

What is Resilience in Hospice Inpatient Nursing? A Participatory Action Research Study

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I declare that this thesis is my own work and has not been submitted for
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ABSTRACT

Background: The palliative care nursing workforce is depleted and faces increased demands due to an ageing population likely to be living longer with life-limiting conditions. Resilience is often suggested as necessary to enable nurses to tolerate rising levels of stress yet is often poorly defined and understood. Assumptions that resilience is the responsibility of individual nurses are challenged.

Aim: To explore resilience from the perspective of hospice nurses; understand what individual, interpersonal and organisational factors influence resilience; develop strategies for enhancing resilience in hospice inpatient palliative care nursing; and to review and evaluate such strategies.

Methods: Participatory Action Research (PAR) was used to identify the nature of adversity in inpatient palliative care nursing and develop strategies, designed by nurses themselves, to enhance resilience. Phase one involved semi-structured interviews with 7 registered nurses and phase two included twelve, monthly meetings of a Collaborative Inquiry Group, who engaged in a process of planning, acting and reflecting on the key issues identified in phase one.

Findings: Resilience in inpatient palliative care nursing is preceded by the following adversities: being affected by certain patients, feeling kept in the dark, and when teamwork is sub-optimal. Resilience occurs when nurses make meaning from adverse experiences in ways that prepare them for future occurrences. Meaning-making involves certain mindsets, team support and cohesion, and the ability to develop a coherent narrative about experiences. It is possible for nurses to innovate, generate and implement strategies to enhance resilience without relying on typically used interventions such as mindfulness, relaxation, CBT or other techniques that lay responsibility to tolerate inordinate stressors on the individual nurse.

Conclusion: There are particular adversities encountered by the inpatient palliative care nursing workforce that influence resilience. Given the opportunity, nurses themselves can identify, develop and test strategies that may enhance resilience in their workplace.

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Abbreviations

CBT	Cognitive Behaviour Therapy
CIG	Collaborative Inquiry Group
COREQ	Consolidated Criteria for Reporting Qualitative Research
ESCR	Economic and Social Research Council
MeSH	Medical Subject Heading
NHS	National Health Service
NMC	Nurses Meet and Chat
P	Participant
PAR	Participatory Action Research
PC	Palliative Care
PhD	Doctor of Philosophy
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
UK	United Kingdom
WHO	World Health Organisation

Chapter 1 - Introduction

There is growing concern about resilience in the palliative care nursing workforce (The Point of Care Foundation, 2015). The demand for palliative care services over the next thirty years will grow exponentially (Etkind et al., 2017) due to an ageing population with an increased likelihood of multi-morbidity, coupled with a shortage of trained nurses in the United Kingdom (RCN, 2015). Stress levels in nurses are reportedly high (Health and Safety Executive, 2016), with exposure to death and dying considered to be a contributory factor. Moreover, there are claims that resilience may be, at least in part, the answer to the impending nursing workforce crisis.

Resilience as the answer to such potentially catastrophic workforce concerns is problematic for several reasons. Resilience is difficult to define and may mean different things to people in diverse contexts; it may be used to inappropriately suggest that responsibility for stress lies at the level of the individual, who could, therefore, withstand any amount of increased pressure at work if only they are 'strong' enough. Traynor (2018, p. 6), for example, argues persuasively that

“promotion of resilience is a purely individualistic attempt to mitigate systemic problems. Individual nurses are basically being asked to take responsibility for political decisions and systematic failures”

Increasing individual tolerance is implicit in many intervention studies, where research focusses on what nurses can do to tolerate workplace adversity regardless of the

cause. One example is McDonald, Jackson, Wilkes, and Vickers (2013, p. 135) who suggest

“using personal resilience as a strategy to heighten the ability of nurses and midwives to withstand workplace adversity”

Typical attempts to render nurses more resilient include learning mindfulness, relaxation, and stress reduction techniques. In this thesis I will argue that attempts to increase individual tolerance are not sufficient and that resilience research could benefit from understanding the relationship between the particular type of adversity encountered, the setting or context within which it occurs, and how those affected believe resilience could be enhanced as a result.

In chapter two, the challenge of defining resilience is addressed through critical exploration and summation of existing resilience concept analyses, culminating in a suggested model that informed the literature review in this thesis. For clarity, the definition of resilience used to guide this study was:

Resilience occurs when there is an effective interplay between risk and protective factors in the face of adversity that most people, under similar circumstances, would find challenging or traumatic. Evidence of resilience should not be exclusively confined to an absence of negative mental health symptoms but considered proportionally to the individual’s subjective interpretation of the adversity encountered. The ability to cope

with the experience and function at a level that is better than could be expected, under the circumstances, is likely due to resilience.

1.1 Research questions, aims and objectives

Two research questions guided this study. Firstly, ‘what is resilience according to specialist palliative care nurses in inpatient units?’ and secondly, ‘what influences resilience in this context?’.

The overall aim of this study was to understand resilience, using participatory action research methodology, from the perspective of hospice inpatient nurses. This study sought to contribute to the resilience knowledge base and identify strategies for supporting and enhancing resilience, designed with and by nurses themselves. Research to date on resilience in nurses is scarce and where it has been undertaken it is to assess the impact of researcher decided interventions upon the workforce (Mehta et al., 2014; Mehta et al., 2015; Perez et al., 2015). It is possible, perhaps likely, that hospice inpatient nurses themselves hold the key to a greater understanding of resilience in their specialist field and may be best placed to plan, test and review strategies for enhancing resilience.

Four objectives were identified to meet the aim of the study:

1. To describe resilience from the perspective of hospice nurses
2. To understand what individual, interpersonal and organisational factors influence resilience

3. To develop strategies to enhance resilience
4. To review and evaluate such strategies

1.2 Thesis structure and overview

Six chapters combine to form this thesis (including this introduction) and the remaining five chapters are outlined below.

1.2.1 Chapter 2: Background

The background chapter sets the scene for this thesis by challenging the idea that resilience is the answer to increased demand and diminishing nursing supply in the palliative care nursing workforce. An overview of the worldwide nursing shortage is explained, coupled with a description of the increasing need for palliative care provision. The nature of workplace stress is reviewed and the potential impact of exposure to death and dying on nurses is explored. The chapter concludes with a critique of the concept of resilience that culminates in the previously stated definition of resilience for this study.

1.2.2 Chapter 3: Literature Review

To understand how resilience is described or inferred by nurses working in hospice inpatient units, a thematic synthesis of qualitative studies was conducted. The synthesis of eight included studies culminated in an analytic theme:

‘Resilience occurs when nurses incorporate stressful aspects of their personal or professional lives into a coherent narrative that

enhances their ability to cope with the demands of their role' (Powell, Froggatt, & Giga, 2019, p. 9)

The findings from this review support the conceptual and methodological approaches in this present study with its aim to address the gaps in existing research.

1.2.3 Chapter 4: Methodology

The methodological choices and assumptions in this study are reported and justified, with reference to the epistemological and ontological perspectives associated with the knowledge sought and generated. To address the gaps in the literature and enhance both practice and theory, Participatory Action Research (PAR) was chosen as the optimal approach for addressing the aims and objectives in this study which comprised two phases. Phase one consisted of individual interviews which were thematically analysed, and the findings were used to inform phase two. Phase two involved a year of monthly Cooperative Inquiry Group (CIG) meetings using PAR to enhance resilience in the workplace.

1.2.4 Chapter 5: Findings

The two phases of this study are reported separately and then combined to summarise the findings. The first phase involved individual interviews with seven registered nurses and thematic analysis of the interviews led to two main findings; firstly, the nature of adversity in palliative care nursing, and secondly, how making sense of adversity prepares nurses for the future. The second phase was a series of Cooperative

Inquiry Groups (CIG) that were held monthly over a course of one year. The strategies that the CIG tested in response to the findings from phase one are reported in detail.

1.2.5 Chapter 6: Discussion

In the final chapter the findings are discussed and critiqued according to existing knowledge. The chapter considers how reflexivity and positionality influence the generation of knowledge and how relevant the knowledge may be for future practice, policy and research.

1.3 My voice

I have nearly 30 years of healthcare experience and developed a keen interest in the way healthcare professionals cope with the challenging aspects of their role. Whilst working as a paramedic, I developed a peer support programme that enabled staff to informally “offload” and support each other, whilst simultaneously promoting the notion that help-seeking behaviour is to be encouraged and supported. I currently work as a senior manager in a large hospice and have concerns about the future of the nursing workforce in such a specialised setting. My concerns include the challenges of meeting increasing need, with limited supply of registered nurses, against a backdrop of decreasing funding to the charitable sector to provide specialist palliative care to those who need it.

Reflexivity is crucial in many aspects of healthcare and research but especially so in participatory action research. As a result, my voice will be included through the use of

first-person pronouns where appropriate. Further consideration of reflexivity and positionality will be addressed in the methodology and discussion chapters.

1.4 The research setting

The research was conducted in one London hospice, deliberately separate from my place of work due to ethical challenges related to my position of authority.

1.5 Introduction summary

The following chapters are devoted to a critical exploration of resilience in the hospice inpatient palliative care nursing workforce. There are several gaps in the extant resilience literature, including a lack of explanation regarding the relationship between adversity and resilience; assumptions that resilience is universal and means the same thing in different contexts and populations; usage of predetermined interventions based on mindfulness approaches; and methods embedded in a quantitative approach that measure resilience as a trait, rather than a process in response to particular adversity.

To address these identified gaps, this study was designed to explore the links between adversity and resilience in one particular, specialist setting, and collaboratively support and empower nurses themselves to generate strategies to improve resilience. These strategies were tested and evaluated using a PAR methodology, commonly used to give voice and empower marginalised groups. In this study, nurses were encouraged to identify organisational and systemic issues that could be improved rather than ‘roll

with the punches' (Traynor, 2018, p. 5) and assume resilience is an issue solely for the individual.

Chapter 2 - Background

In this chapter the state of the UK nursing workforce, the increasing need for palliative care in the UK, stress levels in nursing, and the challenge of regular exposure to death and dying are presented and evaluated. The chapter concludes with a critical review of the concept of resilience, outlines the origins of resilience research, highlights the relevance to the nursing profession and emphasises the importance of resilience research with palliative care nurses.

2.1 The nursing workforce

Nursing vacancies in the UK National Health Service have doubled in recent years, with the number of people entering the profession significantly lower than those leaving (RCN, 2017). This nursing crisis is widespread and inadequate numbers of new nurses are being trained to replace those who leave the profession, leading to a predicted global shortage of nurses within the next 10 to 20 years (Moloney, Boxall, Parsons, & Cheung, 2018). The Royal College of Nursing describes:

“a dismal picture of nursing shortages, recruitment drives in Europe, increased use of agency staff, the degradation of specialist and senior nursing as well as worsening workload, morale and stress levels” (RCN, 2015, p.3)

This trend also affects the palliative care workforce, yet further conflated due to the average age of its nurses who are likely to be over 50 years old (NCPC, 2014). The UK is worryingly faced with an ageing population at ever-increasing risk of multi-

morbidity, coupled with a reliance on a depleted, ageing palliative care nursing workforce to provide the care it needs. Furthermore, the nursing shortage is exacerbated in the UK since the vote to leave European Union (EU) in 2016. There was a 90% decrease in new EU nurse registrations with the Nursing and Midwifery Council since the vote (RCN, 2019). It is, therefore, a matter of urgency to support those staff who do remain in the profession.

2.2 Increasing need for palliative care services

Etkind et al. (2017) estimate a 42% increase in the number of people requiring palliative care services by 2040 if recent trends in the UK and Wales continue, as shown in Figure 2-1 below.

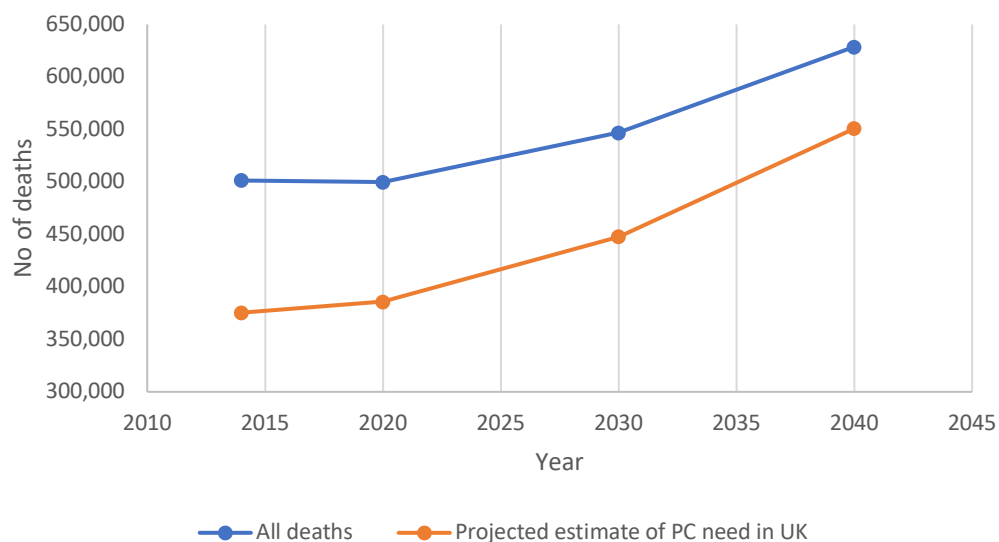


Figure 2-1 Increasing need for palliative care

2.3 Stress in the workplace

Increased demand is just one factor that influences the nursing workforce's capacity to manage future need. Another is the prevalence of work-related stress, anxiety and depression in the United Kingdom, which is significant and accounted for 37% of work-related health issues in 2015-16. Factors that cause workplace stress have remained constant over time and include issues with workload, lack of support from managers and organisational change (Health and Safety Executive, 2016).

There is growing concern about this disproportional prevalence of stress in health care workers. Nursing has much higher rates of stress (3010 cases per 100,000) for example than do skilled tradesmen (550 cases per 100,000), (Health and Safety Executive, 2016). Consequences of excessive or prolonged stress include burnout, compassion fatigue and attrition at a time when the nursing workforce is depleted and struggling to meet the demands of the healthcare system (McVicar, 2016). Furthermore, these issues are prevalent in many other countries and care settings (Sizmur & Raleigh, 2018) with nurses reporting similar issues in their workplaces regardless of how their country's healthcare system is organised (Aiken et al., 2001).

High levels of stress are not only detrimental to staff; the quality of care experienced by patients is also negatively affected (Dawson, 2014). Johnson, Panagioti, Bass, Ramsey, and Harrison (2017) found that stress affects staffs' ability to cope and the subsequent distress this causes undermines healthcare professionals' resilience. This leads to feelings such as shame, depression and anxiety, which in turn increases the

likelihood of further distress and the negative cycle continues, leading to poorer outcomes for both staff and patients.

2.4 Death and Dying

There is a general consensus that exposure to death and dying is potentially traumatic and may negatively affect those who witness it, rendering palliative care nursing especially challenging (Grafton & Coyne, 2012; Herrington, Knowlton, & Tucker, 2012; McAllister & McKinnon, 2009; The Point of Care Foundation, 2015). Nurses who choose to specialise in this area of work need particular skills to cope daily with what may ordinarily be challenging for most people. To understand how it is that palliative care nurses can withstand this regular exposure to death and dying, further research must be done, especially as some argue that nurses working in cancer or palliative care are no more stressed than their counterparts elsewhere (Grafton & Coyne, 2012; Peters et al., 2012). The ability to bear witness to death, dying and suffering, may be due to resilience. A better understanding of resilience may contribute to retention of nurses at a time when the UK is facing problematic levels of nurse shortages.

In the weeks before this thesis was submitted, the world succumbed to the Covid-19 pandemic (Bedford et al., 2020). The impact on the world's healthcare systems is undeniable and the clinical workforce is likely to witness suffering and death at a far greater frequency than they possibly imagined. Whilst this present study was not intended to be generalisable to other contexts and settings beyond specialist palliative

care, it seems plausible that future research efforts towards understanding resilience in the clinical workforce in the context of the Covid-19 crisis will also be necessary.

2.5 Resilience

2.5.1 Relevance

Resilience is becoming increasingly relevant to the nursing profession where there are ever-growing concerns about recruitment, retention and the workforce's capacity to do more with fewer resources than ever before (The Point of Care Foundation, 2015). The future of palliative care is changing, and hospices are under pressure to become more business-like, to see more people, to be more efficient and there is a real-world concern about the resilience of the staff and volunteers in the face of such stressors (Hospice UK, 2013). Resilience may help to mitigate the deleterious effects of stress yet there is a lack of empirical evidence on how it is defined, developed and enhanced in the palliative care nursing workforce.

2.5.2 Resilience research

Academic interest in resilience originated from child development studies in the 1970s (Masten, 2001) and evolved from an initial focus on the individual's capacity to flourish in times of adversity to a more comprehensive understanding of the complex interplay between individual characteristics, external influences and risk and protective factors during challenging times (Dyer & McGuinness, 1996; Rutter, 1998). Earlier trends towards measuring the presence or absence of pathology in individuals have been

rejected in favour of identifying how individuals, organisations, and society influence resilience (Luthar, 1991; Rutter, 2012).

Quantitative resilience research, by definition, focuses on measurable variables to understand resilience. Quantitative resilience studies are typically cross-sectional and capture data at a given point in time (see Chiriboga, Jenkins, and Bailey (1983), for an example that tests an analytic model of stress and coping in hospice nurses). Other studies attempt to measure a change in resilience due to an intervention, such as the study by Gerhart et al. (2016) to test mindfulness-based communication in palliative care professionals. Whilst these studies inevitably contribute to knowledge about resilience, they represent a trend to measure what can be measured at the expense of capturing more specifically the type of adversity likely to affect resilience, and the way a person, community or society responds to such specific stressors. Data generated from widespread surveys of palliative care staff are no doubt informative, however, in this study I sought to identify the nature of resilience in one setting, with registered nurses, in response to the particular challenges they identified as adversities.

Furthermore, previous research has enhanced understanding to a degree, but if the term resilience is used without proper clarification, by stretching definitions too broadly and blurring conceptual boundaries, this confuses rather than elucidates (Bonanno, 2004). Studies with divergent use of the term that purport to advance the

resilience knowledge base may serve to dilute rather than strengthen what is already known about the topic (Luthar & Cicchetti, 2000).

One such example is Alliger, Cerasoli, Tannenbaum, and Vessey (2015) who claim that resilience is essential in the contemporary workforce, yet define resilience simply as an ability to withstand stressors and perform as usual. This implies that resilience is located at the level of the individual without accounting for external confounding factors (something that Karasek (2004) believes will lead to increased dissatisfaction and motivation in the workforce) and demonstrates how resilience can be (mis)used as a “catch-all” term, synonymous with other concepts like coping or hardiness.

Conceptual understanding of resilience appears to rely heavily on early research with children and is often applied to a variety of contexts, people and communities without fully considering the appropriateness of such generalizations in other settings. An example is the transference of a resilience-building program designed for youths in schools to the United States Army, at a cost of millions of dollars, without pilot testing or evaluation of feasibility for a different context (Macedo et al., 2014). Quick (2011, p. 645) challenges those who presume that psychological fitness in one context can be easily assumed as beneficial in different contexts, suggesting ‘let’s learn what is functional in the military and combat contexts of our troops and not impose upon them’.

Validity and rigour in resilience research could be enhanced when the following recommendations (synthesised from a review of the top ten most frequently cited papers on resilience (Bonanno, 2004; Luthar, 1991; Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000; Masten, 2001; Masten & Coatsworth, 1998; Masten et al., 1999; Rutter, 1985, 1987, 1998)) are incorporated:

1. Provide clear operational definitions of the construct
2. Use the term resilience to refer to competence despite adversity and not resiliency (personality trait)
3. Apply “resilient” to trajectories or profiles of adaptation, not to individuals themselves
4. Consider personal attributes and their interplay with environmental forces
5. Disseminate relevant knowledge clearly and openly acknowledge the limitations of empirical findings

2.5.3 Concepts and concept analysis

Following the recommendations above, resilience research should include a clear definition of resilience and sufficient contextual information to enable the reader to understand exactly what it means in the context of any given research. The next section critically explores how concepts and subsequent analyses can support enhanced understanding and concludes with a summary of what resilience means in this present study.

Concepts anatomically contain a definition, characteristics, boundaries, preconditions and outcomes, thereby enabling others to identify, recognise and engage with them. Concepts have defining features or characteristics which *'must be present in all instances in which the concept appears'* (Morse, Mitcham, Hupcey, & Tason, 1996, p.386) and should be carefully explained in academic work to reduce the likelihood of misunderstanding (Morse et al., 1996). One way to achieve this, as Baldwin (2008) suggests, is to strive for contextual clarity by distinguishing between entity concepts (it has meaning in and of itself), and dispositional views of concepts (understood in particular contexts). She illustrates this point with the word 'mouse' to highlight the importance of understanding whether she refers to the electronic accessory used in computing or the member of the rodent family. It is therefore helpful to know whether authors have adopted an entity or dispositional perspective of the phenomena under study, to situate the reader and give fuller meaning to the research.

Sufficient context and clarification, therefore, help to enhance concept definition and utility. This is important in research where terms may be interpreted differently by professionals according to their discipline (Adamson, Beddoe, & Davys, 2012) which increases the need to share a common language and remove ambiguity (Toftthagen & Fagerstrøm, 2010). Resilience is often referred to as the ability to bounce back after adversity or challenge and whilst sensible, it is still unclear what this means to different people in different contexts.

Walker and Avant (2008) argue that concepts are the building blocks of theory and must be clarified before any theory is developed and transformed into practice. Beckwith, Dickinson, and Kendall (2008, p. 385) agree that concepts 'form the foundation of applied theory in the social sciences' and Baldwin (2008) believes that rational inquiry into concept meaning is an essential precursor to any theoretical development. One method for enhancing conceptual understanding is the process of concept analysis, deemed a worthy research endeavour to generate new scientific knowledge, by questioning what it is we presume to know about phenomena (Baldwin, 2008). Concept analysis is frequently used in academic literature to identify, clarify and examine the meaning of words (Baldwin & Rose, 2009) and to advance clinical theory and practice (Beckwith et al., 2008).

There are various methods of concept analysis and Walker and Avant's (2008) method is the most prolific. Another method is Rodgers (1989)'s Evolutionary Method of concept analysis, which involves the steps outlined in Table 2-1. Whether or not explicitly stated, all methods of concept analysis include the following elements: an exploration of a concept's subset of empirical linguistics; an uncommitted inquiry; a grammatical investigation; and an analysis of relationships between phenomena culminating in a complex cognitive construction of empirical experience (Beckwith et al., 2008).

Table 2-1 Rodgers' evolutionary method for concept analysis

1	Identify the concept of interest
2	Identify surrogate terms
3	Choose the setting and sample
4	Identify the attributes
5	Identify the references, antecedents, and consequences
6	Identify related concepts
7	Identify a model case
8	Identify implications for further research and development of the concept

The process of concept analysis as an approach to forming new knowledge and generating new theoretical frameworks is not without criticism. Beckwith et al. (2008) searched twelve years of literature and found a plethora of concept analysis frameworks yet very few explicitly stated their epistemological stance or rationale for the methods chosen. Others found similar concerns, including the lack of epistemological clarity underpinning the approach, lack of methodological rigour and inconclusive or absent definitions in conclusions (Baldwin, 2008; Baldwin & Rose, 2009; Beckwith et al., 2008; Morse et al., 1996; Nuopponen, 2010).

A philosophical debate about what constitutes knowledge is inevitable in academia and wholesale claims that concept analysis per se will contribute to this body of knowledge should be challenged (Duncan, Cloutier, & Bailey, 2007). Concept analyses must do more than simply highlight that concepts could benefit from further

clarification; there should be a robust investigation of antecedents, consequences and defining attributes of concept characteristics (Beckwith et al., 2008; Paley, 1996; Penrod, 2004; Risjord, 2009). Whilst this may produce knowledge, explicit justification and epistemological positioning would support the rigour and validity of the process (Kisely & Kendall, 2011).

