the understanding of compassion and, this same author does indeed write on the subject of compassion and is represented in several of the articles included in both elements of the literature review in Chapter 3.

The idea of '**empathy**' was more controversial and less clearly interchangeable with the idea of compassion but was nonetheless the second most commonly cited surrogate in the literature (37% of the original authors and a very evident theme in the subsequently identified research) and was also described by both sets of fieldwork participants. Empathy was controversial as, unlike caring, some authors felt that whilst possibly allied to compassion, empathy was a distinct and different concept. Edith Stein, a student and later colleague of Edmund Husserl, wrote a seminal text about empathy as far back as 1917 describing it as '*a special kind of act through which the experience of other persons become accessible*' (Bornemark 2014, p261). This may be the appropriate distinction as those authors who felt it to be different to compassion suggested that it was the capacity for empathy which enabled or motivated the compassionate act; empathy was a shared feeling or understanding whilst compassion was an active response. Empathy means that I understand your suffering, compassion means I will do something to relieve or end it.

Again, the conflating of the terms is important, a significant amount of literature and research is devoted to the concept of empathy. As a relevant example, when exploring the idea that the training and education of health care professionals can reduce or impair a student's compassion, a large

amount of the literature and research is, in fact, written about the concept of empathy (Pohontsch et al 2018, Agius et al 2017, Ward et al 2012, Neumann et al 2011). And, when Neumann et al describe empathy as the ability of a physician to understand a patient's perception and feelings, communicate that understanding and then **act** on that understanding in a helpful and therapeutic way, it is obvious where confusion might occur.

One patient in this study, when recounting her story of being looked after in hospital said, '*They had welcomed me back to normality with their kindness, their empathy and their compassion*' (#3). It is clear that the link between empathy and compassion, in whatever form, is important and relevant. This also serves as an introduction to the third frequently used surrogate, that of **kindness** and this was cited by 21% of authors and by participants in both fieldwork elements. Kindness is a requirement of the NHS Constitution's 2010 definition of compassion and Crowther et al (2013, p492) state that '*kindness and compassion are two core human values which are important in society....are the foundation of social and personal relationships*'.

The interchangeability of terminology is a concern highlighted by Jeffery (2016, p446) who describes that empathy, sympathy and compassion are used synonymously in research and in everyday speech and that these characteristics '*also share elements with other forms of pro-social behaviour such as generosity, kindness and patient-centredness*'. Jeffery feels that this confusion of terminology has implications for clinical practice, research and education and this concern was echoed by Sinclair et al (2017) in their study of the concepts of sympathy, empathy and compassion.

The remaining theme that was mentioned enough to merit discussion was that of **love or affection** and 13% of authors felt this to be a surrogate as did both patients and healthcare staff. The idea that there is a need to love patients in order to demonstrate compassion or that compassion demonstrates love is less described in research literature. A rare example of this is Youngson (2012, p vii) in his book 'Time to Care: How to Love your Patients and your Job' but even he acknowledges that the clinical environment '*is not especially encouraging for those who want to talk about loving our patients*'. Clearly 'love' is an emotive word, C S Lewis in his book 'The Four Loves' (1960) explores the idea of love and how differently it manifests in different circumstances and relationships. The description 'agape' was used by one patient to describe their care. In the Christian tradition the term denotes the idea that God is love however, from a philosophical perspective, agape can mean unconditional love and charity.

Certainly, one of the noticeable developments between the first and the second part of the literature review in this study was the increasing emergence of the idea that demonstrating compassion in practice, far from causing 'compassion fatigue' may actually provide job satisfaction (Sinclair et al 2016b, Tierney et al 2017, Mills et al 2017, Leffel et al 2018) and therefore perhaps helping staff to 'love their jobs'? Such a contention needs to be tempered as this study did not seek to examine the significant body of literature relating to compassion-fatigue. It needs to be acknowledged that much of the investigation looking at the link, if one does exist, between compassionate care-giving and job satisfaction is related to the field of research in to compassion-fatigue. The many

contributing and confounding features that impact on job satisfaction also need to be considered so that the idea of compassion as a cause for the 'love' of one's job must be seen as compelling but unproven and requiring significant further examination.

Whilst other terms were used synonymously, such as humane or human, concern, thoughtfulness, warmth and benevolence, none of these featured across all three elements of this study. Therefore, the definition of compassion based on this research should include the terms **care, empathy, kindness and love.**

6.5 The antecedents of compassionate care:

The antecedent qualities of compassion, those which need to be present for compassion to exist, were more apparent in the literature than explicitly within the stories told by the fieldwork participants. Telling stories about specific experiences generally precluded description about what preceded those experiences but there were some themes identified and these, together with the literature analysis are described here.

The literature makes it clear that the most impactful antecedent is that of the **culture of the organisation** where care is delivered. Both the initial search, where 29% of studies make this connection (i.e. Dewar 2013, Curtis 2014) and in the second review where an increased 40% of the research (i.e. Henshall et al 2017, Singh et al 2018) highlights that the conditions and attitude of the workplace were crucial to the provision of compassion. A number of the studies in the second literature review described schemes and interventions that were specifically designed to

promote a compassionate culture in organisations that provide healthcare. Hewison et al (2018) employed interviews and focus groups to evaluate the effectiveness of rolling out a scheme designed to develop compassionate leadership. This study also suggested that it was part of a wider 'trend' in the UK to promote organisational approaches to compassionate care. Curtis et al (2017, p 160) describe an appreciative inquiry approach to evaluate the impact of a toolkit aimed at cultivating compassion and concluded that it, '*demonstrates the importance of an organisational culture that is receptive to, and supportive of, compassionate care*'. Ramage et al (2017, p57) also investigated the effect of the same toolkit and concluded that it '*positively impacted on the values-based culture in the workplace*'.

Bridges et al (2017) used interviews, focus groups and questionnaires to study the effect of an intervention designed to support compassionate care. They found that those who participated valued the scheme and felt it improved both patient care and staff well-being. However, they also highlight another aspect of cultural impact as the study participants felt that the effectiveness of the intervention was mediated by organisations that were focussed on tasks and targets. This possibility was also proposed by Valizadeh et al (2018, p587) in a qualitative study where interviews with staff from four hospitals in Iran found that '*for compassionate care to flourish, policy makers, managers and healthcare providers must foster an organizational atmosphere conducive to compassionate care*'. Following a cross-sectional study using a survey of staff in 269 US hospitals, McClelland and Vargus (2014, p1670) describe the benefits to patients of '*specific and actionable organizational practice*

that provide and reinforce compassion'. This idea that organisational culture could either foster or block compassionate care was also proposed by Sinclair et al (2016b), Tierney et al (2017) and Kneafsey et al (2015) amongst others. Tierney et al (2017) suggested that simply having the will as an individual to provide compassionate care was insufficient to ensure it occurred. They coined the term 'compassionate care flow' and felt that Healthcare staff needed to work in an environment which supported compassionate care which was, in turn, influenced by organisational demands and expectations.

Interestingly, several studies highlighted the fact that often, when failings in compassion were investigated, the blame was often levelled at nurses (Ledoux et al 2018) or at individuals (Crawford et al 2014) rather than at the design or structure of the organisation in which they work. Crawford et al (p 3596) carried out a narrative literature review of publications from 2000 until 2013 and felt that there was an urgent need '*to facilitate beneficial engagement between staff and patients*' by formulating '*a vision for a compassionate culture*'.

Allied to this is the idea that the presence of compassionate role models is important, what Cornwell and Goodrich (2009) describe as 'systematic modelling'. Positive organisational culture is described as that where the promotion of compassionate care was a priority but also as the provision of compassionate leadership (Georges 2011, Forrest 2014). Cornwell (2012) offers the following analysis;

'Nurses, midwives and care-givers look after patients in the context of organisations, not in isolation. It's simply not possible to deliver reliable, compassionate care 24/7 unless the system as a whole makes it a priority and the most powerful people in the system

actively demonstrate their commitment to the values and behaviours that support caring’.

Whilst patients and staff did not describe the need for a compassionate culture their descriptions of the need to have time and to not rush, to be responsive to the individual needs of the patients, to go beyond what is expected and even break the rules if necessary, all speak of creating a compassionate environment. One staff member (#6) said that ‘*worn out staff with no time*’ struggle to be compassionate and this was a theme that was reflected in all three elements of the study. Being **given time** and not feeling rushed was mentioned by over half of the patients and in 10 of the 23 staff stories. Many of the articles and studies that cited culture as key, highlighted the need for adequate time specifically and resource generally and both Horsburgh and Ross (2012) and Trenchard (2013) describe the impact of excessive stress or pressure on the ability to be compassionate. Bridges et al (2017, p970) highlight the benefits of a specific compassion intervention for patients but found that organisational culture could also constrain ‘*opportunities for staff mutual support and learning*’.

Much of the literature and many of the fieldwork participants describe specific traits and attributes that need to be present in order for compassion to be demonstrated – clearly without the required qualities staff would struggle. These attributes will be explored fully in the next section but it is clear that they are both an antecedent and a basic requirement for compassion to exist. However, one trait is clearly antecedent to the ability to provide compassionate care and that is the idea of **self-compassion**. This theme was evident in the original literature (e.g. Greenberg 2011, Nyatanga 2013) but was more prevalent still in the

research in the latter review (e.g. Henshall 2017, Jakimowicz 2017, Secco and Copel 2018, Mills et al 2018). If staff do not attend to their own well-being then they will lack the necessary resource to provide for the needs of those for whom they care. Whilst there is increasing evidence that compassionate practice improved job satisfaction (both in the literature and the staff stories) it is demonstrably evident that without self-compassion patient care may suffer. McPherson et al (2015, p104) sum this up as there needs to be a '*focus on the expression of self-compassion and mindfulness capacities, without which compassion to others is hindered*'. Curtis (2014) also cautions that staff need to preserve their own emotional wellbeing which is allied to the idea of self-compassion.

A requirement of both staff and of the organisation is to be **reflective**, without this approach the barriers to compassion will not be addressed. The need for self-reflection was highlighted by Dewar (2013) and Curtis (2014) while Hughes (2013) suggested that organisations need to invest in enabling continuous education and reflection. **Education** is a complex and contested element in relation to compassion and will be revisited in the next Chapter but a number of authors describe the need for staff to be educated in compassionate practice. Indeed Bray et al (2014) and Mills et al (2017) describe the imperative of compassion as a central tenet of healthcare education. However, too much emphasis on theory and academic attainment was also cautioned against as potentially having a negative effect on compassion (Davison and Williams 2009 and Kearsley 2011) although it is to be noted that this was the author's opinion and not based on any research and nor did such concerns appear manifest in the latter research studies identified.

An environment where patients are **involved in their care** and the decisions that are made about them was seen as important (Dewar 2014). Authors described this as the provision of person-centred care (which was used by some authors as a surrogate term for compassion). Patients made it clear that they valued being given choices and having information about what options were available to them. The most frequently described positive element of compassionate care provision was when staff were responsive and flexible to their individual needs, a couple who's longed for baby was stillborn were allowed to determine the way the birth and the time afterwards that they spent with their son was managed. The baby's mother described it as follows;

'You're waiting to be told you have to leave but that's not the case. It's like, 'he's your son, you do what you like'. There were gentle recommendations that we didn't stay for days and days and days in case he deteriorated a lot but it was all said very delicately very much followed up by, but you're his parents and you decide when you stay or go' (#8).

The final antecedent was that of **suffering**; in order for staff to practice compassionately it was necessary for those in need of care to suffer and for that suffering to be recognised. This notion was described and debated in a significant amount of the reviewed literature and remained a constant theme (Vivino et al 2009, Ekstrom 2012, Dunn and Rivas 2014, Papadopolous and Ali 2015 and Leffel et al 2018 as examples). Several studies found suffering to be inextricably linked with compassion, Schantz (2007) identified it as antecedent, the participants in the study by Sinclair et al (2018, p9) identified '*ameliorating suffering*' as the ultimate goal of compassion. Van Der Cingle (2011, p680) devotes a significant part of the

discussion of her research study to this idea and concludes '*in most literature compassion is directly related to suffering*' and that '*according to some it is the trigger*'. Van der Cingel confirms that this too was the finding of her study but also debates the subjective nature of the idea and cites a nurse who suggested that suffering existed when someone says that they are suffering.

This subjectivity is perhaps echoed, as with the concept of compassion itself, in the interchangeability of terms relating to 'suffering'. Authors have referred to similar triggers as 'need and distress' (Hewison et al 2018), 'vulnerability' (Blomberg 2016, Dewar et al 2013, Chochinov 2007), sorrow and pain (Schantz 2007, Crawford et al 2014) and simply as 'needs' (Sinclair et al 2016b). Tierney et al (2017, p2) sum this up thus, suffering can be '*equated with real or anticipated loss on a physical, social, cultural or spiritual level*'.

Another obvious reason that suffering is so clearly equated with compassion is the simple expediency of shared language. Chochinov (2007) describes the etymological root of the word 'patient' which is derived from the Latin '*patiens*' meaning to endure, bear or suffer and that this also refers to an acquired vulnerability and dependency as a result of changes in health and ability. As previously described, the root of the word 'compassion' is also to be found in Latin and means to 'suffer with'. As such, many authors settled upon either a dictionary definition of compassion based on this understanding or, in the case of Perez-Bret et al (2016) described the result of a literature review. This review clearly also acknowledges the frequency of the link between suffering and the defined idea of compassion. They state (p 602) that suffering is what

'initiates' compassion and that to be compassionate is not intuitive but requires an intellectual understanding of the nature of suffering. Ramage et al (2017, p45) describe this as a need for a '*rational understanding of the suffering that enables identification with it*'. Blomberg et al (2016, p138) further suggest the need for a '*situational awareness in which degrees of vulnerability and suffering are perceived and acknowledged*'.

It would appear evident from the literature that, whatever one's perspective on suffering, there is a significant link between the concept of suffering and that of compassion. Patients did not use the specific term 'suffering' but they did describe themselves as 'devastated', 'heart-broken', 'grieving', 'scared absolutely silly', 'frightened', 'sobbing', in a 'nightmare', having panic attacks that were 'irrational and debilitating', bewildered', 'desperate', 'anxious', 'in pain' and 'bereft'. A comprehensive list of unpleasant and distressing feelings that would seem to very eloquently define suffering.

The Aristotelian (Williams, 2008) definition of suffering as an antecedent to compassion suggests that suffering needs to be identified, that it needs to be significant, it needs to be due to no fault of the sufferer themselves and there needs to be some form of identification or similarity between the sufferer and the carer. This study would agree that suffering needs to be present but the findings from the healthcare staff would seem to dispute the need to recognise that suffering as undeserved. There was a strong theme of being **non-judgemental** and, in fact turning to help those who were marginalised and even seen as culpable. What was apparent was that the staff members generally recounted stories of extreme suffering as a way to demonstrate their understanding of compassion and this may

reflect the idea that suffering needs to be substantial. This presents a challenge, if it is agreed that suffering is a prerequisite, and this study suggests that it is, then perhaps the subjectivity of suffering needs to be addressed. If the level of suffering experienced by someone is perceived by healthcare staff as trivial then it is unlikely to 'trigger' a compassionate response. However, as described by the patients in the field study, their experiences, all very different, were devastating to them. It is impossible to compare the experiences of the patients or of the healthcare staff, how can you quantify someone agreeing to organ donation following the sudden and devastating death of their mother with someone who has lost their limb or who is relieved that they have survived an anaesthetic? All of these people suffered, by looking to the intersubjectivity of the experience, the common features (Creswell's [2012] example of grief for instance) it may be possible to understand and therefore demonstrate compassion.

