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Pause time: a multi-perspective exploration of person-centred care in an acute hospital: an interpretative phenomenological analysis study with older people, families and staff.

WHITTINGHAM, K.A.

2021

“Pause Time” - a multi-perspective exploration of Person Centred Care in an Acute Hospital

An Interpretative Phenomenological Analysis study with older people, families and staff

Katrina Anne Whittingham

February 2021

Self Declaration

This thesis is my own work as part fulfilment of a Doctorate of Professional Practice at Robert Gordon University, Aberdeen.

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“Pause Time” - a multi-perspective exploration of Person Centred Care in an Acute Hospital An Interpretative Phenomenological Analysis study with older people, families and staff

Katrina Anne Whittingham

This thesis is submitted in partial fulfilment of the requirements for
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Abstract

Katrina Anne Whittingham
Doctorate of Professional Practice

"Pause Time" - a multi-perspective exploration of
Person Centred Care in an Acute Hospital

Background

Since the turn of the 21st century, the term Person Centred Care (PCC) has become integral to healthcare language in policy, education, research and practice. In several healthcare arenas, PCC has become synonymous with the delivery of high-quality care along with multiple drivers - politically motivated, research driven and from the health-related voluntary sector - to incorporate a variety of models of PCC in healthcare. Additionally, a growing body of evidence supports embedding PCC focussed approaches, particularly for older people with cognitive impairment. Evidence supporting PCC approaches for older people *without* cognitive impairment is less evident, especially in the context of acute hospital care; as is the exploration of simultaneous PCC experiences from the multiple perspectives of older people, their families and MDT members.

Aim

The study in this thesis explores, interprets and illuminates the experiences of PCC from the perspectives of older people (without cognitive impairment), their families and members of the MDT in an acute medicine for the elderly unit.

Approach and Methods

A hermeneutic phenomenological approach was taken, combining collective case studies with Interpretative Phenomenological Analysis (IPA). The methodological decisions and approach are underpinned by a pluralistic philosophical approach.

The methods employed involved purposive sampling to recruit four collectives, each comprising of an older person, a family member, at least one nurse from the MDT team and (ideally) one other member of the MDT team. The research setting was four acute medicine for the elderly wards, within one acute hospital site, providing care for both males and females.

All participants were requested to keep a diary of their experiences of giving or receiving care for at least 3 days. Each participant was then interviewed, using a face to face semi structured approach. Older people were offered the choice of being interviewed alone or with their family present. All diaries and interviews were transcribed and the qualitative data was subsequently analysed using an IPA approach.

Findings

Four collective case studies, with between 2 and 4 participants in each, participated in the study (n=11). Data analysis resulted in four superordinate themes: the impact of personhood on PCC experiences; the PCC experience of accessing acute hospital; the PCC experience in acute hospital and the PCC experience of leaving acute hospital. Subthemes were evident in all the superordinate themes.

This study adds to the PCC knowledge base most notably in relation to the personhood of participants. Personhood shaped participants' definition and expectation of PCC in ways which are not consistently aligned to current theoretical models of PCC, such as being actively involved in the care experience. Within the context of accessing acute care, participants shared assorted experiences of PCC and non-PCC approaches. Diverse perceptions of positive and negative experiences were also evident in the very rich superordinate theme of PCC experiences in acute care. An expectation of PCC being based on the relational aspects of care, where staff pause time, connect and establish what PCC means to individuals was uncovered. In some instances, PCC experiences were attributed to certain healthcare staff, in others the experiences were assigned to governing systems and processes. Similarly, PCC experiences of discharge from acute care revealed powerful positive PCC approaches, yet both older people and staff shared frustration around health and social care systems not meeting their PCC expectations. Furthermore, a flexible model of PCC where staff, older people and families can be cared about, for and with, is suggested.

The findings present a platform from which to celebrate and learn from positive PCC experiences and to plan strategies for improvements where the experiences of PCC approaches were lacking.

Conclusions

Combining collective case studies with IPA contributes uniquely to the PCC knowledge base by illuminating simultaneous perceptions of PCC experiences from older people, families and MDT staff. There appears therefore a need to base PCC on the relationship building aspects of care, moulding PCC to the personhood and the priorities of the older person.

In order to deliver PCC, the need for the MDT to ‘pause time’ with older people and to get to know them, regardless of the busy medicine for the elderly unit around them, was evident. The data collected demonstrated the perspective of older people and their family was that staff did ‘pause time’, more than staff themselves were aware they did. Findings established that staff participants could be encouraged by their ability to meet expectations of PCC, whilst remaining open to adapting their PCC approach around the personhood of the older people they care for. Finally, if integrated health and social care policy continues to promote PCC as an integral component to high quality care, the findings suggest more flexible and achievable PCC approaches in the long term, are required to generate and embed enduring change.

The PCC experiences and perspectives unveiled by this study support aspects of the current PCC evidence base but illuminate the need to flexibly adapt PCC approaches such as older people’s active involvement and enablement. The findings illustrate how authentic PCC consistently requires idiographic framing to the uniqueness of individuals.

Keywords: Person-centred care, older people, family, staff acute care experiences.

Thesis Word Count: 74,847 words.

Dedication

This thesis is dedicated to my oldest brother ‘Our Jack’. I hope it becomes apparent in reading this thesis, that as my surrogate Dad, he had a major influence on the person I am. His ability to view every situation from all sides and project empathy, inspired my topic selection and methodology, when I believed he had not received the person-centred care he deserved. This deeply personal seed to the research has served as a motivator. Additionally, I now see that I appear to have inherited both his intense interest in viewing every situation from multiple perspectives and his long winded ‘from the chapping of the door’ approach to storytelling and writing! Maybe now that my thesis is complete Jack, you may finally get to rest in peace without my interruption of your perpetual light, asking you to keep me going until the end.

Acknowledgements

I would like to thank my patient, loving and supportive family who have been my scaffolding in this long enduring journey. Douglas, my husband and soul mate, who ensured I kept going when I often felt like giving up. His tolerance to my level of indulgence in this doctoral journey must be acknowledged, my mind space may now be free to be present with him, once more. Thank you to my three children, Stuart, my oldest, logical driven boy who has grown into an emotionally intelligent being during my doctoral time. My middle one Cameron who shares my wide perspective and viewpoints, calmed me when I panicked without even realising he was doing it, with his natural empathetic ways. Mairi, my youngest hardworking, organised, thoughtful girl who helps re charge my world, just by being with me. They have grown into adults as I have reached the end; their certainty in my ability to become Doctor Katrina, is only exceeded in my pride in the people they have turned out to be. My extended McIntyre family must also be acknowledged, they remotely but consistently believed in me and propelled me into action. Their individual uniqueness reminded me why I had decided to explore person centredness in the first place!

I have had a wide and varied supervisory team, who have enriched my journey. Thank you to Professor Karen Strickland and Professor Sally Lawton who began the journey with me. Dr Fiona Work, Dr Lisa Kidd and Professor Kay Cooper, thank you for taking over and bringing your individuality to provide a particular student-centred approach to my supervision. I promise to really think through the use of the word 'this' forever, unpick, whilst reading out loud for clarity, for the rest of my life!

A special thank you to my proof-readers and critical, but true friends. Dorothy Adam for her genuine passion in my study and willingness to support me throughout. Sincere gratitude to Valery Burnett, for her enduring support in my later stages, her dedication to refining this thesis went above and beyond my expectation.

Lastly, thanks to all my colleagues in the school of Nursing & Midwifery who supported me with interest, again throughout the marathon doctoral journey. In

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List of Abbreviations

Abbreviation	**Full Term**
AHP	Allied Health Professional
CASP	Critical Appraisal Skills Programme
CCGs	Clinical Commissioning Groups
CDHN	Community Development and Health Network
CDSR	Cochrane Database of Systematic Reviews
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COPD	Chronic Obstructive Pulmonary Disease
CPcPR	Centre for Person-Centred Practice Research
CPD	Continuous Professional Development
DA	Discourse Analysis
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
DOH	Department of Health
DPP	Doctorate of Professional Practice
ED	Emergency Department
ESRC	Economic and Social Research Council
GDPR	General Data Protection Regulation
GP	General Practitioner
GPCC	Gothenburg’s Centre for Person-Centred Care Practice
GT	Grounded Theory
HF	Health Foundation
HIS	Health Improvement Scotland
HP	Hermeneutic Phenomenology
HSC	Health and Social Care
ICOPE	Integrated Care for Older People
ICP	Integrated Care Pathway
ICU	Intensive Care Unit
IHI	Institute of Healthcare Improvement
IPA	Interpretative Phenomenological Analysis
IPCHS	Integrated People-Centred Health Services
IRAS	Integrated Research Application System
JBI	Joanna Briggs Institute
K	The Researcher
LoF	Loss of function
LTC	Long Term Conditions
MDT	Multidisciplinary Team
MfE	Medicine for Elderly
NA	Narrative Analysis

Abbreviation	**Full Term**
NES	NHS Education for Scotland
NEWS	National Early Warning Score
NHS	National Health Services
NICE	National Institute for Clinical Excellence
NMC	Nursing and Midwifery Council
OECD	Organisation for Economic Co-operation and Development
OPAC	Older People in Acute Care
OPAH	Older People in Acute Hospital
PAR	Participatory Action Research
PMH	Past Medical History
PPI	Public Participation Interest
PCC	Person Centred Care
R & D	Research & Development
RCT	Randomised Control Trial
RCUK	Research Councils UK
RESA	Research Ethics Self-Assessment
RGU	Robert Gordon University
SCN	Senior Charge Nurse
SG	Scottish Government
SIPAIG	Scottish Interpretative Phenomenology Interest Group
SPSP	Scottish Patient Safety Programme
THA	Total Hip Arthroplasty
UK	United Kingdom
USA	United States of America
VIPS	**V**aluing the person with dementia, **I**ndividualising Care, Keeping the **P**erspective of the person with dementia in focus and a Positive **S**ocial environment
WHO	World Health Organization

Background Chapter

1.1 Introduction

This background chapter aims to set the scene for the thesis. It will commence with my rationale for studying Person-Centred Care (PCC) for Older People in Acute Hospital (OPAH). My personal context, my identity as a researcher and my worldview will also be explored, with reference to both relevant literature and personal reflections.

A critique will be provided of the origins of PCC, the philosophical perspectives underpinning it, its theoretical and practical applications to healthcare and its international and national definitions, strategies and models. The PCC model selected as the theoretical lens for this thesis will be discussed. The possibility that PCC is part of an agenda to humanise and enhance public participation in healthcare will also be considered.

1.2 Personal context of researching Person-Centred Care

Several factors inspired me to study PCC: my personhood, my sense of my life's journey (Hewitt-Taylor 2016) and my worldview. Creswell (2014) describes one's worldview as the way in which a person uses perceived experiences to build opinions, assumptions and interpretations of any given situation. These becomes their personal ontology and epistemology. Denzin and Lincoln (2013 p. 26) state that:

> *"Ontology is what kind of being a human being is….*
> *Epistemology is the relationship between the inquirer and the unknown…"*

My ontological and epistemological perspectives have only become clear to me as a reflexive, mature adult. I can now recognise the childhood events that sparked my interest in PCC. As a youngster, I always wanted to gain a *whole picture* perspective of any situation. I was intrigued by people's uniqueness and confused when others made incorrect assumptions about me. The youngest and only girl of five children, I lost my father when aged three. My eldest brother became my surrogate father. I vividly remember thinking:

> *Reflexive Diary Excerpt 21.1.17*
>
> *It was a happy good childhood, yet outsiders looking in sadness, doom and gloom and me to be a child missing out on a father, so sad. Why did adults talk in a condescending gloomy way, when my life was not sad?*

I wished that adults could see my world as I did and understand how I made sense of it – my *way of knowing* (Creswell 2014).

As I grew up, I was actively encouraged to understand all sides of any argument. Though we were an argumentative, debating, loud, talkative, *heart-on-your-sleeve* family, each one was valued as a unique individual. On reflection, this was preparing me to adopt a holistic viewpoint, keen to explore the different ways any situation could be seen.

I carried this natural inquisitiveness into my apprenticeship nurse education (1980s). In the early days of my career, rituals and protocols commonly determined practice, with no consideration for individuality. For example, following varicose vein surgery people remained in hospital until their bowels moved, regardless of whether their normal pattern was daily or weekly.

Gradually, these ritualised practices were superseded by increasingly individualised and holistic care (Pepitrin 2016); patients were consulted regarding their treatment preferences. I noticed that some people and their families preferred my holistic empathy based on my unconditional positive regard and congruent approaches (Rogers 1967). However, many registered nurses, including those responsible for my assessments, continued to favour standardised efficiency and strict adherence to set protocols rather than care tailored to individuals. To meet people / families' expectations whilst passing the competencies of my course, I had to combine holism and efficiency, adapting my practice to the environment. I learned through experience how to navigate care compromises (Dewar 2011).

During twenty-three years of clinical nursing practice I considered myself to be a role model of efficiency whilst still providing holistic care. Gradually the varied roles I held in clinical practice (including Senior Charge Nurse (SCN), Clinical Nurse Specialist and Practice Education Facilitator) allowed me to enable people – individuals, families and staff – to set their own goals and reach their potential. I encouraged cultures of care that were nurturing, individualised and holistic. When I left practice to enter academia, I sought to inspire future generations of nurses to be *patient centred*, as was the Scottish Government's term at the time (2010). I believed that my professional and personal experiences had enabled me to move from 'novice' to 'expert' (Benner 1984) in relation to patient centredness.

However, when in 2011 my eldest brother was diagnosed with an aggressive form of cancer, the focus of my understanding of PCC became much sharper. Whilst I taught the principles of the PCC approaches described in the Scottish Government Quality Strategy's (2010), my brother's care could not have been further from the ethos of that document, causing my family great distress. I witnessed him being *pushed* around an efficiency-driven system, where he often felt dehumanised by the processes around him (Maben et al. 2012; Goodrich and Cornwell 2008). I frequently wanted to complain, but he urged me instead to use his negative experiences to exert a positive influence on future healthcare, reminding me that I had the power to achieve that. I channelled those instructions into my lecturing role and assumed the PCC Theme Leader role in my School of Nursing and Midwifery. Two years after his demise, his challenge to use my influence to achieve improvements in PCC inspired my doctoral plan. On reflection, I now appreciate it was his open-minded attitude to every situation that led me towards a hermeneutic phenomenological approach. My worldview had cultivated an interest into how individuals make sense of their unique situation (Creswell 2014). Thus, my epistemological perspective was that to understand PCC more thoroughly, I needed to view it practically, from the variety of perspectives of those directly involved in giving or receiving it (Bevan 2013).

Since the start of my doctoral journey, my intention has been to develop my personal knowledge of PCC, exploring it from the multiple perspectives of stakeholders in OPAH care: older people, their families and the Multi-Disciplinary Team (MDT). Interpreting how these participants make sense of PCC in an acute hospital will make an original contribution to the body of PCC knowledge, in order to influence both education and practice.

The excerpts from my reflexive diaries will allow the reader to 'hear' my research voice. They also provide transparency to my process for interpreting how the participants made sense of their experiences (Gadamer 1960, 2004). I now recognise that undertaking this study has changed my own horizons and paradigms on PCC (Gadamer 1960, 2004). The excerpt below was recorded one month into my studies – my starting point. It illustrates my initial conclusions regarding possible hindrances to the provision of PCC in practice:

Reflexive Diary Excerpt 24.11.14

I sense the tensions that exist between the ivory towers of PCC theory, policy and actualisation in practice. Healthcare has become a bureaucratic industry where we are so busy proving what we do, how clean we are, how safe we are, we have squeezed time to be with and connect with people in meaningful ways. Now the policy drivers appear to be turning and saying PCC is just as important, but staff in clinical practice in reality are so exhausted, have compassion fatigue, they struggle to "be with" and inspire the next generation of nurses to do what we teach in academia with the competing unpredictable priorities of clinical care.

1.3 Current rationale for PCC in healthcare

Since the turn of the century, people receiving care have gradually been encouraged to assume greater control over decisions regarding their healthcare

(NHS Education for England 2019, 2012; Department of Health (DOH), 2017, 2014, 2009; 2008, 2007; DOH 2001a, b, Scottish Government 2015, 2010). PCC has been advocated internationally as an essential component of high-quality care (World Health Organisation (WHO) 2019, 2017, Institute of Healthcare Improvement 2015), on a par with safety and efficiency. PCC is now an element of quality improvement initiatives around the world as a source of patient, family and staff satisfaction (Marriot-Stratham 2018: Larsson and Bloomqvist 2015; Rathert et al. 2016; Esmaeili, Cheraghi and Salsali 2014).

Despite the national and international drive to incorporate PCC into acute care (NHS Education for England 2019, 2012; Department of Health (DOH), 2017, 2014, 2009; 2008, 2007; DOH 2001a, b, Scottish Government 2015, 2010; WHO 2019, 2017; IHI 2015), there is evidence of older people receiving non-PCC (Berwick 2014, Francis 2013). PCC appears to be experienced differently by those receiving it compared to its providers. This thesis aims to explore these issues.

Sections 1.3 and 1.4 will broadly explore the origins of PCC and current definitions, models and strategies for its delivery. Chapter 2 will explore in more specific detail the experiences of OPAH care in the PCC literature.

1.4 Origins of person-centred care

1.4.1 Understanding personhood comes before person-centred care

The origins of PCC can be explored from many perspectives. Since I was drawn to this topic by my sense of personhood, that seemed to be a logical starting point for my exploration (McCormack and McCance 2017; Hewitt-Taylor 2016; Leibing 2008; Sabat 2002; Kitwood 1997).

Leibing (2008) describes personhood as the sense of what truly matters to individuals; McCormack and McCance (2017) see it as:

> *"… the sum of feelings, desires, motivations and values."*
>
> (McCormack and McCance 2017 p.15)

Hewitt-Taylor (2016) suggests that past experiences, a sense of the present and an anticipated future all contribute to this. My awareness of people's sense of personhood has been very important to me as an individual, a sibling, a nurse and an educator. It has enhanced my self-awareness and my ability to form relationship-based links in society (Krishna, Kumar and Rayan 2015).

An individual's sense of personhood is believed to be uniquely theirs. In the background scoping searches of the person-centred literature it became apparent that a sense of personhood can also be affected by changes in their cognition, whether due to delirium or dementia. There appeared to be a wealth of established literature exploring the impact of altered cognition for older people in acute care (Du Toit, Sanetta and McGrath 2018; Spencer et al. 2014; Baillie, Merrit and Cox 2012; McCance et al. 2011; Bone, Cheung and Wade 2010). McCormack and McCance (2017) argue that both dementia and delirium may affect an individual's sense of personhood; Leibing (2008) believes that cognitive decline reduces it, whereas Sabat (2002) suggests that personhood can be unchanged if people in cognitive decline, are able to maintain connections with others in their social world.

Healthcare professionals wishing to plan, deliver and evaluate PCC must start with a sense of curiosity about an individual's unique sense of personhood (McCormack and McCance 2017; Dewar 2011). The background literature considered suggests that this can be more challenging where cognitive impairment has resulted in memory loss and altered perceptions of reality (National Institute for Clinical Excellence (NICE) 2017). Kitwood's (1993, 1997) model of PCC for older people with dementia can provide a useful guide in such situations (Baillie, Merrit and Cox 2012; McCance et al. 2011; Bone, Cheung and Wade 2010). It focuses on **V**aluing the person with dementia, **I**ndividualising Care, Keeping the **P**erspective of the person with dementia in focus and maintaining a Positive **S**ocial environment (VIPS). It advocates moving away from physical tasks to forming relationships and individualising care. This approach has become embedded in PCC research and practice (Edvardsson 2014, Edvardsson, Sandman and Borell 2014, Olsson et al. 2014a). Nolan et al. (2004) have challenged Kitwood's (1997) model on the basis that cognitive impairment can make relationships difficult to sustain. However, Sabat (2002) argues that if even a single connection can be maintained with someone who is aware of what matters to a person who has dementia, their personhood can survive. Dewing (2008) believes Kitwood's (1997) model to be morally sound. Thus, the presence of an individual who understands someone's personhood can allow PCC to be provided even to those lacking the cognitive ability to express their own wishes (Sabat 2002). I sensed the importance of acknowledging the person-centred dementia care evidence-based foundations, thus it seemed right to include it in this background chapter.

Social connections appear to facilitate relationships that recognise individual personhood and sharing of what matters in any given situation (Health Improvement Scotland (HIS) 2014a). These links may form between members of the older person's family and the healthcare team (Olsson et al. 2014b). McCormack's (2004) literature review suggests that for PCC to be recognisable by those receiving care as well as those delivering it, four core modes of being need to co-exist:

> *"Being in relation, being in a social world, being in place and being with self.*
>
> (McCormack and McCance 2017 p.17)

These modes of 'being' are linked to the relational aspects of care which are key to seeking out people's sense of personhood and forging a connection with them (Nolan et al. 2004, 2001). Nolan et al.'s (2001) '*Senses'* model of care suggests that the co-creation of feelings of security, continuity, belonging, purpose, significance and achievement is dependent on the personhood of both the givers and receivers of care. Both parties need to understand personhood, albeit possibly unconsciously, for the care to be person-centred (Hewitt-Taylor 2016).

Although some authors view the understanding of personhood as the starting point of PCC (McCormack and McCance 2017; Hewitt-Taylor 2016; Leibing 2008; Sabat 2002, Kitwood 1997), preliminary background reading early in the doctoral journey also uncovered a philosophical basis for person-centred approaches (McCormack and McCance 2017; Hewitt-Taylor 2017; Leibing 2008).

1.4.2 The philosophical basis for person-centred care

Building on the ideology of personhood, several theorists have made philosophical links to the origins of PCC (McCormack and McCance 2017; Hewitt-Taylor 2016; Leibing 2008). McCormack and McCance (2017) drew on Kant's theory that a person is intrinsically linked to their own personal moral code, their quality of life, their way of interacting with their world and their right to self-determination. However, Hewitt-Taylor (2016) considered instead the philosophical perspectives of Merleau-Ponty (2012, 1972), who posited that everyone's individual lens allows a different perspective even on the same situation; this resonated with my own views. Leibing (2008) argues that what matters to a person shapes their personhood as well as their expectations of PCC. The concepts of personhood and individuality as seen by Merleau-Ponty (2012,1972) and Hewitt-Taylor (2016) demonstrated to me that individuals can make sense of their world in highly unique ways.

The operationalisation of PCC into healthcare practice can also be linked to Gadamerian philosophy (2004, 1960): the process can be related to the dynamic fusion of horizons between the experiences of those receiving care and those delivering it. Gadamer's (2004,1960) influence on this thesis will be further explored in Chapter 3. Figure 1.1 below represents my understanding of the application of philosophical perspectives to personhood and expectations of PCC. The outermost circle attempts to demonstrate that all the aspects in the inner circles are likely to fuse together to form an individual's personal expectations of PCC.

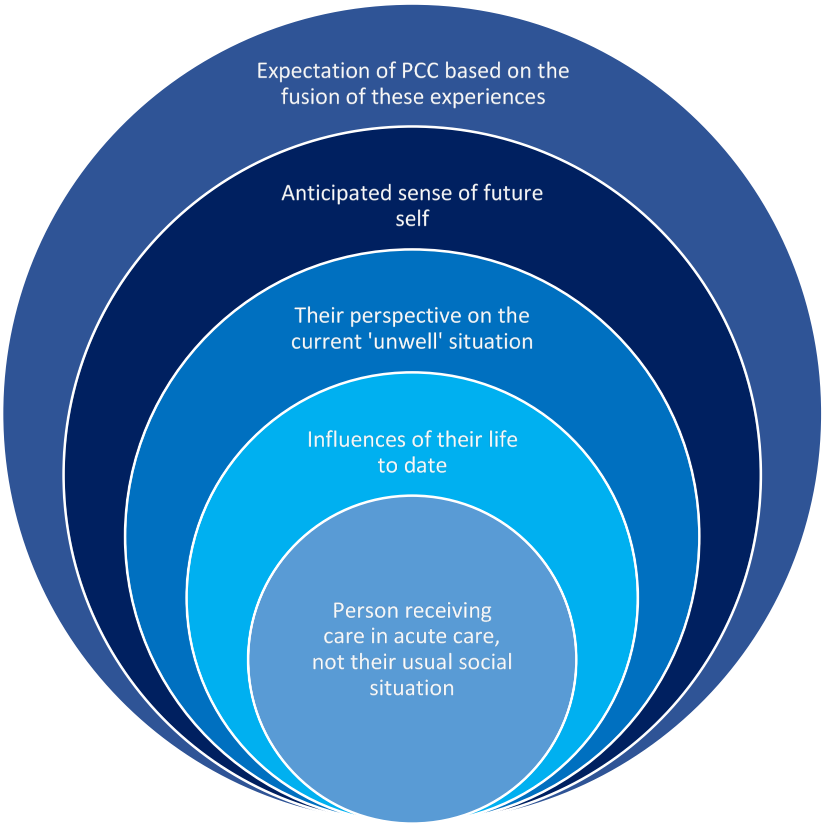


Figure 1.1 Philosophical Application to Personhood and Expectation of PCC

Although some PCC theorists have identified philosophical roots for their views, those delivering PCC are unlikely to be aware of any such basis for their care. Others have drawn inspiration from the principles of Rogers' (1967) counselling work and elements of nursing theory (Jakimowicz and Perry 2015; Balik et al. 2011).

1.4.3 Rogerian counselling linking to person-centred care

During my nursing career I was drawn toward Rogers' (1967) core conditions of empathy, unconditional positive regard and congruence. These are reflected in some of the PCC definitions (Healthcare Improvement Scotland (HIS) 2017, National Voices 2016) which will be discussed later in this chapter. Balik et al. (2011) suggest that PCC approaches should begin by viewing people holistically with their personal history, values and ways of living, ensuring that the power balance is evenly shared between the care giver and recipient.

Conversely, McCormack and McCance (2017, 2010) suggest that PCC requires a *sympathetic* rather than *empathetic* approach, since this can be more authentically achievable when supporting someone who is ill. Sympathy is conveyed when acknowledging another's sadness and extending comfort (Kale et al. 2011), whereas Reiss (2017) argues that accurate empathetic responses can be more deeply meaningful within a counselling relationship (Reiss 2017). Arnolds and Boggs (2016) suggest that empathetic responses in nursing can help to build more compassionate relationships. Since interpersonal communication guided by compassion, empathy and sympathy is a key element of nursing models of care, the potential links from some of these models to the evolution of PCC will now be explored.

1.4.4 Nursing models as a basis for person-centred care

The nursing theories based on individualised care (Henderson 2006, 1978; Peplau 1992; Roy 1970) may have influenced the development and adoption of PCC. Moves toward more holistic care have been accompanied by a transition away from medical and nursing models to broader multidisciplinary and collaborative styles of healthcare provision (Scottish Government 2017, 2010). During a presentation of my early doctoral findings, comments by a senior nursing researcher regarding the influence of nursing theory on PCC development identified by Jakimowicz and Perry (2015) ignited my desire to discover more.

Roy (1970) advocates replacing ritualistic and routinised nursing care with an adaptive, holistic model. 'Roy's Adaptive Model' (RAM) involves assessing how the patient interacts within their current situation so that care can be adjusted accordingly. Subsequently Roy and Andrews (2009) revised the original model, focusing on individual assessment, goal setting, intervening and evaluating care. PCC is similarly adaptable and enabling in accordance with the person's own priorities of care. Peptrin (2016) suggests that the RAM approach could improve nursing care and communication between professionals, as well as being useful in nursing research.

Peplau's (1992) nursing model, originally developed in the 1950's for mental health nursing, also correlates with current person-centred approaches. It is based on the premise that the development of caring relationships involves four phases: orientation, identification, exploitation, and resolution. This process places nurses in an ideal position to plan PCC. Peplau's model also allows them to gain insight into an individual's sense of personhood. Relational models will be further explored in Chapter 2 and 6.

Henderson (1978) was instrumental in shifting perceptions of fundamental support needs beyond physical interventions to include relational, social, spiritual and occupational aspects of care. Hallaron (1996 p.18) suggests that Henderson's (1978) perspectives on individuality and the nurse's role have earned her the title of "modern mother of professional nursing":

> *"Henderson characterised the nurse's role as substitutive, which the nurse does for the patient; supplementary, which is helping the patient; or complementary, which is engaging with the patient … the nurse helps the patient become an individual again."*
>
> (Halloran 1996 p.19)

Thus PCC, rather than being a new concept, may have evolved from these seminal nursing models as a means of improving the provision of holistic care. Healthcare provisions have altered considerably since then. The integration of health and social care and the adoption of MDT care delivery have removed the constraint of reliance solely on the nursing discipline, thus significantly enhancing the quality of the PCC that can be provided (Scottish Government 2017, 2014, 2010).

In summary, the principles of PCC may have emerged from the combined arenas of theories of personhood, philosophical ideas from phenomenology, Rogerian concepts on person-centredness and nursing models of holistic care (Peplau's 1992; Henderson 1978; Merleau-Ponty's 1973; Roy 1970; Rogers 1967; Gadamer 1960, 2004). Adopting a Gadamerian perspective (Gadamer 1960, 2004), my personal '*fusion of horizons'* is that this evolution has occurred in a bricoleur manner (Denzin and Lincoln 2013). This mode of development may have influenced the way that PCC has been defined along with the strategies and models that have evolved to facilitate its provision in practice.

1.5 Definitions, strategies and models of person-centred care

Although the expression *'person-centred care'* has become commonplace in the language, evidence-base and policy of healthcare (McCormack and McCance 2017, 2010; Hewitt-Taylor 2016; The Health Foundation 2014; Berwick 2014), it has been criticised for a lack of clarity and consensus (De Silva 2014; McCrae 2013). More recently Dewing and McCormack (2017), who established the Scottish Centre for Person-Centred Practice Research (CPcPR), warned that although the PCC evidence base continues to evolve with overlapping themes creating greater clarity, caution should be exercised not to oversimplify its definition. They argue that the latter should be based on empirical research. Their definition states:

> *"Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development."*
>
> (McCormack and McCance 2017 p.20)

Early in my doctoral studies I was drawn to McCormack and McCance's (2017) model as it encapsulates PCC from the perspectives of the person receiving care, their family and the MDT. Other definitions appeared less inclusive, focusing solely on the person in need of support whilst ignoring the potential impact on PCC delivery on relationships and healthcare culture.

Early scoping searches of the literature involved a wealth of historical and 'grey' sources. 'Grey literature' can be defined as:

> *"… produced by government departments or agencies, international agencies, local authorities, academic institutions, professional or scholarly associations, think tanks, charities, non-profit organisations, companies and other organisations."*
>
> (Robert Gordon University (RGU) Library 2019)

These sources suggested a general consensus that PCC encompasses empowerment, collaborative practice, holistic individualised care and enabling independence (Sharma, Bamford and Dodman 2015; Fredricks, Lapum and Hui 2015). Jakimowicz and Perry (2015) trace PCC back to Florence Nightingale's (1860) request that physicians focus on managing the disease and allow nurses to treat the person. The infographic timeline of healthcare, political and health related third sector drivers for PCC in Figure 1.2 will be referenced in this chapter and throughout the thesis. It is intended to give an overview of the historic origins of PCC as described above along with influences on my understanding from current 'grey literature'. Lamb and Johnson (2014) recommend using such diagrams to convey the 'bigger picture', allowing the reader to visualise multiple layers or concepts in a single diagram.

Figure 1.2 Person Centred Care Timeline

See overleaf.

PERSON CENTERED CARE TIMELINE

A VISUAL REPRESENTATION OF THE EVOLUTION OF PCC

Pre-1950s

Jakimowicz and Perry (2015) suggest PCC is not a new phenomenon dating the philosophy of PCC dates as far back as to Florence Nightingale's suggestions that medical physicians should focus on managing the disease and allow nurses to treat the person (Nightingale 1860)
In, 1948 Hildegard Peplau challenged healthcare to consider the interpersonal relationships in nursing. By placing a therapeutic relationship between nurses and patients at the centre of health care delivery. Such an approach was seen as revolutionary at a time where nurses were viewed as cheap labour to carry out doctors' order.

BALINT, M.1957.The Doctor, His Patient and the Illness. London: Pittman.

1957

Physicians began to question if the power lying with them was the best way forward to improving health. (Heritage and Maynard 2006).

1960

The International Council of Nurses adopt a definition of nursing by Virginia Henderson as:

"To assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge. And to do so in such a way as to help him gain independence as quickly as possible.."

Late 1970s

Carl Rogers coins the phrase 'Person Centred Counselling' based on three principles on empathy, congruence and unconditional positive regard, said by some to have influenced PCC in Healthcare.

1978

Planetree organisation in USA is formed to promote patient centred approaches in healthcare and empowerment. Now 40 years on, is a not for profit organisation supporting both the public and healthcare providers to take a patient centred philosophy to care.

1983

Goffman E. 1983. The interaction order. Am. Sociol. Rev. 48:1–17

The evolution of how the clinician/patient relationship influences health begins to have an impact on patient empowerment (Ballint 1955, McWhinney, 1989) . Heritage and Maynard (2006) explores thirty years of the historical roots of the movement away from paternalistic healthcare models to patient centred where McWhinney (1989) discusses physicians letting go of their dominance and moving towards collaborative consultations and goal setting.

The foundation of Informed Medical Decision Making is formed in USA. This foundation influences and shapes the concept of shared medical decisions.

1986

Picker Institute founded by Jean and Harvey Picker established Picker in 1986, during Jean's treatment for a terminal condition. They saw the American healthcare system was technologically and scientifically outstanding, but they believed that it was not adequately sensitive to the concerns and personal needs of patients which affected the quality of care received. The Picker Institute has gone to influence the movement towards PCC internationally.

http://www.picker.org/about-us/our-history-impact/

1995

The General Medical Council publishes 'The Good Medical Practice', which included statement "respect the rights of patients to be fully involved in decisions about their care."

1998

The Chronic Care model of care is developed in USA to help overcome the deficiencies in meeting patients with Long Term Conditions (LTC) / Chronic conditions needs, with the ambition to be proactive rather than reactive and co-produce plans of care. This chronic care model relies more on individuals being informed, involved and proactive in their community rather than reliance on healthcare expertise and lead in decision making. The aim of this proactive patient centred model was to improve outcomes for people with LTC.

The phrase "nothing about me without me" is coined at a Salzburg global seminar on disability. The phrase is set to influence leader on PCC, personally Delbanco et al. (2001) and organisations (HIS 2014).

https://www.ncbi.nlm.nih.gov/pubmed/11493320

This signalled a move away from biomedical models to infomedical, where all people involved in healthcare work together those they are caring for, towards shared goals, in a person centred way.

2000

Department of Health (DOH 2000) publishes the NHS 5 year a plan for investment a plan for reform, where it specifies the need to shape care around the patient rather than the other way around and that by 2010 patient centred care should be the norm in practice.

2001

The Institute of Medicine- USA produces Crossing the Quality Chasm: A New Healthcare System for the 21st Century, with patient centredness as one of the six components of high quality healthcare.

NHS England start the Expert Patient Programme (EPP) for people with LTC to peer support each other.

Department of Health (DOH) publishes 'The essence of care: Patient-focused benchmarking for health care practitioners'.

http://webarchive.nationalarchives.gov.uk/20071104154542/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005475

Additionally, the 'National Service Framework for Older People' sets quality standards for health and social care. This aims for older people to stay as healthy, active and independent as possible, for as long as possible.

https://www.gov.uk/government/publications/quality-standards-for-care-services-for-older-people

2002

DOH produces the Medicines partnership policy to encourage education and concordance with prescribed medications rather than compliance with instructions.

The Waness Report is published about building pressures & the growing cost burdens in NHS, the only sustainable way forward in the NHS is for citizens to take full responsibility for their mental & physical wellbeing and be involved in their healthcare decisions.

2007-2010

The Health Foundation is formed and sets up 4 programmes for improvement with the aim of establishing PCC in clinical practice:

- Co Creating Health
- Making good decisions in collaboration (MAGIC)
- Closing the Gap
- The Year of Care

NHS (England) launches NHS Choices to help support people make healthy lifestyle choices/ changes and find information/ treatment for common conditions.

2007

Cure the NHS Website

http://www.curethenhs.co.uk/

set up by Julie Bailie, who's mother died at Mid Staffordhire Hospital, in what her daughter describes as appalling conditions. A letter to the local newspaper sparks local, national, government and regulator interest.

2008

Poor standards of Care at Mid Staffordshire are brought into the public domain and investigations begin.

2009

The Health Commission publishes their report on the high mortality rate & substandard care practices at Mid Staffordshire Hospital Trust.

Scottish Government launches (2008) the "Gaun Yerself "policy to support people with LTC with their own conditions, this is a unique to people with LTC's perspectives and developed in collaboration with them and The Alliance, a 3rd sector organisation which supports people with LTC.

NHS England launches the 1st ever NHS Constitution with the guiding principle that people, and their families are involved in decisions relating to their care and treatment.

NHS England release personal health budgets to involve people with LTCs more in the budgeting of their care & treatment.

2010

The Quality Improvement Productivity & Prevention Programme begins in NHS England with numerous work streams including LTC care and shared decision making.

The Scottish Government launch the Quality in Healthcare Strategy, the key aim of this overarch strategy was for:

"Mutually beneficial partnerships between patients, families and those delivering healthcare services. Partnerships which respect individual needs and values, which demonstrate compassion, continuity, clear communication and shared decision making."

DOH policy Equity and Excellence: Liberty in the NHS is launched with the key phrase *"Nothing about me, without me."* Twelve years after it is first coined in Salzburg.

Elwin (2011) medical commentators suggest that it is unethical not to make always care in a *"Nothing about me without me"* way.

http://www.bmj.com/content/342/bmj.d1745

UK Government recommends an Independent Inquiry into Mid Staffordshire NHS Scandal.

2011

The Scottish Patient Rights Act is passed and 6 months later the Charter of Patient Rights and Responsibilities is launched built on the premise that every patient should receive patient focused care and be involved in any decisions relating to their health, participating in all aspects of their health.

Northern Ireland produced a review of the health & social care provision, and found there to be "strong drivers for change" towards increased productivity, quality and a better experience for patients. In Ireland there is a suggestion that transforming care should always begin with the individual who is being supported to care for themselves and make good healthcare decisions. This led to their 2020, 10-year quality strategy.

https://www.health-ni.gov.uk/

The move towards integrated health and social care with the person in need of health or social care at the centre as apparent in this 10 year plan.

2013

The NHS England publishes guidance and best practice guidance to commissioners on enacting PCC in healthcare.

https://www.england.nhs.uk/2013/11/interg-care-pioneers/

NHS Wales produces it's White Paper, The Listening Organisation: Ensuring Care is Person Centred in NHS Wales.

http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/1000%20Lives%20Plus%20-%20'The%20Listening%20Organisation'%20white%20paper%20WEB.pdf

By becoming a listening organisation, NHS Wales aimed for patients being viewed as people first and healthier relationships between those being cared for and those providing care.

The Francis report, an independent inquiry on Mid Staffordshire NHS scandal is published. This had a dramatic affect on healthcare practices in the UK and internationally. Within it's 290 recommendations, the key messages were: to put patients 1st, involve the public in healthcare, restore compassion and in particular, for older people in hospital ensure their needs, from their perspectives are met. The report called for more transparency in healthcare, improved standards, that should must be openly aimed for, measured by government appointed agencies and published in the public domain.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/279124/0947.pdf

Berwick report recommends that patients and their carers should be "present, powerful and involved at all levels of healthcare from wards to boards to trust boards."

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/226703/Berwick_Report.pdf

The goal should be that patients are not passive recipients of care but that there is "persuasive culture of authentic patient partnership."

Berwick's presentation to the Kings Fund (2013) set out 4 aims in response to Mid Staff:

1. Patient experience 1st
2. Hear the Patient
3. Investigate in capability of Staff
4. Take a leap towards total transparency in the NHS, be open if mistakes are made & learn from them.

https://www.rcplondon.ac.uk/projects/outputs/future-hospital-commission

The future hospital report published by the Royal College of Physicians set out 11 key aims putting the patient 1st in response to the Francis report. Adopting a shared decision-making aim as the way forward in the NHS.

2012

The National Institute for Clinical Excellence (NICE) produce guidelines on improving the quality of Adults experience in hospitals in NHS England. These include ensuring patients are actively involved in decisions relating to their care, treatment and investigations. There is an emphasis on care that reflects what is important to those receiving care.

http://publications.nice.org.uk/patient-experience-in-adult-nhs-services-improving-the-experience-of-care-for-people-using-adult-cg138/quality-statements

The DOH publishes the Health & Social Care Act. As a result of 3rd party lobbying by the HF, Patient Voices, there is much more emphasis on promoting the involvement of patients, their carers, representatives and/or families about their treatment & their care.

http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

- Raise the profile of PCC approaches to care and support.
- Simplify the concepts of PCC and identify high impact interventions that can be implemented using improvement methodologies.
- Focus on what we can do now.
- Provide reliable opportunities to personalise care for every person all of the time.
- Promote sharing of ideas between people who use services and those

http://www.qihub.scot.nhs.uk/quality-dimensions/person-centred.aspx

2014

The Scottish Government create the Health Improvement Scotland (HIS), Person Centred Health & Care Collaborative

http://www.knowledge.scot.nhs.uk/personcentred.aspx

HIS Healthcare Improvement Scotland. (2014(b). Supporting best practice: Healthcare Improvement Scotland annual report 2014.

2015

Scottish Government, Health Improvement Scotland update standards of care for older people in hospital, with PCC as a core theme.

http://www.healthcareimprovementscotland.org/our_work/person-centred_care/resources/opah_standards.aspx

2017

Care Quality Commission, set fundamental care standards for all care providers to aim for. Alike to HIS, CQC sets and measure compliance with the standards.

https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards

2015 - 2020

There has been continued public sector, both from government in Scotland, across the UK and 3rd sector organisations to place person centred approaches to care as a component of high quality healthcare. For example: the current the codes of professional conducts for Health & Social Care in the UK all have a person-centred focus.

https://www.nmc.org.uk/standards/code/read-the-code-online/
https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/
https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice
https://www.basw.co.uk/about-basw/code-ethics
https://www.pharmacyregulation.org/standards-for-pharmacy-professionals

Healthcare and social care policy additionally continue to promote person centredness as part of high quality healthcare.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/437067/nib-delivering.pdf
https://www.england.nhs.uk/wp-content/uploads/2016/04/exec-summary-care-support-planning.pdf
https://improvement.nhs.uk/resources/person-centred-care-resource-centre/
https://www.hee.nhs.uk/our-work/person-centred-care
https://www.gov.scot/publications/person-centred-care-non-executive-directors/
https://ihub.scot/improvement-programmes/people-led-care/person-centred-health-and-care/person-centred-health-and-care-collaborative/

Once more these are examples of the dominance of person-centred approaches, they do represent an exhaustive list

1.5.1 International perspective

This subsection will present definitions drawn mainly from international 'grey literature'. International empirical PCC research is critically reviewed in Chapter 2. The World Health Organization (WHO) promotes PCC as their overarching philosophy for care delivery. They define it as:

> *"...an approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs in humane and holistic ways…"*
>
> (World Health Organization 2007 p.10)

This definition was superseded by the WHO (2017) '*Framework on integrated people-centred health services'* (IPCHS), which promotes active participation in individualised healthcare and preference rather than a diseased-focus approach. Furthermore, in 2019 the WHO launched the *'Integrated Care for Older People'* (ICOPE) approach, specifically supporting PCC of older people, based on the principles of IPCHS. This demonstrates the worldwide support for PCC, especially when caring for older people.

The Institute of Healthcare Improvement (IHI) provides another international perspective of PCC. Its definition is:

> *"Putting the patient and their family at the heart of every decision and empowering them to be genuine partners in their care."*
>
> (IHI 2015)

Whereas the IHI refers to 'patients', the WHO uses the term 'people'. The Health Foundation (2018) argue that this change removes the implied power imbalance between patients and professionals. The IHI views the shift toward PCC as a marker of enhanced healthcare experience within frameworks of organisational change (IHI 2014,2019). However, despite Dewing and McCormack's (2017) recommendation, many of the resources available on the

IHI website are not explicitly linked to empirical research, resulting instead from local audits or shared experiences, with an American focus

The University of Gothenburg's Centre for Person-Centred Care Practice (GPCC) is a highly active research centre, supporting the evolution of PCC knowledge and contributing to the recognition of Sweden as a world leader in PCC practice (GPCC 2019). In 2001, it provided another international perspective of PCC, defining it as:

> *"Seeing patients as persons who are more than their illness. Person-centred care emanates from the patient's experience of his/her situation and his/her individual conditions, resources and restraints. Person-centred care is a partnership between patients/carers and professional care givers. The starting point is the patient's narrative, which is recorded in a structured manner."*
>
> (GPCC 2001 p.1)

This definition focused on the perspective of the person in need of healthcare, with partnership regarded as an essential prerequisite of PCC, based on the person's 'story' as a valuable starting point (Olsson, Hansson and Ekman 2016). However, it made no mention of the organisational culture needed to support person-centredness, as was included in the definitions discussed earlier (Olsson, Hansson and Ekman 2016). More recently, however, the GPCC acknowledged that PCC can help to reduce illness-related suffering and make care more efficient (see *Chapter 2).* It now embraces a vision of:

> *"Sustainable health through sustainable care: to prevent and reduce suffering and strengthen the efficiency of health care through person-centered care."*
>
> (GPCC 2019)

The influence of the international healthcare drivers has extended to the United Kingdom (UK), resulting in an evolving focus on PCC within strategic healthcare policy and operational expectations of care.

1.5.2 United Kingdom perspective

PCC is highly visible in UK government policy (see Figure 1.2). Since control of health and social care is devolved to the four nations (Scottish Parliament 2020), only the UK, DOH and National Health Services (NHS) England perspectives of PCC will be considered. Scottish political drivers will be explored in more detail separately, given that this doctorate was completed in Scotland.

From 2001, the DOH began to adopt a patient-centred approach to care with shared decision-making, viewing the patient as the expert in their healthcare (DOH 2001). However, it was not till 2005 that the goal was set for PCC to become 'normal practice in the UK' by 2010 (DOH 2005). Once more the term 'patient' rather than 'person' is evident in early DOH policy. However, by 2009, the updated NHS Constitution states that:

> *"Being person-centered is about focusing care on the needs of individual. Ensuring that people's preferences, needs and values guide clinical decisions, and providing care that is respectful of and responsive to them."*
>
> (NHS Education for England 2009)

A drive toward greater public involvement in health is evident throughout the UK's healthcare strategies (NHS Education for England; 2019; DOH 2017, 2014, 2009, 2008,2007, 2001). Public responsibility for health as a component of PCC will be further examined in section 1.6.

Older people in the UK are living longer. Many develop multiple long-term conditions (LTC) and co-morbidities, and to live well they must access both acute and primary care (Care Quality Commission 2017; DOH 2014; Bridges et al. 2009). The DOH (2001) standards require constant improvements to the care of older people and the quality of the PCC they receive. Despite that, this vulnerable group are often neglected in acute care, as acknowledged in the renowned Mid-Staffordshire Enquiry (Francis 2013). Its extensive recommendations emphasise an urgent need to re–humanise healthcare and to adopt a more person-centred, values-based approach (Francis 2013; Berwick

2013). Progress toward achieving this within a healthcare system dominated by the drive toward efficiency will be considered in more detail in section 1.5.

1.5.3 Scottish perspective – the national perspective for this thesis

The Quality Strategy for NHS Scotland (Scottish Government 2010) was one of the first national political drivers to explicitly define and promote PCC as a core component of high-quality healthcare, equal in importance to patient safety and efficiency. Again, the language in the first part of the 21st century defines 'patient' centredness as:

> *"Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making."*
>
> (Scottish Government 2010 p.6)

The Scottish Government has expressed a commitment to developing specific departments within Healthcare Improvement Scotland (HIS) and NHS Education for Scotland (NES) to share responsibility for promoting and measuring PCC in practice (Glavill 2018). As a result, Scotland has been being regarded as a world leader in this field (Berwick 2014). However, my brother's truncated, impersonal healthcare journey shows that this strategic ambition has not been matched by a consistent culture of PCC in practice.

Scotland's continued focus on embedding PCC into health and social care is part of a move towards building integrated 'person' centred services (Scottish Government 2017, 2014). In their ongoing work, HIS indicate that:

> *"Person-centred care is delivered when health and social care professionals work together with people who use services, tailoring them to the needs of the individual and what matters to them. …ensures that care is personalised, co-ordinated and enabling so that people can make choices, manage their own health and live independent lives, where possible.!*
>
> (HIS 2017 p.1)

Scotland’s health and social care integration programme aims to achieve joint cohesive services for those in need (Scottish Government 2017, 2014). However, as will become apparent in the findings and discussion of this thesis, people’s experiences of receiving joint up health and social care delivered can vary.

The Scottish CPcPR (mentioned above), which aims to be a world leader in PCC research, defines person-centredness as:

> *“… a concept that is focused on placing the person at the heart of decision-making and to do that effectively requires a commitment to understanding how the context of care impacts on individual, team and organisational experience.”*
>
> (CPcPR 2019)

This organisation’s leaders (Dewing and McCormack) are prominent researchers involved in international projects aiming to develop an impactful knowledge of PCC (CPcPR 2019). The inclusion in their definition of the person receiving care, the person delivering it and the organisational cultural context captures the multiple influences involved in enacting person-centred practice and aligns it closely to that of McCormack and McCance (2017). McCormack (2020) highlights the need to deliver ‘healthful’ PCC, referring to care that is humanised, relational and where power is evenly balanced.

1.6 Humanising healthcare and shifting the balance

The evolution of PCC has occurred at a time of substantial change in the organisation, direction and delivery of healthcare in the UK (The Health Foundation 2014). Its quality is widely considered to be determined by its safety, effectiveness and person-centredness. (Scottish Government 2013; IHI 2011). The humanising and relational aspects of PCC were included in earlier discussions and personal reflections.

Despite the acceptance that PCC is a prerequisite of high-quality healthcare, Parkinson (2004) and McCrae (2013) assert that the drive to humanise healthcare must form part of a political agenda too. Whilst PCC is highly visible in government policy (see Figure 1.2), news reports indicate that the healthcare system is under unprecedented pressure (British Broadcasting Corporation (BBC) 2018, 2010). The public's faith in humanised healthcare will not recover without evidence of adherence to standards, particularly in the care of older people in acute hospitals (Care Quality Commission 2017; HIS 2015; Francis 2013; Berwick 2013; Bridges et al. 2009; DOH 2001). As part of this endeavour, the Person-centred Care Collaborative in Scotland (HIS 2014) set out to use improvement methodologies to embed PCC into everyday clinical practice. Their '*What matters to you'* campaign is based on Delbanco et al.'s (2001) IHI promotion of PCC practices. The thirteen-year delay between its proposal and its adoption by HIS (2014) demonstrates the impact of the theory-to-practice gap (Brown 2010; Ryecroft-Malone 2004). HIS (2014) encourages staff to follow the simple steps of *asking* what matters, *listening* to what matters and *doing* what matters. Dewing and McCormack (2017) warn that mnemonics risk over-simplifying PCC. On the other hand, Sabat (2002) suggests that the first step in recognising someone's personhood is as simple as asking them what matters most to them. A balance is needed between ensuring that those providing care fully appreciate the complexities of PCC whilst at the same time helping them to incorporate it into their everyday clinical practice.

Berwick (2014) praised the Scottish Government for simplifying the national approach to PCC initially set out with their 7 C's in their Quality Strategy (2010):

- Caring
- Compassionate staff and services
- Clear communication and explanation about conditions and treatment;
- Effective Collaboration between clinicians, patients and others;
- Clean and safe care environment;
- Continuity of care
- Clinical excellence.

Likewise, Gawande (2014) has applauded the innovative approaches of the Scottish Government's quality ambition (2010) to empower individuals receiving care to be actively involved in healthcare. However, when assessing PCC in clinical practice, HIS (2015a) continue to discover processes driven by mere efficiency, such as moving older people between acute care areas during the night to create bed spaces, echoing my own negative experiences of non-PCC cultures. Healthcare commentator Gawande (2014) additionally contended that consideration of quality of life must become a priority within PCC for older people:

> *Our most cruel failure in how we treat the sick and the aged is the failure to recognise that they have priorities beyond merely being safe and living longer.*
>
> (Gawande 2014 p.6)

The national Scottish Patient Safety Programme (SPSP) (HIS 2017), recognising that the needs of older people in acute care are unique and complex, have devised guidance and tools. These initially focused on delirium; subsequently tools for the early identification of frailty were developed (HIS 2019). Although these can improve outcomes for older people (Drumm et al. 2017), they have been criticised for encouraging assessments driven by set protocols.

Alongside the move to humanise healthcare, there appeared to be an attempt to shift the balance of responsibility for health from a historical paternalistic model toward an empowering, enabling, individualised approach (The Kings Fund 2013; Christie Report 2011; The Richmond Group of Charities 2010; and see figure 1.2). '*Delivering better integrated care*' (DOH 2015) is an example of this; it aims to help people with LTC to move from a disease-focused approach to the management of their condition to a person-centred, integrated approach. The Heath Foundation (2014) is also keen to enhance the empowerment of those with LTC. However, these healthcare policy drivers fail to explicitly clarify how the public, older people and experienced healthcare staff are to be supported towards a new person-centred focus of care (NHS Education for England 2019, 2012; Department of Health (DOH), 2017, 2014, 2009, 2008, 2007). UK healthcare policy demonstrates a consistent theme of empowering the public to be more actively involved in their health and personal healthcare (NHS England 2016; SG 2017, 2013, 2011). It is my curiosity regarding the steps that will lead the public from becoming interested in their own health to becoming equal partners in planning PCC that led me to embark on this research journey.

Alongside the government drivers devised to shift the balance of care towards a more equally balanced model of responsibility, publicly based third sector organisations have also become involved in the PCC movement. For example, 'The Alliance' (2017), and National Voices (2017) advocate the equalising of the power between people requiring health and social care and those providing it. The shift towards enabling PCC cultures is viewed as essential since the current and foreseeable strain on the healthcare system are unsustainable (Christie Report 2011).

During the data collection period of for this study, it was recognised that the UK's National Health Service was struggling to meet the needs of the country's aging population, in particularly in acute care (Royal College of Nursing (RCN) 2018; DOH 2018). The Heath Foundation (2014) echoes the necessity of making PCC cultures a reality. However, this change could be substantial, particularly for older people, who may prefer a *'doctor knows best'* approach, (Alharbi et al. 2014 a). Additionally, moves towards PCC cultures should be viewed cautiously if they are merely attempting to enhance the efficiency of current healthcare delivery systems (The Health Foundation 2014).

Whereas a move towards PCC may not solve all issues in healthcare, it could be a part of a supportive transition from paternalism toward more congruent responsibilities for health (Waring–Jones 2016). Additionally, PCC has the potential to enhance the perceived quality of humanised care (McCormack and McCance 2017; IHI 2014). Significant satisfaction can be derived both by the providers and recipients of care when it is adapted to meet individual needs. People can become active partners in this process (McCormack and McCance 2017; IHI 2014).

The influence of healthcare policy and scoping searches of the literature led to the exploration of PCC strategies and models.

1.7 Critical comparison of strategies and models of person-centred care

For added clarity, the PCC strategies discussed in this thesis are taken from '*grey literature*' such as government health and social care policy and the vision statements of third sector organisations (RGU 2019). Conversely, models of PCC provide evidence-based ways of delivering PCC, derived from empirical research (The Kings Fund 2018). Table 1.1 summarises the contextual themes of the PCC strategies and models identified during repeated scoping literature searches carried out early on in the doctoral journey. The insights gained by studying them broadened my perspectives on PCC.

Table 1.1 Contextual Summary of Themes from Strategies and Models of PCC

Gerteis et al. (1993)	Law, Baptiste and Mill (1995)	Mead and Bower (2000)	Nolan et al. (2001) *(Relational model)*	Stewart (2003)	Brooker (2007)
Respect for patient's values and needs	Autonomy/choice	Biopsychosocial perspective	Sense of Security	Being realistic in joint goal setting	Valuing the person
Coordination of care	Partnership/ Responsibility	Patient as a person	Continuity	Whole person	Individuality
Communication and education	Enablement	Sharing power and responsibility	Belonging	Common ground	Seeing the world through the older people eyes
Physical comfort	Contextual congruence	Therapeutic alliance	Purpose	Doctor/ Patient Relationship	Providing social environmental support
Emotional support Involvement of family and friends	Accessibility and flexibility	Doctor as a person	Achievement	Preventing Disease & promoting health.	
Transition and continuity	Respect for diversity		Significance	Disease & Illness	
Cooper, Smith and Hancock (2008)	**McCormack & McCance (2010, 2017)**	**Scottish Government (2010)**	**Department of Health (2011)**	**Asimakopoulou and Scambler (2013)**	**Institute of Health Improvement (2015)**
Communication	Care Environment and Culture	Mutually beneficial partnerships	Respect of individuality	Level 1: Information Giving	Partnerships in care design and pathways
Individual care	Staff Competence & Motivation	Respect Individuality	Co-ordination of Care	Level 2: Information giving and choice	Valuing individuality, beliefs and personal value systems
Decision-making	PCC processes, practice and outcomes	Continuity of Compassionate Care	Information, communication & education	Level 3: Information giving, choice and tools for informed choice	Co-ordination Communication Compassion
Information		Clear Communication	Physical & Emotional Comfort	Level 4: Patient in full control	Shift from "What's the matter with you?" to "What matters to you?"
The personality of the physiotherapist		Shared decision making	Family & friend involvement		
Organisation of care		Nothing about me without me	Access to care		
			Transition and continuity		

Table 1.2 illustrates the many common themes within the strategies and models of PCC such as individuality, shared decision making, empowerment and compassionate, dignified care (McCormack and McCance 2017; Institute of Health Improvement (IHI) 2015; Asimakopoulou and Scambler 2013; Department of Health 2011; SG 2010; Cooper, Smith and Hancock 2008; Brooker 2007; Nolan et al. 2004; Stewart 2003; Mead and Bower 2000; Gerteis et al. 1995). Aspects of these shared themes are revisited in more depth within the comprehensive narrative review of literature shared in Chapter 2.

Table 1.2 Analysed Themes from Strategies and Models of PCC

Individuality	Co – ordination of Care & Flexibility in the system	Communication Information and Education	Autonomy	Partnership working	Care & Comfort	Family & Friends Involvement	Empathy	Transition Care
Whole person approach Respect for diversity	Accessibility and flexibility	Clear Communication	Autonomy/ choice	Partnership/ Responsibility	Physical comfort	Involvement of family and friends	Seeing the world through the other people eyes	Access to care
Valuing Patient as a person	Providing social environmental support	Information Giving	Sharing power and responsibility	Enablement	Physical care		Shift from “What’s the matter with you?” to What matters to you?	Being Realistic
Respect for Individuality & Individual care	Organisation & Co-ordination of care	Communication & patient centred education	Shared decision making	Therapeutic alliance	Emotional support		Nothing about me without me	Transition and continuity
Respect for patient’s values and needs	PCC processes, practice and outcomes for the patient		Partnerships in care design and pathways	Mutually beneficial partnerships	Continuity of Compassionate Care			
Healthcare Professional as a person	Recognising uniqueness, system bends flexibly around the people.		Informed Choice Patient in full control	Healthcare Professional/ Patient Relationship				

The number of models of PCC is growing. McCrae (2013) warns that because PCC has become so common, it may start to be viewed as a political slogan. Reference has been made throughout this chapter to the 'bricoleur' nature of the PCC evidence base and philosophical underpinnings (Denzin and Lincoln 2013). Nevertheless, practical working models of PCC are needed to facilitate its implementation within the realities of everyday care.

Most of the PCC strategies and models in Table 1.1 emphasised the importance of seeing care delivery through the eyes of those needing it; fewer models considered the viewpoint of both providers and recipients (McCormack and McCance 2017; Institute of Health Improvement (IHI) 2015; Cooper, Smith and Hancock 2008; Nolan et al. 2004; Mead and Bower 2000). However, Nolan et al.'s (2006, 2004, 2002, 2001) 'Senses' model appeared to encapsulate the holistic relational perspective of the care of older people as viewed by the person receiving it, their family and the staff. Others have successfully applied this framework in a variety of areas where older people receive care (Dewar and Nolan 2011; Dewar 2011; Davies et al.; 2007, Faulkner et al. 2006). However, Nolan (2011) focussed on the relational aspects of care, whereas the current study aimed to explore PCC from all potential experiential perspectives, I wanted to remain open to the possibilities of all facilitators and barriers to PCC experience. Therefore, Nolan's (2011) model was excluded as a theoretical base for this study.

The 'Wellness' and the 'Green House' approach to relational, long term care of older people in the USA were also considered (Bowers 2020, Bowers et al. 2016, Stone et al. 2002). Both of the latter models are based upon delivering high quality clinical older people care, within a staff enabling, organisational culture of relational care (Bowers et al. 2016, Stone et al. 2002). Although considered, as my area of interest lay in acute care, not long-term care of older people, this model was not used as a theoretical lens. Bridges et al. original and updated systematic review focused specifically on older peoples' experiences of acute care (2019, 2010) and created the relational framework of : "creating communities: connect with me, maintaining identity: see who I am and sharing decision-making: include me" (Bridges et al. 2010 p.89). Bridges et al. (2019, 2010) resonated with my starting point personal reflections of dehumanised acute care, therefore I believed to be more open to the wider PCC experiential possibilities in my own study I should consider other potential theoretical lenses. The critical interplay between relational and person-centred models of care will be further explored in Chapter 2 and 6.

1.7.1 Thesis theoretical lenses

The model for PCC developed by McCormack and McCance (2017, 2010) aligned closely with my worldview that phenomena are best understood by being viewed from multiple perspectives. McCormack (2014) challenges researchers to develop an evidence base regarding person-centred cultures of care rather than collective individual moments of person-centredness. Nilsson, Edvardsson and Rushton (2019) echo McCormack and McCance's (2017) proposal that healthcare systems should value and support staff as an integral component of PCC culture development. The model by McCormack and McCance (2017) seemed to focus on this area, rather than placing the basis for PCC merely on the care recipients' experiences. Similarly, Hewitt-Taylor (2016) encourages leaders wishing to develop PCC cultures to:

> *… appraise people's [staff] principles, beliefs, values and priorities related to the matter in question (PCC) and what enables or hinders them in achieving what they would ideally want to do.*
>
> (Hewitt-Taylor 2016 p.15)

My doctoral journey began with a reflection on my own set beliefs regarding non-PCC experiences. Some strategies and models (Cooper, Smith and Hancock 2008; Stewart 2003, Brooker 2000) focussed predominantly on person-centred care viewed through the experiences of the care recipient with fewer links to the professional delivering it. However, the McCormack and McCance (2017) model expanded my exploration to include not only the individual recipient, but also their family and their caregivers as well as the overall *culture* of care around the care experience.

McCormack and McCance's model (2017) has been used in other empirical studies exploring PCC for older people (Hsu and McCormack 2012; McCance, McCormack and Dewing 2011; McCance et al. 2010; McCormack et al. 2010(a), (b); McCormack and McCance 2006; McCormack 2004). It has also been positively evaluated in clinical practice (Marriot – Stratham 2018; Slater, McCormack and McCance 2017; McCance, Slater and McCormack 2009). These factors led to its selection as the theoretical lens for PCC in this thesis. The use of this model facilitated the framing of the data collection tools and analytical processes to explore PCC in OPAH.

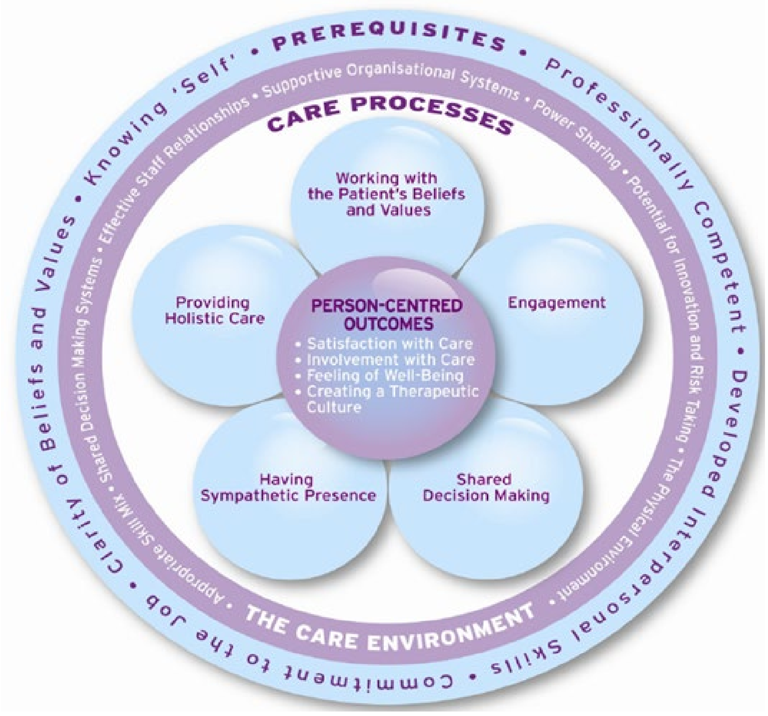


Figure 1.3 McCormack and McCance (2017) model of PCC, the PCC theoretical lens for this thesis

Habermas' (1981) critical social theory also influenced the investigation of PCC experiences in this thesis. It critiques the manner in which society changes in ways deeper than can be explained by traditional social theory (Crossman 2019). Hewitt-Taylor (2016) linked embedding PCC cultures of care to critical social theory, critically considering how the change to PCC had an impact on healthcare culture. Habermas (1981) suggests that despite a clear strategic direction, based on sound evidence regarding how a phenomenon should be enacted, sometimes the message does not work its way into society. The University of Stanford (2014) and Bevan (2012) explain that applying critical social theory can guide an exploration of the dynamics of care; strategic direction and traditional knowledge may be insufficient to change society. Bevan (2012) argues that experience shows that action research and phenomenological studies may be more successful in promoting change. My introduction to Habermas's (1998) in my doctorate was linked to my non PCC experiences.