2.5.3.1 Resilience concept analyses

In their wider review of resilience literature, Bhamra, Dani, and Burnard (2011) found that the context within which the term resilience is used may change yet it appears to have some relatively consistent characteristics across contextual boundaries. Bhamra et al. (2011, p. 5376) state that resilience is always related to “the capability and ability of an element to return to a stable state after a disruption” and fundamentally contains the following aspects: readiness and preparedness; response and adaptation; and recovery or adjustment.

Examples of other concept analyses of resilience include mental health and positive adaptation in those affected by HIV/AIDS (Garcia-Dia, DiNapoli, Garcia-Ona, Jakubowski, & O'Flaherty, 2013); how approaches to resilience have changed over the years with the recent interest in neurobiological factors (Cabanyes Truffino, 2010); a life course multi-method approach to analysing resilience using elements of concept analysis, systematic review and stakeholder consultation (Windle, 2010); and a general overview of resilience using traditional methods of concept analysis to identify

antecedents, consequences, critical attributes and model examples of resilience in various situations (Dyer & McGuinness, 1996).

Further analyses of resilience were reviewed to clarify the concept (Ahern, 2006; Caldeira & Timmins, 2016; Dyer & McGuinness, 1996; Earvolino-Ramirez, 2007; Garcia-Dia et al., 2013; Gillespie, Chaboyer, & Wallis, 2007; Simmons & Yoder, 2013; Windle, 2010) for this study and underpin the working definition of resilience outlined in chapter one. Consistent in all definitions, concept analyses, and research to date is the presence of adversity as a precursor for resilience and consequent positive adaptation. Adversity, like resilience, must be properly defined to understand its relationship to resilience. Synonymous terms include hardship or risk to healthy levels of functioning (Bonanno, 2004) and work stress, burnout, trauma, compassion fatigue and vicarious traumatisation (Adamson et al., 2012).

Gillespie et al. (2007) acknowledge the challenge of identifying resilience in diverse clinical contexts to develop interventions that enhance resilience in the nursing profession. They discovered critical attributes of resilience to be hope, self-efficacy and coping in their review of literature spanning several decades. Earvolino-Ramirez (2007) found similar attributes of rebounding/reintegration, high expectancy/self-determination, positive relationships/social support, flexibility, sense of humour and self-esteem/self-efficacy, however, the methods of literature searching and criteria for inclusion were unclear.

Windle (2010) conducted a concept analysis of resilience and usefully delineates its characteristics based on a review of studies over several decades. These include basic definitions of qualities of elasticity, ability to adapt and evolve, and traits such as hardiness and invulnerability. She importantly identifies how the concept has developed beyond descriptions of personal characteristics, especially those deemed to be static and unchanging, to a postmodern view of resilience as a

‘dynamic process involving an interaction between both risk and protective processes, internal and external to the individual, that act to modify the effects of an adverse life event’ (Windle, 2010, p. 233)

2.6 Background Summary

Defining resilience for this study is challenging as the myriad of existing definitions may not transfer appropriately from one context to another. Research is largely dominated by attempts to identify personal characteristics or vulnerabilities and protective factors that lead to positive outcomes. Protective factors include intellectual functioning; prosocial relationships; satisfactory caregiving relationships in childhood; previous experiences of perceived success/achievement; and social competence, easy disposition and a sense of humour (Luthar & Cicchetti, 2000; Masten & Coatsworth, 1998; Rutter, 1987). The challenge for future research is that these factors are inherently intertwined and cannot easily be separated empirically.

However, concept analyses agree to a large extent on the fundamental characteristics of resilience, regardless of whether this is applied to individuals or organisations.

Resilience is a process, not a personality trait, and includes an ability to bounce back or recover easily when confronted by adversity, trauma, misfortune or change (Dyer & McGuinness, 1996). Resilience enables (but is not limited to) effective coping, successful adaptation and growth (Windle, 2010). Following extensive review of the extant literature, a conceptual model of resilience was developed for this study (see Figure 2-2) and summarised as:

1. Preceded by misfortune, change or adversity
2. Demonstrated by tolerating/withstanding these changes
3. Returning to normal (or as close to normal as possible)
4. Ability to obtain mastery over the situation and become better prepared for future similar occurrences
5. Ability to do the above when others would struggle to cope

The study of resilience has evolved over the past five decades, from initial assertions that resilience was akin to invulnerability or demonstrated by an absence of psychopathology (Dyer & McGuinness, 1996), to an understanding that the ability to thrive under adverse circumstances is complex and multifactorial (Rutter, 2012). Further research on resilience has the potential to improve the lives of vulnerable people or populations (for example, nurses who work with terminally ill patients and their families) before adversity occurs (Luthar et al., 2000). This paradigmatic shift from evaluating resilience in terms of an absence of psychopathology, towards investigations that better understand the processes involved in the complex interplay of all the factors that may influence resilience, in a salutogenic approach, is widely encouraged by resilience researchers (Luthar, 2006; Masten, 2001; Rutter, 1985). A

salutogenic approach focusses on strengths rather than deficits (Lundman et al., 2010) and there is much to be learned from those who demonstrate resilience in response to adversity rather than restricting research to outcomes of those who fare less well (Macedo et al., 2014).

The model in Figure 2-2 goes some way to demonstrate how resilience is viewed theoretically and practically, based on generalisations across studies, populations, settings and evaluations. What is not yet clear is how these conceptual elements combine, as recommended above, to enhance knowledge about resilience in palliative care nurses in relationship to particular adversities they face.

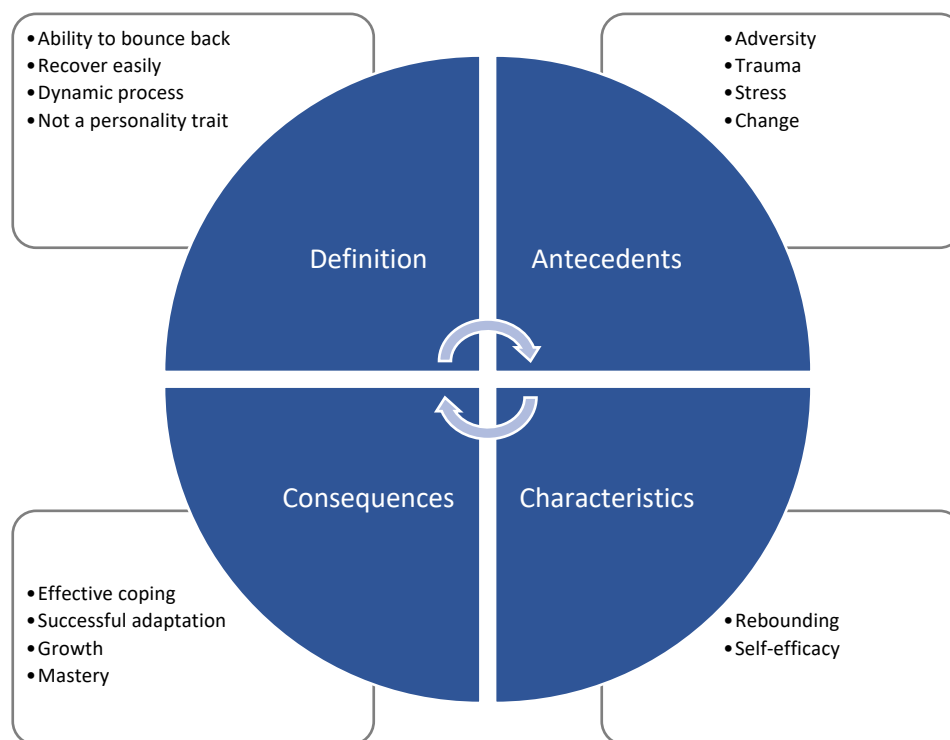


Figure 2-2 What is resilience?

Chapter 3 – Literature Review

3.1 Introduction

The following chapter was published in a peer-reviewed journal (Powell et al., 2019) and then modified for the thesis accordingly.

Nursing is considered inherently stressful and some claim that palliative care is especially so due to exposure to terminally ill patients and their families (Grafton & Coyne, 2012; Herrington et al., 2012; McAllister & McKinnon, 2009; The Point of Care Foundation, 2015). Resilience may help to mitigate the deleterious effects of stress yet there is a lack of empirical evidence on how it is defined, developed and enhanced in the palliative care nursing workforce.

3.2 Aims

The review served to identify, appraise and synthesise data from qualitative research studies that describe resilience from the perspective of inpatient palliative care nurses. The aim was guided by the following question: how do palliative care inpatient unit nurses describe or infer resilience? The aim and question were developed in accordance with the SPIDER tool (Aveyard, Payne, & Preston, 2016); where the Sample was registered nurses in palliative care inpatient units, the Phenomena of Interest was resilience, all Designs that are consistent with qualitative approaches were considered, no Evaluation methods were excluded; and Research type was defined as qualitative or mixed methods as long as the qualitative data could be extracted.

3.3 Methods

3.3.1 Design

Synthesising qualitative data is recognised as a challenging endeavour, particularly for the novice researcher (Soilemezi & Linceviciute, 2018). There are a variety of tools to assist in the process and each has its own strengths and limitations, however, there is no formal guidance available to inform how to select these tools (Soilemezi & Linceviciute, 2018). Most approaches are rooted in techniques used in primary research such as meta-ethnography (to identify new interpretations of concepts); grounded-theory (using constant comparative methods to generate new theory); or content analysis (categorising themes based on frequency counts) (Centre for Reviews and Dissemination, 2009). This present review is designed to identify prominent themes in existing literature about the nature of resilience in the palliative care inpatient unit nursing workforce. The review is not intentionally seeking to generate new theory, nor rely on frequency counts to support thematic understanding of the phenomena. Thematic synthesis was considered the most appropriate choice to align with the review aims and question, described further below.

The review was conducted systematically and comprised the following steps: searching for relevant literature, selecting relevant papers, extracting data from identified papers, and critically appraising identified papers. This process culminated in a thematic synthesis of literature according to the three steps outlined by Thomas and Harden (2008):

- 1) Line by line text coding
- 2) Developing descriptive themes
- 3) Generating analytic themes

3.3.2 Search Methods

The search strategy was devised in conjunction with a specialist librarian, resulting in the identification of three sets of terms, as listed in Table 3-1. Search terms were restricted to English language. The terms in each set were combined with the logical operator 'OR', and each set was combined with the logical operator 'AND' in the following databases: Academic Search Ultimate, Cumulative Index to Nursing and Allied Health (CINAHL), Medline Complete, Psych INFO, and Scopus.

Table 3-1 Search terms

Set 1	Set 2	Set 3
hospice	Coping	Nurs*
Palliat*	Cope	
End of life care	Resilien*	
Terminal care	Hardiness	
	Adaptation	
	Adjustment	

Medical subject headings (MeSH) were modified according to each database and the exact search terms used for each can be found in Appendix 1. The search was conducted initially in October 2017, then updated in December 2018, with each database unrestricted by date range to retrieve the maximum possible number of relevant papers. Due to the time between synthesis and thesis submission, the searches were conducted again in March 2020. Papers that inferred resilience by describing how nurses managed or coped in the face of adversity were accepted, subject to the criteria outlined below.

3.3.3 Inclusion/Exclusion Criteria

Criteria were developed with a decision to focus this review on published peer-reviewed articles only. Financial and language resources were not available to consider texts published in any language other than English. Initial scoping of case reports, conference reports and poster abstracts revealed consistent, insufficient richness of material to meaningfully contribute to a greater understanding of the phenomena of resilience in hospice/palliative care nursing.

Inclusion Criteria:

1. Qualitative research, or mixed methods studies where qualitative data is extractable
2. Participants were exclusively Registered Nurses, or where data for Registered Nurses could be extracted

3. Study was designed to elicit information about resilience or coping when working with patients in a dedicated palliative care inpatient facility

Exclusion criteria:

1. Focus on burnout (a distinct concept, not an inevitable consequence of resilience)
2. Studies not published in peer reviewed journals
3. Studies not published in English
4. Case reports, conference proceedings, poster abstracts and theses,
5. Studies that collected qualitative data but analysed with quantitative methods
6. Studies that focus on the experiences of patients, informal caregivers or family members.

3.3.4 Search outcome

The systematic literature review and thematic synthesis was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) as shown in Figure 3-1. A total of 2566 citations were retrieved and organised with Endnote v.7 (Clarivate Analytics, Philadelphia) and 1329 duplicates were removed. The titles and abstracts of the remaining 1237 papers were screened. The full paper was obtained if the paper met the inclusion criteria or if there was any doubt about suitability for inclusion.

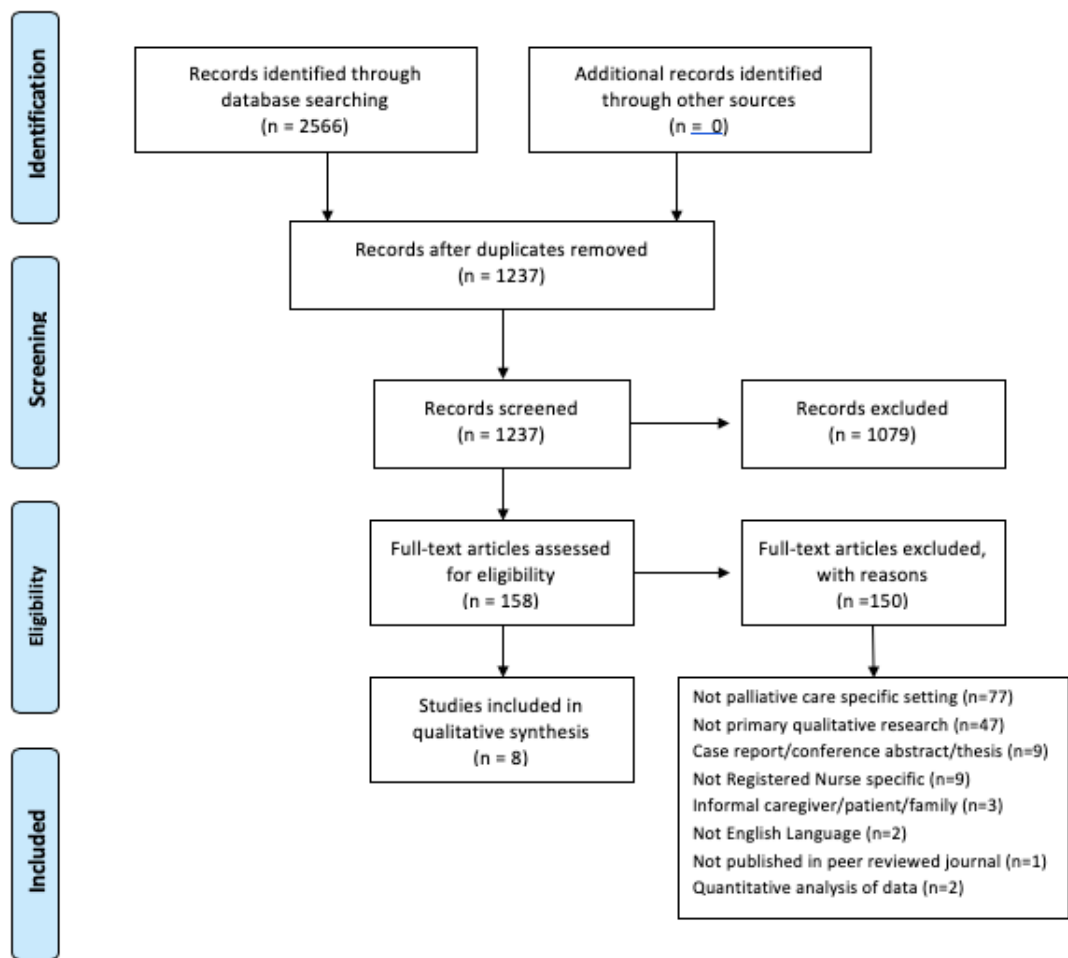


Figure 3-1 PRISMA flow chart

158 full-text articles were assessed for eligibility. Eight studies were included in the review and the characteristics of each, including methods of data collection and analysis were recorded. Additionally, the studies were reviewed according to the Consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007). The studies were conducted in the following countries: United Kingdom

(n=2), Australia (n=2), Japan (n=1), Taiwan (n=2) and the Netherlands (n=1). A total of 154 nurses participated in these eight studies.

All included studies were either qualitative (n=6) or mixed methods with extractable qualitative results (n=2) and used interviews to collect data. One study was published in 1990 and the remaining seven were published after 2002. A summary of included studies' characteristics can be seen in Appendix 2.

3.3.5 Quality Appraisal

Each included paper was assessed for quality using the Hawker, Payne, Kerr, Hardey, and Powell (2002) checklist. Each question is designed to appraise the quality of the following aspects of the paper: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalizability, and implications and usefulness. To assist with quality assessment the following categories were assigned a corresponding numeric score (shown in parenthesis): Good (4), Fair (3), Poor (2) or Very Poor (1). The total score for each paper is shown in Table 3-2.

Table 3-2 Quality assessment of included papers

	ABLETT, J. R. & JONES, R. S.	ALEXANDER, D. A. & RITCHIE, E.	BARNARD, A. et al.	GEORGES, J.-J. et al.	HUANG, C. C. et al.	PETERS, L. et al.	SHIMOINABA, K. et al.	WU, H.-L. & VOLKER, D. L.
Abstract and Title	3	3	3	3	3	4	4	4
Introduction and aims	3	4	3	2	3	4	4	4
Method and data	3	3	4	3	4	4	4	4
Sampling	3	4	3	3	3	4	3	4
Data analysis	3	4	3	3	4	4	3	4
Ethics and bias	3	3	4	2	2	2	3	4
Results	4	4	4	4	3	4	4	4
Transferability	3	4	4	3	3	4	4	4
Implications and usefulness	4	4	4	3	4	4	3	3
Total score (Max 36, Min 9)	29	33	32	26	29	34	32	35

Two studies reported on any previous relationship between the researcher(s) and participants (Ablett & Jones, 2007; Georges, Grypdonck, & Dierckx de Casterlé, 2002) and no studies explicitly reported what participants knew of the researchers.

Information about relationships between researchers and participants may inform any understanding about the nature of knowledge produced and whether ethical considerations have been adequately covered, especially with regard to power and influence (Hawker et al., 2002). Participants were recruited purposively in four studies (Ablett & Jones, 2007; Alexander & Ritchie, 1990; Huang, Chen, & Chiang, 2016; Shimoinaba, O'Connor, Lee, & Kissane, 2015), by convenience in three studies (Barnard, Hollingum, & Hartfiel, 2006; Georges et al., 2002; Peters et al., 2013) and by snowball techniques in one study (Wu & Volker, 2009). One study described the number of participants who refused to participate or dropped out (Alexander & Ritchie, 1990). No studies described returning transcripts to participants for comment or correction and it is unclear whether participants fed back on findings. There is no clear guidance on best practice regarding sharing findings with participants in research studies, however there is growing support for this in some cases, such as at the end of clinical trials (Cox, Moghaddam, Bird, & Elkan, 2011). It is much less clear whether participants should be given the opportunity to give feedback on findings in other approaches. All studies lacked specific descriptions of diverse or minor cases and two gave examples of coding frames (Ablett & Jones, 2007; Shimoinaba et al., 2015).

Overall the studies were judged to be fair or of good quality, however the decision to include all studies regardless of outcome of quality assessment was taken in advance of the review due to the unresolved debate on the utility of quality assessment in reviews of qualitative studies (Dixon-Woods et al., 2006).

3.3.6 Data abstraction

The three steps of the thematic synthesis method (Thomas & Harden, 2008) are to code line by line, develop descriptive themes (attending to similarities and differences between studies (Bristowe, Marshall, & Harding, 2016) and develop analytical themes that ‘go beyond’ primary studies to generate new interpretations. This synthesis creates higher order themes that stay true to the original work of the original authors yet enable enhanced comprehension of the concept of resilience than disaggregated studies permit.

Each identified paper was read multiple times to increase familiarity and obtain a thorough understanding of the study aims, methods and outcomes. All text under the headings ‘findings’ or ‘results’ was imported in to NVIVO (QSR International Pty Ltd, 2014) and coded iteratively, until all content was reviewed. The process was repeated multiple times for each paper and then again after all papers were coded to ensure that all papers were considered against all iteratively generated codes. These codes were aggregated in to descriptive themes, which were subsequently developed in to one analytical theme, the “going beyond” individual papers required in synthesis (Thomas & Harden, 2008). Descriptive themes describe the key content of the papers, whereas analytical themes are higher order interpretations of the descriptive themes.

3.4 Results

The thematic synthesis yielded 10 sub-themes, three overarching themes and one analytic theme, as demonstrated in Table 3-3.

Table 3-3 Thematic synthesis findings

Descriptive themes:	Sub-themes:	Analytic theme
Stressors	This stress is common to all nursing work	Resilience occurs when nurses incorporate stressful aspects of their personal or professional lives into a coherent narrative that enhances their ability to cope with the demands of their role
	Too close to home	
	Some patients are more challenging than others	
Coping	Technical or relational care?	
	Emotional expression or suppression?	
	Giving and receiving support	
	Maintaining a work-life balance	
	Making a difference mind-set	
Exposure to death	Exposure to death is stressful	
	Exposure to death is an opportunity for growth	

3.4.1 Theme 1: Stressors in palliative care nursing:

3.4.1.1 This stress is common to all nursing work

There are many stressors inherent in nursing and these studies reveal that the palliative care inpatient unit is no exception. Participants identified stressors such as unmanageable workloads, shift work, staff shortages, the turnover of patients in beds (Ablett & Jones, 2007) and lack of training on specific issues such as psychiatry and communicating effectively in conflictual situations (Alexander & Ritchie, 1990).

3.4.1.2 Too close to home

The most widely reported stressor is how nurses identify with patients or their relatives. Identification with the suffering or because of proximity in age were cited in particular:

“you tend to identify with relatives particularly if they’re about the same age as you”
(Alexander & Ritchie, 1990, p.31) and:

*‘When I experience a situation at work which overlaps with my
personal experience, it recalls my feelings ... I feel emotional pain
when my experience overlaps’* (Shimoinaba et al., 2015, p.506).

One participant succinctly captures the essence of this stress with the words *“too close to home”* (Ablett & Jones, 2007, p.737).

3.4.1.3 Some patients and relatives are more challenging than others

Certain patients are more challenging for nursing staff, such as those considered manipulative, demanding or reluctant to be discharged (Georges et al., 2002). Furthermore,

“Patients with motor neurone disease fostered ambivalence in some nurses because they found it hard to reconcile the degree of physical dependency with the integrity of the patient’s mental powers. Demanding and manipulative were epithets sometimes used to describe such patients” (Alexander & Ritchie, 1990, p.31).

Patients with psychiatric symptoms were challenging for staff to deal with, as were those suffering from uncontrolled pain, nausea or vomiting, and dyspnoea (Alexander & Ritchie, 1990). The key factor underlying the stress associated with uncontrolled or unmanageable symptoms is how nurses feel helpless in the face of such suffering, which prevents meaningful communication between the patient and the nurse (Alexander & Ritchie, 1990; Georges et al., 2002).

Communicating with patients’ relatives is considered by some to be more stressful than dealing with the death of patients. Unsurprisingly this includes specific tasks, such as informing them of the patient’s death (Ablett & Jones, 2007) but less expectedly includes communication in general (Alexander & Ritchie, 1990; Peters et al., 2013). It is unclear why general communication with relatives was stressful for the nurses.

3.4.2 Theme 2: Coping

3.4.2.1 Technical or relational care?

Palliative care involves caring for the whole person, including their physical, spiritual and psychological well-being, not treating disease in isolation (World Health Organisation, 2017). This ethos underpins the ways nurses care for patients in specialist palliative care environments and likely leads to a level of intimacy and rapport that both patients and nurses value (Barnard et al., 2006). However, this approach may come at a cost to the nurses who give of themselves when striving to ensure patients receive the best holistic care possible, leading to compassion fatigue and burnout if unmediated (Ablett & Jones, 2007).