In terms of this study, the antecedents which will form part of the definition of compassion will include **organisational responsibility**, the need for self-compassion, the need to provide time, to be reflective and appropriately educated and to **acknowledge the suffering** of others.

6.6 The attributes and characteristics of compassionate care:

Many of the characteristics described as being the attributes of a compassionate person were both seen as antecedent to compassion but also part of the necessary demonstration and delivery of compassionate care. As described in Chapter 3, the literature contained over 250 clearly described attributes and characteristics cited as those which demonstrate

compassion. However, there were some that were mentioned with greater frequency and these will be compared with the attributes and behaviours described by the staff and patients in the field study. As with the description in Chapter 3, the attributes will be divided into 2 categories, those which define the characteristics of a compassionate person and those which define compassionate behaviours.

The literature reviewed for this study makes it very clear that compassion as an attribute is an **expectation of healthcare staff**, a basic requirement. Some authors suggested that compassion is an innate or inherent characteristic of healthcare staff (Hudacek 2007, Maben, Cornwell and Sweeney 2009, Curtis, 2013, 2014, Sinclair et al 2016). Innate or not, the findings of this study demonstrate some common characteristics across the 3 elements of the study. The literature cites 12 specific attributes of a compassionate practitioner and all but 4 of these were also mentioned by both participant groups in the field studies. The 8 common characteristics are:

- Empathetic
- Respectful
- Kind
- Non-judgemental
- Loving
- Gentle
- Open/honest
- Caring

Of the remaining 4, sensitive was mentioned by the patient storytellers but sympathetic, concerned and courageous were not themes that emerged from either element of the fieldwork. Many more adjectives were used by

the patient group in their descriptions of those who had cared for them.

Those that were repeated more than once included staff that were seen to be understanding, calm, comforting, helpful, friendly, encouraging, good humoured, supportive, dependable, professional and the less descriptive but frequently occurring 'nice' and 'lovely'. Healthcare staff also highlighted that their colleagues had been selfless, tender, passionate and of not needing recognition for their compassionate behaviour. Obviously, much of what was described by the storytellers and in the examples detailed in the literature could be translated as sympathetic or courageous and so on but, based on the findings of this study, the commonly **cited** attributes of compassionate healthcare staff are the 8 qualities previously listed.

How staff behave and what they do obviously impacts on the patient's perception that they are being cared for compassionately. The stories recounted by patients provided a significant number of definitive behaviours and a number of these were mentioned by a more than one of the patients. As an example, the most frequently cited behaviour was the provision of care that made implicit the **recognition** of the patient as an **individual**, a person and not just a numberless patient, 11 of the 14 patients mentioned this as did 7 of the healthcare staff and this was also a recurring theme of the literature. One patient stated, '*I just think that personal contact, er, just helps. It does help. You don't feel like just another cog in the wheel or just another patient it's just a bit more person-focused care, so that's important*' (#4) and another, '*People respected me. I wasn't just a number*' (#13). A student nurse in the study described by Waugh and Donaldson (2016, p25) stated that '*every patient is a person*' whilst another said, '*...his illness is not the main focus but his needs are*'.

One compassionate behaviour mentioned by 10 of the 14 patients and 5 health care staff was that of being reassuring, and this was characteristic was also explicitly discussed in the literature as were acts which would provide reassurance. The significance to patient and staff alike warrant inclusion, one patient stated '*...it made me feel listened to, it made me reassured that all was well*' (#1) whilst another said '*everyone spoke to me, told me what was happening. I felt reassured*' (#10). One of the health care staff related the experience of caring for an elderly lady at the end of her life, '*she thought it helped her to see her mother die with dignity but also compassion through me and she said it reassured her that her mother was in good hands*' (#6).

Very apparent was the importance of giving patients enough **time** and of not appearing to rush. This is a contentious issue in the current healthcare climate and one that will be discussed more fully in the next chapter however, it was demonstrably important to patients (8 of the 14 patients) and with staff as well (13 of the 23 stories) and is described in the literature and is therefore a finding of this study (for example, Bramley and Matiti 2014, Sinclair et al 2016a). A number of the healthcare staff told stories of sitting with patients and giving them their time and attention, sometimes with patients who were unconscious or dying. One junior doctor stayed with an unconscious patient throughout the night to ensure that they would not die alone, holding their hand and staying by them. The patient had been admitted unconscious, the doctor had never spoken to them nor met them previously but she stayed long after her shift was over until they died.

Such behaviour also highlights another theme that is allied to providing time and that was the idea of being **present**, walking alongside and of witnessing. Half of all the patients and 7 staff stories illustrate this and, in the study of nursing care for older people with chronic illness reported by Van Der Cingel (2011, p678) the findings suggested that it *'...is of such importance that participants mention presence specifically. It is not just a matter of coincidentally 'being there'. It is a conscious choice because the nurse notices the need for her presence'*. A nurse in the fieldwork study who set up a service for people who had been the victims of sexual violence said, *'I spent some time not asking them to necessarily tell me their story but just to say that I was there and that I would walk alongside them through their entire experience'* (#1). Hofmeyer et al in 2017 researched the impact of an intervention to teach compassion and found that 'being present' was one of the four major themes that were revealed, they categorised this as 'putting yourself in their shoes' and 'taking time to listen carefully'. There is a body of evidence related to the therapeutic benefit of the idea of 'presence' (Boeck 2014, Fahlberg and Roush 2016, Mohammadipour et al 2017) but this study does not reference this nor claim evidence of therapeutic benefit, however, this study does demonstrate that 'presence' is a hallmark of compassionate care.

Listening, and the allied notion of being **heard**, was highlighted by 4 patients, 5 staff members and a number of authors. One patient made it clear that she defined the nurses' care of her as compassionate because; *'Oh she was listening to me. She was really concentrating on me and she really listened to my reply.....it made me feel listened to, it made me reassured that all was well'* (#1). A patient storyteller who had delivered a

stillborn child 40 years previously still struggled with the distress of that experience but was referred to a midwife who, along with a colleague, *'took her for a cup of tea and heard her story... we listened to her story'* (#2), the result was that the lady is not only in a *'better place'* but is now able to support other bereaved parents.

Many of the behaviours were intertwined – the next that was frequently cited in the literature was that of **'being held'** and this could be a figurative concept, *'she stood at a respectful distance but was just there, it felt like a metaphorical hand on the shoulder'* (patient #11) to a physical intervention, *'...she came flying out of the staff room arms open, you know, big cuddle...'* (patient #8). Clearly, such examples also speak of *'presence'* and of individualising care – one patient needed the distance whilst one the physical contact. The idea of **touch** and of physical closeness was highlighted by 5 patients who described being hugged and by 3 as having someone hold their hand – all of these stories highlight this as a positive interaction which demonstrated compassion. In 2 stories healthcare staff describe hugging as a means of displaying their compassion for the patients in their care. Sinclair et al (2017a) found that patients described acts such as an arm around the shoulder as indicating that staff were *'there for them'* and this was echoed by Bramley and Matiti (2014, p2795) who cite patients thus, *'Well, they look or touch and feel and put their hands on your shoulders. 'Well... you know, people they respond to that...it makes you feel like a human being'*. It is important to note that one patient made it clear that the sensitivity of staff to recognise that they did not like to be hugged was compassionate, however, this was the only dissenting voice in this study. Therefore, touch as a therapeutic

agent to demonstrate compassion is, with caution and respect for individual preference, a finding of this research.

Another theme that ran across all three elements of this study was that 'going the extra distance' or going '**above and beyond**' what is expected of healthcare staff is demonstrably compassionate (Papadopolous and Ali, 2015). This is an interesting concept when contrasted with the significant body of literature that describes the incidence of compassion fatigue and burnout in healthcare (Peters 2018, Ledoux 2015, Peat 2014, Cronin and Ryan 2019). To go above and beyond what is expected would seem to be an added burden on already hard pressed staff. Yet, this idea was a repetitive and consistent theme. Perhaps when allied with the idea that compassionate staff are also willing to bend or even break rules and override barriers it becomes a little clearer. The nurses who 'hid' the homeless man in the Emergency Room, fed him, let him sleep there and attended to his feet, the physiotherapist who was worried about the patient she had seen so followed him back to his home and, when her concerns turned out to be justified called an ambulance and then made him tea and waited with him. The receptionist who took a patient home in her own car as the patient's unwell husband had suddenly collapsed, the nurse who completed her shift and went and brought a man dying of liver failure a cold beer and sat and drunk one with him. These are just a few of the examples from the stories from staff and patients that describe both going beyond what is expected and breaking the 'rules'.

However, perhaps it is the rules that need to be addressed? Perhaps it is the perception of the staff and patients that suggests that the rules exist or that they cannot be challenged? In a 2017 study by Terry et al of what

book, poem, film or play most influenced nurse educators' understanding of care and compassion they describe one educators' choice of the play 'Wit'. However, they cite this as lacking in 'authenticity' as, in one scene, a nurse is portrayed as sitting with a patient, her feet up and sharing an ice lolly which the authors suggest '*would probably be seen as unprofessional*' (p9). This study was authored by 9 people, 7 are nurse educators from Ireland, the UK and from Canada, the other 2 are biomedical scientists one of whose biography states that they are also a Chaplain working within a London hospital Chaplaincy. The scene in the play 'Wit' they describe where the nurse shares an ice lolly depicts a conversation between the nurse and patient about the patient's resuscitation status. If the perception of nurse educators from 3 different countries is that such interaction may be inauthentic or seen as unprofessional then perhaps there needs to be a change in how nurses are taught and empowered?

Kenneth Schwartz (1995) describes the interaction between him and the staff who cared for him as what made the 'unbearable bearable' and urged them to be prepared to 'cross the professional Rubicon' and reach out to patients, to take the 'risks' of sharing something of themselves to help make a 'personal connection' to his plight. As described in Chapter 3, Schwartz felt that if the 'rule book' frowned on such interactions then it needed to be rewritten. The literature does caution staff and suggest that they need to be aware of professional boundaries (Mills et al 2018, Roberts 2011, Kearsley 2011). The Nursing and Midwifery Councils' Code of Professional Conduct (2018, 20.6) states, '*stay objective and have clear professional boundaries at all times with people in your care (including those who have been in your care in the past), their families and carers*'.

Bradshaw (2009) cautions against too much emotional engagement and Curtis (2014) describes the importance of protecting nurses' emotional wellbeing. Yet, the common humanity of patient and carer is clearly important; 5 stories from healthcare staff highlight their role as surrogates for family or friends, human or humane care was cited in the literature as synonymous with compassion and patients in their stories highlighted the impact of the shared experience. It is a complex and confounding issue, however, the findings of this study suggest that compassion is demonstrated when staff go above and beyond what is expected and override barriers if necessary.

Both patients and healthcare staff highlighted the importance of being responsible. '*...basically although I am taking responsibility for what is about to happen you have the control to be able to say how you want it to be*' (Staff #1). This idea was mentioned by 4 staff in their stories and specifically by 2 patients; the literature was perhaps less implicit however, responsibility was mentioned by Gelhaus (2011) and by Torjuul et al (2007). The description of responsibility, the need to be pro-active in response to patients' need was, however, described frequently (e.g. Tierney et al 2018, Taylor et al 2017, Cameron et al 2015). To take responsibility is a defined element of compassionate care based on this study's findings.

Ensuring that patients are both kept safe and that they feel safe was evident in the stories of both sets of participants. One patients said, '*they put so many options out for us that you just felt safe, we felt very, very safe, is the word I would use*' (#8) and a staff member recounted, '*...to be able to make sure that whatever they told me I didn't respond to with an*

opinion if you like but that I constantly reassured them that they were safe' (#1). The demonstration of compassion by keeping people safe and free from harm was highlighted by a number of authors including Kagan (2014), Kapitan (2011) and Badger and Royce (2012). This then becomes a defined element of compassion in healthcare based on this study.

Being an advocate for the patients in their care was a theme across the fieldwork and literature, the nurse in story #1 clearly felt that she needed to be an advocate for a patient group that she felt were being let down, the patient in story #10 felt that she benefitted from having someone 'to speak on your behalf'. The patient in story # 9 described how the nurse intervened for the patient and liaised between the consultant and the concerns of the patient to ensure she was both informed and reassured. A number of authors cite the link between advocacy and compassion including Hudacek (2007), Greenfield et al (2008) and Chambers and Ryder (2009) even going so far as to suggest that this includes advocating for change at an institutional level if this is needed to ensure compassionate care (Maxwell, 2008). To be an advocate will also form part of the definition of compassion as it is reflected in all 3 components of this study.

Finally, the importance of providing appropriate and timely practical care for patients was described as being compassionate. Patients described examples such as providing blankets when they were cold or food when they were hungry, of bathing them and changing wound dressings and ensuring pain was controlled. The provision of the fundamentals of care were less described by staff but a nurse did tell her story of washing a very ill patient, of getting her clean nightclothes and combing her hair and

another recounted washing a patient's feet. Ensuring that 'basic' care is seen as a priority was a feature of the literature, especially so after the Francis reports (2010 and 2013) which resulted in a number of recommendations relating to ensuring such requirements, nutrition, hygiene, elimination and so on, were seen as priorities. Whilst some authors suggested that compassion was as important as clinical care (Graber and Mitcham, 2004) others reminded the reader that without the basics of care compassion would not be possible (Perry 2009, Durkin et al 2018). This idea will have implications for both education, organisation and for the idea of the importance of role modelling and will be discussed further in the next Chapter but will form part of what defines compassion.

Of the 14 patients who shared stories, 5 of them recalled that they had had a laugh and a joke with those caring for them, 3 described interventions which made them feel at ease. It is significant that none of the 23 stories shared by staff describe the use of humour when it appears to be an important aspect of compassionate care to patients. The literature does highlight that humour can be beneficial (Apker 2006, Kagan 2014). Dewar and Nolan (2013) describe the 'courage' needed to use banter and humour (and, interestingly, the sharing of personal information) but also remind that this needs to be carried only when the appropriateness has been established. The lack of laughter described in the healthcare staff's stories may be allied to the earlier idea that in order for compassion to be present suffering needs to be recognised and, in the case of the staff's stories this suffering was usually presented as no laughing matter. Without the 'triangulation' of humour or laughter from the staff member's stories this will not be included in the definition from this research, however, this

does not preclude the consideration and inclusion of the idea in discussion.

This is also reflected in other ideas or themes that were prominent in one part of the research, the literature but not the stories, or with patients but not staff but were, nonetheless, frequently described. These include the importance of smiling and keeping eye contact mentioned by 4 and 2 patients respectively or of the sense of identification between themselves and the patient identified by 5 staff members. The research detailed in the literature highlights the importance of communication (Hofmeyer et al 2017, Waugh and Donaldson 2016, Lee and Seomun 2015, Kneafsey et al 2015) and, whilst the content of the stories in the fieldwork clearly relate examples of exquisite communication they do not make the need for communication skills implicit.

In terms of common themes of compassionate behaviours identified as compassionate by all 3 elements of the study, the following have been described;

- To treat people as individuals and ensure that their care reflects this
- To provide reassurance
- To give enough time and not rush
- To be present
- To listen and to hear
- To hold – both figuratively and physically as required
- To go above and beyond that which is expected and override barriers
- To take responsibility but not control

- To provide safety and keep free from harm
- To be the patients' advocate
- To provide for the patients' basic, fundamental needs.

6.7 Examples of compassionate care:

Within the large volume of literature reviewed there were numerous examples of what the authors or the study participants they report, thought was compassionate care. Every one of the 39 stories recorded for the fieldwork was an example of the storyteller's experience of compassionate care. No, one story can possibly illustrate the multifaceted nature of compassion as defined by this research. Husserl maintained that the nature of experience is subjective (Koch 1999) but that this could be illuminated and clarified; Stein (Pezzella, 2016) suggests that it is the intersubjectivity of a phenomena that is helpful in determining the essence of it. Pezzella (2016 p49) states that Stein believed,

'experiences lived from within the community represent the indelible, non-erasable substrate that each of us always carries within ourselves, at every instant of our own lives, and in whatever place we find ourselves, on whatever day: community is what we live'.