> *Personal Reflection excerpt – 3.2.15*
>
> *My motivation to study PCC at doctorate level stems from disappointing personal experiences of OPAH care; where the sense of personhood disappeared into a process driven system. There was a level of acceptance from my family that acute hospital care just had to be this way (impersonal, key performance indicator driven), they were colonised, as Habermas (1986) described by poor operationalisation of PCC despite the strategic health board, government and evidence base drive to deliver PCC.*

The background reading for this doctorate identified clear theoretical origins for PCC along with a variety of definitions and models for it, but less evidence on how the giving and receiving of PCC were experienced simultaneously (McCormack and McCance 2017; Hewitt-Taylor 2016). Crucial to Habermas' (1981) theory is giving a voice to those who are not usually heard. This thesis aims to give equal voices to the older person, their families and the MDT. Its overarching intention is to gain new empirical knowledge that will further enhance the actualisation of PCC for OPAH within the cultures of both healthcare and nurse education (Habermas 1986).

> *Personal Reflection excerpt – 4.9.16*
>
> *When considering condensing the background PCC literature which defines and describes PCC evolving and becoming much more transparent, the "What" of PCC is clearer, also the Why, Who PCC is important to, as well, but the HOW, the realisation and how people make sense of PCC remains inconsistent in clinical practice. This is*

the start of my story of investigating and adding to the body of knowledge on the what and the how!

1.8 Structure of the thesis

Chapter 1 sets the scene for the doctoral journey from a personal reflective stance, along with the current rationale for adopting PCC in healthcare and its eclectic potential origins. An exploration of current PCC approaches and the selection of the theoretical lenses for this study have been outlined.

Chapter 2 presents a comprehensive narrative review of the literature in relation to the themes of the doctorate. Key topics are critiqued, highlighting gaps in the existing PCC evidence base to ensure that the research outcomes will make a valuable contribution to the current body of knowledge in this field.

Chapter 3 describes the selected methodology, Interpretative Phenomenological Analysis (IPA) with collective case studies and provides a rationale for this choice. The exclusion of other potential methodologies is also justified. My personal epistemological and ontological stance are revisited in relation to the selection of a constructivist, interpretative phenomenological approach. The influence of philosophy on the methodological choices is discussed in detail.

Chapter 4 provides a rationale for the methods employed in this thesis. Semi-structured diaries and face-to-face semi-structured interviews are critically appraised. Additionally, this chapter outlines the relevant ethical considerations and approaches to ensure that rigour is achieved throughout the study.

Chapter 5, the findings, provides the reader with insights into the lived experience of PCC by older people in an acute care setting, from the simultaneous perspectives of an older person, their family and healthcare staff.

Chapter 6 discusses how this study contributes to the PCC knowledge base in the context of current evidence in this field and explores its strengths and limitations.

Chapter 7 concludes this thesis for the Doctorate of Professional Practice (DPP) with a summary of the most significant findings relating to PCC. It provides recommendations for clinical practice and healthcare education. It identifies specific opportunities for further research and sets out plans for future scholarship.

1.9 Chapter conclusion

My ontological approach and my way of existing in the worlds of nursing and nurse education drew me to endeavour to see the world through the eyes of those requiring care. My personal disappointment when my brother's care did not appear aligned to person-centred approaches led to this doctoral study. Chapter 1 resulted from several scoping searches of the person-centred evidence base conducted at the beginning of this investigation.

My deepening interest and insight into PCC have led me to explore the philosophical and theoretical underpinnings of this concept. I have shared my beliefs about PCC to allow the reader to become familiar with my voice as a researcher and my journey since beginning the study. McCormack and McCance's (2017, 2010) model of PCC and Habermas' (1981) critical social theory inspired me to give voice to all who participated in the PCC experience. The literature on PCC in OPAH in Chapter 2 will substantiate the decisions around setting the aim and objectives of this DPP.

2 Literature Review Chapter

2.1 Introduction

A comprehensive narrative review was conducted and updated during the DPP. This chapter will explain why a narrative approach was taken. The methods of searching and reviewing the literature will be described in a way that others could replicate (Aveyard 2019) and the means of critiquing the literature will be discussed. The results of this literature review will be presented in three key themes:

- What constitutes PCC in everyday healthcare language
- The impact of PCC on OPAH and MDT Staff
- The facilitators and challenges to implementing PCC Practice

Finally, the literature review findings will be summarised to justify the research aim and objectives of this thesis.

2.2 Why a Comprehensive Narrative Review

Various approaches to reviewing the literature were contemplated during the doctoral process. Although systematic review can be viewed as the ‘gold standard’ to answer a specific research question (Armstrong et al. 2011), the purpose of this literature review was not to answer a set question, but to critically examine the broad range of evidence in relation to PCC experiences in OPAH care. Therefore, a systematic review could arguably have taken too narrow an approach by only considering specific components of the PCC evidence base. Additionally, Oliver (2012) suggests that the approach to reviewing the literature should be based on the purpose of the literature review. The purpose of this literature review was to broadly consider the person-centred literature for older people, families and MDT staff, to determine a meaningful way to add to the body of knowledge in this area. A scoping review of the literature may have been appropriate to provide an overview of the current PCC research narrative, Armstrong et al. (2011) explain that scoping reviews do not usually include a critical appraisal of the literature. There was a need to conduct the literature review in a robust way, critically examining both the research methodologies and quality of the literature. An integrative review was primarily considered, as within nursing research they have been viewed as useful for reviewing mature data sets and re-conceptualising contemporary issues, which can support recommendations for suggest further research (Torracco 2005). However integrative reviewing has limitations. Bulmer–Smith, Profetto–McGrath and Cummings (2009) suggest integrative reviews tend to lack critical appraisal or standards for synthesizing the literature reviewed. Thus, as a doctoral student on a research apprenticeship, a more structured approach to broadly reviewing the literature, that encompassed methodologies and quality was deemed appropriate.

Comprehensive narrative reviews identify gaps in the knowledge base and justify aims of the research (Aveyard 2019; Armstrong et al. 2011). A comprehensive narrative review, as was undertaken here, enabled the evolution and clarity of the research aim in the current study which involved continually revisiting the evidence base throughout the course of the study. Such an approach facilitated the identification of key gaps in understanding of PCC policy and practice. Additionally, the narrative approach to reviewing the literature helped to capture the dynamically changing landscape of PCC internationally.

The contemporary perspective of Gregory and Denniss (2018) argues that comprehensive narrative reviews are advantageous when seeking to review a broad evidence base whilst acknowledging that some authors consider such an approach to be outdated. Moreover, Reeves et al. (2017) support the use of comprehensive narrative reviews to identify and establish gaps in the existing evidence base prior to conducting research. Furthermore, Schaepe and Bergen (2015), endorse use of comprehensive narrative reviews from the outset and throughout a research project, to summarise both qualitative and quantitative evidence thereby shaping a research question. Indeed, Holger (2013) suggests that providing a structured, transparent approach to reviewing literature is apparent, comprehensive narrative reviews remain valid in literature reviewing methodologies. Correspondingly, Baker and McLeod (2011) recommend that the rigour applied to other types of literature reviews (such as being explicit around inclusion, exclusion, selection process and quality assessment) can be applied in comprehensive narrative reviews thus strengthening the robustness and repeatability of the review. More recently, Sikes et al. (2019) promote the comprehensive narrative approach to synthesise the breadth of evidence in a specific area that can influence clinical practice and future research. Finally, Corno, Epinoza and Maria Banos (2019) concur that comprehensive narrative reviews are exemplary for presenting a clear representation of the current evidence in a specific area of interest.

Consideration of the PCC literature across the different research approaches, appraising a range of methodologies, was important within this research apprenticeship. Deliberation of the broad spectrum of PCC evidence heightened awareness of how this research could potentially fill a gap in the PCC knowledge base.

2.3 Literature Reviewing Methods

Aveyard (2019) suggests any literature reviewing process can be strengthened by having a transparent methodical approach that others could replicate. Therefore, this review follows the structure employed in recently published comprehensive narrative reviews (Corno, Epinoza and Maria Banos 2019; Sikes et al. 2019; Reeves et al. 2017; Schaepe and Bergen 2015; Baker and McLeod 2011). The search strategy will be shared and justified, with the inclusion and exclusion criteria. Additionally, the methods of title, abstract and full text screening will be presented. The processes that were followed to assess the quality of the literature included will also be explored, before sharing the details of the articles included in this review. Finally, the themes of the literature review will be critically presented to support how this research, in particular, the methodological approach, will add to the body of PCC knowledge.

2.3.1 Search strategy

Munn et al.’s (2018) suggestion of refining the search strategy for reviewing qualitative research, using: Population, Phenomena of Interest, Context, (PICo) was followed. PICo had been employed successfully by several authors, in their comprehensive literature reviews which considered a wider range of methodological evidence (Corno, Epinoza and Maria Banos 2019; Sikes et al.

2019; Reeves et al. 2017; Schaepe and Bergen 2015; Baker and McLeod 2011). In the context of this research the search terms were:

- **Population** - *older people, geriatrics*, *seniors, elderly, older adult, nurses, nursing, multidisciplinary team.*
- **Phenomena of Interest** *person centered care or person-centredcare or patient centred care or patient centered care and* experiences or perceptions or attitudes or views
- **Context** - *hospital or acute setting or inpatient or ward or care setting*

As Gregory and Denniss (2018) suggest, the literature was searched and reviewed repeatedly throughout the study, as this is important particularly during a course of graduate study to keep abreast of the growing evidence base. Additionally, Zetoc and Scopus systems were set up, with an email alerting system when new PCC research was published (Zetoc 2020; Scopus 2020). Initial searching began in 2014, at the start of the doctoral journey, was repeated in 2016 and again during final thesis write up until March 2020. Following the advice of Green, Johnson and Adams (2006) assistance was sought from library staff specialising in supporting graduate research.

The year 2000 was used as a starting point, as this was the date the term 'patient centred care' started to emerge in healthcare policy in the United Kingdom (DOH 2001). Additionally, PCC began to be recognised internationally by the Institute of Health Improvement (IHI) when Delbanco et al. (2001) promoted the "*What matters to you*?" approach to healthcare delivery.

Searches were conducted in CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE, Science Direct, Cochrane Library (Reviews, Protocols and Clinical Trials), Psychinfo and Soc Index databases. To inform the research process thoroughly and comprehensively the literature review included qualitative, quantitative, and mixed methods primary research studies and a variety of different types of literature reviews (Concept Analysis; Systematic mixed-methods review; Qualitative meta-synthesis; Narrative Review; Scoping Review). Relevant reference lists were also scrutinised for pertinent studies that fitted the inclusion criteria selected (Horsely, Dingwall and Sampson 2011).

2.3.2 Inclusion criteria

The inclusion criteria specified studies published in peer reviewed academic journals, where full text was available in the English language. When the scholarship in the journal article related to PhD studies, the original thesis was also considered (Dewar 2011;Pringle 2011). To be included in the review, all participants (MDT or family members) in the studies had to be over 18 years old, older people research participants had to be over the age of 65 years, to align to the planned research focus of older people's experience of PCC. Contention exists around how to classify older people however, HIS (2015) have an unclear definition of people based on age of individuals over 65 or 75 years old whilst the DOH (2001) classify older people as over 65 years old. Ebrahimi et al. (2017) categorise older people as individuals aged over 80 years old or over 65 years old with more than one long term condition. However, the research area and national classification of an older person in the grey literature (NHS Grampian 2017; Scottish Government 2015) considered for this research stated an older person as over 65 years of age, therefore this age classification was applied in this literature review's inclusion criteria. Such an approach ensured that the key area of interest, PCC for older people was the focus of the literature review. Predominantly the literature reviewed included studies of PCC of older people in a healthcare setting but not exclusively in acute hospitals. PCC literature in non-acute settings, where older people, family and MDT staff were research participants was also included, bringing as comprehensive a review to the research as possible.

Inclusion criteria summary:

- Written in the English language
- Published in peer reviewed journals from 2000 – 2020
- Qualitative, Quantitative Studies and Literature Reviews
- MDT or Family participants over 18 years old
- Older people participants over 65 years old
- Older people's experiences of healthcare predominantly but not exclusively in hospital settings

As presented in *Chapter 1*, there was a wealth of literature supporting specific PCC for older people with cognitive impairment and/or dementia. Therefore, a further limit was set to exclude studies specifically relating to older people with cognitive impairment and/or dementia.

2.3.3 Literature exclusion criteria

Following the preliminary scoping searches, studies with a focus on dementia care, or an emphasis on caring for older people experiencing cognitive decline were excluded. As explored in Chapter 1, much of the PCC evidence base for vulnerable older people with cognitive decline, originated from the key dimensions of Kitwood's VIPS model (1997). The VIPS model influenced the creation of both the dementia care mapping tools and extensive PCC related research (Du Toit, Sanetta and McGrath 2018; Spencer et al. 2014; Baillie, Merrit and Cox 2012; McCance et al. 2011; Bone, Cheung and Wade 2010; Edvardsson, Fetherstonhaugh and Nay 2009; McCormack et al. 2009; McCormack and McCance 2006). However, older people's studies where there may have been a degree of implicit cognitive impairment for participants (such as post stroke) were not excluded. The rationale for not excluding the latter studies was to comprehensively review PCC experiences of older people in authentic ways, representing the types of healthcare interfaces older people may find themselves in; with implied but no specific diagnosis of cognitive decline. Appendix 1 details the search terms used.

Studies in relation to specific sub-groups such as individuals with learning disabilities or those with mental illness were also excluded. This ensured the literature focussed on older people, their families and MDT experiences of PCC and avoided restricting the literature to one specific group of older people (for example older people with pneumonia). However, in some of the studies included in this literature review, the research participants were recruited due to a specific medical condition or need for hospital intervention (Olsson et al. 2016; Olsson et al 2014; Jensen, Vedelø, and Lomborg 2013; Lawrence and Kinn 2012; Olsson et al 2009;). Although the latter studies may be researching a narrowed group of society (for example: person-centred personal care experiences of older people with Chronic Obstructive Pulmonary Disease (COPD)

Jensen, Vedelø, and Lomborg 2013), they provide rich insights into PCC experiences, therefore are useful in this review. The variety of reasons for the older people receiving care in the studies was evident within the range of literature reviewed, therefore had the potential to provide a broad comprehensive literature review. Opinion based and non-research based articles were also excluded.

2.4 Quality Checking Process, Credibility of Papers, Rigour

Once appropriate studies were selected, Critical Appraisal Skills Programme (CASP 2018) checklists were employed to assess the quality and rigour in the studies reviewed. Whilst CASP tools comprise sets of numbered questions, these are not designed to give a score on quality or rigour, but instead are an educational tool to assist in the evaluation of literature (CASP 2018). Within this review, CASP tools were used to appraise qualitative studies, quantitative studies and literature reviews and Long's (2005) tool was used to review the mixed methods studies. The results section of this chapter will critically comment on incidences where appraisal tools highlighted concerns regarding quality or rigour, however no studies were excluded due to inadequate quality which can be argued as in keeping with the comprehensive nature of this literature review (Corno, Epinoza and Maria Banos 2019; Baker and McLeod 2010).

The Preferred Reporting Items for Systematic Reviews and Meta – analysis (PRISMA) conventionally used to present the systematic processes followed in systematic reviews (PRISMA 2015), can however be adapted for use in other types of literature reviews (Aveyard 2019). The PRISMA Flowchart in Figure 2.1 below outlines the process of identification, title, abstract and full text screening, around the set inclusion and exclusion criteria. Similarly, other studies have used comparable flowcharts to illustrate the transparent processes followed within their comprehensive narrative reviews (Corno, Epinoza and Maria Banos 2019; Sikes et al. 2019; Schaepe and Bergen 2015; Baker and McLeod 2011). As demonstrated in Figure 2.1, studies where the aim of the study fell out with the scope of this literature review were excluded.

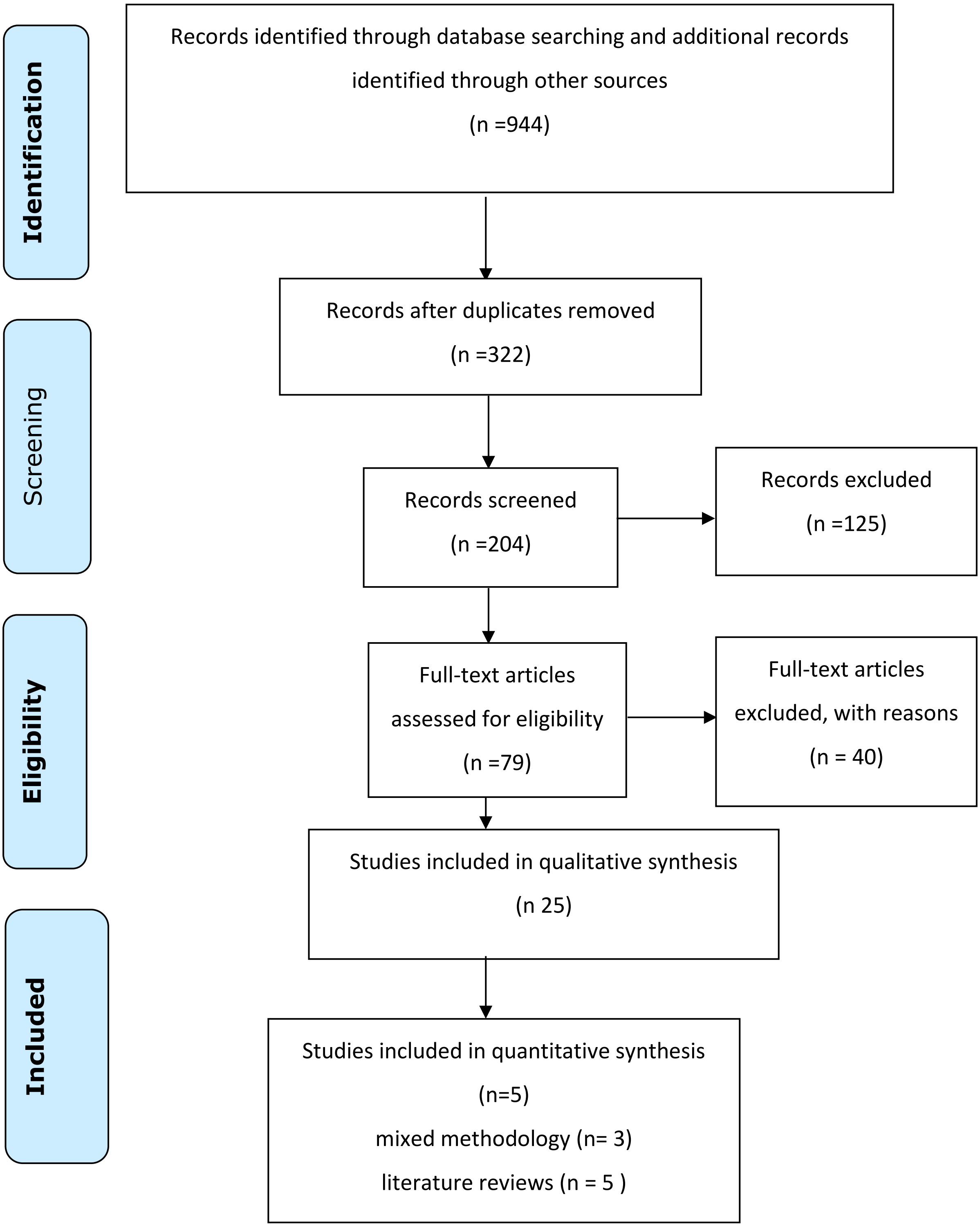


Figure 2.1 PRISMA Flowchart

Identification of potential studies

From the first 944 articles identified, initial screening of all article titles led to removing duplicates and any studies with an emphasis on older people with cognitive impairment or a diagnosis of dementia as this fell out-with the scope of this review (n= 944 reduced to n = 322). Subsequently, abstract screening focussed on identifying research studies eligible to meet the inclusion criteria of this review, i.e. the lived experience of PCC for older people, their families and MDT staff. Such a process resulted in a reduction from n= 322 to n =204. Opinion and non-research-based articles were also excluded at this point - a further reduction from n=204 to n =79 articles. The next stage of screening involved meticulously considering the 79 full texts, excluding studies that did not meet the inclusion criteria. This more detailed check on eligibility led to a reduction from 79 to 38 full articles to be critiqued.

2.5 Results

A broad international range of evidence was found in the review with a dominance of studies originating from the United Kingdom (n=12) and Sweden (n= 11). Australia also demonstrates a research interest in this area (n=6). Whilst publications number less in Canada (n=3), USA (n= 1), Italy (n=1), Denmark (n=1), Norway (n= 1), Tehran (n=1) and Israel (n=1). This international selection of literature arguably demonstrates a worldwide interest in PCC as a concept in healthcare. An overview of the 38 articles is presented in Table 2.1.

The literature reviewed presented a wide variety of perspectives on PCC. There was a dominance of qualitative studies (n=25), with less quantitative (n=5), mixed methodology studies(n=3) and literature reviews (n= 5). The majority (n= 11) had a focus of the perspective of older people (Pettersson et al 2018; Olsson, Hansson and Ekman 2016; Rathert et al. 2015; Olsson et al 2014; Alharbi et al. 2014 (a); Jensen, Vendelo and Lomborg 2013; Dillworth, Higgins and Parker 2012; Marshall, Kitson and Zeitz 2012; Olsson et al 2009; Kvale and Bondevik 2008; Gilmartin and Wright 2008). A smaller number (n= 8) explored MDT experiences (Moore et al. 2017; Larsson and Blomqvist 2015; Slater, McCormack and McCance 2015; Ross, Tod and Clarke 2014; Hebblethwaite

2013; Abdelhadi and Drach-Zahavy 2012; Van Mossel, Alford and Watson 2011; Lamiani 2008) and slightly fewer (n=6) researched the PCC experience from the combined perspectives of members of the MDT and older people (Naldermirci et al 2018; Lui, Gerdtz and Manas 2016; Alharbi et al. 2014 (b) Esmaeili, Cheraghi and Salsali 2014; Maben et al. 2012; Bolster and Manias 2010; Glasson et al. 2006). A similar small number of studies (n=2) jointly explored the three stakeholders (older people, family and MDT staff) PCC experiences (Horrell et al. 2018; Dewar and Nolan 2013; Dewar 2011). Additionally, some authors (n = 4) had already acknowledged a gap in multiple stakeholder perspectives of PCC for OPAH in the evidence base in their findings (Pettersson et al. 2018; De Silva 2014; Ross, Tod and Clarke 2014; Dilworth, Higgins and Parker 2012). Therefore, there appeared to be a need to illuminate the experiences of PCC from the multiple perspectives of those giving and receiving care.

Table 2.1 Overview of Literature Reviewed

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies							
1.	ALHARBI, T.S.J. et al., 2014 (a). Experiences of person-centred care - patients' perceptions: qualitative study. *Biomed Central Nursing*, 13, pp. 28-28.	To investigate whether patients did in fact perceive the intentions of partnership in the new care model 1 year after its implementation.	Deductive content analysis of patients' experiences of PCC.	16 patients	Sweden	Patients valued being listened to and invited to play an active part in their care, but did not always want to share decision making. Patients wanted Doctors to lead their care. The move towards PCC cultures is in its' early stages.	Sweden, the authors recognize the need for research throughout the world. Only considered patients, whereas family and MDT staff are key stakeholders in PCC.
2.	BOLSTER, D. and MANIAS, E., 2010. Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: Qualitative observation and interview study. *International Journal of Nursing*, 47 (2) pp. 154-165.	To examine how nurses and patients interact with each other during medication activities in an acute care environment which has an underlying philosophy of person-centred care.	A qualitative approach was used comprising naturalistic observation and semi-structured interviews	11 Nurses, 25 patients interviews, 16 observed	Australia	Three major themes emerged from the findings: provision of individualised care, patient participation and contextual barriers to providing person-centred care. Nurses valued PCC but did not consistently practice this. Preferring routine-based care	PCC in medicine management is shared with Dr & Pharmacists, but only nurses included, later in Lui, Gertdz & Manias a wider perspective is taken.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
3.	DEWAR, B., 2011. Caring about Care: An appreciative inquiry about compassionate relationship-Centred Care, Edinburgh Napier PhD Thesis. [online] Napier. https://www.napier.ac.uk/~/media/worktribe/output-196625/phdfinalbdewar20111pdf.pdf [Accessed 30th May 2019].	To examine and evaluate processes that enhance compassionate relationship-centred care within an older people care setting in an acute hospital.	Participatory Action Research (PAR) - Appreciative Inquiry	40 members of MDT (Registered Nurses, Health Care assistants & Student Nurses, Allied Health Professionals and Medical Staff). 10 Patients and 12 family members	Scotland	Relational Aspects of Care can be attributed to compassionate care experience. Creation of a new model of Compassionate Relational Care.	Sample bias towards more nursing staff than patients/ families. PAR & AI are time consuming and require participants to be repeatedly involved over a long period of time. Required dedicated full-time dedicated researcher time
4.	DEWAR, B. and NOLAN, M., 2013. Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, 50(9), pp. 1247-1258. Subsequent publication from above PhD.	Actively involved older people, staff and relatives in agreeing a definition of compassionate relationship-centred care and identifying strategies to promote such care in acute hospital settings for older people.	Participatory Action Research - Appreciative Inquiry	Based on Study 3 (above).	Scotland	As above in 3.	As above in 3.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
5.	DILWORTH, S., HIGGINS, I. and PARKER, V., 2012. Feeling let down: An exploratory study of the experiences of older people who were readmitted to hospital following a recent discharge. *Contemporary Nurse*, 42(2), pp. 280-288.	To explore the experiences of older people who have been readmitted to hospital following recent discharge to their homes.	Descriptive hermeneutic qualitative study	10 older patients (over 65 years old).	Australia	Participants expressed concern about being left out, but did feel being cared for and then once re admitted felt let down. A more person-centredapproach to discharge planning for older people is recommended.	Bias sample of older people who required readmission
6.	EDVARDSSON D; NAY R., 2009. Acute care and older people: challenges and ways forward. *Australian Journal of Advanced Nursing*, 27(2), pp. 63–69.	To suggest ways in which acute hospital environments might be modified to better meet the needs of the older person and question whether options other than acute care should be canvassed for older people.	Fictitious Case Study		Sweden	As an alternative to acute hospital admission, 'older people centres' could be developed to which older people could be admitted for triage in older-friendly environments staffed by experts in care of older people~~.~~	Fictitious Sweden 1 hospital case study, limited impact Not all older people would want to be triaged according to their age Unusual method

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
7.	ESMAEILI, M., CHERAGHI, M.A. and SALSALI, M., 2014. Barriers to Patient-Centered Care: A Thematic Analysis Study *International Journal of Nursing Knowledge*, 25(1), pp. 1-7.	To explore nurses' attitudes and experience toward the barriers to achieving patient-centered care in the critical care setting.	Thematic Analysis of transcribed interviews exploring nurses' experiences of barriers to delivering PCC.	Registered Nurses (n= 21)	Tehran	a) Lack of common understanding of teamwork, (b) individual barriers, and (c) organizational barriers. This study goes beyond reporting problems with patient-centered care to try to understand why patients do not always receive high-quality care Staff often feel overwhelmed meeting physical complex needs in a routine based way, rather than individualising care.	Tehran, the authors recognize the need for research throughout the world to find out more about the impact of moving to PCC cultures. Nurses only viewed as responsible for PCC. PCC seen as a marker of satisfaction rather than High Quality Care. Only considering nurses perspectives.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
8.	GILL, S.D. et al., 2014. Understanding the experience of inpatient rehabilitation: insights into patient-centred care from patients and family members. *Scandinavian Journal of Caring Sciences*, 28(2), pp. 264-272.	To describe the experiences, needs and preferences of recent inpatients of a rehabilitation centred, and the needs of their families.	Thematic Analysis of transcribed interviews exploring older people and families' experiences of patient centred rehabilitation	13 patients over 80 years old 11 family members	Sweden	For care to be person centred, participants wanted: interactions with friendly, empathetic staff; regular contact with senior staff and all staff to introduce themselves by name and profession; timely communication of accurate information; and rehabilitation services seven days a week	Concentrates on over 80's misses perspectives of 65 – 79 age group.
9.	GILMARTIN, J. and WRIGHT, K., 2008. Day surgery: patients' felt abandoned during the pre-operative wait. *Journal of Clinical Nursing*, 17(18), pp. 2418-2425.	To describe and interpret patients' experiences of contemporary day surgery.	Hermeneutic phenomenology	20 previous (up to age 85 years) day surgery patients	England	Empowered Pre-operatively pre-Assessment, but abandoned immediately pre-operatively. Nurses need to try to be more person-centred through-out the day surgery experience, so patients feel more supported.	Some of the participants were not over 65 years old. PCC seen as only nursing's responsibility.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
10.	GLASSON, J. et al., 2006. Evaluation of a model of nursing care for older patients using participatory action research in an acute medical ward. *Journal of Clinical Nursing*, 15(5), pp. 588-598.	To improve the quality of nursing care for older acutely ill hospitalized medical patients through developing, implementing and evaluating a new model of care using a participatory action research process.	PAR	60 in-patients over the age of 65 13 registered nurses	Australia	Moving to Orem's model encouraged more pc approaches and led to patients believing they had experienced higher quality nursing care Implementing change works best when there are grass roots involvement.	States PAR methodology, but also mentions mixed methodology, so is not clear. Is about moving to Orem's model of care Just touches upon how this model means more PC approaches.
11.	HEBBLETHWAITE, S., 2013. "I Think that it could work but...": Tensions Between the Theory and Practice of Person-Centred and Relationship- Centred Care" *Therapeutic Recreation Journal*, 47 (1), pp. 13-22.	To explore the perspective of how person-centered and relationship-centred care were put into facility-wide practice.	Thematic Analysis of transcribed interviews with recreational therapists exploring their experiences of PCC.	11 Recreational Therapists	Canada	PCC philosophy of care and intention does not follow on into clinical care of older people Care is medical and routine based.	Only considering one disciplines perspective in multiple perspectives of PCC.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
12.	HORRELL, J. et al., 2018. Creating and facilitating change for Person-Centred Coordinated Care (P3C): The development of the Organisational Change Tool (P3C-OCT). *Health Expectations*, 21(2), pp. 448-456.	To develop a practical tool to support organisations and practitioners to provide personalised and coordinated care for people with multimorbidity. This tool is based in on the principles of promoting person-centred relationships with service users and between practitioners, and highlights how organisations can support its achievement.	Mixed Methods, Scoping Review followed up with focus groups & interviews	Clinical Commissioning Groups (CCGs), clinicians, academics, voluntary organisations and patient representative	England	Core components of this new model of PCC were active listening, shared decision making and coordinated working around a documented co created plan of care. Implementing PCC is complex	Workshops with all participants present may have inhibited free viewing of perspectives, as some participants may have experienced power imbalance. The tool would require further testing.
13.	JENSEN, A.L., VEDELØ, T.W. and LOMBORG, K., 2013. A patient-centred approach to assisted personal body care for patients hospitalised with chronic obstructive pulmonary disease. *Journal of Clinical Nursing*, 22(7-8), pp. 1005-1015.	To explore the patients' experiences of receiving patient-centred personal body care and to document changes compared to the patients' experiences in previous hospital stays.	Qualitative outcome analysis with an interpretive description methodology	11 previous patients (only 2 under 65 years old)	Denmark	The PCC approach to personal care led to experiences of: clear signs of acknowledgement, attentive time and security	Limited transferability directly to COPD patients.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
14.	KVÅLE, K. and BONDEVIK, M., 2008. What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. *Scandinavian Journal of Caring Sciences*, 22(4), pp. 582-589.	To obtain insight in patients with cancers' perceptions of the importance of being respected as partners and shared control of decisions about interventions and management of their health problems and the reasons behind their wishes.	Giorgio's phenomenology	20 cancer in patients with various cancer diagnoses	Norway	empowerment (being respected, listened to, given honest information, being valued); (2) shared decision making about the treatment of the disease (discussing the treatment, but letting the doctor decide in the end); and (3) partnership in nursing care. Doctors must find out the extent to which each patient wants to participate and then provide the necessary information.	Related directly to people with cancer, but directly considers key components of PCC and the challenges PCC can present.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
15.	LAMIANI, G. et al., 2008. Assumptions and blind spots in patient-centredness: action research between American and Italian health care professionals. *Medical Education*, 42(7), pp. 712-720.	To examine how patient-centredness is understood and enacted in an American (US) and an Italian group of health care professionals.	Action Research	4 USA Doctors 5 Italian Doctors	Italy	Exploring the patient's illness experience and handling the patient's emotions were identified as core components of patient-centred care by both the US and Italian participants but were expressed differently in their respective dialogues. Respecting the patient's autonomy was recognised as a component of patient-centred care only by the US participants. The Italian participants demonstrated a more implicitly paternalistic approach.	Video conferenced focus group analysis approach could have inhibited interpretation of par language as thoroughly as face to face.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
16.	LARSSON, H. and BLOMQVIST, K., 2015. From a diagnostic and particular approach to a person-centred approach: a development project. *Journal of Clinical Nursing*, 24(3-4), pp. 465-474.	To investigate changes over time in an interdisciplinary group that was engaged in development work regarding pain and pain assessment.	PAR To simultaneously research and improve person-centred approaches.	3 registered nurses, 2 assistant nurses and 1 physiotherapist	Sweden	The participants changed their attitudes towards the patient in pain, their own caring role and the team's role towards a more person-centred care. Participants experienced more job satisfaction by moving towards a PCC approach	Only Sweden, so cultural influence may play a part.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (studies)							
17.	LIU, W., GERDTZ, M. and MANIAS, E., 2016. Creating opportunities for interdisciplinary collaboration and patient-centred care: how nurses, doctors, pharmacists and patients use communication strategies when managing medications in an acute hospital setting. *Journal of Clinical Nursing*, 25(19-20), pp. 2943-2957.	To examine the communication strategies that nurses, doctors, pharmacists and patients use when managing medications.	Critical Ethnography – with video discourse analysis	76 nurses, 31 doctors, 1 pharmacist and 27 patients	Australia	Doctors normalized disease and illness. Body language conveyed a power imbalance at times where doctors & pharmacists positioned themselves in a position of authority over the patient. Patients use discourse of politeness when raising concerns. Nurses use discourse of safety when discussing medicines. Recommend doctors should involve patients in making medicine related decisions instead of deciding then telling. Good PCC is MDT not just nurses.	Naturalistic ethnographic observation may have allowed for more in-depth interpretation, however, the ability to go back to the event and re analyses may have provided greater depth of analysis

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
18.	MARRIOTT-STRATHAM, K. et al., 2018. Empowering aged care nurses to deliver person-centred care: Enabling nurses to shine. *Nurse Education in Practice*, 31, pp. 112-117.	To enable the nursing workforce to be active participants in the development of an authentic person-centred culture through the lens of the person-centred nursing framework.	PAR To simultaneously research and improve person-centred approaches.	82 older people living in residential homes 80 members of nursing team	Australia	Embedding PCC is complex and takes time This paper reports on the 1st stage of the PAR process, exploring what PCC meant to the older people and staff. Staff feel a greater sense of job satisfaction by moving towards a PCC focus Older people are more satisfied with the care when they believed it was person centred.	Paper is reviewing PAR alongside the move top PCC A further study once PCC is more established would provide more insights.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
19.	MARSHALL, A., KITSON, A. and ZEITZ, K., 2012. Patients' views of patient-centred care: a phenomenological case study in one surgical unit. *Journal of Advanced Nursing*, 68(12), pp. 2664-2673.	To explore patients' understanding and conceptualization of patient-centred care	Phenomenological Qualitative Study	10 patients	Australia	Participants were unfamiliar with the concept of patient-centred care, but despite this, were able to describe what the term meant to them and what they wanted from their care. Patients equated the type and quality of care they received with the staff that provided it and themes of connectedness, involvement and attentiveness. Patients do not view PCC in disciplines rather view care across the professional continuum.	One dimensional perspective on a multi perspective aspect of care. Impactful mainly on surgical areas. No details of ages of participants, but included as insights into how patients define PCC.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
20.	MOORE, L. et al., 2017. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences*, 31(4), pp. 662-673.	To explore the barriers and facilitators to the delivery of person-centred care interventions, in different contexts.	Qualitative interviews	18 PCC researchers	Sweden	Barriers to the implementation of person-centred care covered three themes: traditional practices and structures; skeptical, stereotypical attitudes from professionals; and factors related to the development of person-centred interventions. Facilitators included organisational factors, leadership and training and an enabling attitude and approach by professionals.	Unusual methodology of researching the researcher's perspectives, could be viewed as introspective, or could be argued to be like a Delphi study.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
21.	NALDERMIRCI, A. et al. 2018. Deliberate and emergent strategies for implementing person-centred care: a qualitative interview study with researchers, professionals and patients, *Biomedical Central Health Services Research*,17(527) [online] available from: DOI 10.1186/s12913-017-2470-2. Last accessed 1st February 2020. .	2 aims: first, to analyse deliberate and emergent strategies adopted by healthcare professionals to overcome barriers to normalisation of a specific framework of person-centred care (PCC); and secondly, to explore how the recipients of PCC understand these strategies.	A qualitative study of the implementation of PCC	18 PCC researchers 17 practitioners, 5 registered nurses, 4 assistant nurses, 4 ward managers and 4 physicians participated in the study 20 patients	Sweden	Staff had mixed views some embracing PCC others resistant, assuming the change would lead to more work. Patients unaware anything had changed. Valued feeling at ease with MDT, their working with rather than caring for approach and flattened hierarchy. Nursing team & Drs recruited	Uncertain why PCC researchers were interviewed, reasons are not explicit. I can see the rationale for nurses & patients.
22.	RANKIN, J.M., 2015. The rhetoric of patient and family centred care: an institutional ethnography into what actually happens. *Journal of advanced nursing*, 71(3), pp. 526-534.	To examine technological advances designed to improve nurses work, alongside analysis of how nurses work is coordinated in an apparent commitment to 'patient and family centred care'.	Institutional Ethnography	1 patient 1 family member 5 registered nurses	Canada	'Empty Rhetoric' of PCC philosophy of care, alongside set standard operating procedures in a tech assisted programme of care planning. Individualising or reacting to patient or family requests often ignored.	Based on one unique person's experiences.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
23.	RATHERT, C. et al., 2015. Patient perceptions of patient-centred care: empirical test of a theoretical model. *Health Expectations*, 18(2), pp. 199-209.	To empirically examine a conceptual model of patient-centred care using patient perception survey data.	Regression Analysis	Survey data from patients with overnight visits at 142 U. S. hospitals	USA	Significant support for PCC models of care. Emotional support had the strongest relationship with overall care ratings. Coordination of care, and physical comfort were strongly related as well. Understanding how patients' experience their care can help improve understanding of what patients believe is patient-centred, and of how care processes relate to important patient outcomes.	Only considering survey results has limitations on bigger picture than could be gleamed from interviews, focus groups or observation. Reliant on patients completing the survey, misses perspectives of those who do not complete post admission surveys.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
24.	ROSS, H., TOD, A.M. and CLARKE, A., 2014. Understanding and achieving person-centred care: the nurse perspective. *Journal of Clinical Nursing*. 24 (9-10), pp. 1223 – 1233.	To identify the facilitators of PCC from the perspective of nurses (including registered nurses, support workers and student nurses) what PCC is and consider how the principles can be applied in their own practice.	Action Research	14 members of the nursing team	England	Nurses had a clear understanding of person-centred care in the context of their work. They acknowledged the importance of relationships, personal qualities of staff and respecting the principles of person-centred care as they strived to provide safe, high-quality person-centred care.	Complex Aim, sets PCC as within only nurses' domain, but does outline this is stage 1 of a bigger study incorporating MDT, but has no intention of asking patients what they thought of PCC. Also, although nurses are clear about what PCC is, it is not clear how they put this into practice. Or that their version of PCC is the same as the patient's they care for.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Qualitative Studies (continued)							
25.	VAN MOSSEL, C., ALFORD, M. and WATSON, H., 2011. Challenges of patient-centred care: practice or rhetoric. *Nursing inquiry*, 18(4), pp. 278-289.	To explore how medical oncologists, explain treatment options to patients, how people hear and understand what they are told, and what factors influence their decision-making pertaining to treatment when cancer has recurred.	Qualitative Interviews	Oncologists number not stated	Canada	Consultations with patients appear to begin with the patient's interests at the centre and conclude with the oncologist's interests at the centre too. However, some oncologists define PCC as having thoroughly created the patient's plan before they see them, missing the shared perspective altogether.	Difficult to find Aim & Objective, missing results for example how many participants took part. Again, not completely tied to older people, but limited lit available on doctor's perceptions on PCC, so included.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Quantitative Studies							
1.	ALHARBI, T.S., J. et al., 2014 (b). The impact of organizational culture on the outcome of hospital care: After the implementation of person-centred care. *Scandinavian Journal of Public Health*, 42(1), pp. 104-110.	To measure the effect of organizational culture on health outcomes of patients 3 months after discharge.	A quantitative study using Organisational Values Question-naire and a health-related quality of life instrument.	117 nurses and 220 patients	Sweden	Changing to a PCC focus is complex and requires a flexible approach.	The measure of health-related quality of life was criticised in the study for not being sensitive enough. Sweden, the authors recognize the need for research throughout the world to find out more about the impact of moving to PCC cultures.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Quantitative Studies (continued)							
2.	OLSSON, L. et al., 2009. A cost-effectiveness study of a patient-centred integrated care pathway. *Journal of advanced nursing*, 65(8), pp. 1626-1635.	To compare costs and consequences for an integrated care pathway intervention group with those of a usual care group for patients admitted with hip fracture.	A quasi-experimental, prospective design A cost-effectiveness analysis was performed to compare an integrated care pathway intervention (treatment A) with usual care (treatment B).	A consecutive sample of 112 independently living participants, aged 65 years or older admitted to hospital with a hip fracture, were included in the study. Data was collected over an 18-month period in 2003–2005.	Sweden	Moving to a PCC ICP way of working led to 40% reduction in overall costs. Convincing financial argument for a move towards PCC.	By only focusing on financial aspects miss opportunity to capture other positive or negative aspects of this move. Authors recognised although statistically significant findings, could have been strengthened by a larger sample.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Quantitative Studies (continued)							
3.	OLSSON, L. et al., 2014. Person-centred care compared with standardized care for patients undergoing total hip arthroplasty-a quasi-experimental study. *Journal of Orthopaedic Surgery and Research*, 9(1), pp. 95-95	The primary outcome measures were length of stay and physical function at both discharge and 3 months later.	A quasi-experimental study	A control group (*n* =138) was consecutively recruited between 20th September 2010 and 1st March 2011 and an intervention group (*n* =128) between 12th December 2011 and 12th November 2012, both scheduled for total hip replacement.	Sweden	Focusing attention on patients as people and including them as partners in healthcare decision-making can result in shorter length of stay. The present study shows that the patients should be the focus and they should be involved as partners. There was a with statistically significant reduction in LoS overall positivity on the move to a PCC for planned ortho surgery was reported. Despite positivity staff were reluctant to move to a PCC way of working	Lack of in-depth insights into the experiences of the move towards PCC. The focus is purely on the measurable aspects of Los and physical function.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Quantitative Studies (continued)							
4.	OLSSON, L.-E.; HANSSON, E.; EKMAN, I. 2016. Evaluation of person-centred care after hip replacement-a controlled before and after study on the effects of fear of movement and self-efficacy compared to standard care. *Biomedical Central Nursing*, 15, p. 1–10,	Twofold Aims: (1) to identify vulnerable patients using the general self-efficacy scale and the Tampa scale for Kinesiophobia (2) to evaluate if person-centred care including the responses of the instruments made rehabilitation more effective in terms of shortening hospital length of stay after Total Hip Arthroplasty (THA).	A quasi-experimental study	Patients scheduled for THA, a control group (n = 138) and an intervention group (n = 128)	Sweden	Main area of interest was related to Aim 2: PCC for patients identified as vulnerable, who appeared to benefit from PCC approach with a reduction in Loss of function (LoF) and readiness for discharge post rehab in comparison to vulnerable patients in the control group. The tools to identify vulnerable patients helped MDT focus a more tailored rehab programme to the most vulnerable.	Complex interventions/ aims, at times difficult to follow. Could have been 2 separate papers. LoF is only a positive PCC outcome if this fits with the person's expectations of PCC.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Quantitative Studies (continued)							
5.	SLATER, P., MCCORMACK, B. and MCCANCE, T., 2015. Exploring person-centred practice within acute hospital settings. *International Practice Development Journal*, 5(Supple), pp. 1-8.	To assess person-centred practice in acute hospital settings	Cross Sectional Survey	A purposive sample of 2,825 registered nurses, response rate 24.9% (n=703)	Ireland	The findings indicate that a high level of person-centred care is currently provided in acute hospital settings. Also indicates areas for potential improvement, particularly in the constructs of: clarity of beliefs and values. Lowest scoring was in supportive organisation systems and potential for innovation and risk-taking. Indicating that there is not as much support to be person-centred as the nurses would prefer. Also, there is an inflexible culture to innovate or take risks.	Low response rate, raises the question if this is illustrative of the whole sample. Survey based on 2nd & 3rd authors model of PCC, again could be viewed as a bias but equally could be viewed as using an evidence based and tested tool.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Mixed Studies							
1	ABDELHADI, N. and DRACH-ZAHAVY, A., 2012. Promoting patient care: work engagement as a mediator between ward service climate and patient-centred care. *Journal of advanced nursing*, 68(6), pp. 1276-1287.	A study of the relation of the ward's service climate to patient-centred care, and the mediating role of nurses' work engagement in this relation.	Mixed Survey plus observations of care	180 qualified nurses	Israel	Leadership support for PCC is crucial; this should include an organisational definition of PCC. Nurses who value PCC should be recruited. Nurses should be supported to move away from a focus on physical care to a person centred, open communicating, power- sharing way of working.	PCC viewed only as Nurses responsibility Israel, therefore transferability internationally may be limited due to cultural and healthcare organisational differences.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Mixed Studies (continued)							
2	MABEN, J. et al., 2012. 'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care. *International Journal of Older People Nursing*, 7(2), pp. 83-94.	To examine the links between staff, experience of work and patient experience of care in a 'Medicine for Older People' (MfOP) service in England.	A mixed methods case study	Staff survey (66/192 – 34% response rate), a 48-item patient survey (26/111 – 23%), 18 staff interviews, 18 patient and carer interviews and 41 hours of non-participant observation.	England	Qualitative evidence generated is powerful. Staff burnt out by meeting the complex needs to acutely unwell older people Staff nurtured when leaders appreciate their efforts and when there is a 'family at work' supportive culture. Patients notice when staff avoid more complex patients, move them in a rough dehumanising way like a parcel, show a preference for 'poppets' nice older people with less complex care needs.	Qualitative Component poor response rate Not specific to PCC, but specific to older people, families and nursing staff experiences in OPAH, insightful.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Mixed Studies (continued)							
3	PETTERSSON, M.E. et al., 2018. Prepared for surgery – Communication in nurses' preoperative consultations with patients undergoing surgery for colorectal cancer after a person-centred intervention. *Journal of Clinical Nursing*, 27(13-14), pp. 2904-2916.	To describe preoperative communication after a person-centred intervention in nurses' consultations with patients undergoing surgery for colorectal cancer.	An explorative quantitative and qualitative design was used based on analysis of transcriptions of audio-taped consultations	18 patients undergoing colorectal surgery	Sweden	"Talking with" valued more highly than "talking to" Required a specific research nurse to promote new PCC ways of working. Seeing the person in the patient, listening to the narrative and education for nurses in PCC communication is recommended.	This one intervention was part of a much bigger move towards PCC in the area Nurses viewed as responsible for the success-fulness of PCC, when other MDT members were evidently key stakeholders too in this paper.
Literature Reviews							
1.	JAKIMOWICZ, S. and PERRY, L., 2015. A concept analysis of patient-centred nursing in the intensive care unit. *Journal of Advanced Nursing*, 71(7), pp. 1499-1517.	To report on the analysis of the concept of patient-centred nursing in the context of intensive care.	Concept Analysis	NA	Not shared	ICU presents different challenges from other less critical areas of acute care. However, taking a PC approach has the potential to improve patient satisfaction with their ICU experience and improve nurse job satisfaction. More research required.	ICU focus, but experiential of PCC, so included.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Literature Reviews (continued)							
2.	LAWRENCE, M. and KINN, S., 2012. Defining and measuring patient-centred care: an example from a mixed-methods systematic review of the stroke literature. *Health Expectations,* 15(3), pp. 295-326.	To identify stroke-specific patient-centred outcome measures and patient-centred interventions.	A systematic mixed-methods review	Data Bases searched AMED, ASSIA, BNI, Cochrane Database of Systematic Reviews (CDSR), ACP Journal Club, DARE, CCTR, CINAHL, EMBASE, MEDLINE and PsycINFO	Scotland	3 specific areas of focus for post Stroke PCC were identified from the literature: The meaning-fulness and relevance of rehabilitation activities Quality of Care Communication The authors suggest that PCC for Stroke patients should use these key areas as their framework. Discusses tensions from systematic processes in stroke care and need to individualise and personalise care using the above 3 overarching approaches. Very clear Systematic Review.	Not OPAH acute focused, but informs PCC background knowledge base.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Literature Reviews (continued)							
3.	MCCORMACK, B. et al., 2010. Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences*, 24(3), pp. 620-634.	Using a theoretical framework of person-centred nursing to undertake a qualitative meta-synthesis of the findings of four different research studies of people with long-term health problems.	Qualitative meta-synthesis	The 4 studies were published by the reviewing authors.	Ireland	Professional competence and being clear about your own motivation for PCC is a pre-requisite to PCC. Whilst PCC is articulated in policy and plans in healthcare, care delivery is still routine based with less time dedicated to build the necessary relationships for PCC. Introduces a model of PCC that captures the complexity of PCC in practice in a meaningful way.	There could be author bias when reviewing their own studies. Promotion of the 1st authors model of PCC.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Literature Reviews (continued)							
4.	SAY, R., MURTAGH, M. and THOMSON, R., 2006. Patients' preference for involvement in medical decision making: A narrative review. *Patient education and counseling*, 60(2), pp. 102-114.	To clarify present knowledge about the factors which influence patients' preference for involvement in medical decision making.	Narrative Review	CINAHL, EMBASE, MEDLINE and PsycINFO	England	While patients' preferences for involvement in decision making are variable and the process of developing them likely to be highly complex, this review identified several influences on patients' preference for involvement in medical decision making, some of which are consistent across studies.	Not specifically focused on older people, but given the demographic population of medical care likely to be applicable.

	Reference	Study Aim	Method	Participants	Country	Key Findings	Limitations
Literature Reviews (continued)							
5.	MCCORMACK, B. 2015. Person-centredness – the 'state' of the art, *International Practice Development Journal*, 5(Suppl)[1].	To provide an overview of person-centredness and ways in which person-centred practice has been adopted in healthcare systems internationally.	Scoping Review	Not included, authors acknowledge this is not a compre-hensive presentation of PCC evidence to date at the time of publication.		Provides a synopsis of PCC activity & philosophy internationally. While there have been considerable advances in the development of person-centredness, there is a lot of work to be done in the adoption of more consistent approaches to PCC development and evaluation. In particular, a shared discourse and measurement tools are needed. Internationally, person-centredness is gaining momentum and many countries have strategic frameworks in place to direct its development and implementation.	None noted.

2.6 Themes from the Literature Reviewed

Drawing on other comprehensive narrative reviews as guides on structure (Corno, Epinoza and Maria Banos 2019; Sikes et al. 2019; Schaepe and Bergen 2015; Baker and McLeod 2011), the key themes will now be presented to help the reader visualise the literature which has been critiqued and synthesised will be adopted(Gregory and Denniss 2018. Each study was critically read, notes taken and key themes identified. A summary of the findings is presented in Table 2.1. The emergent themes were then cross referenced across the breadth of the studies included, in keeping with the analytical process for a comprehensive narrative literature review (Baker and MacLeod 2010). Presenting literature review findings in emergent themes also justifies where gaps in the existing knowledge base occur and where future studies can add new knowledge. The three emergent themes from the literature review were:

- What constitutes PCC
- The impact of PCC on OPAH and MDT Staff
- The facilitators and challenges to being person-centred

The sub themes within each of these overarching emergent themes are displayed in Table 2.2 below.

Table 2.2 Emergent themes and subthemes of literature reviewed

Emergent themes	Sub theme
What constitutes PCC	Recognising individuality Level of involvement in care Being present, making connections that influence shared decision making Relational care
Impact of PCC on OPAH and MDT Staff	On older people receiving care, their families: • Being listened to • Connected with and comforted • Length of hospital stay, physical function and quality of life • MDT increased fulfilment at work
Facilitators and challenges to being person-centred	Facilitators: • Leadership supporting a move towards PCC cultures of care • A structured approach to implementing PCC Challenges: • MDT overwhelmed by the complex needs of older people • Older people objectified with a drive for rapid discharge • MDT believing they know best • Older people preferring a paternalistic model of care

2.6.1 What Constitutes PCC

As demonstrated in the background chapter and within the literature reviewed, the language of PCC is now commonplace in international healthcare policy and the evidence base (Manias 2019; Salisbury et al. 2018; Marriot Stratham et al. 2018; Pettersson et al. 2018; Saunders, Green and Cross 2017; Slater, McCance and McCormack 2017; Horrel et al. 2017; Hayden, Brown and Van der Riet 2017; Huang et al. 2017; Moore et al. 2016; McCormack and McCance 2016; Lui, Gerdtz and Manias 2016; McCormack et al 2015; WHO 2015; Esmaeili, Cheraghi and Salsali 2014; Scottish Government 2010, 2011, 2013, IHI 2011; McCormack, Dewar and McCance 2011; Edvardsson and Nay 2009; DOH 2009; DOH 2001). Indeed, many authors promote PCC practices as a marker of high-quality healthcare (Marriot Stratham et al. 2018; McCance and McCormack 2017; Huang et al. 2017; WHO 2015; Slater, McCormack and McCance 2015; IHI 2014). Nevertheless, the rapid review conducted by De Silva (2014) acknowledged that PCC lacked a consistent definition, leading to ambiguity alongside wide variations in the interpretation of PCC.

Although a universal definition of PCC remains challenging to agree upon, as discussed in Chapter 1 , several contemporary models of PCC consistently comprise of components: holistic individualised care, joint decision making, patient autonomy and respectful care (McCormack and McCance 2017; Institute of Health Improvement (IHI) 2014; Asimakopoulou and Scambler 2013; Department of Health 2011; Scottish Government 2010; Cooper, Smith and Hancock 2008; Brooker 2007; Nolan et al. 2004; Stewart 2003; Mead and Bower 2000; Gerteis et al. 1995). Within this chapter, some of these key components of PCC remained evident. However, further specific aspects of what constitutes PCC, that are at odds with the drive for older people to actively participate in their healthcare decisions were revealed. Within this literature review, having a more flexible approach to PCC appears to be intrinsically linked to recognising the uniqueness of the people requiring care, which will now be examined in more detail (McCormack and McCance 2017; The HF 2014; HIS 2014; Sabat 2002).

2.6.1.1 Recognising individuality

Individualising care was a consistent thread within the international scoping searches reported in Chapter 1and through to the results in this literature review. Indeed, Bolster and Manias (2010) found in their Australian qualitative study that older patients expected nurses to individualise their approach in interactions during medicine administration. Using naturalistic observation and face to face interviews with nurses (n=11) and older patients (n=25), the findings from the study reported that nurses valued a PCC approach to medicines administration, however appeared not to individualise medicine administration. Instead nurses administered medicines in a routine task orientated manner, often avoiding opportunities to have person-centred medication- related discussions. There appeared to be recognition when interviewing nurses in this study that individualisation is an essential component of PCC, however, within the practical application of PCC, the nurses appeared to be more at ease with routine task-based based care. The nurses valued what Abdelhadi and Drach-Zahavy (2012) identified as a preference for *getting the job done*, in relation to medication administration, rather than a person-centred approach. However, anecdotal evidence suggested other reasons for a non-person-centred approach to medicine administration such as pressures of work, along with the drive for safety in medicines administration - focussing fully on the 'task' of safe medicines administration rather than engaging in dialogue, could be influencing factors (SPSP 2019).

Reasons for a lack of individualised care were provided in an ethnographic case study of one older person's experiences of PCC in Canada (Rankin 2015). This study found nurses relied upon a technological assisted decision-making tool, where a computer assisted programme directed the nurse's actions according to the patient's vital signs and post-operative phase of recovery. Johansson, Palmqvist and Ronnberg (2017) conducted an integrative review on nursing decision making process and found more individualised nursing decisions can be made when nurses' intuition, alongside track and trigger tools (for example National Early Warning Systems, highlighting physical deterioration) are used. The Nursing and Midwifery Council (2018) have an expectation that nurses would individualise care. Rankin (2015) concluded that the technology assisted decision making tool impeded PCC. This study considered the older person, family member and nurses' perspectives and found that attempting to follow protocols rather than individualising care, failed to meet the older person's complex care needs. The older person in the study had competing co-morbidities and the protocol driven care did not take this or a need for changes in personal social care post discharge, into consideration. The nurses in this study adhered to protocol, which led to the family being deeply dissatisfied with the level of non-person-centredness taken. However, although Rankin (2015) provides rich insights into PCC experiences caution must be exercised in making generalisations for this singular ethnographic case study (Polit and Beck 2014).

2.6.1.2 Level of involvement in care

Alharbi et al. (2014 a.) found in their Swedish deductive content analysis study with 16 older people, that when individualising care, PCC can mean that some patients want to lead their care, whilst others do not. The background chapter established a strong prevalence of PCC being synonymous with being involved, leading your care decisions and healthcare plan. However, in Alharbi et al.'s (2014 a.) study and some further studies considered in this review, the theme emerged where participants, at times, chose to not be actively involved in their healthcare decisions or plan. Participants expressed a preference for healthcare professionals to take the lead in their healthcare (Alharbi et al.2014 a.; Kvale and Bondevik 2008; Say, Murtagh and Thomson 2006). Furthermore, Alharbi et al. (2014 a.) suggested that older people often value being listened to more than leading their own healthcare. Thus, for the older participants in this study, PCC meant doctors leading healthcare decisions. Alharbi et al.'s (2014 a.) study offered a limited viewpoint of only seeking older peoples' perspectives, when PCC experiences can also be influenced by family and MDT member experiences (Horrell et al. 2018; Gill et al. 2014). Furthermore, Kvale and Bondevik's (2008) phenomenological study of people's experiences of patient centred care in Norway, uncovered a fundamental component of PCC is establishing how much a person wants to be involved in their care decisions at each interaction. Say, Murtagh and Thomson's (2006) narrative review of patient involvement, carried out in 2006 in England, also found inconsistencies in how involved patients wanted to be in their care. The authors discovered that people with long term conditions that held higher levels of education or were younger in age (less than 65 years old) demonstrated a desire to be involved in their healthcare decisions. Additionally, their narrative literature review found older people the least willing to be actively involved in their care, preferring medically led care (Say, Murtagh and Thompson 2006). This is a key aspect where this literature review questions current expectations of PCC consistently meaning being actively involved in your care. For some older people, the preference to hand the locus of control (Glanvill 2018) for their healthcare to the healthcare professional, is to them PCC. The 'level of involvement' theme within the literature review led to further exploration of the shared decision-making evidence, post data analysis, to influence the discussions in Chapter 6.

Another perspective of recognising individual preferences around levels of involvement in care was discovered by Gill et al. (2014) in their Swedish based thematic analysis study of older people (all over 80 years old) requiring rehabilitation. Their study which recruited both patients (n=13) and family members (n=11) found that older people placed more importance on knowing individual staff by name for PCC to be experienced, than their personal expectation to be involved in their care decisions. Further to this, Ross, Tod and Clarke (2014) acknowledged the need to recognise the importance of individual qualities which staff members can bring to PCC delivery. Ross, Tod and Clarke's (2014) PAR study, which was conducted in England, investigated nurses' perceptions of PCC experience, in the first stage of a programme of change towards PCC delivery. Subsequently whilst this study found positivity in the movement towards PCC cultures of care, a limited perspective of only one stakeholder (nurses) is presented and as PCC delivery appears to be influenced by those receiving care as well as those delivering it. Despite the usual nature of PAR methodology facilitating gathering multiple perspectives (Balum, MacDougall and Smith 2006; Glasson et al. 2006); Ross, Tod and Clarke's (2014) study could have been enhanced by providing a wider stakeholder perspective.

In summation, recognising the individuality of older people has been demonstrated as a consistent aspect of PCC within the literature reviewed. However, assessing individuals for what level of participation in their care meant PCC was less prevalent, but still present as a lesser theme within this part of the literature review.

2.6.1.3 Being present, making connections that influence shared decision making

Recurring themes of being present through older people experiencing active listening, regular contact and attentiveness from the MDT were found to be valued as components of PCC, in this review (Pettersson et al. 2018; Alharbi 2014a; Dewar and Nolan 2013; Jensen, Vedelø, and Lomborg 2013; Marshall, Kitson and Zeitz 2012; Dewar 2011; Kvale and Bondevik 2008). In the context of this literature review, the term *being present* was represented by dedicated active listening, attention to fine details and a sense of being valued. Berwick (2014) summarised this as a patient feeling as though they were the only patient in the care of the health professional with them.

An additional Swedish study by Pettersson et al. (2018) explored the move towards PCC approaches in pre-operative consultations for patients (predominantly older individuals) undergoing planned colorectal surgery. Pettersson et al. (2018) found patients valued staff actively listening to their narrative and *'talking with'* (p.2908) approaches as opposed to a *'talking to'* (p.2908) stance. This resonates with Alharbi et al. (2014a) who, as considered above, found patients placed higher value on being listened to, than playing an active part in their healthcare decisions. Subsequently to Alharbi et al (2014a) and Pettersson et al. (2018), Naldermirci et al. (2018) carried out a qualitative study of the implementation of PCC in an acute medical area in Sweden, with older people (n=20) and staff (n=35). Results established that patients were unaware of the term PCC but sensed a flattened hierarchy between them and the MDT. Moreover, older people reported a sense of working with, rather than being cared *for* and this reassured and encouraged them to share decisions. The larger number of healthcare professionals(n=35) meant multiple perspectives were gathered from different disciplines, representative of usual working teams. The move towards a PCC approach appeared to contribute staff being present with those they cared for and developing a sense of connection, from the older people's perspective. The healthcare professionals' views will be shared further on in this chapter.

The importance of connection, attentiveness and personal contact in creating a sense of PCC was further resonated in Jensen, Vedelø, and Lomborg's (2013) Danish qualitative analysis of personal care carried out with a very specific group of older people with COPD. The participants in the latter study reported experiencing a sense of being acknowledged and part of the care process, when receiving person-centred personal assistance. Correspondingly, the ten older people in Marshall, Kitson and Zeitz's (2012) phenomenological study reported being unfamiliar with the term PCC, but in describing their experiences of acute care explained what aspects of care were experienced as person-centred. Older people in this study shared positive experiences of staff being attentive to their care needs, shared involvement in care and these experiences led to a sense of connection.

Being present, or as Dewar defined (2011 pp.137) emotionally connecting, 'clicking' with older people requiring care, occurs as a strong theme within her PhD study exploring compassionate care in an acute medical area in Scotland. Using an Appreciative Inquiry approach within a PAR project, Dewar's findings led to subsequent publications, promoting a new framework for relational compassionate care (Dewar and Kennedy 2016; Dewar et al. 2014; Dewar and Cook 2014; Dewar and Nolan 2013, Dewar 2011). Dewar's (2011) initial empirical research explored compassion with older people, families, and a wide range of the MDT caring for older people. Subsequently, the Caring Conversations Framework encompassing a 7 C approach of being: **c**ourageous, **c**onnecting emotionally, **c**ollaborating, being **c**urious, **c**onsidering other perspectives, **c**ompromising and **c**elebrating, resonated with the literature review theme of being present, to be person centred. Despite the topic of Dewar's (2011) research being compassion, rather than PCC, there are substantial commonalities relating to 'getting to know the person' (Dewar and Kennedy 2016 p.1478) and the definitions and models of PCC discussed in Chapter 1. Dewar's (2011) study presented highly insightful data on the importance of caring conversations and connection in order to deliver compassionate care. However, the ratio of participants is heavily balanced towards the MDT participants (n=40), with fewer older people (n=10) and family members (n=12). Such a ratio could infer a richer perspective of compassion being shared from the MDT perspective than the older people and family member participants. On the other hand, the wide range of MDT participants demonstrates breadth of experiences across the MDT, as well as richness of experiences shared. Furthermore, the lengthy and immersive nature of AI / PAR methodology, where the researcher was present over a prolonged period collecting repeated cycles of data, arguably facilitated deep insight into multiple perspectives on compassion (Balum, MacDougall and Smith 2006). Additionally, whilst not categorising shared decision making as an explicit aspect of PCC or compassion, Dewar's (2011) study indicated links between the MDT connecting with the older people and their families led to approaches to care being planned from the older person's preference. A key strength of Dewar's (2011) study was the sharing the multiple perspectives on care experiences in OPAH care, including the key stakeholders of older people, their families and the MDT. The latter study had an influence on the methodological design in the doctoral process, as the multiple perspective design appealed to my worldview.