Nurses reported coping with this level of intimacy, with patients with limited life, by retreating behind a uniform (Ablett & Jones, 2007; Georges et al., 2002) or shifting from 'being with' patients to a stance of 'doing to' them instead. This concept of 'doing' rather than 'being' served in some ways to protect the nurses from vulnerability (Barnard et al., 2006), but also enabled them to adapt and fit with the environment they worked in. This phenomenon is encapsulated by the nurses working in an academic ward of a hospital, who reported a need to be considered professional and taken seriously by their medical colleagues (Georges et al., 2002).

Nurses who adopt a technical approach to care (Georges et al., 2002) believed their professional lifespan in palliative care was limited compared with those nurses who

espouse a relational approach to care, embracing connection and contact beyond the technical with patients (Barnard et al., 2006; Huang et al., 2016; Shimoinaba et al., 2015). This suggests the technical/task approach may be less rewarding or fulfilling, particularly for nurses who believe:

“hospice care stresses that we can’t divide human life into parts, especially that we can’t focus on physical aspects but ignore the others. I like this idea. Hospice care is close to the kind of nursing job I wanted originally” (Wu & Volker, 2009, p.580)

Transforming routine gestures to something more intuitively caring (Huang et al., 2016) seemed likely when there was enhanced self-awareness, contributing to greater appreciation of life and good patient care:

“By monitoring feelings, attitudes, beliefs and ideas about a patient’s holistic being, the meaning of their care-giving role develops” (Shimoinaba et al., 2015, p.506)

3.4.2.2 Emotional expression or suppression?

Closely aligned to coping by ‘doing to’, rather than ‘being with’, is whether to express or suppress emotion when caring for patients. Nurses choose to avoid feeling overwhelmed by feelings (Georges et al., 2002; Huang et al., 2016) or combining a ‘stoical avoidance’ with ‘acceptable crying with patients’ (Shimoinaba et al., 2015, p.507). Overall, the studies suggest that nurses need to express their emotional

responses to others, whether to patients or patients' families, or their colleagues, friends and family.

3.4.2.3 Giving and receiving support

The most reported coping strategy is how nurses 'offload' and gain support from others, primarily with colleagues but also with family and close friends (Ablett & Jones, 2007; Alexander & Ritchie, 1990; Barnard et al., 2006; Georges et al., 2002; Peters et al., 2013; Shimoinaba et al., 2015; Wu & Volker, 2009). The willingness to both give and receive support is a key component of resilience and further distinguishes resilience from coping (Mayordomo, Viguer, Sales, Satorres, & Melendez, 2016).

3.4.2.4 Maintaining a work-life balance

The nurses emphasised the importance of reducing workplace stress by maintaining a work-life balance (Ablett & Jones, 2007; Barnard et al., 2006; Shimoinaba et al., 2015). However, there are challenges in palliative care, such as how nurses wished to retain the memories of patients who died and not forget them as soon as they left duty (Barnard et al., 2006). Alexander and Ritchie (1990) highlight how this could be a conflict of interest for nurses who wish to maintain a division between home and the workplace yet struggle to do so because of their humanity and relational connection to their patients.

3.4.2.5 'Making a difference' mind-set

Nurses were inclined to care for patients in the best way they could, determined to

“make a difference” and “make this day the best day that we can for you [patient], so if there is something we can do for you we will” (Barnard et al., 2006, p.8).

Making a difference to patients and their families was often cited as the reason for entering the nursing profession (Ablett & Jones, 2007; Barnard et al., 2006; Georges et al., 2002; Shimoinaba et al., 2015). Whilst nurses report satisfaction associated with making a difference, adopting this attitude supports them to cope with the challenges they face; for example when they struggle to support patients considered manipulative or demanding (Alexander & Ritchie, 1990). Under these circumstances, a deliberate intention to avoid labelling the patient as difficult and searching for a way to improve their life, supported them to cope with demands that might otherwise seem unreasonable (Huang et al., 2016).

3.4.3 Theme 3: Exposure to death:

3.4.3.1 Exposure to death is stressful

Loss is a universal phenomenon (Nagraj & Barclay, 2009) and will be experienced by all at some point in life and nurses in palliative care are no exception. This exposure may enhance the ability to cope with death and dying, however nurses report how earlier experiences contributed to current stressors, such as being reminded of the experience each time the nurse identifies with a patient in some way:

“I remember that when my grandmother was dying, she did not close her eyes until she saw me, her favourite granddaughter. When I was caring for that elderly patient, I couldn’t help but relive that scene in

my mind's eye. I would never say goodbye to that patient before going off duty" (Huang et al., 2016, p.113).

Another participant was reminded of her perceived failings surrounding her brother's death and tried to redeem herself by caring for others facing the end of their lives (Huang et al., 2016). Vulnerability was often associated with previous personal loss experiences, such as the traumatic death of a close relative yet this also appears to motivate nurses to enter the speciality of palliative care; either to replicate the great care they witnessed or to correct the failings of those before them. However, only examples of negative care were reported in the included articles, for example:

"I had a bad experience when I lost my mother. I found that the nurses did not do all that they could have done", and "The death of her mother was a great loss to Kelly, and she felt that painful wound was reopened when taking care of a dying woman around the same age as her mother" (Huang et al., 2016, p.113).

When earlier experiences of death and dying are unprocessed in some way, it becomes more problematic to witness the death of others, as articulated by one participant:

"However, I probably did not manage my feelings comprehensively. I had special affections for an aged female patient and spent a lot of time accompanying her through the sad process of dying. After she passed away, Afterwards, I no longer experienced the same strong feelings when caring for other elderly women" (Huang et al., 2016, p.113).

It may not be necessary to have emotionally processed all earlier experiences before starting to work in palliative care if caring for patients can be a therapeutic opportunity for the nurse to process unfinished business or unresolved grief, acknowledging that the care may not be considered “genuine”:

“The song was my mum’s favourite and was sung by a choir at her funeral. When I heard the song, I felt really sad and needed to leave the room. I was working as usual after mum’s death, and I had thought I cried with patients and families. However, I realised that I was crying for my grief. I thought I am not offering genuine care while I cry for my sadness and grief. I realised that I can care for someone [only] after I overcome my own grief ... it’s difficult. But I can put it [my grief] aside now” (Shimoinaba et al., 2015, p.507).

3.4.3.2 Exposure to death is an opportunity for growth

Seven of the studies have descriptions about how nurses make sense of life and death in palliative care work (Ablett & Jones, 2007; Alexander & Ritchie, 1990; Barnard et al., 2006; Georges et al., 2002; Huang et al., 2016; Shimoinaba et al., 2015; Wu & Volker, 2009) by reflecting on aspects of previous loss, spirituality, mortality and self-awareness. One nurse believed that an experience of loss is an opportunity to process fundamental life questions and prepare for a role in palliative care:

“I think I had to be ready to come into this before I actually started it. I think with palliative care you’ve got to have been through a

bereavement yourself and sorted out your questions yourself, you know" (Ablett & Jones, 2007).

Another reported how her work:

"helped me understand that I also had to engage in my own spiritual growth and needed to stabilize myself before helping patients face death. After nurses identify their own emotions and problems, they will adjust to cope with these problems" (Huang et al., 2016, p.114).

Two papers report how engaging in spiritual growth, identifying emotions and problems (Huang et al., 2016) and becoming comfortable with spirituality enables nurses to better support patients to deal with their fears and anxieties, for example:

"... I think that until a person is comfortable with their own spirituality, whatever they regard that to be, I don't see how they can be comfortable with the patients, dealing with patients' needs to the full extent" (Ablett & Jones, 2007, p.736).

Awareness of mortality led nurses to appreciate the limited nature of their own lives (Barnard et al., 2006), encouraging them to appreciate their health and families more (Alexander & Ritchie, 1990) or think that '*life is for living*' and '*I just think, today is today and I'm going to enjoy it!*' (Ablett & Jones, 2007, p.736). Working within palliative care enhanced the lives of the nurses, helping them to appreciate life in a way they previously could not:

'...it teaches me to be grateful for what I have and what I've done with my life. It sobers me because I realize that none of us know what tomorrow may bring, so make the most of what we have today as long as we have it.' (Barnard et al., 2006, p.10).

Nurses described accepting what is within their sphere of influence and found ways to tolerate aspects of their work that were outside their control. This included the inherent downward trajectory of the patients' condition, leading to ultimate death (Ablett & Jones, 2007) and accepting that patients may still suffer regardless of the quality of care provided (Georges et al., 2002). Accepting that *'life is a variable I can't control'* (Huang et al., 2016, p.114) enabled one nurse to continue to care for patients facing the end of their lives and the recognition that working in palliative care is often counter to the approaches taught during basic training, where curative intent prevails (Shimoinaba et al., 2015).

3.4.4 Analytic theme:

Resilience occurs when nurses incorporate stressful aspects of their personal or professional lives into a coherent narrative that enhances their ability to cope with the demands of their role.

This synthesis identified a myriad of challenges for nurses who care for those with a palliative diagnosis. These challenges are stressful and relate to the organisation, to patients and their families, and to issues that the nurse brings to the role, such as personality and previous experience. The ability to make sense of the experiences and

incorporate them in to a coherent narrative, referred to as meaning reconstruction (Neimeyer, 2005) in the loss literature, appears instrumental in developing or maintaining resilience in the palliative care nursing workforce, as shown in Figure 3-2.



Figure 3-2 Model of resilience in palliative care

These studies suggest the importance of growth and meaning-making in developing and maintaining resilience in the palliative care context. In all studies, where nurses appear to go beyond coping, they demonstrate psychological assimilation of experience (Payne, Joseph, & Tudway, 2007) through linguistic expression and description of how the exposure to adversity has informed their values and beliefs. It appears this is the defining feature that distinguishes resilience from coping in the nurses in the palliative care inpatient setting. Some nurses reflect on their experiences and make sense of them by constructing a narrative to explain how life's challenges and adversities affect them. This informs how they live their lives and appears to extend beyond coping, suggesting the potential to thrive instead:

“Why are we here? Why does this happen?...well, it made me question life really and what’s it all about.... I think I had to be ready,

and I suppose it does affect your life because you realise life's short really and it changes your values" (Ablett & Jones, 2007, p.736).

3.5 Discussion

The review aimed to explore resilience, or inferred resilience, from the perspective of registered nurses working in dedicated palliative care inpatient settings. Whilst resilience can be challenging to define, it has relatively stable characteristics across contextual boundaries (Bhamra et al., 2011), with consistent reports that it is preceded by stress, trauma or adversity and demonstrated by subsequent positive adaptation (Cabanyes Truffino, 2010; Caldeira & Timmins, 2016; Davydov, Stewart, Ritchie, & Chaudieu, 2010; Delgado, Upton, Ranse, Furness, & Foster, 2017; Dyer & McGuinness, 1996; Earvolino-Ramirez, 2007; Garcia-Dia et al., 2013; Gillespie et al., 2007; Macedo et al., 2014; Windle, 2010). The following discussion will focus on how the review findings relate to resilience, where resilience is the ability to adapt, grow and construct meaning from stressful experiences, as outlined in Figure 3-2.

3.5.1 Stressful experiences

The studies in this review reveal that palliative care nurses experience similar stressors to nurses elsewhere, however they are additionally exposed to regular death, dying and suffering as a core component of their work. The nurses reported stress associated with two broad categories of patients; those they identify closely with and those who were particularly challenging to care for due to psychiatric or physical symptoms that were not easily controlled.

Patients who remind nurses of deceased family members trigger powerful emotional reactions in the nurses and led some to describe their rationale or motivation to enter the speciality of palliative care; either to provide the kind of care they wished for their relative or hope to receive themselves should they find themselves in a similar situation. It is unclear from this small number of studies whether nurses who bore witness to this kind of suffering in their own lives cope better when caring for patients in similar circumstances. Identification with others who are suffering is reported in the general literature (Funk, Peters, & Roger, 2017; O'Connor & Sanchia, 2016) but there is no available evidence to demonstrate how this affects resilience.

Palliative care nursing involves managing emotions daily, either one's own or supporting others to do so. Emotional labour is a term used to describe how nurses manage their emotions in an organisational context, where there may be expectations about how they balance their own needs with that of patients, families and the organisation they work for (Funk et al., 2017). Whilst it is recognised that nurses are likely to experience similar, normal emotional reactions to loss as anyone else, there may be discord between how they grieve personally, and professionally. A degree of emotional labour in palliative care is to be expected and this review found that nurses used 'emotional labour' as a coping mechanism in the workplace rather than citing it as a specific cause of stress.

3.5.2 Coping

Nurses in the studies commented on the need to be prepared for working with patients who have life-limiting disease and to develop coping strategies to deal with it. The main strategies identified in this review were to approach care from either a technical or relational perspective; to consciously decide how much emotion to either express or suppress; to give and receive support; maintain a work-life balance; and to adopt a mindset that reinforces how they 'make a difference'.

O'Mahony et al. (2018) describe how the effects of repeated exposure to loss and suffering in palliative care clinicians may be cumulative, leading to clinically significant levels of distress. Furthermore, they found that overly empathic nurses have higher prevalence of secondary traumatic stress and compassion fatigue. It is understandable therefore that nurses may detach from their patients and adopt a more 'technical' approach to care, to protect themselves from emotional attachments that will be disrupted when the patient becomes less well and consequently dies. However, whilst this may be effective as a coping strategy, nurses who empathise less with patients are less likely to develop a sense of meaning or purpose in their work (O'Mahony et al., 2018), which, according to the review findings, is key to maintaining and enhancing resilience.

Another critical component of resilience is the ability to both give and receive support, which is widely recognised as necessary for nurses to cope with the demands of their role (Chang, 2018). The nurses in this review were no exception and highlighted that

support could take many forms and come from a variety of sources. In addition to external support, nurses reported how they supported themselves by maintaining a work-life balance and adopting a mind-set that enabled them to continue working with palliative care patients. Self-awareness appears to increase not just job satisfaction but enhanced life satisfaction, through an appreciation of the finiteness of life and acknowledging the indiscriminate pervasiveness of disease.

Supporting colleagues with the use of humour as a coping mechanism is reported in the wider literature (Funk et al., 2017; Pinna, Mahtani-Chugani, Sanchez Correias, & Sanz Rubiales, 2018) but was not apparent in this review. Humour, however, is not sufficient to prepare nurses for future experiences (Robalo Nunes, José, & Capelas, 2018), which is a key feature of resilience. Humour may involve paying attention to the stressful situation and perhaps this focus means the nurse will learn from the experience and be better equipped to deal with similar events in future.

Gaining insight through the processing of experience is the basis of reflection and the accompanying increased self-awareness is often referred to as 'growth' (Fisher, 1991; Graci & Fivush, 2016; Lee, Choi, Hwang, Kim, & Hwang, 2015; Ogińska-Bulik, 2015, 2018). Unfortunately studies show that nurses have little time for reflection, especially in organised groups, due to heavy workloads and inadequate staffing (Zheng, Lee, & Bloomer, 2018). Without the space and time to reflect on experiences of caring for palliative care patients, there is increased likelihood that nurses will cope with death by avoiding emotional attachment, relying on previous life/death experience and

adopting a resigned attitude towards death as simply a natural part of life. Whilst the latter is true, it does not encourage greater thought, reflection, growth and learning that will lead to greater preparedness for the complexities of death in a specialist palliative care setting where patients are likely to be highly symptomatic and accompanied by distressed relatives who may not accept impending death.

3.5.3 Growth, adaptation and meaning construction

When hospice nurses have a sense of purpose or meaning in their lives, this enhances self-esteem and buffers against potential negative outcomes following exposure to stress (Barnett, Moore, & Garza, 2018). However, this review identified the importance of making sense of stressful experiences at work and developing a sense of meaning or purpose in their role. Existential coping and the ability to find meaning in life and suffering is referred to as self-competence (Cheung et al., 2018), and failure to develop such self-competence will lead to compassion fatigue and burnout when working in end of life care. Funk et al. (2017) agree and argue that a greater sense of purpose in palliative care work helps to compensate for any emotional exhaustion associated with the demands of the role.

Self-competence may be enhanced through previous exposure to loss and could contribute to enhanced resilience in nurses, especially if they have psychologically processed and created meaning from their experience. The concept of meaning-making is increasingly common in contemporary loss and bereavement literature (Neimeyer, Klass, & Dennis, 2014) and is strikingly similar to the concept of

posttraumatic growth (Calhoun & Tedeschi, 2010), where an encounter with loss becomes a precursor to positive change.

In summary, this review suggests there is potential for growth from experiences of loss, either personally or professionally for nurses working in palliative care. Where growth occurs, this will likely enhance resilience at the level of the individual nurse and enable them to cope better with future adversities. Meaning reconstruction is one way that individuals make sense or create meaning from their experiences, characterised by the ability to linguistically describe and explain to others. Linguistic expression helps to accommodate and assimilate the experience in ways that influence how individuals develop a sense of identity, relate to others and behave in future (Graci & Fivush, 2016).

3.6 Limitations

The review focused on resilience, a poorly or rarely defined concept and therefore a necessary reliance on search terms that infer resilience where it is not explicitly stated was created. Whilst every care was taken to identify appropriate search terms, including the support of a specialist librarian, relevant studies may have been omitted. Researchers sometimes use ostensibly oblique titles for their studies (Flemming & Briggs, 2007), using participant's quotes which may not accurately describe the context or content of the paper.

Due to language limitations, only articles written in English were considered. Two articles were rejected due to language limitations, however they both would have been excluded under other criteria (one was not a study about Registered Nurses and the other was conducted in an intensive care unit). Additionally, the review focussed exclusively on articles published in peer-reviewed journals only and therefore may be subject to publication bias.

Finally, there were eight included articles which may be considered a small number in a thematic synthesis. However, the typical number of studies in syntheses of qualitative studies is commonly reported as between six and fourteen (Booth, 2016).

3.7 Literature review summary

Working as a nurse in palliative care may be stressful at times, especially if patients or situations remind nurses of personal experiences. Nurses appear to cope well with the challenges of the role when there is adequate support available, with 'offloading to colleagues' being the preferred strategy. Coping well with the demands of the role does not necessarily imply increased resilience. Resilience is more likely when nurses cognitively process their experiences by linguistically articulating their thoughts and feelings. This articulation leads to the construction of meaning, helping nurses to make sense of their experience and prepare them for future challenges in a way that merely coping (cognitively or behaviourally managing each adversity as it happens) does not. Further research should be undertaken to explore how nurses themselves might define resilience and suggest ways that resilience could be enhanced in the palliative

care inpatient setting. This in no way suggests that responsibility is solely located within the individual and organisations would do well to look at multifaceted strategies to improve resilience. Enhanced resilience may mean that nurses stay in the profession longer and improve the quality of care that patients receive when they do. Furthermore, resilience research to date has focused on strategies designed and implemented by researchers on multidisciplinary groups (Back, Steihauser, Kamal, & Jackson, 2016; Clitherow, 2011). Curiously, little research has been conducted by nurses on the topic of resilience in palliative care. There is a gap in the literature regarding how nurses, the professional group who spend most time with patients during inpatient stays, believe resilience could be enhanced.

The next chapter introduces the methodology for this current study and is based on the need to explore resilience from the perspectives of nurses. As highlighted above, resilience is often assumed to be the same or similar across disciplines and is often studied according to researcher-led interventions. There are no studies to date that connect particular adversities, to resilience, from the perspectives of nurses who design and test their own strategies to enhance resilience in the hospice inpatient setting.

Chapter 4 - Methodology

4.1 Introduction

Participatory Action Research (PAR) methodology was chosen to meet the objectives of this study. In this chapter, after a brief reminder of the study background and objectives, and outline of the philosophical assumptions underpinning the research and potential knowledge claims, PAR is described and discussed, with emphasis on the associated benefits and challenges. The rationale for the choice of PAR is explained, critiqued and justified. Further evaluation of the impact of the approach on the findings is reported in the discussion chapter.

4.2 Background and objectives

Resilience research has historically focussed on disadvantaged children and their ability to thrive under adverse circumstances. Interest in resilience has developed over the past five decades with a proliferation of the use of the term with healthcare workers, who if 'resilient' could better tolerate the challenges associated with providing care. In this study's literature review, just eight qualitative studies were identified that explored resilience in hospice inpatient nurses. None of these eight studies used a PAR approach. I was interested in whether nurses themselves could participate as co-researchers to generate ideas for action, in their environment, that could benefit them directly. Research is often critiqued for not directly benefitting subjects/participants, at least not for some time, due to the knowledge-practice gap (de Brun, O'Reilly-de Brun, O'Donnell, & MacFarlane, 2016).

The research questions that underpinned this study were ‘what is resilience according to specialist palliative care nurses in inpatient units?’ and ‘what influences resilience in this context?’. The objectives of the study were to: describe resilience from the perspective of hospice nurses; understand what individual, interpersonal and organisational factors influence resilience; develop strategies for enhancing hospice resilience; and review and evaluate such strategies. The study design was informed by the philosophical stance reported below.

4.3 Philosophical perspectives

The framework for the design of this study was aligned with particular theoretical and philosophical underpinnings which are described further in relation to the adapted model (Moon & Blackman, 2014) in Figure 4-1. The diagram includes purple pins to demonstrate visually how the elements of ontology, epistemology, research goals and research approach relate to this present study. Each of these areas will be explained further below.

Any assumptions about knowledge can be made clearer by explaining how they do, or do not, align with the theoretical concepts of ontology, epistemology and methodology (McNiff & Whitehead, 2009). Ontology is the theory of being and is concerned with what constitutes reality (Scotland, 2012) which includes the way we see ourselves, which in turn can influence the way we see others (McNiff & Whitehead, 2009). I saw the nurses in the study as co-researchers and fellow people who could work together to try and address a real problem. This stance could be described as an

'I-Thou' position where I would view myself as in relationship with the other (Coghlan & Brydon-Miller, 2014), compared with an 'I-It' relationship, where I would view myself as detached from the other, as an objective observer. Epistemology is concerned with the nature of knowledge and how it is created (McNiff & Whitehead, 2009), acquired and communicated (Scotland, 2012). Knowledge creation in this study was thought possible through a process of PAR, where participants could create or develop knowledge individually or together. Finally, methodology is the theory of how research is done and should demonstrate that the methods align with underlying epistemology and ontology.

Reflecting on the research question about the nature of knowledge and reality when exploring resilience from the perspectives of nurses revealed assumptions that I should make explicit. I recognised how existing research appeared to be done to, rather than done with, participants in studies. I wondered whether there was an opportunity to discover what resilience means to nurses and whether they may have as yet untapped ideas about strategies to enhance resilience according to their definition rather than that imposed by researchers upon them. I felt very strongly that I wanted the study to be of practical utility and at least attempt to bridge the theory-practice gap commonly cited in criticisms of academic work that research may not be translated into actual practice. PAR was an appropriate methodological choice due to its potential to accommodate the aforementioned elements.

Examining these elements in more detail revealed my assumptions that the knowledge I sought would be socially constructed by the nurses and situated within the specific context of hospice inpatient care. This constructionist stance suggests a view that there is no singular fixed reality and that experience will always be at least partially socially constructed (Cresswell, 2003). This experience can be interpreted using scientific methods leading to rigorous research about the phenomena of resilience and differs from positivistic approaches that might assume reality is universal and can be measured or observed empirically, leading to objective conclusions (Bryman, 2012). My perspective for this study was based on a view that positivistic explanations are not necessarily any more credible than experiential explanations, recognising that both could be fallible. I recognised, in keeping with Fletcher (2016, p. 188), that *“participants’ experiences and explanations of a phenomenon may in fact prove most accurate in explaining the reality”*. I acknowledged my belief that there could be multiple representations of resilience in the study and that there was no predetermined agenda to generate a universally accepted truth, especially as the topic, population, researcher or researched are sensitive to attitudes, behaviours, interpretations and experiences that may be influenced by social, political, cultural or historical contexts (O’Gorman & MacIntosh, 2015).