The importance of the fieldwork in this research has been to demonstrate the common themes within the 'community' of patients and of staff that determine what compassion means to them; they provide the bridge between the personal and the shared experience. Each story shared by the participants in this study was a unique and equally valid experience of compassion, when viewed together it is possible to find that which is common, the intersubjective essence of the compassion experience.

It seems therefore appropriate to allow a story from one of the patients in this study to act as an exemplar. Schwartz-Barcott and Kim (2000, p140) state that a model case is one which '*absolutely reflects an instance of the concept*'. One participant came to the meeting with the researcher with her story written down to be read out and recorded, this lends itself well to the reproduction of that story here. The content of the story also very eloquently demonstrates many of the attributes identified by the other storytellers and the literature within this study. With permission from the participant #3, her story is recounted in full here as a model example of this study's findings.

'My story is about the compassion, empathy and agape love in the quality of care given to me by two healthcare assistants when I was an inpatient some 18 years ago. I had been diagnosed for the third time with the same oral cancer and I had had 18 hours continuous surgery to remove it. This has included removal of about one third of my tongue and floor of my mouth, reconstruction of a free flap from my forearm which had been repaired by skin grafting from my hip, lymph node removal from my neck and other minor procedures like tracheostomy. I spent nearly three weeks in hospital, went home for about five days and was then readmitted after a partial failure of the free flap. I had not coped well with the psychological impact of having cancer. I was very frightened of the implications for my future life and for its quality. I was anxious about the impact of my situation on my 19 year old son who had just completed year one of his 3 year university degree. I was also anxious and distressed about the wellbeing of my much loved cat who emotionally was very important to me. I was still recovering emotionally from an unhappy marriage, a painful divorce, three

cancer diagnoses and a loss of self-esteem and value. I had been back in hospital for about a week and had taken my son's toy lion, Aslan, with me. I had bought Aslan for A when he was about four years old. Aslan was a kind of substitute for both A and for Tigger the cat.

In the early hours one morning I woke up aware that my pillow, my face and my neck were wet and sticky. The nurse rapidly realised that my neck wound was oozing quantities of serous fluid and pus. I was frightened in spite of her calmness and her reassurance. I thought all kinds of horrifying things and spent a hot, sleepless, sweaty, smelly night. In the morning I had to go to the treatment room in max fax ENT for various very unpleasant, frightening investigations. I hated going. I wanted a bath and I wanted my hair washed. I didn't want to be seen in public or by the medics while I was so dirty and smelly. I didn't want the medical complications of what had happened. I didn't want to be like this. I just wanted to be well, and to be normal. The medics were superb, calm, reassuring, informal, empathetic, purposeful, kind, professional and certain it was infection and not cancer that had erupted in the night. I went back to the ward. Two HCAs, P and M had remade my bed. It was all beautiful and clean. I cried at the sight and I asked for a bath and a hair wash. No they said you are exhausted physically and emotionally. You need sleep. Get into bed and sleep. I objected. I would spoil my lovely clean bed. They insisted. I slept for about 4 hours and when I woke up one of the registered nurses helped me bath and wash my hair. I was clean, I didn't smell. I had a lovely neat dressing on my neck and the cancer hadn't come back. We went back to my bed space. P and M had made the bed again. The sheets and the pillows were crisp and white and uncreased. The blankets were new and

clean. There were flowers in a vase on the locker. The sheets had been turned down and Aslan was sitting in the bed waiting for me. P and M helped me into bed, made me comfortable and they stayed just to chat. They had turned the nightmare of the night into the beauty and order of daytime. They had loved me. They had understood my needs and they had met them. They had welcomed me back to normality with their kindness, their empathy and their compassion. They had personified agape love. They had created an unforgettable, unforgettable, beautiful therapeutic experience which has become a valued and very treasured memory'.

6.8 The consequences of compassion in healthcare

In terms of consequences, the literature reviewed for the study identifies both positive and negative consequences of compassionate care. There is certainly, a significant volume of supporting literature highlighting the negative effects of care without compassion as well as new and emerging research that appears more and more to be describing the benefits of compassionate care. The stories recounted for the fieldwork were predicated only on the idea of care that was compassionate and so any consequences are inevitably positive. It is clear that the findings of this study will be liable to bias towards the positive effects of compassion as a result of this, however, how this would detract from the findings is not clear. The negative impact of unkind, uncaring and compassionless care has been extensively documented and examples of relevant reports and reviews have been cited in this thesis. This section of the findings will therefore only concentrate on the positive consequences of compassion and this will then be incorporated into the final definition.

The patient participant's stories contained examples of the consequences of compassion and these were explicit. Patients described how they felt, 'in control' or comfortable' or 'I didn't feel like I was being rushed'. Staff, in contrast, tended to explain what they had done or seen others do.

Consequences were often linked to those behaviours which distinguish compassionate care, for instance, providing reassurance was seen as a compassionate attribute but also resulted in patients who felt reassured and this was the most frequently cited consequence within the stories recounted by patients and was also mentioned by staff. A very definitive example of reassurance was given by one patient, '*and that was very reassuring. He said, firstly I will lead you out of danger for your life, then we will think how to make you better but first we will reassure that you're out of that*' (#2).

The most frequently cited consequence as far as participant health care staff were concerned was that patients were not left alone and that these patients and others felt supported. Participant patients didn't expressly describe health care staff stepping in when they were alone but most of the stories did describe such interactions as 1:1 between them and the member of health care staff. Only 1 patient mentioned that they had a partner with them in the story they recounted.

For participant patients, compassionate care meant that they felt validated as an individual and recognised as a person, '*people respected me. I wasn't just a number*' (#13), '*I wasn't just a cancer case, I was a human being with all the natural, normal human reactions*' (#3) and this was also reflected in the staff stories, '*just to consider them as a whole person is so important*' (#11).

Compassion resulted in patients who felt that they were unrushed and were given enough time and staff recognised that compassion motivated them to provide this. Patients felt they were heard and staff felt that they listened, patients felt cared for and staff both recognised this and felt that they cared, *'I just felt so actually protected and cared for'* (#10) and *'When I think of this I remember the closeness and caring ...it is a good memory'* (#14). In a story about how a team of physiotherapists cared for one of their own colleagues, the storyteller said they were able to *'show her that they were concerned, worried and that they cared'* (#14).

Patients felt that that were being helped and staff acknowledged this and described it, the grieving mother of the baby lost many years previously was able to move on and even start helping others for instance. It was important for patients to feel informed, *'I didn't ever feel they were keeping anything back from me or that they were over exaggerating, I was getting the facts but in a way that I could handle'* (#12). The key intervention for the grieving mother was that the staff member went back to archives to find the relevant information to help put her mind at ease.

Patients reported that they felt both comforted and that they were made comfortable, *'I felt comfortable and safe with them'* (#13), *'S was amazing, she chatted to me the whole way through my scope, made me feel really, really comfortable in a really embarrassing situation'* (#10). The storyteller who recounted being taken by a doctor to be told that her husband's death was imminent said, *'I remember the comfort and seclusion of the room'* (#14). Again, whilst not explicitly described in the staff stories it is easy to find examples of this, soaking a homeless man's feet in a bowl in Accident and Emergency, changing a patient's nightdress as it had vomit on it,

holding a frightened persons hand during a scan or through the night as they came to the end of their life. The stories of both sets of participants were populated with examples of both comforting people and of being made comfortable.

There were a significant number of other descriptors that patients used to recognise the consequences of compassion and the following were used more than once; empowered, relaxed, relieved, positive, safe, held and able to face future care more confidently. The staff stories also highlighted more than once the provision of space for the patient and the fact that they were not judged in any way. An example of a number of these examples is provide by the storyteller who recounted the interaction he and his brother had with the organ donation team,

'it felt like they were circling us and sometimes they were circling quite closely and sometimes they were circling at more of a distance and knowing ..., I felt held by that, not guided but held and I felt we guided it and at no point did I think it wasn't about us and it wasn't about mum' (#11).

The consequences of compassionate care as demonstrated within the literature were described fully in Chapter 3 but those consequences that most obviously resonate with the experiences of the fieldwork participants need to be included here. The common referents in the original literature agree that compassion provides comfort, safety, empowers and ensures patients are heard. Consequences discussed in the literature tended to be more systemic, benefits to the organisation, that it was a healing force that it resulted in efficient care. These elements will be discussed more fully in the following chapter. The latter research that formed the second part of the literature review highlighted many of the same consequences but, also

increasingly the evidence that compassionate care not only benefits the patient but has manifest benefits for health care staff too.

In terms of this study, the consequences of compassionate care provision are; that patients feel reassured, are not alone, are supported, empowered, heard and listened to. Patients are seen as people and their individuality is validated, they are given time and not rushed, they are cared for, helped, informed and will be comforted, made comfortable and kept safe. Finally, compassionate care may benefit not only the patient but the caregiver too.

6.9 Defining Compassion in Healthcare

The synthesis of the 3 elements of this study has resulted in the defined components of compassionate care. This definition will be described here and discussed in the following chapter to enable the findings to be contextualised within current healthcare policy and opinion. Such a definition will also enable recommendations for practice, organisations, education and research and these too will be explored in the next Chapter.

Definition remains a contentious subject, Durkin et al (2018, p57) state that '*compassion consists of a cluster of internationally recognised qualities*' yet also suggests it is lacking definition, and this is a consistent theme in a number of studies (Richardson et al 2015, Perv-Bret et al 2016, Mills et al 2017, Taylor et al 2017, Sinclair 2017a, Fernando and Consedine 2014, Richardson et al 2015). Some authors have suggested their definitions of compassion (Perv-Bret et al 2016, Valizadeh et al 2018, Dewar et al 2014) but Sinclair et al (2016b, p14) state that

definitions lack '*specificity, clinical applicability, conceptual validity and fail to adequately incorporate the understandings of patients*'.

As far as this research has been able to discover, no definition of compassion exists that is based on a concept analysis which utilises a combination of relevant literature, the experience of a range of healthcare staff and the experience of a diverse group of patients. The few studies that do encompass patient experience seem to concentrate on one patient group, those with dementia (McPherson et al 2016, Moore et al 2017) or patients receiving palliative care (Azhe et al 2019, Mills et al 2017, Mills et al 2018, Sinclair et al 2016a) as examples. Only a small number of studies incorporated the views of patients and staff within the same study (Dewar 2011, van Der Cingel 2011, Moore et al 2017). This study has canvassed the views of patients and carers from a range of different experiences and conditions. It is therefore the contention of this study that the following definition provides a unique, responsive, relevant and widely applicable version of what compassion means and looks like in current healthcare.

6.10 The definition of compassion in healthcare

Compassion is the provision of care, empathy and loving kindness based on the recognition of suffering. Compassionate care is the responsibility of both the individual caregiver and the organisation that employs them and can only be provided by staff who have the necessary time and resources. Staff need to have compassion for themselves and their colleagues, be self-aware and reflective and have been appropriately educated for compassionate care delivery.

Staff who provide this care need to be respectful, non-judgemental, gentle, open and honest. They need to treat people as individuals, listen to their opinions, wishes and needs and hear what is said. Health care staff must provide reassurance and ensure patients are kept safe and free from harm. They need to demonstrate that they are present and to hold patients, both literally and figuratively, based on their assessed need. Health care staff need to take responsibility for the care provided to patients but not take control and they may need to go above and beyond perceived limitations and break down barriers that may hinder compassionate care delivery. Finally, staff must ensure the fundamental needs of patients are met and that this is done with the appropriate skill, understanding and professionalism expected.

Compassionate care based on these defined requirements and attributes will result in patients who feel cared for, supported and empowered. It will ensure patients can feel confident that they will not be left alone nor abandoned and that they will be helped when in need. Compassionate care will provide comfort and confidence in the safety of that care now and

in the future. Care with compassion will ensure patients feel like people who are being looked after by their fellow man and that healthcare staff will, in turn, derive benefit from being compassionate carers.

Chapter 7

Conclusions and Recommendations

‘Compassion is an action word with no boundaries’ Prince.

7.0 Summary of Content Chapter 7

Chapter 7 applies the definition of compassion to the realities of practice and makes recommendations based on the findings. A taxonomy of compassionate behaviours and how they are demonstrated is presented. Implications for practice, organisations, leadership, education and research are discussed. Limitations of the study and the acknowledgement of the growing canon of research relating to compassion are discussed. This Chapter also includes a final conclusion and summary.

7.1 Introduction

Compassion as a concept is widely described in healthcare literature and that exploration has both increased and evolved in recent years as demonstrated by this research. A comprehensive review of this literature has both formed the basis of this study and has subsequently informed the continual development of the research. Other studies have examined compassion by reviewing the available literature and these different viewpoints and approaches have been hugely helpful to both this work and

to the increasing awareness and understanding of 'compassion' in healthcare.

A number of studies have also investigated compassion from the viewpoint of patients and healthcare staff, however, these tend to be discreet groups of study participants. Adamson and Dewar (2015) explored the views of student nurses, Bramley and Matitti (2014) focussed on in-patients, Moore et al (2017) studied patients with dementia who were at the end of their lives and others have also researched patients in the palliative stage of their care (Azhar et al 2019, Mills et al 2017, Moore et al 2017, Sinclair et al 2016a).

The findings of this research study are unique as they are the combination of an extensive review of the literature combined with the opinions and experience of a range of healthcare staff and of patients. The synthesis of findings from these three perspectives has enabled the formulation of a responsive and transferable definition of compassion in healthcare.

7.2 Why does defining compassion matter?

A recurring theme in the literature is the lack of a definition of compassion or perhaps more accurately, the lack of a consensus in definition. Some authors have pondered over the similarity or differences between compassion and allied terms such as empathy, kindness and caring. Others have suggested definitions and based these upon the investigations and research that they have undertaken. All of these findings are valid, helpful and relevant, all are also incomplete and an answer to only some of the issues that have been highlighted by this work

and by those authors who are referenced within it. The definition that has been formulated based on the findings of this study will not be the conclusive answer to the perceived lack of a comprehensive, defined idea of compassion in healthcare but it will help to inform a growing consensus of what compassion is and how it can be demonstrated.

The National Health Service is one of the most successful organisations delivering health care to a country's population (Schneider et al 2017). This statement is based on the results of a survey by the Commonwealth Fund, which looked at health care provision in 11 different countries (Australia, New Zealand, UK, USA, Sweden, Canada, Norway, Netherlands, Germany, France and Switzerland) in which the NHS was ranked in first position overall. Whilst the NHS does not perform best in all indicators that were assessed, the overall score across the five domains resulted in first place and this ranking was a repeat of previous years' results. However, it is important to note that the NHS was also the 9th worst funded in comparison to the other 10 health services surveilled, a figure supported by the Organisation for Economic Co-Operation and Development (OECD 2018).

The Commonwealth Fund (Schneider et al, 2017) found that the NHS performed the best in the category 'care process' which encompasses prevention, safe care, co-ordination and patient engagement. The Kings Fund (Dayan et al 2018) in their report looking at the NHS in its' 70th year suggested that the staff who work for the institution believe deeply in the mission to deliver the best healthcare to the population. Therefore, the only logical answer to the conundrum, 'how can the 9th most poorly funded service provide the best care?' is that this gap is bridged by the

commitment, skills, hard work and the compassion of the people who work within it. If the workforce are not encouraged, assisted, educated, rewarded and validated for the compassion that they demonstrate then this bridge could become weakened and will then, inevitably, fail.