McCormack and McCance's (2017) model has been used as the PCC theoretical lens for this thesis due to the theoretical underpinnings used to develop the model of PCC (McCance et al. 2010; McCormack and McCance 2006; McCormack 2004) and because the model suggests developing healthcare culture as an approach to supporting PCC. As discussed in Chapter 1, shared decision making features in the latter model and can also be found as a component in PCC definitions from around the world (CPcPR 2019, WHO 2016, 2007; IHI 2014; GPCC 2010; NHS England 2009; Scottish Government 2010, 2015, HIS 2016). Sharing decision making between patients, families and the MDT requires a flattening of healthcare hierarchy and facilitating people receiving care believing that they hold the power over their healthcare decisions (Naldermirci et al. 2018; Clousten et al. 2018).

Such a sense of locus of control, power sharing and being present also resonated in Kvale and Bondevik's (2008) phenomenological Norwegian study of the lived experiences of twenty people with cancer (including older participants). The participants placed value on medical staff primarily negotiating with them to decide how much they wanted to participate in their healthcare decisions. At the outset of consultations, the participants preferred an invitation around how much they wanted to lead decision making processes around their cancer plan of care and conversely how much they would prefer their medical physician to take the lead. For these participants PCC was not synonymous with consistent shared decision making, instead PCC meant having a choice in whether to participate in decisions or not. Although the focus of this study was around people with cancer, it was included in this review for the insights into how PCC is experienced.

Appreciation of sharing decisions as a component of PCC is presented in a contrasting light in Van Mosel, Alford and Watson's (2011) Canadian qualitative study of Oncologists (number not shared). In this study, some of the consultants shared their experiences of PCC, where they believed having thoroughly considered a patient's medical notes and created a treatment plan prior to a consultation, constituted PCC. The concept of 'being present' and sharing decisions was absent in Van Mosel, Alford and Watson's (2011) study. The study also appeared to lack rigour with no clear aim, objectives and significant missing details, such as number of participants. However, it provided a unique perspective on how medical members of the MDT define and experience PCC, therefore despite lacking rigour, it was still deemed worthy of inclusion. Lamiani et al.'s (2008) Italian study demonstrated a more rigorous approach with a clear aim, explanation of methods were appropriate to the purpose of the study and transparency of the research approach throughout. Lamiani et al. (2008) compared Italian and American doctors' perspectives on PCC. A video conference focus group was used to collect data within a PAR approach and the participants consisted of four American doctors and five Italian doctors. Video conferencing data collection can lead to inhibitions to share information less freely and can be more complex to analyse (Silverman 2013). However, an open sharing of perspectives was evident in Lamiani et al.'s (2008) findings. Clear differences in PCC approaches were shared where *being present* with patients was a much higher priority for the American participants than Italian participants. Differing cultural expectations of PCC were thereby uncovered; with the study concluding that recognising patients' autonomy to be actively involved in their healthcare decisions was vital to American participants. In contrast, the Italian participants believed paternalistic, medically led care was in their patient's best interest. As this was the only Italian study on PCC found via the literature search, it may signify less of a shared decision approach to PCC in Italy. On balance, only one American study (Rathert et al.2015) was identified in the literature review but this study reported a connection between the people receiving and giving care, with shared decision making a cultural norm in America. The participants' essence of involvement resonated in Rathert et al.'s (2015) regression analysis study considering patient feedback from 142 hospitals. The authors found that when patients felt emotionally connected, they shared decisions and experienced a sense of person centredness alongside high levels of satisfaction with healthcare delivery (Rathert et al 2015).

Comparable to Lamiani et al. (2008), Lui, Gertdz and Manias (2016) used clinical practice videos to collect data in a critical ethnographic video discourse analysis study in Australia. Nurses (n = 76), doctors (n= 31), pharmacists (1) (hereafter referred to as the MDT professional) and patients (n= 27), agreed to being videoed during medication related interactions to examine PCC medication related communication. Unlike Bolster and Manias (2010), Lui, Gertdz and Manias (2016) recognised the MDT professional nature of medication management. However, Lui, Gertdz and Manias (2016) discovered people receiving care did not feel comfortable to raise concerns around their medications relying instead on polite discourse. The authors reported a sense of normalisation of the healthcare professional hierarchy, with professionals holding more power over medication management, rather than creating opportunities for person-centred collaboration. This study shared experiences of those receiving care describing a sense of being disempowered, with the locus of control being balanced more towards the MDT member. The MDT professionals' video footage revealed power dynamics within their body language e.g. evident by standing over patients during medication administration, rather than sitting with them and decisions being made in corridors away from the patients' bedside. In this sense, the MDT did not appear to be present with the those in their care; therefore, could have been perceived as less person centred.

Marshall, Kitson and Zeitz's (2012) literature review reveals that MDT members *being present* and *emotionally connecting* emotionally with people in their care can be an influencing factor on how PCC is experienced by individuals. Being present was shown to influence the locus of control in sharing healthcare decisions. Other factors such as healthcare cultural differences and normalised hierarchy, also appeared to influence the sharing decisions component of PCC. Being present and establishing a connection between those receiving and those giving care, was determined as a foundation to establish a person-centred professional relationship within the studies reviewed. Dewar's (2011) PhD work and related publications made explicit links between the connections MDT staff create with older people and their families in relation to compassion. Thus, the association of building relationships between the latter studies of person-centred models of care and relational models of care (Dewar and Nolan 2013; Dewar and Kennedy 2016) informed and directed the next sub theme to be explored: relational care.

2.6.1.4 Relational care

Despite the narrative review by Say, Murtagh and Thompson (2007) finding that some acutely ill older people appear to prefer more traditional paternalistic care rather than being actively involved in their care, this English review also found that that older people value relationship-based care. Indeed, the authors suggested that on occasions, older people prefer staff forming relationships with family members, who can then advocate on their behalf, than taking the lead in care decisions. Other authors considered relational care to be a separate construct to PCC (Dewar and Nolan 2012, Nolan et al. 2001) but relational care was considered vital to older people and their families within Bridges, Flatley and Meyer's (2010) systematic review of older people and their families' experiences of acute care. Furthermore, the latter authors found the need to connect and build relationships was a key finding; concluding that relational care is essential for OPAH, to individualise dignified care and share healthcare decisions. Indeed, within the theoretical framework of this thesis, McCormack and McCance (2017) consider relational care as an essential component of PCC. Dewar's (2011) relational model of compassionate care was based around the 'caring conversations' that take place between older people's families and the MDT. The curiosity suggested in Dewar's (2011) model of relational care, could also be aligned to the WHO (2016) agenda; encouraging people to be actively involved in all aspects of their care. Additionally, Dewar's (2011) work mirrored the aim of the GPCC - that PCC begins with understanding people's personal narrative (2018). As suggested in Chapter 1, in Scotland Dewar's (2011) 'caring conversations' appear similar to the basis of PCC in Healthcare Improvement Scotland's (2011) campaign focusing on 'What matters to you (as the person requiring care)?'.

Other authors (Hurtley and Obe 2012; Gill et al. 2014) argue that relational care is an essential part of PCC; therefore, this thesis will regard relational care as an integral rather than separate concept of PCC. The literature explored recognised individuality and connecting with people as being perceived as the enabling foundations of developing a relationship, thus providing PCC. Horrell et al. (2018) contended that from both older people and MDT perspectives, the relationship formed between the person receiving care and those providing it provides the foundation to developing PCC. Furthermore, Ross, Tod and Clarke (2014) concluded that nurses believed their relationship with the people they cared for was fundamental to tailoring PCC. However, as no patient perspectives were gathered in Ross, Tod and Clarke's (2014) English exploration of PCC, individuals receiving care were not represented. Similarly, in Hebblethwaite's (2013) Canadian study of recreational therapists' experience of PCC, only the

MDT voice was presented, but again relational care was viewed as essential to PCC delivery.

Furthermore, relational aspects of PCC were not viewed as confined to patient and MDT relationships; McCormack and McCance's (2017) model suggested that effective staff relationships are a prerequisite to the provision of PCC. Likewise, Maben et al. (2014) found in their English mixed methodology study of older people, family members and staff experiences in acute elderly care, that staff believed a "family at work" (p. 90) culture encouraged more person-centred approaches. Correspondingly, the PCC theoretical lens for this thesis (McCormack an McCance 2017), moves on from strictly *patient* outcome approaches of the PCC model to *person-centred* outcomes, encompassing staff and patients. McCormack and McCance (2017) set potential outcomes, when taking a person-centred approach, whereby both the people receiving care and those delivering it can experience:

- Satisfaction with Care
- Involvement in Care
- Feeling of Well-being
- Creating a Therapeutic Culture.

However, the PCC literature predominantly emphasised the person in need of care, with minimal inclusion of what PCC means to those responsible for delivering it (Alharbi et al.2014 a.; Kvale and Bondevik 2008; Say, Murtagh and Thomson 2006). Furthermore, McCormack and McCance (2017) propose that when working within a person-centred culture there is the potential for the creation of positivity for all involved.

When components of PCC, such as individualising older peoples' care; working with their values and beliefs; being present, active listening, connecting with and shared decision making were present in clinical research areas, person-centred outcomes appeared to be achieved (Larsson and Blomqvist 2015; Olsson et al. 2014; Alharbi et al. 2014a, Alharbi et al. 2014b; Jensen, Vedelø and Lomborg 2013; Lawrence and Kinn 2012; Bridges, Flatley and Meyer 2010; McCormack and McCance 2006). These positive outcomes appeared to dominate what constitutes PCC in this literature review. Nonetheless, there are challenges in embedding PCC in practice, as reported frequently in studies, where the MDT resisted moves towards fostering a PCC culture (Pettersson et al 2018; Olsson et al. 2014; Alharbi et al. 2014 a.; Alharbi et al. 2014 b.). The cultural acceptance of medical models of healthcare dominating clinical care was evident in the studies considered in this review, with latter studies concluding that to embed PCC more PCC research in clinical practice is necessary (Pettersson et al 2018; Olsson et al. 2014; Alharbi et al. 2014 a.; Alharbi et al. 2014 b.).

2.6.2 Impact of PCC on OPAH and MDT staff

Numerous components of PCC identified in the first theme of the literature review, such as empowering, enabling, individualising care, being connected and building relationships, are accepted as fundamental to healthcare delivery (Nursing and Midwifery Council (NMC) 2018). However, Olsson, Hansson and Ekmann (2016) suggested that carrying out PCC research in clinical areas is essential, to develop clarity on how MDTs could implement a culture of PCC including vision, policy and guidelines.

Despite these components being viewed as essential to embedding PCC it may also be challenging at times to consistently empower, enable, connect, build relationships and provide individualised care; as will be presented in the final sub themes of this chapter. Therefore, acknowledging the impact of PCC has on older people in acute care and on the MDT was a crucial component of this literature review, contributing to the wider picture of why PCC cultures are currently being promoted.

2.6.2.1 Being listened to

The literature review considered Alharbi et al.’s (2014a) deductive analysis of older people’s perceptions and experiences of PCC in Sweden. The study reported that older people valued the sense of feeling listened to, as opposed to feeling like an ailment to be fixed, when cared for within a PCC focussed culture. These older people participants acknowledged the value of family members being included to advocate on healthcare decisions on their behalf as a positive impact of person-centred approaches (Alharbi et al. 2014a). Sabat (2002) promoted the notion that so long as one family member can advocate on an older person's behalf, the older person's usual personhood can be respected, and care planned accordingly. However, as the Alharbi et al. (2014a) did not gather data on family members' experiences there is no way of knowing if family members valued being listened to and advocating, as part of PCC. Additionally, Kvåle and Bondevik's (2008) Norwegian study of people with cancer, found older people valued the partnership relationship they experienced with the doctor, built upon a sense of being listened to. Although Kvåle and Bondevik's (2008) study was not directly related to the PCC of older people in acute care, the study was relevant due to the focus on person-centred decision making for predominantly older people within oncology consultations. Additionally, the study provided insights into PCC experiences from patients, specifically around what they view as PCC experiences, therefore, added to the findings in this literature review in a meaningful way.

Furthermore, Horrell et al. (2018) uncovered, in their English mixed methods study (a scoping review and qualitative focus groups with clinicians, academic staff, voluntary staff and patients), that active listening was a distinct component of the impact of PCC experienced by patients. The study concluded that active listening facilitates shared decision making and coordinated approaches to care. However, the authors acknowledged that progressing towards PCC as normal practice is complex and may take some time to fully embed.

2.6.2.2 Connected and comforted

The impact of being listened to and creating a sense of *being present*, as discussed earlier, contribute to a positive experience of emotional connection between the patient, family and MDT (Rathert et al. 2015; Jensen, Vedelø, and Lomborg 2013; Dewar and Nolan 2013; Marshall, Kitson and Zeitz 2012; Dewar 2011). Such a premise is echoed in Rathert et al.'s (2015) regression analysis study, with the underlying aim of reviewing patient satisfaction and PCC experiences, across 142 hospitals in America. The 142 people (who had spent more than 1 night in acute care) surveyed, in the study rated the emotional connection experienced with staff as the most important impactful factor in person-centred approaches, alongside a strong sense of receiving physical comfort. However, this study relied on data from satisfaction surveys, rather than purposefully recruiting patient participants to explore their PCC lived experiences; therefore, there was not the opportunity for a deeper exploration of what those completing the survey meant by emotional connection or physical comfort. Survey data can provide limited insights into experiences, as opposed to more qualitative approaches, such as interviews (Cresswell 2014).

However, to develop connection, deeper perspectives of being viewed as a ‘person’ and not a ‘patient’ were presented by Naldermirci et al. (2018) using qualitative techniques of thematic analysis of interviews carried out with researchers, MDT staff and patients. This Swedish study established that PCC approaches eased communication by creating a flattened hierarchy, resulting in the patient and MDT reporting that they experienced a sense of being on an equal footing. Again, the sense of connection between the person receiving care and those delivering the care is apparent in this study. Furthermore, older person and MDT connection was uncovered consequently by Pettersson et al. (2018). Although PCC conversations were just one of several interventions examined in this mixed methodology study, the qualitative findings revealed positive experiences in the sense of comfort patients reported experiencing from connecting with their nurse pre-operatively. Thereby, developing a connection has been shown as valued by both older people and the MDT but the impact of taking a PCC approach appears to reach beyond satisfaction with an emotional connection.

2.6.2.3 Length of hospital stay, physical function and quality of life

The impact of PCC approaches on length of stay in acute hospital, physical function and quality of life were areas of interest in Sweden (Olsson, Hansson and Ekman 2016; Olsson et al. 2014, 2009). These aspects were researched in quantitative ways, presenting positive findings around reduced length of stay, improved physical function and quality of life (Olsson, Hansson and Ekman 2016; Olsson et al. 2014, 2009). However, lack of qualitative components to their research meant how older people, families or MDT experienced the change to PCC was absent in the findings.

In 2009 Olsson et al. reported on a Swedish study; a quasi-experimental, prospective design with cost benefit analysis for older patients (n=112) following a hip fracture. The intervention area recruited participants with similar demographics (n=56) to those recruited in the control area (n=56), where usual care without additional PCC education or changes to care occurred. Olsson et al. (2009) defined the PCC approaches as, creating individualised and integrated care pathways with patients pre-operatively, considering pre-hip fracture condition as a baseline, additionally the interventional MDT ensured patients remained in the area, rather than being 'decanted' around the hospital throughout their stay. The MDT (comprising an orthopaedic surgeon, registered nurses, health care assistants, physiotherapists, occupational therapists and a healthcare welfare worker) based in one orthopaedic area, attended staff development, to implement new individualised PCC approaches. Changing to what Olsson et al. (2009) determined as a PCC focus, resulted in a 40% reduction in length of hospital stay. The study acknowledged that although statistically significant results were produced; these could have been strengthened by utilising a larger sample size. Another weakness of this study was a complete focus on the financial implications of changing to a PCC without consideration of more qualitative factors, such as patient, family or staff experience of this change. However, a strength of the study was that older people determined their goals and integrated post-operative plans pre-operatively; acknowledging their sense of uniqueness.

Olsson et al. (2014) subsequently conducted a follow-up study to their earlier study (Olsson et al. 2009), comparing usual care post hip replacement care, standardised pre-operative information on anaesthetic, surgery, expected rehabilitation and expected length of stay. The usual care practices were compared to a new individualised PCC focus, using the GPCC (2011) model of care as the basis of uncovering the patient's personal narrative. Patients in the intervention area experienced MDT individualised integrated care planned pre-operatively, for their post-operative rehabilitation. Older people (n=266 in total, intervention group n = 138, control 128) were recruited to examine how PCC approaches had an impact on their length of hospital stay and physical function 3 months post-surgery (Olsson et al. 2014). Whilst the cost benefit analysis revealed length of stay reduction to 5.3 days in the PCC post-surgical care compared to 7 days in the non-PCC control group, the reduction in length of stay in the interventional group was highly statistically significant (p <0.0005). In addition to the results demonstrating differences in length of hospital stay, positive impact was found around increased physical functionality 3 months post-surgery. Staff in the PCC interventional area also reported overall positively regarding the move towards involving patients as partners in their care. Notably, this study demonstrated the complexities of conducting research with OPAH, who present with co-morbidities, complex and often unpredictable health needs.

Another Swedish quantitative study by Olsson, Hansson and Ekman (2016) also randomly assigned patients to a control and interventional care of OPAH. The interventional care area tailored person-centred rehabilitation post hip replacement based on individual older person’s level of physical vulnerability and self-efficacy, in similar ways to Olsson et al. (2014b). The control group, however, continued the usual care pathway, which was protocol driven, planning care according to the surgical procedure, rather than the individual. The study findings were complex, suggesting that the research could have resulted in two separate papers, one considering PCC for complex physical vulnerability and a separate one on PCC to support self-efficacy. However, the findings supported the ethos that providing PCC to older people, with complex healthcare needs, reduced length of hospital stay and increased readiness for safe discharge home. Absent from these cost effectiveness PCC studies (Olsson, Hansson and Ekman 2016; Olsson et al. 2014b) is the exploration of the impact of the move to PCC on the lived experiences of older people, their families and the MDT staff. Dominance of Swedish research considering the impact of PCC on hospitalised older orthopaedic patients where moving to PCC is associated with greater efficiency in healthcare and faster discharge rates is evident. Within the global context set in Chapter 1, the move towards PCC was ascertained to be driven by enabling and empowering people to be involved in their healthcare (WHO 2015, 2018; IHI 2014; GPCC 2018). The Swedish studies presented in this section focussed on measuring tangible outcomes of PCC for older people in orthopaedic areas of care. Reducing length of stay, as part of person-centred approaches, seems to be considered as a positive impact from the latter author’s perspective.

However, as explored later in this chapter, faster discharge rates are not always considered to be an indicator of a good person-centred care experience (Dillworth, Higgins and Parker 2012).

The preceding discourse demonstrates the impact of PCC on older people has been considered in a variety of clinical specialities, however, it was noted no studies identified in the literature review considered the impact of PCC on older people, families and staff in an acute medicine for the elderly areas. The impact on of PCC on older people and staff was considered, both simultaneously (Rankin 2015; Alharbi et al. 2014a, b; Dewar and Nolan 2013; Bolster and Manias 2010) and separately (Petterson et al. 2018; Ros, Tod and Clarke 2014).

2.6.2.4 MDT increased fulfilment at work

A number of studies were identified which specifically explored the impact of moving towards a PCC approach on the MDT (Marriot Stratham et al. 2018; Jakimowicz and Perry 2015; Larsson and Blomqvist 2015; Ross, Tod and Clarke 2014; Esmaeili, Cheraghi and Salsali 2014; Bridges, Flatley and Meyer 2010). Predominantly moving towards a PCC approach was found to have a positive impact on the MDT however, at times, the move was also shown as stress inducing. The comprehensive nature of this literature review, allows a degree of flexibility including some studies beyond acute care of the elderly areas; where there was a potential to inform the research proposed by this thesis (Gregory and Denniss 2018).

A study worthy of inclusion was carried out by Marriot Stratham et al. (2018). This PAR study was developed around McCormack and McCance’s (2017) PCC framework - the PCC theoretical lens for this research - therefore, was applicably included in this literature review. Although this study was undertaken in a non-acute care of older people setting (Nursing Home) in Australia, arguably the client group presented similar complex health needs to older people in acute care; albeit less critically unwell. Marriot Stratham et al. (2018) found having a PCC focus led to nurses having a greater sense of job satisfaction and created a more positive culture of care. However, the authors cautioned that the move to a PCC focus is complex and attributed success of this to implementing a supportive practice development approach, involving all levels of staff (Marriot Stratham et al. 2018).

Using a similar PAR methodology in an acute medical area in England, Ross, Tod and Clarke's (2014) also found nurses experienced a higher sense of job satisfaction when describing their experiences of PCC. However, the study did not explore any of the challenge's nurses encountered on the journey towards a PCC culture. Furthermore, by only exploring nurses' experiences of PCC, a narrow view of the MDT is presented (Ross, Tod and Clarke 2014). In another PAR project, Larsson and Blomqvist (2015) considered interprofessional approaches to PCC pain assessment and management in acute care. This study explored nurses and physiotherapists experiences following a move towards PCC focus (Larsson and Blomqvist 2015), finding that participants experienced a shift to appreciating the people they cared for as unique individuals, rather than patients. Participants also experienced higher levels of job satisfaction 'joy at work' (Larsson and Blomqvist 2015 p. 468) attributed to moving to a PCC approach. This study would have been strengthened by combining these perspectives with exploring patients' experiences of the move to a more PCC approach; this would have captured the key stakeholder' experiences of those receiving PCC. However, another systematic review of older people, families' and staff experiences of acute care, found similar evidence of greater nursing staff job satisfaction when connections are made to involve older people and their families (Bridges, Flatley and Meyer 2010).

Utilising a concept analysis of literature, Jakimowicz and Perry (2015) considered the evidence base relating to PCC in Intensive Care Units (ICU). Although their research was related to a critical area of care, comparisons can still be drawn from the findings of this study, not least the higher levels of nursing job satisfaction found when a PCC approach was followed in ICU. However, Jakimowicz and Perry (2015) also reported that on occasions nurses in ICU reported feeling overwhelmed by the complex needs and critical nature of the patient group. Hypothetically, it might be challenging to establish PCC with someone who is unconscious; there is likely to be a degree of reliance on family members to understand the person requiring care.

A study exploring the experiences of PCC from the perspectives of critical care nurses in Tehran was conducted by Esmaeili, Cheraghi and Salsali (2014) via thematic analysis revealed an experiential perspective. The nurses in this study shared that, at times they were overwhelmed by the complex needs of patients and this led to reverting to what they considered previous, routine task orientated care delivery (Esmaeili, Cheraghi and Salsali 2014). As the nurses in this study personally valued the individualised care aspects of PCC, reverting to routine-based care had a demotivating effect on their level of job satisfaction. However, it could be argued that healthcare culture may differ in Tehran from the UK, limiting the comparisons which can be drawn.

2.6.3 Facilitators and challenges to being person-centred

2.6.3.1 Facilitator: leadership support for PCC cultures

A recurring theme within the literature was the sustainability of PCC being achievable only where a clear leadership support for this philosophy of care exists (Pettersson et al. 2018; Jakimowicz and Perry 2015; Rankin 2015; Ross, Tod and Clarke 2014; Esmaeili, Cheraghi and Salsali 2014; Abdelhadi and Drach-Zahavy 2012; Hsu and McCormack 2012; McCormack 2010; McCormack 2001). However, Marriot Stratham et al. (2018) and Dewar (2011) and Glasson et al. (2006) suggest that successfully moving cultures of care towards new ways of working must have the support of all stakeholders: those receiving care and delivering care, as well as those leading it.

Pettersson et al.’s (2018) mixed methodology Swedish study demonstrated the move to a PCC focus was highly challenging and required sustained clinical leadership to embed PCC practices. The study reported the need for nurse leaders to employ a specific research nurse to promote the move to PCC in the research area. Furthermore, Jakimowicz and Perry ‘s (2015) concept analysis of PCC nursing experiences in ICU, echoed Pettersson et al.’s (2018) findings that nursing leadership can be a facilitator for PCC practice. Finally, Abdelhadi and Drach-Zahavy (2012) conducted a mixed methodology study (survey and observations of care) of 180 nurses employed in older people acute in Israel. Abdelhadi and Drach-Zahavy (2012) explained that leaders must take a *staff* *centred* approach to implementing person-centred approaches, exploring what staff value within the move towards PCC as part of the transition to this way of working. For example: the latter authors concluded that leaders should identify their staff definition of PCC in order to work towards establishing person-centred cultures of care (Abdelhadi and Drach-Zahavy 2012). However, it may have been more appropriate for leaders to gather the perspectives of those receiving care on how to define PCC, as well as staff views, when establishing PCC practice. Still, caution should be exercised when drawing parallels from PCC in the UK to Israel when arguably Israeli healthcare culture may differ significantly from the UK.

The theoretical PCC lens (McCormack and McCance 2017) employed in relation to this research recognised that achievability of PCC relies on the systems, processes and the people working within them to be person centred. However, as previously noted supporting MDT staff towards PCC cultures of care is not widely evidenced in the literature reviewed for this thesis - only a few authors reported the need for staff education for PCC to become normal practice (Marriot-Stratham et al 2018; Pettersson et al. 2018; Alharbi 2014a, b). It would appear from the review of the literature that implementing PCC can be more effective, when leaders cascade the potential benefits for both those giving and receiving care, to their teams. Marshall, Kitson and Zeich's (2012) phenomenological study of 10 patients in Australia led to the recommendation not to assume the MDT will be naturally committed to applying PCC in practice. The study concluded that being person-centred is not always the priority of all healthcare staff. Furthermore, Naldermirci et al.'s (2018) qualitative study exploring the implementation of PCC from patient, and health care professionals' perspectives, found that while some staff embraced moving towards PCC others were resistant; asserting the assumption that PCC would be more time consuming.

Consequently, this demonstrates that a key aspect of the leadership involved in implementing PCC is supporting staff through this process; in particular, taking a structured approach to manage the move towards PCC was clearly evident within the literature.

2.6.3.2 Facilitator: taking a structured approach to implement PCC

Where there was evidence of strategic and operational leadership, a structured approach was apparent in establishing a PCC as a change in the cultural way of working (Marriot Stratham et al. 2018; Hsu and McCormack 2012; Dewar 2011; Glasson et al. 2006; McCormack 2010; McCormack 2001).

As such, Marriot-Stratham et al. (2018) suggests that moving to a PCC focus would have been significantly more challenging without using PAR methodology. However, PAR methodology is recognised as labour intensive, from the perspectives of the researcher, as well as the key stakeholders in clinical practice (Parahoo 2014), therefore, utilising PAR is not always achievable.

Furthermore, in Dewar's PhD PAR/Appreciative Inquiry (AI) project (2011) and related publication (Dewar and Nolan 2013) examined and evaluated processes that enhanced compassionate relationship-centred approaches in acute care of older people are in Scotland. Whilst Dewar's (2011) work was not specific to PCC, focussing on compassion and relational care, the commonalities (i.e. similarities in the participant groups) with this research, justified inclusion in their literature review. Dewar's work (2011, Dewar and Nolan 2013) also demonstrated that taking a structured approach with the key stakeholders of patients, families and staff supported quality improvements for older peoples' care in hospitals. Notably, Dewar's (2011) work illustrated the labour-intensive nature of PAR; requiring a full-time dedicated researcher, as part of a fully funded research project (NHS Lothian Leadership in Compassionate Care Project).

Glasson et al.'s (2006) Australian PAR project in an acute medical area for older people also demonstrated that including older people (n= 60) and nurses (n= 13) in a joint project, facilitated a move towards a person-centred focus. This study explored the implementation of Orem's (1959) self-care model of care which led to a more PCC philosophy. Again, the authors acknowledge that PAR methodology, although labour intensive, facilitated improvements by giving those involved a voice in shaping the change process (Glasson et al. 2006). Giving voice to both those receiving care and those giving care as part of a move towards PCC, identified in Glasson et al. (2006) and Dewar (2011) was pivotal in the literature review, in shaping the research plan in this doctoral journey. Reflecting, to my own worldview and the origins of PCC (Chapter 1) taking a simultaneous multiple perspective view of PCC appeared to lead to a fuller understanding of the actualisation of how PCC could be experienced.

However, PAR was not the only structured way to support a move towards PCC identified in the literature. Several authors advocated taking a structured practice development approach, involving all staff in clinical areas, in an exploration of what PCC means to them as individuals (McCormack and McCance 2017; Hsu and McCormack 2012; McCormack et al. 2010; McCormack 2001). This practice development approach builds PCC from the healthcare team perspective, planning the move towards PCC through a series of gradual steps, based on a theoretical model of PCC (McCormack and McCance 2017; Hewitt-Taylor 2016; Olsson, Hansson and Ekman 2016; Olsson et al. 2014b). Taking a practice development approach, such as described, recognises that within PCC, the people delivering care require support to work in this way; not only the people receiving care.

Despite positive outcomes when leaders supported MDT staff to deliver a person-centred approach to care, the literature review uncovered challenges in the implementation of PCC.

2.6.3.3 Challenge: MDT overwhelmed by complex care needs of older people

Within acute care of older peoples' environments, the pressure to care for unwell individuals with complex needs may inhibit PCC approaches (Esmaeili, Cheraghi and Salsali 2014; Maben et al. 2012; Goodrich and Cromwell 2008). Although limited parallels can be drawn between Esmaeili, Cheraghi and Salsali's (2014) Tehranian thematic analysis and the research completed for this thesis in Scotland, the links to the sense of being overwhelmed leading to routine rather than PCC are noteworthy. Maben et al. (2012) also reported staff often resorted to de-personalised care for older people when they felt overwhelmed by their workload. Maben et al.'s study (2012) included patients, family carers and nursing staff in the qualitative aspect of their mixed methodology study, which included interviews and observations of care in an English acute medicine of older people area. The latter study reported that the most vulnerable and complexly ill older people appeared to experience objectification, being moved around without explanation or handled roughly. Whereas, the less complex unwell older people were often regarded preferentially and cared for with more dignity. Objectification is defined as the action of degrading someone to the status of a mere object (Cambridge Online Dictionary 2019) and was also apparent in Goodrich and Cromwell's (2008) Kings Fund scoping review of PCC for older people in acute hospitals. The review revealed that older people felt *'pushed around like a piece of packaging'* (p.10); with staff prioritising rapid discharge rather than delivering PCC. In alignment with the title of Goodrich and Cromwell's (2008) review (*Seeing the person in the patient*), recommendations were made to consistently view patients as people, opposed to basing care on a need for efficiency or rapid discharge

2.6.3.4 Challenge: older people objectified with a focus on for rapid discharge

Goodrich and Cromwell (2008) also found that although people are living longer, they are discharged from hospital 20% faster than they were 10 years previously, due to increasing acute healthcare demands. Indeed, HIS (2014) used faster discharge as a marker of quality achievement when inspecting quality and PCC practices in acute care. The previously considered Swedish studies identified faster discharge from orthopaedic areas as a positive outcome of PCC approaches (Olsson, Hansson, Ekmann 2014; Olsson et al. 2014, 2009). However, faster discharge is only person-centred if the person being discharged feels ready to go home from acute care. Dillworth, Higgins and Parker (2012) conducted their study in Australia considering the experiences of 10 older people who had been re-admitted to acute care following a recent discharge home. Data revealed that older people did not feel listened to as part of the discharge procedure and inevitably ended up being re-admitted rapidly after discharge (Dillworth, Higgins and Parker 2012). Participants reported feeling felt let down by the faster discharge process rather than seeing it as a marker of high-quality healthcare. Arguably, Dillworth, Higgins and Parker (2012) presented an unbalanced research design by seeking only participants' lived experience of readmission to acute care. Whilst a larger sample size comparing those discharged from acute care, who were and were not readmitted, may have altered the findings, personalisation of discharge plans was crucial in Dillworth, Higgins and Parker's (2012) study.

Similarly, the focus on an urgency for rapid discharge was found in Gilmartin and Wright's (2008) study exploring older peoples' (up to age 85 years old) perspectives on day surgery. Despite older people feeling empowered by the pre-assessment process, they reported feeling abandoned immediately pre-operatively and a sense of objectification post-operatively (Gilmartin and Wright 2008). The evidence of a focus on efficient discharge, rather than PCC was reported in both Gilmartin and Wright's (2008) and Maben et al.'s (2012) studies of older people and staff in acute care. Both studies concur that older people participants felt objectified and treated less humanely than they expected (Gilmartin and Wright 2008, Maben et al.2012). For example, acutely ill older people felt they were moved from bed to chair/commode in a dehumanising way, without conversation or roughly handled like an object; the parcel analogy was used repeatedly (Maben et al.2012; Goodrich and Cromwell 2008).

Although a sense of objectification was not present in Rankin's (2015) Canadian institutional ethnographic study, based on one case of a complexly ill older person, the focus on rapid discharge was evident. The study examined the use of an electronic technical programme aimed at improving standardised discharge planning alongside commitment to person and family centred care. Rankin (2015) reported on the 'empty rhetoric' of a person and family centred philosophy of care in the research area, while observational data and interviews with the older person, family and nurses revealed non-person-centred approaches. In particular, the family participant expressed deep concern that care was being planned around a set standardised protocol of discharge planning without taking into consideration complex individual home care needs or post-operative complications. Despite the limited generalisability from a single case study, the depth of experiences shared are noteworthy. The nurses appeared to prefer to follow standardised protocol, even when the older person's complex picture did not fit the protocol, Rankin's (2015) study revealed powerful messages around the challenges of technologically enhanced PCC. Rankin (2015) highlighted that at times PCC policy was not evident in the care delivery. Such a premise echoes back to the seed which inspired undertaking the research for this thesis - that despite a multitude of drivers (see figure 2.1), personal and anecdotal experience, PCC policy can be overlooked or absent in practical care delivery.

Although Hebblethwaite (2013) considered experiences of just one discipline (Canadian recreational therapists), findings uncovered, similar patterns emerged when thematically analysing eleven participants shared experiences of PCC across one acute facility for older people. Despite an overarching philosophy of person and relationship-based care, practice remained medically led and based on routine rather than individuality. Linking back to previous points are the locus of power, at times the MDT participants in the studies in this review believed they were in the best position to plan care, taking a more traditional medical model approach; rather than a person-centred one.

2.6.3.5 Challenge: MDT believing they know best

The MDT believing that they are in a better position to set realistic goals than the people they cared for, was evident in Gill et al.'s (2014) study of older people and their families' experiences of person-centred rehabilitation in Sweden. The study found the MDT were reluctant to facilitate older people (over 80 years old) setting their own goals, believing older people would set goals too high or too low. This created a power imbalance, suggesting a dichotomy where the MDT appeared to believe they 'know best' rather than sharing decisions in a person-centred way (Gill et al. 2014 pp.265). The challenges of power sharing and joint goal setting will be further explored in the context of discussing findings in Chapter 6.

Similar patterns were found in Lamaiani et al.'s (2008) study comparing Italian and America doctors' approaches to PCC, whereby PCC was found to be influenced by the doctors' cultural sense of self, rather than involving individuals in what person centredness meant to them. For example: the Italian participants believed that as doctors, patients expected them to lead care. Conversely, the American participants believed all patients wanted to be fully informed and involved in their care. Both the Italian and American participants did not consider changing their approach from person to person. As discussed previously (*section 2.6.2*), Van Mosel, Alford and Watson's (2011) qualitative study of Oncologists experiences of PCC revealed that some doctors believed they were being person-centred by utilising a paternalistic approach to consultations. To these participants, PCC meant having their plan of care ready to deliver, rather than jointly planning cancer care from both their medical perspective and their patients' expectations; or indeed asking what level of involvement they patient may want. Van Mosel, Alford and Watson's (2011) results demonstrated that despite healthcare professionals believing they are being person centred, in practice, they may be displaying their preference towards *"getting the job done"* (p. 1466 Abelhadi and Drach-Zahavy 2012) as opposed to a shared decision making approach to healthcare. However, another perspective could be that the Oncologists in Van Mosel, Alford and Watson's (2011) study could be that they were exercising their clinical expertise in preparing a plan prior to consultation; this may well be perceived as PCC to some individuals. In order to exercise a person-centred approach, it was seem that there is a need for the MDT to develop an understanding of what those in their care value, being actively involved in a plan or being led by the MDT. Abelhadi and Drach-Zahavy (2012) Israelian survey of nurses' PCC experiences found that valued based approaches to healthcare are not always exercised. Instead the authors found that staff often take a routine non individualised approach to care delivery. Abelhadi and Drach-Zahavy (2012) concluded that if PCC cultures of care are to be established, then staff who value theoretical principles of PCC should be recruited. These principles are considered to be working from a patient's value base, shared decision making, shared power and having a sympathetic presence (Pettersson et al 2018; McCormack and McCance 2017; Hewitt-Taylor 2016). Moreover, Abelhadi and Drach-Zahavy (2012) recommended that existing staff who value providing routine -based personal care, as opposed to person centred, power sharing approaches, require support and development to move away from paternalistic models of care. Additionally, Abelhadi and Drach-Zahavy (2012) found that the need to deliver PCC can be stress inducing for nurses, if they do not value this approach. Likewise, Marshall, Kitson and Zeich (2012) pointed out it is important to never assume the MDT knows, understands and is committed to applying PCC in practice. Finally, Alharbi et al. (2014 b) recommended that any move towards PCC should be accompanied by a pedagogical approach to support all involved. However, how older people define PCC may allude to previously accepted medical models of care delivery; this was evident in some of the studies in this literature review (Alharbi et al. 2014a; Bridges, Flatley and Meyer 2010; Say, Murtagh and Thompson 2007).

Reflecting back to the initial seed for this doctoral study, there appears to be an international drive to involve people in their healthcare (WHO 2017, 2019; IHI 2015). However, my personal and professional experiences of my brother being left out of his healthcare choices seemed to lack the person-centred approaches I advocated in teaching nursing (Scottish Government 2010). Instead, my discomfort with what I perceived as non-person-centred approaches appeared aligned to Gill et al.'s (2014); Lamaiani et al.'s (2008); and Van Mosel, Alford and Watson's (2011) findings, where the medical staff appeared to believe they were being person-centred by holding the locus of control (Glanvill 2018) over healthcare. Within the current literature review the possibility that some older people preferred paternalistic approaches to healthcare, for these individuals the MDT leading could be construed as PCC. Until discovering this perspective within the literature, I had not considered the wide range of possibilities PCC could mean to individuals.

2.6.3.6 Challenge: older people preferring paternalistic care

The uniqueness of individuals was found to impact on definitions and expectations of PCC. Alharbi et al. (2014 a) focussed on the move from paternalistic care to PCC, involving patients and nursing staff, one-year post implementation of a PCC model of care. Alharbi et al. (2014 a.) found that although patients reported valuing being cared for as a person, on occasion's patients would have preferred nursing and medical staff to lead their care. The authors acknowledged there were positive aspects of moving towards PCC cultures of care for both patients and staff, such as a greater therapeutic culture. However, challenges prevailed in delivering highly individualised PCC consistently when some patients did not want to be actively involved in their care.

Further to Alharbi et al. (2014 a.), Say, Murtagh and Thompson (2007) found from a narrative review, that acutely ill older people often have criticisms of PCC, at times preferring a more traditional paternalistic, less collaborative model of care. However, Say, Murtagh and Thompson (2007) also suggested that older people do value relationship-based care and whilst prefer family advocating on their behalf on occasion. Say, Murtagh and Thompson (2007) proceed to point out that across this narrative review, inconsistent approaches to PCC were evident. PCC was often synonymous with relational care and shared decision making (Say, Murtagh and Thompson 2007). However, relational care was considered vital to older people and their families, in Bridges, Flatley and Meyer's (2010) systematic review of older people and families' experiences of acute care. Thus, a consensus exists in the literature that relational care is essential to PCC (Gill et al. 2014; Dewar and Nolan 2012, Hurtley and Obe 2012; Bridges, Flatley and Meyer 2010; Nolan et al. 2001); however, the literature does not consistently suggest that for some older people PCC may mean the MDT leading their care (Alharbi et al 2014 a.; Say, Murtagh and Thompson 2007).

2.7 Summary of the Strengths and Gaps in the Literature

This literature review demonstrates strength in uncovering consistent themes that embedding PCC, can be challenging. Although the term PCC is now commonplace in healthcare, the philosophy may not be demonstrably present in practice. An additional strength in the literature reviewed was the widespread supporting evidence that PCC approaches provide opportunities for higher quality of care experiences and person-centred outcomes to be met (McCormack and McCance 2017). Furthermore, although there are many facilitators for PCC in practice, there remain challenges to be overcome. Moreover, research has been generated from older people, their families and some from members of the MDT, providing evidence of an ever-expanding PCC knowledge base. However, few studies incorporated all of these stakeholders experiences of PCC and limited numbers of studies were found considering simultaneous person-centred perspectives on the same experience of acute care.

The international interest in generating PCC evidence was seen by the wide range of countries publishing PCC evidence, as described and critiqued in the foregoing review namely: United Kingdom, Sweden, Canada, USA, Italy, Norway, Denmark, Israel and Tehran. Additionally, the variety of qualitative, quantitative, mixed methodology and literature review papers provides a comprehensive evidence base on the complexities of PCC in OPAH care. However, the weight of evidence uncovered by this literature review lies with qualitative studies, providing some insights into the essence of PCC for OPAH (Horrell et al. 2018; Marriot-Stratham et al.2018; Naldermirci et al. 2018; Moore et al.2017; Lui, Gerdtz and Manias 2016; Larson and Blomqvist 2015; Rankin 2015; Rathert et al. 2015; Alharbi. et al.2014a;Dillworth, Higgins and Parker 2014; Esmaeili, Cheraghi and Salsali 2014; Gill et al. 2014; Ross, Tod and Clarke 2014; Dewar and Nolan 2013; Jensen, Vendelo and Lomborg 2013; Abdelhadi and Drach-Zahavy 2012; Marshall ,Kitson and Zeitz 2012; Dewar 2011; Van Mosel, Alford and Watson 2011; Van Mosel, Alford and Watson 2011;Bolster and Manias 2010; Edvardsson and Nay 2009; Gilmartin and Wright 2008; Lamaniani et al. 2008; Kvale and Bondevik 2008; Glasson et al. 2006).

The framing of the inclusion and exclusion criteria for the literature review contributed to illuminating a summary of PCC for OPAH without cognitive impairment, their families and the MDT 's delivering care. There seemed to be some acceptance in the literature reviewed that PCC was influenced by older people, their families and the MDT (Horrrel et al 2018; Marriot-Stratham et al.2018; Glasson et al. 2006). However, several of the qualitative studies only considered one specific stakeholders' perspective on this phenomenon, when the lived experience of PCC. There were less studies found in this review that considered the variety of OPAH care experiences from a range of stakeholders' perspectives (Naldermirci. et al. 2018; Marriot-Stratham et al. 2018; Larsson and Blomqvist 2015; Rankin 2015; Gill et al. 2014; Dewar 2011; Dewar and Nolan 2013; Bolster and Manias 2010; Glasson et al 2006), Only Dewar's (2011) study and subsequent publications (Dewar and Nolan 2013; Dewar and Kennedy 2016) of compassion in OPAH explicitly attempts to capture experiences from the MDT and older person and family perspectives, based on all stakeholder's perspectives of the same care experience. There appeared to be strength in

Dewar (2011) multiple perspective study, which also seemed to be aligned to my worldview of developing insights from differing perspectives.
Notably, the quantitative studies (Olsson, Hansson and Ekman 2016; Olsson et al. 2014; Alharbi. et al.2014 b.; Olsson et al. 2009) in this thesis literature review provided additional motivators to move towards PCC cultures of care, suggesting that PCC can reduce length of hospital stays and improve physical function. However, these quantitative studies miss the deeper experiential barriers and facilitators to PCC in practice.

To ensure a broad knowledge base was captured in this literature review, studies which did not explicitly state a direct link to older people within acute care settings were appraised as appropriate for inclusion. Despite the research being carried out in a disease or interventional based area (for example orthopaedics, which featured repeatedly), these studies recruited older people as their participants (Olsson, Hansson and Ekman 2016; Olsson et al. 2014; Alharbi. et al.2014 a., b.; Olsson et al. 2009). Other studies (Esmaeili, Cheraghi and Salsali 2014; Ross, Tod and Clarke 2014; Hebblethwaite 2013; Abdelhadi and Drach-Zahavy 2012; Van Mosel, Alford and Watson 2011; Lamaniani et al. 2008) specifically considered either nurses or doctors perspectives of PCC, again providing insights directly, relevant to this thesis. A few studies considered patient, families and staff experiences when adopting PCC as a new area of practice (Naldermirci et al. 2018; Horrel et al. 2018; Lui, Gerdtz and Manias 2016; Rathert 2015; Rankin 2015).

However, none of these used collective case studies within a phenomenological approach; finding this potential gap in the methodologies influenced my methodological choices. One of the aims of conducting the comprehensive narrative literature review was to attempt to ensure the subsequent doctoral research would not replicate existing research, thus would add to the PCC evidence base. The discovery that a phenomenological approach to explore the simultaneous experiences of PCC of older people without cognitive impairment, their families and MDT staff in OPAH, appeared to have not been explored was significant in relation to this literature review completion. This facilitated planning the subsequent research anticipating that it would add to the PCC knowledge by employing and innovative and original approach

The conclusions drawn from this literature review demonstrated a gap in the PCC evidence base in capturing and reporting the simultaneous lived experience of PCC in acute older people hospital care, from multiple key stakeholders' perspectives: older people, their families and the MDT. Thus, guided the research aim and objectives, which were:

> **Aim**: To explore and interpret experiences of person-centred care from the perspectives of older people, families and the Multidisciplinary Team in an acute medicine for the elderly unit.
>
> **Objectives**
>
> This research intended to:
>
> 1. Illuminate how Person-Centred Care in acute care is experienced from key stakeholder perspectives:
>   a. older people
>   b. families of older people
>   c. members of the Multidisciplinary Team
> 2. To uncover the facilitators and barriers in practice to PCC

Utilising a collective case study approach, combined with an overarching IPA methodology was employed to facilitate exploration of deep insights into PCC experiences; with the intention of influencing future knowledge development and application to PCC practice (Smith, Flowers and Larkin 2012). The methodological choices will be critically explored and justified in depth, in Chapter 3.

As stated previously, personal reflections are shared throughout, to permit the reader to comprehend the personal growth throughout this doctoral study, in addition to presenting transparency around the processes followed and conclusions reached. The excerpt below, demonstrates my early perceptions of PCC and how through data collection and analysis my PCC paradigm shifted.

Reflective Excerpt: 11.1.17

… one of my supervisor's set me the challenge of by the end of 2017, from my literature review, to have a PCC as according to Katrina W.

Uniqueness of self/person - no matter what role we are in, patient, family, nurse, AHP, Dr, any healthcare staff, family or friend.

When attention is paid to uniqueness – everyone wins, gets better quicker, out of hospital, rehab, staff feel satisfied, fulfilled, lower staff turnover, higher retention. Families/friends feel more content/less stressed.

The system needs to be flexible to allow for uniqueness – efficiency is seen as following Standard Operating Procedures, however human beings are not standard. There needs to be flexibility in process driven healthcare to allow for uniqueness.

Self-awareness and ability to compromise is essential for all involved, with the direction of travel and priorities being set by the person receiving healthcare, if that is their choice. Analogy of a taxi driver comes to mind, the passenger is in charge, at times they will say which way they prefer to go, at other times leave it to the driver. There is a shared responsibility, but the passenger has the power, the fare!

Permission from leaders to be PCC – if systems of care are to be PC, then throughout the hierarchy and throughout the healthcare team there needs to be permission that PCC trumps routine, rituals and efficiency is seen as being PCC. THIS IS THE BIG CHANGE!
SO…I have McCormack -itis, I believe he has already figured out PCC, but supervisors question me, well if that is the case why is PCC not perfected in practice?

PCC values the uniqueness of all people involved in healthcare, the way care is organised is flexible to allow for individuality and attention to what matters most to those in need of care and those important to them. This leads to compromise, shared goal setting, where the person receiving care sets the direction and all involved celebrate achievement.

30.5.19

I am surprised I viewed this so clearly in 2017, as I feel data collection, analysis, revisiting the literature muddied my thought processes.

3.7.19

I had not considered at the beginning, or middle of the DPP, that PCC might mean paternalistic care, but now I do. I was caught in the place that it feels like my MDT participants are, where there is such a push for full patient involvement and shared decision making, that they almost need permission to adapt and lead care when that is their patient's preference. PARADIGM shift!

2.8 Chapter Summary

This chapter commenced by outlining the rationale for completing a comprehensive narrative review to develop and establish a critical and comprehensive understanding of the current PCC in OPAH care evidence base. The methods employed in this comprehensive narrative review provide the reader with transparency of the processes carried out (Aveyard 2019). Additionally, the weight of evidence available on PCC in OPAH care demonstrated tensions remain apparent in establishing PCC in acute care. Therefore, the results of this literature view support and confirm the potential to explore and interpret the lived experiences of older people, their families and the MDT in OPAH.

The conclusion of the literature review contributed to shaping the aim and objectives of this research, with the intention of providing a meaningful contribution to the PCC evidence base. The approach to conducting this research aimed to simultaneously provide views of the lived experiences of older people, their families and the MDT in OPAH. The foregoing literature review supports the methodological approach adopted in providing an innovative, meaningful addition to the existing PCC evidence base.

3 Methodology Chapter

3.1 Introduction

Creswell (2014) advises researchers to select the methodology that will best address the study's aim, as well as their personal epistemology and ontological world view. A reflexive approach will further explore and develop my rationale for selecting an interpretivist constructivist approach. Several rejected qualitative methods will be presented with explanations for their elimination. The choice to combine Interpretative Phenomenological Analysis (IPA) with a Collective Case Study approach will be also critiqued. My personal reflections on the process of reaching this decision will be shared, thus demonstrating a clear audit trail.

3.2 Epistemological and Ontological Influences on Methodological Choices

The doctoral journey led me to the realisation that my natural empathetic tendencies were an unconscious part of both my ontology and my epistemology – my way of making sense of the world and the unknown (Denzin and Lincoln 2013). Some authors believe that being a researcher can assist an investigator's self-awareness of their epistemological perspective and ontological view of the world; others suggest that it is epistemology and ontology which influence the study's objectives (Creswell 2014; Polit and Beck 2014; Silverman 2013; Denzin and Lincoln 2013). The development of personal insights into these concepts is therefore vital to the research process (Bryman 2012), adding rigour to the research design (Patel 2015). Since my ontological approach is to explore the world through various lenses, and my epistemological view is that investigating multiple perspectives can help develop new knowledge. The McCormack and McCance (2017) theoretical lens for this study appeared to align to my holistic perspectives, that PCC should be viewed organisationally, alongside the perspectives of those giving and receiving care. My personal and professional intention was to gain a more holistic understanding of PCC, therefore, for me it was my ontological and epistemological perspectives which determined the aim of my research: *To explore and interpret experiences of*

person-centred care from the perspectives of older people, families and the Multidisciplinary Team in an acute medicine for the elderly unit.
I reached my conclusion that my worldview is aligned to developing an understanding of how people live, work and make sense of in their social world, which Creswell (2014) associates with constructivism.

3.3 Research Paradigms

Once personal epistemology and ontology are established, researchers must locate their place within a research paradigm, which can be defined as a set of assumptions and perceptual orientations shared by members of a research community (Silverman 2013). Although Polit and Beck (2014) suggest that researchers' previous experience reveals their natural preferences, paradigms are not fixed (Iofrida et al. 2018): investigators may carry out studies across several paradigms (Silverman 2013). Furthermore, fundamental changes in the basic concepts or practices of a scientific discipline may lead to 'paradigm shifts' (Kuhn 1962).

3.3.1 Positivism and post positivism

Positivism is based on the premise that reality can be explained by a cause and effect process (Parahoo 2014). In the context of research paradigms, it can be defined as:

> *…a theoretical position derived from eighteenth century philosophy believing that scientific truth can only be derived from that which is observable by the human senses. Positivists would apply the methods of traditional scientific enquiry to the study of human behaviour.*
>
> (Gerrish and Lacey 2014 p.538)

Positivist researchers expect their investigations to contribute new truth to the knowledge base in a logical deductive, usually quantitative, paradigm (Polit and Beck 2014; Denzin and Lincoln 2013). They believe that only one reality and explanation of a phenomenon can be reached (Creswell 2014). One example is the Randomised Control Trial (RCT), commonly regarded as the gold standard of quantitative research (Joanna Briggs Institute (JBI) 2013). Olsson et al.'s (2009, 2014 b.) use of RCTs in Chapter 2 demonstrated its valuable contribution to the PCC evidence base.

In contrast, post positivists recognise that because knowledge is continually evolving, research regarding human behaviours permits no 'absolute truths' Creswell 2014 (p. 7) accepting the existence of multiple influences on studies investigating participants' experiences (Denzin and Lincoln 2013). Thus, both Alharbi et al. (2014 a.) and Olsson et al. (2016) used mixed methods to explore the complexity of achieving a PCC culture for older people requiring acute healthcare interventions. They recognised multiple causes for PCC-related experiences rather than a single truth (Creswell 2014). Silverman (2013) suggests that quantitative studies have now evolved to a post-positivist paradigm where RCTs aim to uncover multiple theories that can be tested, proven or disproven. Table 3.1, below, summarises the different research paradigms of positivism, post positivism, interpretivism and constructivism.

Table 3.1 Summary of Research Paradigms

Research Alignment	Positivist	Post Positivist	Interpretivist	Constructivist
Usual Research Intention	Seeking absolute 'truth' Generate new theory	Acceptance of no absolute truth Reductionist Investigating cause and effects Determine new knowledge	Explores human experiences Generate new knowledge Knowledge is interpreted from experiences	Develop new understanding Multiple participant perspectives Social construction of new knowledge Adding to an existing knowledge base

Methodological Approach	RCT Scientific Laboratory based investigations Hypothesis testing	Mixed methodological approaches of qualitative and quantitative approaches Theory verification	Qualitative approaches, ethnography, grounded theory, phenomenology Adding rich deep insights into a phenomenon	Qualitative approaches, ethnography, grounded theory, phenomenology, collective case studies, singular case studies Constructing new rich insights into a phenomenon

3.3.2 Interpretivist constructivism

Rather than adopting a positivist or post-positivist paradigm, I believe that every reality can be considered from multiple perspectives. Bryman (2012) explains that researchers with an ontological interest in multiple perspectives, and an epistemological curiosity in exploring experiences, usually adopt an interpretivist approach.

Interpretivism can be defined as:

> *…a belief that people continuously make sense of the world around them and different people may have different interpretations of the same phenomena.*
>
> (Parahoo 2014 p.469)

Here new theory is built from the analysis of participants' experiences as they construct their 'social reality' (Chandra 2019 p. 69). According to Polit and Beck (2014) and Iofrida et al. (2014) this paradigm can support the generation of new knowledge from human experiences. In this study the interpretivist approach was used to elucidate simultaneous PCC experiences from multiple perspectives in OPAH and then analyse the data to construct new PCC knowledge.

Interpretivism may influence constructivist approaches (Chandra 2019, Creswell 2014; Iofrida et al. 2014). Constructivist research explores how participants use multiple subjective realities to make sense of a phenomenon (Lincoln et al. 2011), in terms of what it means to them and how they experience it (Silverman 2013). Polit and Beck (2014 p.377) define constructivism as:

…an alternative paradigm to the positivist paradigm that holds that there are multiple interpretations of reality and that the goal of the research is to understand how individuals construct reality within their context; associated with qualitative research.

Chandra (2019) suggests that constructivist approaches facilitate meaningful exploration can add deep new insights into a phenomenon. My epistemological view appeared to align with both interpretivism and constructivism (Creswell 2014; Iofrida et al. 2014; Higginbottom and Lauridsen 2014). Since Creswell (2014) suggests that they can be combined, the current study will use both approaches to explore the multiple perspectives of PCC experiences and interpret how participants made sense of their reality.

3.4 Justification for qualitative approach

Polit and Beck (2014) suggest that qualitative approaches facilitates the development of a rich understanding of a phenomenon, constructed by people living within it. Therefore, a qualitative approach was deemed to fit with my reflexive epistemology and ontology as well as the objectives of the research. According to Denzin and Lincoln (2013), qualitative methodologies can lead to a deeper, inductive understanding of complex phenomena when exploring personal, social and cultural experiences. De Silva (2014) recommends their use for exploring the less tangible, compassionate, empathetic, dignity-enhancing aspects of PCC.

3.4.1 Determining the specific qualitative approach

Determining the methodology for a doctoral thesis is challenging, attention must be paid to the theorical considerations, the philosophical orientation and the researchers personal ontology (Creswell 2014). Janesick (2012) compares selecting a methodology to a dance, where the choreography is an evolutionary process; meticulous preparation leads to a better performance. Silverman (2013) concurs with Janesick's (2012)'s advice that good planning is essential. However, my experience reflected Polit and Beck's (2014) explanation that qualitative research designs develop flexibly during an investigation, often because of the research process itself. In 2015, I began the process of selecting the most appropriate approach for this study, starting by excluding unsuitable designs (Parahoo 2014).

3.4.1.1 Approaches excluded

I will critically explore the potential methodologies scrutinised to address the aims of this study, rather than presenting an exhaustive list of all exclusions. Grounded theory, discourse analysis, ethnography, participative action research and phenomenology were all considered, since they were the dominant methodologies identified within the PCC literature reviewed.

Grounded theory (GT) aims to develop new theory in areas where little is known about a topic or a new perspective is needed, Creswell (2014 p. 243) defines GT as:

> *…a qualitative strategy in which the researchers derive a general, abstract theory of a process, or interaction grounded in the views of participants in the study.*

Unlike other traditional qualitative approaches where new knowledge is built from existing theories, in GT it is "grounded" from the data collection (Charmaz 2009) before the literature review is conducted. Data is gathered in multiple stages using diaries, interviews, and participant observations along with records or notes (Denzin and Lincoln 2013). Analysis then involves refining and processing the relationships between the sources of data.

GT was excluded because a theoretical body of evidence for PCC already exists, especially in OPAH (McCormack and McCance 2017; Olsson et al. 2016; 2014; 2009; WHO 2017; IHI 2001; 2014; McCormack et al. 2015; HF 2014; McCormack and McCance 2011; McCormack and Titchen 2009). Furthermore, the gap in the PCC evidence base is not theoretical in nature; instead, the deep insights into how PCC is experienced simultaneously from multiple stakeholder perspectives in practice.

Discourse analysis (DA) and narrative analysis (NA) were also considered. Parahoo (2014 p. 467) defines the former as:

> *…an approach based on the analysis of discourse (verbal, non-verbal, and written communication). The purpose of this type of analysis is to uncover the values, meanings and intentions in the interactions between people.*

DA focuses on gaining new knowledge by analysing dialogue between participants (Denzin and Lincoln 2013), including their intonation, the context of conversations, silences, body language and the structure of written descriptions (Hallet et al. 2000). NA explores narrative contextual meanings including those hidden in the text and in the choice of linguistics (Polit and Beck 2014). For example, a reader’s perception of an experience can be altered depending on whether the writer selects positive or negative connotations to describe it. However, by analysing only the narrative, DA and NA could have limited the deeper exploration of the multiple stakeholder perspectives of PCC in OPAH care. Other methodologies were therefore sought that would allow the researcher to delve more deeply into how the participants made sense of their experiences.

Ethnography explores human interactions in their usual social and cultural context (Denzin and Lincoln 2013), enabling researchers to learn from participants by completely immersing themselves in the study’s setting (Polit and Beck 2014). Investigators are required to spend enough time in the research area for participants to view them as part of their environment (Silverman 2013). To apply ethnography, the investigator would need to adopt an 'insider nurse researcher' collaborative role as a member of the MDT (Pringle 2011). This would require spending extensive hours in clinical practice; 360 hours of observation were required for Goldberg et al. (2014) to observe staff in an OPAH unit during their ethnographic study. Dewar (2011)'s employment as a researcher allowed her to spend three years using natural observation to study compassion. Pragmatic decisions to exclude ethnography were based on the limited time I would have as a lecturer in nursing, no longer based in clinical practice. Further reasons for exclusion were, the observation may result in a 'hawthorne effect' if it causes participants to change their behaviour (Creswell 2014). In addition, none of the participants in the current study would be in their own familiar environment whilst in an acute hospital setting, as would be usual for an ethnographic study.

Participatory Action Research (PAR) was also considered since it was a dominant methodology in Chapter 2. PAR is built on Lewin's change management philosophy of 'unfreeze, change, refreeze' (Polit and Beck 2014, Burnes 2004); seeking to understand and improve the world by changing it (Balum, MacDougall and Smith 2006). PAR is usually based around a problem in practice which is researched, then plans are made with improvements implemented in an iterative manner. Finally, the impact of the changes is evaluated (Glasson et al. 2006).

However, the emphasis of PAR is on enhancing practice through collaboration, whereas the aim of this research is to explore experiences of PCC (Glasson et al. 2006). Therefore, PAR could be useful to evaluate the impact of changes to PCC approaches that might follow the current study (Polit and Beck 2014).

Additionally, success of PAR depends on participants' willingness to devote their time to its repeated cyclical process (Polit and Beck 2014). Both Glasson et al. (2006) and Ross, Tod and Clarke et al. (2014) used PAR to explore and improve aspects of PCC in acute care but researchers in each of these studies reported challenges in maintaining participation. Since the research setting of this study was known to be under pressure during the period of data collection (HIS 2017, 2014), it was deemed unreasonable to expect staff to participate in repeated interviews. Furthermore, older people who had recently been acutely unwell might feel reluctant to volunteer to participate in a demanding study.

Extensive further reading about qualitative methods led to the identification of phenomenology as a possible option for this study. Gerrish and Lacey (2014 p. 538) defined it as:

> *…an inductive approach to qualitative research that focuses on understanding the human experience from the 'inside'. Phenomenologists interpret the meaning of the lived experience of the study participants through their description.*

Gradually it became clear that this approach would be a good fit with the proposed aims of exploring and interpreting participants' lived experiences of PCC (Creswell 2014). It also aligned closely with the premise that every situation can be perceived in various ways. A handwritten note I made in 2015 can still be seen next to the phenomenology section of the Creswell (2014) textbook: 'This is it!!'

3.4.2 Exploring phenomenology – philosophical underpinnings

3.4.2.1 Descriptive phenomenology contrasted with interpretative

Since there are of the two schools of phenomenology – 'descriptive' or 'interpretive' (also entitled 'hermeneutic') (Parahoo 2014) - the next step was to select the most apposite. Exploration of the philosophical underpinnings of phenomenology begin in this section and are further considered in subsequent sub sections.

Descriptive phenomenology supports the close exploration of lived experiences from both a scientific and a philosophical stance (Malhotra 2012; Finlay 2009). Such an approach requires the researcher to focus purely on participants' accounts of their experiences whilst avoiding bias by setting aside or 'bracketing' their own preconceived views (Brocki and Weardon 2005). The term 'bracketing' originally referred to the use of brackets to isolate parts of a mathematical equation (Creswell 2014); it was then adopted within the philosophical movement of phenomenology developed by Edmund Husserl (1959-1938) (Polit and Beck 2014). Husserl (1931) believed that the analytical process must not be inhibited by the researcher's preconceived ideas. However, Parahoo (2014) acknowledges that excluding these may be difficult. Instead, Creswell (2014) recommends being open about one's initial awareness of the phenomenon of interest whilst remaining willing to alter one's perspective in accordance with the outcomes of the study.

Using descriptive phenomenology to gather powerful descriptions of participants' experiences of PCC in OPAH could provide new insights and perspectives to shape future thinking about this phenomenon (Silverman 2013), so long as these accounts contained the necessary level of depth and detail (Gerrish and Lacey 2014). However, throughout this doctoral process I have acknowledged my personal experiences, passion, interests, and professional alliance to the concept of PCC. 'Bracketing' these out would have been contrary to my ontology and epistemological perspectives on developing new knowledge, so descriptive phenomenology was rejected.

Heidegger (1959), a student of Husserl disputed the use of bracketing, developing 'interpretive' phenomenology (IP). Polit and Beck (2014) attribute the foundations of IP to Heidegger (1959), who advised researchers to acknowledge the impact of their experiences which had ignited their interest in a particular topic, whilst remaining open to new possibilities (Pringle 2011). The process of interpretation would then enable them to gain a 'hermeneutic' understanding of the phenomenon under investigation (Creswell 2014) which appeared to fit with the aims of this study, as well as my personal worldview.

Under the influence of other philosophers, IP continued to evolve. In his magnum opus, 'Truth and Method', Gadamer (2004) (a student of Heidegger) lists four key concepts he believes to be influencing this process: prejudice, tradition, authority, and horizon. He suggests that within each of these areas individuality and situational awareness can lead to an ever-changing perspective. For example, he considers 'horizon' to represent an individual's understanding of their situation at any given time; being influenced by their current circumstances along with the way they describe and interpret these. A ‘fusion of horizons’ (Gadamer 2004) can occur whenever the researcher’s analysis merges with the interpretation of how the participant has made sense of their world. New knowledge is thus generated (Gadamer 2004).