At this point, it may seem as though the methodological choices in this study align with an interpretivist paradigm, and to a large extent, they do. I believed that any knowledge created in this way would be valuable and could answer the research questions. However, the relevance of generating knowledge from a socially

constructed viewpoint notwithstanding, there is an alternative approach that emerged from interpretivism that also actively accounts for how reality may be shaped by historical, political, societal, gender, ethnic or cultural values. This approach is known as the critical paradigm and has the potential to address issues of social injustice or marginalisation, for example (Scotland, 2012). An interpretivist approach to generating knowledge about resilience in inpatient palliative care nursing could be sufficient to answer the research questions straightforwardly. However, less emphasis would be placed on the importance of context and the neoliberal assumptions about resilience located at the individual level, leading to assertions that if nurses become resilient enough, it does not matter how much stress is placed upon them. I would also be another white, male, middle-class researcher interpreting findings through my worldview, which runs the risk of reducing validity and authenticity for the very people this present study sought to help. A key feature of the critical paradigm is change, designed to enhance the lives of participants.

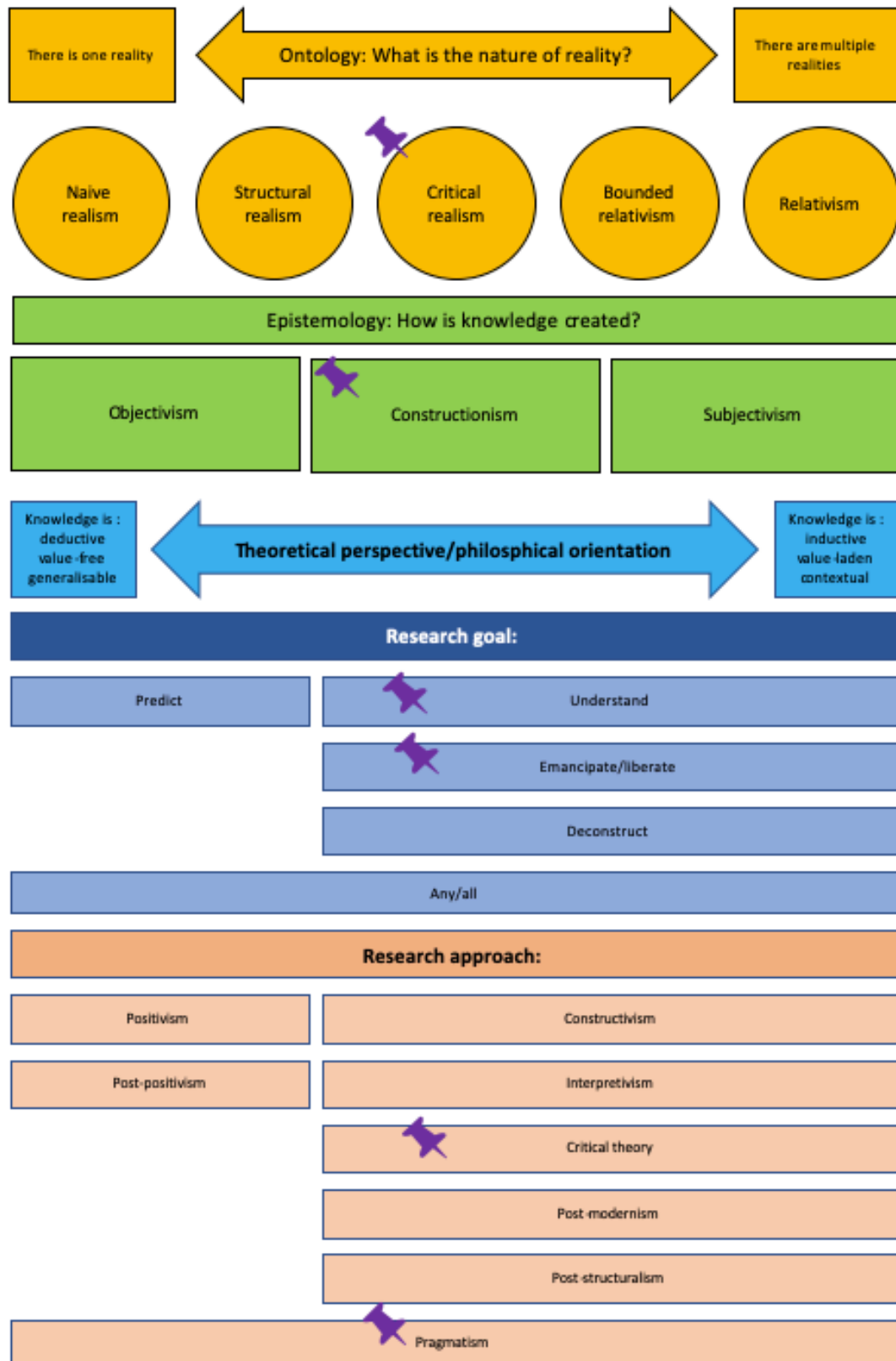


Figure 4-1 Methodology map

Critical realism offers a useful perspective that challenges typical debates about the polarisation between positivist and constructivist paradigms in social research and further informed the design of this study. To identify the nature of resilience in hospice inpatient nursing, a PAR approach was overall determined to be the best fit. Within this approach, one of the overarching aims was to identify relationships between the nature of adversity in palliative care, the ways these affect resilience, and ways in which resilience could be enhanced in this particular setting. Critical realism can accommodate an inquiry that may result in mixed methods to better understand the phenomena of resilience and associated causal relationships, without an over-reliance on statistical generalisations or one-sided accounts from actors' interpretations (Mills, Durepos, & Wiebe, 2010). Mills et al. (2010, p. 256) furthermore identify how critical realism could be used to *"explore, refine, and test the character of proposed mechanisms and contexts and the ways they link to outcomes"*. A participatory approach to research emerged in the 1980s by protagonists such as Friere and Habermas who believed that postpositivist approaches were insufficient to truly address issues of inequality, injustice or meet the needs of marginalised people (Cresswell, 2003). A critical theory perspective is concerned with empowering those where constraints are imposed through issues of race, class, power or other inequality.

To summarise the philosophical approach, this study was designed not only to understand resilience but to develop and test strategies to enhance it in the palliative care nursing workforce. I sought to generate knowledge based on the following explicitly stated assumptions: that there may be more than one truth and multiple

ways of knowing what that truth is. Reality could be different for people according to their own unique experiences and may not be deduced through empirical observation alone, where I would be a detached observer assuming no influence on participants. Finally, to address concerns that resilience is problematised at the level of the individual, it was imperative to conduct the research through a critical lens, acknowledging how political, societal and organisational influences may impact research findings. The diagram in Figure 4-1 supported the decisions about the research approach, resulting in the choice of PAR, which sits in the 'critical theory' category of the research approach section.

4.4 Participatory Action Research (PAR)

PAR is a scientific approach to improving a situation for participants, a community or organisation whilst increasing the understanding of the researchers, the participants and the community as a whole. PAR has been defined as

"a participatory, democratic process concerned with developing practical knowledge in the pursuit of worthwhile human purposes... It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concerns to people, and more generally the flourishing of individual persons and their communities" (Reason & Bradbury, 2008, p. 1)

Dick (2015) reviewed the SAGE Encyclopaedia of Action Research (comprised of 314 entries by respected leaders of the approach) and identified five key aspects which are not mutually exclusive and likely to be intertwined in practice. He found that action research is 1) extensive and united by values, intentions and processes; 2) usually participatory; 3) action-oriented and designed to bring about improvement; 4) contains critical reflection; and 5) uses cycles of action and reflection. Whilst there are many and varied types of action research there is consensus that all are characterised by a process of planning, acting and reflecting, as depicted in Figure 4-2 below.

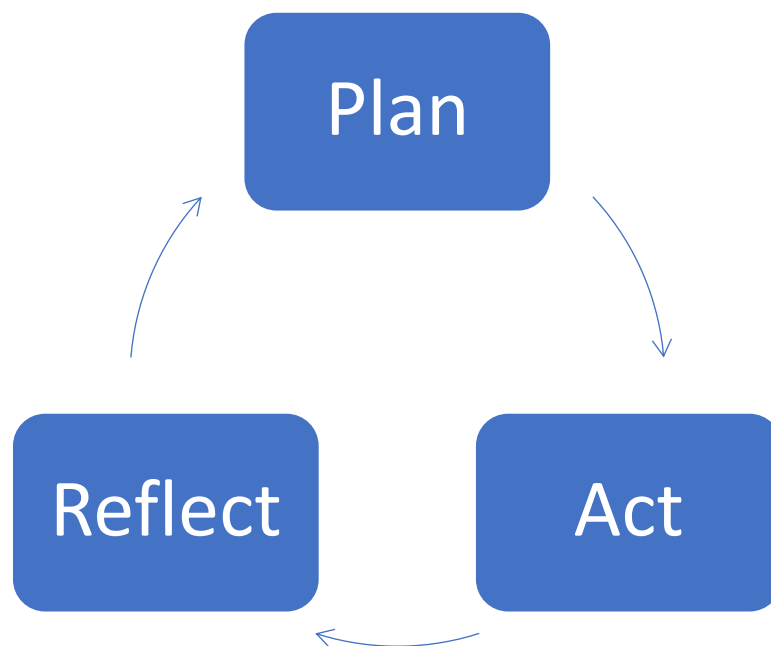


Figure 4-2 Action research cycle

4.4.1 Principles of PAR

PAR is an approach that, by definition, involves participation/collaboration and the generation of knowledge and action in one or more cyclical processes, as described

above. There are various descriptions in the literature of key underpinning principles that serve as foundations for PAR processes. In this study I used those described by Genat (2009, pp. 103-104) who suggests researchers strive to:

1. Establish reciprocity and an equal relationship of trust with the key group of research participants
2. Collaboratively develop a research project that is valued and of benefit to the key group of research participants
3. Build solidarity around a research question significant to the key group of research participants
4. Acknowledge, respect, value and privilege local knowledge
5. Facilitate learning and develop local capacity
6. Bring a self-reflexive component to practice by consistently interrogating their standpoint and use of power along the dimensions of gender, race and class
7. Ensure emergent representations are credible with the key group of research participants.

These principles were key to achieving some of the aims of this study, such as the inquiry into how nurses themselves saw resilience and identifying strategies for meaningful change.

4.4.2 Rationale for PAR

There were multiple factors to consider when designing the approach to this study. The nature of the research question aligns with a qualitative approach; to better understand a phenomenon that is poorly understood, especially in particular groups of people or settings (Cresswell, 2003). Common qualitative study designs in research with nurses include ethnography (based on anthropology) with a focus on culture (De Chesnay & Abrums, 2015); phenomenology and its focus on individual's lived experience of the world (De Chesnay & Bottorff, 2015); grounded theory and the importance of trust in emergence (Beck, 2013); and case study research with its focus on understanding real world phenomena in a given context (Cope, 2015). Each of these approaches would be applicable and useful to partially answer the research question in this present study, however, the aim here is to go beyond understanding and strive for transformation of understanding into practice that can bring about change for the better.

The decision to use PAR in this study was based on evidence from change management theory, where change is likely to be successful when *conducted with people* rather than *done to people* (Lewin, 1943). This approach means research is of the people, by the people, generated through critical reflection of experience, with the potential to generate theory (Torre, Cahill, & Fox, 2015). PAR can produce valid results when the expertise through research knowledge and expertise of participants combine to test generated knowledge in action by those stakeholders most closely invested (Brydon-Miller, Greenwood, & Maguire, 2003). The best research occurs when the needs of a

community coincide with scientific interest (Smith, Bratini, Chambers, Jensen, & Romero, 2010).

Creating an opportunity for nurses themselves to participate as co-researchers to generate ideas for action in their environment that could benefit them directly was a key aim of this study. Research that does not directly benefit subjects/participants, at least not for some time, due to the knowledge-practice gap is often criticised (Mackenzie, Tan, Hoverman, & Baldwin, 2012) and this influenced the design of this study. The number of resilience studies is increasing yet none appear to include registered nurses as co-researchers; thereby missing opportunities for local expert knowledge to be directly translated into meaningful action. PAR has the potential to bridge this knowledge-practice gap, to address real-world concerns and is done with participants in a study rather than to them (Zuber-Skerritt & Fletcher, 2007).

4.4.3 PAR limitations and challenges

Creating the potential for expert, local knowledge to be transformed into changes in practice for the betterment of a system, culture or organisation is not without its challenges. Burnes (2004) observes that any attempt to implement organisational change without due consideration to organisational culture, issues of power and appropriate scepticism is a flawed approach.

PAR is collaborative in nature, situation or context-specific and 'methodologically eclectic' (Zuber-Skerritt & Fletcher, 2007). With this in mind, it becomes impossible to prescribe all methods in advance of the study. The idea that the research could proceed without clearly defined methods a priori is challenging in PAR studies, particularly with regards to ethical review, yet Khanlou and Peter (2005) argue persuasively that it would indeed be unethical to prescribe methods without the involvement of the interested parties/stakeholders.

Action research can be described as 'fuzzy' (Dick, 1993) in that it need not begin with a precise research question, to be tested hypothetically with rigorously generated results and conclusions. However, this present study was underpinned by distinct research questions stated at the beginning of the chapter. These questions were useful throughout the PAR process when they were reconsidered and assessed for appropriateness as the PAR cycles were conducted. The purpose of the study, through the action cycles, is to render the outcomes less 'fuzzy' through the iterative refinement of the question, methods and answers as they are consequently determined through the process (Dick, 1993). The research questions were not changed in this PAR process, however, but the Cooperative Inquiry Group (CIG) recognised the potential for this, if required, based on emergent findings. Social science research typically attempts to generate knowledge either through quantitative studies that aim to produce generalisable, statistically significant results, or qualitative studies that aim to produce rich, detailed accounts of experiences. Action research differs in that it allows possibilities to include less impersonal voices, such as that of

the researcher(s) using first-person and second-person voices to generate data (Chandler & Torbert, 2003).

No predetermined philosophy underpins PAR per se. PAR may span a broad spectrum of approaches and may include various methods depending on the study design and could therefore align with a pragmatist approach. This may lead to criticisms of PAR with concerns that it becomes 'amorphous' and used as a label for 'sloppy research' that is ill-defined and planned (Hart & Bond, 1995, p. 39). This risk that research is amorphous, without coherent structure and methodological congruence may be amplified in PAR, where study design is not entirely prescribed a priori and is subject to evolution and change throughout the process. However, when an overarching framework or paradigm and any assumptions about the nature of knowledge claims, are explicitly stated, such risks can be mitigated (Cresswell, 2003).

Participation and action are underpinned by principles such as equalising power between researchers and the researched, sharing control about definitions, methods, analysis and actions, mutual trust and respect, solidarity and mutuality (Livingston & Perkins, 2018); others summarise the nature of PAR as democratic participation, cooperation and empowerment (Mackenzie et al., 2012). These principles sound fundamentally sensible however there are risks to assuming these principles are easily adopted. Dick (2015) cautions that well-intentioned empowerment can seem patronising and therefore requires skilled facilitation. This view is similarly echoed by Bergold and Thomas (2012) who helpfully identify the challenges of seeking views and

opinions from a group who may have dissenting views and may not share these for fear of appearing stupid or different. They liken this to how openness to this degree tends to happen more among friends, where relationships are developed over time and lead to levels of trust that support views to be heard. Brydon-Miller et al. (2003) demonstrate the importance of enabling and empowering those who may not share majority views and keep silent in the face of dominant opinions. Without these alternative perspectives, there is a risk that PAR creates knowledge that reinforces the perspectives of dominant groups (Smith et al., 2010). Adopting the principles of PAR and aiming for democratic participation attempts to mitigate this risk. Finally, there is a risk that PAR may not be successful and achieve the desired outcomes (Klocker, 2012).

4.5 Researcher positionality

Herr and Anderson (2015) assert that researcher positionality and reflexivity is vital to explore when undertaking any research, but especially so in action research approaches, not least because it determines the approach to epistemological, methodological and ethical issues. My position changed depending on the phase of this study. During phase one, where I collected data from participants, I conducted the analysis and then reported my findings as a precursor to stage two. This approach would be classified in Cornwall's (1996) mode of participation as partly 'consultation', as local opinions were asked and the outsider (me) analysed the results and then 'Cooperation', where we collectively determined the priorities for action, a process facilitated, but not dictated, by me. A different mode of participation was achieved

during stage two, which would be described as 'Co-learning'; where we shared knowledge to generate new understandings and worked together to form action plans. This was particularly important to generate knowledge that was context-specific and relevant to the nurses.

Positionality in this study was not straightforward. Ostensibly, it may seem most appropriate to categorise my position as "reciprocal collaboration" in Herr and Anderson (2015)'s matrix, which outlines six types of position, each with varying degrees of insider-ness and outsider-ness. I became very aware through the research process that I viewed myself as an 'outsider', yet the participants often included me in their collective stance on matters we considered, viewing me as an 'insider' because I too worked in a hospice.

4.6 Quality and validity in action research studies

Zuber-Skerritt and Fletcher (2007, p. 417) state that quality action research theses should meet the following requirements:

- 1) Be practice-oriented
- 2) participative
- 3) focussed on issues of relevance to the wider community/organisation/world, not just themselves
- 4) Use multiple perspectives of knowing
- 5) Demonstrate rigour in methodology to contribute new theory and practice

- 6) Be explicit about assumptions
- 7) Be reflective, critical, self-critical and ethical

Traditional notions of validity and reliability stem from positivist research, however, these are determined differently in action research, where authenticity is to be striven for. Authenticity occurs when results are recognisable and considered real to those involved in the study (Zuber-Skerritt & Fletcher, 2007). Data generated during this study were considered by participants throughout, with opportunities to reflect, challenge and discuss findings concerning their real-world experiences.

4.7 Methods

4.7.1 Recruitment - Site

PAR is considered complex and time-consuming, with researchers often spending more time in the field than in many other approaches (Herr & Anderson, 2015). A requirement for monthly site meetings, over a year, meant that the recruited site needed to be within relatively easy access of either my home or my workplace. Additionally, larger hospices were considered more likely to have sufficient numbers of trained nursing staff and this also factored into recruitment decisions. Hospital palliative care teams were not eligible as they have a different function, usually advisory, and do not have the same full-time caring responsibilities for patients.

London was chosen as the geographical location for the study, as there are multiple larger hospices and therefore more recruitment opportunities. Potential sites were

found using the Hospice UK (2016) website, which has a facility to search for registered hospices in any locality. The term “London” was entered for area and distance “within 15 miles” selected. Thirteen hospices were found. Three were discounted as they are children’s hospices, one because it was a duplicate (one hospice with two sites) and another for ethical reasons (my place of work). Whilst PAR can be successfully used in one’s workplace, it mostly occurs when issues of power are less problematic, such as in the case of researchers primarily investigating their practice. In the hospice where I work, I hold a senior position and I was concerned that this might negatively affect the research. The remaining eight sites were entered into an Excel spreadsheet in the order listed on the results page of the website and assigned a number from one to eight. A website (Randomizer.Org, 2016) was used to generate a random list of numbers from one to eight and the hospice that corresponds with the first number in the list was sent information about the study and invited to participate. This approach to site selection was not because of a philosophical alignment with a positivist approach, rather that I knew my counterparts in some other London hospices and considered this a way of selecting a site fairly and without undue influence. It would also avoid a situation where multiple hospices could request participation when only one was appropriate for the study. The first hospice I approached did not respond, therefore the second hospice was contacted and subsequently agreed to participate.

The recruited site is an independent charity that cares for more than 4000 patients every year with an inpatient registered nurse workforce of 21 wholetime equivalent nurses. The site agreed to support a minimum of six and maximum of twelve staff to

participate throughout the study. They have a facility to support staff psychologically/emotionally (if necessary) because of participation, through an employee assistance programme. This service is confidential, and no participants reported needing to use it. I met with the senior staff to explain the project in detail and answered any questions they had before recruiting participants.

4.7.2 Recruitment – Participants

Existing resilience research in palliative care settings tends to be multidisciplinary (Back et al., 2016; Perez et al., 2015) and/or multi-site (Levine et al., 2017; Sansó et al., 2015). Embedded in such approaches is the assumption that resilience is generalisable across different settings and different professions. As previously stated, nurses are the professional group that spends most time with patients during inpatient stays and are likely to be the group of staff who respond to patients' distress in the first instance. Alexander et al. (2014) found that emotional distress was very common during palliative care consultations in hospitalised patients; expressed frequently as fear, anxiety and anger. However, the research included a variety of professionals and it is unclear to what degree nurses were exposed to these challenges compared with their non-nursing colleagues. Given the concerns about the nursing workforce outlined in the introductory chapters, this present study was designed to explore resilience from this particular group of professionals, rather than assume they experience challenges in the same way as other disciplines, regardless of workplace setting.

One of the senior managers at the recruited hospice notified all registered nurses (RNs) of the study, by circulating an email that included the Participant Information Sheet (PIS) (Appendix 4). The RNs were invited to contact me directly to participate in phase one (qualitative individual interviews) or phase two (PAR based on findings from phase one) or both phases. The inclusion criteria for participation can be seen in Table 4-1 below. Participants were given opportunities to ask questions about the study before deciding whether to consent. The consent form can be seen in Appendix 5 and was signed at the initial meeting.

Table 4-1 Participant inclusion criteria

Criteria	Phase one	Phase two
Works more than 15 hours per week in the inpatient unit	✓	✓
Agree that interviews will be recorded, transcribed, analysed and results will be shared with the hospice	✓	✗
Willing to keep a reflexive electronic journal (sent weekly to the researcher for analysis)	✗	✓
Willing to attend monthly meetings, lasting up to 90 minutes each for up to one year	✗	✓
Willing to have meetings audio recorded and data analysed/shared with hospice	✗	✓

The participants in the study could be easily identified if characteristics are described at the individual level, therefore summary information is presented to preserve anonymity and where characteristics are thought to influence findings, these are

discussed in the discussion chapter. Of the eight participants, four were British and four were non-British. All were female and had worked in the hospice for an average of 21.3 months ($s=10.5$) at the start of the study. The average age was 39.5 years ($s=10.3$) and the average time since qualification was 9.9 years ($s=7.6$).

4.7.3 Data collection

Data were collected differently according to the two phases of the study:

4.7.3.1 Phase one

Seven registered nurses with experience of hospice inpatient nursing care (per inclusion criteria above) participated in an individual qualitative, semi-structured interview lasting up to 90 minutes to identify individual perspectives on the nature of resilience and factors that influence it using a topic schedule (Appendix 6). The interviews were audio-recorded and transcribed verbatim by an independent professional who signed a confidentiality agreement (Appendix 7). A key function of the interviews was to identify potential barriers and/or facilitators to resilience that may form the basis for change projects in phase two.

4.7.3.2 Phase two

Phase two began with a presentation of the findings from phase one to all relevant interested stakeholders, including all inpatient registered nurses and senior managers. This presentation was designed to pique interest in joining a Cooperative Inquiry Group (CIG) for the PAR element of the study. Cooperative Inquiry is an approach

where a group of people with a shared interest join together in processes of action and reflection whilst working towards meaningful change. Livingston and Perkins (2018) recommend that meetings are held before starting a research project with all those who may be interested, not just with participants once the project has started, to ensure there are as much engagement and involvement as possible from the beginning. This engagement is said to increase effectiveness and improve the quality of decision-making (Mackenzie et al., 2012).

According to Bergold and Thomas (2012), there are fundamental principles of participatory research, including democracy, creating a 'safe space'; defining the community, and understanding the varying degrees of participation possible. With regards to democracy, the willingness of the recruited organisation to embrace a participatory approach to improving conditions for its staff could be considered a litmus test for a democratic self-concept (Bergold & Thomas, 2012).