Reflecting on the devastating consequences of failings of care in certain well-documented cases, detailed in this thesis, it can only be imagined what the impact of a systemic failure of compassion would be.

The importance and strength of this study is that it offers a unique approach to defining how compassion is seen based on a concept analysis which presents a synthesis of 3 different perspectives all of which are relevant to contemporary healthcare in the UK. More importantly, the research has identified distinct behaviours that demonstrate compassion to staff and patient alike. Once there is an understanding of how compassion can be demonstrated, compassion can arguably be modelled, taught, identified and mandated. Definition is clearly a contentious although worthy ambition but perhaps more relevant is the ability to demonstrate how compassion can be enacted in practice and this may enable these outcomes. Although, Tierney et al (2017, p 2) highlight that *'lack of clarity around how to define compassion in healthcare specifically means attempts to ensure it occurs in practice are limited'*. And this is echoed by Richardson et al (2015) who suggest that the nebulous nature and interrelatedness of terminology can make it challenging to establish if everyone is talking about the same thing. The main aim of Concept Analysis is to try and establish clarity and mutual understanding (Foley and Davis 2017) and that doing so enables *'operationalisation, informs research design and informs potential measurement instruments'* (p73).

Cronin, Ryan and Coughlan (2010) highlight the need for concept clarification to ensure consistency in meaning and understanding. Rodgers and Knafel (2000, p24) cite Ryle (1949) who states that the philosophical analysis of concepts should be the basis for producing standards and guides to ensure appropriate use of a concept. As mentioned, compassion is described as a core requirement (Francis 2013, Health Confederation et al 2012, Cummings and Bennett 2012, NMC 2018) for healthcare providers, and this would seem to require a definition of what exactly is required. Sinclair et al (2016, 2018) concurs and suggests that the model that they constructed,

'..provides a foundation that defines compassion in healthcare and its provision at the bedside. It may lead to the development of clinical tools to cultivate the requisite knowledge, skills, behaviours and qualities to enhance compassionate care to others. For example, it could potentially inform the development of a patient-reported compassion measure or serve as a blueprint to develop targeted and evidence informed educational interventions for healthcare systems aiming to enhance patients' experiences of compassion specifically'.

7.3 How does this study's definition and defined behaviours relate to current healthcare practice and policy?

The literature review was analysed using the evolutionary method described by Rodgers (2000, p81), described as *'the cluster of attributes that constitutes the definition of the concept may change over time, by convention or by purposeful redefinition'* and that this maintains a *'useful, applicable, and effective concept'*. The initial literature encompassed 10 years of inclusions in the specified databases to support this evolutionary view, the addition of the second, limited review was specifically aimed at establishing how 'compassion' had been viewed over time but also by

convention and by those who attempted definition. As stated earlier, the attributes of compassion did not seem to alter, however the conventions, the use, did. More research relating to the understanding and utility of compassion in healthcare was apparent but so to was the increasing inclusion in policy, guidelines and even mandated within practice (NMC, 2018).

In 2012, Jane Cummings and Viv Bennett, on behalf of the Department of Health and the HNS Commissioning Board, produced 'Compassion in Practice'. This 'vision and strategy' was underpinned by six fundamental values, collectively known as the '6 Cs', including compassion, and aimed to make these values part of service provision for all patients, underpin leadership, inform training and development and create appropriate cultures. All of these ambitions are undoubtedly laudable and hard to criticise, however, the document did not seem to include a great deal of practical guidance as to how the changes described might be achieved. The demonstrable increase in literature about the subject of compassion, the evolution of the subject as described by Rodgers (2000), was, in part, a response to 'Compassion in Practice'. The lack of either evidence of impact nor of investment or practical solutions to the perceived failings (Francis, 2013, CQC 2011, Health Service Ombudsman 2011) which initiated the report resulted in some significant approbation. Crawford et al (2014) described it as a 'patronising mnemonic' and research by O'Driscoll et al (2018, p e1098) found that there is professional '*anger, distress and resistance*' to the initiative and that health care staff viewed 'Compassion in Practice' as a '*top-down initiative which did not sufficiently recognise*

structural restraints on nurses' ability to deliver compassionate care'.

Crucially, the research also highlighted that participants felt that compassion for patients was only sustainable if there was also compassion for staff and that this was not the case.

Such a position is fully supported by the findings from the research study reported in this thesis, however, O'Driscoll and colleagues based their findings on a survey of nurses, midwives and HCAs. 'Compassion in Practice' was clear that the vision was supposed to encompass all health care staff whether porter, doctor, health service manager or allied health professional. The literature suggests that 'Compassion in Practice' is viewed as predominately relating to nursing (Baillie, 2015, Bivins et al 2017, Barchard et al 2017). However, the findings from all 3 elements of this study emphasise the importance of compassion as a requirement of all healthcare staff. Bivins et al (2017) noted that compassionate care received greater attention from nursing and health service journals than from the medical press. The stories shared by patients as reported in this thesis demonstrate unequivocally that the care provided by compassionate medical and allied healthcare staff was as important, maybe more so in terms of potential impact (a doctor will usually be the professional likely to give diagnostic or prognostic information to patients for instance) as that provided by nurses and other health staff.

The NHS Constitution (2015) contains a description of compassion and a commitment to provide compassionate care to all. The Willis Report (2012) 'Quality with Compassion' about the future of education for nurses and the

'Shape of Caring Review' (Health Education England, 2015) which expands and updates these recommendations both make it clear that compassion is a key value to underpin education and recruitment in nursing. However, none of these documents contains clear, defined or agreed examples of how compassion is viewed or how it should be enacted in practice. A government web page which provides updates about compassionate care in the NHS (UK Government, 2019) currently has a list of 5 guidelines or regulations, none of which specifically mention nor emphasise compassion as a key component or content according to the titles.

Compassion as a core component of healthcare is referenced in a significant number of policies, guidelines and regulations. However, it is apparent that whilst referred to as a desirable or even a mandatory component of these documents there is little in the way of practical advice about how this can be achieved.

7.4 A taxonomy of compassionate behaviour:

In the previous Chapter a definition of compassion in healthcare was proposed based on the findings of this research study. This definition is the result of a transparent, comprehensive and rigorous investigation in to the views of patients and staff and of how compassion is represented in relevant professional literature. As such, it is a useful addition to the body of understanding that informs and underpins the understanding of

compassion. However, this definition in isolation will provide for only a small increase in the canon of available knowledge, important but potentially lacking in impact. In order for compassion to be understood as more than a concept the behaviours that demonstrate compassion need to be identified and agreed.

Based on the findings of this study as described in Chapters 3, 4 and 5 it is possible to identify compassionate behaviours and the way in which these behaviours can be demonstrated. By using the compassionate behaviours that informed the intersubjective experience of the fieldwork participants in conjunction with the behaviours described in the literature it is possible to present the reality of compassionate practice. To better demonstrate this a 'taxonomy of compassionate behaviours and their attributes' has been compiled and is presented below:

Compassionate Behaviour	How the behaviour is demonstrated in practice
Recognise each patient as an individual	<ul style="list-style-type: none"> • Establish preferences of the patient including their preferred name. • This requires focussed assessment – documentation should be meaningful, not simply a tick box • Align expectations and priorities • Involve the patient in decisions • Attitude = partners, shared humanity
Provide reassurance	<ul style="list-style-type: none"> • Provide accessible information • Explain options and choices • Be honest but also gentle • Put people at ease – judicious use of :- <ol style="list-style-type: none"> 1. Humour and banter 2. Touch and proximity 3. Smile • Demonstrate competence
Give patients necessary time, ensure they are not rushed.	<ul style="list-style-type: none"> • Prioritise and use resources well • Be mindful of language used – be specific • Adopt a positive mind-set – time often is available. • Support one another – create the time
Be present	<ul style="list-style-type: none"> • Make the time spent with patients meaningful – prioritise them • Witness and acknowledge their circumstance • Try and see the situation from the patient's perspective • Act as surrogate for friends and family if absent • Treat patients as you would wish to be treated.
Listen and hear	<ul style="list-style-type: none"> • Ensure distractions are kept to a minimum • Concentrate on the patient (be present) • Allow the patient to tell their story • Be interested – keep eye contact, sit beside or near • Use open questions – allow time for response
'Hold' patients	<ul style="list-style-type: none"> • First, ensure that you are 'held' • Use physical touch, hugging, hand holding etc. judiciously • Be present even for those patients who do not want physical contact • Keep appropriate boundaries but do not let these become a barrier, establish a personal connection where appropriate for patient and/or staff • Be courageous in the face of suffering
Go above and beyond if necessary	<ul style="list-style-type: none"> • Challenge circumstances or cultures that do not allow compassion to flourish • Share experiences and information if appropriate for both patient and healthcare staff • Be courageous in the pursuit of the common humanity of patient and caregiver – if it is the right thing to do....do it
Take responsibility	<ul style="list-style-type: none"> • Be pro-active in response to assessed need • Ensure adequate monitoring and assessment • Act as a resource – liaise between care environments and providers • Be consistent, be reliable and complete any agreed plan of care • Ensure that the patient remains at the centre of their care

Keep patients safe and free from harm	<ul style="list-style-type: none"> • Ensure adequate resources – challenge when inadequate • Staff must be updated and appropriately trained and educated • There must be a culture of reflection and subsequent responsiveness • Patients must be adequately monitored and reviewed • Organisational culture must be open and transparent • Ensure patient's choices are informed • Culture of being non-judgemental and accepting of difference
Be an advocate	<ul style="list-style-type: none"> • Speak up for those who cannot speak for themselves • Ensure that the patient's voice is heard whenever possible • Challenge situations that impact on patients but do not involve them • Challenge prejudice, dogma and unsafe or unkind care
Provide for all patient's basic. Physical needs	<ul style="list-style-type: none"> • Adequate assessment and identification of need • Timely response • Ensure 'basic' care is seen as a high priority and resourced accordingly • Provide role modelling – 'basic' care is not basic, it is the foundation of compassion and should be provided by all • Challenge the perception – such care is not 'basic' but 'fundamental'

Table #12 Taxonomy of compassionate behaviours.

The determination of what constitutes 'compassionate behaviours' are those which were evident in all 3 arms of the study and which informed the definition in Chapter 6. The examples of how each behaviour may be demonstrated have been based on a synthesis of the 'invariant constituents' of the fieldwork participants and the 'behavioural attributes' of compassion in the literature review findings. Schwartz-Barcott and Kim (2000) describe the fieldwork as a refinement of the theory presented within the literature review. It is an important aspect of the hybrid approach, the theory component of the synthesis has no less weight than the fieldwork in the analysis but does get re-examined in light of the fieldwork (Schwartz-Barcott and Kim, 2000). This also echoes the epistemic approach of subjectivity described by Denzin and Lincoln (2005) who suggest that knowledge is influenced by the characteristics of those who hold it and also by Benoliel (1996) that it is interpreted by individuals (section 1.3). The literature described the importance of communication in relation to the provision of compassionate care (although listening skills were highlighted more frequently than the more 'generic' communication). Neither healthcare staff nor patients specifically use the term 'communication' and the importance of presenting the findings as transparently as possible means that this element is not included as a discreet category within the taxonomy. However, as a clear theme within the literature it is important to see how the fieldwork did 'refine' this characteristic of compassionate care. Communication, as it relates to compassion, is presented and represented as the *behaviours* within the taxonomy. Good communication skills would need clarification in terms of how these are manifest but 'involving patients in decisions', 'provide

accessible information', 'be honest but also gentle' and a number of other behaviours within the taxonomy reflects both the 'lived experience' (Moustakas, 1994) and the theory that has underpinned this study.

This way of presenting the concept of compassion reflects the hybrid approach to concept analysis but also ensures theoretical constructs are related to the reality of the healthcare environment (Kim, 1987). The literature described the relational nature of compassion (Trueland 2009, Perry 2009) and the need for emotional engagement (Straughair 2012, van Der Cingel 2011). Such ideas, however compelling, benefit from the refinement provided by the fieldwork and the participants' experience of compassion. How to explain 'relational nature' better than to describe the need to have an 'attitude that patients are partners, a shared humanity' or 'establish a personal connection where appropriate for patient and/or staff'. Having emotional engagement can be 'operationalized' (Foley and Davis, 2017) by 'being present', 'putting people at their ease by judicious use of humour or touch or by smiling' and so on.

Importantly, based on the definition of compassion in healthcare and the taxonomy of compassionate behaviours it is now feasible to make recommendations for future practice, education and research and to inform organisational culture.

7.5 Recommendations and challenges based on the research findings:

This section of the Chapter will be divided into four sections each containing the recommendations based on the study findings but also in light of the limitations of these findings.

7.5.1 Practice:

That to act compassionately can be challenging and can have an impact on care staff is undisputed based on the literature reviewed in this study. However, the research has also highlighted the positive impact of providing compassionate care, the increase in job satisfaction and staff wellbeing. In her 2009 article, 'Kindness, not compassion, in Healthcare', Faust argues that 'compassion' is a pervasive term used in healthcare and cites the definition provided by Nussbaum (2001, p301), '*compassion is a painful emotion occasioned by the awareness of another person's undeserved misfortune*'. Faust (2009) explores this idea and that there is a need for a '*eudemonistic judgement*' on behalf of the patient by the caregiver in order for there to be a sense of 'commonness' with the sufferer, that there is a need for an emotional attachment. Faust makes a compelling argument for replacing the idea of compassion with 'kindness' and suggests that this is much easier and less demanding to demonstrate than compassion and therefore more realistic.

Others have suggested that empathy is the key (Lelorain et al 2018, Holmes and Wang 2017, Chaitoff et al 2017), or that caring is what is required (Leffel et al 2018, Flynn 2016, Chochinov 2014). Faust (2009)

suggests that to be kind instead of compassionate releases staff from the burden of needing to relate to the suffering patient. This study demonstrates that on the contrary, it is this very connectedness, the identification that occurs between carer and cared for, that was important to staff. The semantic ambiguity relating to the virtues of care staff is complex and confounding – this study brings clarity as it has supported the definition of those attributes which are required to demonstrate compassion. Importantly, rather than assume that a compassionate approach which demands these characteristics will be detrimental to staff, it is necessary to consider that the ability to provide compassionate care is the reason and motivation that many healthcare staff actually cite for a career in healthcare. The evidence is clear that the impetus for people to seek employment in healthcare careers is generally prosocial (McLaughlin et al 2010, Nesje 2014, Marynissen and Spurrier 2018), if compassion can be facilitated, recognised and acknowledged as part of practice then staff should feel fulfilled and successful. This has significant ramifications in terms of recruitment and for the overall wellbeing of the health care workforce. As Lown (2018, p218) eloquently describes, compassion is ‘*a source of both healing for those who suffer and of purpose and meaning for those who seek to heal others*’. It is important for the practice environment to enable and recognise compassionate relationships, to bridge the Rubicon of connectedness that Schwartz describes (1995).

As mentioned previously, the literature review that informs this study cannot claim to be exhaustive. The need to filter the significant volume of literature necessitated a search strategy that excluded some literature that would have undoubtedly added to and, maybe even, altered the findings of

this work. The transparency of the search should enable it's replication as a means to establish reliability but it also means that recommendations must be viewed in the light of this and as a limitation. An example is the idea that staff need to have self-compassion in order to have enough inner-resources to subsequently provide compassionate care to patients. The exclusion of the terms 'compassion-fatigue' and 'compassion-focussed mindfulness' have potentially weakened this argument. Whilst this is a finding of this study this idea needs to be further examined in the light of a more robust research base. For instance, studies by Upton (2018), Duarte et al 2016 and Gustin and Wagner (2012) did suggest that there is a correlation between self-compassion and compassionate care-giving but are not included in this study as the titles of the reports were not encompassed within the search criteria for the literature review. However, the need for organisations to foster the idea of self-compassion without staff feeling 'selfish' (Mills, Wand and Fraser, 2015) or needing 'permission' (Andrews, Tierney and Seers, 2020) would seem to be a logical and proportional recommendation.