The application of Gadamerian horizons within this study appeared to intuitively link to my ontology, epistemology, and the research aim. My combined experiences as a nurse, an academic and primarily, as a person, have led me to undertake this study to gain deeper insights into the lived experience and practice of PCC in OPAH. Throughout the entire doctoral journey, I have thus been guided by Gadamer’s (2004) philosophical approach of laying bare the factors influencing my research process whilst remaining open to new knowledge, often captured in my reflexive diary. Chapters 6 and 7 demonstrate the shift in my understanding and PCC ‘horizon’ because of my exploration and interpretation of the experiences of PCC.

Undertaking the research gradually allowed philosophical links to emerge in a more meaningful way. Finlay (2009, 2002) warns that students’ early attempts to conceptualise complex philosophical theories may dampen their enthusiasm for their research. However, studies by nurse researchers who failed to establish these connections clearly have been less robust; coined as the ‘Paley trap’ (1997). More recently, Petroyskaya (2014) claims nursing researchers have progressed to a ‘life after Paley’ stage, giving due regard to the underlying philosophical principles. On reflection, at times I felt compelled to give highly detailed interpretations of how philosophy had influenced this doctoral journey, to convince examiners I had explored it sufficiently. Towards completion of the thesis, I believed I had permission to approach philosophy with more brevity.

The doctoral journey’s iterative process led to the conclusion that the interpretation of the experiences of PCC was essential. Yet, there are several types of interpretive phenomenology (IP), traditional IP seeks to make sense of participants’ experiences through the application of the hermeneutic circle (Schleiermacher 1998). However, Interpretive Phenomenological Analysis (IPA) adds an extra layer of hermeneutic analysis (another hermeneutic circle) to also incorporate seeking meaning from *how* the researcher makes sense of the participants interpretation of their experiences (Smith, Flowers and Larking 2012). IPA thus follows a double hermeneutic circle (Charlick et al. 2015).

3.4.3 Overview Interpretive Phenomenological Analysis (IPA) and Philosophy

IPA has been described as a variant form of hermeneutic phenomenology (Finlay and Ballinger 2006). Smith, Flowers and Larkin (2012 pp. 1-3) define it as:

> *…a qualitative approach committed to the examination of how people make sense of their major life experiences…it is an interpretative endeavour…the researcher needs to interpret the account from the participant in order to understand their experience.*
>
> (Smith, Flowers and Larkin 2012 pp.1-3)

Several factors contributed to the decision to adopt IPA for this study. Parajuli, Holley and Avgoulas (2019), Charlick et al. (2015) and Pringle, Hendry and McCafferty (2011) concur that IPA allows a rich, deep, analytical exploration and interpretation of specific meaningful experiences in people's lives. It could therefore potentially add powerful insights from multiple perspectives to the evidence base regarding PCC for older people in acute care.

Hefferon and Gil-Rodrigrez (2011) critically defend the growing international popularity of IPA within clinical psychology and health-related research. However, they also warn against viewing it as an easy option. They advise researchers to pay close attention to the philosophical underpinnings of IPA as they plan and implement their studies; to strengthen the evidence base supporting future IPA use.

The phenomenological component of IPA is based on the joint philosophical stances of Husserl, Heidegger, Gadamer, Merleau-Ponty, Sartre, and Schleiermacher (Hefferon and Gil-Rodrigrez 2011; Sadala and Adorno 2002). Gibson (2018) recognised pluralistic philosophical influences within his Scottish IPA study exploring the role of therapeutic photography in social work. Wibberley (2017) suggests that this bricolage approach provides a way to weave together different perspectives. Similarly, Hefferon and Gil-Rodrigrez (2011) acknowledged the potential value of exploring the viewpoints of several philosophers. I was also drawn to the pluralistic philosophical underpinnings of Smith, Flowers and Larkin (2012) approach to IPA (2012). Such diversity matched my epistemological view that the world can be viewed in many alternative ways through the application of different lenses being the same principle applies to the delivery of PCC, with its need for flexibility since no one way of delivering care will meet the needs of all recipients.

The effect of Husserl's (2012), Heidegger (2010) and Gadamer (2004) perspectives on phenomenology was discussed earlier. Other philosophers who have influenced IPA will now be critically explored in the context of their application within this study (Smith, Flowers and Larkin 2012).

3.4.3.1 IPA Philosophical underpinning to Merleau-Ponty

Merleau-Ponty's (1962) emphasis on the importance of recognising uniqueness further enriches the philosophical perspectives of Heidegger and Gadamer. He stated that although science may seek solutions to problems, knowledge generation can never be completely objective, since individuals will invariably develop their own interpretations of scientific findings. The links between subjectivity and embodiment are demonstrated in this quote:

> *I will never know how you see red and you will never know how I see it. But this separation of consciousness is recognised only after a failure of communication, and our first movement is to believe in an undivided being between us.*
>
> (Merleau-Ponty and Edie 1964 p.17)

Relating this statement to participants' accounts, interpretation of a lived experience cannot begin until a dialogue is explored and analysed. Thus, seeing red might indicate that a red object had been observed, but it could also refer metaphorically to a person's rising anger. Examples of the application of Merleau-Ponty's principles to the interpretative process are shared in Chapters 5 and 6. Merleau-Ponty's (1962) influence also led to the acceptance that IPA research findings can only reveal the pertinent elements of participants' interpretations in a specific time and place in their world, rather than capturing the entirety of any lived experience (Smith and Osborne 2003). Although the findings from this IPA study will add new knowledge regarding PCC in OPAH, they cannot be expected to redefine the whole concept.

3.4.3.2 IPA Philosophical underpinning to Sartre

Sartre was the creator of existentialism in philosophy, advocating that:

> *…the world has no meaning and each person is alone and completely responsible for their own actions, by which they make their own character.*
>
> (Cambridge Online Dictionary 2019)

In 1948, Sartre (re-published in 2007) extended Heidegger's concept of 'daesin', literally means 'there-being', affording a much deeper significance:

> *Daesin is essentially being-with … Even Daesin's being alone is being with the world. The other can be missing only in and for a being with.*
>
> (Heidegger 2010 p.156)

Sartre, along with Merleau-Ponty's (1962) further explored ideology around uniqueness. My conceptualisation of Sartre's (2007) notion of deep self-awareness is linked to existential phenomenology and 'daesin' (Heidegger 2010); where all individuals' experiences are influenced by past understandings and the social world. When applying Sartre's philosophical perspectives to IPA, the lived experience of the participants may be linked to how individuals exist in their world and make sense of their experiences. Sartre's (1948) work suggested that the first step in beginning to interpret any lived experience is developing insight into how the research participants view themselves existentially. Parallels can be drawn between Sartre's (2007) philosophical influence on IPA and how PCC practices are planned and initiated. The first step must begin with understanding a patient's narrative, values and beliefs (GPCC 2017; McCormack and McCance 2017).

3.4.3.3 IPA Philosophical underpinning to Schleiermacher

Schleiermacher was a theologian (1768-1834) who, like Gadamer albeit much earlier in the historical trajectory of philosophy, explored the dynamic relation between the interviewer and interviewee. Initially, he was concerned with the phenomenological interpretation of theological texts (Smith, Flowers and Larkin 2012), using the hermeneutic circle (see Figure 3.1 below). Subsequently, he moved the interpretative process from being a mechanical task to a more intuitive, holistic, analytical process (Schleiermacher 1998 posthumous re print). Lawn (2006) suggests that deep insights can be gained by using this psychological interpretation of speech and writing, to the point where the interviewer may understand the interviewee's perspective better than they do themselves. To achieve this, Schleiermacher (1998) suggested that interpretations should be based on an analysis of language along with a psychological perspective. Smith, Flowers and Larkin (2012) suggest that he has strongly influenced IPA's analytical process of considering the linguistics, descriptions and conceptual areas of text. According to Pringle (2011), utilising such an approach within the construct of the hermeneutic circle can reveal deep idiographic insights into the lived experiences under investigation.

3.5 IPA Hermeneutic Circle and Idiography

When analysing and interpreting phenomenological texts, Schleiermacher (1998) advises researchers to use their intuition whilst being cognisant of the psychological elements of the experiences. Smith, Flower and Larking (2012) suggest breaking the text into smaller components and considering these in a cyclical way, following the stages depicted in the hermeneutic circle (Fig 3.1 below).

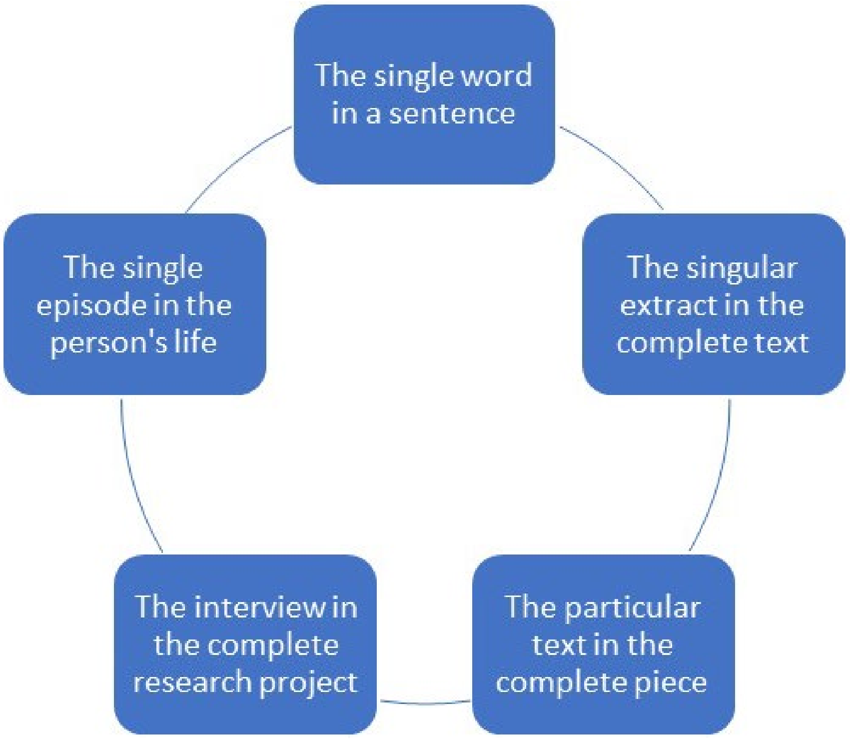


Figure 3.1 The Hermeneutic Circle as described by Smith, Flowers and Larkin (2012) p. 28.

Whereas traditional hermeneutic phenomenology (HP) focuses the analysis to the researcher's interpretation of the data, in IPA a double hermeneutic circle is used (Gibson 2018; Polley, Highfield and Neal 2015; Skinta et al. 2014). The first step of this process provides an account of how the participants make sense of their situation and experiences, and the second explores the researcher's interpretations of how the participants achieved this (Parajuli, Holley and Avgoulas 2019; Smith, Burgess and Sorinola 2018; Sallis and Birkin 2014; Dickson, Knusson and Flowers 2008). The double hermeneutic circle applied in this research is illustrated in figure 3.2, later in this chapter. In their methodological paper based in Australia, Charlick et al. (2015) suggest that participants' experiences are usually contextualised within an event that felt significant to them. In the data collected within the current study, these events were encapsulated by participants' experiences of PCC in an OPAH environment. Patel (2015) suggests exploring the links between philosophical theory and the methodology enhances the robustness of the research findings. However, Smith, Flowers and Larkin (2012) point out that whilst philosophy is an influencing factor (Petrovskaya 2014), it does not own phenomenology and should not dominate the research process. Therefore, philosophy should not be the only basis of methodological choices made, chosen methodologies should be critiques as part of a doctoral process.

3.5.1 Examination of IPA

Hefferon and Gil-Rodrigrez (2011) and Pringle, Hendry and McLafferty (2011) concur that IPA has become a well-established form of phenomenological research in the 21st century. It has enabled several authors to draw rich, insightful conclusions (Gibson 2018; Strickland 2015; Pringle 2012). Malhotra (2012) favours IPA because it allows researchers to conduct idiographic studies, where close attention is paid to the experiences of individual participants. In the field of social science research, idiography has been defined as an approach or style within social research that focuses on specific elements, individuals, events, entities, and situation (Jupp 2006).

The idiographic nature of IPA increases the suitability for exploring PCC experiences of individuals (Brocki and Weardon 2007). Smith, Burgess and Sorinola (2018) and Smith and Shinebourne (2012) suggest that findings from idiographic studies could add significantly to the PCC knowledge base. Deeper understanding of specific concepts can be derived from rich and powerful data gathered from only a few participants (Silverman 2013), so long as these have been purposively selected and carefully situated in within the research interest (Hefferon and Gil-Rodrigrez 2011). Adherence to this sampling advice will be discussed in Chapter 4.

However, Paque et al. (2018), Charlick et al. (2015) and Malim et al. (1992) warn that focusing closely on data from a small number of individuals, usual in IPA studies, could limit the impact of the study. Nevertheless, Smith (2017) argues that the purpose of qualitative studies is to provide deep, focussed insights rather than widely generalisable findings. For this study, the idiographic features of IPA were used to gather accounts of experiences of PCC from multiple perspectives. The resulting findings contain some overlapping themes and others unique to individual participants.

Smith, Larkin and Flowers (2012) suggest that another strength of IPA is its ability to flexibly interpret lived experiences; they view the combination of hermeneutics and phenomenology when investigating the lived experience as a hermeneutic turn:

> *IPA requires a combination of phenomenological and hermeneutic insights. It is phenomenological in attempting to get as close as possible to the personal experience of the participant but recognises that this inevitably becomes an interpretative endeavour for both the participant and the researcher. Without phenomenology there would be nothing to interpret; without hermeneutics the phenomenon would not be seen.*
>
> (Smith, Flowers and Larkin 2012 p.37)

Some traditional phenomenologists, including Sousa (2015), Giorgi (2010) and Willig (2008), argue that IPA's links to philosophy are too tenuous to provide a theoretical basis with sufficient academic depth. Others take a different view, for example, Dickson, Knusson and Flowers (2008) claim that IPA allows the operationalisation of interpretive phenomenology in a user-friendly philosophical way. Shinbourne (2011) suggests that IPA is congruent with existentialism (Sartre 2007), with a base within the three key areas of phenomenology, hermeneutics and idiography. Smith (2007) asserts that IPA elevates the traditional philosophical perspectives of Schleiermacher, Heidegger and Gadamer to a new, contemporary status. Furthermore, Pringle, Hendry and McCafferty (2011) believe that when IPA studies are well constructed and supported by sound philosophical and theoretical underpinnings, they can add to the knowledge base on a phenomenon in meaningful ways. The double hermeneutic circle for analysing the participants' interpretations fits with Schleiermacher's (1998) recommendation that data should be analysed linguistically or grammatically first, and then psychologically to uncover its deeper meanings. Tuohy et al. (2013)'s overview of interpretive hermeneutic methodologies concluded that the '*deep hermeneutic thinking'* (p.18) encouraged by this double circle can deliver insightful research outcomes.

Figure 3.2 below illustrates the manner in which the double hermeneutic circle was applied in the current study. The grey inner circle represents the research participant, the dark blue spiral the research participant's interpretation of their PCC experiences. The bright blue spiral represents my interpretation of how the research participant made sense of their PCC experiences; then the green spiral represents the intended addition this study brings to the PCC knowledge base.

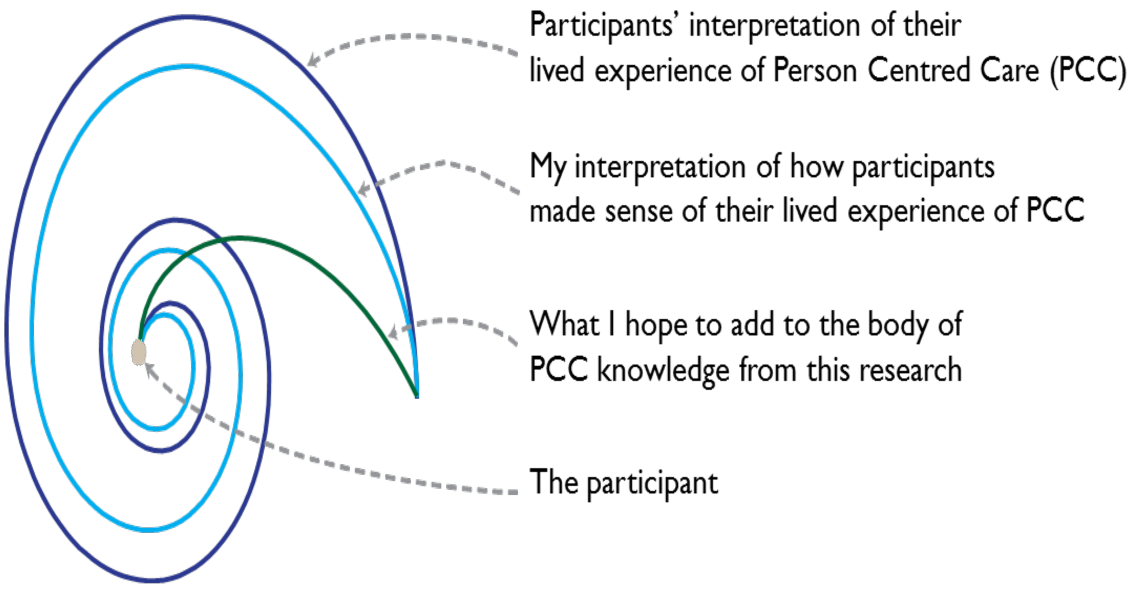


Figure 3.2 The double hermeneutic process applied in the current study

IPA can also be moulded around other methodologies without diluting the underpinning philosophical or theoretical frameworks (Gibson 2018; Tuohy et al. 2013). IPA has enabled me to explore and analyse the process whereby participants have made sense of their experiences of PCC to illuminate these within the context of OPAH care.

Although Smith, Flowers and Larkin (2012) advocated the use of single cases for IPA studies, a broader range of PCC experiences was needed to achieve the aims of this investigation. Most of the IPA studies critiqued during the exploration of methodologies, used small, purposive samples rather than focusing on a singular experience (Hunter and Bick 2019; Parajuli, Holley and Avgoulas 2019; Pague et al. 2018; Smith, Burgess and Sornola 2018; Polley, Highfield and Neal 2015;

Beeston, Hugh-Jones and Gough 2014; Skinta et al. 2014; Mathias, Parry-Jones and Huws 2014;Sallis and Birkin 2014). For example, Hunter and Bick (2019) recruited 21 early-career midwives who had specific experiences of perineal assessment and repair to gather multiple perspectives on this experience. Mathias, Parry-Jones and Huws (2014) only recruited six participants when they used face-to-face interviews to investigate experiences of chronic pain.

More than one perspective was required to discover how different members of each stakeholder group (older people, family members and the MDT) experienced PCC, in the current study suggesting data from several case studies would need to be collected. Consequently, a collective case study approach combined with IPA was selected.

3.5.2 Examination of collective case studies

After determining that IPA was the most appropriate methodology for this study, the next step was to plan the research proposal. It was decided that the best way to explore and interpret the PCC experiences of the key stakeholders in OPAH would be to incorporate a collective case study approach. This can be defined as:

> *…an empirical method that investigates a contemporary phenomenon ('the case') in depth and with its real-world context, especially when the boundaries between the phenomenon and the context may not be clearly defined.*
>
> (Yin 2018 p.15)

Yin (2018) suggests that recognition for case study research has grown during the last twenty years, cautioning that it should always be aligned to research aims, such as to interpret healthcare experiences. Denzin and Lincoln (2012) further recommend collective case studies for exploring holistic experiences in their natural environment.

The table below sets out Denscombe's (2017) criteria for determining whether a case study approach will be suitable, along with their application to the present study.

Table 3.2 How Case Study methodology can be aligned in an IPA study

Denscombe (2017) case study criteria	Applicability to this IPA study
Naturally occurring situation and a current social phenomenon	Older people are living longer and occupy most acute care beds in Europe (Searmus 2017). By recruiting older people in a medicine for elderly clinical area, PCC experiences of older people in acute care could be explored. PCC is advocated internationally, nationally and locally in health and social care (NHS Grampian 2018; WHO 2015; HIS 2015). IPA seeks to explore significant experiences in people's lives, although older people being hospital is a naturally occurring event, it is likely to be impactful to the older person.
Set selection criteria	Purposeful sampling was employed with set inclusion and exclusion criteria (listed in Chapter 4).
Data will describe case in depth and compare findings with similar studies	Following the steps of IPA analysis explained in Chapter 4.
Every case would be self-contained	The sampling technique confined each case to the older person, a family member and MDT members who met the inclusion criteria.
Boundaries and Implications	Clear inclusion and exclusion criteria set the boundaries and implications. This study aimed to add to the body of PCC evidence for older people in hospital without cognitive impairment.
Generalisations from research although limited have implications	Although limited to hospital care of older people without cognitive impairment, key stakeholder experiences were explored. Simultaneous perspectives of the same situation from the different stakeholders' perspectives provide novel implications.

Usual method of data collection is diaries, interviews and observation	Diaries and interviews were used. Justification for excluding observations are explained in Chapter 4. These methods are often used in IPA studies (Smith, Flowers and Larkin 2012).
Gives attention to relationships, processes of care and aims to provide a holistic picture.	Collecting the multiple perspectives of older people, their family and the MDT, permits investigation of professional relationships and holistic care experience. Other IPA studies have explored holistic perspectives on specific experiences, for example: Smith, Burgess and Sorinola (2018) explored stroke survivor and the partners post stroke experiences.

Further to the criteria above, Yin (2018) also advises that the cases need not be singular, and that their nature should be defined at the start of the study. In this investigation, the sampling and ideal case collective were set out at the point of seeking ethical approval. The plan was to recruit an older person, a family member, a nurse and one other member of the MDT for each case collective. The resulting exploration and interpretation of PCC experiences would illuminate the facilitators and barriers to PCC along with the multiple simultaneous realities (Crowe et al. 2011).

Denzin and Lincoln (2013) suggest that experiences can subsequently be repeatedly compared across cases, distinguishing commonality, whilst identifying what is unique, thus rendering the data even more persuasive. Repeating cases allows a variety of naturally occurring circumstances in OPAH care to be captured, authentically exploring the lived experiences from multiple perspectives. The intention was to enhance the PCC knowledge base in a novel, yet meaningful way. Participants decide what matters to them, with the researcher assiduously emphasising those issues from the participants' perceptions, in keeping with the idiographic nature of IPA (Polley, Highfield and Neal 2015, Charlick et al. 2015). A valid research case should be realistic, impressionistic, confessional, critical, formal, literary, and jointly told by the strong participant voice and researcher analysis (Van Maanen 2017a., b.). Denscombe (2017) values the attention to relationships and processes of care within collective case studies, allowing holistic pictures to emerge. However, Yin (2018) suggests that a minimum of three collectives or cases should be repeated to achieve the optimal opportunity to elicit convergences and divergences within the data.

Despite the evident benefits of the collective case study approach, such as its ability to provide deep insights into individuals' lived experiences (Yin 2018), this methodology has been criticised because of its potential lack of impact (Young et al. 2015). Thus, this study is unlikely to achieve a definitive understanding of PCC for OPAH since each case can only explore those participant's perceptions. Anthony and Jack's (2009) integrative review of research using case study approaches criticised the lack of rigour in some of the studies, but also acknowledged that it can produce high quality powerful data in the areas of health and social care. They emphasised the importance of providing a strong theoretical and philosophical basis (Anthony and Jack 2009). Within the present investigation, combining the collective case study approach with IPA facilitated a shared but robust philosophical and theoretical foundation for the data collection and analysis.

3.5.3 Combining IPA with other methodologies

As indicated earlier, the philosophical underpinnings of IPA can also be applied to the idiographic nature of collective case studies. Both approaches allow the analysis of experiences to add to the existing knowledge about a phenomenon. Since Hefferon and Gil-Rodrigrez (2011) assert that IPA can be successfully combined with other approaches, I considered IPA to be the overarching methodology, with the collective case study design providing the way to operationalise it. IPA was the *what*, and collective case studies was the *how*, using both may strengthen the methodological design.

Smith and Osborne (2003) warn that to be successful, IPA must be integrated into the entire study rather than being added as an afterthought, as is the case in this current study. Gibson (2018) drew on the philosophical underpinnings of IPA to support his creative study using photograph elicitation. Beeston, Hugh-Jones and Gough (2014) used IPA to help structure their narrative analytical process in their investigation of the impact of post-natal depression on new fathers (n=14).

The flexibility of IPA has allowed it to be used in a range of fields (Charlick et al. 2015). Since its development within psychology research (Smith and Osborne 2015), it has now become prominent in health and social care investigations (Parajuli, Holley and Avgoulas 2019; Smith, Burgess and Sornola 2018; Gibson 2018; Polley, Highfield and Neal 2015, Charlick et al. 2015; Skinta et al. 2014). Despite, Silverman (2013) cautioning qualitative researchers against *methodology blurring*, Hefferon and Gil-Rodreigrez (2011) support that IPA can successfully combined with other methodologies, so long as rigour is applied to the methodological decision-making process. Polit and Beck (2014) advise that any combination of approaches must be supported by a sound rationale; the preceding chapter serves as the rationale for the combination of IPA and collective case studies.

The following personal reflexive excerpts will help to clarify the methodological decision-making processes used throughout this study.

Personal Reflection Excerpts - 26.6.15

…Met with Fiona W about research philosophy. Your philosophical approach finds you not the other way around! That made me relax, I did feel so overwhelmed about research philosophy, but intuitively was pulled towards a constructivism approach, however also drawn to Gadamer's more inclusive holistic worldview.

The McCormack & McCance model considers this wide lens of PCC from person receiving, giving care, set within the wider cultural perspectives.

21.1.17

Moments of clarity in the swimming pool! Why phenomenology? Why IPA, Why Collective Case Studies? Why combining these? I need to be able to articulate this in a way that CONVINCES them and examiners this is the right approach for my ontology, *epistemology and research question. So, moment of clarity…Even as a small child I was interested in the whole picture, the other side or the many sides of a coin, or situation. I wanted to understand and expect the unexpected.*

July 10th 2019

Re-visiting old drafts of the Methodology chapter was quite painful at times. My thought process was disorganised and I could not see clearly the links between, philosophy, research theory, methodological choice and the practical application of the actual research in my DPP. It feels as if now, my head is out of the murky swap and I have a clear map through from philosophy to how the research was conducted. I did not know what I did not know! I now see what I did not know and have a practical application that has enabled my understanding.

3.6 Chapter Conclusion

Building on the personal epistemological and ontological reflections, this chapter has demonstrated how my personal worldview has impacted on my methodological decision. My intention to contribute to PCC knowledge has guided my endeavour to make appropriate methodological choices. The exclusion of potential alternative options has been justified. After selecting a phenomenological approach, detailed explanations were provided regarding the processes and rationale that contributed to the choice of HP, and specifically IPA, within a collective case study design. The wider philosophical influences on HP and IPA were also critically explored. Finally, personal reflections completed the presentation of a clear rationale for the methodological decisions made for this study, thus providing a clear decision trail of decision to take an IPA approach using collective case studies to structure the data collection.

4 Methods Chapter

This chapter will describe and critique the methods employed in this research, including the choice of research setting, the data collection methods and the overall analytical processes. The means used to ensure rigour in achieving the research aim will also be critically examined. Personal reflections on the application of the methods will demonstrate correlations with the philosophical underpinnings. Therefore, reflexive excerpts embedded throughout the chapter present a transparent audit trail of the methodological choices made during the data collection and analysis

4.1 Choice of Research Setting and Participants

4.1.1 Setting

The setting was an NHS Acute Medicine for the Elderly Unit (MfE: 79 beds) within a large teaching hospital (approximately 900 beds) in the North East of Scotland. This facility serves the local population of around 600,000 people, and provides acute services for the northern islands of Scotland (NHS Grampian 2019). The MfE unit comprised of one immediate mixed sex assessment ward (25 beds), and three 'step down' ongoing care wards - two female (21 and 16 beds) and one male (17 beds). The patients were over 65 years old, and could be admitted via the Emergency Department (ED) or be referred by their General Practitioner (GP). Holistic assessments were conducted in the assessment ward. Acute interventional care (such as intravenous fluids, pharmacological care and intense physical mobility rehabilitation) occurred in the 'step down' wards until the individual's condition was stabilised. Each ward had a dedicated team of nurses, doctors, physiotherapists, occupational therapists, speech and language therapists, dieticians, pharmacists and social workers. From admission, staff aimed to work with the older people and their families to plan for discharge to the most suitable environment (another hospital area or supported home care) (HIS 2015).

4.1.2 Participant inclusion and exclusion criteria

4.1.2.1 Inclusion criteria

To participate in this study, people had to be over 65 years old, deemed by the medical and nursing staff to be clinically stable, and predicted to be in hospital for at least 72 hours. This age requirement fitted with the admission criteria for the MfE area (NHS Grampian 2017), and also aligned with the specifications of the National Standards for Older People in Hospital (Scottish Government 2015). In the literature reviewed in Chapters 1 and 2, over 65 was also widely considered to be a determinant of the term ‘older people’.

Polit and Beck (2014) indicate that researchers in healthcare settings should select methods that will minimally disrupt care delivery. Assessing older people’s physical and cognitive condition was a normal part of the duties of the nursing and medical staff (NMC 2018; Royal College of Physicians 2017). Therefore, the verification that participants were physically and cognitively stable enough to participate in the study did not increase staff workload.

Participants also had to be able to nominate a family member who was willing to take part. The routinely administered ‘4 AT’ cognition assessment (MacLullich, Ryan and Cash 2011; discussed further in exclusion criteria below) demonstrated the older person’s capacity to do this. Participants were also required to have at least one member of the nursing team and preferably also one member of the MDT who had cared for them and were willing to take part in the study. Since no translation services could support the study, participants also had to be able to communicate in English. The family member was required to show willingness to participate in the study.

To allow newly qualified staff time to develop professionally and personally in their new posts, local NHS Research and Development (R & D) policy stipulated that they may only participate in studies aimed specifically at gathering their perspectives (NHS Grampian 2017). Recruitment was therefore limited to MDT members with 6 months of post-graduation / qualification experience who had held their current role within the research setting for at least 6 months. MDT participants were also required to have delivered direct care for the older person for at least three days prior to their face-to-face interview; this was verified by checking the older person's clinical record. Those identified were approached and given written information about the study.

4.1.2.2 Exclusion criteria

Routine objective assessments including vital signs monitoring and *track and trigger systems,* such as a National Early Warning Score (NEWS) above 3 (indicating medical deterioration/instability), enabled nursing and medical staff to identify older people whose condition was too unstable to allow their participation.

Cognitive impairment and reduced capacity to make decisions also resulted in exclusion from the study. The Office of the Public Guardian Scotland (2020) defines "incapable" as incapable of:

> *acting; or*
> *making decisions; or*
> *communicating decisions; or*
> *understanding decisions; or*
> *retaining the memory of decisions.*
> *in relation to any particular matter due to mental disorder or inability to communicate because of physical disability.*

Standard daily administration of the 4 AT tool (MacLullich, Ryan and Cash 2011) by medical and nursing staff resulted in exclusion where the score was above zero, indicating diminished cognition.

4.2 Data Collection Process

4.2.1 Ethical approval

Initial ethical approval for this study was granted by the RGU School of Nursing & Midwifery Ethical Review Panel (SERP), and the RGU Graduate School Research Ethics Self-Assessment (RESA) process. Approval from the NHS Ethics committee and R & D department was then sought via the Integrated Research Application System (IRAS) (Appendices 2- 10). As a registered nurse, I was required to adhere to the NMC Professional Code (NMC 2018). The stipulations of the RGU Research Ethics policy (2014) and General Data Protection Regulation (GDPR) (2018), along with the research setting's general principles of research and development (NHS Grampian 2017), were rigorously followed.

4.2.2 Ethical issues

Ethical practice was implemented throughout the identification, recruitment and data collection phases of this study (NMC 2018; GDPR 2018; Medical Research Council 2017). A robust informed consent procedure (Medical Research Council 2017) ensured that all participants' autonomy to choose whether or not to participate was respected. Autonomy is defined by Beauchamp and Childress (2013, p.101):

> *At minimum, personal autonomy encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice.*

The principles of beneficence (intending to do good) and non-maleficence (doing no harm) are integral to healthcare work (Gallagher and Hodge 2012) and therefore guided this study. Examples of the former included the provision of transparent information sheets and ongoing support following data collection if it led to any personal distress (see appendices 4, 5, 10-12). The study's overarching aim of positively influencing future healthcare and educational practice also reflected its beneficence. Non-maleficence was demonstrated by allowing participants to withdraw at any point for any reason they believed to be in their best interests.

Every effort was made to avoid harm by adhering to the a priori protocol approved by ethics and R & D, including the provision of clear communication with the nursing staff since they were the gatekeepers to access the participants. DPP supervision enabled me to recognise differences between the ethical practice required of me as a nurse educator compared to that of a researcher (Medical Research Council 2017). Whereas the former often involved stepping in with potential solutions to a problem, the latter could require the facilitation of deeper discussions of challenging experiences (Silverman 2013). Clear strategies were therefore established for follow-up support should any of the participants become distressed whilst participating in the research. As McConnel-Henry et al. (2010) point out, re-visiting stressful events such as a hospitalisation in a research interview can be emotive. In this situation, the research protocol stipulated that participants should be encouraged to access their GP or the NHS Board feedback services.

The 'Duty of Candour' stipulates that sub-standard care practices must be reported (Scottish Government 2017). The process for doing this is outlined in fig. 4.1 and further explored in Chapter 5.

Figure 4.1 Process for Reporting Errors in Care or Unsafe Care

The overarching aim of this study was to give a voice to older people, their families and MDT staff regarding their lived experience of PCC, in order to influence future improvements in practice and education.

The nursing staff in the research area were relied upon to uphold the standards set within the NMC Code (2018) by only approaching older people who met the study's inclusion criteria; they thus constituted one of the many layers of gatekeepers (Parahoo 2014) governing recruitment within this study.

4.2.3 Participant identification and recruitment

4.2.3.1 Setting up for recruitment and participant identification

Following receipt of primary endorsement by the Chief Nurse for Acute Care, the local Nurse Manager and each of the Senior Charge Nurses (SCN) for four wards granted permission for the research to take place in their areas. Emmel et al. (2007) point out that nurses can act as gatekeepers who facilitate or hinder access to participants. Face-to-face pre-research briefings were therefore held in order to build strong working relationships with the nursing staff whilst enhancing their grasp of the recruitment process. To avoid the tendency of nurses to select participants likely to present views similar to their own, as identified by Denzin and Lincoln (2013), nurses were requested to seek pre-consent (Appendix 8) from all of the older people who met the inclusion criteria. This allowed me, as the researcher, to recruit the actual participants, thus reducing potential selection bias.

Posters (Appendix 9) displayed in prominent positions around the research setting raised awareness of the study amongst the older people, as well as family members and MDT staff. As Parahoo (2014) points out, the ethical principle of justice demands equal access to research and fairness of participation. Older people and family members who expressed an interest in taking part were asked by the nurses to sign a pre-consent sheet (Appendix 8). Staff reassured those who declined to participate that they would not be contacted about the study again.

During the initial period, I contacted the SCN or Discharge Nurse for each ward daily at a pre-arranged time, thus minimising the disruption to care delivery, to ask whether any potential participants had been found. When after four weeks none had been identified, I raised the issue with the supervision team (see reflexive excerpts below).

Reflexive Excerpts:17.2.18

> *I am thinking my gatekeepers are too busy, so I fall down their priorities all the time. Physically going to go into the areas each day, as suggested by Supervisor Fiona…*
>
> *14.5.18*
>
> *... I look back and see that I struggled to recruit anyone, spent 4 weeks phoning each day and could not get older people, to get the process started. As it was the winter crisis, many older people were simply too ill/delirious. Or screening for the inclusion criteria to my study fell off the nurse/gate keeper's radar. Then I started visiting the wards every day for three weeks and got an older person, family member each week.*

I overcame these challenges by visiting the setting daily and designing a flowchart of the research process (Appendix 10) clearly highlighting the inclusion and exclusion criteria on order to boost the staff's confidence in their ability to correctly identify potential participants (see Chapter 6 for further discussion). The McCormack and McCance (2017) theoretical lens was used at these planning stages of the study. I was mindful of the model when carrying out pre data collection research setting briefings and during data collection, noticing cues around the wards about PCC cultures of care, such as PCC visiting and PCC notice boards. The model PCC outcomes were used to help structure the diary and the interview prompts, around:

- Satisfaction with Care
- Involvement in Care
- Feeling of Well-being
- Creating a Therapeutic Culture

These PCC outcomes were also used as a guiding influence within the analysis of the data too.

The first stage of data collection, a diary of care, was completed by participants on recruitment. The second consisted of individual face-to-face interviews; those with members of the MDT took place in the acute setting, whereas those with the older person and their family were held at a place of their choice. The recruitment and data collection process are outlined in Figure 4.2.

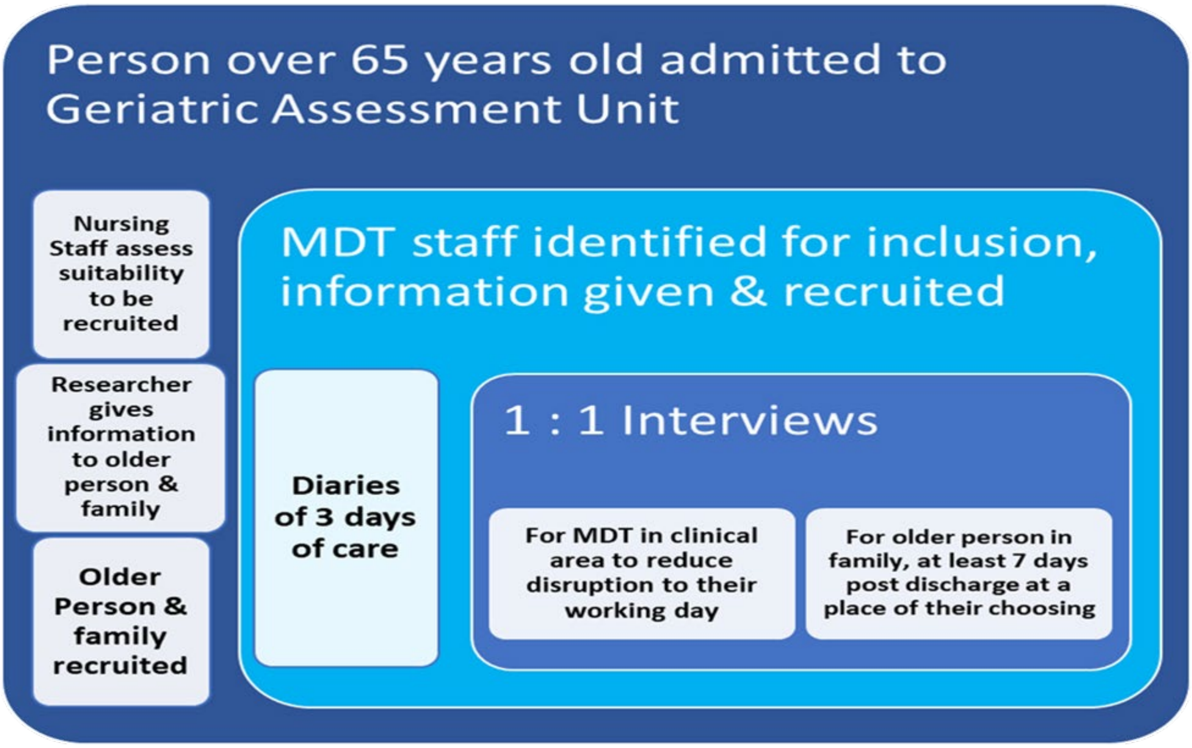


Figure 4.2 Process of Recruitment

A recent launch in the research setting of 'person-centred visiting' (NHS Grampian 2018), where patients set boundaries on who could visit and when, meant that the older person's family were often present during my recruitment visits. Their availability allowed simultaneous discussion of participation, thus streamlining the recruitment process. Each older person and family member were given a research study information sheet (appendices 11, 12). After a minimum of 24 hours, I visited them again to ascertain whether they still wished to participate. Those who did were asked to sign a consent form (appendices 13, 14), which included an agreement to allow the researcher to access their nursing and medical notes in order to identify the potential MDT participants who had cared for them. Potential MDT participants were also given a 24-hour period between receiving information about the study and consenting to take part.

Participants were reminded of their right to withdraw at any time and the older people were reassured by nursing staff that neither declining to participate nor withdrawing at any time would negatively impact on their care.

4.2.4 Sampling

Purposive sampling enables the recruitment of participants who meet the inclusion criteria and have the potential to address the research aims and objectives (Creswell 2014; Hefferon and Gil-Rodrigrez 2011). Brocki and Weardon (2005) suggest that a broadly homogenous sampling technique is most effective to gain a perspective on a specific phenomenon such as, in this case, the lived experience of PCC in OPAH care. However, Pringle (2011a) warns that selecting a narrow group (such as individuals of the same gender admitted for the same reason) may limit the impact of the study. For example, the results from Jensen, Vendelo and Longorg’s (2013) study of the PCC experiences of predominantly older people of both genders who had COPD could only relate to those in that age group with that condition.

The sampling process for this study was therefore designed to recruit both male and female participants admitted to hospital for diverse reasons and from a variety of backgrounds. Thus, although the older people shared a degree of homogeneity in relation to age, their background and reasons for admission varied. Using an IPA methodology with a collective case study approach permitted the simultaneous investigation of PCC from multiple perspectives involving both the delivery and receipt of care. This allowed the exploration of the practical application of McCormack and McCance’s (2017) model of PCC, including individuals’ experiences of healthcare culture.

4.2.4.1 Sampling frame

This study’s sampling frame included one older person, one family member, one nurse and at least one other member of the MDT in each case collective, thus following the injunction by Goodrich and Cromwell (2010) and De Silva and Naldermirci et al. (2019) to give older people a voice in PCC research. Olsson, Hansson and Ekman (2016) and Alharbi et al. (2014 a, b) viewed the perspectives of older people’s families as crucial. Background reading and the literature review in Chapter 2 concluded that further consideration should be afforded to the wider MDT’s contribution to PCC.

As established in Chapter 3, small sample sizes are commonplace in qualitative studies (Polit and Beck 2014), particularly those exploring older people and their family experiences (Herron and Wrathall 2018; Janssens et al. 2018; Burmeister et al. 2015, Olsson et al. 2012). Creswell (2014) acknowledges that seeking out rich, in-depth data is more crucial than the specific number of participants.

Significant knowledge has been generated through IPA studies with varying sample sizes: fourteen in Dickson, Knusson and Flowers’ (2008) research on Chronic Fatigue syndrome; twenty four in Pringle’s (2011b) study on the effects of strokes, and twenty six in Strickland’s (2014) investigation of multiple sclerosis. This study aimed to follow Yin’s (2018) recommendation of using three collective case studies, in this instance, of up to four people in each, with a target sample size of n=12.

Polit and Beck (2014) acknowledge the necessity in qualitative studies to adapt methods to accommodate the circumstances of the research process; indeed, Silverman (2013) advises novice researchers to expect it. Reflection on such situations can result in valuable learning, as demonstrated in the following excerpt.

Reflexive Excerpt: July 1st 2019

…I remember my absolute enthusiasm to get started with data collection, almost immediately deflated by the challenges I faced in recruiting… early in my DPP journey saying the novel way of having simultaneous perspectives of the lived experience of PCC had not been done before. To that end, one supervisor had added, maybe the reason for that it is too challenging! However, my theoretical lens the McCormack and McCance (2017) model suggested that PCC should include all these aspects. In retrospect, this was a novel and at times troublesome way to conduct this study. However, as the findings will reveal this does add knowledge to the PCC evidence base in a new way.

The impact on the recruitment process of extreme weather conditions and unprecedented pressure by winter flu on acute healthcare beds will be examined in Chapter 6*.*

4.2.5 Consent and capacity issues

As outlined in sections 4.2.1 and 4.2.2, potential participants who met the required criteria regarding cognition and communication were approached by nursing staff to establish their level of interest in participating in the study. The two components of the informed consent process are summed up by Beauchamp and Childress (2013):

> *... in this first instance occurs if and only if a patient or subject, with substantial understanding and in absence of control by others, intentionally authorises a professional to do something quite specific.., in the second sense, informed consent to conformity of social rules of consent that require professionals to obtain legally or institutionally valid consent from patient or subjects before proceeding with diagnostic, therapeutic or research procedures…*
>
> (Beauchamp and Childress 2013 p.122)

However, since older peoples’ condition can change swiftly, particularly for those with complex illness and comorbidities (HIS 2015), a dynamic process of ongoing informed consent was required (Hun 2014). The researcher asked the participants and the nursing staff about each older person’s medical and cognitive condition prior to every interaction, and confirmed that they remained aware of the study and in agreement to take part; these checks were repeated after discharge when arranging the face-to-face visits with the participant and their family member.

Given the seriousness of the conditions of patients admitted to OPAH care, it was possible that some might deteriorate too much to participate, or die after giving consent. Physical and cognitive deterioration did occur in one case, demonstrating the study’s authenticity in representing a typical OPAH environment.

4.2.6 Public involvement

The UK Research and Innovation body (2018) recommends that public involvement is embedded in every stage of research from proposal to dissemination. Members of a local University's public involvement group formed a public participation interest (PPI) group consisting of six members who were either over the age of 65, with recent personal experience of acute hospital care (within the previous 12 months), or who had an elderly relative who had recently received acute care. They helped to refine the research aim, objectives and data collection processes, resulting in several amendments to the participant information sheets, consent forms, diary format and interview prompts. This helped to ensure that members of the public would find the processes clear and explicit, and that the research addressed pertinent issues, as advised by the National Centre for Public Engagement (2018).

Three face-to-face meetings were augmented by email and telephone communication at the group members’ request. Subsequently, the PPI group was emailed an annual update of the progress of the study and a summary of the findings presented in layman’s terms (appendix 17).

4.3 Rigour

Morse (2015) and Tuckett (2005) consider rigour to be a measure of quality in qualitative research. Guba and Lincoln (1985) have transformed the way that rigour is assessed and valued, using criteria such as:

> *Credibility (i.e., internal validity): Prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member checks (process and terminal).*
> *Transferability (external validity, or generalizability): Thick description is essential for "someone interested" to transfer the original findings to another context, or individuals.*
> *Dependability (i.e., reliability): Attainable through credibility, the use of "overlapping methods" (triangulation), "stepwise replication" (splitting data and duplicating the analysis) and use of an "inquiry audit" or audit trail.*
> *Confirmability (Objectivity): Using strategies of triangulation and the audit trail.*
> *The use of a reflexive journal.*
>
> (Guba and Lincoln 1985 p. 316-317)

Forty years later, Tucket (2005) asserted that these characteristics of rigour or 'trustworthiness' in qualitative research are still regarded as essential. Morse (2015), on the other hand, argued that the following components are also necessary in order to achieve genuine rigour in social science research:

> *…prolonged engagement, persistent observation, and thick, rich description; inter-rater reliability, negative case analysis; peer review or debriefing; clarifying researcher bias; member checking; external audits; and triangulation.*
>
> (Morse 2015 p.1212)

Parahoo (2014), elaborating on the work of Guba and Lincoln (1985), identified four distinct characteristics of rigorous qualitative research: a clear audit trail, reflexivity, verification by experts and or research participants, and the production of impactful research that contributes to the knowledge base.

Several researchers using the methodology of IPA combined with collective case studies have adopted Guba and Lincoln’s (1985) criteria for assessing rigour (Yin 2018; Smith and Osborne 2015; Smith, Flowers and Larkin 2012). However, Smith and Osborne (2015) and Smith, Flowers and Larkin (2012) recommended also applying Yardley’s (2000) four principles of rigour when using IPA: sensitivity, commitment, transparency and impactful findings; the latter areas are within Guba and Lincoln’s (1985) empirical work on rigour. Since Yardley’s (2000) principles have been specifically applied to IPA studies, they will now be explored in more detail.

4.3.1 Sensitivity & commitment to exploring PCC in OPAH care – audit trail

Yardley (2000) argued that rigour could only be achieved when sensitivity to the context of the research was observed throughout every stage. To achieve this, Smith, Flowers and Larkin (2012) suggested that the research area must be carefully chosen and the recruitment of participants must be closely aligned with the study’s aim. Charlick et al. (2015) argued that rigour is also enhanced when the study is planned flexibly to accommodate the characteristics and life circumstances of the participants.

Parahoo (2014) suggested that sensitivity should be visible through the researcher’s transcript annotations of the interviewees’ paralanguage such as intonations, pauses or silences. Hefferon and Rodriguez (2011) indicate that these non-verbal cues should guide the researcher’s interpretation of the content. The application of this principle is discussed in section 4.5.2.

Although Yardley (2015) does not explicitly link sensitivity with the provision of an audit trail, Parahoo (2014), Smith, Flowers and Larkin (2012) and Guba and Lincoln (1985) concur that these are related In this study, a rigorous audit trail was provided of all methodological decisions (see Chapter 3), the preparation of the research area, the recruitment of participants, the data collection and analysis, making these processes transparent and replicable (see sections 4.5

and 4.6). Reflexive excerpts have been provided to add depth to the rationale for decisions taken throughout the research process.

The commitment to in-depth inquiry and analysis required by IPA studies advocated by Yardley (2000) is discussed in section 4.6. The intention to show commitment to exploring person centredness with rigour lies in aligning the study, methodological choices and in-depth analysis to the theoretical lens of McCormack and McCance's (2017) model. Additionally, there was commitment to the idiographic nature of IPA can be aligned to exploring 'what matters' to participants (Polley, Highfield and Neal 2015, Charlick et al. 2015).

4.3.2 Transparency, coherence and verification – reflexivity

The term 'coherence' as it relates to rigour is defined as:

> *…the fit between the aim, the philosophical perspective adopted, and the researcher role in the study as well as the methods of investigation, analysis and evaluation undertaken by the researcher.*
>
> (Vaismoradi and Salsali 2011 p.359)

The argument and findings presented in the final thesis should follow on logically from the study's methodological decisions (Yardley 2015). Smith, Flowers and Larkin (2012) warn that considerable redrafting in the analysis and write up stages may be needed to achieve this. The requirement for transparent reflexivity to demonstrate rigour in qualitative studies is well documented (Parahoo 2016; Morse 2015; Silverman 2013; Tuckett 2005; Finlay 2002; Guba and Lincoln 1985). Finlay (2002) outlined strategies to assist qualitative researchers engage reflexively in their work. This process,

> *… where researchers engage in explicit self -aware meta-analysis – has a long history spanning at least a century… the project of examining how the researcher and intersubjective elements impinge on, and even transform, research, has been an important part of the evolution of qualitative research.*
>
> Finlay (2002 p.209 -210)

I recognised that to align myself with the pluralistic philosophies of Gadamer (2004) and Heidegger (2010) and succeed in presenting a transparent and coherent thesis, I needed to candidly share my reflexive journey and diligently apply supervision feedback. Carefully selected reflexive excerpts were therefore presented throughout the thesis, further enhancing the transparency of the methodological audit trail. The reflexive journal I kept throughout the doctoral journey proved invaluable as a means of cathartically documenting personal and professional challenges, supervisory guidance and potential solutions. Completing the reflexive journal facilitated personal and professional growth as a graduate student and much deeper insights into my personal ontology and epistemology.

According to Tucket (2005), verification is also an important component of rigour. It can include sharing transcripts and initial analysis within research teams, allowing verification alongside deeper exploration of the data, thus supporting novice researchers. Building on Guba and Lincoln’s (1985) seminal work on ensuring credibility, Morse (2015) identified several levels of verification, including peer reviewing, member checks and triangulation. For example, initial transcripts shared with my supervisory team resulted in personal insights around the need to adopt a more ‘researcher-based’ approach to the interviews rather than my customary solution focused nurse or nurse educator stance (Tod 2014).

However, in IPA studies ‘member checking’ differs from the traditional hermeneutic phenomenological approach (Smith and Osborne 2015). Since analysis using the double hermeneutic circle includes the researcher’s interpretations of the participants’ *making sense* processes. Smith, Flowers and Larkin (2012) advised that findings need not be verified by the participants. This aligns with Gadamer’s (2004) approach to analysis where each pass through the data may result in adjustments of the findings until a ‘fusion of horizons’ is finally achieved. The new perspectives of the PCC experience in OPAH care are thus derived from the combination of the participants’ and researchers’ interpretations

4.3.3 Impactful findings

Lastly, Yardley (2015) agreed with Guba and Lincoln (1985) and Parahoo (2014) that an important criterion for assessing the rigour of qualitative studies is their ability to have a significant impact within their relevant sphere of knowledge. Chapter 1 demonstrated the importance of PCC in OPAH and Chapter 2 showed the framing of the research aim and objectives with the intention of making a valuable contribution to the PCC knowledge base.

However, Smith, Flowers and Larkin (2012) and Yin (2018) acknowledged that when IPA is combined with a collective case study approach, the findings tend to be closely linked to the specific phenomenon of interest (in this case, PCC in OPAH care). Despite this, Chapter 1 demonstrated the growing international interest in PCC, particularly since the turn of the century. The literature review supported the research aim and objectives of the current study, suggesting the potential to produce findings providing new impactful knowledge around the PCC experience, from the unique simultaneous perspectives of several stakeholders in OPAH care.

4.4 Methods of data collection

When research aims to explore and interpret experiences, Gerrish and Lacey (2014) recommend using qualitative research methods such as the completion of diaries, interviews, focus groups and observations. Such methods are typical sources of qualitative data for hermeneutic phenomenological, and more specifically IPA and collective case study research (Yin 2018; Wilson 2015; Silverman 2013; Smith, Flowers and Larkin 2012; Pringle, Hendry and McCafferty et al. 2011).

4.4.1 Justification of diaries to collect data

Snowden (2015) and Polit and Beck (2014) suggested that diaries provide a valuable method for accessing the feelings and experiences of everyday life. Hyers (2018) advocated their use in clinical research to grasp the *'nuances of people's reality'* (p.55). As Wilson (2015) points out, a diary can capture the

moment of a lived experience, where memory might interrupt the reality of that experience. Herron and Wrathall (2018 p.77) suggested the diary provides a "safe space" (p.77) for the participant to document their feelings and experiences without worrying about upsetting their family member, making confidentiality essential (Hyers 2018).
However, some participants may record only minimal information in a research diary, and others may decline to engage with the task altogether (Hyers 2018; Horrel et al. 2018; Snowden 2015). Their fear of being pressured into sharing deep, intimate feelings and perspectives may deter them from consenting to participate in any research involving this method (Janssens et al. 2018; Hyers 2018).

In this study it was hoped that diaries might mitigate the potential loss of memory resulting from older participants' natural ageing process (NICE 2018). It could also help family members to recollect their lived experiences despite the stress of having a loved one in hospital. Furthermore, the diaries could act as a reminder for MDT participants to find time to record specific patient experiences despite their busy work schedules (Nichol 2010).

The format initially adopted for this research (see Appendix 18) was informed by the work of several researchers (Berhland et al. 2014; Hyers et al. 2012; Valimaki, Vehviläinen-Julkunen, and Pietilä 2007). It was then modified in line with the recommendations of the PPI group to include space for free text and a larger font.

Whilst diaries are clearly valuable, several authors including Smith, Flowers and Larkin (2012) and Valimaki et al. (2012) have observed that when used alone, they do not permit the further probing and clarification of participants' experiences that can be achieved when they are combined with interviews. Pringle et al. (2011) advise that using both methods can enhance the richness of the data and add rigour to the IPA process. Numerous authors have successfully used this combination of approaches (Herron and Wrathall 2018; Janssens et al. 2018; Burmeister et al. 2015; Lofgren and Norrbrink 2012; Worral and Hickson 2008; Valimaki, Vehviläinen-Julkunen, and Pietilä 2007). Herron and Wrathall. (2018) used diaries to inform the content of their face-to-face interviews in their study of family members of people with dementia. Within this study, the themes in the diary narratives provided prompts to explore PCC more deeply, maximising the personalisation of the face-to-face interviews.

4.4.2 Justification of semi-structured interviews to collect data

Polit and Beck (2014) advocated the use of flexible semi-structured interviews because they allow the researcher to select a direction that aligns with the research aim. Conversely, Crowther et al. (2016) argued that by focussing on the participants' narratives, unstructured interviews empower them to choose the direction of the interview content. Valmiki (2009) asserted that whilst unstructured interviews may be cathartic for the interviewee, they may add little to the body of knowledge. Nevertheless, when used by Work (2013), this approach resulted in deep insights into male experiences of grief.

The structure of interview schedules used in IPA must be associated with the narrow but deep exploration of the research area (Hunter and Bick 2019). Charlick et al. (2015) recommended that the direction of the IPA interview should be controlled more by the participant than the researcher, to facilitate the sharing of the former's perceptions of their experiences. Therefore, whilst a semi structured interview may be planned at the outset, the underlying principle of IPA is to 'give voice' to the participant (Smith, Burgess and Sorinola 2018 p.1726). Within Sallis and Birkin's (2014) IPA interviews(n=7) with participants who had experienced sickness/absence related to depression, unplanned additions to a flexible interview plan proved to be deeply insightful. The researcher's role is to actively listen and explore useful tangents in more depth as long as they don't stray too far from the research purpose (Sallis and Birkin 2014). The flexibility in the IPA interview process allows a combination of semi-structured and unstructured processes to interplay (Smith, Burgess and Sorinola 2018), resulting in unique contributions. Hyers (2018) and McConnel-Henry et al (2010) concurred that using a standardised but flexible approach increased the richness of the findings. Indeed, Charlick et al. (2015 p. 52) indicated that it is key to a deeper exploration of the participants' 'making sense' processes.

Parahoo (2014) suggested that since the researcher is a tool in the data collection, she must analyse and evaluate the interview as it happens, intuitively probing in the directions that seem appropriate in the moment. Active listening and responding to verbal and non-verbal cues, probing further or recognising when the participant wishes leave a topic, are crucial elements of qualitative interviewing, according to Silverman (2013). Although the dialogue must have a clear purpose in order to elicit rich data, it should also adopt a degree of 'conversational style' to allow both the researcher and participant to relax while information is shared. Smith, Larkin and Flowers (2012) recommended establishing an open, purposeful conversation without straying into developing a therapeutic relationship.

In this study, a standard introduction at the outset of the interview proved effective in establishing rapport; this was therefore used in all interviews (Appendix 19). Thereafter, inquiries suggested by Tod (2014) such as "Tell me more about that?", "What happened next?" or "How did you feel?" were used as adjuncts. I hoped that the skilled verbal and non-verbal communication skills I had acquired as an experienced nurse and educator would enable me to uncover previously undiscovered experiences of PCC. On reflection (see excerpt in section 4.5.5), I recognised that as a novice researcher, I needed guidance to avoid adopting the problem-solving approach so typical of healthcare professionals (Tod 2014). Gradually as I interviewed more participants and reflected on the transcripts, I observed changes in my active listening and probing. This is reflected in the field notes below:

> *I felt elated after this interview, for a variety of reasons. Firstly, at last I had got a stakeholder other than a nurse's perspective, secondly, this meant I had a full collective, thirdly this doctor had been hard to pin down, signed up, but then kept missing her to plan a time for the interview.*
> *However, mostly I was elated at the richness of her interpretations of lived experience of PCC in OPAH.*
> *On reflection I was better at staying quiet, much more the participant voice than me, I think good at probing.*

> *5th read through while re-listening. I think my interview technique is much more researcher, much less nurse... I think there are gems of passion for PCC OPAH care here as well as the realities of the challenges of being PC.*
>
> FIELD NOTES

As Smith and Osborn (2007) point out, time and practice are needed to develop the interpersonal research skills required for IPA interviews. I needed to let my curiosity regarding the participants' experiences of PCC in OPAH drive my inquiries deeper. Instead of the prescribed semi-structured method, I adopted a focussed approach, using a broad list of questions to guide the interactions (Parahoo 2014; Silverman 2013). Occasionally my participants drifted off the research topic, discussing instead their life prior to their admission. Nevertheless, the analysis demonstrated the value of these exchanges not only in building rapport but also by providing a context to their personhood in relation to their experiences of PCC.

The interviews by Eggenberger and Nelms (2010) of families (dyads and focus groups, n=7) during the hospitalisation of a critically ill family member showed that participants valued opportunities to share their emotional perspectives. Poignant and emotive disclosures can occur in the intimacy of face-to-face interviews (Hyers 2018; McConnel - Henry et al. 2010); the researcher must therefore always have a plan for the provision of support at the end of data collection.

The rigour of interview data may be compromised by participants' unconscious bias; when they only share the aspects that they imagine the researcher wants to hear (Polley, Highfield and Neal 2015; Tod 2006). Polley, Highfield and Neal (2015) found that when nephrologists were interviewed regarding their relationships with long-term patients, their fear of appearing less professional or more vulnerable reduced their willingness to share deep reflections. Tod (2014) also cautioned researchers using semi-structured interviews to consider the possibility that participants may be attempting to give what they perceive to be the 'correct' answer; this will be discussed in Chapters 5 and 6.

4.4.3 Critique of offering participants choice: interview alone or together

Affording participants the choice of being interviewed together or separately emphasises IPA's view of the participant as the expert (Dickson, Knusson and Flowers 2008). It also aligns with Habermas' (1990) critical social theory which stipulated that participants should be given voice in a way that best suited them. Several authors acknowledged that people selected by participants to be interviewed with them often enrich the interview (Smith Burgess and Sorinola 2018; Finlay, Lloyd and Finucane 2017; Eggenberger and Nelms 2010), providing deep insights from multiple perspectives. One participant may prompt the other to share more than they had initially intended (Finlay, Lloyd and Finucane 2017). The presence of a family member may boost the interviewee's confidence (Smith Burgess and Sorinola 2018; Davidson, Worrall and Hickson 2008; Dickson, Knusson and Flowers 2008). Interpretations may be gleaned during the joint interview regarding impact on the family dynamic of the recent hospitalisation (Eggenberger and Nelms 2010). In the current study, both the older person and their family member at the interview had signed consent forms permitting all data to be used.

Gardner and Randal (2010) advised researchers to ensure that the interviewees have an equal voice, rather than allowing one person to dominate or direct the discussion. Eggenberger and Nelms (2010) warned that powerful family dynamics can influence the narrative in joint interviews. The mere suggestion that an older person might prefer to be interviewed alone rather than with a family member may itself lead to conflict. Either may feel obliged to be involved despite preferring not to be (Smith, Burgess, Sorinola 2018). However, no such conflicts appeared to occur in the current study.

Allowing participants the choice to be interviewed either alone or with a family member is aligned to my flexible ontological perspective and fits with my desire to adopt a person-centred approach to data collection. As Yardley (2015) indicated, staying true to the research topic is a vital component of rigour in IPA studies.

4.5 Data handling

All electronic materials were stored, processed and destroyed in accordance with standard operating procedures (RGU 2014), in the 'R' research drive of the IT system, only accessible to the research team. Data was held in accordance with GDPR (2018). As outlined in section 4.3.5, all participants were made aware during the informed consent process of how personal data would be used and stored. All paper files (consent forms, participant contact details, handwritten completed diaries) were stored in a locked filing unit, situated in a secure area of the School of Nursing and Midwifery. All files were kept there throughout the study then archived for audit trail purposes in line with RGU research governance (2014), the research setting's guiding research principles (NHS Grampian 2017) and the principles of GDPR (2018). All electronic files, transcriptions, analyses and themes from the handwritten diaries were stored on the R drive accessed via a password protected personal computer situated in a secure area of the School of Nursing and Midwifery.

In order to become fully immersed in the data (Smith, Flowers and Larkin 2012), the initial plan was for the researcher to transcribe all of the diary and interview data. However, after the transcription of one collective proved to be unrealistically time consuming, a pragmatic decision was made to employ an RGU-approved confidential transcription service for the remaining voice files. This approach increased the time available for immersion in the data though listening rather than typing.

Personal details (names, contact details and pseudonym links) were saved separately from the data, thus ensuring a rigorous audit trail (Polit and Beck 2014). Initially, members of the collective cases were given a unique identifying code to establish the link connecting the older person, family member and MDT member. However, as analytical stages progressed, each participant was given a pseudonym in keeping with hermeneutic phenomenological reporting (Crowther et al. 2016). This protected confidentiality, in line with the UK Research and Innovation (2018) and the NMC code of conduct (2018). Limited identification and biographical details were shared to create a picture of participants without compromising their anonymity.

4.6 Process of analysis

The content of the diaries guided the direction of the face-to-face interviews. The latter were recorded digitally and transcribed verbatim; data from field notes were then added. The data was analysed in accordance with the analytical structure of IPA, described below. The steps were aligned to the double hermeneutic circle (critically explored earlier). In keeping with IPA's idiographic underpinnings, both Smith, Larkin and Flowers (2009) and Yin (2018) recommended analysing one case at a time to ensure that each one is viewed individually rather than being influenced by others. Although this research used a collective case study approach (older person, family member and MDT member) combined with IPA methodology, the analytical steps for IPA, as the overarching methodology, were followed.

The first stage of the double hermeneutic process involved gaining an understanding of how the participants made sense of their lived experiences of PCC in OPAH. This was achieved through immersion in the data by re-reading, noting *linguistics, descriptive and concepts* within the transcript (Smith, Flowers and Larkin 2012). The second hermeneutic cycle then required the interpretation of the participants' 'sense-making' of their experiences (Charlick et al. 2015). This resulted in the emergence of themes across the individual cases. Some phenomenologists are critical of the rigid structure that IPA imposes on the analysis of lived experiences (Crowther et al. 2016; Pringle, Hendry and McCafferty 2011), advocating instead a more fluid, interpretive approach. As a less experienced researcher, I valued the guidance and scaffolding provided by the carefully structured IPA approach. Appendix 20 illustrates the stages of IPA analysis in several versions of excerpts from the same transcript.