The CIG was established with four registered nurses agreeing to participate. Three of these nurses also participated in the individual interviews and the fourth joined slightly later as a result of the first action cycle. To maximise adherence to the principles described above, the first CIG meeting established collaboratively agreed ground rules as follows: to attend to issues of mutual respect, confidentiality and managing expectations; to achieve a shared understanding of the construct of resilience and how participants relate to the topic; to understand the research process including PAR

methodology; and finally, to understand the principles of action cycles: inquiry, action and reflection (Brydon-Miller et al., 2003).

To empower all participants to have a voice and contribute to a greater understanding of the nature of resilience in their workplace, a safe space was essential. This study relied heavily on participants engaging with the topic and disclosing thoughts and feelings that might otherwise be unexpressed, and therefore sensitivity, confidentiality and respect were key. The first meeting of the group focussed on creating the group agreements and conditions that could be expected of one another and we used the following three steps outlined in the Future Workshop Methodology (Andersen & Bilfeldt, 2016) in an informal way to guide the CIG process:

Step 1: The Critique Phase – identify what is wrong and what we want to change

Step 2: The Utopian Phase – identify what the perfect scenario would be

Step 3: The Realisation Phase – identify which Utopian ideas can be transferred into reality.

The transferring of ideas into reality per PAR principles involved ascertaining the answers to the following questions in each cycle: WHAT will be done? WHO will be involved?; WHERE will it take place?; WHEN will each stage happen?; and HOW will we do this? This information was captured in an agreed template by the group (Appendix 8) and considered data for the study.

4.7.4 Data analysis

Two main data sets were generated from this study; one from the individual interviews in phase one and another from the PAR cycles in phase two. I analysed phase one data independently using Thematic Analysis according to the six steps outlined by Braun and Clarke (2013) in Table 4-2, to identify a) what the data is concerned with, b) overarching topics that the data connects with; c) what is happening; d) what people are doing; and e) how people interpret what they do (Bryman, 2012). The analysis was facilitated with a professional transcription of interviews which were uploaded into NVIVO software (QSR International Pty Ltd, 2014).

Table 4-2 Thematic analysis steps

1	Familiarizing yourself with your data
2	Generating initial codes
3	Searching for themes
4	Reviewing themes
5	Defining and naming themes
6	Producing the report

Braun and Clarke (2006) argue that thematic analysis is a method in its own right and should not necessarily be seen as an adjunct to other methodological approaches to qualitative research. Phase one interview data were actively analysed to identify themes and patterns related to resilience that would likely be of interest and further knowledge and practice. This proactive analysis goes beyond 'giving voice to

participants' which suggests themes passively reside in data and are waiting to be discovered (Braun & Clarke, 2006, p. 7). Furthermore, thematic analysis can straddle a variety of research approaches or paradigms, to identify experiences, meaning and reality for participants and is considered suitable for the contextualised understanding of phenomena.

Themes are identified based on utility to the research question and do not depend on frequency across data sets. An absence of predetermined rules about the nature of themes is a challenge when analysing qualitative data yet when done well can develop and enhance what is known about a topic (Braun & Clarke, 2006). Thematic analysis itself can be inductive or theoretical depending on how much the analysis is influenced by pre-existing theory. Given this study was designed to explore resilience from the perspectives of nurses themselves, I was keen to adopt an inductive approach to the analysis, albeit recognising that I would be influenced both by previous theoretical knowledge and my philosophical assumptions. Where these influences can be known, they are acknowledged explicitly. In this way, data can be analysed at the latent, not just semantic level, with a search for underlying theoretical implications rather than simple descriptions of the data (Braun & Clarke, 2006).

I followed the steps in Table 4-2 to develop an analysis of the interview data. This began with familiarisation through a process of reading and re-reading to identify patterns and meanings. This process was aided through extensive note-taking and ensuring the transcribed, verbatim accounts were accurate accounts of the interviews

held as sometimes, misplaced punctuation for example, can dramatically alter the meaning of participants' speech. I sent each participant their transcript for review and received no requests for amendments.

Step two involves the generation of initial codes based on what I found interesting about the data and were formed according to elements that could contribute to an understanding of the phenomena of resilience. Codes were predominantly data-driven but theoretical knowledge may likely have influenced coding to a degree. First attempts at coding generated hundreds of codes which I realised I had begun to interpret too soon. These codes were reviewed and revised to ensure they were the most basic segment of the data that could be meaningfully assessed (Braun & Clarke, 2006). This approach was applied to the entire data set. An example of early codes that required further development can be seen in Appendix 9. The final code structures, as they relate to identified sub-themes and themes can be seen in Figure 5-1 and Figure 5-2.

Step three is the process of identifying themes from the coded data. This process was aided with NVIVO and the use of an Excel spreadsheet to develop both themes and sub-themes and the relationships between them.

Step four is the process of reviewing themes and this stage took much longer than originally anticipated. I realised I tended to group things according to similarity and then label the codes with a superordinate description of the contents. Braun and Clarke (2013) caution against this type of bucket coding and suggest it means

insufficient attention has been paid to the data. This process culminated in a review of the themes across the entire data set with multiple iterations and development as the themes were tested against all data and each other.

Step five is where themes are defined and named, reviewed to ensure that the essence of the theme sufficiently captures the data within it. This process involved renaming themes to accurately reflect the contents and developing a story that could contribute to the overall narrative about resilience in this context.

Step six was the final stage in which the results were written up so they could be shared with stakeholders. Sharing the findings served several purposes. Firstly, participants were able to consider them, and they reported that the findings were indeed believable and authentic, an important validity check in action research. Secondly, the findings were explained as potential areas for a PAR change process in phase two of this study.

Phase two data were largely analysed collectively by the CIG with the method of analysis depending on the actions that were generated and tested. Due to the heterogeneity of methods involved, these are made explicit in the section of PAR cycles in the findings chapter. Notes from each meeting were written and circulated amongst the group for comments and changes if required. These notes were then uploaded into NVIVO for further analysis and integration with findings from phase one. Of interest was the need to identify factors which influenced resilience, whether

individual, interpersonal or organisational. Where these factors were identified through CIG discussion these are reported in the findings from the associated action cycle. Where these factors are identified based on my own reflection, these are reported in the critical reflection section in the summary at the end of the findings chapter.

4.8 Ethics

In this study, the six core principles developed by the Economic and Social Research Council (ESRC, 2020) were used. Ethical approval was granted by the Faculty of Health and Medicine's Research Ethics Committee at Lancaster University in February 2017 (Appendix 3) and with the recruited site. The six core principles are described further in sub-headings below:

4.8.1 Research should aim to maximise benefit for individuals and society and minimise risk and harm

One aim of this study was to improve resilience for nurses working in palliative care and therefore participants described experiences in which resilience was felt to be compromised. Psychological distress could ensue, and this was carefully considered to minimize the potential for harm. No participants expressed psychological distress during the study.

4.8.2 The rights and dignity of individuals and groups should be respected

PAR is a collaborative process and the initial meeting between co-researchers established the ground rules and values that underpinned how the group works. These

ground rules and values were recorded and available for each subsequent meeting as an aide-memoire to treat all members with dignity and respect. In keeping with the approach, this list was generated and discussed by all participants and included mechanisms for ensuring that all voices are treated equally regardless of faith, ethnicity, sexual orientation or disability. Participants were free to leave the study at any time without explanation or repercussion.

4.8.3 Wherever possible, participation should be voluntary and appropriately informed

Information was shared with participants in advance, including the research proposal, a participant information leaflet, ethics application and a consent form. Opportunities for participants to contact me directly to ask questions were provided and participants were accepted into the study after due care to ensure they had read and understood the study design and voluntary commitment required.

4.8.4 Research should be conducted with integrity and transparency

One reason PAR was chosen for this study was the inclusive, collaborative nature of the approach with a commitment to transparency and joint decision-making. PAR is underpinned by a value-driven approach to improving things for those concerned. Mechanisms for recording decisions and actions were essential and any areas of discord were highlighted and worked through to reach democratic decisions about actions. A clear audit trail of all elements of the study was available to the group at

each stage in the PAR process. Sound ethical principles are likely to lead to better quality research, with the underlying constructs that inform the beliefs we have, and the choices we make are made transparent as a part of the research process (Coghlan & Brannick, 2014). These active decisions to explore and follow ideas collaboratively, under the auspices of the sound ethical principles described above enhanced a commitment to working together to bring about worthwhile change.

4.8.5 Lines of responsibility and accountability should be clearly defined

My position as a PhD student at Lancaster University was outlined in the supporting documentation for participants. My research supervisors and their contact details were highlighted in the Participant Information Sheet in addition to the faculty lead for any issues that participants wished to discuss independently of these relationships. In PAR, participants must understand the collaborative nature of the approach, with shared responsibility for evaluating and decision-making throughout the process. However, the ultimate responsibility for monitoring the project and ensuring risks are minimised was mine and I sought support and guidance from supervisors whenever clarification was needed.

4.8.6 Independence of research should be maintained and where conflicts of interest cannot be avoided, they should be made explicit.

I deliberately conducted this study away from my workplace to avoid potential conflicts of interest. There was some possibility that participants may be known to me

through professional networks, however, this was not the case with the recruited participants.

4.8.7 Consent:

Eligible nurses were given written information about the study and an opportunity to discuss any involvement before deciding whether to participate. Informed consent in PAR necessarily focuses on ensuring participants understand the processes involved and that action cycles vary and are dependent on discussion and negotiation. It is impossible to say in advance of the study exactly what may happen and therefore particular attention was paid to ethical issues throughout the research process.

4.8.8 Confidentiality and Anonymity:

Participants are not identified in this thesis and are therefore guaranteed anonymity with regards to this component of the research. In respect of the action cycles within PAR, however, many participants prefer to be identified and credited with the work they do, and this must be considered carefully, especially when the work is owned collectively. Ownership and confidentiality were negotiated within the first meeting, so the group had a shared understanding of confidentiality and this was carefully documented in the meeting notes. Circulated notes did not use full names of participants and agreement was sought during the first meeting about how best to identify participants in written communication to aid learning, avoid confusion and respect confidentiality.

4.8.9 Data storage and access:

This study involved generating data in different ways and this necessitated careful consideration of data storage and access. Reflective Journals belong to the individual participants and were to be submitted weekly for analysis. During the process, however, the nurses informed me they did not have time to complete these journals and we collectively agreed they would share insights during the CIG meetings instead. Meeting notes were written by me and circulated after each meeting to all members of the group for review and discussion. These notes captured all planning and decisions made. Audio recordings were kept securely by me for analysis for the PhD award and to assist in the accurate summarising of meetings in the notes (described above). The recordings of the groups were not made available to individual participants but audio recordings from individual participants could be shared with the interviewee only, upon request. Individual interviews were transcribed verbatim by a professional transcriber, subject to a confidentiality agreement. All data was kept securely on Lancaster University's encrypted storage facility and accessed only via my password-protected computers.

4.9 Methodology summary

PAR was considered an appropriate methodological choice for this study to explore the phenomena of resilience from the perspective of hospice inpatient nurses and create opportunities to change practices that may enhance resilience. PAR has the potential to develop knowledge about theory and practice in particular contexts and

was chosen to address the gaps in the extant literature. Existing literature on resilience tends to focus on positivistic variables related to perceived traits, and therefore not necessarily related to particular adversities. Furthermore, resilience studies in palliative care assume there is little difference between professions. Typically, interventions are often designed in advance and without active engagement of participants as co-researchers.

The next chapter reports the findings that resulted from the approach outlined in this methodology chapter. In summary, the approach was deliberately designed to address gaps and offer a novel contribution to the resilience literature in the following ways: resilience was explored from the perspectives of nurses; a definition of resilience was posited and subject to critique throughout the research process; elements of power, control, context and politics were considered influential throughout the process; and finally, nurses were supported and encouraged to design strategies to enhance resilience from their perspectives, rather than adopt researcher imposed interventions.

Chapter 5 - Findings

In this chapter, the findings from both phases of the study, from one hospice, are presented. Phase one consisted of individual interviews designed to identify barriers and facilitators of resilience to form the basis of intervention in phase two. Phase two consisted of the formation of a Collaborative Inquiry Group (CIG) that developed action cycles of planning, acting and reflecting on the problems and interventions that were collectively agreed. In phase one, seven registered nurses participated in individual interviews, designed to identify the nature of resilience, from their perspective, in their particular workplace. Interviews were transcribed verbatim, and subjected to Thematic Analysis (Braun & Clarke, 2006), culminating in two overarching themes:

1. The nature of adversity in palliative care nursing
2. Constructing meaning from adversity prepares nurses for the future

5.1 Adversity in palliative care nursing

The conceptual map in Figure 5-1 demonstrates how three sub-themes were developed to describe how the nurses in this study perceived adversity in their work.

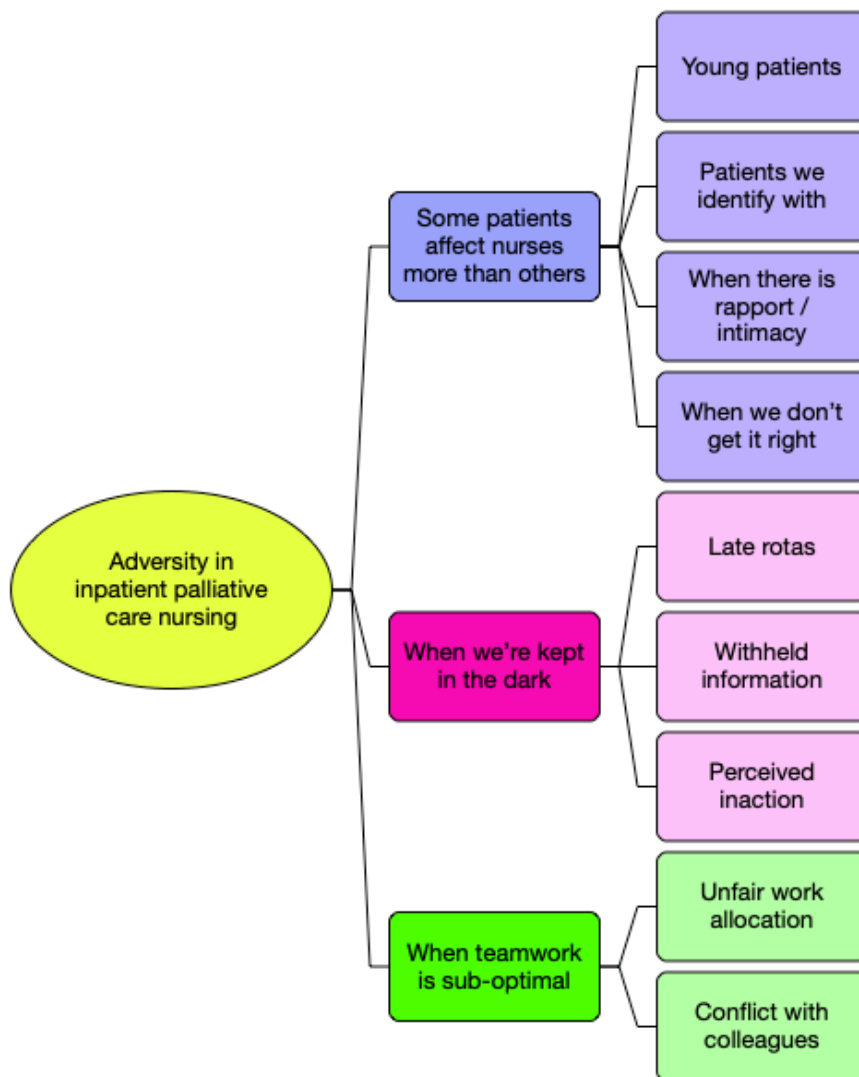


Figure 5-1 The nature of adversity in palliative care nursing

5.1.1 Some patients affect nurses more than others

There are particular types of patients that the nurses found challenging, regardless of impending or actual deaths. These patients included the young; those with whom the nurses identified with most strongly; where there were higher levels of rapport/intimacy; or when the nurses believed they did not 'get it right' for patients.

The nurses expected to deal with death when working in a hospice and described how this is inevitably linked to sadness both for them and for the families they support. They accept this is part of the role they inhabit, by adopting a philosophical approach to life and death:

"I know that every person is going to pass away so it's, you know, I'm not happy with that but I cope well with that, it's okay. So, we're born, we grow up, we have children or not and then we die. So, it's okay." (P02)

Some patients are harder for nurses to care for than others, especially those the nurse identifies with due to proximity in age, background, or shared values; especially where this leads to a greater sense of rapport or connectedness:

"If you're an emotional person, your first emotion is to get involved and you're normally affected. In that case, I saw some colleagues have difficulties, especially if their favourite one is dying or something" (P04)

The nurse quoted above captured the nature of enhanced rapport with her description of some patients who become the nurses' 'favourite'. The relationship also appeared to intensify when the nurses identified with the patient, further compounded due to longer periods of inpatient stay.

When nurses perceived they did not get it right, this caused stress both in the workplace and outside in their time off. When patients died in pain or had

uncontrolled symptoms, this bothered the nurses, leading to feelings of guilt that persisted over time:

"I sometimes feel guilty, if a patient is dead in great agony or pain or sometimes, we try our best with pain management. With some patients, it's very difficult to do. Yes. I think in that case, we often feel so bad and it's a very lasting... quite a long time. ..." (P04)

Whilst acknowledging the stressors inherent in caring for patients, the nurses explained how the patients are the greatest source of satisfaction in their work and issues with their colleagues and/or the organisation were far more problematic:

"but the thing the most stressful is not the patients or the family, most stress is the staff, the colleagues or the team, for me is not the patient or the families, the environment and the colleagues or the doctors or the you know, the team is the most stressful, not the family or the patient" (P02)

In summary, some patients are likely to affect resilience in the inpatient nursing workforce, especially when there is a connection that leads to more intimacy in their relationship. Nurses did not report that death and dying per se affected resilience and were more likely to be troubled by issues with their colleagues. Adopting a philosophical approach to life and death appeared to help them cope with the challenges of their role.

5.1.2 When nurses are “kept in the dark”

Three sub-themes combined to form the main theme of ‘kept in the dark’: late rotas, withheld information and perceived inaction.

The rota was the biggest source of stress for staff and affected all nurses, resulting in a collective culture of complaining that it negatively affected mood and morale. One nurse exclaimed how she perceived the lateness as indicative of a lack of respect for nurses:

“The rota is always late. I cannot plan my life... it is a lack of respect for us!” (P03)

Participants also believed that better communication about the reasons for rota lateness may prevent staff from feeling disrespected. Staff acknowledged there may be reasons why the rota could not be produced with sufficient notice and thought that explanation could go a long way to mitigating the frustration they felt.

Advance notice was one rota factor that the nurses believed could improve their ability to withstand work stressors. Another factor was the ability to work shifts that suited their circumstances. This made a difference to their work-life balance and resulted in them feeling happier at work and better able to cope with any challenges.

When nurses believed that information was withheld from them, including issues related to the rota described above, this caused them to feel stressed. Similarly, when staff do not know what is expected of them due to an absence of clear guidance or

procedure, this can also be unsettling, especially for new or inexperienced nurses. An example was the implementation of new practice regarding the administration of controlled drugs, however, there was confusion and dissatisfaction due to perceived lack of information/consultation about the change:

“What doesn’t help is there’s a lot of paperwork for patients, and I think there, for me there’s lack of communication and it’s like if you ask someone, how do they do this and they give you different answer... so, if you was to [ask] five people, five people is doing five different things. So and I think this is not good” (P04)

The nurses repeatedly highlighted the importance of good communication, emphasising how this may often mitigate the stressors frequently encountered in the hospice. When there was a lack of information and communication, nurses reported feeling alone and isolated. The relationship between felt levels of stress and feeling alone was exemplified when nurses described how issues were often manageable on the workplace but played on their minds when away, such as when they were on holiday with more time to think.

A shared approach to problems helped to overcome some of the feelings of isolation and solitude that nurses may feel in busy environments where there is little opportunity for dialogue and contact with their peers, due to workload, short-staffing, over-reliance on unfamiliar agency staff or a general lack of dedicated time together.

Nurses being able to spend time together is contingent on the way staffing is organised and may explain why all participants felt very strongly about the unit's rota.

Nurses report feeling better about issues when they are kept informed, as in the case of the rota notice mentioned above. Similarly, nurses felt stressed when they perceived that issues were not being dealt with, followed up or communicated effectively. Whilst there was some recognition that on occasions this lack of communication might be appropriate (for reasons of confidentiality, for example), the nurses were negatively affected if communication about a range of issues was not complete or timely.

The nurses acknowledged how stressors or challenges are inevitable in the workplace but often referred to a perception that issues were 'swept under the carpet' and they found this difficult to bear. One example was a belief that some staff, in particular, were permitted to bully other staff and the perceived lack of action (from management) about this seemed to bother the nurses more than the bullying itself.

"every time we complained [we were told] that it is in hand or we are dealing with it and because everything is confidential they didn't see that actually a lot of work was going into sorting the situation out, helping the nurses, but they didn't see it because no one was open with them and said we can't give you the details, all I can tell you is this is our aim or this is what we are sort of doing or this is all I can tell you" (P05)

The need for good communication between all levels of the workforce is apparent and nurses feel better about issues when they are kept informed rather than 'kept in the dark'. Where it is not possible to be told information, due to confidentiality requirements, they appreciated being told so. This level of communication appears to require a level of openness and honesty, which is more likely to occur when teams are supportive.

5.1.3 When teamwork is sub-optimal

There are many ways in which a workplace team could be high-functioning and work effectively together, some of which are discussed further in the next section. However, there were two main ways that nurses reported teamwork to be sub-optimal in this study. They lamented on issues related to conflict, and when work was unfairly apportioned – either through formal allocation, or a perceived unwillingness by some to 'pull their weight'.

Conflict with colleagues negatively affected staff, especially when related to issues that were not focussed on the patient's best interests. One nurse highlighted that it is only natural to disagree with colleagues, and indeed, such disagreement may be healthy, but the patients' needs should remain paramount:

"in palliative care we need to be, we need to have a common goal that we cannot agree in something, but we don't need to agree in everything, you can have your ideas and I can have my ideas but I

*think we need to be scientific when we talk about our ideas and so
we have to think in the best interest for the patient” (P02)*

Almost all of the nurses referred to an especially difficult earlier period with a medical colleague whose style of relating left nurses feeling unvalued and disempowered in their professional role. The nurses’ confidence was undermined, and some left the organisation as a result. Sub-optimal teamwork has a negative impact on the nurses in this study, whether related to bullying, conflict, or perceptions that work is distributed unfairly.

5.2 Summary – adversity in palliative care nursing

Nursing is considered a stressful profession and typical adversities reported in the literature include death and dying, workloads (due to staff shortages) and rota management. The findings from this present study partially concur, with the rota management in particular. However, the nurses did not find exposure to death and dying stressful per se. The death, dying or suffering of patients with whom the nurses bonded was likely to be the most challenging adversity to overcome in the palliative care inpatient setting.

5.3 Constructing meaning from adversity prepares nurses for the future

Making sense of adversity when it occurs helps prepare nurses to deal with future challenges, as demonstrated conceptually in Figure 5-2. Making sense of adversity, in this context, appears to rely on mindset, team support and the development of a coherent narrative through telling their story and reflecting on experience.