This study also reiterates the importance of the provision of responsive and humane 'basic' care to patients. Changing a soiled bed, changing a stained nightdress for a dying patient, getting a blanket for someone who is cold may not seem like clinical priorities in the busy and stressed environment of modern healthcare. Yet, it is these simple yet exquisite, humble yet complex, easy to do yet seemingly hard to provide elements of care that patients identify as significant and as compassionate. The stories recounted by healthcare staff tended to describe really impactful and even

harrowing events, the need for compassion to be demonstrated in the 'everyday' interactions between staff and patient needs to be emphasised.

The provision of such fundamental care needs to be embedded in the cultural priorities of practice environments. The impact of role modelling was highlighted by authors in this study (Leffel et al 2018, Ali and Terry 2017, Zamanzadeh et al 2017) and it would therefore seem clear that the importance of getting this crucial aspect of compassionate patient care right should be modelled by all healthcare staff. The clear and unequivocal emphasis that such fundamental care is a priority for all those who manage, provision and deliver care to patients has to be evident and manifestly so.

Finally, the idea of 'time' needs to be addressed. Perhaps the most consistent theme across the 3 elements of this study – the need to provide adequate time, not to rush or be rushed in order to facilitate compassionate care. This resource, or rather a lack of it, is also mentioned as a significant barrier to this provision (Valizadeh et al 2018, Ledoux et al 2018, Tierney et al 2017, McPherson et al 2016). The challenge for practice would seem in changing the approach to time as, clearly, there can be no alteration in the amount of physical time available. However, time is not simply a measure of minutes and hours and this is not a new idea, Kant (1724-1804) in the Critique of Pure Reason explores the nature of time and determines it as the most essential element for human experience (Gardner, 1999 p 53).

The fact that Healthcare staff often felt the need to provide care that was compassionate in their own time (see Healthcare participants stories #3, 4,

5, 12, 13, 15, 19) needs to be addressed. This theme was also present within patient's stories (#6 and 7) and within the literature (Hehir 2013, Graber and Mitcham 2004, Crowther et al 2013) suggesting it was not simply the perspective of the healthcare staff. Providing adequate time features within the definition and the taxonomy herein but this potential pressure on the resources of healthcare staff needs to be acknowledged. The literature, and certainly the research reviewed (the examples above were anecdotal rather than research findings) did not explore this link. It may be that the lack of literature relating to compassion fatigue included in this study, as already discussed, results in these comments serving only to highlight future directions for investigation. However, it would seem proportionate to suggest the importance for practice environments to be adequately resourced so staff feel that they have sufficient time without having to contribute their own time and resources.

Those who work in healthcare should also adapt their approach to time, firstly because time invested in compassionate care is efficient. As described earlier, compassionate staff may not be so susceptible to 'burn out' and leave. Healthcare staff in the fieldwork were clear in their belief in the importance but also the need to be compassionate, to the extent that they were willing to break rules and go 'above and beyond'. Youngson (2019) presents the 'Top Ten Scientific Reasons Why Compassion is Great Medicine' and cites studies that demonstrate that investing in compassionate time with patients prevents readmission, improves patient adherence, reduces health costs, improves pain control and even reduces mortality, amongst other positive effects. This concept has also been explored by Trzeciak et al (2017) who have labelled it 'compassionomics'

and hypothesise that compassion is a science and can be seen as evidence-based medicine. They cite evidence of compassion's benefit to patient and provider alike across a number of different quality and efficiency markers. Practice environments need to see time spent compassionately not as a drain on their resource but as a way of providing efficient care.

Secondly, the idea of presence and of attentiveness was evident across the findings of all 3 elements of this research, time spent well is as important as the amount of time spent. The patients in the study who said 'she was really concentrating on me...it made me reassured that all was well' (#1) and '*...she came in with us and stood at a very respectful distance but was just there...it felt like a metaphorical hand on the shoulder*' (#11) both encapsulate this theme. Patients need to feel seen, to have their experience witnessed and this can be achieved with less time that staff may believe. One study demonstrated that the difference in perception of compassionate care took only 40 seconds (Fogarty et al 1999), it was intent and connection that impacted on the patient. Health care staff need to be taught, encouraged and enabled to understand the therapeutic impact of presence and of intention.

7.5.2 Organisations:

The clearest message that came from the literature and in evolutionary terms, this became more prevalent over time, was that organisational barriers to compassionate care were demonstrable and impactful. This was explored in Chapter 3 but an exemplar is provided in the comment by Crawford et al (2014, p3594),

'Effectiveness and efficiency in health care could be compatible with compassion; yet, the way this is implemented has often been felt to damage practitioners and patients in the current factory-style, conveyor belt health service'.

As with the previous section, time is a factor that all organisations must consider alongside all resource allocation – no matter how compassionate an individual is, no matter how present or how much good intent, if the simple tools to do the job are not available it cannot be done. In fact, Bloomberg et al (2016) went as far as to suggest that rather than investing in training nurses to be compassionate efforts would be better directed at addressing organisational barriers, Seager (2014) concurs suggesting that rather than teaching compassion as a 'pseudo-skill' there needs to be an emphasis on the conditions that sustain compassion. This idea is not new, the research findings in this thesis simply confirm and reiterate the need for adequate resource.

However, a recommendation of this study based on the findings is that there needs to be a change in the culture of organisations that deliver healthcare and more pertinently that this needs to be systemic and not an isolated phenomena. In contrast to Bloomberg et al (2016) and Seager (2014), Cole-King and Gilbert (2014) assert that compassionate actions and feelings can be taught but they agree that often it is the organisations and structures that need to be addressed. The research reviewed for this study highlights a number of programmes, frameworks and initiatives all designed to promote compassionate care (Bridges et al 2017, Curtis et al 2017, Ramage et al 2017, Kirby et al 2017, Sinclair et al 2016a, Kneafsey et al 2015, Dewar and Nolan 2013). Kirby et al (2017, p790) carried out a meta-analysis of compassion-based interventions and concluded that

they, *'hold promise as a form of intervention to help cultivate both compassion and self-compassion, reduce suffering (specifically depression, anxiety, and psychological distress), as well as increase well-being'*. Whilst Kirby et al acknowledges that the research base often relies on predominately small sample sizes the positive outcomes highlighted by other authors add considerable weight to the possible utility and benefits of such initiatives. Considering Henshall et al (2017) concluded that compassion is a systemic issue and that when there is an increase in the perceived compassion from the organisation there is a resultant increase in compassion by staff to patients and each other it is clear that this issue needs addressing. If programmes exist, i.e. the Cultivating Compassion Programme (Curtis et al 2017) or the Leadership in Compassionate Care Programme (Adamson et al 2011) and these programmes are now being evaluated as beneficial then the logical response is for widespread adoption.

Finally, organisations need to ensure that compassionate care is the responsibility and remit of all staff, that the pervasive attitude that caring and compassion is the preserve of nursing should be addressed (Bivins et al 2018). The old adage that nurses care and doctors cure (Kottow, 2009) is no longer relevant in healthcare, when a study demonstrates that having a caring doctor cuts the five-year risk of a heart attack more than aspirin does (Kelley et al, 2014) all health care staff need to embrace compassionate care.

7.5.3 Education

Teaching compassion has been a contentious subject in this research and the recommendations herein are based predominately on the literature review as education and training was not a significant feature in the stories within the fieldwork. One patient (coincidentally a retired head teacher) who did describe the qualities of a student nurse they had encountered said, *'You know it doesn't matter what bloody course that she's on or how many sectors she's passed and all the rest of it, this is what we want in the NHS' (#6)*! Some authors echoed this sentiment somewhat and questioned whether a quality that some see as innate or as a virtue can be taught (Sinclair et al 2016a, Barker 2013) or highlighted a level of contradictory and ambiguous evidence (Bray et al 2014). However, the weight of evidence that was reviewed suggested that compassion could and should be taught, Mills et al (2017) went as far as to assert that it 'must' be taught.

As with programmes designed to implement compassionate care there was also evidence to support developments in educational initiatives to teach and enhance compassionate practice (Hofmeyer et al 2017, Jack and Tetley 2016, Waugh and Donaldson 2016, Papadopoulos et al 2016, Adamson and Dewar 2015). Programmes and initiatives such as these need to be adopted more widely and the benefit to student and patient need to be assessed. The Nursing and Midwifery Council's newly published Standards framework for nursing and midwifery education (2018) do not make it implicit that compassion should be taught but they do suggest that education needs to be compliant with the Code of Conduct (2018) and point 1.1 of the Code is to 'treat people with kindness, respect

and compassion'. The new standards do demand that educators and assessors '*act as professional role models at all, times*' (2018, section 4.2). The importance of role modelling is a finding of this study, the lack of definitive direction towards compassion as a key component of education in the standards enables Higher Education Institutions (HEIs) to interpret the need as they deem necessary, to role model it. It is the recommendation of this research that HEIs take the opportunity to ensure their new programmes highlight, promote and teach the importance of compassionate care, the results of providing compassionate care and the behaviours that demonstrate it.

Education should not be seen as confined only to the pre-registration phase of health staff development, the need for continuing professional development is beyond the remit of this study but the need to ensure that compassion is a part of such continuing education is not. Ali and Terry (2017, p86) wrote that the participants in their study '*identified role modelling, reflection, action learning, mindfulness, emotional intelligence and compassion in care projects as useful education strategies*'. They describe the importance of compassionate leadership, the skills required to enhance and strengthen leadership should therefore inform continuing development for healthcare staff. The stories shared by healthcare staff in the fieldwork frequently demonstrated the qualities of leadership and willingness to challenge when patient care seemed to be at risk from the 'system' that delivered it.

Along with Bray et al's (2014) assertion of ambiguity and confusion, Durkin et al (2018, p56) feel there is not enough evidence that compassion can be taught as a '*clearly defined theoretical basis in nursing is missing*'. A

lack of a 'defined theoretical basis' for compassion has, in part, been addressed by this study however, there clearly needs to be a more comprehensive understanding and so the nascent work on teaching compassion needs to be expanded and tested. Medical education needs to ensure that compassion is not seen as optional, Gillies (2018) suggests that the adoption of medical humanities is gaining ground as is the understanding of the 'complex interstices of humanities and medicine' but a formal curriculum is still needed.

Finally, the importance of 'basic' care needs to be demonstrated throughout health care education. The new Care Certificate introduced following the Cavendish Review (2013) with the non-regulated workforce in mind does highlight the importance of fundamental care to provide 'compassionate, safe and high-quality care' (Health Education England, 2019). The new NMC standards (2018) place greater emphasis on skills in practice, the HEIs will need to ensure that skills and compassionate care are not mutually exclusive. Role modelling of both compassion and the importance of fundamental care provision can and must begin in the classroom.

7.5.4 Research

The definition and taxonomy provided as a result of the findings of this research is unique in reflecting evidence from 3 perspectives. However, much of the reviewed research highlights that there is a lack of consensus as to exactly what defines compassionate practice (Richardson et al 2015, Perv-Bret et al 2016, Mills et al 2017, Durkin, 2018). It is for this reason that this study recommends that there needs to be a consensus, an

agreed concept of compassion. This also needs to acknowledge that the research base related to the allied concepts of empathy, care and kindness needs to be cross-referenced. For research to be meaningful the surrogate terms need to be included or at least explored, as an example, when looking at values based recruitment or when studying the apparent decline in caring and empathy in health care students. There is little benefit in reinventing a wheel that is actually rolling in the same direction but under a different title.

The research base needs to be extended to better represent all disciplines in healthcare, nurse researchers are over represented in compassion studies yet underrepresented in healthcare research overall and this imbalance needs to be addressed (Whitehouse 2018, Bivins et al 2018).

The staff who contributed to the fieldwork in the study detailed in this thesis came from 12 different disciplines, however nurses made up over a third of these participants. Nurses are the single, largest group of healthcare professionals in the UK (NHS Confederation, 2017), this is not a suggestion that nurse researcher reduce their engagement in studying compassion, but simply that the other disciplines do all that they can to catch up. The need to engage staff from a wide range of experience and level of qualification is also required for the results to have resonance for all those who work with patients.

Patients are underrepresented in healthcare research (Simaceek et al 2018, Sacristán et al 2016, Buck et al 2014) and this unhelpful fact is also reflected in the findings of this study where the vast majority of the 89 studies included in the literature review did not directly engage patients in the research. Even when researching compassionate healthcare, the

recipients of that care do not adequately inform the evidence (Sinclair et al 2016b). Therefore, future research should ensure that patient involvement is a priority, as Bramley and Matitti (2014, p2790) stated, '*patients believe their experiences can offer legitimate and valuable learning for nurses in relation to compassion*'.

Patients were obviously included in the study reported here but there needs to be a wide range of backgrounds and experiences represented. This study demonstrated bias towards women (25 women and 11 men within the 2 fieldwork cohorts) and included no patients from black or ethnic minority backgrounds. The patients, even those with life limiting illnesses, were generally in a quiescent stage of their illness or had been told they had been 'cured'. However, losing a baby, a limb or a loved one or living with a chronic illness or the threat of a recurring one would seem to epitomise the definition of suffering that has been discussed extensively within this study.

Studies that did canvas opinions of patients and carers seemed to relate to one patient group only and patients from palliative care and end of life services seemed to be dominant (Sinclair et al 2017a, Sinclair et al 2016a, Azhar 2019). Obviously, the position the patients find themselves in will impact on their perception of compassionate care. Sinclair et al (2016a) state that they had produced the first 'empirically based clinical model of compassion' and this model is undoubtedly helpful. However, this claim is based on interviews with 53 patients with advanced cancers and therefore can really only profess to be an empirical model of compassion as perceived by terminally ill cancer patients. More patients from more diverse backgrounds need to be recruited to help inform the future

research base. The impact of research findings must also be considered when assessing the settings for much of that research, most of the reviewed studies emanate from the USA or the UK and this will impact on the relevance and ability to apply the findings across settings. However, the concept of compassion does seem to cross borders and provide for universal descriptors and understanding (Papadopolous et al, 2016).

Finally, the type of research now needs to be addressed, the literature demonstrates a move away from rhetoric and editorial discussion. The 'Francis effect' coupled with the other truly disturbing reports of failures in care mentioned in this thesis have clearly galvanised the move towards finding answers and conducting research. In the appraisal of the research since 2004 it was evident that a significant number of studies were reliant on reviewing literature. This is undeniably useful, in fact the confirmation of some of the findings in these literature reviews with those of this research have provided corroboration, strength in repetition and a degree of 'inter-rater reliability'! However, there is now a need for theory generation rather than examining existing ideas and proposals. Blomberg et al (2016) assessed the impact of interventions aimed at promoting compassionate care in nursing, their study could find little evidence of the effectiveness of these interventions. It is the premise of this study that such a lack of evidence is not reflective of a lack of impact of compassionate care but of a lack of research evidence and that this needs to be addressed. How '*good people can offer bad care*' (Iles, 2014, p183) has got to be addressed and this can only be done by using evidence based on rigorous and inclusive research to provide the answer to this unsettling conundrum.