4.6.1 Reading and re-reading transcripts and diary entries

This step involved transcribing, then reading and re-reading both diary entries and field notes from the interviews; this allowed me to enter into the participants' world to make sense of the meaning of their lived experience of PCC in OPAH and try to interpret their perspectives. It was essential to listen repeatedly to the audio recordings, transcribing each collective, interview by interview. I was surprised by the strength of the recollections of tone, facial expressions and body language evoked by the data, indicating a powerful connection to it. Skinta et al. (2014) suggests noting such cues within the transcripts to assist with the analytical process.

Smith (2018) highlighted the value of noting *hot* emotive responses (such as sadness or joy) as participants share how they make sense of meaningful experiences. This occurred in several interviews – some participants laughed; others became tearful. Noticing changes in intonation allowed me to gain insights into the participants as people within their lived experiences of PCC.

At this stage, analysis was focused on the topic by drawing a line through any of the data that did not relate directly to the aim and objectives of the research. However, no data was deleted, in case its relevance became evident at a later stage.

4.6.2 Initial noting

At this point the first stage of the hermeneutic interpretive cycle was employed (Polley, Highfield and Neal 2018; Charlick et al. 2015; Sallis and Birkin 2014, Dickson, Knusson and Flowers 2008). The data was reviewed word by word, line by line, observing any initial points of interest. The diaries were examined first to elicit key themes for further exploration within the interview transcripts. These, along with the relevant field notes, were then considered in the same way. Smith, Burgess and Sorinola (2018) along with Polley, Highfield and Neal (2015) recommended the use of colour-coding to highlight three components of this raw data: *descriptive* (what the experience was like), *linguistic* (the language used, such as metaphors) and *cognitive* (deeper reasoning of silences or the repetition of certain words by the participants). This process allowed an initial interpretation to emerge of how participants made sense of their lived experiences of PCC in OPAH. This use of colour fitted with my visual learning approach (VARK 2010). Furthermore, the exploration of the domains of linguistics, description and conceptualisation within the analysis allowed me to gain deeper personal insights into the data. Charlick et al. (2015) state such an approach can help the researcher to begin to understand the participant within the context of their lived experience. For example, repeated use of the term *"I"* created the impression of taking personal responsibility, whereas *"they"* suggested that others were perceived to be in control. This process can be clearly seen in the stages of transcript analysis in Appendix 20 and Chapter 5.

4.6.3 Considering emergent themes

The next step in the analytical process was to focus more deeply on the interpretative component of IPA, where the participants' interpretation of their lived experiences of PCC was uncovered. Appendix 20 provides an example of this stage of the process. Initial notes were recorded on the left side of the transcript, whilst emerging themes were noted on the right.

Although the discrete components of the transcriptions were scrutinised individually, careful attention was also paid to the analytical hermeneutic circle (Hefferon and Gil-Rodriguez 2011). Whilst being mindful to the McCormack and McCance (2017) theoretical lens to the study, I was cognisant to participants sense making processes of what PCC experiences meant to them. This level of deliberate attention to detail allowed superordinate themes to be uncovered within the data. Finally, the whole lived experience of PCC for OPAH was examined within the context of the participant's life (Skinta et al. 2014). More extensive notes were recorded at the end of each transcript. The emerging themes further illuminated how participants made sense of their lived experience of PCC in OPAH care. The case-by-case analytical process implemented within this study, along with the consideration of the unique, idiographic details of each participant to obtain multiple perspectives, will enable this research to make a unique contribution to the PCC evidence base.

4.6.4 Making connections across themes

This stage of the analytical process involves moving from the first hermeneutic circle of making sense of participants' interpretations, to forming wider interpretations from the data (Smith, Burgess and Sorinola 2018; Hefferon and Gil-Rodriguez 2011). This is done by firstly identifying patterns within each stakeholder group, such as similarities and differences between the older people’s expectations of PCC. Comparisons are then drawn between the views of the older people and those of other stakeholders; for example, differences between older people’s definitions of PCC and those of the family members and the MDT staff might be explored. At this stage, attention was paid to polarised themes in individuals’ lived experiences.

In keeping with interpretative hermeneutical approaches, a ‘strong’ theme was not necessarily one shared across all participants, but one that was important to their lived experience of PCC (Silverman 2013). The frequency with which a theme appeared within the transcripts could also give some indication of its strength (Smith, Larkin and Flowers (2012). Although Smith and Shinebourne (2012) ague that this approach strays too far into the realms of quantitative analysis, Hannah and Lautch (2010) disagree, suggesting that when used as a supplementary tool, numeration can also be useful in qualitative analysis. In this study one participant laughed spontaneously 47 time during their hour-long interview; this fact was interpreted as supporting the conclusion that this person had a positive demeanour. Hannah and Lautch (2010 p.17) refer to numeration in such situations as ‘credential counting’. Although this strategy was not included in the original plans for the data analysis, it was adopted when the frequency of recurring words and paralanguage became apparent in the raw data. I believe that it added strength to the other analytical strategies described in this section.

All themes were continually evaluated in the wider context of the participants’ whole lived hospital experience and of their usual life outside of hospital.

4.6.5 Repeating process of analysis with the next case

Each case was fully analysed before examining the next one, as advised by Charlick et al. (2015) and Skinta et al. (2014). I focused my attention solely on themes emerging from the case in hand. In keeping with the pluralistic philosophical perspectives of Heidegger (2003) and Gadamer (1960), no attempt was made to bracket out any previous experiences. Instead, I viewed each new transcript with open-mindedness and curiosity whilst uncovering what mattered most in the participants' lived experiences of PCC and remaining mindful of what had been uncovered to date.

I used a reflexive journal to help me to separate new personal insights from those gained from earlier case collectives (Finlay 2009); I also recorded new literature searches and experiences from my research journey. The content of this journal was different from that of my field notes from the data collection; it added depth to the subsequent transcripts of interviews (see Appendix 20).

My supervision sessions led to supplementary discussions relating to the transcripts and emerging themes, resulting in an open approach to the analysis. As I progressed, I became more immersed in the data and was able to explore it more intuitively.

4.6.6 Identifying patterns in the data across cases

The final stage of analysis involved looking for connections across cases whilst recognising the unique idiosyncrasies of individuals' lived experiences (Smith, Larkin and Flowers 2009). This allowed superordinate themes to be clarified and connections between cases to be identified. These are presented in Table 4.1 below and are identified by the older person's case. The format of the presentation of the findings based on the superordinate and subthemes was guided by other IPA studies (Smith, Burgess and Neal 2018; Polley, Highfield and Neal 2016; Strickland 2014; Beeston, Hugh-Jones and Gough 2014)

Table 4.1 below also demonstrates how IPA processes were followed, acknowledging convergent and divergent superordinate themes across the case collectives.

Table 4.1 Connections in the Superordinate Themes

Superordinate Theme	Sub-themes	Experienced by which participants
The impact of participants personhood on their experience of PCC	• How life to date shaped participants personhood	• All participants
	• How participants personhood influenced their definitions & expectations of PCC	• All participants
The PCC experience of accessing acute hospital	• Emergency services versus out-of-hours access to hospital	• 1 older person, 3 family members
The PCC experience in an acute hospital	What participants valued as enhancing their experiences of PCC:	
	• Meeting Fundamental care needs: “They couldn’t have done more.”	• All participants
	• Little things make a big difference	• 2 older people, 2 family members
	• Positive Culture: “A happy place”	• 1 older person, 2 family members, 3 MDT participants
	• Making time: “They never rushed you	• 2 older people, 2 family members
	• Information sharing and decision making: “It was in their hands”	• 2 older people, 2 family members All MDT participants
	• Safety	• 1 older person, 3 family members, all MDT participants
	• Acute Care stepping in: “they couldn’t believe that I was managing”	• All family members
	• Complex illness in person centred decision-making: “Opposite of protocol”	• 1 family member, 3 MDT participants
	What participants believed diminished their experience of PCC:	
	• Aspects of hospital systems	• All MDT, 1 older person, 1 family member
	• Aspects of care by ward staff	• 2 older people, 2 family members
The PCC experience of leaving an acute hospital	• Discharge arrangements: the impact of PCC experience	• All participants

In-depth discussions regarding the IPA analytical process in supervision resulted in many moments of reflection, as exemplified in the excerpts below.

4.7 Personal reflections

The following excerpts demonstrate how supportive supervision, along with quiet times for 'mind space', enhanced my clarity around those decisions.

Reflexive Excerpt 14.5.18

… I found the semi-prescriptive nature of analysing within an IPA study increased my confidence on this doctoral research apprenticeship. Having the IPA guiding principles helped assure me that I was analysing with sufficient depth (Dickson, Knusson and Flowers 2008).

However, as I progressed from one case collective to subsequent ones the analytical steps of IPA I began to be more intuitive (Shinbourne 2012) in line with my growing interpretation of the data… the analysis was mainly conducted on repeated versions of word documents, as I re-listened, re-read and took notes on themes as they became apparent. When attending the Scottish Interpretative Phenomenology Interest Group (SIPAIG 2018) for specific workshops on analysis, emphasis was placed on using word documents …

4.8 Chapter conclusion

This chapter presented the rationale for the choice of research setting in order to gather data from multiple perspectives to understand PCC experiences in OPAH care. The data collection methods of diary completion and face-to-face interviews were justified alongside the process for obtaining ethical approval. The methodological decisions regarding each stage of the research process were critically examined, including the flexibility in their use to accommodate participant preferences and situational factors. As advocated by Smith, Flowers and Larkin (2012), each step of the analysis leading to the study's findings was explained.

5 Findings Chapter

5.1 Introduction

This chapter is a collective account of the interpretation of participants' perceptions of their lived experiences of Person-Centred Care (PCC) in an Older Persons' Acute Hospital (OPAH). The chapter illuminates perceptions of PCC from the perspectives of older people, their families and the Multidisciplinary Team (MDT), exploring key facilitators and barriers to PCC. Throughout this chapter participants are named in order to recognise their uniqueness and not label them as part of a homogeneous group (Creswell 2014). However, in line with ethical considerations (GDPR 2018; Polit and Beck 2014) participants are referred to by a pseudonym. An overview of participants' demographic details enables the reader to identify the participants and begin to see their uniqueness (more details within *section 5.1.1*). Verbatim quotes (colour coded according to the corresponding collective) are used to ensure participants' voices are ever present (Polit and Beck 2014). Participant quotes are identified by their name immediately following the direct quote; where the direct quote involves dialogue between the participants, the researcher or others in the participant dyad, initials will be used to identify who was speaking. To allow the reader clarity around the connections between participants, the links within the collective participants will be re-iterated around the direct quotes, (for example Nurse Sarah who cared for Davina). Where participants placed emphasis on a point within their dialogue, or the interpretation of their choice of linguistics is particularly significant, bold text is used in conjunction with supplementary explanation. The local Scottish dialect features in some of the direct quotes, these are explained in plain English within the quotes. Eleven participants in four collectives, consisting of an:

- older person, family member, nurse and doctor
- older person, family member and nurse
- older person and a nurse
- family member and a nurse

took part in the current study. The collectives are presented in table 5.1 in the order they were recruited. Four superordinate themes that were constructed from the data are presented:

- the impact of participants' personhood on their experience of PCC
- the PCC experience of accessing acute hospital
- PCC experience in an acute hospital
- the PCC experience of leaving an acute hospital.

Throughout the chapter, excerpts from the researcher's field notes are also included to illustrate aspects of the analytical IPA process (Finlay 2002) and the learning journey. A reflexive excerpt is included at the end of the chapter, this highlights the changes in the author's PCC perspectives, as a consequence of analysing and presenting these findings. The findings will then be critically compared and contrasted in Chapter 6.

5.2 Lived Experience of Person-Centred Care (PCC) for Older People in an Acute Hospital Ward

5.2.1 Demographics

Table 5.1 Overview of Participants

These colours will be used when directly quoting throughout to enable the reader to clearly identify which case is being referred to.

Colour coding and type/s of data collected	**Case Collective 1** **Diaries: Davina, David & Nurse Sarah** **Interviews: Davina & David together** **Nurse Sarah**	**Case Collective 2** **Diaries: Nurse Yvonne** **Interviews: Douglas, Nurse Yvonne**	**Case Collective 3** **Diaries: Nurse Nicola** **Interviews: Phyllis, Nurse Nicola**	**Case Collective 4** **Diaries: Grace, Catherine, Nurse Kathy** **Interviews: Grace & Catherine together, Nurse Kathy, Doctor Isobel**
Older People	**Davina (age 95)** Worked as a senior administrator until she had her only son, 67 years ago. Widowed for 27 years. Lives alone in a bungalow in a city suburb. Close family, and friends. Enjoys daily crosswords, gardening and getting her hair done.	**Douglas (age 78)** Worked as a fisherman, was the 'skipper' for 34 years. Widowed three years ago. Has three children, one living locally, another at a distance in local region and one abroad. Lives alone in a rural community. Enjoys time with his family and friends.	*George (withdrew)* Wife shared her lived experience of her husband being in OPAH care.	**Grace (age 86)** Worked as a machinist in a city factory until the birth of her four children, three sons (now estranged) and one daughter. Lives alone in sheltered housing complex in a rural community. Reliant on her family, particularly her daughter, daughter's children but enjoys time with friends.
Reason for Admission	Fall (head & back injury) at home. PMH: Osteoporosis.	Urinary sepsis. PMH: bladder cancer with bone metastases, severe lymphoedema, immobility.	Reduced mobility. PMH: six long term conditions. Active treatment stopped following deterioration.	Fall at home, completely immobile. PMH: reduced kidney function.

Colour coding and type/s of data collected	**Case Collective 1** **Diaries: Davina, David & Nurse Sarah** **Interviews: Davina & David together** **Nurse Sarah**	**Case Collective 2** **Diaries: Nurse Yvonne** **Interviews: Douglas, Nurse Yvonne**	**Case Collective 3** **Diaries: Nurse Nicola** **Interviews: Phyllis, Nurse Nicola**	**Case Collective 4** **Diaries: Grace, Catherine, Nurse Kathy** **Interviews: Grace & Catherine together, Nurse Kathy, Doctor Isobel**
Care Trajectory Overview	999, Emergency Department (ED), acute OPAH assessment (24 hours), 4 weeks in step down OPAH. 1 week in day surgery (boarded out). Discharged home with 2 daily carers.	Admitted from rural GP bed. 4 weeks in step down OPAH, developed hospital acquired pneumonia. Discharged to rural GP bed.	Several calls to GP & Out of Hours over 4 days before acute OPAH assessment (24 hours). One week in step down OPAH. Discharged to interim care area for palliative care.	999, ED, acute OPAH assessment (24 hours) 4 weeks in step down OPAH Discharged to rural GP bed for rehabilitation.
Family	**David – main carer (son, age 67)** Retired Civil Servant. Married with two grown daughters and four grandchildren. Lives very close to Davina.	*Bruce (withdrew)*	**Phyllis - main carer (wife age 69)** Recently retired carer/ sheltered housing warden (due to breast cancer, now well). Married to George 41 years. One grown son, one daughter, one stepson, one stepdaughter, four grandchildren and one great grandchild all living close by.	**Catherine - main carer (daughter age 58)** Recently retired personal carer. Married with a grown son and daughter and six grandchildren who all lived close to Grace.

MDT Members	**Nurse Sarah (age not shared)** Senior Staff Nurse - Band 6	**Nurse Yvonne (age 57)** Staff Nurse – Band 5	**Nurse Nicola (age 48)** Staff Nurse - Band 5	**Nurse Kathy (age 44)** Senior Staff Nurse - Band 6	**Dr Isobel (age 31)** Registrar
Healthcare Experience					
OPAH	Just over 10 years	12 years	9 months	15 years	4 years
Prior to OPAH Experience	Gynaecology, Respiratory, Rehabilitation	1year surgical experience.	12 years as a Senior Carer in Long Term care of the elderly and Learning Disabilities.	5 years in international medical care.	4 years' experience across: ED, Obstetrics, Renal, Intensive Care.

The four superordinate themes and subsequent sub-themes are listed below (Table 5.2) and provide the reader with an overview of the distinct themes that emerged in this research. Within each superordinate theme, the sub-theme will be presented with the intention of allowing the reader deep insight into participants' experiences of PCC. The analytical processes that led to these themes and the conclusions reached were described in *section 4.5*. The McCormack and McCance (2017) model of person- centredness was compared and contrasted to the findings throughout the production of this chapter. Critical comparisons are drawn between the doctoral findings and the theoretical model in Chapter 6.

The findings in the first superordinate theme are presented around each individual collective, facilitating a *getting to know* the participants' personhood process. Thereafter, in keeping with the iterative process of IPA, the shared and unique lived experiences of PCC are woven either individually or collectively around each of the themes (Charlick et al. 2015; Hefferon and Gil-Rodrigrez 2011).

Table 5.2 Overview of Super ordinate and Sub-themes

Superordinate Theme	Sub-themes
5.3 The impact of participants personhood on their experience of PCC	5.3.1 How life to date shaped participants personhood 5.3.2 Participants' personhood influence on their definitions & expectations of PCC
5.4 The PCC experience of accessing acute hospital	Emergency services versus out-of-hours access to hospital
5.5 The PCC experience in an acute hospital	5.5.1 Connecting with older people & their family 5.5.1.1 Attention to finer details: "Little things make a big difference" 5.5.1.2 A positive culture of care: "A happy place" 5.5.1.3 Making time for people: "They never rushed you" 5.5.1.4 Information sharing and decision-making: "It was in their hands" 5.5.1.5 Complex illness in person centred decision-making: "Opposite of protocol"
	5.5.2 Experiences that participants identified as PCC 5.5.2.1 Meeting Fundamental care needs: "They couldn't have done more." 5.5.2.2 A Multidisciplinary approach to care: "I can't think, one person wouldn't be able to coordinate all those things" 5.5.2.3 Acute Care stepping in: "they couldn't believe that I was managing"
	5.5.3 Experiences that diminished participants PCC 5.5.3.1 Aspects of hospital systems 5.5.3.2 Aspects of care by ward staff
5.6 The PCC experience of leaving an acute hospital	5.6.1 The impact of discharge arrangements on participants' PCC experience

5.3 Superordinate Theme: Impact of Personhood of Participants on their Experience of PCC

5.3.1 Sub-theme: How life to date shaped participants' personhood

According to Hewitt-Taylor (2016), our past, present and anticipated future influence our understanding of the world around us, along with our perceptions of each lived experience. These experiences determine who we are in our world (Creswell 2014) and subsequently our sense of individual personhood. The analysis of each participant's account indicated that their life to date had played a key part in determining what was most important to them whilst in the current situation of being in an OPAH environment. Experiencing PCC meant supporting participants as individuals to continue to fulfil their sense of personhood in their unique situation of giving or receiving care.

Verbatim quotes demonstrated that, for each participant, certain aspects of their life to date were crucial to their sense of personhood: family closeness, social contact and previous occupation. Support to maintain independence was also an important factor for some of the participants. For the MDT, personal and professional life experiences seemed to contribute to dedication to OPAH care. The section below presents evidence to support these findings in relation to each of the collectives.

5.3.1.1 Case Collective 1 Davina, David and Nurse Sarah

The importance of family relationships to Davina was demonstrated by the daily hospital visits shared amongst her family (son, daughter-in-law, two adult granddaughters and four great granddaughters). Their regular physical presence contributing to her sense of being comfortable in the acute hospital environment was evident.

> *"The youngest great grandchild, as soon as she come in, she knew where everything was, the crayons, the little scissors were out…Oh, yes, a comfortable chair, tea if you wanted it."*
>
> Davina

Continuing social contact also presented as a priority for Davina's quality of life. Despite being aged 95, prior to admission she had regular meetings with friends for coffee, and thought nothing of travelling for over an hour, taking two buses to attend hairdressing appointments, so that she could look nice on these occasions.

> *"…Oh, yes, I was away to the hairdresser, bus into town, change buses and then my hairdresser in [place]…" (7 miles away)*
>
> Davina

Maintaining a degree of independence, despite the availability of support from her family, was also a key element for Davina. Being able to hold on to her sense of self in her world helped her to maintain her positive outlook despite this hospital admission. Although recognising that advancing age required resilience and willingness to compromise, Davina insisted completing daily crossword puzzles kept her mind active. Davina had recently employed a gardener and a cleaner, enabling her to maintain her standards rather than allow her loss of mobility to interfere with maintaining her home and garden. Receiving compliments in regard to how well she was managing despite her advancing years was important to her, confirming her unique sense of personal value.

> *"There was one nurse and she'd been taking me the toilet and she said, "Ninety five, I can't believe it!" I thought, 'That's good' (laughing)."*
>
> Davina

Maintaining his mother's family and social relationships was also important to Davina's son David who adopted the role of coordinator to ensure his mother had regular visitors throughout the day:

> *"…if any of Mum's friends got in touch with us to ask about visiting, we could advise them more or less immediately, "Okay, just avoid these times", and a lot of people found it very, very convenient. For their own particular reasons, some people said,*

> *"Oh, that's fine, I could be there for four o'clock", or whatever time, and it also meant that we could just make up our minds in the morning [visited daily] and say, "If we pop up now between 10 and 11."*
>
> David, Davina's son

Another key factor contributing to David's ability to maintain his own sense of personhood was ensuring his mother was safe and well cared for, not only in hospital but also at home after discharge:

> *"Well, Mum was obviously safe in the hospital environment and much safer than she would have been at home without carers, if she needs to go to the toilet just pressing a buzzer and she would get attention. Mum… I don't know if you've noticed but [points to his Mother's wrist]…They came and installed it. Mother has this on her wrist now so that is something else that just…Carer management has taken over and everything seems to be coming together."*
>
> David, Davina's son

David did not convey that supporting Davina in maintaining her independence was in any way burdensome. His relationship with her demonstrated the level of respect and thoughtfulness he hoped she would also receive from others, including those caring for her.

> *From the outset the respect David has for his Mum radiates in the interview, he always lets her speak 1st, then adds his answers, unless I ask specifically to him. Even when his Mum is unsure (role of the dietician) he waits until she is finished and then adds his perception.*
>
> FIELD NOTES

For Davina and David to perceive that their PCC needs had been comprehensively met, they expected acknowledgement of individuality. Their nurse, Sarah, demonstrated keen awareness of the importance of adapting her care to each individual.

> *"Yes, but I would also say I worked in an area where we had… it was quite a number of years ago, we used clinical pathways. It was a rehab ward and it was seen that this is the path that everybody would follow with a few exceptions, but really nobody followed the path because everybody was an individual and the clinical pathways well they were great for a surgical ward, for a rehab ward wasn't quite the same…"*
>
> Nurse Sarah, who cared for Davina

All the MDT participants were recorded as expressing a preference for person-centred ways of working which had led them to elect to work with older people receiving acute care. Nurse Sarah acknowledged the difficulties presented by busy wards and staff shortages; these will be explored in more depth later in this chapter. The opportunity to provide individualised care was identified by Nurse Sarah as providing the greatest professional satisfaction and fulfilment. She was moved to tears recalling occasions when older people had acknowledged her contributions to their well-being. In this direct quote, there is a short probing question from the researcher (K = the researcher).

> *"There are sometimes within nursing that you go home and you think, 'I didn't do as well as I could do' if you're really short staffed but it just takes one individual when you're having a day like that to say to you, 'Thank you so much for what you did for me today'. I would say most of the staff and myself go home every day thinking that we did the best we could for our older people and we looked after their needs as best we could." (voice shaky)*
>
> *K: "Does that gratitude mean a lot to you then?"*
>
> *"It does because, as I say, if you're a little bit tired and the ward is really busy and you feel a bit of pressure from above (gestures pushing down from above) that it just takes somebody to pat your*

> *hand and say, "Thank you, my dear" (emotional again), and that just makes everything worthwhile when you're having that low moment." (appeared emotional, tearful eyes)*

Nurse Sarah, who cared for Davina

Nurse Sarah, Davina and David presented as experiencing a sense of connection; clarity between all of the participants in this collective regarding their sense of personhood was evident. Davina's sense of valuing family, social connection, pride in personal appearance and determination to be as independent as possible was recognised and supported by her son David and her Nurse (Sarah). David's respectful support as part of his personhood was acknowledged by his Mum and Nurse Sarah. Lastly Davina and David seemed cognisant of Nurse Sarah's self-awareness that working in OPAH nurtured her professional satisfaction of having a person-centred focus to care delivery.

5.3.1.2 Case Collective 2 Douglas, Nurse Yvonne

As with Davina, it was important for Douglas that he could keep his sense of who he was in his world intact, appearing determined to maintain contact with family and friends. Despite one son living close by, one daughter living further afield and one son living abroad, Douglas found ways to maintain close contact with all his family. Memories of his late wife also remained an important part of Douglas's view of the world and he valued opportunities to share his memories of her, which lifted his mood in spite of his health challenges.

> *"Oh, yes, a beautiful wife, wonderful…She was absolutely brilliant…But eh.. She got involved with…pause, (thinking) eh... the fisherman's wives. We got an invitation down to the garden party, through her, aye my wife. Then I escorted the Queen aboard my boat. Yes, because, aye well they were building the new fish market in Aberdeen and they wanted a boat for the Queen so I was the boat that was picked. Aye me and my crew, sorry bunch [laughs]."*

Douglas

Maintaining independence also presented as a key factor contributing to Douglas's sense of personhood, just as it had been for Davina. Although he accepted help from one of his sons, he used the word 'I' repeatedly in this description of his normal routine; (in bold in the quote below) signifying what can be interpreted as a strong desire for independence.

> *"**I** would get up and have breakfast, cornflakes, and then have lunch, a big pot of soup, beautiful. **I** used to micro the soup and then in the evening, my son comes home from his work, he made a meal or if he was away biking with his pals, he'd have already a meal which **I** heated up, which was good."*
>
> Douglas

Despite being retired, Douglas's past role as the captain of a fishing boat for 34 years influenced his sense of himself in his world through the pride and meaning he still derived from his achievements in this area of his life emerging throughout the interview. These disclosures imparted a sense of who he was as a person, enabling the establishment of a deeper connection with Douglas's sense of personhood, within the interview.

> *At times he [Douglas] finds it hard to focus and drifts off to talk about his working life, this creates this picture of a strong proud captain of his ship, so I can see how tremendously hard it must be for him to be dependent. He is used to being in charge, in a way that everyone worked well to achieve a common goal. He talks as if he wants more information than he has been given, as if he wants to know the full picture, to have person-centred focus in his relationship with doctors and physios.*
>
> FIELD NOTES

Douglas appeared to anticipate active involvement in his care decisions in hospital and plans for his discharge home. His past occupation seemed to contribute to the expectation to be in more control than he seemed to experience. Possibly his previous occupation of being in charge of a fishing boat for a prolonged period of his younger life had influenced his expectations of leading his own care. Douglas's previous occupation influenced his expectations of how his healthcare team would work together to provide his PCC whereby he demonstrated anticipation of the healthcare team being efficiently led, working together towards shared goals, in the same way he experienced teamwork as a ship's captain.

> *"Well, being a fisherman, you're your own boss. You had nobody to tell you what to do. I never had to tell the crew anything. They knew their jobs and just got on with it. You could trust them."*
>
> Douglas

The MDT participant involved in providing Douglas's care was Nurse Yvonne whose identity as a nurse was influenced by several factors. On one hand, despite being an experienced nurse, a lack of confidence appeared apparent through her requesting her diary entries be checked for mistakes prior to submitting them. On the other hand, Nurse Yvonne's perception of the impact of busy wards on PCC differed from Nurse Sarah's, through her reporting that she valued the fast pace of the ward. Nurse Yvonne had left a career in retail to become a qualified nurse; throughout twelve years nursing experience she had chosen eleven of these to be based within OPAH care environments. Her professional satisfaction presented as deriving from the fast pace of meeting the needs of older people, when they were acutely unwell.

> *"I find it's always busy, which I like. I'd rather be busy than standing about. I just find it's good. I like being busy (laughing). The time passes quicker. I would hate to work somewhere where you were just constantly looking at the time and thinking, 'Gosh, so many hours to go yet'. It's never like that here. Even sometimes a 12-hour shift, you think it's not long enough to do everything that you need to do."*
>
> Nurse Yvonne, who cared for Douglas

However, at times Nurse Yvonne demonstrated frustration with systems and processes which she believed obstructed person-centredness (this aspect is further deliberated on in section 5.6).

In contrast to Davina, David and their nurse (Sarah), the level of connection between Douglas and his nurse (Yvonne) was not as apparent. Nurse Yvonne did not share finer details of Douglas's sense of personhood, she did not appear to have an awareness of his pre acute illness life, for example. The importance of connection between older people, family and the MDT is investigated in section 5.3.2 and within Chapter 6.

5.3.1.3 Case Collective 3 Phyllis, Nurse Nicola

Whilst family, social contact and previous occupation were important contributors to Phyllis's sense of personhood, her perceptions of PCC presented differently from the other participants. Phyllis's expectations can be perceived as being shaped by her 27 years of experience as a sheltered housing warden/paid carer and main carer for her mother and her husband.

> *"…even my mother, she suffered from depression, even when I was young that was hard, it was hard, back & forth to the mental hospital…Well, aye and the job I did (carer/home help in sheltered housing),* ***but here it was 24/7 you never got away from it. Never get a break."***
>
> Phyllis, George's wife/carer

As indicated in the introduction to Chapter 5, where text on the direct quotes are in bold, this is where I interpreted that the point seemed particularly important to the participant' *sense making* of the experience they were sharing. At this point, the bold dialogue can be perceived as demonstrating that whilst Phyllis appeared to feel overwhelmed by the burden of George's care, her altruistic values and ethos of looking after others prevented her from prioritising her own needs.

> *"Well, this happened to me, points to breast [had Breast cancer]. Well, George would have been at that time about 18 stone then, well* ***I'm little****…Well, I was about cracking up****, but I'm a fit person,*** *I have had a lot of operations, if something is going to go wrong..* ***but I'm fine****, everything goes wrong with me.. 9 operations in my life,* ***but I'm fit as a fiddle****, but then I took a chest infection…This is meant to be about George, but never mind, I was back & forth my son had the flu…"*
>
> *K : "So were you run down from running about after everyone?"*
>
> *"Aye folk have said that to me before…."*
>
> Phyllis, George's wife/carer

Phyllis proceeds to explain that her expectations for PCC appeared to mirror her previous demands upon herself as a care provider and self-perceived stoic care-giver. Therefore, once George was in the care of others, Phyllis's sense of personhood influenced her expectations of others including the MDT taking responsibility for meeting George's needs through caring for him rather than enabling his independence. Phyllis's sense of personhood influencing her definition and expectation of PCC will be further explored in the next section 5.2.2. Aspects of Phyllis's PCC expectations were quite different from Nurse Nicola perspectives, who cared for George and Phyllis. This is illuminated in the conversations around George's sleep apnoea, in the quotes below.

> *" Yes, so like he had, he had sleep apnoea, he had his own CPAP machine [Continuous Positive Airway Pressure equipment]…most of us, the nurses, had not used this before, so the wife like, brought it in and showed us how to operate it.* ***So he could do as much as possible.*** *Then George himself he showed the night nurses what to do. So we encouraged him* ***to stay independent with this****."*
>
> Nurse Nicola, who cared for George

> *"Aye and George, his CPAP…Aye, that's the thing, every time George has been in, no one knows how to work it (seems surprised) …Oh I suppose they canna train them in everything?"*
>
> Phyllis, George's wife/carer

Nurse Nicola's sense of personhood appeared influenced by her twelve years' experience in healthcare during the period PCC focus had evolved (as outlined in Chapter 1). Nurse Nicola's sense of personhood appears influenced by the recent completion of her nursing degree, where the Nursing and Midwifery Council (NMC) educational standards have a person-centred focus (NMC 2010). These influences are apparent in her definition of PCC, which is closely aligned to current political drivers and the joint approach, PCC evidence base (McCormack and McCance 2017; HIS 2015; SG 2014). The bold dialogue in these excerpts denote where Nurse Nicola paid particular attention to the involving and enabling aspects of PCC. These appear to be in direct opposition to Phyllis, George's wife's sense of personhood, in terms of how people should be cared for, revealing a disconnection of PCC expectation between George, Phyllis and Nurse Nicola. The need to build connections in order to align PCC experiences will be explored in section 5.3.2 and Chapter 6.

> *"Person-centredness is mostly* ***about getting the person involved in their care****, having discussions about their care, them being at the centre (gestures with her hand in the middle of a circle) about having the patient at the centre of their care.* ***Respecting the person giving them choices of their care. Caring for them with dignity****…*
>
> Nurse Nicola, who cared for George

On reflection, these differing perspectives could have been explored in more depth but on the night of the data collection, Nurse Nicola was the most junior nurse on duty and was anxious to return to her shift.

> *I was interviewing at 7.45pm at the start of a night shift… she was the 2nd nurse on, not on in charge, but another member of staff*

> *had called in sick at last minute, so they were short staffed. The nurse on charge "allowed" her off for the interview … This could have contributed to the relatively short interview.*
>
> FIELD NOTES

Within the data, Phyllis presented unique experiences in terms of a directly opposing expectation of PCC from her nurse's PCC definition, where being cared for, rather than involved and engaged in their own care, was more important to Phyllis. Further divergences were apparent in Phyllis' sense of personhood, whereas the other participants derived comfort from their family relationships, this was not the case for Phyllis. She and her husband George both had two children from previous marriages. Although Phyllis valued her role as wife, mother and step-mother, cultural differences between the members of her family appeared, at times, to lead to conflict and disappointment.

> *"Oh.. Well aye, me and George we were both married before, but I have been with George 41 years. My son and daughter Matthew and Gail they have been with George* ***since they were 3 and 6****. But we have also got also got George's two, John and Jane,* ***49 and 52****.* ***We have always got on well****. Jane visits every 2 weeks. I was always telling her, how her Dad was, and if he had a hospital appointment,* ***but she never remembers, never calls in between the visits. Well, if it was my Dad I would have been phoning****."*
>
> Phyllis, George's wife/carer

Within the above quote, Phyllis described her own children as being the age they were at the time of the marriage, even though they are now adults. This could be interpreted as Phyllis conveying her grown children's sense of vulnerability and reliance on her and George. George's children, however, were referred to in the present tense as independent adults, less involved with her and George. Initially Phyllis spoke of her relationship with her stepchildren in positive terms, but then immediately criticised her stepdaughter for failing to show adequate concern for George. Phyllis was unique, as a participant with this type of complex family dynamic as part of her sense of personhood and this appeared to be an influencing factor on how she viewed herself and the expectations she had of her blended family.

5.3.1.4 Collective 4 Grace, Catherine, Nurse Kathy and Dr Isobel

Similar to Phyllis, Grace and her family member Catherine had experienced family conflict that presented as impacting on their sense of personhood. Grace had four grown adult children (3 sons and a daughter); however she only had contact with her daughter, Catherine, on whom there appeared to be a strong reliance. Grace's grown up grandchildren (Angela and Peter) were also involved in supporting her; despite the latter support, her estrangement from her sons was a source of sadness.

> *K: "You mentioned already, Grace, that family is really important to you?"*
>
> *"Yes, Yes. Oh Aye. Well, I know I have only got Catherine, Angela, and Peter looking after me. Aye. Well, why I … I have got three sons and they don't bother. No.   It's a long time. I don't worry about them now, but, when you think, and when you see other people with their sons coming in to see them, and they don't come in to see me"…(hangs head, looks sad)…(pause)*
>
> *K: "How do you feel about that?"*
>
> *"Sad, in a way, but I have got Angela and Catherine, and everybody in the family."*
>
> Grace

Nurse Kathy, who cared for Grace, made it clear that for Grace maintaining her close relationship with Catherine was important. Nurse Kathy also expressed that social activities in her sheltered housing complex were important to Grace's sense of personhood prior to her admission.

> *"She shared that she has got actually four kids, three sons and one daughter but the sons, they are not coming to see her and nothing to do with them. She would prefer probably that they come to visit her but the daughter only is visiting her…She said every Tuesday (when Grace was at home), they will do knitting and things so there are some activities that she will be able to participate when she is back on her baseline."*
>
> Nurse Kathy, who cared for Grace

With Grace and Catherine there had been a change in their family dynamic from daughter reliant on mother, to mother depending on daughter. Grace appeared at ease with the dynamic shift.

> *A lot of the time in the interview Grace looks to her daughter for clarification support. A lot of the time she simply agrees with Catherine, rather than giving me rich detail. Grace appears well supported by her daughter, but this seems a tiring role for Catherine.*
>
> FIELD NOTES

A significant aspect of Catherine's personhood appeared to derive from fulfilling her commitment to providing support for her mother, rather than sharing this task with her estranged brothers. Like Phyllis, Catherine indicated stoic continuance of her caring responsibilities regardless of being overwhelmed. Catherine's altruistic approach could potentially link to her previous occupation as a paid carer and was evident in the quick repetition of the bold words, '*very tiring*', in the quote below.

> *K: "So, how was that for you? Were you coming in every day [over one hour round trip daily]?"*
>
> *"Every day, for the first few weeks. Then, my niece she stays in Aberdeen and she would give me a day off. Yes, but it was **very tiring**. Yes, it was **very tiring**."*
>
> Catherine, Grace's daughter

Nurse Kathy, who cared for Grace, was a senior staff nurse in the ward, with 15 years' experience. She appeared to relate delivering PCC as a priority for her as a person and a nurse and enthusiastically welcomed the opportunity to participate in research in this field.

> *This nurse was eager to help me identify older people and keen to be involved, but twice I came to interview as planned and she was simply too busy. The 1st time a patient's condition had rapidly deteriorated and she was leading the care delivery. Another time, there was a last-minute staff shortage. So, the 3rd time, when we got to interview, she was equally keen & apologetic...her demeanour was one of genuine compassion to "be with" her patients.*
>
> FIELD NOTES

Nurse Kathy perceived PCC as an intrinsic normal part of care delivery, demonstrated in the way she used the word *'just'* in the direct quote below, illustrating that for her, the sense of personhood as a nurse is synonymous with delivering what she sees as PCC.

> *"**Just** give them holistic care, treat them with dignity, respect, and **just** according to their wishes and needs, **just** give the person their care, what they need, so their physical, social, spiritual, all their needs. Assist them and care for them holistically…They are the priority so **just** treat them **like a normal individual** and assist them with their needs and provide."*
>
> Nurse Kathy, who cared for Grace

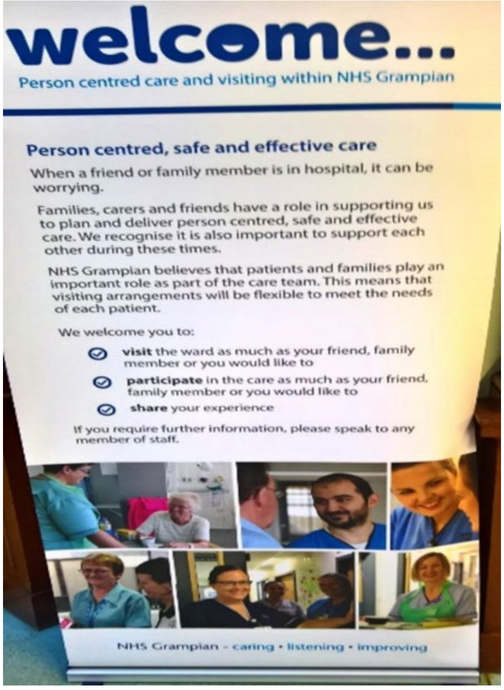
Like Nurse Sarah, and Nurse Kathy, Doctor (Dr) Isobel was noted as radiating enthusiasm for the OPAH speciality. Dr Isobel's past life experiences led her to choose to focus on older people acute care, where she also regarded PCC in OPAH as 'normal'. In terms of her personhood, OPAH care appeared to provide a good fit for Dr Isobel both personally and professionally, observed through her sense of present personhood emanating a passion for OPAH care. Dr. Isobel appeared to be aware the others who did not value OPAH care may not care for older people or even communicate with them, as 'normal people'; whereas she believed this to be fundamental.

> *"I didn't want to do geriatrics when I went to medical school or even when I left medical school but it was my first job when I was an FY1 and I really liked it. I think it comes quite naturally to me. Some people are really good with kids and I don't understand people who are really natural around kids but people always said that I was quite good at talking to old people. I never really thought of it as a thing to be good at. I just thought, 'Well, you just speak to them'. I guess because I worked in a care home and both my grannies had dementia so I got quite used to just tailoring however you were talking and talk to them* ***like normal people****."*
>
> Dr Isobel, who cared for Grace

The study findings demonstrate how participants' backgrounds and life experiences have shaped them as people and thereby the way in which what matters to them as people influences their interpretation of PCC experiences. The following subtheme reveals how these factors have led participants to develop different understandings of the nature of PCC.

5.3.2 Subtheme: How participants' personhood influences their definitions and expectations of PCC

The research area recently implemented the 'Welcome Ward' approach (NHS Grampian 2018), where older people and their families were invited to take an active part in giving care and to visit according to the pattern best suited to them. The NHS area appeared to be providing strategic leadership to embed PCC within normal care with initiatives such as the 'Welcome Ward' approach.



welcome...

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Person centred, safe and effective care

When a friend or family member is in hospital, it can be worrying.

Families, carers and friends have a role in supporting us to plan and deliver person centred, safe and effective care. We recognise it is also important to support each other during these times.

NHS Grampian believes that patients and families play an important role as part of the care team. This means that visiting arrangements will be flexible to meet the needs of each patient.

We welcome you to:

- ✓ **visit** the ward as much as your friend, family member or you would like to
- ✓ **participate** in the care as much as your friend, family member or you would like to
- ✓ **share** your experience

If you require further information, please speak to any member of staff.

NHS Grampian - caring • listening • improving

Figure 5.1 Welcome Ward banner

All the nurse participants (Sarah, Nicola, Yvonne and Kathy) shared a belief that to meet the currently accepted standards of PCC, care must focus on empowerment, enabling and person-centred decision making. For these participants, PCC centred on encouraging full participation in these principles, not a variable spectrum of empowerment, enabling or shared decision making. The latter concepts appear in keeping with current evidence-based definitions of PCC (Hewitt – Taylor 2016, The HF 2014). Nurse Sarah used hand gestures to describe this, as if trying to convey the older person requiring care as the fragile centre of a flower, needing strong off-shoots around them, to flourish in ways that they could be empowered or enabled. Nurse Sarah shares her experience of PCC as supporting vulnerable older people to be at the centre of their care experience, with them holding the locus of control (Glanvill 2018).

> *"Person-centred care has evolved so much over the years from holistic care, patient centred care. To me, it's looking at each person as an individual and their individual needs and tailoring your care as best you can and as best they can to suit their needs and having the* ***individual at the centre of the care****.* ***We're all offshoots of it but they're at the centre*** *(uses her hands*

> *gesturing the middle of a circle) of the care and it's what is best for them…**You're centering it around them** and their needs and helping them come to terms with the fact that maybe their life has changed. To me, it's **focusing on the individual with us being offshoots to help them**."*

Nurse Sarah, who cared for Davina

Nurse Sarah's description is similar to Nurse Nicola's definition of PCC, using hand gestures to demonstrate the person receiving care being in control at the centre of the experience, with Nurse Sarah and Nurse Nicola being enabling scaffolding, "off shoots".

Excluding the MDT, the only research participants who were familiar with the actual term 'PCC' were those with previous paid carer experience; Phyllis and Catherine. However, they each had differing views on how PCC should be provided. Catherine's definition was congruent with Nurse Sarah and Nurse Nicola's perspectives, emphasising the importance of knowing the person individually and working *with them*, rather than *caring for* them.

> *K: "Have you heard that term before, person-centred care?"*
>
> *"I have heard it, being a carer. Yes. Well, it is just having that **'one to one'**. It is all about trying to help with what you do, and what you can do yourself, but **with them** working along with you."*

Catherine, Grace's daughter

The value of providing individualised care, "looking after", rather than enabling, was central to Phyllis's view of PCC:

> *"Well, [PCC is to her] for him [George] alone…there are ones who, no George, but others, they are worried about falling and if they go to get up, they are right there **looking after them**. The care is really specific to each different individual."*

Phyllis, George's wife/carer

Phyllis's perception of PCC suggested being shaped by previous years of caring, when *caring for* was valued over *doing with*, therefore influencing her expectation of the PCC provided for George.

> *"Well, **I thought it was strange**, there was this one day I don't know, this girl**, I thought it was strange**, this day, if she was a nurse or an Occupational Therapist, but she came in about, the family were in, she was wearing the blue (points at top area of the body). I think she was a nurse and she said "Well, she says, "Can any of you suggest how to get George out of bed, because he is refusing to get up". **Well what's a nurse doing ask us? She should know how to get him out of bed. What's a nurse doing asking us**, how to get him out of his bed?"*
>
> Phyllis George's wife/carer

Phyllis's view suggests she saw this as a lack of nurse competence as opposed to seeing this interaction as an attempt to develop a person-centred approach, by involving her in choices about George's care. Such a contribution from Phyllis suggests that implementing current definitions of PCC, without first considering different stakeholders' views on the nature of PCC, could result in unmet expectations and conflict. The discrepancy between the expectation of PCC from Phyllis's perspective and how nurse participants (Case Collective 2) experience delivering PCC was acknowledged by Nurse Yvonne:

> *"They think because they're in hospital that we should do everything. It's a fine line. It's very difficult. Sometimes you feel bad saying, "No, but you can do that", because I think some of them think, 'Well, that's what you're here for'. It's very difficult sometimes not to take their independence away from them. Sometimes you feel cruel, "Oh, but you can do that yourself", and they think, laughs 'She is not a very nice nurse."*
>
> Nurse Yvonne, who cared for Douglas

For Dr Isobel, these differing expectations of PCC represented significant divergence during the process of decision-making. Dr Isobel demonstrated endeavouring to support older people in reaching their own choices, only to find that on occasions they passed the responsibility for decisions back to her. Dr Isobel's slight laugh, noted below, may have been an attempt to mask her discomfort as she openly discussed such a challenging area.

> *"I think generally, maybe it's a generational thing rather than… I don't know that today's young people will be the same when they're older. I think it's just traditionally people like to think that the doctor will do what's best. That's quite a lot of pressure* ***(smiling)*** *because sometimes you're like, 'Well, I don't actually know what's best for you'* ***(slight laughing)*** *because does best mean you want to live for as long as possible or does best mean that you want me to stop giving you lots of pills* ***(slight laughing)****.You know they'll probably be fine with whatever you decide in that case but at the same time,* ***you worry that maybe it's not the right thing for them****."*
>
> Dr Isobel, who cared for Grace

In particular, end of life decisions appeared more challenging when families' priority for longevity conflicted with quality of life. Dr Isobel reported feeling particularly torn when older people confided in her that they did not desire any further active treatment, but then relented to the wishes of family members who insisted that active treatment should be continued.

> *"I guess sometimes there are some peoples' families that almost seem too worried about what will happen to their Dad, Mother and with the best intentions in the world but sometimes I feel like they're maybe not listening to what their dad or mum actually wants…"*
>
> Dr Isobel who cared for Grace

These findings reveal an eagerness of the MDT participants in this study to enable and empower people to set goals and reach decisions about their care. Contrastingly, some older people and family member participants voiced a preference for the MDT to lead medical decisions and care to be demonstrated through *caring for* rather than *caring with*. These findings advocate that PCC needs to flexibly align with older peoples' and families' expectations. This presents a challenge whereby families' expectations of PCC did not always align with current person led, enabling, person-centred healthcare principle (Scottish Government 2010, 2017; The HF 2014). This discrepancy between participatory and non-participatory PCC has the potential for older peoples' and families' to experience dissatisfaction, regardless of the efforts of staff to provide what they viewed as 'good PCC'. Such findings challenge current thinking on PCC for OPAH.

The impact of personhood influenced definitions and expectations of PCC. As previously discussed current PCC drivers are centred around the person in need of care being actively involved, empowered, enabled and jointly sharing healthcare decisions (NHS Grampian 2018; McCormack and McCance 2017; IHI 2014; The HF 2014; Asimakopoulou and Scambler 2013; DOH 2011; SG 2010). However, this first superordinate theme, demonstrates that the participants personhoods, influenced their perspective of PCC and did not necessarily mean active involvement, empowerment, enablement or shared decision making. This was not consistent for all older people participants - definitions or expectations of involvement in their own care varied according to who they were as people rather than current PCC evidence or definitions.

In each interview, participants' interpretations of PCC commenced by exploring their experiences of accessing acute care. The varying experiences of PCC from the perspectives of the older people and their families when accessing acute hospital care will now be presented.

5.4 Superordinate Theme: The PCC Experience of Accessing Acute Hospital, Emergency Services versus Out of Hours Access to Hospital

Since the participants' overall experience of PCC was reported as beginning before reaching hospital, the intention of this theme is to provide the reader insights into how PCC corresponded with accessing OPAH care. The older people participants reported accessing OPAH care particularly challenging in a variety of ways.

Table 5.1 displays the multitude of contributing factors causing participants admission to acute hospital care. Davina, Phyllis (discussing George) and Grace reported an acute and severe reduction in their independent mobility. Davina presented as fearful of the rapid decrease in her mobility but reported, as did her son David, having experienced good support during this stressful event; meeting their expectations of PCC, as illustrated by the choice of words used to describe the experience (‘terrific’).

> *“How I got through, I don’t know, I don’t know but it was an ambulance job anyway.*
> *They came…They were **terrific**.*
> *David (Son): They [ambulance staff] were **terrific**. It took a long time because they didn’t know at that point if she’d broken anything so they were very careful and gave her morphine and…They took her into A & E.”*
>
> Davina, and her son David

Conversely, when George’s condition deteriorated, Phyllis reported that she sought help from her GP and the out-of-hours service; not emergency services. Over a four-day period, as George’s mobility deteriorated, Phyllis reported receiving triage advice by phone on several occasions with two assessments conducted in person. Whilst recognising that her husband now required more assistance that she could provide, Phyllis reported obtaining person-centred assistance as a challenge. The repeated use of ‘I’ in the quote below emphasises Phyllis’s attempts to cope independently. The impersonal phrases (e.g. ‘they’, ‘he’, she’), could be regarded as a measure of Phyllis depersonalising her contact with primary care and out-of-hours care, where she perceived the individuals she consulted with face to face and via telephone blocked access to what she believed would be appropriate, person-centred acute hospital care for her husband. The following elongated quote reveals the prolonged process Phyllis experienced when accessing acute care for George.

> *"The knee was that bad, he was limping, **I** phoned an ambulance, on the Saturday, 4 days before… he started acting funny, like delirious... the ambulance came, **they** checked him over, were happy enough with him, **ok I will try**, but **I** did say to them, but it was knee, **he canna walk**… So **they** were happy enough to leave him ... **So okay**, a couple of days, he was staying up there [upstairs] because he was struggling to walk, **so I try** to get him up from his chair with his zimmer, to get to his bed (for the night), but **I couldn't move him**, **I'm little**, George was **a big bloke, I'm little.** Never mind, **I'll** manage he said, **I** said you winnae, but **I** couldn't, so **I** called the doctors ken…111(out of hours), got through **... I** took his levels again (blood glucose, points to fingers), they were fine, **she**'s asking me all about stroke and everything, **I** said no, no, **he just canna get up**…Well, what annoyed me, well **I** called 111, when **I** got the ambulance (on the Saturday before), they said that the GP our own doctor would come in and check on him on the Monday…Well we waited in all day, but **they** never came, **they** just phoned, spoke to him on the phone, now she just presumed it was his knee again with his arthritis, **she** wanted him to go for an X Ray, he said **but I canna walk**…So **she** just prescribed stronger painkillers that day (Monday), but then this happened again on the Tuesday night, the doctor[out of hours Dr] came in and said we will get an ambulance and get you to hospital."*
>
> Phyllis, George's wife/carer

Phyllis reported devoting much of her life to caring for others, despite the personal sacrifices this had entailed, finding herself defeated by her husband's immobility, she tried in vain to convey the gravity and urgency of their situation. The GP and out-of-hours service assessed George, for specific acute and chronic medical concerns, via the phone suggesting a lack of connection between Phyllis and those she was interacting with and resulting in Phyllis feeling unheard when attempting to access acute care for George. Communications were evident as failing to address Phyllis's concerns and desperation when she could no longer physically move her husband, this is emphasised by her choice of words:

> *"I'm little, George was a big bloke, I'm little…".*
>
> *Phyllis, George's wife/carer*

Phyllis conveyed that accessing acute hospital care was much more challenging than she had hoped it would be and she appeared frustrated by this.

Contrastingly, Douglas reported no specific recollection of accessing acute care only recalling that he had been admitted to a rural hospital after falling at home and 'ended up' in this ward. His lack of clear memories could be attributed to a period of acute confusion due to urinary sepsis.

> *" Just ended up here, here in hospital.."*
>
> *K: "So, what happened at home that meant that you ended up coming in?"*
>
> *"God knows. It just happened."*
>
> Douglas

Douglas initially presented as unperturbed by his inability to recall the circumstances of his admission, however his preference changed once he became cognitively aware, subsequently requesting detailed information regarding his condition and future. This change in PCC expectation, demonstrates how a person's perception of acceptable PCC at one point in time, can alter in relation physical/cognitive ability changes. Douglas' expectation to be more involved in his PCC is explored further later in the chapter.

Overall, participants in the current study reported that they found emergency services access to be more person-centred than accessing acute care via primary care/out of hours services.

5.5 Superordinate Theme: The PCC experience in an Acute Hospital

This superordinate theme reports participants' experiences of PCC during hospital admission and resonates as the richest and broadest theme of this study. The simultaneous presentation of PCC experiences of giving and receiving care is presented from multiple participant perspectives. The theme is divided into three sub themes:

- connecting with older people and their family
- experiences that participants identified as PCC
- experiences those participants expressed as diminishing PCC

Table 5.2 illustrates the further subsections within these sub themes.

5.5.1 Connecting with older people & their family

All participants discussed their individual perspectives of the connection between them, how connections were reported as being formed from a wide variety of experiences has been sub themed. To allow explicit insight into the interpretations of how participants made sense of connecting with each other further sub themes were developed and are presented.

5.5.2 Attention to finer details: "Little things make a big difference"

Participant's sense of being cared for in a person-centred way was reported as being enhanced when MDT members attended to the small details that mattered to them. Davina, Grace and Catherine reported valuing occasions where they received assistance with their personal appearance, especially their hair as illustrated in this quote:

> *K: "I remember how pleased you were that you had got your hair done and you said to me that you told the nurses if they couldn't find you, you'd be going out to the dancing that night because you'd had your hair done and you were feeling good (laughing)."*
>
> *"Yes. It was one of the nurses that came around and tonged it. It looked lovely. There was another one further up, she got hers done, and she said, "I'm just as good" (laughing)."*
>
> Davina

Prior to admission, Davina invested considerable effort in regularly visiting the hairdresser, despite advanced age (95 years old) and the need to take two buses to get there. Staff recognising the importance of appearance to Davina's sense of self and endeavouring to support her in maintaining this by doing her hair, resulted in her feeling cared for in a person-centred way. Davina reported noticing the importance of this aspect of her PCC for herself, but also in the care of others around her. Grace's daughter, Catherine, echoed this sentiment

> *K: "What makes you think, "Yes, they do know my Mum"?*
>
> *"Mmm, (both Catherine and Grace look at each other) pause… quiet... They knew that she liked her hair. Yes, her hair to be nice. She likes to be nice and fresh, you know. "*
>
> Catherine, Grace's daughter

Phyllis regarded her experience of PCC as being enhanced when staff noticed George was lying awkwardly and took the time to rearrange his pillows, making him more comfortable. Phyllis verbalises this as '*a little thing*' yet notably she goes on to further clarify staff ensuring George's comfort as making '*a big difference'* to her.

> *"George never looked comfortable with the way the pillows were…So anyway, I goes in this day and I says, oh me you look so comfy, one of the nurses had took one of the pillows and put it in*

> *between him and the side rail, because he kept putting his hand through the rail…But made a big difference, so now I do it, when I go in (laughs).* ***Just little things like that, it does make a big difference.****"*
>
> Phyllis, George's wife/carer

An example of compassionate fundamental care, such as this, can be seen to demonstrate the creation of a bond of trust between Phyllis and the staff. At a time when Phyllis was experiencing anxiety and distress, this reassured her that when she was absent, George would still be made comfortable appearing to create confidence that he was in capable, caring hands.

> *"…here they can look after you better. And by god they have."*
>
> *K:" You seem so relaxed about.."*
>
> *"Oh I am, I am fine with leaving him there with them."*
>
> Phyllis, George's wife/carer

Meeting fundamental and individualised aspects of care will be explored in Chapter 6*.* Meanwhile*,* the influence of attentiveness on older people and family's perceptions of the overall culture in the research areas will now be explored.

5.5.2.1 A positive culture of care: "A happy place"

The findings suggested the atmosphere of a ward as an important factor in determining people's perceptions of the quality of PCC they receive. Older people and their families reported experiencing positivity in the settings related to this study. Phyllis attributed this to staff's demeanour, along with their compassion for older people, speaking highly of staff's dedication to looking after others in comparison to other areas she had experienced in her role as a care worker, a patient and as George's carer. In line with her view of PCC, Phyllis particularly valued the staff’s determination to look after people by providing all care, rather than enabling.

> *”Well I must admit… I have* ***never seen*** *a ward working like that the way they work because he is not well. They are* ***absolutely amazing****, I have* ***never seen*** *anything like it. It is the way they treat them (older people) the way they look after them. Make sure they are comfortable. Okay, always asking if … offering them tea, offering us tea. I said to the Dr, the way they look after,* ***I have never seen such good care. I have been in and out hospitals my whole life.*** *I have* ***never ever seen a ward like that. Amazing.*** *Aye, well it is good to get a bit of praise, like you say, they hear a lot of folk complaining, honestly all I could say they have been* ***amazing****.“*
>
> Phyllis, George’s wife/carer

Phyllis repeats the word/s ‘*amazing’* and *‘never seen anything like it’*, three times in the above quote. Phyllis appears to place herself as an informed person to comment on the atmosphere in the ward, given her previous personal and carer experiences of healthcare.

The older people participants also demonstrated valuing staff’s informality and moments of joviality, which were reported as helping to relieve tension and anxiety from being in a hospital environment. Davina valued an example of individualised care from one nurse who had endeavoured to identify her areas of interest, regularly chatting to her about them. The same member of staff is identified in the quote below, as empathising with sadness which Davina and others experienced due to spending Mothers’ Day away from their families. The quote depicts Davina appreciating a concerted effort to ensure the female patients he was caring for felt special. The combination of attention to Davina’s individual hobbies combined with a sense of fun contributed to Davina experiencing a positive culture of care, as a component of what she views as PCC.

> *"There was a male nurse and I was doing my crosswords and he said, "Ok, crosswords, I'll give you the answer to that one" (laughing), "Thank you" (laughing), so that made it… it was a happy ward. [On another occasion]… this male nurse was dancing down the ward and we're all saying, "Goodness me", and he said, "Well, it's Mother's Day, I'm giving you a dance", so that made us all cheer up (laughing)."*
>
> *K: "Was the fact that it was quite a happy atmosphere, did that make it okay to be in then?"*
>
> *"Oh, very. What a difference, yes. Absolutely. It was really a quite happy place."*
>
> Davina

Davina expressed no desire to return to the more strictly regimented healthcare practices she remembered from earlier times in her life. Instead, Davina shared a preference for a more good-humoured atmosphere and open approach to visiting, which she seems to value as part of her PCC experience.

> *"Before, oh my goodness, this little man was at the door and you weren't allowed in until three o'clock!"*
>
> Davina

Some of the changes noted above could be attributed to the introduction of a new '*Welcome Ward'* initiative (see start of section 5.5) (NHS Grampian 2018; Care Opinion 2018). The PCC philosophy behind the 'Welcome Ward' relied on implementation by staff. Staff reported commitment to the provision of PCC for older people. The nurses/doctor study participants shared that they had elected to work in OPAH care which may be interpreted as influencing the positive culture experienced by older people and their families in their care.

> *K: "Do you feel care of the elderly allows you to be… it fits with who you are then because you can…?"*

> *"… interrupts …Yes. I feel that I can show my caring side and I can feel that I can take the individual's needs into account and not… as I say, sometimes… I'm not saying that every place is like this but we are aware of the fact that, especially in the past, because I've been qualified for quite some time, people have 'the lady in this bed that's had this and this done' but that's not who they are. Everybody's got a name, everybody is a different person and they should all be treated as individuals."*
>
> Nurse Sarah, who cared for Davina

> *"K: … just when you were speaking about your work here, there's a passion comes through for geriatrics. Is that how you feel about it?"*
>
> *"Yes, totally. TOTALLY…I think it comes quite naturally to me…Yes, it's a very rewarding place to work."*
>
> Dr Isobel, who cared for Grace

The above quotes also convey an enthusiasm to work in OPAH also influencing the nurses/doctor participants' motivation to make time for the people they care for and their families. Working in the research setting through choice also impacted on the next sub theme, of making time for people.

5.5.2.2 Making time for people: "They never rushed you"

A significant proportion of participants reported *making time* as a precursor and enabler of PCC. Data gathered from Davina, Grace, Phyllis, Nurse Sarah and Nurse Kathy suggests a belief that *making time* is essential to build a close professional rapport. To experience PCC, Davina conveyed a need to feel that nurses were actively listening to her without rushing; this aspect led to heightened satisfaction of PCC, emphasised in the following quote through Davina's approval by repeating *'very, very good'.*

> *"Yes, and she chatted away. It was great. Yes.* ***They never rushed you.*** *They took time and if you wanted to speak about something, they would listen. Oh, yes, they were* ***very, very good.****"*

Davina

Nurse Sarah conveyed concern that unless she created opportunities to spend time with those in her care, older people might feel isolated during their admission. Nurse Sarah reported 'having a chat', going on to select words to emphasise the importance of this time, viewing it as '*really important'*.

> *"In the afternoon when we do the tea round at three o'clock when we go around with tea and biscuit.... choose a patient and we sit with the patient and* ***have a chat****, and they like …you're* ***just sitting there having a chat*** *as you're eating your Tunnock's Teacake and* ***that extra few minutes*** *with someone is* ***really important****, especially if they don't have anybody to visit or they are a long way from home or their families are often fractured and they live in different parts of the country (intense eye contact). It's having that."*

Nurse Sarah, who cared for Davina

Of note, is the contrast where Davina, who received care from Nurse Sarah and reported experiencing being actively listened to through a non-rushed approach, yet Nurse Sarah reported dedicating time to achieve this was an aspiration, not routine.

> *K: "Last question; is there anything gets in the way of you being person-centred within your day to day work?"*
>
> *"I would sometimes say time constraints and occasionally staffing constraints. I sometimes wish I could just* ***pause****…****Pause time,*** *spend some time with my older people and then restart it again just so you can have that time with them. That's what I wish I*

> *could do. That would make my job so much easier if I could just… I could say more staffing, I could say more equipment but the reality is it is time.* ***Time is the most important thing you can give somebody, your time****."*
>
> Nurse Sarah, who cared for Davina

The quote "time is crucial" resonates with a poignancy where making time was viewed as a desire by staff, but in the older person's experience was already happening. The field notes below recognise that this quote was significantly powerful when gathering Nurse Sarah's data.

> *TIME is crucial, great quote!*
> *Sacrificed paperwork, or professional communication, in order to have time for the OPAH. It feels like it would be impossible to do it, so some things need to be put to the bottom of the priorities, such as personal time... Finishing late, or documentation.*
>
> FIELD NOTES

Whilst at this point Davina's data had not been collected. Davina and Nurse Sarah's experiences illuminate how making time to get to know older people emerges as a first step in connecting and building relationships. Subsequently, the concept of investing time in *getting to know,* then, flexibly moulding PCC along a non-participatory to participatory continuum, contributed to the concluding findings of this study. As such the poignancy of '*pausing time'* emerges as fundamental to PCC; therefore became the title of this thesis. Collecting data through collective case studies within an IPA approach, where the multiple perspectives of the same time in hospital were shared, permitted clarity of both the nurse and older person's experiences. Uncovering that pausing time was aspirational for staff in OPAH, but an experienced reality for the older people participants is a crucial finding of this study. This aspect reveals a new positive perspective of OPAH care, where older people can experience PCC, whilst those delivering the care appear to believe they could do better.

Allowing time for less formal communications to occur alongside essential care activities was uncovered as particularly valuable. Nurse Kathy conveyed recognition that the intimate contact during personal care delivery provided opportunities for patients to share personal information about what mattered to them. Like Nurse Sarah in the previous quotes, Nurse Kathy referred to these interactions as *chatting,* however these interpersonal exchanges assisted in building foundations of a therapeutic relationship.

> *"Most of the time, you may not get time just to sit and have a chat so whenever you are doing something, even morning washing time, there are a few minutes to have a* ***chat****. I mean, I had a* ***chat*** *with her. It depends if you are getting time, you can have a good conversation. They'll be happy…You can* ***get to know the older people more. What matters to them****. She shared that she has got actually four kids, three sons and one daughter but the sons, they are not coming to see her and nothing to do with them…"*
>
> Nurse Kathy, who cared for Grace

Both participants communicated belief that any opportunity to build their relationships with older people should not be missed; that time should be used creatively around the person they are caring for.