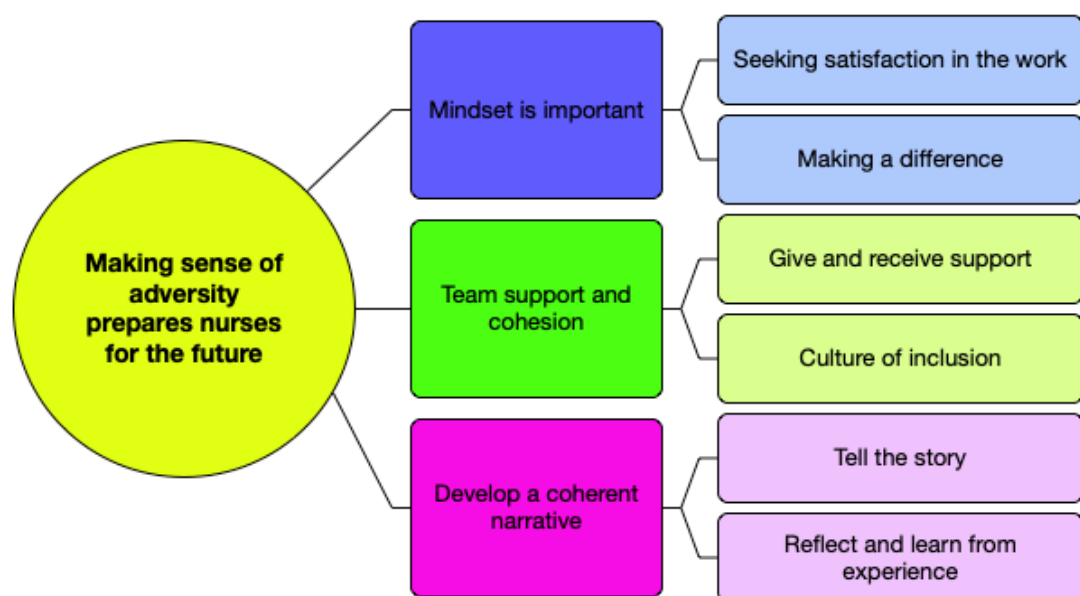


Figure 5-2 How nurses make sense of adversity

5.3.1 Mindset is important

Nurses described certain mindsets that appear to help them cope with the demands of their role. Those who reported the ability to find satisfaction in their work and appreciate how they made a difference to patients and families described how this mitigated the impact of workplace stressors.

One nurse described nursing care as an opportunity to learn about life and believed such lessons were akin to an “extra salary” (P02). Furthermore, these lessons appeared to be learnt due to the individuals’ receptivity, underpinned by a desire to continuously improve:

“the nurses here, with the exception of very few, want to be the best.

They want to be really, really good” (P05)

Striving for improvement underpinned a desire to reflect and learn from experiences. Such an approach seems to be closely aligned with a conscious acceptance of certain realities, for example, that all patients are going to die, that no workplace is perfect, and an ability to recognise sources of satisfaction in the work, wherever that could be found. Accepting and acknowledging the realities of palliative care nursing work appeared to mitigate the impact of stressful events.

Nurses found many elements of their work satisfying, especially when uncontrolled symptoms can be improved or when family members express gratitude:

“especially when the patient has passed away and you know your relative or your patient, your relative just passed away the first thing you’re going to do what, is cry but no, they come to the nurse and they say thank you” (P02)

Flexibility in approach and mindset appeared to contribute to changes in beliefs and behaviours with patients to improve care and better tolerate presenting challenges.

One example was the nurse who reconceptualised patients perceived to be 'demanding' as 'suffering' instead:

"this is not about me, this is because they are in very stressed moment, a very stressed situation and my role here is try to find where is the suffering or why is the suffering and try, and which kind of suffering, I can make any interaction to decrease the suffering, and so if you decrease the suffering you decrease the [distress]" (P02)

In summary, when nurses are psychologically adept/agile in their responses to adversity, this appears to enhance resilience. The key findings in this area were that nurses who actively seek satisfaction in their work and maintain awareness of how their work makes a difference, are likely to experience enhanced resilience.

5.3.2 Team support and cohesion

When faced with stress/adversity there is a need to articulate and share the experience. This sharing of experience appeared to take different forms for different people and there was no 'one size fits all' approach. Some nurses sought support from their peers, and this was more likely when there are good connections and relationships:

"I speak about the complicated or the death that touch you, is helpful I think. And not with your friends or with your family, it's in your place of job, and not with the colleagues you don't like, it's with a colleague you more or less have a good relation" (P02)

A key element of support seeking was that it was directed towards those who would understand the issues involved, rather than friends and family or external professionals. One participant stated, *“you are going to want to go to someone who gets it” (P05)*. Social support was considered important, however, tended to be non-specific and would not necessarily be used to articulate the exact stressors involved in palliative care work, such as dealing with death and dying or heightened emotions in patients and their relatives. Similar criticism was levied towards external clinical supervisors, who may not readily know what it is like to work consecutive nights, or the relevance of certain things that are common knowledge to the ward insiders.

Participants seemed certain that this need to share through the giving and receiving of support is a component of resilience and expressed concern for those who appeared to be resilient or able to cope without doing so:

“resilience to me is someone who appears they can get on with things and manage things and cope, but I think we also need to be mindful that someone can put a façade on” (P03)

This suspicion that all may not be as well as it seems with colleagues led the nurses to develop a culture of looking out for one another; monitoring and caring for colleagues in a similar way to their care for patients, to *“look for signs of distress, even with each other” (P03)*.

Members described numerous examples of wanting to belong, with a shared identity and sense of working together to achieve aims and objectives. This shared endeavour becomes more apparent when it was challenged or threatened in some way, such as when consultants disagree with each other or try to implement changes that are contradictory or considered unnecessary. This leads to a sense of us and them, which was experienced as unhelpful and stressful by the nurses, especially if patient outcomes are negatively affected:

“there is always going to be a what could we have changed there, what could we have done differently, especially with him because, you know, 6-week courses of IV antibiotics for no reason but he got exactly what he wanted under our last consultant, and then he went and died in hospital” (P05)

One way in which a sense of team was established seemed to be through shared ‘moaning’ or ‘complaining’ about issues, however, some wanted to go beyond the complaining and bring about change for the better. The nurses reported how a division between those who wanted to change, and those who did not, could undermine resilience.

Team cohesion and honest communication appear to lay the necessary foundations for a crucial element of resilience: the ability to support one another. Support takes many forms in the hospice and it is clear that one size does not fit all, as different staff

need different things to do their best when providing care in often challenging circumstances.

5.3.3 Develop a coherent narrative

When nurses reflected and learned from adverse experiences, they were better prepared to encounter similar situations in future. This learning and processing did not happen in a vacuum and it appeared that telling the story to others was fundamental to the construction of a coherent narrative.

“I need to of course look after the patient and try and do all this right, it’s completely crazy but exciting as well because in this situation I learn more and more what I need to do” (P01)

All nurses described how they reflected on their practice and considered how this impacted on their own beliefs and value systems. This willingness to learn and critique practice was considered necessary, even if difficult to do, to develop as a nurse and improve care for patients in the future. One participant described generically how *“past experience really helps me”* and *“we are talking about how we felt, what we can do, or what we can improve”* (P04) when facing challenges in the role; another experienced a particular challenge when caring for someone with whom she closely identified:

“It is something that I will never forget. It was a really good learning point for me. But it did make me realise that actually I wasn’t quite as resilient as I thought I was but I think I’ve been better since” (P05)

Learning was not limited to personal experience or practice. Nurses described how they learned from their peers but even more so from their patients:

“if we see the regret for something, don’t regret, ... people regret because they didn’t travel or... because I spent twenty years with the husband who didn’t love me at all, I regret because I spent thirty years in the job I didn’t like it, you can make your decision, not through these patients but thinking about, reflecting about yourself, okay, don’t want to be at end of my life regretting the same that they are regretting, so I should change before, to get the end of life. So I think they are our teachers” (P02).

This attitudinal change, prompted by reflection on the experiences of their patients was similarly mirrored in another nurse who described the transformation in her personal life:

“I like my life more intense than I did before because I’m more conscious. We never know what’s going to happen... I don’t do any drama in my private life now” (P01)

One nurse, through the process of reflection, recognised the need to maintain appropriate boundaries with patients and not give away too much information about oneself when patients demand a level of intimacy beyond that which is comfortable. She realised that giving too much to patients can *“ruin you” (P05).*

When nurses articulate their experiences of adversity, reflect and learn from these experiences, they may then transform this learning into enhanced self-awareness that creates opportunities to be or act differently in future. Nurses who make sense of their experiences appear to gain a greater understanding of their attitudes, perceptions of themselves, and their role.

*“if you know why you are here, it’s another thing that helps you to
get up in the morning then and continue the job you are doing’ and
‘if you know why you are here it’s easier to be here” (P02)*

5.4 Summary - Constructing meaning from adversity prepares nurses for the future

In summary, resilience is enhanced when nurses consciously adopt a mindset that involves seeking satisfaction in the work they do and remind themselves that their practice is meaningful and makes a difference. Furthermore, when there is a sense of belonging to an effective team that both gives and receives support nurses benefit from opportunities to share their stories and experiences with colleagues who understand. This sharing of experience appears both cathartic and educational; learning from others’ experiences seems to increase capacity to deal with similar events in future. The next section reports how nurses considered the findings from phase one and developed strategies for change.

5.5 Phase two - PAR Action Cycles

The Collaborative Inquiry Group (CIG) met twelve times at monthly intervals over one year and consisted of a maximum of five and minimum of three members. The first meeting democratically agreed on the principles and rules of the group, followed by reviewing the findings from phase one. There were five areas for action identified based on the findings generated from phase one:

- 1) Insufficient nurses in the Collaborative Inquiry Group
- 2) Nurses feel 'kept in the dark'
- 3) Teamwork can be sub-optimal
- 4) Nurses are affected by some patients
- 5) Nurses need to tell their story

Each of these five areas was subjected to the PAR process (Plan, Act, Reflect) per Figure 5-3 below. In some cases, multiple actions were taken within each of these areas and to assist with description and flow, these are reported within the 'reflection' section when this occurs as a direct consequence of CIG reflection on previous action. Quotes from the data are presented in various ways, either as direct quotes from participants (expressed as CIG 1,2,3 or 4), or quotes from the meeting notes which were typed immediately after the meetings and circulated to all CIG members. These notes were agreed for accuracy at the start of the subsequent meeting.

A diagram to show the overall structure of the project and the relationships between the PAR cycles and identified issues can be seen in Figure 5-4.

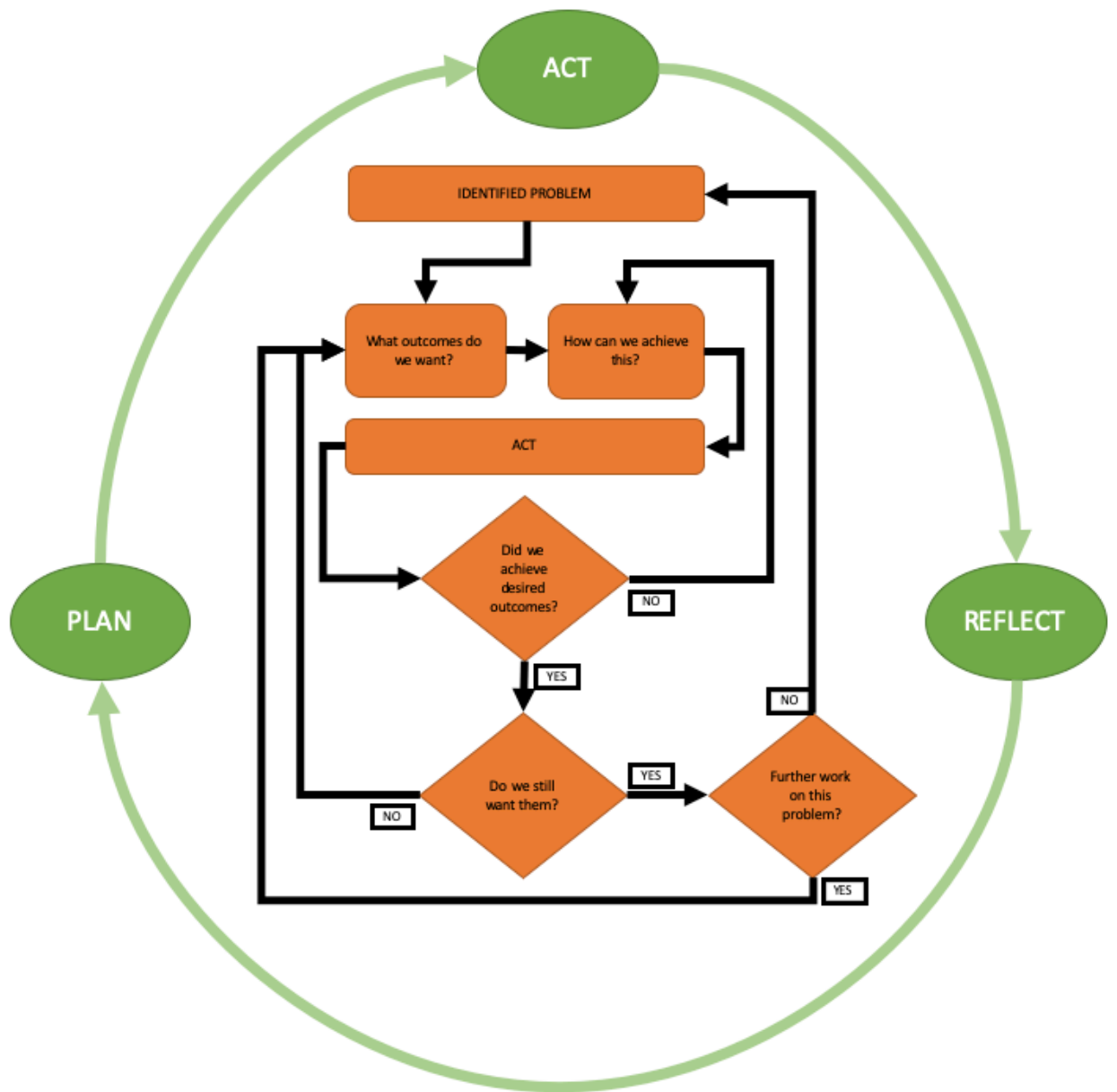


Figure 5-3 PAR process

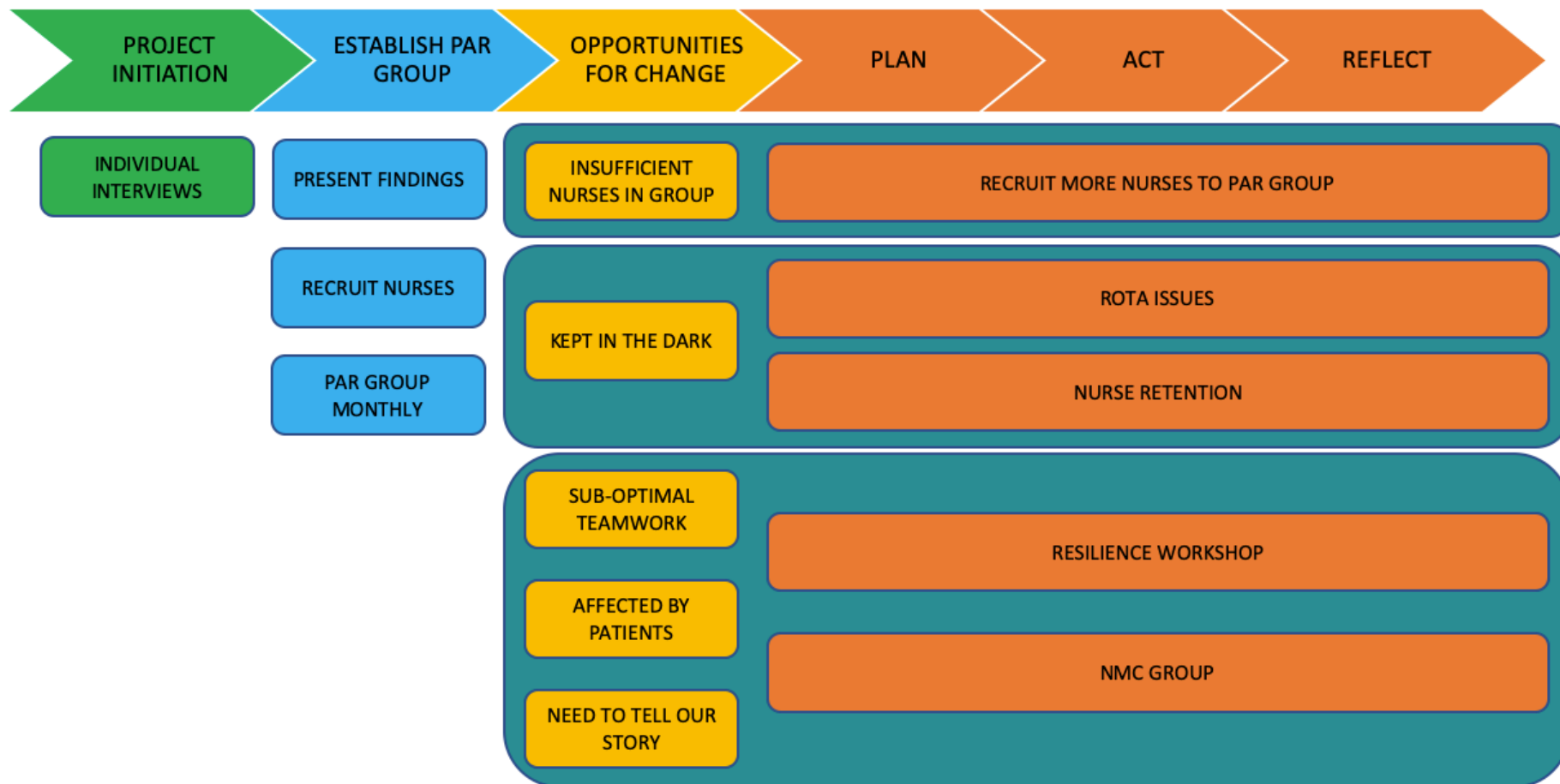


Figure 5-4 Project overview

5.5.1 Insufficient nurses in the Collaborative Inquiry Group (CIG)

Problem:

The first problem the CIG wanted to tackle was the insufficient number of nurses in the CIG itself. Phase two required a minimum of four nurses for the CIG and just two nurses signed up and attended the first of the CIG meetings. Without the agreed minimum number of participants in the study, it would not be possible to continue and therefore this was the priority for action.

Planning:

The group's curiosity focussed on the perceived reluctance to participate, and this became as important as any potential recruitment drive. Ideas about reluctance were generated and included suggestions that staff were protective about their time away from work or believed that any attempt to improve morale on the unit would be futile.

Action:

Both nurses in the group gave printed copies of an invitation to join the study to all registered nurses at the site. We asked in as neutral a fashion as possible, so as not to coerce, asking nurses to tell us if there were any reasons why they did not wish to participate.

Reflection:

We received five responses. Two more nurses joined the group and another stated that she may have been interested, however, she would be on leave for the next two meetings. The remaining two stated they were not prepared to participate if any meetings coincided with off duty days. We considered what the conditional nature of participation from two potentially interested nurses might tell us about resilience ('I will only participate if it is in working time'), wondering if this was due to feeling overstretched, or perhaps a need to protect time away from the workplace. We noted how a refusal to give up one's own time for a work-related issue may well be connected to resilience and would be worthy of further exploration should the opportunity arise in future.

We realised there may be ways in which the wider workforce would be willing to participate in the study without signing up as co-researchers and agreed that our earlier decision to consider the group 'closed' (no further recruitment) after meeting two to be appropriate.

5.5.2 Nurses feel kept in the dark

Nurses reported feeling kept in the dark in several ways during phase one. The CIG reviewed the findings and identified two main concerns related to nurses feeling kept in the dark that could be actioned in phase two: issues with the rota and nurse retention.

“The rota has been produced with just 1 week’s notice again and many staff are now resigned to this as the norm. You described how communication about the lateness might make a difference to people – if they understood why it was late, they might be more accommodating” (PAR 10 Meeting Notes)

In addition to the rota, staff also felt stressed if the workload was ‘overwhelming’ or if there was a lack of experienced staff available to help (which may not always be due to improper planning). Staff were more likely to feel stressed if there was uncertainty about staffing on shifts and if there might be a need to ‘carry’ agency or bank staff, which may, at least in part, explain the depth of frustration about the rota issue.

5.5.2.1 Issues with the rota

Problem:

The nurses in the group reported how the rota was frequently published late and how this negatively affected staff on the unit.

Planning:

The group wanted to identify the nature of the rota issues, realising there could be multiple factors connected to the rota that could influence resilience.

Action:

Each CIG member talked to their colleagues and wrote a summary about rota issues for discussion at the subsequent meeting. Furthermore, one group member suggested identifying the average time between the rota being published and the start date of that rota, to indicate how much notice the nurses receive of their shifts.

Reflection:

Three CIG members returned summaries, and all mentioned how the lateness of the rota was a problem for the nurses, stating how it negatively affected their work-life balance:

“Short notice rota had huge impact on working lives. Almost impossible to plan anything with family and friends. This in turn has effect on their personal life trying to create some healthy work life balance” (CIG 3) and “The rota is always late. I cannot plan my life. It makes me feel frustrated and angry” (CIG 2)

Skill-mix was another problem for the nurses, with multiple senior/more experienced nurses on some shifts and very few on others:

“several senior nurses working one day, the next very junior staff on duty. Makes them feel unsupported and when they have to coordinate the ward feel they are stepping up to do a job they are not being paid for” (CIG3)

In addition to the planned skill-mix of regular staff, participants explained how reliance on agency and bank staff to cover shifts was also problematic, as irregular staff do not know the unit or the patients very well:

“At night only one permanent staff nurse working with agency staff. They feel unsupported, anxious and vulnerable. As there is only limited medical cover and they also need to deal with OOH community calls which also adds to their stress” (CIG 4)

External staff may not know the patients as well as regular staff but there was also concern about their ability to support the regular staff in similar ways that their usual colleagues might. There was frustration that those staff who should not be re-engaged have been allowed to work on the unit even after staff have expressed concerns about their suitability:

“Rely heavily on agency staff. Although some agency staff have worked extremely well and have built up a good rapport and work well with the team others do not. Even when concerns have been raised by staff regarding their attitude professionalism and safety they have been booked again to work on the ward.” (CIG 4)

One group member investigated the time between rota publication and the start date of each rota over one year, discovering that the average time between was 10 days. The participants felt this was not sufficient notice and agreed that one member would speak to the ward manager about this, to try and increase the notice period. The

manager was receptive to the issue raised and agreed to publish the rota sooner, wherever possible.

In summary, there were issues with the rota, predominantly the notice period and skill-mix. The group decided the notice period was the most pressing and likely to have the biggest impact and addressed this with the ward manager. The subsequent rota was produced much earlier, and the nurses noticed the benefits immediately, stating that they went home after a shift feeling tired because they worked hard for patients, rather than because they listened to staff complaining about the rota. Furthermore, the participants *“described how some of the usual challenges are still present but they have become easier to bear with the rota issue resolved” (PAR 4 Meeting notes)*. Unfortunately, this improvement was temporary and rota publication reverted to less than 2 weeks’ notice shortly afterwards

5.5.2.2 Nurse retention

Problem:

CIG members reported a perception that nurses were leaving the unit and that the reasons for departure were unknown, leaving them ‘kept in the dark’, with discrepancies between what was reported to managers and insider knowledge. They wondered if establishing the ‘real’ reasons for leaving would help to identify areas for enhancing resilience in future.

Planning:

The group discussed how nurse retention rates might be an indicator of a healthy workplace and resilience. During the discussion, it became apparent that members believed that staff did not always tell employers of the 'real reasons' for leaving the organisation and that some members had information about leavers that was not communicated to the employer. This issue was interesting, and the group wanted to identify any reasons for leaving that could be addressed in future action cycles.

Action:

One member agreed to identify recent leavers and their reasons for leaving – both those stated to the employer and those stated privately to peers.

Reflection:

Seven nurses had left the unit during the preceding nine months, a turnover of approximately 30%. Of these seven, there was just one nurse who gave a different reason to the employer than that discussed privately with her peers and this was related to dissatisfaction with the way the consultant was managing the end of life care for patients. The participants reflected on how this was a particularly challenging time for many nurses and was not necessarily representative of the issues the unit was currently facing as the consultant concerned was no longer in post.