7.5 Conclusions

This research does not claim to be the definitive definition or taxonomy of compassion, indeed other studies with very similar titles, Taylor et al's 2017 'Compassion in Healthcare: a concept analysis', Schantz's 2007 study 'Compassion: A Concept Analysis' and Cameron et al's 2015 'In search of compassion: a new taxonomy of compassionate physician behaviours' produced evidence that clearly predates or is contemporary with this study. The literature relating to compassion in the study described in this thesis was analysed using the evolutionary approach described by Rodgers (1989, 2000). The most evident evolution of the concept is the increasing amount of research and investigation that has taken place since the initial literature review and which was reported during the conduct of the research that informs this study. At the outset of the research in 2012 the literature indicated that whilst much was written on the subject of compassion in healthcare little had seemingly been researched. Over the duration of this study the body of evidence relating to compassion has grown, studies by teams in Canada (Sinclair et al 2016, 2018), in Scotland by Dewar (2011), in England by Curtis et al (2017), Bridges and Fuller 2014 and Hewison et al 2018 amongst others have been reported.

In 2011 van Der Cingel interviewed 30 nurses and 31 older patients with chronic health conditions to establish the nature and significance of compassion to them. Her study found that compassion had seven dimensions and these do share some of the characteristics with the

definition and taxonomy presented here. Sinclair et al (2016, 2018) conducted two studies aimed at clarifying both the definition of compassion but also at how it might be operationalised. The first study researched the views of patients receiving palliative care and the second, as a method of confirming whether there was agreement, studied the views of healthcare staff. Dewar and colleagues report the implementation of the Leadership in Compassionate Care Programme (Dewar 2011, Dewar and Nolan 2013). It had four main strands: embedding the principles of compassionate care in the undergraduate nursing curriculum; supporting newly qualified nurses during their first year in practice to facilitate the transition from student to competent and compassionate staff nurse; establishing centres of excellence in compassionate care – called Beacon Wards; and supporting the development of leadership skills in compassionate care.

The Cultivating Compassion project involved two universities, four NHS organisations and service users (Curtis, 2017). Its aim was to develop a sustainable programme of compassion awareness training for a wide range of health care organisations. Using a “train the trainer’s model”, and an on-line toolkit, the project sought to develop an evidence-based programme of compassion awareness training to promote compassionate care. In the Creating Learning Environments for Compassionate Care programme (Bridges et al, 2018) participating nursing teams attend a study day, with a focus on team building and understanding patient experiences. A senior nurse educator supports the team to try new ways of working on the ward, including regular supportive discussions on improving care. Ward manager attends learning groups to develop their

compassionate care leadership role, some team members receive additional training in doing observations of care and feeding back to colleagues. And Hewison et al (2018) describes a study evaluating a leading-with-compassion recognition scheme and a new framework for compassion derived from the subsequent data.

As well as evaluations of these initiatives there are also more reports of smaller scale studies looking at, for example, compassionate leadership (Ali and Terry 2017), education (Richardson et al 2015, Hofmeyer et al 2017, Jack and Tetley 2016) and, increasingly, measuring compassion (Papadopoulos and Ali 2015, Sinclair et al 2017, Lee and Seomun 2015, McSherry et al 2017) amongst others.

All of these studies highlight the contributions that they make to increasing understanding and the relevance of compassion in healthcare. All of them also describe the limitations of the research and, often, recommendations for future investigation. The study described within this thesis will add to and augment this increasing body of information and may address some of the limitations highlighted within the research conducted by others.

Wiles, Crow and Pain (2011) suggest that there can be a tendency to over-claim innovation in qualitative research. A concern that perhaps links to the differing approaches and flexibility related to research design in qualitative studies (Creswell, 2016). If that is a risk with established researchers it must also be acknowledged as a potential and perhaps more likely fault in the novice researcher? An ethical imperative in any work is to ensure that it adds to the body of what is already known about a subject. The NHS Research Authority (2017, 9.2) suggest that a study must take in to account relevant evidence that exists at the time of the

research proposal but also developments that occur whilst the research is taking place. It is therefore important to highlight that this study does make a unique contribution however it is acknowledged that this contribution is allied to and builds upon the growing canon of research and understanding relating to compassion in healthcare.

7.5.1 Aims and Limitations

The limitations within this study have been described within the methodology and within the sections on the literature review and the fieldwork. However, at the conclusion of the study it may be useful to re-examine the findings in the light of the limitations.

The aims of the study were threefold:

1. To establish whether perceptions of compassion described in relevant professional literature and held and experienced by healthcare professionals and healthcare service users are in accordance.
2. To develop a comprehensive definition of compassion and of compassionate behaviours in contemporary healthcare based on the synthesis of the intersubjective experience of the fieldwork participants with information demonstrated by the literature.
3. To use the resultant definitions to make recommendations to inform healthcare organisations, healthcare practice and future educational development and research.

The limitations already described relating to the literature review mean that the first aim can only be viewed as completed in the light of the literature that was included in the review. It was felt that the volume of literature was

adequate to present a comprehensive viewpoint but no review can claim to be exhaustive. The omission, as described in the methods chapters, of literature relating to 'compassion fatigue', 'compassion-focussed therapy' and 'mindfulness based compassion' obviously exclude articles that would have contained relevant information. The search term 'compassion' has also resulted in the exclusion of some literature and the discussion earlier in this thesis related to synonymous terms also highlights that evidence that would also be helpful may have been excluded.

However, the perceptions of compassion highlighted within the literature review and demonstrated by the experiences of the participants within the fieldwork did clearly establish the existence of common themes. The sample of healthcare staff were selected from only those working in one NHS Trust and was predominately female but did represent a wide range of ages, disciplines, specialties and levels of seniority. The themes within their stories demonstrated obvious and repeating themes and so can be said to represent the intersubjective experience of that group of participants. The sample of patients was smaller, predominately female and all resided within a relatively small geographical area. However, they too provided clear and demonstrable evidence of the intersubjective experience of that group of participants. The synthesis of the three elements looked for the common themes and there were a significant number that represented the shared experience of compassion within the literature and for healthcare staff and patients. It is therefore the contention of this study that there is an understanding of the nature of compassion within healthcare that is common to those who write and

study the phenomena and those who experience it as either healthcare staff or as patients.

This common understanding did then enable a definition and taxonomy of behaviours and so fulfilled the second aim of the study. However, this also needs to be tempered by limitations of the research process. No matter how hard a researcher tries to 'bracket' their own preconceptions and their influence on the data collection and subsequent analysis it has to be acknowledged that this can never be totally achieved. Moustakas (1994) requires only that the researcher acknowledges their prejudices and any bias they have and are transparent in exploring their own experience of the phenomena. The supervisory process and the inclusions within the thesis of the researchers' own stories have achieved this to some degree. The clear exposition of the research process including examples should enable replicability and scrutiny of the data analysis.

The inevitable subjectivity that is inherent within qualitative research (Sandelowski 1993) can at least be acknowledged and explored in terms of the impact on the research. In discussion with the supervisory team and during subsequent reflection the researcher realised that the reflexive process was perhaps too reliant on the supervisory process. Better use of field notes to record observations and feelings whilst carrying out the fieldwork may have provided deeper insight. Whilst it was not appropriate to write these contemporaneously these could have been completed more frequently and much sooner after recording the participants' stories. This may have provided what Phillippi and Lauderdale (2018) describe as enhancing data to provide a richer context for analysis.

The third aim of the study was to enable evidence-based recommendations for future service provision, organisations, education and research. This has been possible but also needs to be viewed in the light of the limitation already described but also in light of the evolution of the concept over the duration of the study. A part-time research study carried out over a significant time span poses two challenges, the emerging evidence base that develops alongside the study and the growth in knowledge and understanding of the researcher. At the outset the premise that informed the study was that there was a limited amount of research concerning compassion in healthcare and that definitions of compassion were not common. The growing body of research during the conduct of the study now means that such an assertion is harder to defend. The aim therefore became much more about trying to contribute to a consensus of definition and understanding related to compassion. This did however enable a more focussed set of recommendations for future research as this is now based not just on what existed at the onset of the study but also in light of the increasing research base.

Finally, as a reflection on the research process, the researcher acknowledges that the level of understanding of methodology and of methods that they now possess is very different to that with which they started out. As such, how this study has grown and developed has mirrored the growth and development of the researcher – this has undoubtedly impacted on the process and this has been explored and acknowledged within the thesis.

7.6 Concluding statement

The uniqueness of this study is the use of the hybrid concept analysis method based on the synthesis of findings from 3 different perspectives. This study has reviewed and analysed professional opinion and built on the existing research base as well as discovering the essence of the common experiences of compassion as recounted by patients and health care staff. Therefore, this research is both theory generating and theory confirming and thereby adds a valid, qualitative contribution to the subject of compassion in healthcare. Adding a definition of the concept of compassion is beneficial, as described there is confusion and debate about compassion and presenting a definition as valid and comprehensive as this study has enabled may assist in providing clarity and developing consensus.

Prince, the perhaps unlikely source of the quote that underpins the title to this Chapter, eloquently put in to words that anyone can understand, the idea that 'compassion is a verb' (Thich Nhat Hanh, in Salzberg, 1999) and that it is a universal need. Gilbert (2017) suggested that there was no common agreement relating to the attributes of compassionate care, this research has attempted to address this. Importantly, developing an evidence-based taxonomy of compassionate behaviours and how these behaviours are operationalised in practise could be a significant contribution to practice, to education and therefore to the provision of more accessible, active, meaningful and compassionate patient care.

Appendices

Appendix I

S. was a 59-year-old nurse, working in a senior position in a high tech department in a London teaching hospital. A single woman with a large and close family, her plan was to retire at 60 and travel the world using the savings she had worked hard to accumulate. Following an episode of dysphagia she was investigated and subsequently diagnosed with cancer of the oesophagus. S. retired and, following chemotherapy, underwent radical surgery from which she recovered exceptionally well. She travelled around India and tried to get on with her life.

I met S. when, 2 years after her initial treatment, she came to clinic for routine follow-up to be told that a scan had shown that the cancer had recurred. She was understandably devastated. Struggling to retain her composure she asked what the plan was to treat her – every question she asked seemed to elicit a more dreadful and depressing answer. No, there was no cure; treatment was aimed at improving quality of life and buying time, which would now only be measured in terms of months rather than years.

It is my job to be with patients in this circumstance, but there are always certain patients whose situation moves you just that little bit more – who get to you. S. was one of those patients – a very self-possessed person, she had come to clinic alone and watching her walk away at the end of her appointment was heart wrenching. Over the next few months I would be in

contact with S. with increasing frequency as her disease began to take its toll. I got to know her and her sister well – as well as S. would allow at any rate.

Her condition continued to deteriorate and a subsequent scan demonstrated that the disease was progressing rapidly despite the chemotherapy that she was having – it also showed that she had pulmonary emboli and needed urgent treatment. A colleague had arranged for S. to come to the hospital to have an injection of an anti-coagulant and had asked her to go to the oncology ward where I would catch up with her. I found S. and her sister in the day room, S. was, for the first time ever, in tears. They told me that the nurse on the ward had been so rude and unhelpful that, in her words, ‘it made me ashamed to be a nurse.’ Her requirements had not been excessive or complicated; she had needed a wheelchair to get from the car to the ward – a request that was greeted with an attitude of ‘not my problem’. Arriving on the ward she was met not with understanding or courtesy but with comments that made it clear that this, admitted, breach of normal ward routine was an inconvenience and moreover one that would not be sorted out easily or quickly.

I looked at this inestimable lady, so diminished by the ravages of this awful illness, with no hair, sitting in a wheelchair looking sick and vulnerable and realised that despite her knowledge that death was imminent; the cause of her tears and distress was the lack of simple kindness and understanding of a colleague. At that moment, I too, was ashamed to be a nurse.

Appendix II

Literature Review Table of Articles 2004-2014

	Article title	Author and date <small>For full author details see reference list</small>	Type of data	Location
1.	Compassion in Healthcare – lessons from a qualitative study of the end of life care of people with dementia.	Crowther et al. 2013	Qualitative research study	UK
2.	Compassion benefits patients, but can be a big emotional drain on staff.	Keogh, K. 2014	Report	UK
3.	A critical analysis of Compassion in Practice.	Dewar, B and Christley, Y. 2013	Article	UK
4.	Compassion is the key.	Trenchard, S. 2013	Opinion	UK
5.	Compassion into action.	Adamson, L. 2013	Report.	UK
6.	No hope without compassion: the importance of compassion in recovery-focussed mental health services.	Spandler, H and Stickley, T. 2011	Review.	UK
7.	The Language of Compassion in Acute Mental Health.	Crawford et al. 2013	Qualitative research study	UK
8.	Promoting compassion starts from the top.	Snell, J. 2013	Editorial	UK
9.	How to encourage compassion.	Patel, K. 2013	Opinion	UK
10.	Bringing compassion back into caring: an equation of reciprocation.	Nyatanga, B. 2013	Opinion	UK
11.	Report 'A crisis of compassion: Who cares?' Battle of Ideas. 20-21 October 2012, London.	Hehir, B. 2013	Report	UK
12.	Compassion tests make sense if well executed.	Scott, G. 2013	Editorial	UK
13.	Lessons in compassion.	Adamson, L. 2013	Report	UK
14.	A call for reflection: Medical student driven effort to foster empathy and compassion.	Ramesh, A. 2013	Opinion	USA
15.	Liars, Medicine and Compassion.	Ekstrom, L.W. 2012	Discussion	USA
16.	You can't mandate compassion. Does a commitment to caring set the tone for	Hawkes, N 2012	Opinion	UK

	Jeremy Hunt's entire term as health secretary?			
17.	Compassion and professional care: exploring the domain.	van der Cingel, M 2009.	Article – exploration.	Netherlands
18.	Compassion for keeps. How do you carry on caring in the face of competing pressures?	Trueland, J. 2012.	Article – report.	UK
19.	Practising engagement: infusing communication with empathy and compassion in medical students' clinical encounters.	Warmington, S. 2011	Article.	Australia
20.	Compassion in care: A qualitative study of older people with a chronic disease and nurses	van der Cingel, M. 2011	Qualitative research study	Netherlands
21.	Respect, compassion and dignity: the foundations of ethical and professional caring	J Reid, 2012	Clinical feature	UK
22.	Maintaining compassion in care planning	Larkin, 2011	Editorial	Ireland
23.	Can We Mandate Compassion?	Paterson, R. 2011	Essay	New Zealand
24.	Care and Compassion	Greenberg, M. A. 2011	Article - opinion	USA
25.	Just compassion: implications for the ethics of the scarcity paradigm in clinical healthcare provision	B, Maxwell. 2008	Article – ethical discussion	Canada
26.	Cultivating compassionate care	Dewar, B. 2013	Article	UK
27.	Compassion through human connection	Trueland, J. 2009	Report	UK
28.	Conveying compassion through attention to the essential ordinary.	Perry, B. 2009	Qualitative research study	Canada
29.	Measuring nursing care and compassion: the McDonaldised nurse?	A, Bradshaw. 2014	Critical examination	UK
30.	Compassion: A Concept Analysis	Schantz, M. L. 2007	Concept Analysis	USA
31.	The Power of Compassion	Black, S. 2008	Report	UK
32.	Cultivating compassion across cultures,	Kim, S and Flaskerud, J. H. 2007	Opinion/ Personal Account	USA
33.	Compassion and responsibility in surgical care.	Torjuul, K., Elstad, I and Sorlie, V. 2007	Qualitative research study	Sweden