> *"I like to write the Kardex beside the patient's bed so we can speak to them as we're writing them because you're getting that few minutes…"*
>
> Nurse Sarah, who cared for Davina

> *"Sometimes you are taking her to the toilet so we don't want to leave in case they get up and fall so we will ask them whether they want us to stay or go. Most of the time, they'll say just stay so they don't mind. When you're standing there, you just have a* ***chat****."*
>
> Nurse Kathy, who cared for Grace

Such creative use of time to get to know older people in more depth was reported as valued by the nurse participants, but a sense that they believed this could be improved was conveyed. Nurse Nicola illustrates what she perceives as barriers to her being as person centred as she wants to be, in the quote below.

> *"…you know sometimes, shortages of staff, stops you from being person centred. If a person wants something done at a specific time, you might plan to do this, but then there is no one available to do it at this time because of the others in the wards need something else at this time. Maybe someone else is sick or something. Something else gets in the way*. "
>
> Nurse Nicola, who cared for George

From older people and family perspectives, appreciation of the MDT attempting to 'pause time' and connect with them in a more effective way was more evident than MDT participants realised. When time was invested, connections were built between older people, their families and the MDT, clearer communication was experienced, this contributed significantly to some shared decision making. Contrastingly, despite connections being made, data also showed that some older people and families preferred not to share decisions with the MDT. Such a premise will now be explored.

5.5.2.3 Information sharing and decision-making: "It was in their hands"

Casual interactions were deemed to add to the positive culture of care in the ward. However, two forms of more formal communication emerged across the cases as key elements in determining participants' experiences of PCC: information sharing and decision making.

Openly sharing information was advocated by Dr Isobel ensuring older people and families were enabled in making choices and decisions for themselves; her preference was to work with open lines of clear communication. In the quote below, Dr Isobel explains how she endeavours to avoid adopting a traditional, medical model, paternalistic approach (CDHN 2017). The quote also recognises how, despite her willingness to support person-centred, joint decision making, older people may elect to request the doctor or a family member to make important healthcare choices for them. Nevertheless, despite this tension, her flexible PCC approach is still demonstrated, through supporting older people who wish herself, or family to make decisions on their behalf.

> *"We do try and speak to almost everyone's families,* ***emmm*** *however if it's stretched then I guess we try and focus on speaking to people who we're pretty sure they won't take in anything or they can't make decisions for themselves…generally we do like to include family in whatever it is because usually people want their family involved to check…quite often, they just want their family to make the decision or they want the doctor to make the decision…I find it* ***quite challenging*** *from the point of view that sometimes you say to people, "There's not really a right answer here", especially if it's about…****emmm****… if it's about something like do they want us to do everything we can to make them live for as long as possible or do we focus just on their symptoms which might mean that they don't live as long but they're more comfortable. So, I think that is a very personal decision* ***emmm****… like* ***I can't make that decision*** *for them but they still sometimes ask you to make that decision.* ***I find that difficult****."*
>
> Dr Isobel, who cared for Grace

The quote conveys a reluctant willingness by Dr Isobel who appeared to accept responsibility when older people preferred her to make deeply personal healthcare decisions. Despite the apprehension presented, the quote demonstrates her acknowledging that if this was the older person's preference it was her belief that her professional role was to support them. However, Dr Isobel's sense of discomfort in making decisions on behalf of patients, when this was their choice, was evident in viewing this as potentially non-person centred and not aligned to her preferred way of being person centred. This is discernible in the pauses and '*emmm's*' along with negative word choices e.g. *challenging/difficult*. Taking this approach, aligning to the older person's preferences despite not jointly sharing decisions, could still be viewed as being person-centred.

However, taking over decision making processes could only be construed as PCC if that is the older person's preference. In the first quote below (Nurse Nicola) appears to exclude the older person in the precise decision-making process in relation to care and discharge, initially indicating that staff and relatives would be part of decision making and only mentioning older person involvement when I directly asked. Reasons for this may include patient inclusion being fundamental to normal practice and as such taken for granted. Contrastingly, the family members' experiences expressed in the second quote below would suggest that older people were not always involved centrally in these decisions.

> *"What happens is the MDT meet & make the decision, the doctors, the physios, they all meet and his wife she was very hands on/ family would also be there…"*
>
> *K: "And George, would he be part of this?"*
>
> *"Oh yes and George too, yes, he would be involved in coming to the decision of where to go…"*
>
> Nurse Nicola, who cared for George

Information sharing and decision making from Phyllis's (George's wife) perspective conveys a perception of being included to a minimal level. Despite evident assurances (from Nurse Nicola), George's transfer from acute to interim OPAH care area was expressed by Phyllis as unexpected.

> *"I was just getting ready to leave with my son, the Staff Nurse phoned she said, he is moving to [place]…. so we just went up there."*
>
> Phyllis, George's wife/carer

This data suggests the perception of open communication may not entirely correspond with family experiences. In comparison, positivity around information sharing and decision making as an enhancing aspect of PCC was reported by David and Catherine who shared experiences of regular updates on their relative's condition, proposals for interventions and plans for discharge.

> *"The doctors would come over. The junior doctors would come, and the nurses, and you could speak to them and they would keep you right."*
>
> Catherine, Grace's daughter

> *"The staff were actually very, very good. I saw the Dr on a number of occasions. Oh, yes. We were getting regular updates…We had to keep asking but they're busy but once you asked, you got the answer."*
>
> David, Davina's son

The quote above demonstrates David's willingness to make allowances for having to ask the staff for information rather than receiving it routinely.

However, Douglas expressed frustration at feeling he was receiving no information apparent in the quote below through the repeated use the term 'asking' Douglas conveyed that, on occasions, he felt excluded altogether from conversations with the MDT, that concerned him. For example, when his son became ill, he reported being left with no one to advocate on his behalf

> *"You don't get a lot of information from the doctors. You have to* ***ask****. You don't feel as if you're getting that unless you* ***ask*** *and* ***ask****?"*
>
> *K: "Are the doctors talking to you about the next step? You said you were just waiting on a bed."*

> *"No, not really. There's no word…Of course, my son is out of the picture now. Nothing will happen."*

Douglas

This could be interpreted as linking to Douglas's personhood. Whilst he expressed frustration at feeling in limbo in acute care, Douglas demonstrated acceptance of this situation, relating to his life experiences as a captain of a ship, surviving being stranded at sea, without any communication to enable a safe return. Douglas conveys experiencing a sense of disempowerment and exclusion from joint decision making, as opposed to being empowered through active involvement in a person-centred discharge from acute care.

In comparison, David communicated an acceptance that, while he valued open communication with doctors, decisions about Davina's care would be reached by the MDT, after which he would be informed. David displays a recurring acceptance of being disempowered but respectfully accepting decisions around his mother's care being '*in their hands*', evident in the quote below.

> *"One time I asked him [the Dr in charge of his Mother's care] because he'd said at that point that medically, Mum was fit and able to go back home again, so at that point, I said, "Does that mean that you would stay here or move somewhere else". I was thinking … [local interim care/rehabilitation area], for example, and he said, "No, no, she'll stay here"…No, no, you'll stay here until such time as we can get the care organised". You [referring to himself as Davina's son] were quite happy with that decision.* ***It was in their hands.****"*

David, Davina's son

The sub-theme the data has generated regarding information sharing and decision making opens a PCC debate by adding new insights into the tensions that can exist in delivering PCC for OPAH. The *how* of PCC experience uncovered by the current study questions whether participatory PCC happens consistently or is expected from older people or their families. Despite data revealing MDT perceptions of open communication and joint decision-making, the MDT participants revealed a lack of awareness that older people and family predominantly perceive the balance of power to be held by the MDT. Moreover, the data shows older people and their families not only accept the balance of power remaining with the MDT, but on occasions expressing an explicit preference for the MDT to hold the power of decision making. Arguably, employing collective case studies within an IPA approach has uncovered these multiple perspectives, illuminating PCC in OPAH more clearly. This is further discussed in Chapter 6*.*

5.5.2.4 Complex illness in person centred decision-making: "Opposite of protocol"

Admission assessments for Davina, Douglas, George and Grace documented many factors contributing to their sudden loss of mobility, meaning no single protocol could be used to guide their individual care. Consequently, specific and individual review was crucial in identifying the appropriate approach for each of their complex conditions. Data indicates the MDT focused on aspects they perceived as the key priorities within the complex health issues the older person presented with, revealing that prioritising in this way was part of PCC for the MDT.

Douglas's case presented complex health issues; advanced cancer, with spread to his bones and lymphatic system, recent urinary sepsis and hospital acquired pneumonia, but both Douglas and his nurse minimised this in articulating it as to '*being not too well'* and it's *'My leg'.* The quotes below demonstrate the complexity of Douglas's condition), yet the concluding minimalising remark starkly contrasts with the variety of challenges he was facing. Douglas mentions only what he perceives to be the main problem, his leg stopping him from mobilising. In contrast, Nurse Yvonne seems to view Douglas holistically, considering the complexity of his physical condition, whereas Douglas appears focus on his priority to mobilise again. Later on, in this chapter, Nurse Yvonne reports using this holistic view of Douglas's complex illness through, prioritising pain management in what she perceived as delivering PCC.

> *"I think it was a urine sepsis. He got treated for that. In his medical history, he's got cancer of lung and somewhere [bladder, bone & lymphatic system] else.* ***He's not too well****."*
>
> Nurse Yvonne, who cared for Douglas

> *"My leg, I reckon it's been like this for three or four years now...Well, I used to get out and about. Yes, I would go about...Until this [pointing to swollen leg]. It just gradually took over."*
>
> Douglas

However, what Nurse Yvonne sees as the priority within Douglas's complex care needs, pain management, is misaligned in comparison with Douglas's priority to mobilise. It is plausible that Nurse Yvonne perceived managing pain as a conduit to increasing Douglas's potential to improve his mobility. However, neither Nurse Yvonne nor Douglas related these two aspects of care in their dialogues.

Similarly, data from Nurse Nicola (who looked after George and Phyllis) demonstrated minimising George's severely complex presenting symptoms whilst focusing on his immobility. George had six co-existing long-term conditions, yet his reason for admission was described as *'being off legs'*. Staff appearing to accept complex health pictures, then focus on immediate perceived priorities, which could be because complexity appeared to the norm in OPAH areas. Therefore, in order to be person centred staff prioritised what they perceived to be the most significant presenting aspect of care; in George's case this was his immobility. George's immobility was also a priority for wife, Phyllis. This was evident in her anxious attempts to access acute care when she could no longer assist George to move at home. Whereas Douglas and Nurse Yvonne's misaligned priorities within complex care needs did not appear to present any tension. In comparison, Nurse Nicola's enabling approach to George's immobility did cause antagonism and concern from Phyllis's perspective, as discussed in *section 5.2.2*.

> *"When he came to us, well the main reason he was in was because he was "off legs", his legs were very swollen, he had type 1 diabetes, has COPD too as well and sleep apnoea. But the main issue was he was off legs… he had sleep apnoea as well..*
> *I think he had become immobile, so could not manage at home. They just said he was "off legs".*
>
> *Nurse Nicola, who cared for George*

The need to assess and consecutively care for a wide variety of often intertwined healthcare issues emerged from the data. For Dr Isobel, this complexity frequently meant treatment to improve one issue could potentially make another worse. In this respect, each care plan had to be tailored to the individual patient, making her medical management person-centred by design.

> *"I think, to me, it's [Person-centred Care] like **the opposite of a protocol**. So, I just think it's something we don't use much of in geriatrics where they use it quite a lot in the rest of the hospital. Yeh, the person. In all medicine, they won't describe it exactly as it says on the tin. People don't present however they tell you they will in the textbook…"*
>
> *K: "Is it quite frequent for people you look after here that they have other things going on in their life?"*
>
> *"Yes, **almost universal really**. Well, just certain **other multiple illnesses**. They might have other tablets that will interact with whatever you would otherwise start them on or you want to start them on a tablet to thin their blood but they've recently had a bleed of some kind, or you think they have a horrible diagnosis, possibly cancer or something, and whether the knowledge of that will change their life in any way. If you … you can't do anything about it, do they want to know? "*
>
> Dr Isobel, who cared for Grace

From Dr Isobel's shared experience, older peoples' complex conditions often necessitated detailed discussions and decisions regarding their future care. Interestingly, Dr Isobel conveyed a change in perspective when sharing her perspective on these conversations, initially seeing them as difficult, then deciding, that they were not. It can be seen that Dr Isobel experienced older people often adopting a pragmatic view of their health issues, easing what could potentially be more challenging interactions with a younger age group.

> *"We would usually try and speak to the person plus or minus their family and say, "We don't know but there might be that this is caused by something like a cancer. If we did a scan. We can do a scan", but make sure they know we don't think, 'Oh, you're old, we won't bother doing a scan'…"*
>
> *K: "So, it's quite challenging conversations, would you say?"*
>
> *"Emhmm, **yes, yes…. Emhmm, no. It's usually actually not challenging. It's remarkable** the number of times people say, "Oh, I thought something was going on", and maybe they want something done or they say, "Oh, why would you do that? I'm 90 years old."*
>
> Dr Isobel, who cared for Grace

The quote above presents Dr Isobel as deriving personal and professional satisfaction from her highly person-centred approach to the medical care she provided, despite facing challenges when her older people or their families passed decisions back to her.

Dr Isobel conveys a perception of her intentional, individualised medical care planning as being a component of connecting with older people and their families. Correspondingly the aspects which other participants identified as components of PCC experiences while in OPAH care will now be explored in more detail.

5.5.3 Experiences that participants identified as PCC

Overall, participants identified that meeting fundamental care needs was a crucial component to them either giving or receiving PCC. However, there were distinct differences in how this was experienced, the MDT participants experienced PCC when they were able to enable, share decisions and facilitate older people leading their care. However, older people appeared to experience PCC when the MDT stepped in and cared for them

5.5.3.1 Meeting Fundamental care needs: "They couldn't have done more."

Davina, George and Grace were each admitted due to sudden loss of mobility, consequently, the MDT appeared to view improving mobility as top priority in delivering PCC. Nurse Sarah's perspective that 'I do absolutely nothing' in the quote below, demonstrates her experience of enabling older people to be in control, as they regained independence.

> *"Initially, we were walking her to the toilet with two and we are now walking her to the toilet with one. Because she came in with a fall, we have classed her as high risk of falls, not that we needed telecare or anything like that … Usually by the time she's pressed the nurse call, she's up on her feet with the Zimmer and she's like, "Let's go", and **I do absolutely nothing**. When she goes home, I'm very confident that she won't need, she's not going to need anyone to supervise her at home."*
>
> Nurse Sarah, who cared for Davina

Dr Isobel concurred with this approach, conveying a belief that on a daily basis the focus should be on enabling older people to return to their home lives. However, rather than focussing on what can be interpreted as an empowering approach to improving mobility as a component of PCC, both Nurse Sarah and Dr Isobel displayed use of negatively balanced language to convey these points: 'I do absolutely nothing' and 'Why can't this person go home today?'.

> *"...I guess what we try and do is focus mostly on our discharges, so like, the person, their main goal is often to get out of hospital, so what can we do today that can help that person get out of hospital. I guess that's why we have our multidisciplinary meetings, usually just to say, "**Why can't this person go home today**?"*

Dr Isobel, who cared for Grace

In comparison older people participants perceived themselves as relying heavily on support from the MDT to increase their mobility. Davina reported feeling that staff had done everything possible to enable her to walk independently, conveying a connection and trusting bond between Davina and the MDT. Use of the word 'they' in her interview could suggest she potentially attributed her progress more to their input rather than her own efforts. Davina expresses a belief that the MDT *fixed* her immobility, rather than seeing this as something they had *enabled her* to improve herself.

> *"Now, I can't remember how long I was in there, and then I was shifted to another ward, a wee while in that then I was in the ward where you do a lot of walking on your own. **They** make you ready for going out. **They** were all very, very nice. **They** couldn't have done more."*

Davina

Furthermore, Grace and her daughter Catherine communicated both pleasure and surprise by the improvements in Grace's mobility and by her being almost independent on discharge. Again, use of the word 'they' emphasises the MDT role in the decisions made rather than focusing on Grace's role in her progress.

> *"Well, **they** started using an aid. A hoist. Then, eventually, went onto the stand aid. She had been in for three weeks and she had never really been walking, and **they** started her with walking with two nurses then down to than one nurse…. You just seemed to see*

> *her improving, you know? Whereas,* ***I thought it would never end… (pause)"***
>
> *K : "Right. When you went in at first?"*
>
> *C: "Yes. Definitely. "*
>
> *K: "Was there a kind of fear factor?"*
>
> *C: "****Yes. There was actually (looks me straight in the eye, anxious)."***
>
> *Catherine, Grace's daughter*

A sense of foreboding is suggested in the above account, through Catherine reporting that initially she feared her mother's mobility would not improve Although Catherine's account does not directly verbalise this, her paralanguage (observable intense eye contact and choice of negative language: 'I thought it would never end…') conveys Catherine's anxiety in relation to her mother's severe deterioration in independent mobilisation.

Contrastingly, rather than conveying aspiration for George's mobility to improve, Phyllis reported anxiety in realising the intention of the physiotherapist caring for George, to pursue the goal of enabling George's mobility. This is emphasised in her statement *'he wasn't really able',* however it became apparent that the physiotherapist had assessed the situation and communicated awareness of Phyllis's expectations of PCC. The quote below suggests Phyllis may have felt listened to as George's advocate in this situation, believing this led to the physiotherapist understanding George's functional ability (*'she kent [knew] that was all he was able for')*. Evidence of a compromise between empowering George to be mobile and a more limited, arguably more person-centred, aim of *'getting up for ½ an hour'* can be seen.

> *"Aye, the girl, the physio [attempting to get George up for a walk around his bed space], but* ***he wasn't really able****. But she came*

> *and tried to get him up on his zimmer, he wasn't really keen. But she said, "Come on George, come on do a deal come on we will try?" How about "I will do you a deal George, if I get you up, sit in your chair ½ hour then I will get you back to your bed? And she did. Aye, **she kent** [knew] **that was all he was able for**."*
>
> Phyllis, George's wife/carer

Furthermore, the quote reveals effective communication skills in negotiating a shared goal that Phyllis believed manageable for George. A respectful connection in establishing trust between Phyllis and the physiotherapist is implied. Mutual negotiation respecting Phyllis's knowledge of her husband appeared to align with her view of good PCC, where greater value was attributed to *caring for* than *enabling*.

On the other hand, Douglas reported feeling that the MDT had not adapted their care to fit his mobility needs in a person-centred way. Douglas reported the MDT continuing to urge him to stand, despite him finding this impossible. As a former fishing boat captain Douglas's interview conveyed his ability to solve any problems he faced while maintaining his independence. Douglas seemed to have accepted that he would no longer walk and had concluded that a self-propelling wheelchair would be the solution for him. Instead, he was provided with an attendant propelled ward wheelchair leaving him stranded unless someone was available to push him. Douglas appeared frustrated that his goal to be enabled through access to a self-propelling wheelchair was misinterpreted, expressing this as experiencing a non-person-centred approach.

> *K: "What kind of things have been happening?"*
>
> *"Not much, just the bed."*
>
> *K: "Have you been seeing the physiotherapists or anything like that?"*
>
> *"Yes. **They** can't do anything. I can't get up, you see. I can try and stand on this leg, on my right leg… **They** got me a wheelchair. **They***

> *were saying whether I could get a wheelchair and I could. I needed somebody to push which is no use."*
>
> Douglas

The quote above demonstrates the repetition of *'they'*, corresponding with Douglas verbalising in an impersonal way regarding the MDT who he seems to believe are blocking what he is hoping for in terms of person-centred mobilisation. A sense of disconnection between Douglas and the MDT, who appear to be making decisions about his mobilisation goals, can be discerned. The expectation of enabling Douglas to mobilise without the use of a self-propelling wheelchair, in contrast with his own mobility goal will be reported, alongside Nurse Yvonne's experience, later in this chapter *(section 5.5.2.2)* and explored in Chapter6.

This sub-theme reveals occurrences where older people and their families conveyed an appreciation of what they valued as highly PCC regarding mobility. Alongside this, however, were reported experiences where the disconnection between older people and the MDT led to mismatched mobility goals and what participants experienced as non-PCC approaches.

The provision of effective pain control tailored to meet changing needs was considered by some participants to be a fundamental element of PCC. Although pain had not been recorded as the main reason for their admission, both Davina and Nurse Yvonne, who cared for Douglas, discussed ongoing pain management in their interviews. Successful pain management therefore appeared to be a facet of delivering PCC. Douglas, however, did not discuss the topic of pain directly within his interview, again suggesting a misalignment in what Douglas hoped for in terms of PCC and what his nurse perceived as PCC priorities. This topic appeared as a theme only for Davina and Douglas's nurse, Yvonne; however, it seemed to present a significant component of their lived experience of PCC and has therefore been included.

In caring for Douglas, Nurse Yvonne narrated that she perceived his pain control as her top priority, her first response around what mattered most in Douglas's care was around ensuring he was pain free. Douglas on the other hand simply referred to his ‘swollen leg’ as his main concern. Yet multiple complex conditions (urinary sepsis, followed by hospital acquired pneumonia, secondary lymphoedema related to spreading cancer metastases) contributed to his admission and his severe immobility. This suggests the complexity of Douglas’ health condition led to Nurse Yvonne’s understandable concern that Douglas was as pain free as possible. Observation of Douglas’s responses whilst providing his care also allowed Nurse Yvonne to establish what was likely to exacerbate his discomfort and then administer analgesia proactively.

> *K: “When you looking after him, are there things you really need to think about for him’?”*
>
> *“**That he’s comfortable, pain free.** He’s not too bad. He’s on MST [Morphine Sulphate Tablets] 50mg twice a day. He’s on other paracetamol, gabapentin. He can also have oramorph for breakthrough but he’s only been having that about once a day... **Yes, you don’t want anybody to be in pain. It’s not nice…** he just needs to ask or if we’re doing his leg dressing…so I think it’s lifting his leg is painful. We give him some oramorph before the procedure.”*
>
> Nurse Yvonne, who cared for Douglas

Nurse Yvonne appears to convey a sense of compassionate care in the above quote, with a desire to remove any anticipated pain. Given Douglas’s complex health conditions and despite him not identifying pain as a concern, the expectations of the NMC (2018) would be for the registrant to assess and intervene.

In contrast to Douglas, Davina appeared to be more aware of staff’s attentiveness to her self-managing pain whenever it occurred, rather than waiting for analgesia at set times. As previously seen, Davina links pain management with praiseworthy language *‘they certainly looked after you’* seemingly highly valuing this aspect of care delivery.

> *“**They certainly looked after you**. I got all my pills when I was there (laughing)…Right away. They said, “Don’t lie in pain, just use your buzzer and get it sorted”, and it did work. I knew once I’d taken the painkillers, it would be just about a quarter of an hour, 20 minutes, it would kick in and you were fine for an hour or two.”*
>
> Davina

A connection leading to a shared experience of PCC care around Davina’s effective pain management is again evident. Effective pain management as a fundamental aspect of care delivery appeared to enhance Davina’s sense of receiving PCC, whilst correspondingly enhancing Nurse Yvonne’s sense of delivering PCC.

Another fundamental aspect of care revealed through open discussion in interviews related to nutritional care. For Davina, Phyllis, Grace and Catherine a link emerged between the provision of good nutritional care and their sense of having received PCC. Poor nutrition was not the main reason for admission, however Grace presented as underweight. The following quote demonstrates ways of improving Grace’s nutritional status and weight in a person-centred way, was viewed as an important aspect of her care, to both Grace and her daughter Catherine.

> *K: “What I have got here (diary entry) is that you looked forward to the food that you got, and that you enjoyed it. That is what you wrote in your diary. You had fish and chips, and, a roast beef dinner?”*
>
> *C: “Yes. Yes. They used to give a menu.“*
>
> *C: “You enjoyed that, didn’t you?”*
>
> *G: “Yes. It was very good. Yes.”*
>
> Grace and Catherine, her daughter

It can be noted that whilst Grace had written positively in her care diary about being enabled to improve her nutrition her verbal responses recorded in the interview lacked depth. Grace's focus appeared to rest on one episode of non-PCC she had experienced rather than any positive PCC experiences.

Good nutrition was also presented as a particularly high priority for Davina, demonstrated below in the choice of the highly positive adjective 'tremendous':

> *"I went down, I think, to seven and a half stone. But I did put on weight twice,* ***especially when I was waiting to go home****. They would say, "Oh, you've put on weight", and I said, "Great" (laughing). Of course, you're not doing anything, you're just lying there, and I wasn't hungry, but… Oh, it was* ***tremendous****."*
>
> Davina

Davina perceived her weight gain and improved nutritional status as a positive element of her unplanned prolonged stay in the acute hospital, reflected in the words '*especially when I was waiting to go home*'. Data showed how Nurse Sarah collaborated with Davina in setting joint goals; the bold components in the quote below clarify how nutritional care led to shared satisfaction. Nurse Sarah shared in her patient's excitement when goals were achieved, deeming such success as a source of professional satisfaction for her.

> *"The other thing that I had noticed is she came in quite low at 43kg and she's now up to maybe 47kg, which most people* ***wouldn't see that as a big thing but for us and Davina, it's a really big thing*** *because as her appetite has come back so has her confidence… Every Sunday when we weigh her, it's a* ***source of excitement*** *for her because she looks forward to seeing if she's putting on any weight and every week, she's delighted. Now, she's looking at her menu card and she's making different choices, not always what's on the menu but she'll maybe add in at the bottom could she have ice cream and jelly, or could she have something slightly different.* ***That's great because you feel as***

> ***if you've empowered her by encouraging her to eat and drink better**…"*

Nurse Sarah, who cared for Davina

Phyllis also discussed the value she placed on the way that George's nutritional care was specifically tailored to his needs and wishes, reporting clear communication as the means of establishing his food preferences and ensuring all staff were aware of these. Phyllis appeared to value the physical assistance George was given, with particular attention given to the patience of the nurse feeding her husband with a teaspoon. This presented as compatible with Phyllis's expectations of PCC in hospital, involving individualised *caring for*, rather than enabling approaches. Her satisfaction was demonstrated by her choice of highly positive words 'amazing'.

> *"Aye, they are ay asking him, and if he doesn't fancy what is on the menu, then I hear the nurse saying, well, what about an omelette? Or fit do you fancy? Then they wrote up on his board (gestures to above his bed), George likes soup, ice cream and juice. I went in and seen the staff nurse giving him the ice cream…Aye, aye, this nurse she was **amazing** with him, feeding him with a teaspoon."*

Phyllis, George's wife/carer

Another aspect of care family members interpreted as being a component of PCC was attention to personal safety for their older relative whilst in OPAH care. A concurrent reason for admission to acute hospital, shared by all older people participants, was a severe and acute decline in mobility. Plans, including the provision of aids by the MDT, appeared to be put into place immediately to assist older people with mobility and minimise risk of injury from falling. The MDT participants, older people and family members expressed valuing the safe environment of the ward, seeming relieved that the staff were always present to supervise and support as needed.

> *"I could walk on my own even through the night with the zimmer but I could feel somebody was watching so they were watching you, yes."*
>
> *Davina*

> *"Well, Mum was obviously safe in the hospital environment and much safer than she would have been at home without carers."*
>
> David, Davina's son

However, for David, it was not only safety, in terms of falls risk, that appeared an area of concern. Following a discussion with his mother's physician about her prolonged hospital stay, David reported he was worried initially about the risk of infection. However, as the following quote illustrates, these fears appeared alleviated by his interpretation of 'cleanliness' in the ward area.

> *"Yes. It was actually the doctor that mentioned it to me, the hospital is full of people that are ill and infections around can be taken in by visitors as well. That's one of the main problems but it was the doctor who said, "We don't want to keep Mum in here too long because the place is full of bugs. We want to make sure that she doesn't pick up anything", and that is a concern. It would be a concern for you or I going in but when you've got someone like Mum going in, you think, 'Great, if something suddenly ripped through the ward or whatever', but no, infection control there, to me, and I'm not an expert on it by any means, but I was very pleasantly surprised at the level of cleanliness."*
>
> David, Davina's son

Safety can be considered as a separate construct from PCC within Quality Healthcare (IHI 2015; SG 2014). However here David's experience concurs with PCC commentator Berwick (2014) in that safety is an integral component of PCC.

The experiences reported in this study of enabling and supporting mobility, nutrition, pain management and safety of the older people also appear to be components of how they experienced PCC whilst in OPAH. Given the idiographic nature of this IPA study, this does not infer that these specific aspects of care are generalisable as components of PCC; however, for these participants, they were valued as part of their PCC experience.

5.5.3.2 A multidisciplinary approach to care: "I can't think, one person wouldn't be able to coordinate all those things"

When describing the PCC to enable meeting individual needs, each participant referred to the adoption of a multidisciplinary approach to their care (both receiving and delivering). The contributions by nurses, doctors, physiotherapists, occupational therapists and dieticians were mentioned specifically in every interview. Some participants also identified involvement by members of other disciplines, such as social care coordinators. There appeared to have been meaningful connections with members of the MDT beyond those who were research participants in this study. Although the *voice* of the Allied Health Professional (AHP) as part of the MDT is absent in the current study, the essence of MDT approaches to care has been captured in the participants' experiences of being in acute care.

Some participants found difficulty remembering the different roles undertaken by members of the MDT but were able to recall ways in which person-centred support was provided.

> *"..the physios were involved because on a couple of occasions, we had visited and someone came along and said, "Right, time for you to walk up and down…I don't know if it's Occupational Therapy or if it was physio that were instrumental in getting the zimmer… because they were interested to know what environment you were in and what aids you had in the house."*
>
> David, Davina's son

Interviews with Nurse Sarah and Nurse Kathy reflected a view of themselves as leading the provision of PCC, since they spent the most time with patients. Their belief that they gleaned a fuller perspective on the older people in their care as unique individuals, is evident through word choices that emphasised the length of time they cared for someone during their shift. Sharing statements such as (*'look after someone for 12 hours')* and how this afforded the opportunity to *'actually notice' what was happening with their patients*. These nurses appeared to believe this gave them greater insights than the other MDT team members, who they viewed as having episodic contact*, stating they were 'in and out in ten minutes'* to adapt interventions specifically to each person. These nurse participants conveyed a need to observe the MDT spent more dedicated time getting to know the older people and what mattered to them, to connect in a person-centred way. Both Nurse Sarah and Kathy viewed their role in the MDT as leading the *getting to know* process, then influencing the MDT to personalise PCC based on nursing assessment.

> *"I would say we encourage all our older people and we promote patient centred care by catering to their needs and working at* ***their*** *(emphasis) pace and what's best for them as an MDT but with nursing staff especially because no disrespect to OT and PT and medical staff but* ***they're in and out in ten minutes****.* ***I look after someone for 12 hours a day. I see the down times, the high times****…"*
>
> Nurse Sarah, who cared for Davina

> *"We can* ***actually notice*** *their improvement or if they are deteriorating or if there are any changes because* ***we are here****). They come and they just assess and they'll go. They're not here all the time but if there are any changes, we can easily notice that and inform them."*
>
> Nurse Kathy, who cared for Grace

A specific intonation was evident in both Nurse Sarah and Nurse Kathy's accounts, implying their perception of themselves as the *patient's advocate* in terms of influencing the wider MDT's PCC. However, Dr Isobel's views seem much broader and appeared to value both the AHPs and nurses as leaders in the implementation of PCC.

> *"I think the multidisciplinary teams that we have here really help because we know the people we're working with. We trust the peoples' opinions that we're working with and it's a team-based decision regarding how we manage things along with the family. It's not a 'whatever the doctor says is right'. It's often... times that we're led by what the therapists say, what the nurses say."*
>
> *K: "Do you feel that within that multidisciplinary team, is there an equality of voices?"*
>
> *"I'd like to think so, yes. I mean, obviously there's variability depending on personalities and things like that but, yes, I think so."*
>
> Dr Isobel, who cared for Grace

Despite Dr Isobel hoping that the MDT portrayed a flattened hierarchy, this contrasted Douglas's shared experience of MDT PCC. Douglas projects holding self-determined roles that different members of the members of the MDT should fulfil. His expectation of nurses within the MDT was different from Nurse Sarah and Kathy's, who described the role of the nurse in the MDT as leading PCC. Douglas seems to confine the nurse's role to the delivery of direct physical care: '*They (nurses) just look after you…'* He suggests he could only fully trust information received from medical staff, appearing to view them as in charge of decisions relating to his care journey.

> *"The nurses are all good. They can't really give me the information because if it's wrong, you see. Oh, yes. It's the doctor's information that it's to come from. They (nurses) just look after you. The bed washing and… yes, they're pretty good…"*
>
> Douglas

In the above quote, Douglas's explanation conveys a hierarchy in opposition to that which Dr Isobel states as her experience of delivering PCC.

> *"It's not whatever the doctor says is right."*
>
> Dr Isobel, who cared for Grace

Similar to Dr Isobel, Nurse Yvonne seems to experience an MDT approach to PCC in a comparable way, suggesting a cohesive approach by the MDT, with no single discipline taking the lead.

> *K: "Would you say when you're thinking about the care of Douglas, it is a whole team approach to looking after him or would you say that it is more balanced one way or the other to any specific members of the team? What do you think?"*
>
> *"No, I would say everybody has an input and everybody really, not just anybody specific, I wouldn't say. I can't think, one person wouldn't be able to coordinate all those things. I think it's important to get things done. I'm not sure really how to describe…I would say you need all these people for everything to fit together."*
>
> Nurse Yvonne, who cared for Douglas

Despite Nurse Yvonne portraying her experience of the MDT working collaboratively, the team's efforts to provide a high standard of PCC appeared challenged by Douglas's goals for enablement with his mobility. The tension between Douglas's hope for a self-propelling wheelchair and the MDT's goal of more independent mobilisation appeared to leave Nurse Yvonne, torn between her duty to advocate for Douglas and her desire to work cohesively with her MDT colleagues (NMC 2018).

> *"There was an occasion, he asked… this was not last week but the week before when he was a bit better than he is now. He wanted to be in a wheelchair…I think so that he could get himself… mobilise around the ward himself. I said, "Okay", so I went and got a wheelchair but the wheelchair that we've got in the ward, it's*

> *not one of the ones that you can (gestures self-propelling a wheelchair) … and I said, "We don't have that", but I could speak to the OT (Occupational Therapists) the next day, which I did. They spoke to him and they said that they were still working with him to try and get him mobile and that wasn't going to be considered at the moment,* ***so I did try****. "*
>
> Nurse Yvonne, who cared for Douglas

Nurse Yvonne's account appears to view her attempts to act as an advocate for Douglas as unsuccessful, and in the end, both appear to reluctantly accept the decision of the OT. Conceivably, Nurse Yvonne's lack of self-confidence (identified earlier in her sense of personhood) resulted in her being less assertive than Douglas might have hoped. Given the advanced stage of his illness, there were so few areas left in his life over which he could exert any control (Glanvill 2018), this could be considered to be a non-person-centred outcome for Douglas (this will be further explored in Chapter 6).

Intervention from the MDT to enable or care for the older people in this study was uncovered as a component of the PCC experience, in particular in relation to acute care services stepping in to provide care.

5.5.3.3 Acute Care stepping in: "they couldn't believe that I was managing"

Events precipitating older people's hospital admissions presented as a source of stress for family participants, whether a sudden event - in Davina or Grace's case - or an ongoing progressive decline as Phyllis experienced with George. Family burden of care appeared eased when their loved one was admitted into acute hospital care. For example, Phyllis stated she had felt overwhelmed by the deterioration in George's condition while in their home but when admission was implemented, Phyllis appeared relieved with the empathetic approach she experienced from the out of hours team.

> *"A doctor from the hospital came and well, the ambulance men,* ***they couldn't believe that I was managing to look after him,***

> ***neither could the doctor fae [from] the hospital****… Took him into the assessment ward, well it was the knee, but I had noticed that he was getting weaker, like a few days, 3 - 4 days wisnae [was not] his normal. …they all* ***say I'm too soft with him, you need to try, but he was struggling****."*

Phyllis, George's wife/carer

The above quote suggests Phyllis is relieved by other healthcare professionals recognising her personal struggle to maintain safe care for George's, appreciating the need for acute hospital intervention. Previously, Phyllis's view of her small stature in comparison to George was noted. But her stoicism in her care of him, by keeping going despite the personal physical challenge, was evident. Here, however, she depicts an acceptance of George's admission to hospital because '*he was struggling';* when it appeared from her narrative that she was also finding caring for George challenging.

Once older people had been admitted, families discussed ongoing support in relation to hospital visiting. The '*Welcome Ward'* initiative was launched during the period of data collection, with person-centred visiting at its core. There was an objective that the person in hospital and their family would plan visits and participate in care. David appeared to feel that his personal need or responsibility to visit was reduced due to the flexible person-centred visiting arrangements adopted.

> *"It [Person-centred Visiting] also meant that … For their own particular reasons, some people said, "Oh, that's fine, I could be there for four o'clock", or whatever time, and it also meant that we could just make up our minds in the morning and say, "If we pop up now between 10 and 11", so it was fine."*

David, Davina's son

Similarly, Catherine's view below indicates the wider range of times available permitted the potential burden of visiting to be shared amongst a greater number of people. It was evident that Grace relied heavily on Catherine as the only grown child she had contact with, therefore initially the burden of responsibility remained with her. However, person-centred visiting reduced this pressure, when Catherine involved other family members. Notably however, Catherine was observed as usually present on the ward during the recruitment phase of this study, appearing quite exhausted.

> *"It [Person-centred visiting] made a big difference for me, and for the family that we could come in at any time. There definitely weren't any restrictions.*
>
> Catherine, Grace's daughter

Phyllis appeared to present a different perspective on hospital visiting, relating to their unique family dynamic. As both George and Phyllis were previously married with grown children from both marriages involved in George's visiting schedule. The findings so far have conveyed Phyllis's stoic persona, however her matriarchal family position emerged in her approach to George's PCC visiting regime. The flexibility of person-centred visiting seemed challenging for Phyllis, who appeared to have a more traditional approach to hospital care, including hospital visiting. Furthermore, Phyllis intimated having become overwhelmed by George's complex needs and was now content to pass this burden of care over. However, she seemed challenged when George's children did not follow her traditional visiting plans, as we can see in the quote below.

> *"Aye [Yes], so I have said, we will all go in the same times each day from now on, so maybe like quarter to 1 to quarter to 3, then, maybe 6 quarter past 6 for the evening, a couple of hours... I hate coming away, but he has started saying "Far [colloquial term for where] have you been?" …but no with Gail and Matthew because he is used to them but with the step, well his daughter my step son and daughter he gets agitated when they are in… Aye, but when you go in and my step daughter has been sitting there since 10 in the morning…George has told them, they are staying too long. They go when we go in…* ***what are they doing sitting there all the time****…Aye, he (George) will be thinking what they*

> *doing sitting here, no at work, my stepson too? Why they no working. When I go in, he just looks (rolls her eyes) I mean to say like, what have they been doing here all this time? But then he relaxes…Aye, no to be horrible but mine being there is his usual. I ken she is his daughter but, with my son & daughter that is their father, (tearful)...I have said to Jane, but it's no up to me. He (George) has telt [told] her.. I don't want to upset them. I said you come and go as you please, because I don't want to upset them."*
>
> Phyllis, George's wife/carer

The above quote suggests Phyllis's grown children collaborated with her coping strategies, visiting their stepfather at set times, experiencing relief from the burden of physical care. In contrast George's grown children appeared to seek out more information, preferring to dedicate significantly more time visiting their father. Additionally, they appeared to hold a different cultural perspective in preparing for their father's imminent demise. Active treatment had stopped at this time, however their dedication to visit more appeared to lead to a degree of animosity within the blended family. Phyllis's sense of personhood noted earlier (*section 5.2.1*), meant that she preferred to influence others to plan PCC delivery around her expert view of what was best for her husband. Phyllis's demeanour and direct quotes appear to demonstrate her attempts to influence her grown children and stepchildren, to follow her lead. Tension within the blended family was apparent through different approaches to palliative care highlighted in the dialogue, which started out as discussing visiting times. Phyllis presented as appearing to view this with suspicion, believing that George also suspected an ulterior motive for their presence.

> *"…my step daughter came,* ***they stayed 5 hours and George said to me "Fit*** *[what]* ***are they awe*** *[all]* ***doing hanging about here so long?"****, then he said to her, he told her [that he didn't want them staying so long], it upset her, he had his daughter in tears...but he is wondering why are they all hanging about, he says to me it just shows you, he says* ***" Are they all***

> ***hanging about, thinking something is going to happen to me and they are going to get something?"***
>
> Phyllis, George's wife/carer

Although person-centred, open approaches to visiting were reported as being valued by family participants, the open approach appeared to cause Phyllis a degree of tension, due to the complex family dynamics. Once more this illuminates a new aspect within the PCC evidence base, whereby some older people may prefer traditional visiting times as opposed to an open approach to visiting their family while in acute care. The uniqueness of what person-centredness is in terms of visiting is highlighted by these experiences.

A wide variety of perspectives was uncovered within this superordinate theme. Where a sense of connection was built between older people, family and the MDT, participants articulated key aspects of what they perceived as positive PCC experiences. However, at times there seemed to be a disconnection between the older person, family and the MDT having a consistent awareness of what PCC meant to each person, within the individual collectives. Tensions were evident between some participants' definitions, expectations and experiences of what they believed to be PCC; but more PCC enhancing experiences were shared than diminishing ones.

Factors that diminished PCC were related both to hospital systems/processes and individual staff.

5.5.4 Experiences that diminished participants PCC

5.5.4.1 Aspects of hospital systems

As elaborated on in sub theme 5.5.1, a sense of connection between the older people, their families and staff was uncovered as highly valued through the current study. Consequently, absence of these connections appeared to diminish PCC experiences. On occasions, hospital systems appeared to be perceived by participants as having been designed without consideration of the potential impact on older people and their families. For some of the older people and their families, the sense of disconnection during admission to hospital appeared to be a source of anxiety. In Catherine's case, this distress appeared exacerbated when she found herself alone, while Grace was being assessed in the ED (Emergency Department).

> *"Just, well.. I was sitting in the waiting area at A & E, and Mum was through there. So, I didn't see her for a couple of hours. Pause… Then, the doctors came out and said, "Grace Bruce's daughter?" So, yes, they spoke to us.* ***It was scary actually.***
>
> *K: Were you on your own?*
>
> *Yes. I was. They said that once the doctor had been, I would get through. It just seemed to be dragging."*
>
> Catherine, Grace's daughter

At this point in Grace's care trajectory, Grace was described as completely immobile and experiencing delirium (according to her daughter Catherine). Whilst Grace had no memory of this time in her care journey, Catherine's quote can be interpreted as indicating a more person-centred approach would include Catherine and Grace being together in the ED. This is further explored in Chapter 6.

Within the research setting, the process of OPAH care is to be transferred from the ED to the 24-hour acute MfE (Medicine for the Elderly) unit, which has predominantly single rooms. Although providing privacy, Davina and Grace conveyed this also left them feeling isolated and disconnected from others in the area.

> *"I mean, you had your own en suite and it was lovely. Well, it was in a way but most of the time,* ***you were on your own****. If I had*

> *my visitors, it was fine,* ***whereas in a ward, there's always something going on.****"*

Davina

> *C: "Do you prefer being on your own in hospital, or, do you like being in the big ward?"*
>
> *"In the big ward. Well, I thought I would get somebody to speak to and be seeing* ***everything that is going on****."*

Catherine, Grace's daughter and Grace

The quotes above suggest that if a choice had been given, both Davina and Grace would have selected a multi-bedded room, where they seemed to sense connection with staff and other patients.

Another procedural aspect in the research setting is transferring patients over the age of 65 to the 'step down' acute MfE wards, via the acute MfE assessment unit. However, Phyllis presented as associating the label 'geriatric' or MfE, with a lack of cognition, conveying this did not apply to herself (age 69) or her husband (age 71). As they both recently retired, Phyllis did not regard herself or George, as *older*. Phyllis also portrayed a concern that George may not receive the intense physical medical interventions she believed his condition warranted. In Phyllis's view, MfE was presented as an area for older people who merely required companionship, not acute care. In this respect, Phyllis appeared to fear that her husband's medical needs would not be fully considered. However, current organisational systems in the hospital meant that no alternative options were offered. This aspect is examined further in Chapter 6*.*

> *"But then, the only part I didn't like,* ***well I know they are short of beds, but they put him into that geriatric ward****. It wasn't what he liked. Nae [not] that I'm bothered, but for him, I mean he was ill, and ken [you know]* ***they (older people) just want to walk about and speak to you, to someone, well he couldn't***

> ***be bothered with that, too ill.*** *I said do you need to put him there?"*
>
> *"Aye, maybe if he was* ***in a ward say for his heart if that was the problem?*** *The place where there was a bed. That wasn't a nice bit to be in?"*
>
> Phyllis, Georges wife/carer

This quote depicts Phyllis as associating the term 'geriatrics' with a significantly older patient group with long term care needs. Whereas, within Dr Isobel's account, the current perspective of *'geriatrics'* was care of complexly ill people, often with a multitude of comorbidities. This is an accurate reflection of Phyllis's husband George's presenting medical condition. George did present with more than one health issue, he was not placed in the MfE setting due to bed shortages but was placed there in line with the OPAH organisation process in the research setting. A recurrence of different PCC perspectives (of OPAH care) emerges here, which is potentially the cause of Phyllis experiencing dissatisfaction with this aspect of their PCC experience.

On occasions throughout the data collection period, availability of acute MfE beds was insufficient to meet the service requirements leading to older people, who were medically stable with no cognitive impairment, being moved to other areas. This process of decanting did not adhere to the research setting's own set OPAH principle whereby complexly ill older people should be cared for in the MfE area. Nurse Sarah, who cared for Davina, expressed concern when her patient was 'boarded out' to a day surgical ward for the final week of a five-week hospital admission. This demonstrates the tensions that can arise in the decision-making across the MDT, particularly when resulting in care designed to fit the needs of the hospital system rather than those of the patient group.

> *"What's basically happened is the hospital has gone on red alert [no available acute bed] and we had been requested to board older people out. I was reluctant to do that but her consultant agreed to her being boarded out because she was medically fit. If*

> *her [home] care was in place today, she could go home today. Davina was disappointed but was fine with this."*
>
> Nurse Sarah, who cared for Davina

Nurse Sarah reports above that Davina was initially disappointed. Nevertheless, in keeping with her generally positive and resilient personhood, Davina used this opportunity to make friends and build connections in her new ward area.

> *"It [in the day surgery boarded out area] just was constant bed moving away and another bed would come. Oh, yes. You're more interested in who'll be coming (laughing). Yes, and there was one young woman right opposite me and we used to wave to one another and then in the evening, she would come over and sit and chat. That was great."*
>
> Davina

Davina again praises her hospital stay, using notably positive summarising terms such as '*That was great*'. Therefore, whilst Nurse Sarah expressed concern about her perceived lack of continuity in Davina's MfE care, Davina's perspective differed through her satisfaction of PCC continuing despite being decanted. Davina appears to be presenting a perspective of contentment with compromise when she received PCC in OPAH that was over-stretched, whereas Davina not being cared for in MfE appeared to be a source of emotional distress for Nurse Sarah.

Not all participants were as accepting of non-PCC systems that potentially resulted in a lack of individualised care. For example: the apparent necessity for rigid mealtimes, which was also raised as a barrier to PCC for Nurse Nicola who seemed unable to consider any form of compromise that would accommodate George's sleep pattern.

> *"…like with George himself, the breakfast timing. On the 2nd day I was looking after him, I noticed. Here it is 8am, the trolley came too early for when he prefers to eat it is too early for him, he does*

> *not like breakfast early. He did not want to eat at this time. He prefers eating his breakfast later, so he missed his breakfast. So we could not accommodate when he wanted to eat. We cannot control this. The trolley had been and gone."*
>
> Nurse Nicola

This dilemma may be interpreted as Nurse Nicola, in her role as a relatively newly qualified nurse (9 months experience) wanting to fit into the ward routine rather than challenge mealtimes being more flexibly approached. Notably, Nurse Nicola freely shared these perspectives in the research interview but did not appear to have raised her concerns within the MDT. This presents lack of confidence as a key aspect in delivering PCC, this will be explored further in Chapter 6.

For some participants, care that was perceived to be less than person-centred was not attributed to organisational systems but rather to the MDT. The data evidencing this issue will now be explored.

5.5.4.2 Aspects of care by ward staff

Returning to the importance of a sense of connection (discussed in *section 5.5.1*), fractured connectivity between older people, their family and the MDT seemed to result in dissatisfaction with care. The examples provided to illustrate these care experiences, presented as non-person centred from the older people and their families' perspectives.

One example was reported by Grace, who opened her interview by describing an incident involving care provided by staff, which overshadowed her entire experience of hospital admission. Far from being cared for in a person-centred way, Grace shared feelings that her needs for fundamental assistance, compassion and dignity had been ignored.

> *"I am glad that I am away from the City with what happened in the hospital (shaky voice). When I asked them, as I was wanting the toilet, somebody said, "Go back to sleep. You have been up*

> *before. Get back to sleep (shouting)!". I said, "I want the toilet. I am really bursting". She went away, but I pressed the buzzer again. I said, "I told you. I was peeing my pants and I was soaking. I was really wringing".*
>
> *K: "You look like that upset you?"*
>
> *"I was shaking. I said, "I told you I was wanting the toilet and you told me to go back to sleep. I am soaking, now". A nurse came. She took me with the walking thing and I went into the toilet. I was ringing. I was soaking. Oh me, I said to myself, 'I hope I never do that again'."*
>
> *Grace*

This incident occurred at the end of Grace's four-week admission, the night before she was due to be discharged to a rural community hospital. During the admission period, Grace's condition had markedly improved and this appeared to be an isolated incident. However, it completely eclipsed any prior experiences of PCC and was the main focus of most of the interview. Interestingly, her daughter Catherine adopted a different perspective.

> *"**Well, they are busy**". You know, sometimes, they can just have been to the toilet and **they think** they want again, but she was very upset about it. As I say, no, I can't fault it. **That was just a blip. No. They did look after her.** "*
>
> Catherine, Grace's daughter

Although Catherine appeared to be unhappy with the incident Grace described above her personal insight, as her mother's carer, and as an experienced personal carer, appeared to lead to different *sense making* conclusions, from Grace's. Catherine almost excuses staff, who '*were busy'* and views this lapse in care as '*just a blip'*. Catherine seems to convey an ability to step back from this situation and view it from a wider perspective, alongside the more positive aspects of her mother's entire admission.

In line with conditions of the NHS ethical approval for this study, Grace and Catherine were informed of the researcher's duty to report this incident to the SCN, Nurse Manager and Chief Nurse of the research setting. Due process for this type of incident and duty of candour were then followed (SG 2018, NMC 2018, RGU 2018, NHS Grampian 2017).

Whereas Grace's perceptions of a lapse in PCC related to a single significant event, Douglas appeared to experience more subtle incidents, where some staff had been less compassionate than others. George appeared reluctant to share details, eager to point out that any lapses were short lived. This reticence to criticise was demonstrated by phrases such as '*a couple*', and '*on the verge of*', suggesting that the staff were not quite but almost providing what he perceived as poor care.

> *"They look after you. There were a couple of nurses just* ***on the verge, mind you. They are worth watching****. Just their attitude.* ***Just a couple*** *of… you would see* ***indifference compared to the rest."***
>
> *K: "Just the way they were moving and the way they were acting?"*
>
> *"Just their actions really. Things they were doing.. Nods, sighs.* ***They would come alright, you see, once they started going to other people. Yes, they were alright then."***
>
> *K : "What things were they doing?"*
>
> *"Well, just what they did for you. You can't really say a thing against them. It's, you know, sitting here and asking, you know, about the good things and the bad things.* ***There are not any bad things, you know*** *(seems annoyed that I am probing, looking for both good and bad)."*
>
> *Douglas*

However, a sense that Douglas almost regretted mentioning these instances became apparent. Sensing Douglas's discomfort, further probing within the interview was respectfully discontinued.

A further area presenting as a challenge, emerged from the interview with George's wife, Phyllis in relation to decisions to place a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place for him. The Resuscitation Council (UK) Guidance (2015) indicates that any DNACPR order should always be discussed with the patient unless they lack capacity. The guidance also advises that when reduced capacity issues exist, the person holding the Power of Attorney, (in this case Phyllis), should act as proxy. From Phyllis's perspective George had already expressed the choice to be resuscitated, but she now viewed him to be too unwell to survive resuscitation. However, Phyllis reported that the MDT reached a decision not to resuscitate George and *then* informed her. Phyllis appears to be at ease with reaching the decision in this way, which fits with how Phyllis defines PCC and her PCC expectations - healthcare staff know best and should lead care.

> *"Oh aye, the doctor did say that when the time comes…I just don't mind her name. Well, she says when it does happen, it will be very quick. Well, to let you understand when that heart failure nurse was coming from the surgery, she asked him to sign a do not resuscitate form, but he wanted to be resuscitated.* ***But he was feeling better then, not too bad****. Oh, she said that's good he signed that and I thought,* ***she has picked me up wrong****. No, I said, he wanted to be resuscitated.* ***She said, I don't think we would get to him, because I think it would be that quick. But he was better then.****"*
>
> Phyllis, George's wife/carer

Two areas for concern arise from Phyllis's dialogue above. Firstly, a decision appeared to have been reached, without taking into consideration George's previously expressed wishes. Secondly, the word choices Phyllis reported the Dr used did not appear to explain that DNACPR may be futile and George would not survive, instead that staff would not '*get to him in time*'. My interpretation of how Phyllis made sense of George's DNACPR decision was that, whilst the dialogue reported above could be construed as not strictly adhering to the resuscitation guidelines (Resuscitation Council (UK) Guidance 2015), Phyllis herself stated she appreciated the Dr's approach. In this sense, the approach taken by medical staff could be interpreted as adapting their person-centred approach, in meeting Phyllis's expectations, in an emotionally charged situation.

Whilst aspects of OPAH care that diminished PCC experience appeared much less apparent in comparison to positive PCC experiences, nevertheless they are still important perspectives that present opportunities for future improvements in PCC cultures of care.

As anticipated, the participant PCC experience of acute care was the richest and broadest subtheme of the findings, illuminating the simultaneous PCC experiences in OPAH care, from multiple perspectives.

5.6 Superordinate Theme – Impact of Leaving an Acute Hospital

5.6.1 Subtheme: discharge arrangements: the impact on participants' experience of PCC experience

Planning person-centred discharge from the research area was presented as frequently challenging. For the MDT participants there appeared to be competing priorities around meeting physical needs for ongoing care and older people's preferences on how/where they would like to live. In particular, family members' views needed to be considered and families priorities did not always coincide with those of the older people. Alongside pressures on OPAH beds, insufficient opportunities to provide ongoing PCC non-acute health and social care (HSC) were apparent. As a result, patients remained in hospital longer than medically necessary. Douglas's nurse, Yvonne perceived this changed the clinical ward focus.

> *"It's meant to be an acute, elderly medical ward but it's just getting to be, you know, more like a nursing home because there's older people we're not able to get them moved on…It's just a shortage of beds everywhere in nursing homes, community*

> *hospitals, there's always waiting lists & waiting lists. It's very difficult."*

Nurse Yvonne, who cared for Douglas

Nurse Yvonne seemed to sense that some older people who became *stuck* in acute care might be deprived of the most appropriate type of care for their needs. She appeared particularly concerned about Douglas, whose disease had become so advanced that in her view, he appeared to require palliative care.

> *"The thing is, it takes so long to get all this [supported home care] because we've got people waiting for months for double up care [two people required for health and safety to provide personal care]. I'm doubtful [that Douglas will get home] because knowing the length of time it will probably take… I'm not quite sure if it'll be… but I have my doubts. It doesn't always… he could deteriorate, and it might not happen"...(pause)*
>
> *K: "How is that for you, as his nurse?"*
>
> *"Very, very frustrating...Because I've seen that they deteriorate. It takes so long and sometimes they just don't get out of hospital at all."*

Nurse Yvonne, who cared for Douglas

Without verbalising fears of Douglas dying in hospital, apprehension of imminent death seemed to concern Nurse Yvonne and Douglas; without either of them discussing this with each other. Independently, in his face to face interview, Douglas shared his own fear of dying without ever being able to live in his own home again.

> *"Now, I'm here, that's it. When will I get out or* ***will I get out*** *(intense eye contact)?"*

Douglas

Phyllis also shared that George had verbalised a similar statement of foreboding concerns when he was being admitted to acute care.

> *"Yeh, well the ambulance crew asked George, if he was okay to go in (to hospital) and he said oh* ***if I go in I will never get out****."*
>
> *K: "So, do you think he was worried?"*
>
> *"He just said* ***if I go in there, I might never get out****."*
>
> Phyllis, George's wife/carer

Both dialogues shown above indicate a deep concern that, rather than admission to acute care might not provide a solution to support older people becoming well and home again. However, admission to acute care could also be viewed by older people as bringing their mortality into sharper focus. Nurse Yvonne describes her own professional discomfort in the quote below. She seems to find it challenging to be honest with families around the HSC system, at times slowing up PCC discharge planning to such an extent, that older people do not get back home; despite that being their wish.

> *"I was speaking to the son that comes in and telling him what the plan [supported discharge with 2 carers to Douglas' home] was. He did say, "Can you actually see that happening?", and it was a bit difficult because I thought, you know, I'm not sure (again, opens hands like in a gesture of despair)."*
>
> *K: "So, your experience is even if you're planning for it…?"*
>
> *(Interrupts) "It doesn't always… he could deteriorate and it might not happen. I think his son must have been thinking along the same lines as me because he's kinda like asking my opinion and I'm not sure."*

> *K: "Do you find it a difficult question to answer?"*
>
> *"Yes. Well, probably because I didn't want to say. I didn't really want to say what I was thinking."*
>
> Nurse Yvonne, who cared for Douglas

Although not stating directly that Douglas might die in acute care while waiting for supported social care, Nurse Yvonne appears to be alluding to this fact. Nurse Yvonne presented strong views on this subject, evidenced in her quote (above) where she interjects, eager to share her experiences. The length of time needed to arrange suitable home care emerged as a source of professional tension for Nurse Yvonne. The dilemma appeared to be whether to agree with George's discharge plan or share her personal perspective, based on her nursing experience, that Douglas might not live long enough for the PCC discharge plan to be enacted.

Prior to the end of the data collection period, Douglas suggested a compromise to his discharge plan, and he was transferred to a local community hospital to make family visiting easier. My interpretation of this was that Douglas was able to exert some control over his discharge plan; enabling a more PCC discharge plan to take place. Similarly, Grace also wanted to return to her own home but the MDT recommended more rehabilitation. Grace appeared to unwillingly compromise to be transferred to the rural community hospital where she and her daughter, Catherine lived. This aspect of her care can be viewed as person-centred, in that it fitted her physical needs, but it did not allow her to live as she would have chosen. Grace presented as distant during the interview when discussing this topic, suggesting that she had accepted the loss of control over where she lived with some reluctance.

> *"Well, I'd want to go home to my own house. I wasn't able. I wasn't walking right."*
>
> Grace

Grace's daughter Catherine, on the other hand, believed this to be a person-centred discharge because the location was much closer to where she lived, from her point of view the choice was tailored to fit both her and Grace's needs.

> *"The doctor had spoken to us and said, "Would you prefer …[place]. I had said, "Yes. It would be absolutely nearer to the family". So, yes, it is the ideal place for her."*
>
> Catherine, Grace's daughter

The divergence between these two points of view illustrates Dr Isobel's previous point, that older people will often consent to what suits their family despite this not fitting with their own preferences. Dr Isobel believed that family members could become so preoccupied by safety aspects, they could lose sight of risks that the older person may have been willing to accept, to have an improved quality of life. This created instances where older people would have opted to be in their own home rather than a care home. In Dr Isobel's experience, families often put undue pressure on their relatives to move into a nursing home prematurely even if this was not their preference, making person-centred discharges more challenging to achieve.

> *"I guess sometimes there are some peoples' families that almost seem too worried about what will happen to their dad, mum and with the best intentions in the world but sometimes I feel like they're maybe not listening to what their dad or mum actually wants because they think, 'Oh, if they move into a care home, they'll be safe', but they'll be miserable. That can be challenging as well."*
>
> Dr Isobel, who cared for Grace

For Davina, returning home meant adjusting to new home-carers, hoping that they would work in a person-centred way. Initially Davina was unsure about what it would be like to have carers involved in her everyday life. However, carers visiting each day, assisting and interacting with her, turned out to be more fulfilling than Davina had anticipated. This acceptance could be due to her resilient and accepting nature, as discussed earlier (*section 5.1*).

> *"Well, I had no idea until [the home carers] came just what they did but I'm quite happy with them. They'll say, "Would you like this for your lunch or that?", and they'd bring it. They're great. They chat."*
>
> Davina

Companionship and social contact was important to Davina which was explored earlier, demonstrated her high levels of care satisfaction having continued into her discharge home. Davina appeared extremely satisfied that PCC has been present throughout her care trajectory, through the elements of care she valued and hoped for being delivered.

Within this subordinate theme experiences around leaving acute care that were perceived to be person centred other non-person-centred experiences are evident. Divergences around perceptions of PCC were uncovered as linking to whether connections were made between the older people, families and the MDT. Additionally, divergences were the result of care experiences being determined by a system-based approach to care. The MDT reported experiencing positivity and a sense of professional fulfilment when they believed they had been person-centred. In contrast, they experienced despondency when they believed they could have been more person-centred. Notably, data from older people and family participants presented a greater acceptance of compromise around their PCC experience, than that of the MDT participants.

5.7 Personal Reflections

As previously acknowledged, personal reflections are shared throughout this thesis, to allow the reader to interpret the researcher's personal growth throughout this doctoral journey. The reflective accounts are presented to enhance transparency around the processes followed and conclusions reached. A decision was taken to leave reflexive excerpts to the end of this chapter following the presentation of the findings. There were several reasons to present the personal reflections in this way.

Foremost such an approach facilitated the reader to immerse themselves in the PCC experiences shared by the participants and the interpretations of how the participants made sense of these experiences. Presenting the findings in this manner maintains authenticity to the theoretical underpinnings of IPA (Charlick et al. 2015; Smith 2011). The analytical processes outlined in Chapter 4 led to the superordinate and sub themes presented. Particular attention was paid to giving voice to the multiple and simultaneous perspectives of the participants (Bevan 2013). The participants' experiences, with the extensive use of direct quotes are shared, aligning to the Habermas critical social theory (1986). Thus, a more respectful approach to the participants' voices was to keep the researcher's reflexive perspective separate but providing continuity after presentation of their experiences. Whilst there are acknowledgments to the interpretations within the findings and excerpts of field notes explaining interpretations gathered during data collection, the excerpt below explores the shift in researcher perspectives of PCC as a consequence of delivering the preliminary findings back to the research setting, based on the contents of my early draft findings.

Reflexive Excerpt: 7.6.19

Another moment of clarity today, reflecting on my 1st NHS Findings presentation yesterday, to the staff in my research area. I have become more calmly aware that even when PCC is not experienced it is not usually with malice, but good intention. This reminds me of Jack, not wishing to complain, but trying to see things from the other side, like the serenity prayer: God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.

I now see that there is a highly complex picture of PCC in the acute hospital where I carried out my research; that may or may not mirror *other such areas. At times the person receiving care truly feels it is centred on them, like Davina and her son David; but even then their nurse's experience was 'I should be doing better' when actually both David and Davina were highly satisfied with the attention to details, being kept informed and getting safely back home. However, for others, Douglas, he wanted to change the goals the MDT had set for him; but found himself disempowered by the MDT who led his healthcare decisions. Conversely Phyllis wanted the MDT to lead the assessment, delivery and evaluation of her husband's care, but she was viewed as an active partner. Then lastly, with Grace, despite four weeks of what appeared to be highly PCC, one episode of poor care erases all good PCC experiences for her. Fortunately, Grace's family had a wider perspective and could see the bigger picture beyond one omission.*

I now see that the PCC experiences being aligned is not as crucial as I did at the start of this journey. Older people and their families appear to expect to compromise on personal perspectives while in acute care. However, alignment of what PCC is for the older person and the MDT seems to happen through chance rather than concerted effort, at times. The level of 'getting to know me' required to be person-centred is deep, it now appears to me there is a long way to go in acute hospital care to allow the MDT to know people this well. This makes me wonder, should I have used the McCormack model or maybe a relational model would have been better?

I feel I have some serenity and accept that cannot change the choices I made or that acute healthcare is consistently under pressure to care. But I feel I have courageously started to share the positives of this study to celebrate the excellent PCC experiences, alongside the barriers and challenges. I now feel, I have a degree of wisdom, that these findings have the potential to add to the existing PCC knowledge base and positively influence more PCC approaches on the enduring journey towards PCC cultures of care.

5.8 Chapter Conclusion

The impact of participants' personhood, and subsequent definitions and expectations of PCC emerges as a significant and enduring thread throughout the findings of this study. Who people are, their past, present and anticipated personal future is shown to have had a direct inference of what mattered most to them in terms of PCC. Accessing hospital presented some challenges for older people and their families, but others experienced efficiency, alongside person-centred approaches. Once admitted to the hospital, a concentrated effort to build connections between older people, their family members and the MDT, presents as having a direct positive impact on PCC experiences shared - which should be celebrated. Older people and their family participants indicated appreciating a greater essence of PCC than the MDT, who revealed self-criticism in relation to this, creating the sense that they believed they should endeavour to be more person centred. Building these connections transpires as vital in order to plan how participatory the PCC approach should be for each of the collectives in this study. Connections between the stakeholders in this study will be critically explored in Chapter 6.