In summary, it appeared that there was less of an issue with different versions of reasons for leaving than previously thought and nothing identified that could be useful in future action cycles. The nurses felt reassured by the information that was gleaned through this process, further validating the finding from phase one; that nurses are likely to experience stress if they feel 'kept in the dark'.

5.5.3 Sub-optimal teamwork; affected by patients, and need to tell our story

In phase one, three themes were identified that the CIG wanted to address. These were issues with teamwork; how nurses are affected by some patients more than others, and the importance of enabling nurses to tell their stories. Participants believed that there could be many actions that would cover several, if not all of these issues together but struggled to find clarity about how best to address some of these concerns.

Perceptions of unfair work allocations were related to nurses either opting out of certain tasks regardless of grade or role or where staff felt they were being expected to work at a higher grade, often due to staff shortages:

"Fair allocation of workloads – either regarding perception that B5s are doing B6 work, or that not all staff pull equal weight during shifts themselves" (PAR 3 Meeting Notes)

Belonging to the hospice and distinguishing themselves as separate from the National Health Service appeared to help build a sense of community and shared identity. This

was noticed by agency staff who were known to remark on the 'ivory tower' they believed hospice nurses occupied. One aspect of this 'ivory tower' was a shared view between those within and without that patients in hospices appear to receive better care.

Agency staff were less likely to participate in the supportive culture of the hospice, which includes monitoring others for any sign of needing help and providing this without being asked. This culture was adopted by staff of all grades, yet agency staff were considered noticeably separate in this regard:

"You noticed that agency staff also don't see, or benefit from the supportive culture that you especially try to create in the unit. You both tend to offer support and notice when colleagues need help, whereas agency staff either don't notice or don't seem to care" (PAR 4 meeting notes)

Nurses were affected by patients and needed help and support from their colleagues when this happened. An example was when a very young patient stayed in the hospice for a considerable length of time before he died and was initially prevented from seeing his mother due to her immigration status. This fundamental need for his mother, which was not easily met, seemed to evoke strong maternal feelings in the staff, who tried their hardest to meet these unmet needs in him. When this teenage man died, staff needed much support, with one nurse reporting how she had spent

more time with this patient than she had with many of her friends over the year he was an inpatient:

“You highlighted how this patient was popular, and due to his youth, probably touched the ‘mother’ in staff. The patient desperately wanted his mother at various times during his stay too. He settled better when she flew in and was with him. You said how you have probably had more conversations with this patient than had with many of your friends” (PAR 11 meeting notes)

Participants were concerned about the need to advocate for quieter patients who may be overlooked or treated less favourably than those who demand more from their care providers:

“You gave a couple of examples where ‘pushy families’ were able to get more from the hospice than less demanding patients do”

(PAR 11 Meeting Notes)

One member explained how staff need support with *“different aspects of the work, it’s not just about coping with deaths”* (PAR 4 Meeting Notes) and *“to be supported in their role, on a daily basis rather than waiting until a monthly meeting”* (PAR 8 Meeting Notes). This partially explains why some of the organised sources of support did not appear to work for the nurses, such as the sporadic clinical supervision or group counselling provided by the organisation. Another criticism of this model of group

counselling was the sense that it was formulaic and structured, with staff permitted to speak only when invited.

Staff also expressed concern about another forum that could be supportive but was not experienced as such. All hospice staff, as part of a much larger healthcare organisation, can attend monthly meetings about organisational issues, however, this was criticised as not meeting their needs and staff wanted something more localised and about the hospice exclusively, fitting the desire for team cohesion and hospice identity described above. When there is a sense of shared purpose or identity, staff are more likely to share their thoughts and feelings in a way that minimises the stress burden and contributes to resilience.

“things can happen between shifts, such as a death or discharge. When time isn’t taken to fill in the blanks, this can cause worry (often unconsciously) and it may not be immediately apparent that you have been worried about issues until triggered much later on by a similar event” (PAR 9 Meeting Notes)

Absent or missing information was likely to cause distress such as when a nurse who believed that a patient’s death was far from acceptable, due to her views about the patient’s previously stated wishes at an earlier stage in their disease. The nurse was unaware that the patient had changed her mind, and once this was explained and effectively communicated, the nurse changed her perception of the death, resulting

in feeling far less anguished about how and where the death happened. For effective communication to occur there needs to be opportunities for time together. One nurse reflected on how *“nurses take breaks alone... they go home alone...”* (PAR 8 Meeting Notes) and prompted further discussions about the ways nurses can help each other.

Problem:

How do we identify what the issues are that are affecting the workforce related to teamwork, being affected by patients, and needing to tell the story?

Planning:

We explored the idea of a workshop for all hospice staff, regardless of profession, with a presentation on resilience based on the literature review and also the findings from the individual interviews completed during phase one of the study. The CIG members each facilitated one of four smaller groups. To help guide the discussions, we developed 3 questions that each facilitator used to guide the discussion and enable data collection:

1. what helps resilience?
2. what hinders resilience?
3. what's the one thing that would improve the ability to cope with death, dying and suffering regularly?

Action:

We organised the workshop, as described above. Eleven self-selected people attended plus all five CIG members. The workshop lasted 90 minutes and consisted of the presentation with time for questions and answers before moving to the smaller facilitated groups.

Reflection:

Each facilitator captured the answers to each of these questions above and collated them for further analysis and discussion by the group. The workshop participants believed that resilience can be enhanced when staff are recognised for their work and listened to, teams are effective and supportive, and there is a good balance between work and home life.

We identified the importance of support for staff working in palliative care to enhance resilience. This support could be informal and peer-led or provided by specialists (such as psychologists) and is most likely to be effective when coupled with a perception of appreciation through recognition. In determining what hinders resilience, we noted how workshop participants emphasised the importance of beneficial factors identified above, confirming that the opposite factors would be detrimental to resilience in the unit. If there is a lack of support, team cohesion and no sense of togetherness, the participants believed this would undermine resilience. Also, rota factors discussed

earlier were repeated here and affirmed how relevant these issues are to the workforce.

Suggestions about how to improve the ability to cope with working in a specialist palliative care inpatient unit setting were consistent with responses above, with participants describing how important a sharing, supportive environment and colleagues are to resilience in the unit. Participants reflected on the issues raised in the workshop and agreed that the need for support and sharing was the most potent issue for further action.

5.5.4 PAR Cycle 5 – The Nurses Meet and Chat (NMC) Group

Problem:

What interventions could we implement that would enable staff to feel supported, listened to, appreciated and valued?

Planning:

After much discussion and reflection on the workshop, the participants explored possible actions that would enhance support in the workplace. One participant was particularly struck by a workshop attendee's comments afterwards – *“wasn't it great that we all had an opportunity to talk?!”*. The desire for support and a space to share experiences was prominent and the participants decided to implement a 'NMC' (Nurses' Meet & Chat) group, a deliberately chosen acronym shared with the Nursing

and Midwifery Council. Participants expressed concern for the Health Care Assistants who may feel excluded and we recognised the importance of monitoring this and recording their thoughts/opinions if possible. We identified the benefits of a skilled facilitator and the group suggested a member of another discipline who knows the staff and unit well, rather than an 'outsider'.

Action:

Participants divided up key tasks such as identifying the optimum day/time (through a poll to all trained nurses), developing promotional material, ascertaining buy-in from staff and management, and booking meeting space. The group was promoted by email and word of mouth, with posters being sent to staff rather than displayed publicly because of sensitivities about excluding non-nursing staff.

Reflection:

The NMC group happened once, with five nurses attending. All the nurses who attended were Band Six Ward Sisters/Charge Nurses as there were no Band 5 nurses on the day of the meeting. The CIG members present during the NMC meeting reflected on their experience of the group and noted that the ward nurses who did attend described their perception that:

- 1) Everyone is stressed
- 2) Everyone wanted to talk about it
- 3) There are different ways of managing it and appearances can be deceptive

One attendee said, *“we’re never going to fix it... but it’s good to talk about it isn’t it?”*.

Participants discussed the group and how best to continue in future. We noted the lack of band five staff and whether we could do anything in the future to increase the likelihood of attendance from this group of trained nurses. We decided to administer a small survey to previous and future attendees to help us evaluate the group.

Another group was booked, however, no one replied to the invitation or attended. During discussion, we attempted to identify reasons why it was not successful, and participants mentioned how staff seemed reluctant to attend, as it was seen as ‘yet another meeting’ and involved questions like “will I be paid for it if I come in?”.

Whilst this study focuses on Registered Nurses in hospices, much debate was had about the inclusion of Health Care Assistants in the ‘Nurses Meet and Chat’ (NMC) group, further highlighting a desire to be inclusive and together, not segregating parts of the workforce with whom there is close working relationships. One member described:

“how much influence HCAs can have on whether a day is good or not.

We wondered if happier HCAs might ultimately mean happier RNs in

the workplace” (PAR 11 Meeting Notes)

PAR participants reflected on the outcome of the intervention and how disappointing the lack of uptake was. They concluded that they believed the intervention to be

sound, but possibly not the right intervention for this particular cohort of staff at this time. Future consideration could be given to whether renaming the group may help, or whether tying it more closely to some of the requirements of nursing registration, such as learning and reflection could be of value.

5.6 Findings summary:

5.6.1 Phase one summary

Adversity in palliative care inpatient nursing includes challenges associated with particular patients, feeling kept in the dark, especially when related to the rota, and when teamwork is suboptimal. Resilience, in response to such adversity, involves mindset, team support, and the development of a coherent narrative about the adverse experiences.

5.6.2 Phase two summary

The chief strategy to enhance resilience was the formation of the NMC group. The purpose of the group was to enable nurses to come together, support each other and learn both from their own and others' experiences. Whilst many agreed with the principles of the group it was unsuccessful due to non-attendance. It is apparent, however, that nurses can identify issues related to adversity and strategies they believe could be tested and evaluated.

5.6.3 Overall summary

The two phases of this study combine to form knowledge about the nature of adversity in palliative care and how the nurses in the Collaborative Inquiry Group believed these adversities should be addressed in order to bring about change for the better. This knowledge is cumulative and the findings from phase one informed the PAR process in phase two. An advantage of action research approaches, however, is the ability or opportunity to:

“go beyond the boundaries of traditional theoretical and disciplinary approaches, which define research topics and establish a linear sequence of hypothesis application and result verification” (Cassell, Cunliffe, & Grandy, 2018, p. 287).

Cassell et al. (2018, p. 287) elaborate further to describe how knowledge exists within and between systems of activity and is likely to be ‘tacit and unconscious’ and therefore needs to be understood from the perspectives of those involved and the attributed meanings they attach. Whilst privileging the voices of the insider participants in the overall process, I conclude this section with a summary of my interpretation of the data; particularly with regard to my perspective on how the organisation (which did not, and cannot, have its own voice) influences resilience in the hospice inpatient setting.

Interestingly, the first hospice I approached to participate in this study did not respond and whilst I am unlikely to ever know the reasons why, it brings into focus how the second hospice did respond and was willing to engage in a lengthy, time-consuming project to improve resilience in its workforce. Initial conversations with the management team revealed how they thought this would be useful due to a recent, complex set of issues with a consultant who apparently caused significant distress in many staff members. Whilst the consultant no longer worked in this hospice, the managers recognised the opportunity to develop resilience overall as there would always be adversity to tackle in future. The willingness to participate seemed borne from a genuine place of concern for staff and desire to improve working lives for the nurses in the team.

Considering the findings from the two phases of the study, there appear to be opportunities for an organisation to enhance resilience for its nurses if it can find ways to successfully identify the unique challenges the nurses face (rather than assuming the typically reported stressors for nurses apply). In this study, nurses were affected by particular patients and organisations would do well to proactively consider how best to support nurses in these situations. Furthermore, timely rota production would reduce stress levels and improve staff relationships with managers. This relationship would be further enhanced when there is open, honest and transparent communication to prevent nurses feeling 'kept in the dark'.

Teamwork is identified as both a stressor and a source of support for nurses and it appears that the organisation could improve resilience if it finds ways to address the associated challenges, such as ensuring work is properly and fairly allocated; dealing with conflict swiftly and appropriately; and seeking ways to ensure nurses have opportunities to tell their stories that enable reflection and learning from experience.

Finally, these findings suggest the importance of attitude in enhancing resilience. Whilst attitude is often thought of as an individual concept, the organisation may well want to consider the collective attitude or culture, and how this could enhance resilience. A collective culture that encourages nurses to not only seek satisfaction in the work they do but finds ways to help nurses acknowledge how they really do make a difference, is likely to enhance resilience.

Chapter 6 - Discussion

6.1 Introduction

The aim of this study was to understand resilience from the perspectives of hospice inpatient nurses, developed from a systematic search of extant literature, a qualitative enquiry with thematic analysis, and a year of Participatory Action Research (PAR) to develop and test strategies that may enhance resilience in the hospice nursing workforce. In this chapter the findings are critically evaluated in relation to recognised limitations of existing research. Criticisms of previous studies include inadequate or missing definitions of resilience; the use of interventions that are predetermined and imposed by researchers; and that resilience is problematised at the individual rather than organisational or systemic levels.

The present study contributes to the resilience knowledge base in palliative care nursing through the creation of a relevant definition of resilience and the identification of the particular adversities that palliative care nurses face in a hospice inpatient setting. Furthermore, the study explored how the nurses themselves considered resilience to be affected by these adversities. Finally, the study concluded with a period of collaborative inquiry, with the nurse participants as co-researchers to enhance resilience based on the findings generated by the previous phases of the study. The chapter concludes with a consideration of limitations and recommendations for further policy, practice and research.

The literature review for this study (Powell et al., 2019) examined qualitative studies that researched resilience in palliative care nursing. A subsequent, recent systematic review complements this with a focus on quantitative studies (Zanatta, Maffoni, & Giardini, 2019) but missed key studies that appear to meet the inclusion criteria. Notwithstanding these omissions, Zanatta et al. (2019) identified just two intervention studies; one was an educational programme, designed by the researchers with a focus on compassion fatigue (Klein, Riggerbach-Hays, Sollenberger, Harney, & McGarvey, 2018) and the other was designed to teach clinicians how to elicit a relaxation response when required (Mehta et al., 2015). Neither of these studies was specifically about nurses and included a range of professionals in their populations.

A slightly older but more comprehensive review of interventions to improve resilience in health professionals (Cleary, Kornhaber, Thapa, West, & Visentin, 2018) synthesised 33 studies, almost all of which were varieties of mindfulness/mind-body awareness interventions to varying degrees. The remainder used principles of psychological therapies (such as counselling, cognitive behaviour therapy, acceptance and commitment therapy) or workshops to teach a range of topics such as stress management, compassion fatigue, and relaxation. Cleary et al. (2018)'s systematic review did not focus on nurses in palliative care and none of the studies involved a collaborative or participatory approach in designing interventions. In other words, it appears that all interventions were decided by researchers in advance and then tested on subjects/participants in the included studies.

6.2 Summary of Findings

There are three groups of findings that combine to answer the questions and objectives of this study. Firstly, the systematic review of qualitative literature culminated in the analytical theme:

resilience occurs when nurses incorporate stressful aspects of their personal or professional lives into a coherent narrative that enhances their ability to cope with the demands of their role (Powell et al., 2019, p. 9).

This finding was instrumental to the development of this study but not sufficient to meet the aims and objectives as it does not adequately address resilience issues beyond the level of individual nurses.

Secondly, phase one of this study sought to determine the nature of adversity in inpatient palliative care and ways resilience could be enhanced. Conceptually, resilience is always preceded by adversity and the nature of adversity in this specific context includes particular patients, feeling kept in the dark and sub-optimal teamwork. Resilience is enhanced when there is a process of meaning-making as a result of encountering such adversity. Meaning-making enhances nurses' preparedness to deal with future adversity and is influenced by mindset, team support/cohesion and the development of a coherent narrative about one's

experiences. These components of resilience in palliative care nursing are incorporated in the model in Figure 6-1.

Finally, the study culminated in a PAR process to test strategies for improving resilience. The main finding was how nurses need to feel supported yet despite creating opportunities for this to happen, uptake was poor. These findings are discussed sequentially in more detail below.

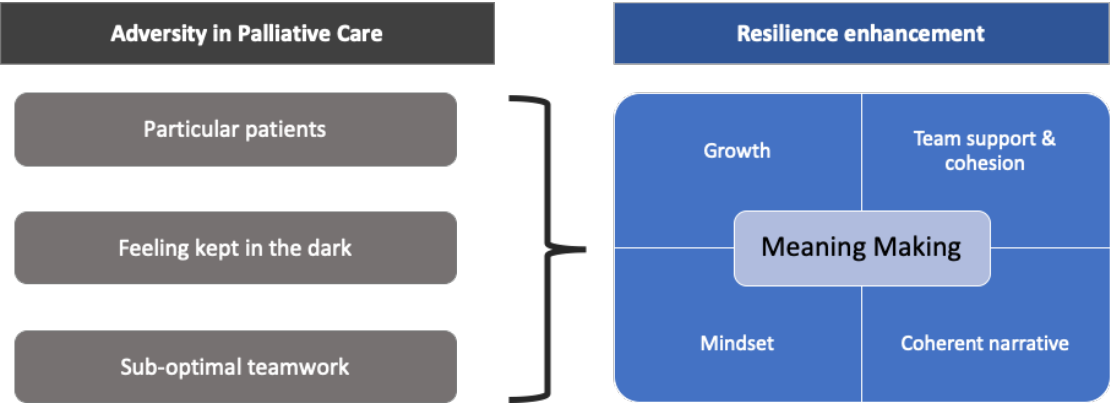


Figure 6-1 Resilience in palliative care nursing

6.3 Adversity in Palliative Care Nursing

6.3.1 Particular patients

The theme of ‘some patients affect nurses more than others’ was based on widespread views from participants that young patients, patients the nurses identified with due to similarity in age or experience, patients where there was a particular level

of rapport or intimacy; or patients for whom the nurses perceived they failed in their care in some way, were more likely to affect resilience. This finding, whilst not surprising, complements existing literature that assumes nurses experience similar emotional responses to patients as physicians do. Sherman (2004, p. 50), for example, writes articulately about the nature of stress and burnout for nurses but based the following assertion on a theoretical paper about doctors' emotions:

“not unusual for nurses to bond strongly with patients who remind them of someone special in their lives or identify with patients who are similar to themselves in age, appearance or background”

Caution should be applied when assuming all healthcare professionals are similarly affected, as nurses spend more time with patients than any other professional (Schroeder & Lorenz, 2018). The findings from this present study show that nurses bond with patients, especially when they identify with them.

The nurses in this study recognised that they liked some patients more than others and forming relationships with people who were going to die was identified as a threat to resilience. This finding challenges previously long-held beliefs that exposure to death and dying per se is stressful for nurses (Gray-Toft & Anderson, 1981). It seems that issues with particular patients derive from the nature of the relationship and how much the nurses like or identify with patients. A possible theoretical explanation for this finding is the nature of empathy and compassion in nursing work; people are more

likely to empathise with those perceived as similar (Vachon, Huggard, & Huggard, 2014). This is consistent with findings from Carvalho, Reeves, and Orford (2012) who highlight the increased likelihood of becoming friends with those with shared values.

Nurses described how important it was to make a difference to families and appreciated closeness and connection in their relationships with those they cared for. This capacity to bond with patients is an important part of nursing practice and contributes to levels of satisfaction with work yet appears to be a particular source of adversity with the types of patients described above. This finding is similar to Walsh and Buchanan (2011), where the witnessing of suffering and or/death is identified as stressful in acute care nurses, however, this is assumed to be global rather than specific to certain patients or types of patients. Sharing intimate experience likely leads to increased rapport and this appears to happen between palliative care nurses and their patients where there is a greater emphasis on the alleviation of psychosocial suffering and distress than perhaps in other areas of nursing (Hawkins, Howard, & Oyeboode, 2007). This is further reflected in a systematic review by Sekse, Hunskar, and Ellingsen (2017) who describe this concept of closeness as being dedicated, present and open to the other. Of note, the Sekse et al. (2017) study was not restricted to hospices and looked at palliative care for nurses across any setting or system. The findings of this study concur that closeness/intimacy becomes a source of adversity as these patients are considered more challenging to care for.

The nurses in this study demonstrated a passion for palliative care work and genuine care for patients and this appeared to contribute to a strong desire to make a difference and get it right. They described how they wanted to be the best they could for their patients and be fully present to care for them in meaningful ways. This was evidenced in the level of detail that nurses reported regarding how well they knew their patients, such as the amount of sugar they took in their tea or preferences about food. This level of knowledge is akin to what is usually known about the closest people in one's life and signifies a degree of intimacy. Intimacy in nursing has been researched in some settings, such as medical/surgical wards, psychology and psychiatry, with reported findings that few relationships would ever become close (Williams, 2001). Williams (2001) further suggests that for nurse-patient relationships to become intimate, there is likely to be an affinity between them to begin with, which mirrors the findings in this study. Whilst not specifically tested empirically in this study, it seems plausible to suggest that the greater the degree of intimacy, rapport or connection with the patient, the greater the adversity experienced when the patient suffers or dies.

Relational nursing practice is not a new concept (Hartrick, 1997) and involves a professional partnership where nurses rely on dialogue to learn about patients and what matters to them (Jonsdottir, Litchfield, & Pharris, 2004). This poses many challenges for nurses, not least because relational practise requires a degree of empathy and compassion, and whilst this may contribute to increased satisfaction for

both patients and nurses, it may also come at personal cost (Ingebretsen & Sagbakken, 2016). Without appropriate support to practise in a relational way, nurses may be at risk of negative consequences, such as burnout and compassion fatigue (Zanatta et al., 2019). Empathy and compassion are words frequently espoused in nursing care, “compassionate care can be acknowledged as a cornerstone of nursing practice” (Peters, 2018, p. 466) for example and are therefore important to understand in relation to this study’s aims and objectives. When nurses are emotionally connected to patients, through the vehicles of empathy and compassion and denoted by felt intimacy and connection, there appear to be risks involved. These risks could be considered according to the concepts of emotional labour (Brighton et al., 2018), attachment theory (Graci & Fivush, 2016) or the nature of demand and control theory (Dawson, O'Brien, & Beehr, 2016). Nurses are therefore at risk of adversity due to the intrinsic nature of care required as a result of their role.

6.3.1.1 Empathy and compassion

The nurses’ strong desire to provide the best care possible may be driven by empathy and/or compassion, terms that appear to be used interchangeably at times. Compassion is different from empathy, as Vachon et al. (2014, pp. 976,977) remind us that *‘Humans are more likely to empathise with those who are similar to us’*, which is distinctly different to compassion, which is the felt thought *“may all beings be free of suffering and the causes of suffering”*. This finding is similar to that of Strang, Henoch, Danielson, Browall, and Melin-Johansson (2014) who emphasise how empathy and

compassion form the basis of 'presence' in palliative care nursing. In their study, they found that presence was more than 'just being there' for the patient and required an active commitment on the part of the nurse to focus on the patient in ways that go beyond nursing tasks, such as being with the patient in existential ways.

The extent to which the nurses wanted to know patients as well as they could and alleviate their suffering wherever possible was clear in this present study. They used various terms to describe their commitment to this process, including making a difference, being the best they could, and getting it right. Achieving this was not possible without commitment and presence. Presence involves sensitivity, holism, intimacy, vulnerability and involves more than just being with the patient; when conducted compassionately, it demonstrates a willing commitment on the part of the nurse to alleviate suffering (Sabo, 2011). Hotchkiss (2018) shares this view and emphasises how compassionate presence in nursing can lead to better outcomes for both nurses and their patients when appropriate boundaries are maintained, and states these are essential components of good palliative care. However, compassionate presence is not possible simply by donning a uniform, it requires investment and commitment on the part of the nurse and could, if unmitigated, lead to a blurring of boundaries and issues with separating self from the other. This ability to balance the needs of patients with self-preservation is a challenge for the nursing profession as the suffering of the other should not be adopted as suffering of their own (Sabo, 2011). Unmitigated, a blurring of boundaries between oneself and the

patient may lead to what Vachon et al. (2014) refer to as ‘palliative care martyrdom’, a stressful condition where the nurse assumes misplaced responsibility for the patient’s suffering, coupled with feeling helpless to change the situation. This stance seems to lead to a withdrawal from patients and a likelihood that nurses adopt a technical rather than relational approach to care, as identified in this study’s literature review (Powell et al., 2019). However, the nurses in this present study did not describe the use of withdrawal or distancing as a strategy for managing this type of adversity. Rather, they were keen to find ways to support their colleagues to continue caring for patients, which indicates resilience.