34.	Comments, critique and inspiration: The gift of compassion.	MacCulloch, T. 2007	Opinion	New Zealand
35.	The Qualities of a Compassionate Nurse According to the Perceptions Of Medical-Surgical Patients	Kret, D. D. 2011.	Quantitative research study	USA
36.	Compassion as a basis for ethics in medical education	Leget, C and Olthuis, G. 2006	Opinion	Netherlands
37.	Compassion.	Dossey, L. 2007	Opinion/Review	USA
38.	Nursing praxis, compassionate caring and interpersonal relations: An observational study.	Fry et al. 2013.	Observational study	Australia
39.	A Model Long-Term Care Hospice Unit: Care, Community, and Compassion	Kayser-Jones, J., Chan, J and Kris, A. 2005	Observational Study	USA
40.	Recognizing care and compassion in nursing	Castledine, G. 2005	Opinion	UK
41.	Leadership with conscience, compassion, and commitment	Wollenburg, K. G. 2004	Published lecture	USA
42.	Dimensions of caring: A Qualitative Analysis of Nurses' stories	Hudacek,, S. S 2007	Qualitative research study	USA
43.	What the NHS needs to improve: four behaviours to sort out the health system	Hadridge, P and Pow, R 2008	Essay	UK
44.	Moral competence in nursing practice	Jormsri, P et al, 2005	Article	Thailand
45.	Compassion	Kagan, S. H. 2014	Article/Opinion	USA
46.	Cancer patients' descriptions of their nursing care	Radwin et al. 2005	Qualitative research study	USA
47.	Virtue in Emergency Medicine	Larkin et al. 2009	Article	USA
48.	Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting	Dewar and Nolan 2012	Qualitative research study	UK
49.	Meaning of Caring to 7 Novice Physical Therapists During Their First Year of Clinical Practice	Greenfield et al. 2008 2008	Qualitative research study	USA
50.	Student nurse socialisation in compassionate practice: A Grounded Theory study.	Curtis, K., Horton, K and Smith, P. 2012	Grounded theory study	UK
51.	Compassion and communication in cancer care	Staren, E. D. 2006	Presidential Address	USA

52.	Is compassion possible in a market-led NHS?	Flynn, M and Mercer, D. 2013	Review	UK
53.	The desired moral attitude of the physician: (II) compassion	Gelhaus, P. 2011	Article/review	Germany
54.	Compassion: what history teaches us	Bradshaw, A. 2009	Discussion/article	UK
55.	Can you measure compassion?	Mooney, H. 2009	Article	UK
56.	Exploring how to enable compassionate care in hospital to improve patient experience.	Cornwell, J and Goodrich, J. 2009	Article	UK
57.	Compassion in nursing 1: defining, identifying and measuring this essential quality.	Davison, N and Williams, K. 2009.	Article	UK
58.	Compassion in nursing 2: factors that influence compassionate care in clinical practice	Davison, N and Williams, K. 2009	Article	UK
59.	Leading with compassion	Poll, S. 2013	Opinion	UK
60.	Describing Compassionate Care: The Burn Survivor's Perspective	Badger, K and Royse, D 2012	Qualitative, focus group study	USA
61.	Teach students compassion by being an excellent role model.	Newton, V. 2010	Comment/Article	UK
62.	How the 6 Cs relate to clinical leaders 2013	Foster, D.	Discussion/Article	UK
63.	Are Doctors Who Have Been Ill More Compassionate? Attitudes of Resident Physicians Regarding Personal Health Issues and the Expression of Compassion in Clinical Care	Roberts et al. 2011	Quantitative research study	USA
64.	Compassionate Solidarity suffering, poetry, and medicine	Coulehan, J. 2009	Article	USA
65.	Care and compassion: the experiences of newly qualified staff nurses	Horsburgh, D and Ross, J. 2013	Qualitative research	UK
66.	Keep compassion alive Effective role models can help nursing students deliver compassionate care under pressure	Curtis, K. 2012	Article	UK
67.	Lessons in compassion A study of what patients see as compassionate care can guide nursing students on placement	Adamson, L. 2013	Article	

68.	Poor organisational cultures erode compassionate care	Ross, F. 2010	Article/Personal account	UK
69.	Compassion: more than just chemistry?	Mickel, A. 2008	Article	UK
70.	Exploring compassion: implications for contemporary nursing. Part 1	Straughair, C. 2012	Article	UK
71.	Exploring compassion: implications for contemporary nursing. Part 2	Straughair, C 2012	Article	UK
72.	Taught to be kind.	Gould, D. 2008	Article	UK
73.	Love me tender.	Wright, S and Sayre-Adams, J. 2006	Article	UK
74.	Embedding NHS values: a framework and learning tool to support practice	Sykes, C and Durham, W. 2014	Article	UK
75.	Dignity and the essence of medicine: the a, B, C, and d of dignity conserving care	Chochinov, H. 2007	Article/Opinion	Canada
76.	The future of clinical nursing: meeting the needs of patients for compassionate and skilled nurses?	Bradshaw, 2011	Editorial	UK
77.	More than a feeling.	Buchanan-Barker, P and Barker, P. 2004	Article	UK
78.	Should compassionate practice be incentivised?	Smajdor, A. 2014	Article	UK
79.	In the night time of your fear: The anatomy of compassion in the healing of the sick	Kearsley, J. H. 2011	Article	Australia
80.	Learning the requirements for compassionate practice: Student vulnerability and courage	Curtis, K. 2014	Grounded theory study	UK
81.	An Emancipatory Theory of Compassion in Nursing.	Georges, J. M. 2013	Article/ critique	USA
82.	Evidence of the Unspeakable. Biopower, Compassion and Nursing.	Georges, J. M. 2011	Article	USA
83.	In praise of compassion	Maben, J., Cornwell, J and Sweeney, K. 2009	Editorial	UK
84.	Listening to the still small voice: the role of palliative care nurses in addressing psychosocial issues at end of life	Larkin, P J. 2010	Invited review	Ireland

85.	Compassionate Clinicians Take Patient Care Beyond the Ordinary	Graber, D.R and Mitcham, M.D 2004	Qualitative Research Study	USA
86.	Mobilizing Compassion to Counteract Denial and Despair	Kapitan, L. 2011	Editorial	USA
87.	Could Schwartz 'rounds' improve compassion in care?	Hughes, R. 2013	Article	UK
88.	Are you for real? A personal view of compassion in nursing	'Grumbling Appendix' 2013	Comment/Blog	UK
89.	Delivering compassionate care	Harrison, P. 2009	Article	UK
90.	Nursing with kindness and compassion	Forrest, C 2014	Article	UK
91.	Nursing with compassion	Chambers, C and Ryder, E 2014	Article/Abstract from book	UK
92.	Recommendations for a New Curriculum in Pain Medicine for Medical Students: Toward a Career Distinguished by Competence and Compassion	Murinson et al, 2013	Quantitative research	USA
93.	Dying Patients' Need for Emotional Support and Personalized Care from Physicians: Perspectives of Patients with Terminal Illness, Families, and Health Care Providers	Wenrich et al, 2004	Qualitative research	USA
94.	What Keeps Nurses in Nursing?	Dunn, D.J. 2012	Qualitative research	USA
95.	21st Century challenges faced by nursing faculty in educating for compassionate practice: Embodied interpretation of phenomenological data	Curtis, K 2013	Qualitative research	UK
96.	Time, touch, and compassion: effects on autonomic nervous system and well-being.	Kemper, K, Shaltout, H and Rosenberger, J. T. E. 2012	Quantitative research	USA
97.	Collaboration, Credibility, Compassion and Co-Ordination: Professional Nurse Communication Skill Sets in Health Care Team Interactions.	Apker et al 2006	Qualitative research	USA
98.	The Development and Evaluation of a Compassion Scale	Martins et al, 2013	Quantitative research	USA
99.	Compassion: An Investigation into the Experience of Nursing Faculty	Peters, M. A. 2006	Qualitative research	USA
100	Compassion in psychotherapy: The perspective of therapists nominated as compassionate	Vivino et al. 2009	Qualitative research	USA

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Participant Information Sheet

Compassion: A Concept Analysis

Protocol V3 – June 2013.

This Participant Information Sheet is designed to explain the background of the above research study and to describe what would be entailed if you were to choose to be involved in that study. Please read it carefully and talk to the researcher if you wish to enable you to make an informed decision about whether you may want to be involved. This study forms part of a wider PhD project which is aiming to establish the current state of healthcare education in terms of 'compassion' as a concept. Thank-you.

1. Who is the Principal Investigator?

Sarah Tobin

2. Who is supervising the research?

Prof. Ruth Endacott, Director of Studies

Prof. Janet Richardson

3. Lay summary - what is the background to the research aims?

Compassion is a quality that it is generally assumed to be demonstrated by and inherent in all healthcare workers, it is certainly mentioned with great frequency within both healthcare literature and policy and increasingly within the media. As with many supposedly innate qualities, compassion is frequently mentioned but rarely defined. Most people will have an idea of what compassion means to them but can this be clearly described and is there a common understanding of the term? In order to carry out a PhD research project which aims to try and establish the level of educational provision concerning compassion in current pre-registration healthcare education it is first necessary to establish a definition of the term. In order to achieve this aim a Concept Analysis is being carried out.

Concepts are seen as the building blocks of theory so concept analysis or clarification is an important element of ensuring that we create accurate and purposeful theory. The concept of compassion will be analysed using 2 methods of data collection – the first will involve a review of current literature and the second will be a fieldwork study.

4. How will the fieldwork study be conducted?

Initially, 20 healthcare professionals who work in South Devon will be asked to recount a story of a time when either they or a colleague behaved in a way that they believed demonstrated compassion. The story must relate to their role as a healthcare professional and describe something that occurred within a healthcare context. The story can be as short as they like but should take no longer than 10 minutes to recount. They are asked not to name any colleagues or patients directly and may use a pseudonym if that helps to recount the story. The story will be audio recorded and subsequently transcribed verbatim. These transcripts will be analysed to try and find common themes.

5. Why have you been asked and what will you have to do?

You have been asked because you are a healthcare worker and you work within South Devon. You will need to give enough time to read this leaflet read and sign a consent form and recount your story – this should not take up more than 30 minutes of your time. The time and place for you to take part will be negotiated and will be arranged for your convenience. You do not have to take part and can simply decline the invitation with no further obligation or contact. Your manager will not be aware if you have declined or agreed to participate.

6. What will happen to the information that I give?

The story you recount will be audio recorded, the recordings will be kept by the Principal Investigator and will be stored digitally on a password protected computer. The recorded stories will then be transcribed verbatim; the transcription will be performed either by the Principal Investigator or by an audio typist who is aware of the University's Principles for Research Involving Human Participants Guidelines concerning confidentiality and data storage. The details of each participant will be kept anonymous, each story will be given a number and the details of each participant will be known only to the Principal Investigator and the Supervisory team. All data generated by the study will be kept securely for a minimum of 10 years after which it may be destroyed.

You are free to withdraw from the study if you change your mind; you do not have to give a reason for withdrawal. You will need to contact the Principal Investigator who will ensure that the transcription of your story will be destroyed and not used in the final analysis of data collected. However, once your story has been analysed and the themes merged with those of other stories it will not be possible for your transcription to be withdrawn. Withdrawal from the study will not have any consequences for you and your employer will not be informed that you have withdrawn.

7. What are the benefits and disadvantages of taking part?

There will be no direct benefit to any of the individual participants however it is hoped that the information will assist in the development of greater

understanding about the concept of compassion and that this, in turn, will benefit future research. The only disadvantage will be the time required to participate in the study. It is not anticipated that any harm will come to you. However, in the event that something does go wrong and you are harmed due to someone's negligence then you may have grounds for a legal action for compensation against the University of Plymouth but you may have to pay your legal costs. The University has vicarious liability for researchers' actions with indemnity insurance schemes in place should any harm occur.

8. What will happen to the results?

The results of this study will be presented as part of a PhD research study with the University of Plymouth. The results will also form the basis of an article that will be submitted for publication in an academic journal and may also be presented at relevant conferences. Your details, your place of work or any details which may lead to this information being known will not be identifiable in any publication or presentation

9. Who is funding the study and who is reviewing the study?

The research is being carried out as part of a PhD which is being self-funded by the Principal Researcher with support from their NHS employer who is funding some of their time to carry out the study.

The research process and results will be scrutinised by the supervisors who have been appointed by the University of Plymouth. The research has been granted ethical approval from both the University of Plymouth and the NHS Trust where the Principal Investigator works and where the research will be conducted. The University of Plymouth is the designated research sponsor for this study.

10. Further information and contact details

Any further information needed prior to taking part in the study or for subsequent follow-up information or help please contact the Principal Investigator, details below.

Sarah Tobin:- sarah.tobin@plymouth.ac.uk or 01803 655293

SDHCT Staff Counselling Service:- 01803 655823.

Any complaints that may arise as a result of this study should be addressed in the first instance for the attention of the Director of Studies:-

Professor Ruth Endacott,

Faculty of Health, Education and Society,

University of Plymouth,

8, Portland Villas,

Drakes Circus,

Plymouth,

PL4 8AA.

ruth.endacott@plymouth.ac.uk

Thank-you for your consideration.

Appendix IV

Transcript of story #5 with horizons highlighted.

Researcher - So thank you for taking part in this study. Can I just confirm that you have read and understood the participant information sheet?

Storyteller - I have

Researcher - and you understand that all the information that you give to me today is going to be kept safe by myself, accessed by myself and accessed by an audio typist and a supervisor of this study. Please remember that your story needs to relate to health care but be mindful not to mention specific colleagues or patient names but don't worry if you do we will delete this for you. Please take the time you need but please try and keep your story under 10 minutes, if you do get near that, I will give you a bit of warning around 8 or 9 minutes time just to let you know, but you can over run if you need to if you want to finish any point for completeness etc. Ask me at any time if you need any clarifications but otherwise in your own time please tell me the story that came to your mind when I asked you for example of compassion in health care practice.

Storyteller - Okay well this incident happened about 7 years ago **so it must have been quite memorable** to still **remember it today**. I was a ward manager on a gastroenterology ward and I was coming onto the night shift. I had hand over from one of the junior staff nurses at the time and we had a gentleman come in who was an **alcoholic gentleman** and he had a massive gastrointestinal bleed and basically we had been handed over from a medical point of view that **nothing could really be done**. He wasn't eligible for a transplant and he was a 40 year old gentleman and still **actively drinking alcohol**. The staff nurse that handed over to me **spent a great deal of time on her late shift doing the best she could**, he was still for active treatment but in the event if anything happened he wasn't for resuscitation and we would just let him go. He had **no family and very much alone** in the world probably because of his illness and drinking behaviour that caused all that. The staff nurse was due off shift, she **had done a really really long shift already, already done a double shift because we were really short staffed at the time** so basically had **worked for 14 and half hours** from 7.30am till 10.00 o'clock at night. This guy that she spent time with after she handed over to

me, I overheard a really lengthy conversation, **which still brings a lump to my throat really now**. She **asked him what his dying wish would be**, you know because we all understood that this man was going to die, he said his dying wish would be a couple of Budweiser's **and you know ethically kind of frowned upon** because we shouldn't be inducing alcohol intoxication in our patients even if they are known alcoholics but this nurse, **I thought she had finished her shift** and what **she did was drove to Sainsbury's and got this gentleman a couple of Budweiser's** and drove back and proceeded **to sit with him for 2 or 3 hours, she had 1 he had 1 and they just sat there**. He then **went into a coma** later that evening and **that's when she went home** at that point. To me I felt this nurse **went above and beyond what was expected of her**, and you know ... oh, the lump is in my throat now..., **she was just so compassionate to that man and his needs at the time, you know, she just went against what we're taught**. The doctor in charge of the ward **probably would have gone mental at that time** because her views of alcoholics continuing to drink were very strict but you know we had a very small time frame in which she could treat this man to his dying wish you know **she didn't ask for any recompense** for the alcohol you know **it was just one of the loveliest things I have seen**.

Researcher - That's great.

Storyteller - The flip side to the story is the man made it through the night and he went on to have a procedure that actually saved his life and 6 months later gave up alcohol and had a transplant so.... but at that point **I still get goose bumps talking about it now** because as a ward manager **I was proud of what this person had done**.