However, a dichotomy presented on occasions where some older people and the MDT presented the belief that enablement and participation in joint decisions was synonymous with PCC. Whilst for other older people, their family and other MDT members this was not their expectation of PCC. These findings illuminate current PCC evidence and practice. For some participants, PCC meant: time invested in relational care, fundamental care needs being met, acute care stepping in and resolving complex illness. At times, all participants experienced a preference for the MDT to lead acute care. However, instances were revealed where some older people would have preferred a more active role in their goal setting, healthcare decisions and future care planning, than they experienced. These tensions appeared to present challenges to some of the participants. A flexible approach to the uniqueness of participatory PCC appears as a continuum of fully participating, in a 'caring with' approach. This premise contrasts with a 'caring for' approach, where there is an expectation of the MDT providing care, with less participation and joint decision making with older people and their families. A continuum of participatory PCC, 'caring with' to a less participatory PCC approach of 'caring for' may be one way to compromise around these divergences will be further explored in Chapter 6.

6 Discussion Chapter

6.1 Introduction

The findings chapter highlighted the direct impact of people's personhood on their understanding and expectations of PCC. At every stage from their access to acute care to their discharge, it was the connections established between the older people, their families and those providing their care that most significantly influenced the participants' experiences of PCC. Aspects of these findings are not new. Instead, the findings provide contemporary empirical support for seminal theories and models of care which identified such interpersonal connections as the foundation to high quality care experiences (Henderson 2006, 1978; Peplau 1992; Roy 1970; Rogers 1967). They shine a light on the experiential aspects of PCC from the MDT, older person and family's simultaneous perspectives of their time in OPAH care. The relational aspects of these findings also build upon previous relational models of care such as those developed by Bridges et al. (2019), Bowers (2016, 2002), Nolan (2013) and Bridges, Flatley and Meyer (2009).

Following on from those findings, this chapter will present a flexible framework of PCC based on the principles of *caring about, for* and *with* older people. Three specific precursors will be explored which were identified thanks to the richness, depth and breadth of the experiences shared by participants: *being present, pausing time* and *connecting.* Areas of alignment, contribution and challenge will be discussed in relation to McCormack and McCance's (2017) theoretical model of PCC, which was adopted throughout this thesis. The strengths and limitations of the study will be discussed. Personal reflexive excerpts will conclude the chapter.

6.2 A Flexible PCC continuum of participation: *caring about*, *caring for* and *caring with*

6.2.1 Caring about

Caring about the older person's sense of uniqueness emerged as crucial to the participants in this study. This aligns with the recommendation from Maben et al.'s (2012 p. 83) English mixed methods study that OPAH care must include '*caring about'* rather than merely '*caring for'*. Bridges et al. (2019) also advocated working in a relational way based on connection, valuing individuality and involvement in decision-making.

The MDT participants in this study attributed their high levels of professional satisfaction to their experiences of caring *about* as well as *for* the older people. Indeed, it was their passion for OPAH care and the opportunity it afforded to adopt a values-based person-centred approach that drew them to select this field of work. They also reported caring about the wellbeing of older people in general. The recipients of their care in this study, despite their divergent expectations of PCC, predominantly praised the high standards of relational and fundamental care. Although the staff's care met the standards advocated by Bridges et al. (2019) they also acknowledged sensing that they wished to improve in order to achieve the best possible level of PCC.

These findings contrast with those of Maben et al. (2012 p.85), who found that OPAH care was associated with poor job satisfaction, with wards often being labelled as 'difficult'. Esmaeili, Cheraghi and Salsali's (2014) qualitative Tehranian study attributed this to the overwhelming nature of meeting older people's fundamental care needs, resulting in an abandonment of PCC in favour of routine-based care. This study's findings suggest a positive move away from previous explorations of poor care, such as the loss of compassion and dignity that led to the poor practices highlighted by Berwick (2014), Francis (2013) and Goodrich and Cromwell (2010). The older people in this study predominantly did not experience the level of substandard acute care of older people identified within Bridges et al.'s (2019) systematic review of 61 qualitative studies and two systematic reviews

6.2.2 Caring for

Participants in all four case collectives indicated that feeling 'cared for' was also an essential requirement for care to be experienced as person-centred, particularly when attending to fundamental aspects such as personal hygiene, nutrition, pain management and mobilisation (Ocloo et al. 2020; Bridges et al. 2019; Jakobsson et al. 2019; Guastello and Jay 2019; Richards et al. 2018). Family members and older people particularly valued 'little things that made a big difference' (Phyllis, George's wife/carer). As NES (2009, 2020) points out, attention to small details that reflect people's uniqueness can significantly enhance their experience of PCC. One would hope that these fundamental elements of care could be assumed to be normal practice. However, Parke and Hunter (2014 p.1573) remind practitioners that no assumptions should be made around the care of older people, asking the question: 'If it's common sense why isn't it common practice?'

Breakdowns in PCC can be experienced by participants as a double blow since they can be perceived as indicating the staff's failure not only to *care for* but also to *care about* them as individuals. This occurred one night when Grace's request for assistance to go to the toilet was refused, resulting in an episode of incontinence. In keeping with the ethical principle of candour, the research area was informed and undertook an investigation, resulting in an apology from the SCN. Grace's daughter felt able to dismiss this event as merely a 'blip' in otherwise good care, possibly thanks to the earlier provision of good relational and fundamental care. However, Grace's deep and lasting experience of shame and humiliation overshadowed every instance where good PCC had been provided. She expressed a hope never again to return to acute care. The poignancy of one experience that overshadowed an individual's overall interpretation of PCC could and should instigate measures to prevent any future repetition. A participant in Ocloo et al.'s (2000) PAR study of person and family centred care following hip surgery and strokes reported a similar incident, with the same impact on their overall experience. Although single instances hold significance, these should not overshadow the numerous highly positive PCC experiences of older people and their families within this study; overall they reported feeling cared for.

The staff's perspective of this lapse in PCC was not explored because it only came to light after the staff interviews had been completed. Staff may have felt reluctant to discuss mistakes in their care.

6.2.3 Caring with

The *caring with* approach to PCC gives the recipient of care control over healthcare decision and the plan of care (discussed in detail in *Chapter 1*). Thanks to its methodological approach exploring multiple stakeholder's simultaneous perspectives, this study was able to reveal a number of divergences in relation to participants' perceptions of PCC. As Dewing and McCormack (2017) De Silva 2014; McCrae (2013) and Nolan et al. (2004) point out, the complexity of PCC must be acknowledged rather than assuming that one approach will fit all.

Some older people and family members only perceived their care to be person-centred when they were involved in the decisions regarding their health, in keeping with the participatory models of PCC described by McCormack and McCance (2017), Sharma, Bamford and Dodman (2015), Fredricks, Lapum and Hui (2015), Asimakopoulou and Scambler (2013) and those presented in grey literature (see fig. 1.2). For example, Douglas anticipated being supported when he requested access to a self-propelled wheel-chair in order to maintain a modicum of independence despite his advancing illness.

However, other participants only experienced their care as truly person-centred when it was led by the MDT. This was illustrated by Davina's son's acceptance that his mother's care decisions were 'safe in the hands' of the MDT. This position can be challenging for the healthcare professional. For example, Dr Isobel from Grace's collective indicated that the *'Doctor knows best'* stance can be uncomfortable for the staff. Entwistle et al.'s (2018) exploration of PCC experiences with 26 UK doctors also found that they often experienced moral and ethical tension around whether they or the patients should lead care decisions. Wyman et al. (2020) and McKinnon (2014) also warns that shared decision-making may be particularly complex when older people are acutely unwell.

The MDT in this study favoured a participatory approach and endeavoured to *enable* the recipients of their care. Hudon et al. (2011 *p.143*) define enablement in the context of OPAH care as:

> *"a professional intervention that recognises, supports and empowers older people to be in control over their health and their lives."*

The divergences between the perceptions and expectations of the MDT compared to those of older people and their family members resulted in some misalignments, when older people and family hoped to be *cared for* but the MDT were trying to *care with.* For example, when Nurse Nicola invited George to be active in his own care, his wife (Phyllis) perceived this as a failure to provide PCC. Thomas (2016) and Say, Murtagh and Thompson's (2007) found that when an older person's condition deteriorates, they often prefer to have family members or healthcare professionals take the lead. Tobianio et al.'s (2016) Australian qualitative study of older people' experiences (n=20) also concluded that the strategic perspective of PCC as patient enablement and participation did not consistently meet the expectations of the older people and families in their research. Whereas at times nurses held the power and older people longed for greater participation, on other occasions the latter preferred to be passive recipients of care.

The participatory approach implemented by this MDT has not been universally adopted by other healthcare professionals. In Ocloo et al.'s (2020) English PAR study, observations of care showed that their MDT actually lead 90% of care decisions. When Seben, Smoreburg and Buurman's (2019) qualitative study explored the MDT's (n=7) willingness to share decision-making as part of a person-centred approach in a geriatric rehabilitation area (n=10 people over 80 years old), they discovered that the MDT believed themselves to be better placed to set realistic goals than the older people. Furthermore, community stroke nurses across Scotland in Kidd et al.'s (2020) research rejected some of the self-management plans developed by those in their care, arguing that they were unsafe. This view may have been shared by the AHP who cared for Douglas. They may have prioritised maintaining his safety because they subscribed to their need to comply with the relevant code of conduct and ethics (Health and Care Professionals Council 2016). Perhaps there was a need to consider Douglas's perspectives on his quality of life rather than potential safety risks, as Gwande (2016) recommends.

Since these findings show that some older people wish to be closely involved whereas others prefer to be informed rather than sharing control, they challenge the current drivers for enablement and participation in PCC, suggesting instead that it should be delivered flexibly along a continuum of control according to individual preference. To enable the healthcare professionals to adjust their approach to PCC to fit with each individual's desires and needs, Bridges et al. (2019) and Thorarinsdottir and Kristjansson (2014) recommended striving to achieve a connection and a therapeutic relationship before trying to set joint goals. As Ulin et al.'s (2018) Swedish study of older people post cardiac surgery showed, when therapeutic connections are built, goal setting compromises can be achieved that value and respect care recipients' personhood without compromising the professionals' duty of care. Thomas et al. (2016) also advocated using dialogue to reach shared decisions. Cooper, Smith and Hancock's (2008) Scottish qualitative exploration of PCC physiotherapy concurred that therapeutic communication and connection are vital to understand the patient in MDT approaches to PCC. When Morris et al. (2017) explored motivation in relation to physical activity following strokes (n=38), they found that more person-centred approaches to rehabilitation occurred when connections were built between the participant and their physiotherapist. The latter approach may have allowed Nurse Yvonne to become better attuned to Douglas's sense of personhood and apparent comfort with risk, after his years facing the dangers of the high seas. Recognising that his time was short, he might have opted to maintain independence and mobility despite the risks to his safety, but was never given that choice. Furthermore, if a more relational foundation had been built, it may have allowed Nurse Nicola to acknowledge the distress that Phyllis and George were experiencing meant her usual participatory PCC model did not fit with their PCC expectations. Instead of Nurse Nicola 'caring with', the expectation was to 'care for', comfort and reassure them.

The findings of this study consistently showed that PCC is experienced when *connection* and *caring about* approaches were practised; *caring about* is conveyed by *pausing time* to connect and build a therapeutic relationship. These are the experiential precursors for PCC. However, the idiographic nature of what older people and their families expect around *caring for* and *caring with* in OPAH care is more perplexing. The challenge of establishing consistent yet flexible person-centred cultures - where adaptable PCC moves along a continuum of participation - may be challenging and take time to integrate. PCC has become so intertwined with participation and enablement that MDT members may require permission to flexibly align their approach with older people's needs and preferences in the moment.

All four case collectives consistently agreed that OPAH staff should, and in most cases did, invest time in the relational aspects of being *present, pausing time* and *connecting* in order to provide better PCC. These findings provide new empirical support for the recommendations of Bridges, Flatley and Meyer's (2010) systematic review: *connect, see me and involve me*.

Three collectives demonstrated tensions due to the mis-alignment of PCC expectations of older people, family member and the MDT. The relational foundations to PCC appeared to be weaker. A breakdown in the connection between the older person, family and MDT was associated with less clarity around meeting expectations of PCC, in particular around whether PCC meant *caring about, for* or *with* older people.

6.3 Being Present, Pausing Time and Connecting

6.3.1 Systems and individual approaches that help and hinder connection

The experiences of *being present, pausing time* and *connecting* identified in the findings of this study led staff to a sense of valuing the uniqueness of older people. The provision of personal care in particular enabled them to use these tools to gain a deeper understanding of the older people's personhood. The findings also suggest that being person-centred does not necessarily fit into one care process, such as the admission procedure; it involves taking every opportunity to be curious and form connections, thus benefitting both providers and recipients of care (Dewar 2011). The creative use of all interactions enabled the staff to build a rapport and a therapeutic relationship from the point of access until discharge in order to meet the varied expectations of those in their care. From writing nursing documentation to providing assistance with walking to the toilet, every activity could be used creatively as a valuable opportunity to build relationships with patients and discover their personhood. The staff's positive attitudes, resulting in their willingness to invest time in the care of older people, were in sharp contrast to those described in Bridges et al.'s (2019) systematic review.

Similarly, Jenson, Vendelo and Lomborg's (2013) research with people with COPD (n=11), demonstrated that time dedicated to personal care led to a deeper sense of security and attentiveness. Whereas their Danish interpretative analytical study specifically explored personal care, this research considered the whole care experience from multiple stakeholder's perspectives. Moore et al.'s (2017) Swedish qualitative study (n=18) concluded that healthcare systems should allow staff more time to uncover older people' narratives. Their Swedish descriptive phenomenological study with 10 registered nurses concluded that working in a person-centred way allowed staff to come closer to the patient's world. Similarly, Albinsson and Arnesson's (2019) advised that healthcare organisations must allow staff sufficient time to build connections and facilitate an emotional, values-based approach to their usual nursing care. White et al.'s (2019) participants found that their increased professional job satisfaction outweighed the cost in time from being person-centred.

The findings of this study also highlighted the need for PCC to begin even before the ward admission since the participants' journeys began when they first attempted to access acute care via emergency services or primary care. Nilson, Edvardsson and Rushton (2019) argue that PCC should begin in the Emergency Department (ED); however, Banerjee, Conroy and Cooke (2012) acknowledge that frail and vulnerable older people may receive poor care in a fast-paced environment designed primarily to assess, intervene and move people on. At that point, clinical interventions may receive a higher priority than relational aspects of care such as *pausing time* and *connecting.* For example, the staff required Catherine to leave her mother’s side, contrary to the Ombudsman for NHS England’s (2011) recommendation that in the ED family members should be allowed to remain with vulnerable older people. Magnuson (2014) argued that it should be just as acceptable for adult children to remain with a vulnerable parent as it is for a parent to stay with their child.

The primary care telephone triage used by Phyllis to access acute care also lacked a humanistic connection. Although safety appeared to be its prime aim, the system missed Phyllis’s sense of fear, when trying to care for George who at this point had become completely immobile. Berwick (2014) considers PCC and safety to be inextricably linked. Open questions such as ‘What is your main concern right now? or ‘What are you hoping to achieve by calling us tonight?’ could have resulted in a much more person-centred approach to George’s admission into acute care.

The negative experiences continued when George was admitted to the MfE area (NHS Grampian 2017). Having only recently retired, Phyllis did not consider an OPAH to be an appropriate area for herself or her husband. Nevertheless, Ebrahimi et al.’s (2016) RCT of PCC versus usual OPAH care advised that this setting is the most appropriate for those over 80 years and over 65 years with more than one long term condition – George had six of these. The research setting’s admission criteria were based on the National Standards for Older People in Hospital (2015), which stipulated that those over 65 years should receive a complex needs assessment in a MfE ward. An explanation might have helped Phyllis to grasp the potential benefits from a review of her husband’s condition carried out by staff who had the level of specialist expertise available in that area.

6.3.2 Leadership supporting a PCC culture

McCormack and McCance (2017) argue that organisational support is needed in order to create a person-centred culture of care. In their English PAR study with 14 nurses in OPAH care, Ross, Tod and Clarke (2014) also found that clinical leadership was essential to deliver PCC. In the current study, PCC and leadership were not specifically explored. Nevertheless, the research area followed the

Scottish Government (2015) initiatives such as *'What matters to you'* and *'Nothing about me without me'*, alongside the 'Welcome Ward' health board operational work (NHS Grampian 2018). The latter fits with the GPCC's philosophy (2016) that the patient's narrative must form the basis for developing their care. As Dewar (2011) pointed out, developing greater curiosity about those in their care will help staff to provide support that is more individualised and compassionate.

Furthermore, in interactions throughout recruitment and data collection, the research setting's MDT staff referred to PCC as being their normal way of working. All of the participants indicated that the strategic move to person-centred visiting had a positive impact on their care experiences in OPAH. These changes appeared to have been initiated by the NHS organisation, then implemented by leaders at wards level. The MDT participants and some of the older people appeared to recognise that some of those receiving care and their families had gradually became more actively involved.

Hardiman and Dewing's (2019) Irish PAR study of the experiences of five healthcare leaders showed that careful preparation of the staff was needed in order to successfully develop a culture of PCC. An authentic relationship between the leaders and staff was found to be important. Mutual respect and shared values between staff and patients were also considered to be key factors. However, it would be wrong to equate 'shared values' with 'identical values', particularly in relation to the level of participation through enablement, engagement and joint decision-making that older people and their families desired or felt able to cope with. MTD participants in this study sought to use their time creatively in order to gather the information that would allow them to ascertain how best to deliver the PCC that would most effectively fulfil those desires and needs for involvement for each individual at any given time in their journey. Ideally, this would enable the staff to adjust their approach to care flexibly along a continuum between *caring with* and *caring for* in a truly person-centred way.

Although the research setting's 'Welcome Ward' PCC strategy (NHS Grampian 2018) appeared to be aligned to offering choices and control, circumstances sometimes restricted these. For example, Douglas appeared to be stuck in acute care because rural home care was unavailable. Hebblethwaite's (2013) Canadian exploration of PCC experiences with 11 recreational therapists showed that even where there was strategic leadership, circumstances could dilute the philosophy before it was completely embedded in care delivery. The Swedish ethnographic study on an acute medical ward by Dellenborg, Wilstrom and Anderson (2019) concluded that staff dedication was insufficient to ensure that healthcare systems and processes were consistently person-centred. These same authors observed Nursing Auxiliaries (n=3), Registered Nurses (n=8) and Medical Physicians (n=12) during a five-day education programme in preparation for a move to PCC. However, since 'success' was measured by determining whether the recipients of care succeeded in holding the locus of control over their healthcare, this basic premise of their research does not align with the view of PCC adopted here.

This study has highlighted the divergences between the level of participation the staff wished to offer and that which the older people and their families felt able to manage. However, when *connections* had been made, *time paused* and the MDT staff had *been present* with the older person and/or their families, no tension arose from the misalignment regarding whether or not PCC should be participatory. Thus, where therapeutic relationships had been established, older people and their families felt able to accept those differences. These findings reflect the fundamentals of interpersonal nursing care and shine an experiential light on the importance of relational care in PCC (Henderson 2006, 1978; Peplau 1992; Roy 1970; Rogers 1967).

6.3.3 Connecting more or less than the MDT realised

The staff in this study did not recognise the extent to which the participants' experiences of PCC were enhanced when they succeeded in being *present, pausing time* and making *connections*. Whilst Davina's nurse (Sarah) viewed *being present* and *pausing time* as merely aspirations rather than reality, Davina and her family member reported feeling actively listened to and never rushed. This contrasted with Bridges et al.'s (2019) finding that their older participants had consistently felt rushed to the point where they feared requesting assistance. Bridges, Flatley and Meyer's (2010) earlier systematic review of older people's acute care experiences, alongside other studies (Alharbi 2014 et al.a, b; Gill et al. 2014; Hurtley and Obe 2012 and Gill et al. 2001), all concurred with this study's finding that older people valued being listened to more than leading their own care. In previous research (Dewar and Nolan 2013; Dewar 2011; Nolan et al. 2004) relational aspects of care were sometimes viewed as separate from PCC. However, participants in this study viewed the relationships created between older people, families and the MDT as valuable elements integral to their PCC experience. Similarly, Dewar's (2011) Scottish PAR study concluded that the experiences of being listened to and cared for with compassion were essential for the development of bonds of connection and trust with the staff. McCormack and McCance (2017) suggested that the following relational aspects are necessary to achieve person-centred outcomes:

- Satisfaction with care
- Involvement with care
- Sense of Wellbeing
- Therapeutic culture of care

For these participants, the establishment of mutual respect through *being present, pausing time* and *connecting* prevented the development of tension when expectations of PCC differed. Hardiman and Dewing's (2019) PAR study concluded that PCC leaders should promote mutual respect between their MDT and people receiving care. The establishment of emotional connections as part of PCC was also highly valued in Guastello and Jay's (2019) international mixed methods study which comprised surveys and focus groups involving patients, families and all grades of staff in USA, Canada and Saudi Arabia. Guastello and Jay's (2019) evaluation of the Planetree (2017) processes for international PCC certification identified several factors that contributed to positive PCC experiences, including connection between patients and the MDT staff, more flexible meal-times and assistance with personal hygiene. They noted that the levels of engagement and shared decision making were lower than expected, but did not explore the possibility that this may have resulted from some older people's preferences.

The collection of data from both care giver and recipient using an IPA/Collective Case Study approach identified areas of divergence between the MDT, older people and their families regarding the very nature of PCC. This extended beyond the issues of control and decision-making discussed earlier. George's nurse, Nurse Nicola, sought to help George to maintain his independence in relation to mobilising and personal care for as long as possible, but Phyllis, his wife and carer, perceived this as a dereliction of Nurse Nicola's duty of care. Say, Murtagh and Thompson's (2007) narrative review suggested that expectations of PCC were influenced by participants' sense of self and that being listened to should be given a higher priority than either enablement or shared decision-making. More recently, however, the PCC evidence base has emphasised the importance of those features (McCormack and McCance 2017; Sharma, Bamford and Dodman 2015, Fredricks, Lapum and Hui 2015; Institute of Health Improvement (IHI) 2014; Asimakopoulou and Scambler 2013; Department of Health 2011; SG 2010). The misalignment between Phyllis's wishes and Nurse Nicola's approach may have resulted from a difficulty in establishing the necessary relational precursor aspects of PCC. As Bridges et al.'s findings (2019) indicate, if *connections* had been made, Phyllis's persona and expectations may have been *'seen'.* The MDT staff may have then ascertained George and Phyllis's preferences and expectations with regard to *caring for* and adjusted their approach to take into account George's rapidly deteriorating condition. Thus, the findings of this research study suggest that older people and their families may not always be comfortable with embracing all aspects of a participatory PCC approach.

McCormack and McCance's (2017) theoretical model of PCC used throughout this study aligns with some of its participants' experiences. However, as anticipated, these findings may also add to and challenge this model.

6.4 Alignment, additions and challenges to McCormack and McCance's theoretical model of PCC (2017)

6.4.1 Alignment

This study did explore staff PCC experience but not the specific component of professional competence, defined as:

> *The knowledge, skills and attitudes of the practitioner to negotiate care options and effectively provide holistic care.*
>
> (McCormack and McCance 2017 p.42)

Nevertheless, the knowledge and proficiency in OPAH care of the experienced MDT participants was clearly conveyed in their interviews. In contrast, Nurse Nicola, only nine months' qualified, appeared less confident in her ability to flexibly mould PCC. The PCC experiences she discussed aligned with the current enabling and participatory PCC drivers, as opposed to flexibly moulding her care to the older person. Parahoo's (2014) suggestion that research participants may offer what they believe to be the 'best answer' to a research question rather than sharing their experiences, may have relevance here. Since I had taught Nurse Nicola the theoretical elements of PCC as part of her recently completed pre-registration nursing course, the resulting power dynamic may also have influenced her responses.

The members of the MDT met several of the pre-requisites stipulated in McCormack and McCance's (2017) model of PCC. They demonstrated well-developed interpersonal skills and a commitment to their respective roles in OPAH care. They also showed a determination to provide individualised care. This contrasts with the negative staff experiences within care for older people identified by earlier researchers (Berwick 2014; Francis 2013; Maben et al.2012; Goodrich and Cromwell 2010).

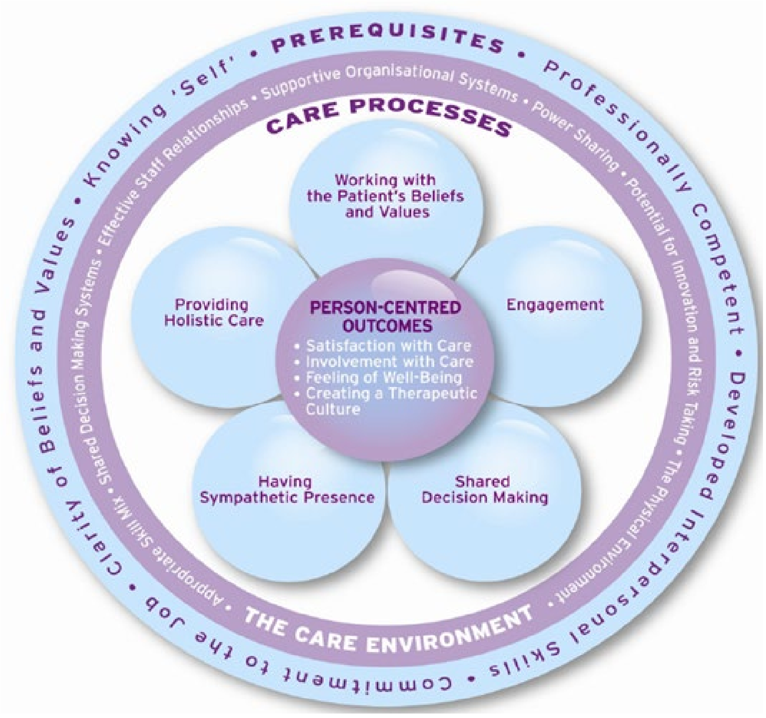

Figure 6.1 McCormack and McCance model of PCC (2017)

Several acts of strategic leadership in the research setting (NHS Grampian 2017) were also in line with the care environment components of McCormack and McCance's (2017) model. MDT discussions focused predominantly on collaborative working and whilst the study did not explore the skill mix, the effectiveness of the staff relationships or the physical environment, no concerns were expressed regarding any of these areas during the interviews. On the other hand, the staff expressed some frustration when the organisational systems made PCC more challenging; examples included the inflexibility of meal times, the decanting of older people when homecare was unavailable, and the lack of rural healthcare to facilitate discharge. Dellenborg, Wilstrom and Anderson's (2019) Swedish ethnographic study demonstrated similar issues. The provision of relational care along with clear communication appeared to help the older people and family members to cope with these compromises, as when Davina was decanted because of a shortage of acute beds.

This study's findings also aligned with the elements at the centre of McCormack and McCance's (2017) model's care processes: as the staff gained an understanding of each individual's sense of personhood, they were more able to provide care in a way that fitted with that person's beliefs and values. It was clearly evident within the first superordinate theme that the divergent definitions and expectations of PCC were determined by the personhood of the participants. Similarly, the sense of *caring about* and *for* can be aligned to holistic care and a sympathetic presence.

6.4.2 Additions and challenges to the PCC theoretical lens and views on OPAH care

The relational precursors required for PCC to be experienced which were identified in this study were similar to those stipulated by McCormack and McCance (2017). However, the study also highlighted more explicit relational factors around *being present, pausing time and connecting* (see figure 6.2 below) with older people's sense of self. Positive PCC outcomes were reported whenever these specific relational aspects of care were integral to the participants' experiences, even when their definitions and expectations of PCC were different from the staff's. These divergences were illustrated by Douglas's desire to take more control over his care and Phyllis's expectation that the MDT would take over all aspects of her husband's care. These findings therefore indicate that the provision of genuine PCC to older people and their families requires dedicated staff who use their time creatively to understand what PCC means to the individuals in their care right from the point of access to discharge, and then deliver that care with flexibility.

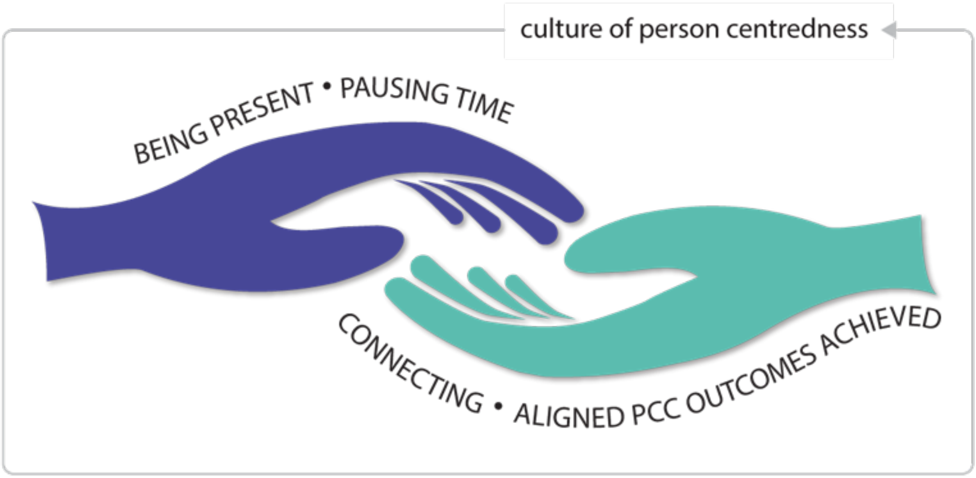

Figure 6.2 Precursors to Person-Centred Care

In Tingle's (2011) research and Bridges et al.'s (2019) systematic review, most of the older people's experiences in acute care were reported to be poor. In this study, the older people and their families gave clear examples of PCC provision that had fulfilled their best hopes. They acknowledged and valued the dedication of the whole MDT. Generally, they were willing to overlook the occasional lapses in care. The staff, however, sometimes doubted their ability to achieve the high standard of values-based care that their team consistently aimed for and that had become part of their ward culture. This self-doubt may have been more prevalent in the participants of this study as a result of selection bias, since those who took part may have been motivated by a pre-existing personal and professional bias toward values-based PCC. On the other hand, the recruitment of the older person and their family member before the staff member reduced the potential impact of this factor. Furthermore, the collection of multiple perspectives of PCC allowed the older people and family members to counterbalance the staff's self-critical voices.

The MDT did not share the intense sense of failure highlighted in earlier research where staff had reported feeling overwhelmed by the needs of acutely unwell older people with complex conditions (Bridges et al. 2019; Rankin 2015; Esmaeili, Cheraghi and Salsali 2014; Berwick 2014; Francis 2013; Maben et al. 2012;). Tingle (2015) warns that pressures on healthcare systems are rising as life-expectancy increases. Scammel (2017) warns that this perception may be aggravated by the negative images of older people in the media, where they are sometimes portrayed as a homogenous group and labelled as 'beds blockers' (Manzano-Santaella 2010). Research by Koh et al. (2012) shows that even student nurses prefer placements in areas of critical care – emergency or intensive care - to those in OPAH. This is in sharp contrast with the MDT in this study, who had elected this speciality and experienced a sense of professional fulfilment in their daily work. This positivity is surely to be celebrated.

Whilst in many ways the findings in this study support McCormack and McCance's (2017) model, those in relation to engagement and joint decision-making present a challenge. The model suggests that to be genuinely person-centred, care must be designed to support patient engagement and shared healthcare choices. In common with other research in this field (Jakobsson et al.

2019; Guastello and Jay 2019; Seben, Smoreburg and Buurman 2019), the shared decision-making and power sharing aspects of all of the participants' experiences of PCC were explored in detail. This research concludes that PCC can be experienced at any point on a continuum between one end where the MDT is directing all of the care and the other where the older person and their family are leading it with support from the MDT (see figure 6.3). Coulter and Collins's (2011) admonition in the Kings Fund report '*Nothing about me without me'* suggests that joint decision making should be the norm in healthcare practices. In this study, although the MDT strived to engage recipients of care in jointly making decisions, some older people and their families did not experience this as being person-centred because it ignored their preference at that time to simply be *cared for*. Participants needed permission to select their own placement on the participation continuum of PCC. It is this placement of PCC on a flexible continuum of *caring for, about* and *with* that enables this study to shine a new light on current PCC thinking, healthcare policy and the current evidence base (as discussed in *Chapter 1*). The infographic below (fig 6.3) depicts the flexible approach to PCC which fits with the findings of this study.

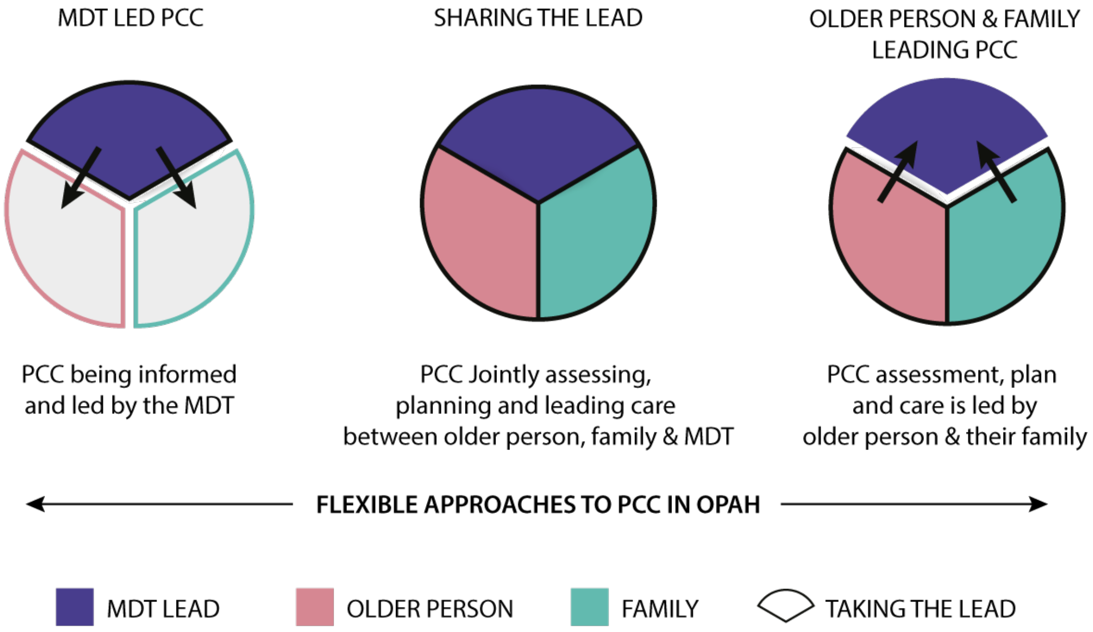

Figure 6.3 Model of Flexible Person-Centred Care

Although the current drive for PCC is represented by the central diagram, this study suggests that at times older people and families experience a need to be cared for in a way that fits with those depicted toward the left or right on the flexible PCC continuum.

6.5 Limitations and strengths of the study

6.5.1 Limitations

6.5.1.1 The challenges of recruiting

Despite the pre-arranged daily phone calls to the research setting, the first month of recruitment yielded no recruits. Following discussions with research supervisors, permission was sought from the SCNs to visit daily at set times to minimise interrupting care delivery (11:00, 15:00 or after 17:00). Although this approach presented logistical challenges for me as a nurse lecturer, it proved worthwhile since participants were successfully recruited after one week.

The critical review of PCC literature (*Chapter 3*) concluded that the wider MDT's contribution to PCC needed to be explored. Despite this intention and my increased visibility in the ward, the recruitment of AHP participants was unsuccessful. Although all were invited to the pre-research briefings to raise interest in the study, only nursing staff attended. The other MDT members who met the inclusion criteria and expressed an interest withdrew following the initial contact. I felt concerned about interrupting their busy schedules since they covered multiple clinical areas. On reflection, they could have been more specifically targeted. As De Brun and McAuliffe (2018) point out, healthcare professionals' priority rightfully lies with direct care, making it challenging to recruit them to clinically based research. They advise researchers to be flexible in their approaches to reach MDT members.

The recruitment of one nurse to each of the case collectives and a doctor to the final complete collective was not without challenges either. Interviews with nursing and medical staff had to be rescheduled up to three times due to clinical need, shift work and on-call rotas. In one instance, a doctor was recruited to one case collective, but following four attempts to conduct the research interview, the decision was made to abandon it. This doctor's emotional stress due to their workload made insisting on their participation unethical. This fits with Kay's (2017) contemporary accounts of the realities of being an NHS doctor.

As Creswell (2014) and Silverman (2013) point out, unpredictable events can disrupt well laid plans, compromising the recruitment process. During the study's primary recruitment phase (February – March 2018) several variants of 'flu affected vulnerable older people (DOH 2018), resulting in a winter bed crisis in the NHS (RCN 2018). With so many very ill patients in their care, this study was not the nursing gatekeepers' priority. Furthermore, an extreme weather front *(*Met Office 2018) with freezing temperatures and high winds disrupted travel for older people and nurses, and hampered my visits to the research area. None of these events were within my control.

Despite these challenges, an extension of the data collection period allowed the recruitment of four case collectives and eleven participants. Their insightful PCC experiences enhanced the PCC evidence base.

6.5.2 Elements of limitation and strength

6.5.2.1 Giving stakeholders their voice

Chapters 1, 4 and 5 outlined the critical rationale for the participants' voices in IPA research, indicating that participants should be supported in sharing not only *what* they want to about their experiences, but also *in the way* and *in the location* that suit them best (Charlick et al. 2015). An equal relationship is fundamental to IPA studies: the locus of control over data collection is to be shared between participants and researchers (Smith, Flowers and Larkin 2012, Smith and Osborne 2015). Therefore, in this study older people and family members were allowed to choose whether to be interviewed independently or in dyads. The older people opted to be interviewed with their family members, but unavoidable circumstances led to Douglas (the older person in case collective 2, whose son became unwell) and Phyllis (George's wife/carer in case collective 3, George's physical and cognitive condition deteriorated) being interviewed alone.

In some ways, being alone provided a safe space for emotionally charged experiences to be shared freely, as suggested by Herron and Wrathall (2018). Since these participants both shared fears of imminent death, their deep openness was a strength of this study. However, the interviews of dyads provided more breadth of data around the shared experiences of PCC in OPAH. The support the older person appeared to gain from the presence of a family member may have enabled them to delve more deeply and widely across their whole experience in a way that was less apparent in the independent interviews. Finlay, Lloyd and Finucane's (2017) Scottish study of older people and carers' experiences of frailty found that carers could at times be inhibited from sharing their deeper feelings in the presence of an older relative. In this study, however, family participants did not hold back from discussing emotive aspects of their care experiences. The interpretation of their paralanguage supplemented the findings from these dialogues alongside their linguistic interpretation (Smith, Flowers and Larkin 2012).

In keeping with Polit and Beck's (2016) advice to facilitate, as far as possible, participants' choice for the location of the research interview, the older people and family members were given the options of being interviewed in acute care, interim care or in their home setting. This factor appeared to impact on how participants shared details of their PCC experiences. As Greenwood (2008) suggests, participants who opted to be interviewed at home (David and Davina; Phyllis, George's wife/carer), spoke for longer and shared more emotive aspects of their experiences. However, in the interviews conducted in acute and interim care, participants were more inhibited from sharing any perceived negative experiences in detail. For example, Douglas only provided limited details regarding occasions when the staff had appeared less caring, balancing this up with other positive aspects of his experiences. Being interviewed in the environment in which he was still receiving care may have limited what he felt able to share.

The MDT participants were interviewed close to the research area to lessen disruption to clinical care delivery and minimise upheaval, as recommended by Silverman (2013). This environment suited the more experienced and confident MDT participants (Nurses Sarah, Kathy and Dr Isobel). However, those who were less confident (Nurse Yvonne) felt guilty for taking time away from the clinical area, only relaxing sufficiently to provide richer disclosures halfway through the interview. Cunningham, Weatherington and Pittenger (2013) caution that clinical staff may need time to build rapport and trust with research interviewers. Nurse Nicola, the least experienced of the MDT participants, spoke less confidently and gave the shortest, least detailed account of her PCC experiences; she appeared to be distracted by the close proximity of the ward. Nevertheless, her insights provided a moving account of the impact of divergent definitions and expectations of PCC and the resulting tensions. On reflection, offering MDT participants a choice of locations for the interviews may have enhanced their disclosure of their experiences.

6.5.2.2 Idiographic nature of the study

In hindsight, the idiographic nature of an IPA study using a collective case study approach has proven to be a robust method for illuminating experiences of PCC in OPAH from multiple stakeholders' perspectives. Idiography can be viewed both as a strength by providing deep insights, as well as a limitation in terms of the research's impact (De Luca Picione 2015). The rich, deep and broad insights within the findings of this study may not be generalisable to PCC in healthcare. However, meaningful and powerful inferences can be made which can be impactful in OPAH environments. Leung (2017) acknowledged that the individual and unique experiences of even a small number of participants can provide significant additions to knowledge. As Gadamer's (2004) philosophical fusion of horizons suggests, these experiences may differ from those collected from other similar stakeholders in other OPAH environments at other times, depending on the participants' and researchers' worldview and the circumstances in that moment.

6.5.3 Strengths

6.5.3.1 Richness and depth of PCC experiences

The rich, multi-layered data collected using diaries and face-to-face interviews created clear perspectives of the care experienced in the OPAH environment.

Diaries served as an aide-memoire rather than a data collection tool providing deep insights. Hyers (2018) supported the flexible use of diaries as an adjunct to data collection. Whilst their completion was useful as precursors to interviews, the latter were the essential instruments, providing clarity regarding the participants' definitions, expectations and experiences of PCC. This combination of data collection tools has also been shown to strengthen other hermeneutic phenomenological studies (Herron and Wrathall 2018; Davidson, Worral and Hickson 2008).

During the interviews, a sense of connection and openness developed between the participants and myself. They all provided clear examples illuminating the essence of PCC for older people, their families and the MDT in OPAH care. The double hermeneutic approach for analysis of IPA studies (Smith, Flowers and Larkin 2012) led to deep immersion in the data and contributed to the profound yet specific findings, adding to the PCC evidence base. Combining IPA with the collective case study approach facilitated the development of a perception of the participants' personhood, in turn leading to meaningful insights into their definitions and expectations of PCC care. The addition of extensive direct quotes provided a window into the participants' experiences. Additionally, the essence of the voice of each unique individual is present, sharing what mattered most to them during their time in OPAH care. Whilst some commonalities emerged, the idiographic nature of collective case studies in an IPA approach also led to divergences. As a researcher, I felt privileged to enter the participants' world in order to attempt to view it from their perspective.

Throughout this research and the resulting thesis, I set out to communicate a sense of my own authenticity. This is evident through my ontology and epistemology to enter into the world of others and view their PCC experiences through their eyes, as far as possible. This aspiration became a reality as the findings were analysed. The alignment between the methodological idiographic approach and the area of interest (PCC) enhanced the rigour of the research throughout the study (Polit and Beck 2014).

Another aspect of my ontology and epistemology was to develop a clearer understanding by viewing a phenomenon from several different perspectives. In retrospect, although I could have aligned the study to Bridges, Flatley and Meyer's (2010) relational model of care, this could have hindered the exploration of PCC beyond its relational aspects. Furthermore, the negative mindset with which I came to the research fitted with their findings, whereas selecting McCormack and McCance's (2017) model helped me to be more open to all potential experiences.

6.5.3.2 Breadth of PCC experiences – multiple simultaneous perspectives

The collection of multiple perspectives of the same experience of care and the use of a collective case study method within an IPA approach to explore PCC were not identified in any other literature accessed in preparation for this research, making these unique features. Other studies have collected PCC data about patients, families and staff, but have not endeavoured to view the same experiences simultaneously. These aspects have facilitated broad and deep insights into the phenomenon of PCC, showing how it can be experienced uniquely and collectively.

This approach from multiple perspectives has also demonstrated how PCC can be misaligned despite providers' best intentions, and how tensions can arise when PCC definitions, expectations and healthcare systems do not consistently match the anticipations and hopes of older people and families. It has also established that older people and their families acknowledge the need for compromise around PCC in a complex healthcare system. This study has highlighted the praise that older people and their families expressed about the care they received, in direct contrast to the negative connotations of OPAH care often found in the literature relating to this field (Bridges et al. 2019; Scammel 2017; Tingle 2015). The receipt of relational and fundamental care was especially valued, despite MDT participants' belief that they could do better. Staff in the research area should recognise older people and families' overall sense of satisfaction with the PCC described in this study and view the limited failures as areas for improvement.

The reflexive process has proved vital throughout this research and doctoral study process, particularly in relation to this chapter; therefore, this extended excerpt has been included:

6.6 Personal Reflections

Reflexive Excerpt 6.7.19

This chapter is the 2nd last chapter to write in the production of the thesis... I lacked confidence around my addition to the PCC knowledge base, despite having certainty that my findings were robust. I experienced a real paradigm shift during the pulling together process of the findings, re-visiting the literature and writing this chapter. I go back, frequently to without Jack being cared for in what I believed was not a person-centred way, I would never have carried out a PCC study. My friend shared a metaphor around resentment with me yesterday that resonated with my paradigm shift on PCC and my lived experience of Jack's non-PCC. Resentment is like a burning hot piece of coal, if you hold it, you will get burned. If you put it down, it will burn out. I feel I held my resentment close at the start of this journey, but by researching PCC lived experiences, I have re – ignited a new fire of PCC knowledge. I now see that at times, Jack did not want the involvement, to share the decisions or the shared power I craved for him. Like Phyllis and George, he wanted to be cared for by Dr's who knew best. My new 'fire' of PCC knowledge will hopefully warm hearts and ignite in others more flexible approaches to bend PCC around what the person receiving care hopes for, even if they have an outspoken sister who is a nurse lecturer who expects something else! It's all about the person who needs the care."

4.9.19

"Walking Belle last night, I had a light bulb moment, it was the 'pausing time' that was missing from Jack's care. The MDT did not connect with him, therefore could not begin the process of developing and delivering what he expected as PCC. This is the crux, pausing time, being connected THEN PCC

6.7 Chapter conclusion

This chapter has elaborated on the study's key finding that in order to create a sense of PCC, the MDT must strive toward *being present, pausing time* and *connecting* with the older people and families in their care. In contrast with previous studies, the MDT experienced a greater sense of professional satisfaction in OPAH care, particularly when they succeeded in using their time creatively to create therapeutic bonds. It also highlighted the deliberate choice made by all of the MDT participants to work in OPAH care, a rewarding area that enabled them to combine their values of *caring about, with* and *for* older people.

Where connections were made, the older people and families in this study experienced positive PCC outcomes even when the MDT and older people's expectations of PCC were not aligned with each other. Some participants preferred a more paternalistic, medical model of PCC which was out of step with the current participatory models (CDHN 2017). Others, however, expected more involvement and participation. This study has therefore concluded that relational aspects of caring are integral to the establishment of a more flexible PCC continuum of participation built around the principles of *caring about, caring with* and *caring for*.

The overarching aim of doctoral studies should always be to add to the current evidence base in the relevant field of interest (Marshall 2019). Key areas within the findings of this study can be aligned to McCormack and McCance's (2017) theoretical model of PCC. However, this research also adds specific experiences as seen from the perspectives of multiple stakeholders in OPAH care which have the potential to enhance PCC practices in this area. In particular, it has highlighted the need for *being present, pausing time* and *connecting* within a flexible culture of person-centred care. An exploration of the expectations of engagement and joint decision-making within McCormack and McCance's (2017) model has led to the recommendation of a more flexible approach to participation in healthcare in order for more older people to feel their care is person-centred.

The limitations of this study have been shared, adding rigour through transparency around the researcher’s reflexivity. Reflection as part of the doctoral journey has allowed the identification of some of the limitations that could have been avoided, as well as those that were completely out-with the researcher’s control. Despite these, this work demonstrates several strengths. Not only are the findings rich and deep, but they also have a breadth across the experiences of both giving and receiving PCC, thus providing a platform to further develop PCC practices in OPAH care and healthcare education.

7 Study Conclusion

7.1 Concluding Summary

This short concluding chapter will focus on the original contribution the current study has made to the PCC evidence base, the potential impact of the study could have and subsequent recommendations. The chapter and thesis will draw to a close with my final reflexive excerpt.

7.2 Original Contribution to PCC Knowledge

New additions to the knowledge base of PCC for OPAH found through this study included specific themes relating to positive cultures in OPAH linking with MDT fulfilment in delivering PCC in OPAH. These new additions challenge previous evidence on the negativity around OPAH care, indeed OPAH was promoted by the MDT participants in this study as a place of choice to work if you value PCC delivery, both personally and professionally. The complexity of OPAH healthcare needs was revealed as a facilitator for more person-centred approaches. This is an area for potential future research, to assess whether this is a new emerging phenomenon, or if it was unique to this research area.

This current study also adds to the OPAH evidence base around meeting the complex needs of older people, where a need for an MDT approach to care was shown. Whilst the recruitment challenges prevented AHP participation in this study, the AHP contribution to care was reported as being highly valued by all participants. Again, this presents an area for future dedicated research, with a specific focus on recruiting AHP's perspectives on PCC for OPAH.

Furthermore, the finding that illuminates aspects of McCormack and McCance's (2017) theoretical model of PCC is the evidence that older people and family participants did not consistently value enablement, shared decision making or engagement as PCC. Rather than power sharing and enablement, the participants focused more on precursors of relational care: being *present, pausing time, connecting* then PCC that met fundamental care needs in an individualised way. Crucial to a PCC experience therefore is the need for the MDT to seek to understand before being understood (Covey 2013). Thereby actively listening to older people and their families to develop an understanding of who they are and their personal expectations of PCC. *Being present, pausing time, connecting* were established as be specific precursors of relational care in this study, which led to positive PCC experiences, even when the MDT and older people had divergent PCC expectations.

Older people and their families had mixed perspectives of whether they should be actively involved in their care or whether the MDT should take the lead, adapting around hospital systems and processes. Some participants reported being at ease with the MDT leading their care and compromising their recovery goals around the MDT perceptions of the best way forward. A sense of older people and families accepting compromise was evident, providing this was accompanied by relational care and compassionate communication. However, some older people preferred sharing decisions within the direction of their PCC. Thus, rather than PCC being viewed as synonymous with enablement, shared decision making or patients and families directing care, this study's findings advocate that PCC should be viewed along a continuum of non-participatory to full participatory PCC. The crucial component of setting the tone of PCC for older people and their families relates appropriately to the title of this study 'Pause Time'. If time is taken to *get to know* older people and their families, meaningful relationships are formed and PCC can therefore be moulded to suit the expectations and perceptions of older people and their families. Interestingly, this study found that where pressures on OPAH systems were evident, (such as a need to decant older people out of MfE care) older people and families were less critical of necessary compromises than staff were.

From a reflective perspective the analysis of the findings led to a paradigm shift in my thinking. I began to see how I had concurred with current evidence and models of PCC that assumed enablement, shared decision making or directing care would be valued by older people, families and MDT staff. In reality, there is a spectrum of expectation or definitions of what PCC means to individuals. Indeed, the study demonstrated that, even from day to day, an older person's expectations of PCC may change. My shift in thinking permitted me to view PCC along a new continuum of non-participation to full participation, rather than assuming older people, families should be consistently enabled, share decisions or that MDT should facilitate people leading their own care. Thus, as a consequence of the findings of this study, a new model of PCC for OPAH is introduced - *caring about, for and with* older people, in a culture of compassionate compromise.

7.3 Recommendations for PCC clinical practice, healthcare education and research

7.3.1 Recommendations for PCC clinical practice

The first recommendation is that the MDT in OPAH care recognise the way in which the uniqueness of the people they are looking after will determine what person-centredness means to them. The relational aspects of care, including but not limited to actively listening, being curious about the person's past, present and hopes for the future should be assessed, identified and re-visited from pre-admission to discharge. Such a premise relates directly to the title of the thesis, *to pause time* between the MDT, older people and their family, at every care junction. Correspondingly, the specific relational precursors of *being present, pausing time and connection* should be considered in OPAH care and be integral to educational preparation for OPAH care.

Secondly it is recommended that PCC practices should allow both the person receiving care and those delivering it, permission to flexibly mould the participatory level of care according to the person requiring care. There should be a recognition that PCC can and should flexibly move along a continuum of *caring about, for and wit*h older people, in essence, non-participatory involvement to complete involvement and enablement.

A third recommendation is that the multiple PCC enhancing factors, such as: creative use of time and complex OPAH care needs leading to a more PCC culture experienced in this study, should be celebrated and aimed for in other OPAH areas. Meanwhile the barriers for PCC identified through this should become a focus for quality improvements in PCC experience for OPAH.

Furthermore, the appreciation that OPAH is a desirable work setting for professionals who value PCC, should be promoted.

7.3.2 Recommendations for healthcare education

Healthcare educational programmes should recognise that the findings from this study present a unique and distinctive perspective on current PCC experiences within OPAH. Therefore, promoting relational care of *being present, pausing time and connecting* with compassionate compromise should be viewed as a foundation to deliver PCC. Additionally, acknowledging that *caring about, for and with* older people exists throughout a non-participatory to participatory continuum of PCC, presents a new PCC concept for OPAH care. Therefore, the collective findings from this study merit incorporation into undergraduate and postgraduate programmes of healthcare education.

7.3.3 Recommendations for further research

Ultimately, this current study demonstrates that OPAH should be viewed in a more positive light, where the complex needs of acutely unwell older people can facilitate PCC. Indeed, further research investigating the care orientation of MDT staff working in OPAH areas, could build upon this initial preliminary finding.

Whilst the voice of the AHP is absent in this research, the contribution of AHPs to MDT PCC experience should be acknowledged as a fundamental area of PCC for OPAH. This current study highlights the need to explore the role of AHPs in the PCC of OPAH in future studies.

Furthermore, the implications of interviewing older people in dyads with a family member in future research may enhance the depth of experiences shared.

7.4 Intended Impact and Dissemination Plan

At the outset of this study the research seed of my own personal negative experience of perceived non-person-centred approaches was shared. My intention was to explore PCC experiences in OPAH care, with the hope that new knowledge could make a positive difference to PCC experiences in the future. Such was the initial intended impact. The Research Councils UK (RCUK) defines impact in two categories:

> ***Academic impact***
>
> *The demonstrable contribution that excellent research makes to academic advances, across and within disciplines, including significant advances in understanding, methods, theory and application.*
>
> ***Economic and societal impacts***
>
> *The demonstrable contribution that excellent research makes to society and the economy. Economic and societal impacts embrace all the extremely diverse ways in which research-related knowledge and skills benefit individuals, organisations and nations by:*
> *fostering global economic performance, and specifically the economic competitiveness of the United Kingdom,*
> *increasing the effectiveness of public services and policy,*
> *enhancing quality of life, health and creative output."*
>
> (RCUK 2018)

It is intended that the knowledge gained from this research will be transferred into academic and clinical practice.

The UK Research and Innovation body (2018) and the Economic and Social Research Council (ESRC. 2015) recommends early plans are made in research strategies for knowledge transfer and impact. According to Bastow, Dunleavy and Tinkler (2014), impact is sub divided into traditional *academic groups, middle mediation* and *external society* (Table 7.1).

Table 7.1 Knowledge Transfer Impact Plan

Academic Groups	Middle Mediators	External Society
Robert Gordon University *School of Nursing and Midwifery* *Graduate School* *Other schools of Nursing in Scotland, UK and internationally* *NHS Education for Scotland* *Wider MDT Educational institutions, UK and Internationally*	*NHS Grampian* *NHS in Scotland* *Healthcare Improvement Scotland* *Scottish Government PCC leads*	*Older people who will use acute healthcare* *Older people in Scotland, and UK*

To date, the research findings have been presented and delivered to academic groups at RGU, School of Nursing and Midwifery (May 2019) and the wider RGU Graduate School Student body (June 2019).

Further presentations have been delivered locally, sharing the findings with the MDT in the specific OPAH research setting (June 2019). Additionally, presentations to the wider NHS area at an annual *Celebrating Excellence* Event (July 2019), the Acute Care Medical Consultants Group (July 2019) and the Medical Registrars CPD meeting (January 2020) have been delivered. The presentation to the Strategic Nursing, Midwifery and Allied Health Professional Executive group is currently postponed due to the Covid19 pandemic. There have been tentative plans made with the Director for Innovation in the research setting, to create plans for embedding the findings from the current study into PCC practices in OPAH care. Ideally, there could be post doctorate joint academic and clinical practice projects such as PAR/QI work to further embed the research findings.

As highlighted in the Methods Chapter, a small core group of older people from the public were involved at each stage of this research study. Subsequently a short lay person's summary of the research findings (see appendix 16) has been shared with them and likewise with all participants who took part in the study.

Beyond the local area, key PCC leaders and champions in NES and at the Scottish Government will be contacted to share the findings of the research. This will be completed once the completed thesis has been submitted for examination.

On completion of the study writing process, a publication plan (appendix 20) intends to ensure the dissemination of findings to widen the academic and societal impact of the research. Alongside this, a plan to submit abstracts to the RCN International Research Conference (2020) and other appropriate arenas as advised by the academic supervisory team. However, the current Covid19 pandemic is likely to impact on this aspect of dissemination. Conference presentations and meetings may have to become virtual online presentations or postponed until public arena type meetings are permitted again. The underlying intention of this dissemination plan is that healthcare practitioners, educators and scholars will consider the importance of the specific relational precursors to PCC. Additionally, another intended impact from disseminating this study is that, PCC for OPAH could be viewed more flexibly, where the MDT may feel they have evidence to support a *caring for* approach in a flexible model of participatory PCC, if this is the older person's preference.

7.5 Personal Reflection

13.9.19

I cannot believe how hard I found it to write the concluding chapter of this   I cannot wait for this marathon journey to be complete, but there is such a mix of emotions:

Exhausted with the juggle of home, family, work and study.

Joy, I have a complete thesis!

Trepidation…Will the study meet the external examiners expectations?

Concern, have I met my objectives? Am I adding to the PCC knowledge base? Will my research make the difference I hope it will? Have I done Jack's journey justice?

Even once the study is complete, the viva is over, graduation (which I can now visualise!) I now see this will not be the end but will be the beginning of using the doctorate to have an impact.

Gratitude must be shared with the all research participants; personal thanks were offered at the time of data collection however, at the completion of this thesis. I am once more overcome with what a privilege it was to have had access into the personal and professional worlds of: Davina, David, Nurse Sarah; Douglas, Nurse Yvonne; George, Phyllis, Nurse Nicola; Grace, Catherine, Nurse Kathy and Dr Isobel. Without you, none of this scholarly, deeply personal marathon journey, the subsequent insights and contributions to the PCC evidence base would have been possible. Thank you.

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APPENDICES

Appendix 1 Literature Search Terms

Databases/Search engines	Search Terms
CINAHL (Cumulative Index to Nursing and Allied Health Literature) MEDLINE Cochrane Library (Reviews, Protocols and Clinical Trials)	(“person centered care" or "person centred care" or “person-centered care” or “person-centred care" or “patient centred care" or "patient centered care") or “patient-centered care” or “patient-centred care”) AND (MH “aged”) or "older people" or "older adult*" or geriatric* or elderly) AND (MH “hospitals”) or hospital* or "acute setting" or inpatient or ward* AND (MH “nurses”) or “nurse” or “nurses” or “nursing” or (MH “physicians”) or physicians or “doctor*” or “medical staff” or “multidisciplinary team” or (MH “allied health personnel”) or “allied healthcare professional*” AND (MH “life experiences”) or “life experiences” or “experiences” or (MH “perception”) or perception* or (MH “attitude”) or attitude* or “view* NOT (MH “dementia”) or dementia or (MH “alzheimer’s disease”) or alzheimer* or "cognitive impairment*" or "cognitive decline")
Science Direct Psychinfo Soc Index	**Search Term** “person centered care" or "person centred care" or "patient centred care" or "patient centered care **Keywords in abstracts** “older people" or "older adult" or geriatric or elderly AND hospital or "acute setting" or “inpatient or ward”

Appendix 2 RGU School of Nursing & Midwifery Ethical Review Panel (SERP) Approval confirmation

Katrina Whittingham
DPP student
School of Nursing and Midwifery
Robert Gordon University

28th July 2017

Research proposal number: 17-14

Dear Katrina,

Research proposal name: The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT).

The School of Nursing and Midwifery Ethics Review panel has now reviewed the above research proposal. Please find details of the outcome and recommended actions below.

Your proposal has been approved. You may go ahead with your research, providing approval from any relevant external committee/s has been obtained.*

* Where the project involves NHS patients, approval through the NRES system must be obtained.

Where the project involves NHS staff, approval through the NHS R&D Office must be obtained.

Members of the School Panel can advise on this process if necessary.

Comments

Thank you very much for supplying your amended documents for your study to SERP. We are pleased to provide approval for your study to proceed. There are, however, a couple of additional points below to consider. We will not need to review again but you should provide finalised versions to SERP.

As reviewers, we have had some discussion about whether it is appropriate for the GP to be informed of participation for any of your sample group. We do not believe it is, and are confident you will be able to support people and to signpost them where necessary. The purpose for contacting the GP, or what a GP would do with such information has never been clear. We advise you remove from all you documents anything related to contacting the GP.

There is a small wording change still to be made in the MDT member demographic information questions: the question on duration of experience in elderly care as it is still unclear.

We look forward to hearing how you progress with data collection and analysis of your data. Your findings will be of great interest to School staff, colleagues in practice settings, and a wider audience.

SERP is available to support you at all stages of your study, so please do not hesitate to discuss with us any further ethical concerns or protocol changes you may wish to make.

Yours sincerely

Audrey I. Stephen

Panel member 1

Position held: SERP convenor/Research Fellow

M. Bain

Panel member 2

Position held: Senior Lecturer

If you require further information please contact the Panel Convenor, Audrey Stephen, on 01224 263150.

Dr Audrey Stephen

School of Nursing and Midwifery

Robert Gordon University

Garthdee Road

Aberdeen

AB10 7QG

Email: a.i.stephen@rgu.ac.uk

Appendix 3 RGU Graduate School ‘Research Ethics Self-Assessment’ (RESA) Confirmation approval

ROBERT GORDON
UNIVERSITY ABERDEEN

OFFICE OF THE VICE-PRINCIPAL RESEARCH
RESEARCH STRATEGY AND POLICY
Robert Gordon University
Garthdee House
Garthdee Road
Aberdeen
AB10 7QE
United Kingdom
Tel: +44 (0)1224 263750
Email: p.hagan@rgu.ac.uk
www.rgu.ac.uk

8 November 2017

Dear Sir or Madam

Ref: "The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT)"

In my capacity as Vice Principal for Research, I write to advise you that the University is pleased to sponsor the project entitled "The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT)".

The project will be conducted by Katrina Whittingham of the School of Nursing and Midwifery under the supervision of Dr Kay Cooper and Dr Fiona Work. This letter acts as confirmation of the University's support.

I trust that this provides the necessary reassurance to accompany the study's IRAS Ethics application and NHS Grampian R&D application.

Yours faithfully

Paul Hagan

Professor Paul Hagan FRSE
Vice-Principal (Research)

INVESTOR IN PEOPLE

Vice-Principal Research
Professor Paul Hagan
FRSE

Appendix 4 Integrated Research Application System (IRAS) Approval

Page 1

North West - Liverpool Central Research Ethics Committee
3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ
Telephone: 020 71048008

22 December 2017
Mrs Katrina.A. Whittingham
Lecturer in Nursing/ Doctorate of Professional Practice Student
Robert Gordon University
School of Nursing & Midwifery
Garthdee Campus
Garthdee Road, Aberdeen
AB107QG

Dear Mrs Whittingham **Study title:** **The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT).**
REC reference: **17/NW/0700**
IRAS project ID: **234721**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation. .
The further information has been considered on behalf of the Committee by the Chair.
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study. Page 2

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below). Page 3

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]	1	01 August 2017
Interview schedules or topic guides for participants [Interview Prompts]	5	05 June 2017
IRAS Application Form [IRAS_Form_28112017]		28 November 2017
IRAS Application Form XML file [IRAS_Form_28112017]		28 November 2017
Letter from sponsor [Sponsor Letter]	1	08 November 2017
Letters of invitation to participant [Pre consent Sheet]	5	05 June 2017
Other [3rd Supervisor CV]	1	16 October 2017
Other [2nd Supervisor CV]	1	15 September 2017
Other [Patient Interview Prompts]	5	15 May 2017
Other [RGU Lone Working Policy]	2	05 October 2017
Other [RGU Lone Working Authorised Activites Form]	2	05 October 2017
Other [Responses to REC meeting queries]	1	19 December 2017
Participant consent form [Consent Sheets]	7	16 December 2017
Participant information sheet (PIS) [Participant Information Sheets]	6	16 December 2017
Referee's report or other scientific critique report [School of Nursing & Midwifery Ethical Approval]	1	28 July 2017
Research protocol or project proposal [Proposal to go to IRAS]	2	28 August 2017
Sample diary card/patient card [Diary structure]	5	05 June 2017
Summary CV for Chief Investigator (CI) [Katrina Whittingham CV]	1	16 September 2017
Summary CV for supervisor (student research) [Fiona Work CV]	1	15 September 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [PCC OPAH Flowchart]	1	10 September 2017

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/ **17/NW/0700 Please quote this number on all correspondence**

Yours sincerely
Mrs Julie Brake
Chair
Email:nrescommittee.northwest-liverpoolcentral@nhs.net

Enclosures: “After ethical review – guidance for researchers” *Copy to:* *Ms Jill Johnston*
Dr Susan Ridge , NHS Grampian

Appendix 5 Process for Follow Up Support

Post Research Support – Older People or Family Participants

Person Centred Care for Older People in Acute Care

Thank you for taking part in the Person Centred Care for Older People in Acute Care research. Your contributions are highly valuable to the study and to me as a student.