Researcher - Thank you, is there anything you would like to add?

Storyteller - No, If you're asking me what I thought what was compassionate about it, very difficult to say really.....**using her own time, on her own initiative** just the whole you know **way she treated a man that society would kind of cast aside**, you know **a lot of other people would have been quite judgemental** in that situation and I'm not saying that he deserved what he, you know dying of his alcoholic liver disease but just **there was no judgement there**.

Researcher - Thank you very much.

xxxxxx 2016

Dear xxxxxxx

I am writing to you as the leader/facilitator of the xxxxxxxxxx Support Group in the hope that you and the group members may consider helping me with a research study that I am undertaking with the University of Plymouth. I am a nurse currently working in the National Health Service but also a lecturer with the University helping to educate the nurses and healthcare professionals of the future. I am currently carrying out a research project as part of a PhD programme and am looking at how we can identify compassionate care in order to then try and ensure this is taught to healthcare students more effectively.

I am hoping to record short stories (10 minutes or less) from people who have been patients and who believe that the care they have received was compassionate. Compassionate care is that which was seen to be kind and caring by the patient or by their family or carers. If anyone within your group feels that they have such a story and would be willing to share it with me I would be very grateful if they would contact me. I would then arrange to meet at a time and place convenient for them with the aim of listening to their story. This would be recorded on a digital recorder and then copied out word for word by an audio typist. Only I, the typist and the two Professors who supervise the research would have access to the recordings and all information would be anonymised and kept securely.

Healthcare professionals have already recorded their stories and now the patient experience needs to be captured. The information in the stories will be analysed and any common themes and experiences will be identified. The aim is to establish what patient's believe compassionate care 'looks' like and, if possible, to identify specific behaviour and practice that is seen as resulting in compassionate care.

Please would you be kind enough to bring this study to the attention of the members of your group. If you have any further questions or if anyone would like to volunteer their story please contact me (e mail preferred) – my contact details are below. I will then get in touch and will give any volunteer storytellers more information and an opportunity to ask any further questions prior to getting their consent to hear and record their story.

Thank-you very much for taking the time to read this letter and for sharing the contents with your group.

Kind Regards,

Participant Information Sheet

Patient's Experience of Compassionate Care

V4.0 – October 2016.

This Participant Information Sheet is designed to explain the background of the above research study and to describe what would be involved if you were to choose to participate. Please read it carefully and, if you wish, talk to the researcher so that you can make an informed decision about whether you may want to be involved. This study forms part of a wider PhD project which aims to explore the concept of compassion in healthcare. Thank-you.

11. Who is carrying out the research study?

Sarah Tobin (known as the Principal Investigator or PI)

Who is supervised by:-

Prof. Ruth Endacott, Director of Studies

Prof. Janet Richardson

All of the above work at the University of Plymouth

12. What is the study about?

Compassion is a quality that it is generally assumed to be demonstrated by healthcare workers, it is mentioned frequently in healthcare literature and policy and increasingly within the media. However, compassion may be frequently mentioned but it is rarely defined. Most people will have an idea of what compassion means to them but this study aims to explore whether this can be clearly described and if there is a common understanding of the term. The concept of compassion will be analysed using 2 methods of data collection – the first will involve a review of current literature and the

second will be a fieldwork study where people's stories of compassion in healthcare are recorded.

13. What will be involved if I chose to get involved?

The aim is to record stories from those who have been the recipients of healthcare in any setting. The story can be as short as you, the teller, likes but should take no longer than 10 minutes to recount. You are asked not to name any healthcare professionals or fellow patients directly and you may use a pseudonym (false name) if that helps to recount the story. You will need to give enough time to read this leaflet, read and sign a consent form and recount your story – this should not take up more than approximately 30 minutes of your time. The time and place for you to take part will be negotiated and will be arranged for your convenience. The story will be audio recorded and subsequently transcribed (written out) verbatim (word-for-word) which is why the need to keep them under 10 minutes. These transcripts will be analysed to try and find common themes.

After you complete your story you will be given time with the researcher to ask any further questions you may have and to ensure that you are satisfied with the process before the researcher leaves.

14. Why we are interested in you and do you have to take part?

You have been asked because you are a participant in a support group in Devon and, therefore, will have likely experienced some form of healthcare support – such experience is necessary for you to be involved. You do not have to take part and can simply decline the invitation with no further obligation or contact.

15. What will happen to the information that I give?

The story you recount will be audio recorded, the recordings will be kept by the Principal Investigator (Sarah Tobin) and will be stored digitally on a password protected computer. The recorded stories will then be transcribed (written out) word for word; the transcription will be performed either by the Principal Investigator or by an audio typist who is aware of the University's Principles for Research Involving Human Participants Guidelines concerning confidentiality and data storage. Your details will be kept anonymous, each story will be given a number and these details will be known only to the Principal Investigator and the Supervisory team. All data generated by the study will be kept securely for a minimum of 10 years after which it may be destroyed.

16. What happens if I change my mind?

You are free to withdraw from the study if you change your mind; you do not have to give a reason for withdrawal. You will need to contact the Principal Investigator who will ensure that the transcription of your story will be destroyed and not used in the final analysis of data collected. However, once your story has been analysed and the themes merged with those of other stories it will not be possible for your transcription to be withdrawn. Withdrawal from the study will not have any consequences for you and no one will be informed that you have withdrawn.

17. What are the benefits and disadvantages of taking part?

There will be no direct benefit to any of the individual participants however it is hoped that the information will assist in the development of greater understanding about the concept of compassion and that this, in turn, will benefit future research. The only disadvantage will be the time required to participate in the study. It is not anticipated that any harm will come to you; the stories are, by definition, positive experiences. It also needs to be acknowledged, however, that any relationship within a healthcare setting can have an emotional impact. If subsequent concerns or

distress result from participation in this study then appropriate help and support is available. You can choose to stop your story at any time and the researcher will sign-post you to help as appropriate.

In the event that something does go wrong and you are harmed due to someone's negligence then you may have grounds for a legal action for compensation against the University of Plymouth but you may have to pay your legal costs. The University has vicarious liability for researchers' actions with indemnity insurance schemes in place should any harm occur.

18. What will happen to the results of the research?

The results of this study will be presented as part of a PhD research study with the University of Plymouth. The results will also form the basis of an article that will be submitted for publication in an academic journal and may also be presented at relevant conferences. Your details, the support group details or any details which may lead to this information being known will not be identifiable in any publication or presentation. You are welcome to have a copy of any published material that relates to this section of the research study.

19. Who is funding the study and who is reviewing the study?

The research is being carried out as part of a PhD which is being self-funded by the Principal Researcher with support from their NHS and University employer who are also providing some of the time to carry out the study.

The research process and results will be scrutinised by the supervisors who have been appointed by the University of Plymouth. The research has been granted ethical approval from the University of Plymouth where the Principal Investigator and the supervisors work. The University of Plymouth is the designated research sponsor for this study.

20. Who should I contact if I have any questions or concerns?

Any further information needed prior to taking part in the study or for subsequent follow-up information or help please contact the Principal Investigator, details below.

Sarah Tobin:- sarah.tobin@plymouth.ac.uk or 01752 586574

Any complaints that may arise as a result of this study should be addressed in the first instance for the attention of the Director of Studies:-

Professor Ruth Endacott,

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Thank-you for your consideration

Appendix VII

Article title and author	Type of data	1.Surrogate terms	2.Antecedents	3.Attributes	4.Examples	5.Consequences (+ive and -ive)
1. Compassion in Healthcare – lessons from a qualitative study of the end of life care of people with dementia. Crowther et al 2013	Qualitative research study	Yes. Humanistic care Kindness Empathetic Humanity (+ of strangers) Caring Kind-hearted Putting yourself in another's shoes	Yes. The need to be compassionate with ourselves in order to be compassionate with others.	Yes. Core human value The foundation of social and personal relationships. '...we respond with humanity and kindness to each person's pain, distress, anxiety and need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for those we serve and work alongside. Gentle Benevolent	Yes. 'I believe your husband likes nice coffee, he can have a nice cup of coffee with me' so she brought special cups in, biscuits and special coffee for him. 'Another little act of kindness, I brought my husband new jogging bottoms and a top....nurse didn't put it on until just before he was going to see the oncologist....so he wouldn't make a mess of it....I just thought...they are so busy there...little acts of kindness like that are very important aren't they?'	Yes. 'Nine years since the death of her father, we can see evidence of the negative impact and lasting effects upon a carer when poor communication and target driven care from professionals are perceived to have occurred.' '...routinisation and traumatic events appear normal to staff employed within hospitals....an increase in exposure to traumatic events may result in an absence of certain behaviours in order to maintain self-preservation and protection.' Having compassion leads a person to show kindness.

Appendix VIII

2014-2018 Research Studies

Author	Title	Location
Tanco et al, 2017	The Effect of Message Content and Clinical Outcome on Patients' Perception of Physician Compassion: A Randomized Controlled Trial	USA
Hewison et al, 2018	Leading with compassion in health care organisations. The development of a compassion recognition scheme-evaluation and analysis	UK
Dunn and Rivas, 2014	Transforming Compassion Satisfaction.	USA
McClelland and Vorgus, 2014	Compassion Practices and HCAHPS: Does Rewarding and Supporting Workplace Compassion Influence Patient Perceptions?	USA
Leffel et al, 2018	Project on the Good Physician: Further Evidence for the Validity of a Moral Intuitionist Model of Virtuous Caring.	USA
Tierney et al, 2017	Enabling the flow of compassionate care: a grounded theory study	UK
Bridges et al, 2017	Optimising impact and sustainability: a qualitative process evaluation of a complex intervention targeted at compassionate care.	UK

Durkin et al, 2018	Qualities, teaching, and measurement of compassion in nursing: A systematic review.	UK
Richardson et al, 2015	Nursing therapeutics: Teaching student nurses care, compassion and empathy.	UK
Papadopoulos and Ali, 2015	Measuring compassion in nurses and other healthcare professionals: An integrative review.	UK
Perev-Bret et al, 2016	Definition of compassion in healthcare: a systematic literature review.	Spain
Mills et al, 2017	Palliative care professionals' care and compassion for self and others: a narrative review	Australia
Blomberg et al, 2016	Interventions for compassionate nursing care.	UK and Sweden
Papadopolous et al 2016	Developing tools to promote culturally competent compassion, courage and intercultural communication in healthcare.	UK
Sinclair et al, 2016	Compassion: a scoping review of the healthcare literature	Canada
Tierney et al, 2018	Having the "Headspace" for Compassion Toward Self and Others: A Qualitative Study of Medical Students' Views and Experiences	UK

Ledoux et al, 2018	The effect of organizational and personal variables on the ability to practice compassionately	Canada
Hofmeyer et al, 2017	Teaching compassionate care to nursing students in a digital learning and teaching environment	Australia (among others)
Mills et al, 2018	Examining self-care, self-compassion and compassion for others: a cross-sectional survey of palliative care nurses and doctors	Australia
Taylor et al 2017	Compassion in healthcare: a concept analysis	UK
Terry et al, 2017	A research-based mantra for compassionate caring	UK
Sinclair et al, 2017	Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences	Canada
Lown et al, 2017	How important is compassionate healthcare to you? A comparison of the perceptions of people in the United States and Ireland	US/UK/Ireland
Ali and Terry, 2017	Exploring senior nurses' understanding of compassionate leadership in the community	UK

Jack and Tetley, 2016	Using poems to explore the meaning of compassion to undergraduate nursing students	UK
Waugh and Donaldson, 2016	Students perceptions of digital narratives of compassionate care	UK
Sinclair et al, 2016	Compassion in Health Care: An Empirical Model	Canada
McPherson et al, 2016	Distress in working on dementia wards – a threat to compassionate care: A grounded theory study	UK
Cameron et al, 2015	In search of compassion: a new taxonomy of compassionate physician behaviours.	USA
Adamson and Dewar, 2015	Compassionate Care: Student nurses' learning through reflection and the use of story	UK
Fernando and Consedine, 2014	Development and initial psychometric properties of the Barriers to Physician Compassion questionnaire	New Zealand

Whitehead et al 2014	Compassionate care? A critical discourse analysis of accreditation standards	Canada
Bray et al, 2014	The role of professional education in developing compassionate practitioners: A mixed methods study exploring the perceptions of health professionals and pre-reg students.	UK
Curtis et al, 2017	Using Appreciative Inquiry to develop, implement and evaluate a multi-organisation 'Cultivating Compassion' programme for health professionals and support staff	UK
Ramage et al 2017	Developing and Using a Toolkit for Cultivating Compassion in Healthcare: An Appreciative Inquiry Approach	UK
Valizadeh et al 2018	Nurse's perceptions of organisational barriers to delivering compassionate care: A qualitative study	Iran + UK
Moore et al, 2017	Implementing the compassion intervention, a model for integrated care for people with advanced dementia towards the end of life in nursing homes: a naturalistic feasibility study	UK
Azhar et al 2019	Impact of physician attire on Pall Care pts perception of physician compassion and professionalism: A RCT	USA

Sinclair et al 2017	Measuring Compassion in Healthcare: A Comprehensive and Critical Review	Canada
Brown et al. 2014	Practical compassions: repertoires of practice and compassion talk in acute mental healthcare	UK
Kirby et al 2017	A Meta-Analysis of Compassion-Based Interventions: Current State of Knowledge and Future Directions	Australia
Lee and Seomun, 2015	Development and validation of an instrument to measure nurses' compassion competence	South Korea
Richardson et al, 2015	Nursing therapeutics: Teaching student nurses care, compassion and empathy	UK
Crawford et al, 2014	The design of compassionate care	UK and Norway
Dewar et al, 2014	Clarifying misconceptions about compassionate care	UK

Sinclair et al, 2018	What are healthcare providers' understandings and experiences of compassion? The healthcare compassion model: a grounded theory study of healthcare providers in Canada	Canada
Singh et al 2018	Healthcare providers' perspectives on perceived barriers and facilitators of compassion: Results from a grounded theory study	Canada
Jakimowicz et al, 2017	Insights on compassion and patient-centred nursing in intensive care: A constructivist grounded theory	Australia
Henshall et al 2017	The relationship between perceived organisational threat and compassion for others: Implications for the NHS	UK
McSherry et al, 2017	Measuring health care workers' perceptions of what constitutes a compassionate organisation culture and working environment: Findings from a quantitative feasibility survey	UK
Zamanzadeh et al 2017	Factors facilitating nurses to deliver compassionate care: a qualitative study	Iran + Netherlands
McClelland et al 2018	Compassion Practices, Nurse Well-Being, and Ambulatory Patient Experience Ratings	US
Sacco et al 2018	Compassion satisfaction: A concept analysis in nursing	USA

Carson et al 2017	Caregivers Are Heroes: An Innovative Educational Strategy Designed to Promote Compassion/Caring in Health Professional Students.	USA
Barron et al 2017	Community mental health nurses' and compassion: an interpretative approach	UK
Popadapolous et al 2017	Exploring Nurses' Meaning and Experiences of Compassion: An International Online Survey Involving 15 Countries	UK + multiple
Jones et al 2016	Delivering compassionate care in intensive care units: nurses' perceptions of enablers and barriers	Australia
Kneafsey et al 2015	A qualitative study of key stakeholders' perspectives on compassion in healthcare and the development of a framework for compassionate interpersonal relations	UK
Bramley and Matiti, 2014	How does it really feel to be in my shoes? Patients' experiences of compassion within nursing care and their perceptions of developing compassionate nurses.	UK
Brown et al, 2014	Practical compassions: repertoires of practice and compassion talk in acute mental healthcare	UK

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