If you feel emotionally upset following taking part in this research you can contact you GP

Dr

Contact Details:

Alternatively you can contact NHS Grampian directly to give them feedback on your experience.

You can contact them to praise staff, comment on our standards of care or let them know your views on any other aspect of NHS services in Grampian by the following:

Post:

NHS Grampian Feedback Service
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Tel: 0345 337 6338

E-mail nhsgrampian.feedback@nhs.net

The Feedback Service is open during the office hours of Monday to Friday 9:00am to 5:00pm.

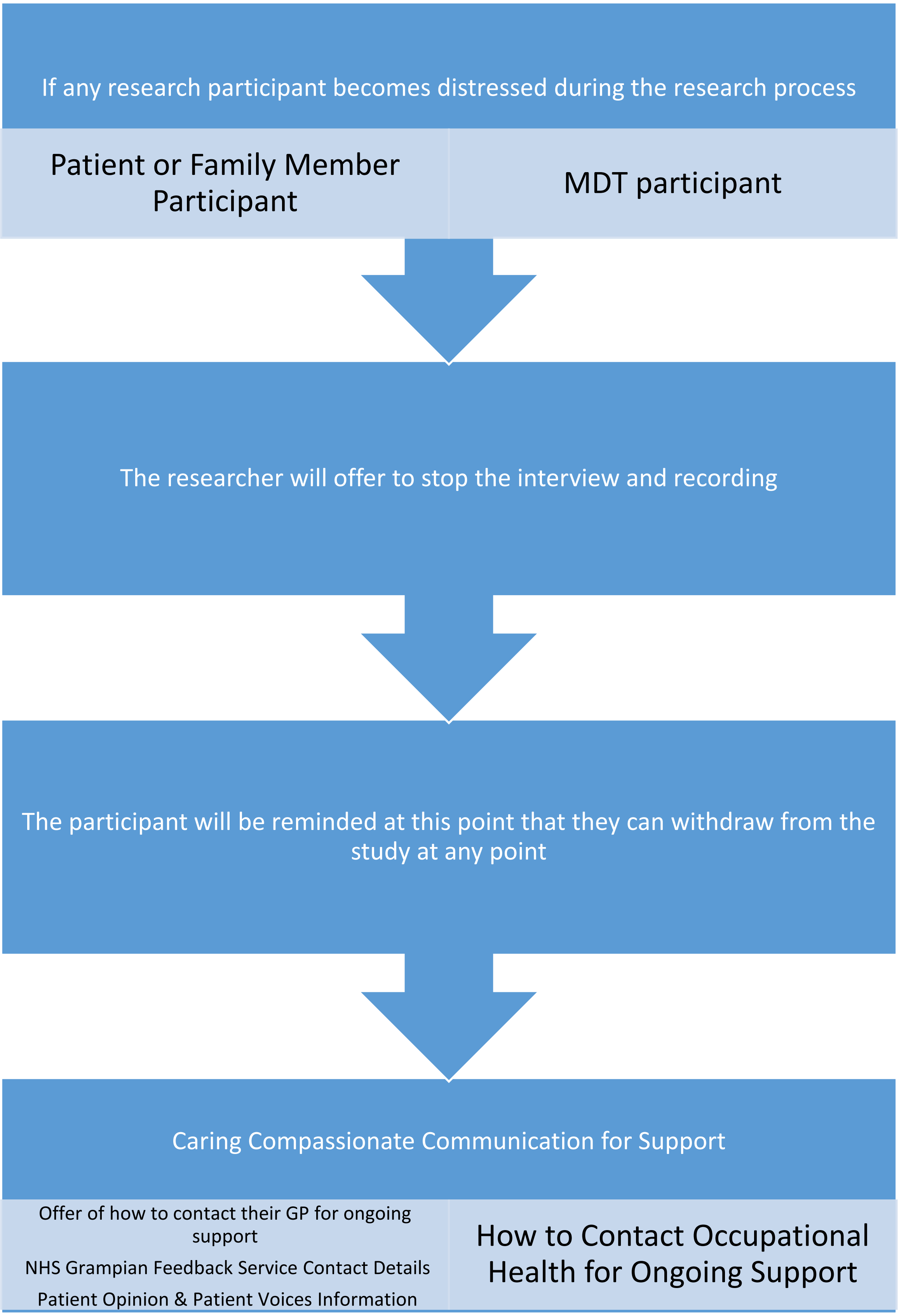
Post Research Support – MDT Participants

Person Centred Care for Older People in Acute Care

Thank you for taking part in the Person Centred Care for Older People in Acute Care research. Your contributions are highly valuable to the study and to me as a student.

If you feel emotionally upset following taking part in this research you can contact NHS Grampian Occupational Health Services for support on 01224 553663, they are open Monday – Friday 9 am – 5pm.

- If any research participant becomes distressed during the research process



If any research participant becomes distressed during the research process

Patient or Family Member Participant

MDT participant

The researcher will offer to stop the interview and recording

The participant will be reminded at this point that they can withdraw from the study at any point

Caring Compassionate Communication for Support

Offer of how to contact their GP for ongoing support

NHS Grampian Feedback Service Contact Details

Patient Opinion & Patient Voices Information

How to Contact Occupational Health for Ongoing Support

Appendix 6 Duty of Candour Process

ESCALATION OF CONCERNS IN RELATION TO PROFESSIONAL DUTY & DUTY OF CANDOUR

As the researcher is a registered nurse she has a professional responsibility to raise concerns about errors in care and or unsafe care practices is these are disclosed during the research process. This is particularly important since one of the groups of research participants, older people are considered to be vulnerable adults. Therefore if any unsafe practices are revealed during the research process the following actions will be taken.

Errors in care and or Unsafe care practices revealed in diaries or in interviews. Research partipants informed that the researcher will be escalating these concerns.

Written report sent to the nurse manager for the research area for further investigation within 1 working day. Confidentiality of participants maintained.

Investigation carried out, NHS board area processes followed and areas for improvements, lessons learnt put into place.

Appendix 6 Copy of email from Chief Nurse endorsing the study

Dear Katrina,

I can confirm that I am supportive and consent for you to undertake doctorate research on Person Centred Care for Older people in Acute Care in the GAU in ARI. I have copied Ruth Jones as Nurse Manager and Fiona Robertson as Chief Nurse.

Kind regards,

Caroline

Caroline Hiscox

Deputy Director of Nursing & Midwifery NHS Grampian

NHS Grampian

Room 3.01

Ashgrove House

Aberdeen Royal Infirmary

AB25 2ZA

Extension 54514

Tel : 01224 554514 Mobile : 07883301897

carolinehiscox@nhs.net

PA June Smith

Tel: 01224 553714

june.smith10@nhs.net

Appendix 8 Pre-Consent

Research Study

What matters to you while you are in hospital?

What do we want to know?

We want to find out about what being cared for in hospital has been like for you, your family and the staff looking after you.

The nursing staff on the ward have identified you as someone who could help with this research. The research study will explore person centred care from the point of view of older people who are in hospital, their families and staff providing their care.

If you say yes, you will be asked to keep a diary of your experiences for 3 days while you are here in hospital. You will also be asked to nominate a member of your family who will also be asked to keep a diary of their experiences. Once you are home, the researcher will visit you and your family member to talk through your experiences of being cared for in hospital in more detail. Staff who care for you will also be asked to take part in the research in the same way.

Want to know more?

Contact Katrina Whittingham at k.a.whittingham1@rgu.ac.uk / 01224 262984.

Please sign and print your name on the tear off slip below, to give consent for the nurses to pass your name onto the researcher, who will come and give you more information about the study and then you can decide if you want to get involved.

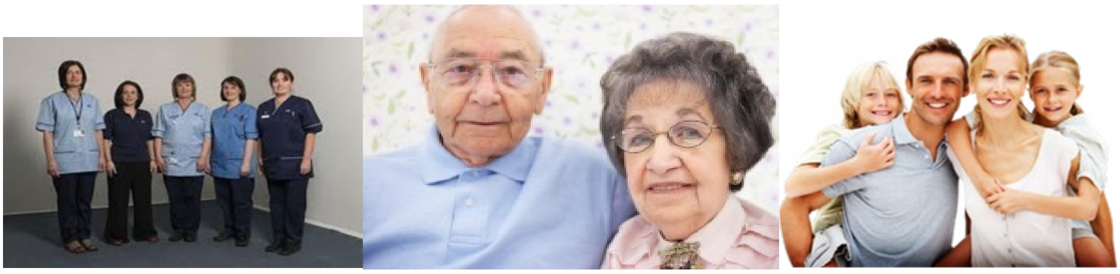
……

Name :	**Date**
Signature:	
Name of person obtaining consent to share:	**Date:**
Signature:	

Appendix 9 Posters to Recruit

Research Study

What matters to you while you are in hospital?



What do we want to know?

We want to find out about what being cared for in hospital has been like for you, your family and the staff looking after you.

The research study will explore person centred care from the point of view of older people who are in hospital, their families and staff providing their care.

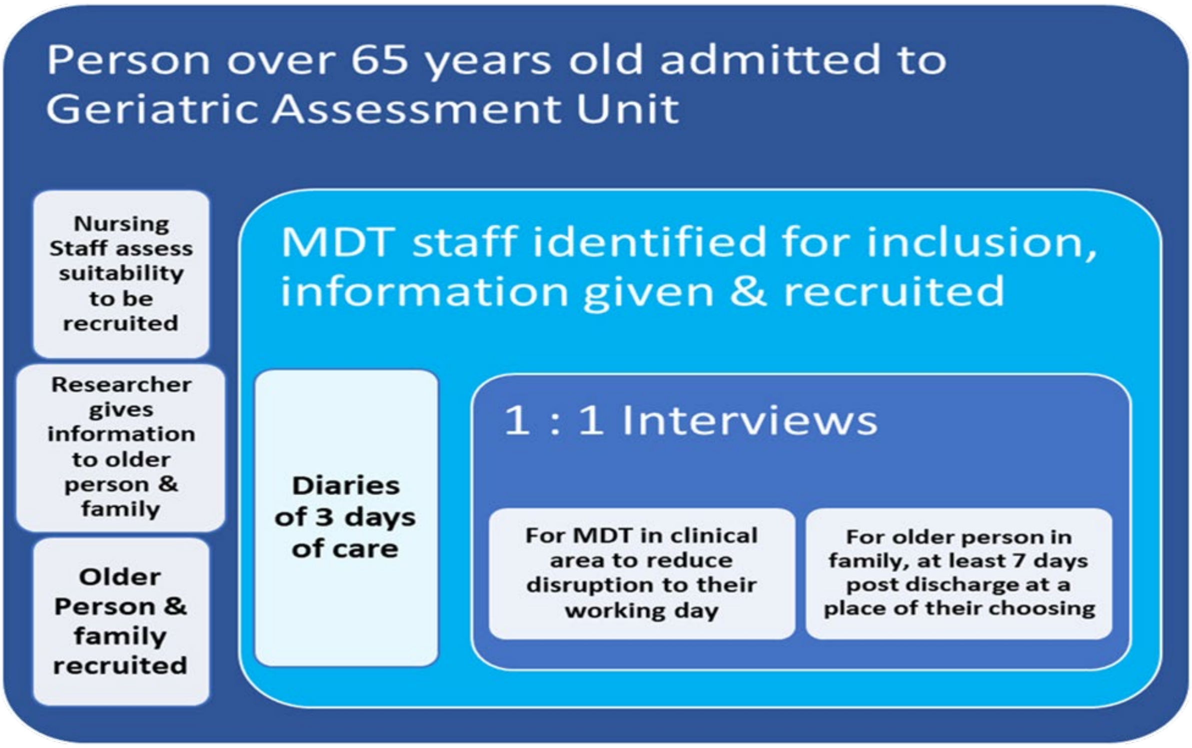
If you want to take part, you will be asked to keep a diary of your experiences for 3 days while you are here in hospital. You will also be asked to nominate a member of your family who will also be asked to keep a diary of their experiences. Once you are home, the researcher will visit you and your family member to talk through your experiences of being cared for in hospital in more detail. Staff who care for you will also be asked to take part in the research in the same way.

Want to know more? Tell any of the nurses

OR

Contact Katrina Whittingham at k.a.whittingham1@rgu.ac.uk / 01224 262984.

Appendix 10 Research Process Flowchart



Person over 65 years old admitted to Geriatric Assessment Unit

Nursing Staff assess suitability to be recruited

Researcher gives information to older person & family

Older Person & family recruited

MDT staff identified for inclusion, information given & recruited

Diaries of 3 days of care

1 : 1 Interviews

For MDT in clinical area to reduce disruption to their working day

For older person in family, at least 7 days post discharge at a place of their choosing

Appendix 11 Patient Participant Information Sheets

INFORMATION SHEET FOR OLDER PERSON PARTICIPANT

Person Centred Care for Older People in Acute Care

Study Title: The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT).

Brief Overview and Invitation

My name is Katrina Whittingham. I am a Nurse Lecturer at Robert Gordon University (RGU). As part of my studies, I am carrying out a piece of research to find out how older people, their families and staff experience "person centred care" in hospital. You are invited to participate in this piece of research that I am undertaking. This information sheet may help you to decide whether you would like to do so. Feel free to discuss your decision with others. I will return tomorrow and will be happy to answer any questions then.

Background

Person centred care is important for helping to ensure that your personal care needs are met in a respectful, dignified and compassionate way. This can mean working with you, towards achieving what is important to you.

What is the purpose of this study?

The purpose of this study is to explore how person-centred you feel the care that you have been given whilst in hospital has been for you, your family and the staff looking after you. The intention is that your shared experience will enhance understanding of how person centred care is being provided in clinical practice. Finding out about your experiences and thoughts in this way could help hospital staff to give good quality person centred care and will help educators to teach student nurses person centred care more effectively.

Why have I been chosen?

You have been chosen because you have been admitted to the Geriatric Assessment Unit and we are inviting people of a similar age group to you to take part in this research.

Do I have to take part?

No. The choice is yours and you have at least 24 hours - longer if you would like it - to think it over. You can decline without giving a reason and this will have no impact on the care you receive.

What will happen to me if I take part?

You will be asked to sign a consent form and another form telling me a bit about you.

As part of the research, you will be asked to fill out a diary (whilst you are still on the ward) and take part in an interview with me, once you have returned home, to talk about your experiences of your care.

- Diary – you will be asked to fill this out for one - three days during your hospital stay. This can either be written, typed on your own electronic device of your choice then e mailed to me on paper or using a voice recorder to speak into if you preferred. When you have completed your diary entries, or you are well enough to go home, you can return the diary in a sealed stamped addressed envelope that I will provide or I will collect it from you on the ward.
- Interview – around one week after you are home I will call to arrange a convenient time and place to visit you and to talk more about your experiences of being in hospital. This will take no longer than 1 hour of your time. I will use a tape recorder to record our interview so that I have an accurate record of your experiences. You can choose whether to have this interview alone or with your family member who is also involved in the study. Although I may use quotes from our conversation in my research, personal details will be changed so that you cannot be identified.

If you reveal any errors in your care or unsafe practices I have a duty to inform the senior nurse for the research area about this, so that this can be further investigated, apologies made and lessons learned for the future.

I will also ask you to nominate a member of your family who may be willing to be involved in the research study too. I will ask two members of staff from the ward who are caring for you to be involved in the study too.

What are the possible benefits of taking part?

Your experiences, both positive and negative, will help to understand how you experienced "person centred care". Whilst there may not be a direct benefit to you, you may find it helpful or therapeutic to have someone to talk to about your experiences of being in hospital. The findings will also be useful for helping to ensure good quality person centred care is delivered and will help educators to teach student nurses person centred care more effectively.

What are the possible disadvantages and risks of taking part?

You may find that thinking about your time in hospital is an upsetting reminder of being unwell. If you wish, you can have a family member present with you for support. As an experienced nurse I will support you throughout the research process. If at any time you become distressed, emotional, upset or tearful, you can stop recording your experiences. When I am visiting you in your home I will offer to stop the interview and recording, if this upsets you in anyway. You can withdraw from the study at any point. If you remain upset, I will ensure you know how to contact your GP or sources of support within NHS Grampian's services for further on-going support.

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. When you consent to take part in the study, you will be given a unique identification number so that it is not possible to identify anyone by name. All information that is collected from you will be stored securely within the School of Nursing and Midwifery, RGU for ten years. Personal data will be deleted within 12 months. If you withdraw from the study, I will delete any identifiable information relating to you. If you agree, information collected until your withdrawal will be used in the analysis.

Who has reviewed this study?

The study has been approved by the RGU School of Nursing & Midwifery Ethical Review Panel, Research and Development and NHS Grampian's Ethics Committee. Their role is to ensure that research is properly conducted and the interests of those taking part are protected.

What happens to the results?

At the end of the study, the results will be used to write a doctorate thesis. You will receive a lay summary of the research findings. The research findings will be shared with the staff on the ward you were in, wider within NHS Grampian and RGU. The results will be submitted for publication in a healthcare education journal and presented at conferences relating to healthcare and healthcare education.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study. For enquiries please contact:

Katrina Whittingham - 01224 262984/ k.a.whittingham1@rgu.ac.uk

Alternative Contact

If you wish to discuss any matters relating to this research with someone out with the research team, Sundari Joseph, who oversees all programmes of study relating to research can be contacted on 01224 262975/ s.joseph@rgu.ac.uk

Appendix 12 Family Participant Information Sheets

INFORMATION SHEET FOR FAMILY PARTICIPANT

Person Centred Care for Older People in Acute Care

Study Title

The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT).

Brief Overview and Invitation

My name is Katrina Whittingham. I am a Nurse Lecturer at Robert Gordon University (RGU). As part of my studies, I am carrying out a piece of research to find out how older people, their families and staff experience “person centred care” in hospital. You are invited to participate in this piece of research that I am undertaking. This information sheet may help you to decide whether you would like to do so. Feel free to discuss your decision with others. I will return tomorrow and will be happy to answer any questions then.

Background

Person centred care is important for helping to ensure that your personal care needs are met in a respectful, dignified and compassionate way. This can mean working with you, towards achieving what is important to you.

What is the purpose of this study?

The purpose of this study is to explore how person-centred you feel the care that you have been given whilst in hospital has been for you, your family and the staff looking after you. The intention is that your shared experience will enhance understanding of how person centred care is being provided in clinical practice. Finding out about your experiences and thoughts in this way could help hospital staff to give good quality person centred care and will help educators to teach student nurses person centred care more effectively.

Why have I been chosen?

You have been chosen as your family member who is a patient in the Geriatric Assessment Unit has nominated you to take part in this study, your experiences are important and very relevant to the research.

Do I have to take part?

No. The choice is yours and you have at least 24 hours - longer if you would like it - to think it over. You can decline without giving a reason and this will have no impact on the care your member of family receives.

What will happen to me if I take part?

You will be asked to sign a consent form and another form telling me a bit about you. As part of the research, you will be asked to fill out a diary (whilst your family member is still on the ward) and take part in an interview with me, once your family member has returned home, to talk about your experiences of their care.

- Diary – you will be asked to fill this out for one - three days of your family member's hospital stay. This can either be written on paper or typed on your own electronic device of your choice then e mailed to me or using a voice recorder to speak into if you preferred. When you have completed your diary entries, or you are well enough to go home, you can return the diary in a sealed stamped addressed envelope that I will provide or I will collect it from you on the ward.
- Interview – around one week after you are home I will call to arrange a convenient time and place to visit you and to talk more about your experiences of having a family member in hospital. This will take no longer than 1 hour of your time. I will use a tape recorder to record our interview so that I have an accurate record of your experiences. You can choose whether to have this interview alone or with your family member who is also involved in the study. Although I may use quotes from our conversation in my research, personal details will be changed so that you cannot be identified.

If you reveal any errors in your care or unsafe practices I have a duty to inform the senior nurse for the research area about this, so that this can be further investigated, apologies made and lessons learned for the future.

What are the possible benefits of taking part?

Your experiences, both positive and negative of "person centred care" of your family member will help develop an understanding of this experience. Whilst there may not be a direct benefit to you, you may find it helpful or therapeutic to have someone to talk to about your experiences of your family member being in hospital. The findings will also be useful for helping to ensure good quality person centred care is delivered and will help educators to teach student nurses person centred care more effectively.

What are the possible disadvantages and risks of taking part?

You may find that thinking about the time your family member was in hospital is an upsetting reminder of them being unwell. If you wish, you can have a family member present with you for support. As an experienced nurse I will support you throughout the research process. If at any time you become distressed, emotional, upset or tearful, you can stop recording your experiences. When I am visiting you in your home I will offer to stop the interview and recording, if this upsets you in anyway. You can withdraw from the study at any point. If you remain upset, I will ensure you know how to contact your GP or sources of support within NHS Grampian's services for further on-going support.

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. When you consent to take part in the study, you will be given a unique identification number so that it is not possible to identify anyone by name. All information that is collected from you will be stored securely within the School of Nursing and Midwifery, RGU for ten years. Personal data will be deleted within 12 months. If you withdraw from the study, I will delete any identifiable information relating to you. If you agree, information collected until your withdrawal will be used in the analysis.

Who has reviewed this study?

The study has been approved by the RGU School of Nursing & Midwifery Ethical Review Panel, Research and Development and NHS Grampian's Ethics Committee. Their role is to ensure that research is properly conducted and the interests of those taking part are protected.

What happens to the results?

At the end of the study, the results will be used to write a doctorate thesis. You will receive a lay summary of the research findings. The research findings will be shared with the staff on the ward you were in, wider within NHS Grampian and RGU. The results will be submitted for publication in a healthcare education journal and presented at conferences relating to healthcare and healthcare education.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study. For enquiries please contact:

Katrina Whittingham - 01224 262984/ k.a.whittingham1@rgu.ac.uk

Alternative Contact

If you wish to discuss any matters relating to this research with someone out with the research team, Sundari Joseph, who oversees all programmes of study relating to research can be contacted on 01224 262975/ s.joseph@rgu.ac.uk

Appendix 13 Patient Participant Consent Sheet

ROBERT GORDON UNIVERSITY ABERDEEN

Title of Project: The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Healthcare Team (MDT).

Name of Researcher: Katrina Whittingham

Participant Identification Number for this study:

Contact Number for setting up interview:

Please initial box

1. I confirm that I have read the information sheet dated.................. (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. [Please note: if you withdraw, permission will be sought to use any data collected up until that time].	
3. I understand that I will be asked to nominate a family member who will be asked to participate in this research.	
4. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers, clinicians and student nurses.	
5. I understand I will be asked to complete a diary for up to three days whilst I am in hospital and asked to take part in a face to face interview.	
6. I understand that the researcher will look at my nursing and medical notes to identify a staff member who has looked after me to ask them to participate in this research	
7. I understand that if unsafe care practices come to light during the study then the researcher has a duty of care to inform appropriate staff and ensure that this is followed up.	
8. I understand that I can contact my GP if I need further support as a consequence of being involved in this study.	
9. I understand that direct quotes from the data collected may be used in the researcher’s thesis, subsequent publications and conference presentations but it will not be possible to identify any individuals from any of these.	
10. It is with the understanding that all of the above conditions are met that I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 14 Consent Form – Family Member

ROBERT GORDON UNIVERSITY ABERDEEN

Title of Project: The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Healthcare Team (MDT).

Name of Researcher: Katrina Whittingham

Participant Identification Number for this study:

Contact Number for setting up interview:

Please initial box

1. I confirm that I have read the information sheet dated................... (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. [Please note: if you withdraw, permission will be sought to use any data collected up until that time].	
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers, clinicians and student nurses.	
4. I understand I will be asked to complete a diary for up to three days of the time that my family member is in hospital and asked to take part in a face to face interview.	
5. I understand that the researcher will look at my nursing and medical notes to identify a staff member who has looked after me to ask them to participate in this research	
6. I understand that if unsafe care practices come to light during the study then the researcher has a duty of care to inform appropriate staff and ensure that this is followed up.	
7. I understand my GP will be informed that I have taken part in this study and with further discussion may be contacted if I need further support as a consequence of being involved in this study.	
8. I understand that direct quotes from the data collected may be used in the researcher's thesis, subsequent publications and conference presentations but it will not be possible to identify any individuals from any of these.	
9. It is with the understanding that all of the above conditions are met that I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 15 Information Sheet for Multidisciplinary Team Member Participant

Person Centred Care for Older People in Acute Care

Study Title
The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Team (MDT).

Brief Overview and Invitation
My name is Katrina Whittingham. I am a Nurse Lecturer at Robert Gordon University (RGU). As part of my studies, I am carrying out a piece of research to find out how older people, their families and staff experience "person centred care" in hospital. You are invited to participate in this piece of research that I am undertaking. This information sheet may help you to decide whether you would like to do so. Feel free to discuss your decision with others. I will return tomorrow and will be happy to answer any questions then.

Background
You will be familiar with the term Person centred care as a way of delivering care in a respectful, dignified and compassionate way. This can mean working with patients, towards achieving what is important to them.

What is the purpose of this study?
The purpose of this study is to explore the experience of older people being in acute hospital. The intention is that your shared experience will enhance understanding of how "person centred care" is being provided in clinical practice. Sharing this new knowledge could help hospital staff to ensure good quality person centred care is delivered and will help educators to teach student nurses person centred care more effectively.

Why have I been chosen?
You have been chosen as a member of the MDT of this ward who is caring for an older person who has agreed to take part in this study, your experiences are important and very relevant to the research.

Do I have to take part?
No. The choice is yours and you have at least 24 hours - longer if you would like it - to think it over. You can decline without giving a reason.

What will happen to me if I take part?
You will be asked to sign a consent form and another form telling me a bit about you. As part of the research, you will be asked to fill out a diary (while you are caring for the patient who has volunteered to take part is on the ward) and take part in an interview with me, once the patient has been discharged home, to talk about your experiences of delivering their care.

- Diary – you will be asked to fill this out for one - three days of your care delivery to the patient who has volunteered to take part in the study. This can either be written on paper, typed on your own electronic device of your choice then emailed to me or using a voice recorder to speak into if you prefer. When you have completed your diary entries, or the patient has been discharged, you can return the diary in a sealed stamped addressed envelope that I will provide or I will collect it from you on the ward.

- Interview – once the patient has been discharged, I will call to arrange a convenient time to meet you near to your work place and to talk more about your experiences of delivering care to the patient who has volunteered to take part in this study. This will take no longer than 1 hour of your time. I will use a tape recorder to record our interview so that I have an accurate record of your experiences. Although I may use quotes from our conversation in my research, personal details will be changed so that you cannot be identified.

If you reveal any errors in your care or unsafe practices I have a duty to inform the senior nurse for the research area about this, so that this can be further investigated, apologies made and lessons learned for the future.

What are the possible benefits of taking part?
Your experiences, both positive and negative, will help to understand how you experienced the delivery of "person centred care" from your perspective. Whilst there may not be a direct benefit to you, you may feel good that sharing your experiences and considering that this may help hospital staff to ensure good quality person centred care is delivered and may help educators to teach student nurses person centred care more effectively.

What are the possible disadvantages and risks of taking part?
You may find re-visiting your time caring for this specific older person upsetting. As an experienced nurse I will support you throughout the interview process. If at any time you become distressed, emotional, upset or tearful, you can stop recording your experiences. When I am carrying out the face to face interview, I will offer to stop the interview and recording, if this upsets you in anyway. You can withdraw from the study at any point. If you remain upset, I will ensure that you can contact Occupational Health or sources of support within NHS Grampian's services.

Will my taking part in the study be kept confidential?
Yes, all the information about your participation in this study will be kept confidential. It will be stored securely within the School of Nursing and Midwifery, RGU, for ten years. Personal data will be deleted within 12 months. If you withdraw from the study, I will delete any identifiable information relating to you. If you agree, information collected until your withdrawal will be used in the analysis.

Who has reviewed this study?
The study has been approved by the RGU School of Nursing & Midwifery Ethical Review Panel, Research and Development and NHS Grampian's Ethics Committee. Their role is to ensure that research is properly conducted and the interests of those taking part are protected.

What happens to the results?
At the end of the study, the results will be used to write a doctorate thesis. The research findings will be shared with the staff on your ward and wider in NHS Grampian and RGU. They will be submitted for publication in a healthcare education journal and presented at conferences relating to healthcare and healthcare education.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study. For enquiries please contact:
Katrina Whittingham - 01224 262984/ k.a.whittingham1@rgu.ac.uk

Alternative Contact
If you wish to discuss any matters relating to this research with someone out with the research team, Sundari Joseph, who oversees all programmes of study relating to research can be contacted on 01224 262975/ s.joseph@rgu.ac.uk

Appendix 16 MDT Participant Consent Sheet

Title of Project: The lived experience of Person Centred Care (PCC): Giving a voice to older people in acute hospital care, their families and the Multidisciplinary Healthcare Team (MDT).

Name of Researcher: Katrina Whittingham

Participant Identification Number for this study:

Contact Number for setting up interview:

Please initial box to confirm your consent to each point below	
1. I confirm that I have read the information sheet dated................... (version...........) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without legal rights being affected. [Please note: if you withdraw, permission will be sought to use any data collected up until that time].	
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with the public involvement group who informed the research, other researchers, clinicians and student nurses.	
4. I understand I will be asked to complete a diary for up to three days of caring for the patient volunteer in the study in hospital and asked to take part in a face to face interview.	
5. I understand that the interview I take part in will be audio recorded.	
6. I understand that if unsafe care practices come to light during the study then the researcher has a duty of care to inform appropriate staff and ensure that this is followed up.	
7. I understand that direct quotes from the data collected may be used in the researcher's thesis, subsequent publications and conference presentations but it will not be possible to identify any individuals from any of these.	
8. It is with the understanding that all of the above conditions are met that I agree to take part in the above study.	
9. I have decided to withdraw from the study on …… (date), I do/do not (delete as appropriate) consent to information shared so far to be included in this study.	

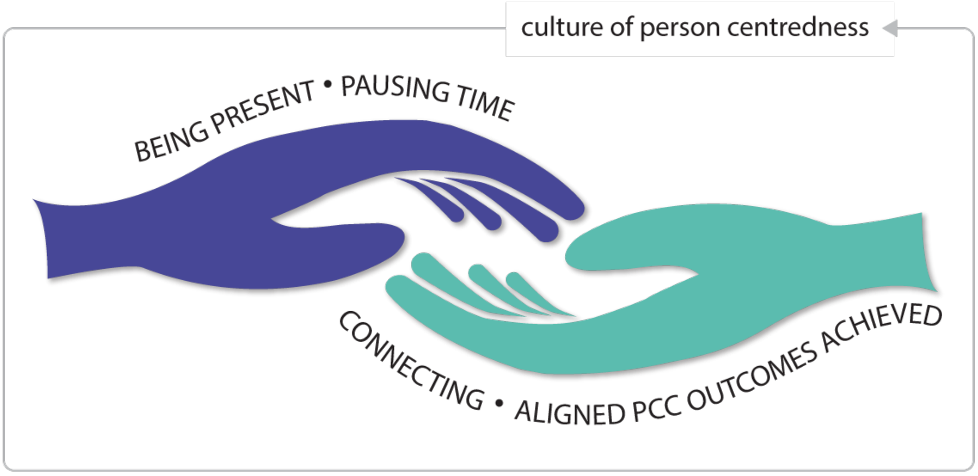
Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 17 Lay Summary

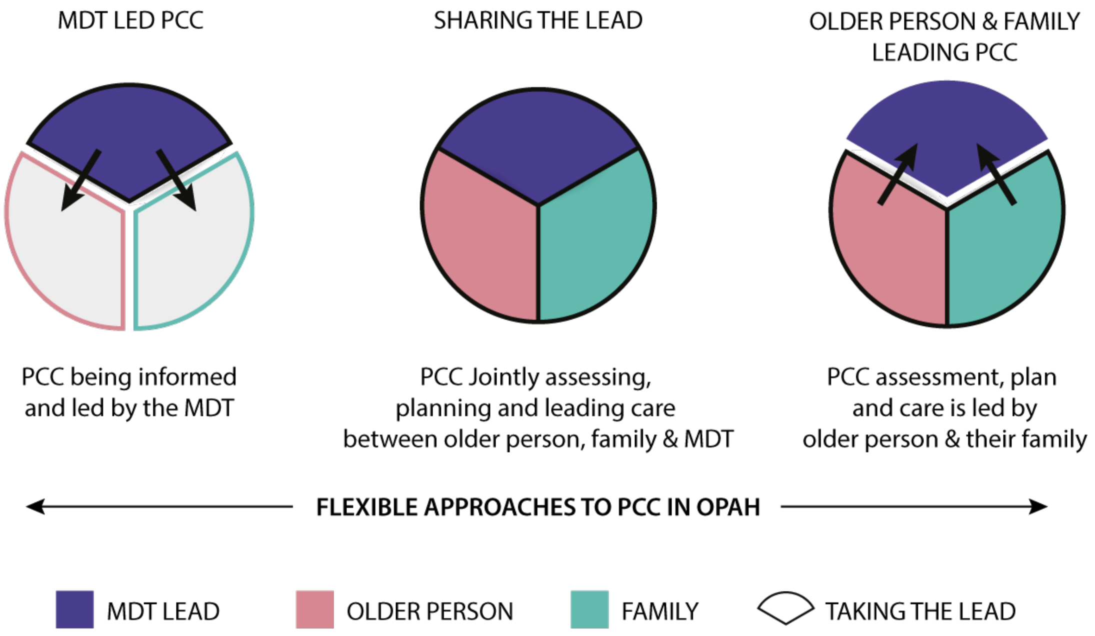
This study of Person Centred Care was conducted by a researcher who is a university nurse educator with an intense interest in inspiring person centred care practices and was motivated primarily in response to a significantly challenging personal experience where an older loved one received non-person centred care. The 6-year Doctorate of Professional Practice was completed alongside working almost full time as a nurse lecturer.

Globally, people are living longer and those over the age of 65 are often found to occupy more of the beds in acute hospital care than younger people. Around the world efforts have been made to ensure people receiving healthcare, along with their families, are more involved in their care. Scotland is viewed internationally as a world leader in promoting Person Centred Care, where those receiving care are *actively* involved in all aspects of their care. This study explored the experiences of receiving or delivering acute care from the perspectives of older people, their family and care staff, in four wards that made up a Medicine for Elderly area, in a large NHS Acute hospital in North East Scotland. Eleven people took part, three older people, three family members and five members of staff. The individuals who participated each kept a 3-day diary of the care they either received or provided and took part in face to face interviews.

Data was collected between February and August 2018, analysed throughout 2019 and the associated doctoral thesis was completed in 2020. The study found that for Person Centred Care to be experienced, time had to be spent building relationships between older people/their family and staff. Pausing time on busy acute care areas, to connect and then tailor care around the uniqueness of older people and their families, was found to be essential. In the main, older people and their families shared positive experiences of care they believed was individualised to them. However, at times individual staff members and hospital systems did not meet their care expectations.



For those involved, Person Centred Care was uncovered as a combined approach of caring *about, for and with* older people and their families. Notably, Person Centred Care did not always mean being *actively* involved in care decisions for the individuals who took part in this study. At times Person Centred Care meant healthcare plans and decisions being led by Multi disciplinary Team(MDT) rather than older people and their families. As a result, this study recommends the following model of Person Centred Care for older people in acute care.



Appendix 18 Structure of Diary

Participant Identification Number for this study:

The purpose of this research is to explore your experiences of person centred care whilst in hospital.

Please feel free to write whatever you feel is important to you. The diary will be used in the interview with the researcher to help you remember what happened to you whilst you were in hospital.

You are free to withdraw from the study at any point and this will have no impact on the care you receive.

Write before lunch

What are you hoping for in terms of your hospital care today?

Write in the evening

In terms of your hospital care today, please write about your day:

What stood out as being good about today, for you?

Anything else you want to add?

Appendix 19 Semi Structured Interview Schedule

Participant Identification Number for this study:

The purpose of this research is to explore your experiences of person centred care whilst having a family member in hospital.
Are you still okay to take part in this study? I will use the prompts I have sent you and your diary entries to guide this conversation and it will be recorded. Are you okay with that?

- How are you feeling, now that your member of family is home?
- Tell me about their stay in hospital?
- Tell me a bit more about (specific areas)?
- Can you give me an example of when you felt their care really met their personal needs?
- Was this an everyday event or unusual?
- Can you explain the reasons this was important to you?
- Can you give me an example of when your care did not meet their individual needs?
- Was this an everyday event or unusual?
- Can you explain the reasons this was important to you?
- Did you feel involved in your family member’s stay in hospital (care or decisions relating to care)?
- If yes, how?
- If no, why?
- What would have helped their hospital stay be more tailored to what mattered to them?
- Before being involved in this research had you heard the term “Person Centred Care”?
- Can you describe for me what you think Person Centred Care means to you?
- Is there anything else you want to add?

Other prompts from the previously completed diary entries will be used to further structure each interview.

ROBERT GORDON UNIVERSITY ABERDEEN

STRUCTURE OF SEMI STRUCTURED INTERVIEWS – MEMBER OF MDT

Participant Identification Number for this study:

The purpose of this research is to explore your experiences of delivering person centred care.
Are you still okay to take part in this study? I will use the prompts I have sent you and your diary entries to guide this conversation and it will be recorded. Are you okay with that?

- How are you today?
- Tell me about this older person's stay in hospital?
- Can you tell me a bit more about that (specifics from diary entries)?
- Can you give me an example of when you felt the care you gave really met their needs?
- Was this an everyday event or unusual?
- Can you explain the reasons this was important to you?
- Can you give me an example of when your care did not meet their needs?
- Was this an everyday event or unusual?
- Can you explain the reasons this was important to you?
- Can you give me an example of when others in the multidisciplinary team gave care that really met this person's needs?
- Was this an everyday event or unusual?
- Can you explain the reasons this was important to you?
- Can you give me an example of the care others in the Multidisciplinary Team gave did not meet their needs?
- Was this an everyday event or unusual?
- Can you explain the reasons this was important to you?
- Before being involved in this research had you heard the term Person Centred Care?
- Can you describe for me what you think Person Centred Care means to you?
- What would have helped you to tailor their time in hospital to be more about to what mattered to most to this person?
- Is there anything else you want to add? Other prompts from the previously completed diary entries will be used to further structure each interview.

Appendix 20 Example Excerpt of Analysed Transcript

Stages of Data Analysis **This excerpt provides the first 5 pages of a 40 part transcript of the interview with David and Davina, in the first 4 stages of data analysis.**		
P1F1 Transcription STAGE 1 Reading and re-reading transcripts		
Initial Thoughts Intuitive Interpretations Reflections	Transcription	Super ordinate Themes Sub Themes
	Just to make sure you're both still okay to take part in the research? Is that okay? *Yes.* Yes. **You're quite happy to be interviewed together?** Yes. *Certainly, yes.* **That's fine. If you can tell me a bit about your time in hospital, so you told me that what happened Davina is you fell in your bathroom and that took you into hospital. Did you go into one ward to start with and then end up moving around? What happened?** Well, I was taken into hospital and they took me for a scan and said there was nothing broken but I was very badly bruised. **Right.** From there, I went to one ward. Now, I can't remember how long I was in there, and then I was shifted to another ward, a wee while in that then I was in the ward where you do a lot of walking on your own. They make you ready for going out.	

	Okay, yes. They were all very, very nice. They couldn't have done more. **Yes.** Very patient. The food, I couldn't eat it all (laughing). Terrific menu. **Yes, lots to choose from.** So, really great. **Yes, good. Were you taken in by ambulance when you fell?** Yes. **Yes. So, when you fell, did you get knocked out, do you remember?** No. **No, and so did you manage to get hold of a phone and phone…?** Well, I got from the bathroom to the phone, yes. *She got the phone and then phoned me and I was up within minutes.* **Yes.** How I got through, I don't know. *I don't know but it was an ambulance job anyway.* **Right, okay.** *They came…* They were terrific.	

It took a long time because they didn't know at that point if she'd broken anything so they were very careful and gave her morphine and…

Right, they'd be super cautious, yes.

They took her into A&E.

Of course, it was my birthday weekend.

Oh, that's a shame, yes.

It was into A&E and then into the ward and as far as I remember, you were four weeks in the first ward and because of pressure on beds, you were moved to another ward for a week and half.

Yes, for the last week or so. So, when you went in initially, usually you'll go to one of the assessment wards and then from there, up to the ward that I spoke to you in where they did most of the getting ready for home things, is that what you think?

That's right, I beg your pardon.

101 or 102 maybe to start with?

102, that's it, yes. You were in there for the weekend and then it was the Monday… I think you were two or three nights in 102 and then moved to 30… whatever.

I think 303 but I'm not 100% certain, yes.

306 then 302.

Yes, that's right. 306 is where I spoke to you and that would be where you got most of the getting ready for home in 306, yes.

For home, that's right.

Can you remember any differences between the assessment ward and then when you went to 306? Was there any different at all, can you remember?

No, I couldn’t say. Of course, I was in pain and everything was strange but, no, I couldn’t…

It’s a long time ago as well now, I suppose.

It is.

Do you remember any differences?

Yes. There was a difference between the two wards. I’m not being critical but 302, they seemed to have less coming and going. 306, I wouldn’t say it was day patients but they’re in very short term for minor operations, as far as I could gather.

Yes, it was constant, the bed shifting.

Constant change in that ward. There were just differences in the flow.

So, the place where they were in and out, was that the place where your mum spent most of the time?

No.

The first place?

302, mum spent most of her time, three or four weeks.

Was that the coming and going?

No.

No, it was slower there. The very first place, there was coming and going?

306 is where she spent most of the time and that was very stable, yes.

Whereas the place that she was before that, there was more coming and going?

No, it wasn't before that. It was a single room, that was fine. That was the assessment.

Right, okay, so where she went just before she left?

302 is a busy ward.

A day surgery, yes.

Yes. It's a busy… no criticism.

Just different.

Just slightly different, that was all.

In that initial, in the single room one, was there anything that stood out to you about that area at all or was there nothing at all that stood out to you?

That was terrific. I mean, you had your own en suite and it was lovely.

Okay, yes.

It was excellent.

That first couple of days, yes.

Yes. Extremely nice nurses there but they were all good.

They were all good, yes.

All the nurses were.

The first two or three days were excellent.

Yes, and was that important to you having your own privacy, would you say, and having your own toilet close by?

It was in a way but most of the time, you were on your own. If I had my visitors, it was fine, whereas in a ward, there's always something going on.

	Okay, so there's more to watch. *Pros and cons.* **Yes, absolutely.** There were good and bad things	

P1F1 Transcription STAGE 2 – Initial Noting		
Initial Thoughts Intuitive Interpretations Reflections	Transcription **Bold KW** Normal Davina Older person *Italics – David Davina's son*	Super ordinate Themes Sub Themes
Introductions, setting the scene. Davina had already told me at recruitment , each visit to the ward & when collecting	**Just to make sure you're both still okay to take part in the research? Is that okay?** *Yes.* Yes. **You're quite happy to be interviewed together?** Yes. *Certainly, yes.* **That's fine. If you can tell me a bit about your time in hospital, so you told me that what happened Davina is you fell in your bathroom and that took you into hospital. Did you go into one ward to start with and then end up moving around? What happened?**	

demographic information that she had fallen.	Well, I was taken into hospital and they took me for a scan and said there was nothing broken but I was very badly bruised.	
Unexpected fall – acute event	**Right.**	
+ve from –ve , nothing broken, badly bruised. 3 wards during stay, Acute Assessment, Step Down Geriatrics, then boarded, Step down is where 'do a lot of walking on your own'	From there, I went to one ward. Now, I can't remember how long I was in there, and then I was shifted to another ward, a wee while in that then I was in the ward where you do a lot of walking on your own. They make you ready for going out.	
Rehabilitation	**Okay, yes.**	
	They were all very, very nice. They couldn't have done more.	
Up prompted praise	**Yes.**	
	Very patient. The food, I couldn't eat it all (laughing). Terrific menu.	
Specific praise for nutritional care	**Yes, lots to choose from.**	
	So, really great.	
	Yes, good. Were you taken in by ambulance when you fell?	
Tring to start at very beginning and get a clear picture, on reflection I should have probed more about nutritional care here as this is the direction Davina wanted to go in.	Yes.	
	Yes. So, when you fell, did you get knocked out, do you remember?	
	No.	
	No, and so did you manage to get hold of a phone and phone…?	
	Well, I got from the bathroom to the phone, yes.	

	She got the phone and then phoned me and I was up within minutes.	
David waits until his Mim has finished then adds his clarification.	**Yes.**	
	How I got through, I don't know.	
Gives the impression of very respectful, but also his response shows how close in proximity he lives and willingness to be there immediately to help his Mum.	*I don't know but it was an ambulance job anyway.*	
	Right, okay.	
	They came…	
Again unprompted praise	They were terrific.	
	It took a long time because they didn't know at that point if she'd broken anything so they were very careful and gave her morphine and…	
Paramedics being cautious in case of fractures	**Right, they'd be super cautious, yes.**	
	They took her into A&E.	
	Of course, it was my birthday weekend.	
Davina's cognition appears very sharp for a lady of 95 years old!	**Oh, that's a shame, yes.**	
3 wards during stay, Acute Assessment Ward , Step Down Geriatrics 4 weeks , then boarded for 1.5 weeks.	*It was into A&E and then into the ward and as far as I remember, you were four weeks in the first ward and because of pressure on beds, you were moved to another ward for a week and half.*	
	Yes, for the last week or so. So, when you went in initially, usually you'll go to one of the assessment wards and then from there, up to the ward that I spoke to you in where they did most of the getting ready for home things, is that what you think?	
	That's right, I beg your pardon.	

Clarifying what I knew was usual process. No perceptions about differences in initial care to longer term, as strong painkillers affected perception. I was interested in the difference from acute assessment to step down, but Son answers about differences from geriatrics to being boarded out. The pace in the geriatric ward was slower, there was a buzz about the	**101 or 102 maybe to start with?** *102, that's it, yes. You were in there for the weekend and then it was the Monday… I think you were two or three nights in 102 and then moved to 30… whatever.* **I think 303 but I'm not 100% certain, yes.** *306 then 302.* **Yes, that's right. 306 is where I spoke to you and that would be where you got most of the getting ready for home in 306, yes.** For home, that's right. **Can you remember any differences between the assessment ward and then when you went to 306? Was there any different at all, can you remember?** No, I couldn't say. Of course, I was in pain and everything was strange but, no, I couldn't… **It's a long time ago as well now, I suppose.** It is. **Do you remember any differences?** *Yes. There was a difference between the two wards. I'm not being critical but geriatrics ward, they seemed to have less coming and going. Boarded ward I wouldn't say it was day patients but they're in very short term for minor operations, as far as I could gather.* Yes, it was constant, the bed shifting. *Constant change in that ward. There were just differences in the flow.*	

boarded ward, always something going on.		
	So, the place where they were in and out, was that the place where your mum spent most of the time?	
	No.	
	The first place?	
	302, mum spent most of her time, three or four weeks.	
Clarification.	**Was that the coming and going?**	
	No.	
	No, it was slower there. The very first place, there was coming and going?	
	306 is where she spent most of the time and that was very stable, yes.	
Stable in step down geriatrics		
	Whereas the place that she was before that, there was more coming and going?	
Now, what I was asking, I was not clear, I could have been much more specific!	*No, it wasn't before that. It was a single room, that was fine. That was the assessment.*	
	Right, okay, so where she went just before she left?	
So Acute assessment – single room, fine	*302 is a busy ward.*	
Boarded area day surgery very busy, not bad just different.	**A day surgery, yes.**	
	Yes. It's a busy… no criticism.	
	Just different.	
	Just slightly different, that was all.	

	In that initial, in the single room one, was there anything that stood out to you about that area at all or was there nothing at all that stood out to you?	
	That was terrific. I mean, you had your own en suite and it was lovely.	
Davina again, unprompted praise, appreciating own en suite .	**Okay, yes.** *It was excellent.* **That first couple of days, yes.**	
Strongly positive word choices terrific & excellent, extremely nice nurses.	Yes. Extremely nice nurses there but they were all good. *They were all good, yes.*	
Again, unprompted praise from both, all good, excellent.	All the nurses were. *The first two or three days were excellent.*	
	Yes, and was that important to you having your own privacy, would you say, and having your own toilet close by? It was in a way but most of the time, you were on your own. If I had my visitors, it was fine, whereas in a ward, there's always something going on.	
Reluctance to complain, liked the single room, but when there were no visitors , lonely/ bored. Preference to seeing what was going on in an open ward.	**Okay, so there's more to watch.** *Pros and cons.*	
Son can see +ve	**Yes, absolutely.** There were good and bad things. **Yes, so there were positives and…**	

	Good and not so good (laughing). **Yes, that's understandable. So, you were there a couple of days and then you moved up to the ward where you spent most of your time.**	
Field Notes Davina lived on her own in a bungalow, around a 5 minute drive from her only son. Her two grown up gran daughters live in the same city, they have young great grandchildren. All appear to play an active role in Davina's life. From the outset the respect David has for his Mother radiates in the interview, he always lets her speak 1st, then adds his answers, unless I ask specifically to him. Even when his Mum is unsure (role of the dieticDavid) he waits until she is finished and then adds his perception. Davina appears frail physically but strong in character. She is very content with her care experience in acute care, felt very well looked after and content with the processes of slow social care support as she flourished in her almost 5 weeks of acute hospital care. Being moved into a day surgery ward for her last week does not put her up nor down, there is an acceptance with both her & her son of the pressures in the NHS, so you as an older person/family member have to be flexible around the needs of the service. PCC Visiting a a real winner for them and use of a social space for time with family, the dayroom is really appreciated. There is a sense of compromise with Davina, used to garden, get buses to meet friends, get her hair done, now in her mid-nineties she seems to see I need to change/ adapt. There is also a real sense of contentment and happiness in her caring family unit. Her house is immaculately clean & tidy.		

P1F1 Transcription Descriptive Linguistic Conceptual ~~Strike through if not relevant to the research question~~

STAGE 3 - Considering emergent themes

Initial Thoughts Intuitive Interpretations Reflections	Transcription **Bold KW** Normal Davina Older person *Italics – David Davina's son*	Super ordinate Themes Sub Themes
Introductions, setting the scene. Davina had already told me at recruitment , each visit to the ward & when collecting demographic information that she had fallen. Unexpected fall – acute event +ve from –ve , nothing broken, badly bruised.	**Just to make sure you're both still okay to take part in the research? Is that okay?** *Yes.* Yes. **You're quite happy to be interviewed together?** Yes. *Certainly, yes.* **That's fine. If you can tell me a bit about your time in hospital, so you told me that what happened Davina is you fell in your bathroom and that took you into hospital. Did you go into one ward to start with and then end up moving around? What happened?** Well, I was taken into hospital and they took me for a scan and said there was nothing broken but I was very badly bruised. **Right.**	

3 wards during stay, Acute Assessment, Step Down Geriatrics, then boarded, Step down is where 'do a lot of walking on your own' Rehabilitation Up prompted praise Specific praise for nutritional care Tring to start at very beginning and get a clear picture, on reflection I should have probed more about nutritional care here as this is the direction Davina wanted to go in. David waits until his Mim has finished then adds his clarification. Gives the impression of very respectful, but also his	From there, I went to one ward. Now, I can't remember how long I was in there, and then I was shifted to another ward, a wee while in that then I was in the ward where you do a lot of walking on your own. They make you ready for going out. **Okay, yes.** They were all very, very nice. They couldn't have done more. **Yes.** Very patient. The food, I couldn't eat it all (laughing). Terrific menu. **Yes, lots to choose from.** So, really great. **Yes, good. Were you taken in by ambulance when you fell?** Yes. **Yes. So, when you fell, did you get knocked out, do you remember?** No. **No, and so did you manage to get hold of a phone and phone…?** Well, I got from the bathroom to the phone, yes. *She got the phone and then phoned me and I was up within minutes.*	

response shows how close in proximity he lives and willingness to be there immediately to help his Mum.	**Yes.** How I got through, I don’t know. *I don’t know but it was an ambulance job anyway.*	
Again unprompted praise	**Right, okay.** *They came…*	
Paramedics being cautious in case of fractures	They were terrific. *It took a long time because they didn’t know at that point if she’d broken anything so they were very careful and gave her morphine and…*	
Davina’s cognition appears very sharp for a lady of 95 years old!	**Right, they’d be super cautious, yes.** *They took her into A&E.*	
3 wards during stay, Acute Assessment Ward , Step Down Geriatrics 4 weeks , then boarded for 1.5 weeks.	Of course, it was my birthday weekend. **Oh, that’s a shame, yes.** *It was into A&E and then into the ward and as far as I remember, you were four weeks in the first ward and because of pressure on beds, you were moved to another ward for a week and half.*	
Clarifying what I knew was usual process.	**Yes, for the last week or so. So, when you went in initially, usually you’ll go to one of the assessment wards and then from there, up to the ward that I spoke to you in where they did most of the getting ready for home things, is that what you think?** *That’s right, I beg your pardon.* **101 or 102 maybe to start with?**	

	102, that's it, yes. You were in there for the weekend and then it was the Monday… I think you were two or three nights in 102 and then moved to 30… whatever. **I think 306 but I'm not 100% certain, yes.** *306 then 302.* **Yes, that's right. 306 is where I spoke to you and that would be where you got most of the getting ready for home in 306, yes.**	
No perceptions about differences in initial care to longer term, as strong painkillers affected perception.	For home, that's right. **Can you remember any differences between the assessment ward and then when you went to 306? Was there any different at all, can you remember?** No, I couldn't say. Of course, I was in pain and everything was strange but, no, I couldn't… **It's a long time ago as well now, I suppose.**	
I was interested in the difference from acute assessment to step down, but Son answers about differences from geriatrics to being boarded out. The pace in the geriatric ward was slower, there was a buzz about the boarded ward, always something going on.	It is. **Do you remember any differences?** *Yes. There was a difference between the two wards. I'm not being critical but geriatrics ward, they seemed to have less coming and going. Boarded ward I wouldn't say it was day patients but they're in very short term for minor operations, as far as I could gather.* Yes, it was constant, the bed shifting. *Constant change in that ward. There were just differences in the flow.*	

Clarification.	**So, the place where they were in and out, was that the place where your mum spent most of the time?**	
	No.	
	The first place?	
	306, mum spent most of her time, three or four weeks.	
Stable in step down geriatrics	**Was that the coming and going?**	
	No.	
	No, it was slower there. The very first place, there was coming and going?	
Now, what I was asking, I was not clear, I could have been much more specific!	*306 is where she spent most of the time and that was very stable, yes.*	
So Acute assessment – single room, fine	**Whereas the place that she was before that, there was more coming and going?**	
Boarded area day surgery very busy, not bad just different.	*No, it wasn't before that. It was a single room, that was fine. That was the assessment.*	
	Right, okay, so where she went just before she left?	
	302 is a busy ward.	
	A day surgery, yes.	
	Yes. It's a busy… no criticism.	
	Just different.	
Davina again, unprompted praise, appreciating own en suite .	*Just slightly different, that was all.*	

Strongly positive word choices terrific & excellent, extremely nice nurses. Again, unprompted praise from both, all good, excellent. Reluctance to complain, liked the single room, but when there were no visitors , lonely/ bored. Preference to seeing what was going on in an open ward. Son can see +ve & -ves.	**In that initial, in the single room one, was there anything that stood out to you about that area at all or was there nothing at all that stood out to you?** That was terrific. I mean, you had your own en suite and it was lovely. **Okay, yes.** *It was excellent.* **That first couple of days, yes.** Yes. Extremely nice nurses there but they were all good. *They were all good, yes.* All the nurses were. *The first two or three days were excellent.* **Yes, and was that important to you having your own privacy, would you say, and having your own toilet close by?** It was in a way but most of the time, you were on your own. If I had my visitors, it was fine, whereas in a ward, there's always something going on. **Okay, so there's more to watch.** *Pros and cons.*	

P1F1 Transcription Descriptive Linguistic Conceptual ~~Strike through if not relevant to the research question~~ STAGE 4 - Making connections across themes		
Initial Thoughts Intuitive Interpretations Reflections	Transcription **Bold KW** Normal text Davina Older person *Italics – David Davina's son*	SUPER ORDINATE THEMES Sub Themes
	Just to make sure you're both still okay to take part in the research? Is that okay?	
Introductions, setting the scene.	*Yes.* Yes.	
	You're quite happy to be interviewed together? Yes. *Certainly, yes.*	
Davina had already told me at recruitment , each visit to the ward & when collecting demographic information that she had fallen.	**That's fine. If you can tell me a bit about your time in hospital, so you told me that what happened Davina is you fell in your bathroom and that took you into hospital. Did you go into one ward to start with and then end up moving around? What happened?**	
Unexpected fall – acute event	Well, I was taken into hospital and they took me for a scan and said there was nothing broken but I was very badly bruised.	IMMOBILITY
+ve from –ve , nothing broken, badly bruised.	**Right.**	Sudden event led to acute care IMMOBILITY

3 wards during stay, Acute Assessment, Step Down Geriatrics, then boarded, Step down is where 'do a lot of walking on your own'	From there, I went to one ward. Now, I can't remember how long I was in there, and then I was shifted to another ward, a wee while in that then I was in the ward where you do a lot of walking on your own. **They** make you ready for going out.	Enablement PCC SYSTEMS for OPAH "They" MDT are responsible for improvement
Rehabilitation		
		PRAISE
Up prompted praise		Staff
	Okay, yes.	
Specific praise for nutritional care	They were all very, very nice. They couldn't have done more.	Nutritional Support
	Yes.	
Tring to start at very beginning and get a clear picture, on reflection I should have probed more about nutritional care here as this is the direction Davina wanted to go in.	Very patient. The food, I couldn't eat it all (laughing). Terrific menu.	
	Yes, lots to choose from.	
	So, really great.	
	Yes, good. Were you taken in by ambulance when you fell?	
	Yes.	
	Yes. So, when you fell, did you get knocked out, do you remember?	
		ACCESS TO ACUTE CARE
David waits until his Mim has finished then adds his clarification.	No.	Family Support
	No, and so did you manage to get hold of a phone and phone…?	
Gives the impression of very respectful, but also his	Well, I got from the bathroom to the phone, yes.	IMMOBILITY

response shows how close in proximity he lives and willingness to be there immediately to help his Mum. Again unprompted praise Paramedics being cautious in case of fractures Davina’s cognition appears very sharp for a lady of 95 years old! 3 wards during stay, Acute Assessment Ward , Step Down Geriatrics 4 weeks , then boarded for 1.5 weeks. Clarifying what I knew was usual process.	*She got the phone and then phoned me and I was up within minutes.* **Yes.** How I got through, I don’t know. *I don’t know but it was an ambulance job anyway.* **Right, okay.** *They came…* They were terrific. *It took a long time because they didn’t know at that point if she’d broken anything so they were very careful and gave her morphine and…* **Right, they’d be super cautious, yes.** *They took her into A&E.* Of course, it was my birthday weekend. **Oh, that’s a shame, yes.** *It was into A&E and then into the ward and as far as I remember, you were four weeks in the first ward and because of pressure on beds, you were moved to another ward for a week and half.* **Yes, for the last week or so. So, when you went in initially, usually you’ll go to one of the assessment wards and then from there, up to the ward that I spoke to you in where they did most of the getting ready for home things, is that what you think?**	Fear ACCESS to ACUTE CARE Critical event PRAISE Ambulance staff PCC SYSTEMS FOR OPAH Person missing Boarded out of Geriatric Care PCC SYSTEMS FOR OPAH

No perceptions about differences in initial care to longer term, as strong painkillers affected perception. I was interested in the difference from acute assessment to step down, but Son answers about differences from geriatrics to being boarded out. The pace in the geriatric ward was slower, there was a buzz about the boarded ward, always something going on.	*That's right, I beg your pardon.* **101 or 102 maybe to start with?** *102, that's it, yes. You were in there for the weekend and then it was the Monday… I think you were two or three nights in 102 and then moved to 30… whatever.* **I think 306 but I'm not 100% certain, yes.** *306 then 302.* **Yes, that's right. 306 is where I spoke to you and that would be where you got most of the getting ready for home in 306, yes.** For home, that's right. **Can you remember any differences between the assessment ward and then when you went to 306? Was there any different at all, can you remember?** No, I couldn't say. Of course, I was in pain and everything was strange but, no, I couldn't… **It's a long time ago as well now, I suppose.** It is. **Do you remember any differences?** *Yes. There was a difference between the two wards. I'm not being critical but geriatrics ward, they seemed to have less coming and going. Boarded ward I wouldn't say it was day patients but they're in very short term for minor operations, as far as I could gather.* Yes, it was constant, the bed shifting. *Constant change in that ward. There were just differences in the flow.*	Normal to move from ward to ward PCC SYSTEMS FOR OPAH 1st stages blur due to acuity of illness PCC SYSTEMS FOR OPAH Differences in patient flow once boarded out

Clarification. Stable in step down geriatrics Now, what I was asking, I was not clear, I could have been much more specific! So Acute assessment – single room, fine Boarded area day surgery very busy, not bad just different. Davina again, unprompted praise, appreciating own en suite .	**So, the place where they were in and out, was that the place where your mum spent most of the time?** *No.* **The first place?** *306, mum spent most of her time, three or four weeks.* **Was that the coming and going?** *No.* **No, it was slower there. The very first place, there was coming and going?** *306 is where she spent most of the time* *and that was very stable, yes.* **Whereas the place that she was before that, there was more coming and going?** *No, it wasn't before that. It was a single room, that was fine. That was the assessment.* **Right, okay, so where she went just before she left?** *302 is a busy ward.* **A day surgery, yes.** *Yes. It's a busy… no criticism.* **Just different.** *Just slightly different, that was all.*	PCC SYSTEMS FOR OPAH Geriatrics gave a sense of stability from family perspective. PCC SYSTEMS FOR OPAH PCC value of single room in acute assessment. PRAISE Environment PCC valued ensuite when in acute assessment PRAISE

Strongly positive word choices terrific & excellent, extremely nice nurses.	**In that initial, in the single room one, was there anything that stood out to you about that area at all or was there nothing at all that stood out to you?** That was terrific. I mean, you had your own en suite and it was lovely.	Environment, Nursing and All MDT team care
Again, unprompted praise from both, all good, excellent.	**Okay, yes.** *It was excellent.* **That first couple of days, yes.**	PRAISE Acute Assessment Process
	Yes. Extremely nice nurses there but they were all good.	PCC SYSTEMS FOR OPAH
Reluctance to complain, liked the single room, but when there were no visitors , lonely/ bored. Preference to seeing what was going on in an open ward.	*They were all good, yes.* All the nurses were. *The first two or three days were excellent.* **Yes, and was that important to you having your own privacy, would you say, and having your own toilet close by?**	Contradiction, single room leads to isolation, preference for watching a busy ward.
Son can see +ve & -ves	It was in a way but most of the time, you were on your own. If I had my visitors, it was fine, whereas in a ward, there's always something going on. **Okay, so there's more to watch.** *Pros and cons.*	PCC SYSTEMS FOR OPAH

Field Notes

Davina lived on her own in a bungalow, around a 5 minute drive from her only son. Her two grown up gran daughters live in the same city, they have young great grandchildren. All appear to play an active role in Davina's life. From the outset the respect David has for his Mother radiates in the interview, he always lets her speak 1st, then adds his answers, unless I ask specifically to him. Even when his Mum is unsure (role of the dieticDavid) he waits until she is finished and then adds his perception. Davina appears frail physically but strong in character. She is very content with her care experience in acute care, felt very well looked after and content with the processes of slow social care support as she flourished in her almost 5 weeks of acute hospital care. Being moved into a day surgery ward for her last week does not put her up nor down, there is an acceptance with both her & her son of the pressures in the NHS, so you as an older person/family member have to be flexible around the needs of the service. PCC Visiting a real winner for them and use of a social space for time with family, the dayroom is really appreciated. There is a sense of compromise with Davina, used to garden, get buses to meet friends, get her hair done, now in her mid-nineties she seems to see I need to change/ adapt. There is also a real sense of contentment and happiness in her caring family unit. Her house is immaculately clean & tidy.

On 3rd read through & initial noting, there is more than I thought I had on 1st read through. Not as much depth as F3. But a different highly +ve perspective, where the OP voice is clear. Specific personal , mobility & nutritional care + what she perceives PCC in OPAH to have been about for her. Things are better now than they used to be, , a happy ward, rather than a strict one, males & females, different races of nurses, PCC visiting and use of a dayroom, all make for positive moves forward for OPAH. Very few –ves, on a couple of occasions OP is missing in the system, informed of a decision, rather than involved in making it. . Joint H & SC is helping her live at home in her 90’s and her family although really involved highly respect her desire to remain as independent as possible.

Another 3 trips through the data and I see so much more!

4. Repeating process of analysis with the next case
5. Identifying patterns in the data across cases

This was the 1st interview to be analysed, superordinate and sub themes were further developed and refined as more data was analysed.

Appendix 21 Publication Plan

Publication Plan		
What	**Where** **(aiming for)**	**When**
1.DPP Findings **2.Reflections on DPP**	International Journal of Older People Nursing Aging and Health Journal of Clinical Nursing Journal of Advanced Nursing International Journal of Nursing Studies	Start working on, once whole draft thesis is complete – February 2021 Submit to August 2020
3.Literature Review	Qualitative Nursing Research Journal BMC Research Methodology BMJ Open Nurse Researcher	Start working refining the Lit Review Chapter on, once 1, 2 are submitted plan to submit by Dec. 2021
4.Methodology **5. IPA in Nursing Research**	International Journal of Older People Nursing Aging and Health Journal of Clinical Nursing Journal of Advanced Nursing International Journal of Nursing Studies	Start working on, once above 3 have been submitted, plan to submit by Dec 2021