When nurses assume misplaced responsibility for patients’ suffering, it can lead to feeling overwhelmed, can obscure one’s sense of self and negatively affect personal and professional boundaries. All nurses in Vachon et al’s study mentioned the importance of professional boundaries, citing this as a key factor in how successful they were in minimising the degree to which suffering affected them personally (Vachon, Fillion, & Achille, 2012). The findings from this present study, however, suggest that a reliance on professional boundaries is not a sufficient strategy to enhance resilience.

6.3.2 Feeling kept in the dark

Nurses felt stressed when they perceived information to be withheld, or not forthcoming in a timely fashion, whether this was accidental or intentional. This

finding was multifactorial and highlighted how an absence, or perceived absence, of information can undermine resilience. The nurses gave numerous examples of issues or challenges in this area, including information about patients, colleagues, or a lack of guidance about particular tasks, policies or procedures. In some cases, they felt kept in the dark by their managers and in others, by their colleagues. They did not indicate this was a deliberate or intentional act of deprivation. The most frequently raised aspect of being “kept in the dark” was persistent lateness of the rota publication. Interestingly, the stress caused by late rota publication could be mitigated by better communication of any reasons that were causing a delay. The strength of feeling about this particular finding is demonstrated by the nurses’ desire to act on this as a matter of priority in the PAR process discussed later. Another example included a lack of communication about patient preferences and choices, leading a nurse to believe a patient did not die in their preferred place. These examples combined to form the overarching theme of feeling kept in the dark as it was not particular to any discrete set of circumstances, rather any experience of feeling this way appeared to be a source of adversity that affected resilience in the workplace.

These findings are consistent with guidance from the Health and Safety Executive (HSE., 2019) that one of the indicators of stress in the workplace is when employees say they do not receive enough information, support, or control over their job. Communication issues are known to negatively impact on workforces generally, and this is similar for nurses. Vachon et al. (2014) discovered that the chief strategies for

managing workplace stress, according to nurses, include manageable rotas, informal support from peers, management of conflict and feedback, which are consistent with the findings of this study.

6.3.3 Sub-optimal teamwork

The two main components of this thematic finding were conflict with colleagues and a sense that work was not distributed fairly. This is consistent with the findings from the literature review and further supported by an analysis of levels of job satisfaction in hospice interdisciplinary team (IDT) members by DeLoach (2003). She found that IDT members were more likely to be satisfied with their job if they perceived their team to be functioning well; however, these results should be interpreted with caution as they include a range of disciplines and were not specifically about nurses. Whilst the present study did not seek to establish levels of job satisfaction *per se*, the nurses described the negative impact of team conflict and unfair workloads. This unsurprisingly aligns with previous research that reinforces how workloads are consistently highly ranked as stressors in nursing (McVicar, 2003). When coupled with insufficient support from colleagues and feelings of isolation, reduced self-esteem/effectiveness at work and a desire to leave the work setting (Sherman, 2004) may occur. These feelings, in extremis could lead to illness, substance abuse and suicide (McAllister & McKinnon, 2009; Vachon et al., 2014) and are therefore clearly a matter of concern.

A different understanding of the impact of workload on resilience was generated in this study. Existing studies report the negative effects of workload generally referring to the amount of work the nurse has to do, perhaps increased through staff shortages (Duffield et al., 2011). The present study, however, identified how perception of unfairness was a contributory factor rather than the amount of work per se.

Team members and teamwork have long been recognised as both a source of stress and support depending on how a team functions. When staff lose their sense of connection with their peers or the organisation this causes distress (Vachon et al., 2014) and the emotional overload that may occur is intensified if there is a lack of professional and organisational support for the nurse (Sabo, 2011). This is consistent with the present study, where one nurse felt very strongly that issues with colleagues were more distressing than any of the care she gave to patients and suggested that working on shared goals for patients is a way to unite teams in conflict and ensure care for patients is not compromised. This finding is similar to that of Vachon et al. (2014) who report how a disagreement between professionals about the goals of care further compounds felt levels of stress.

Another study that explored relationships between variables such as workload, conflict and resilience found that nurses who reported lower levels of resilience experienced higher levels of negative emotions in conflict (Lanz & Bruk-Lee, 2017). The study by Lanz and Bruk-Lee (2017) does focus on nurses but not palliative care

specifically. Resilience in this context was also self-assessed by nurses using a validated tool, but one designed to measure general trait resilience rather than the capacity or ability to respond to particular stressors.

Gupta and Woodman (2010) implemented interventions to counter the high levels of staff sickness that were partially attributed to a lack of team cohesiveness and overwhelming workloads in community children's palliative care team. They investigated common stressors and found that increasing complexity, referrals and deaths were problematic for the nurses. Also, staff communications were challenging, particularly with regards to both feeling supported and heard. Of particular interest was how Gupta and Woodman (2010) acknowledge that doing something in response to the stressors experienced was better than doing nothing, as participants found the process of developing a stress management strategy was as valuable as its implementation. The support gained through the sharing of experiences led to nurses feeling less isolated and they conclude by emphasising the importance of self-reflection to better understand the impact of personal and professional factors on practice.

When nurses are reflexive and supported by colleagues, they are more likely to find meaning and satisfaction in their work, especially when coupled with a sense of autonomy and validation by peers and managers (Vachon et al., 2014). These findings from this and others' studies unsurprisingly emphasise the need for effective

teamwork and support to cope with the demands of palliative care nursing. Team conflict and an unwillingness to pull one's weight is detrimental to team cohesion; however, other research has shown that individual differences may also contribute to ineffective teamwork. For example, nurses with fearful or dismissing attachment styles are likely to avoid intimacy and therefore not seek closeness or support from others due to distrust that others may provide psychological safety, security or support during stressful times (Hawkins et al., 2007).

6.4 Discussion summary - adversity in palliative care nursing

It appears that nurses in inpatient palliative care units are likely to experience adversity about particular patients, if they feel kept in the dark, or when teamwork is sub-optimal. There are various ways one could conceptualise these challenges which would influence how they could be mitigated, if not addressed entirely. Existing literature on workplace stressors tends to generalise and group these challenges according to either an interactional/structural model, or transactional/process models (Chirico, 2016). Interactional models include the Demand-Control-Support model (Karasek, 2004) which attempts to classify typical workplace stressors to identify how best to reorganise work to reduce job stress. A common theme in the study by Karasek (2004) was how open communication between management and staff can reduce stress and improve productivity, which is indicated in this present study in various ways, such as the need for timely rota publication.

Transactional or process models of work-related adversity include the Effort-Reward Imbalance model (Siegrist, 1996) which could enhance understanding about how nurses invest themselves in relationship with patients. This model explains how this works well when the nurses perceive their impact on the patients' suffering as a source of satisfaction and reward. However, when there is a significant investment from the nurses and they are negatively affected by witnessing suffering or the patients' deaths, they may experience stress as a result of feeling that the demands outstrip the rewards. It is still unclear, however, to what extent workplace adversity can be attributed to the work environment, to the individual, or the interaction between these variables (Siegrist, 1996). The present study did not attempt to generate broad generalisations to answer such questions; rather it sought to identify the particular adversities nurses faced in the context of palliative care nursing. Having identified these, attention is now turned to a discussion of the findings that identified how resilience could be enhanced in these circumstances.

6.5 Meaning-making enhances resilience

The finding that meaning-making is an integral part of resilience in palliative care nursing is an important contribution to knowledge and has implications for practice, policy and future research. This is important because it appears to be crucial in preparing nurses for future challenges, thereby distinguishing resilience from coping, as defined by Folkman, Lazarus, Gruen, and DeLongis (1986). Coping involves cognitive and behavioural efforts to manage situations that are perceived as stressful. Stress

occurs when individuals perceive that demands made on them in a person-environment encounter exceed their resources. There are two types of coping that tend to be present in stressful experiences, namely problem-focused coping and emotion-focused coping. These two categories of coping describe how one attempts to manage the problem itself or the emotional responses triggered by the problem (Folkman et al., 1986). Whilst coping may appear beneficial it may be detrimental if it involves avoidance strategies (Naceur & Zriba, 2015). The literature review in this present study identified that coping was necessary but not sufficient for enhancing resilience, in contrast to O'Dowd et al. (2018), for example, who found that physicians, when asked to define resilience, believed it was predominantly about coping. This further supports the need to be cautious when interpreting findings from studies and not to assume that resilience means the same thing for different professionals in different settings.

The ability to make sense of one's experiences involves both adopting particular mindsets and sharing the story with others who understand, a finding supported by Wagner, Johns, Brown, Hanna, and Bigatti (2016) who emphasise that meaning construction happens in the context of relationship with others, not as an isolated process. For this to happen, the individual must be willing and able, and the organisation receptive to creating opportunities for such processes. These findings support the heightened relevance of context in resilience research; that it should not

be limited to understanding how individuals cope with stressors at the exclusion of environmental influences.

Meaning-making is not a new phenomenon and has been studied in various matters such as psychological trauma (Taubman-Ben-Ari & Weintroub, 2008), bereavement (Neimeyer et al., 2014), cancer diagnoses (Wagner et al., 2016) and other stressful life events (Park, 2010). Wagner et al. (2016) argue persuasively for the consideration of meaning-making in relationship, emphasising that the process does not happen in a vacuum and is dependent on relationships with others to occur effectively. This argument is forged on the foundation that awareness of death is likely to motivate people to seek intimacy and proximity to others. The nurses in the present study were most affected by patients with whom there were intimacy and rapport. Evidence from other studies suggests this level of intimacy means that patients are more likely to explore their existential issues with nurses and, when done well, could be a considerable source of satisfaction rather than distress (Wagner et al., 2016).

Philosophically, human beings are likely to question the significance of their existence leading to a construction of the individual's meaning or purpose in life, which in turn influences the goals, beliefs and actions of that person (Park, 2016). When one faces trauma, either directly or indirectly, this challenges one's world-view, based on a realisation that the world is generally not controllable or predictable, that life is finite

and potentially vulnerable to a myriad of possibilities that could threaten existence (Park, 2010).

In this study, meaning-making appears to involve several factors, including mindset, team support and the development of a coherent narrative about adverse experiences. Whilst these factors are reported independently in the literature, this study identifies how they, in combination, enhance resilience in the hospice setting.

6.5.1 Mindset is important

A particularly interesting aspect of this finding was the importance of individual mindset in the enhancement of resilience. Whilst there is much literature available on the function of job satisfaction as a mitigating factor to workplace stress (Fillion et al., 2007; McVicar, 2003, 2016; Moloney et al., 2018), this study found that proactively seeking satisfaction in work, rather than feeling satisfied inconsequentially, was relevant in developing or enhancing resilience. Similarly, the nurses described how they actively sought to make a difference, which contributed to a sense of purpose. This finding suggests the importance of intentionality in mindset, actively adopting a particular stance of seeking both satisfaction (and thereby creating more opportunities to be satisfied) and opportunities to make a difference (contributing to a sense of meaning or purpose in their work). This finding is reminiscent of aspects of the Demand-Support-Control model, which posits that where there is greater control over the work environment, the impact of demands is diminished (Karasek, 2004).

Attitude has been studied in palliative care but with a particular focus on conceptualising and responding to suffering (Vachon et al., 2012). In Vachon's study, exposure to suffering was considered much harder than exposure to death and those who successfully negotiated this exposure were likely to view it as inevitable, coupled with a willingness to engage with it, accepting it as part of the caring experience and to seek meaning within that experience, even if painful. Others in Vachon et al. (2012)'s study struggled to tolerate suffering, and became particularly angry or frustrated, especially if a patient's suffering was psychological. This mirrors the experience of a participant in this present study, who exclaimed how she was not a psychologist and a belief that patients did not always get the right level of psychological support from nurses. It seems plausible that nurses who believe they are not providing the right care, in the right way for patients' psychological issues will become frustrated and disheartened. Findings suggest that a proactive attitude in response to such adversity will lead to better outcomes, through seeking support from others.

The challenge of feeling that psychological care is inadequate in some way is connected to the identified theme of "when we don't get it right". Nurses in this study were more distressed when they felt unable to deliver optimal care for patients, such as expectations that they should provide greater levels of psychological support than they were trained for. Not getting it right seems connected to a perception of

increased suffering for the patient. The way nurses perceive their care and the suffering of their patients seems highly likely to influence resilience. This finding is similar to that of Ingebretsen and Sagbakken (2016), where hospice nurses identified how witnessing suffering was a skill that needed to be developed to maintain presence. Without this skill, nurses can use distancing as a coping strategy, which is similar to the identified theme of 'technical versus relational' care in this study's literature review.

According to the nurses in this study, a mindset that involves proactively seeking meaning and satisfaction in caring for the dying is an essential component of resilience. Mindset involves an attitude that encompasses cognitive, affective and behavioural attributes (Altmann, 2008) and a better understanding of how these aspects combine to enhance resilience in palliative care nursing is a worthwhile endeavour. The relationships between cognitive processes, appraisal of experience and outcomes are well documented in the trauma literature (Taubman-Ben-Ari & Weintraub, 2008). Park (2016), for example, found that the way one appraises a stressor correlates strongly with outcomes; those who perceive the event as threatening become more likely to experience more distress and lower quality of life. Those who experience an event as less stressful, less threatening but highly challenging will experience lower levels of distress and higher perceptions of growth.

There are multiple examples to demonstrate how personal beliefs can influence responses to tragedy. Park (2016) reviewed responses to traumatic events and found in a study of flood victims in Germany, where those who believe in a just world, that bad things sometimes happen indiscriminately, were likely to have lower levels of psychological distress. Park (2016) found similar results in a study about an earthquake in Turkey, where a strong belief in the ability to cope was also associated with lower levels of distress. Conversely in the study of survivors of the Sri Lankan tsunami, pessimism was associated with higher symptoms of post-traumatic stress disorder and poor health in general. Supporting these views, Taubman-Ben-Ari and Weintroub (2008) emphasise how people with higher self-esteem, coupled with optimism fare better in adversity than those who are more pessimistic, as did Moreno-Milan, Cano-Vindel, Lopez-Dóriga, Medrano, and Breitbart (2019) in their study of personal protective factors in palliative care professionals. It may be that optimistic people are more likely to invest in goal-achievement. Furthermore, optimistic people tend to experience a better quality of life, satisfaction, well-being and enhanced abilities to cope with stressful life events. Park (2016, p. 1237) concludes that

“these studies suggest that holding global beliefs in a world that is controllable and fair and that one can competently handle disaster can be adaptive even in extremely stressful circumstances”.

6.5.2 Team support and cohesion

In this study, the nurses' ability to withstand adversity in the workplace depended on feeling supported by colleagues. In some cases, this resulted in a need to monitor colleagues to identify when stress levels may be heightened and to be able to offer support as well as receive it. This is consistent with findings from (Cameron & Brownie, 2010) who found that nurses would find the work overwhelming without the support of their colleagues, and Ingebretsen and Sagbakken (2016) who report that the majority of their participants emphasised the need for fellowship to deal with challenging situations. The nurses recognised the importance of this camaraderie, illustrated by their strong desire to form a support group.

Desbiens and Fillion (2007) suggest nurses in palliative care tend to experience less stress than their counterparts elsewhere due to higher levels of support from colleagues than other nurses may experience. Whilst this may be true under those conditions, in contrast, nurses in this present study highlighted the potential for increased stress levels when this condition (of feeling supported by colleagues) is not met. It seems the findings from Desbiens and Fillion's study, and those from this present study combine to form two sides of the same coin. Both suggest that stress is amplified or increased when there is insufficient support from colleagues, and when it does happen, the level of stress is less than experienced by nurses elsewhere. This suggestion is supported by other studies, such as Pronost et al. (2012) who identified that better support in the workplace leads to reduced stress levels, increased coping

abilities and better quality of life for caregivers. Furthermore, the better the professional quality of life for caregivers, the better the quality of care provided to patients.

Sherman (2004) highlights the need for nurses to receive emotional support to help mitigate the effects of secondary traumatic stress, caused by an unmet need to alleviate suffering. Sherman (2004) suggests regular team meetings to enable nurses to reflect on death and the lessons that can be learned from the care that was given are likely to minimise the stressful impact of palliative care nursing. Fillion, Dupuis, Tremblay, De Grace, and Breitbart (2006) found that support groups are effective in decreasing stress in palliative care staff and recommend logotherapy as an approach to supporting palliative care nurses. The approach has some assumptions such as humans having a basic will to search for meaning and an ability to choose their attitudes towards life, consistent with findings from this study.

The nurses in this study needed to feel supported in their work and this includes finding recognition and acknowledgement that their work means something outside the patient relationship, consistent with findings from Sabo (2011). Validation seems to be a crucial element of the ability to continue caring, especially when there is an investment of self in the work they do. The nurses in Sabo's (2011) study reported feeling less isolated when they felt heard and supported, normalising their

experiences of challenging care. Furthermore, their level of job satisfaction increased when the nurses felt valued and had a degree of autonomy in their work.

There is much emphasis in the literature on the value of support in the palliative care workplace:

“Supportive relationships such as buddies, mentors, and supervision help staff sustain their compassionate care. Participants who feel most supported in their hospice work were most likely to have higher ProQOL [Professional Quality of Life]” (Hotchkiss, 2018, p. 1107).

The optimal way to ensure nurses do feel supported in the workplace is unclear. Hawkins et al. (2007), for example, note that clinical supervision and opportunities to reflect on practice are important elements that help nurses to manage their responses to multiple losses, however, the efficacy of support groups remains contested. This may be due to perceptions of professionalism or perceived weakness in those seeking support. Francis and Bulman (2019) found that the benefits of clinical supervision for community hospice nurses depended on individuals’ length of time in palliative care, personal preferences for coping strategies and organisational support. In their study, nurses appeared frustrated when sharing in supervision, especially if they were unable to resolve issues beyond their control: *“... we’ve got no solutions because we haven’t got the authority to sort it out”* (Francis & Bulman, 2019, p. 391).

6.5.3 Develop a coherent narrative

To make sense of adversity the nurses in this study described different ways in which they developed a coherent narrative about their experiences. This involved the ability to reflect and learn from experience and articulate their story to others who understand, underlining the importance of the team support described above. Telling the story to others who understand served to form a coherent narrative of the experiences. This understanding could then prepare the nurse for similar adversities in future through increased self-awareness and competence. This theme overlaps with the 'team support and cohesion' discussed above, in that this appears to be an important mechanism through which nurses tell their story, leading to reflection and learning from experience. This learning from experience and preparedness for the future finding is consistent with other studies with palliative care nurses (Vachon et al., 2012) and aged care nurses (Cameron & Brownie, 2010). Of particular interest was the benefit nurses reported about how this learning from experience not only prepared them professionally for the future but also enhanced their own lives, such as one nurse who suggested these lessons were like an extra salary.

Sharing experience was an important aspect of enhancing resilience in the face of adversity for the nurses. Detailed examination of why this might be the case was beyond the scope of the present study but there are reported similar phenomena in the literature that may, at least in part, contribute to greater understanding. One example is the potential to bond with others over negative experiences, referred to as

identify fusion (Jong, Whitehouse, Kavanagh, & Lane, 2015). Furthermore, Jong et al. (2015) highlight how one's sense of self is often constructed via transformative autobiographical episodes and enhanced when shared with others. These claims are supported by their experiments with certain groups of people. One group who experienced the 2013 Boston Marathon bombing directly were unsurprisingly more likely to have reflected on the event than those who were not directly exposed. Less surprisingly, there was a positive correlation between the degree of reflection and the degree of identity fusion with their group.

In this study, the nurses did not explain why they thought sharing their experiences with others contributed to resilience. A possible explanation may be that this provides further opportunities to learn from others' experiences, without directly encountering these themselves, thereby providing opportunities to develop or grow without direct exposure to adversity. Jolly, Tamir, Burum, and Mitchell (2019) found in their extensive study on motivations for sharing experiences that, contrary to popular belief, there was an absence of support for hedonistic motivation. Their study did not find any evidence that emotions were amplified as a result of sharing experience with others. Alternatively, they suggest a strong desire to share information is a motivational factor, leading to a collective body of knowledge that informs future decision-making.

6.6 Collaboratively designed interventions to enhance resilience

This study was designed to generate a better understanding of resilience in hospice inpatient nurses by testing strategies in addition to evaluating and generating theory. Existing resilience research has evolved over decades yet there are often-cited criticisms which influenced the methodological choices in this study. These criticisms include the lack of definition of resilience (Cleary et al., 2018); using an absence of psychopathology as a proxy indicator; measuring resilience at discrete time points rather than over time; not attending to contextual differences; assuming resilience should be enhanced at the level of the individual (Chaudhari, Mazumdar, Motwani, & Ramadas, 2018); and designing interventions to be done to people, rather than collaboratively designing with people, based on their knowledge and experience of the challenges they face in particular contexts (Moustaka & Constantinidis, 2010). An important contribution from this study is the involvement of nurses themselves as coresearchers rather than subjects. This methodology, using Participatory Action Research (PAR), enabled many of the criticisms of existing resilience research to be addressed differently; however, this is not to say that different criticisms may arise, which are discussed further in the limitations section to follow.

In addressing the challenges reported in the literature regarding existing research, this study was designed to combine the following elements: understand resilience from the perspective of nurses themselves who work in inpatient palliative care; use this understanding to generate a working definition of resilience for this inquiry; to

collaboratively design (rather than impose) strategies to enhance resilience in this particular context, and to test and collaboratively evaluate those strategies to further identify what may or may not work at the system rather than individual level. This part of the study was achieved through the formation of a Collaborative Inquiry Group (CIG) which used the findings from the first phase of the study to identify areas for consideration and possible interventions.

6.6.1 PAR Cycle 1: Insufficient nurses in the CIG

The first challenge the group faced was insufficient nurses in the CIG based on initial recruitment. The PAR cycle attached to this issue was designed to not only increase numbers of participants but to establish any reasons for reluctance to participate, especially where this was related to resilience. The conditional nature of participation cited by two nurses was revealing in that it appeared to be driven by a need to protect their time away from work. The importance of achieving a work-life balance is not new and its importance is emphasised across multiple studies as a protective factor in workplace stress (Jamieson, Kirk, & Andrew, 2013), however, there could reasonably be many more reasons for a reluctance to participate, such as an inadequate comprehension of research; time; and a perception that the research lacks value perhaps due to a lack of personal relevance (Hagan & Walden, 2017). To mitigate these possibilities, introductory sessions were held at the research site to explain the nature of the study, and relevant information was circulated via email to all trained nurses as many were unable to attend due to shift patterns and other commitments. The

intervention in this PAR cycle led to the recruitment of two more nurses and was therefore considered successful.

6.6.2 PAR Cycle 2: Rota Issues

The CIG wanted to tackle the issue with the lateness of the rota as it appeared to be the biggest stressor for staff. Two actions were completed; one to establish precisely the extent of the perceived delay, and another to present the findings to the manager responsible for the rota with the expectation that it would be completed sooner. Participants reported how the subsequent earlier publication of the rota was very well received by staff, who appeared less distressed as a result. Rota issues are frequently cited as a cause of workplace stress for nurses, however, this study identified that it appears to be a component of the finding 'being kept in the dark'. The PAR process was particularly helpful as it supported the nurses to identify the exact issues regarding the rota, precisely define the extent of the lateness, empowered them to speak with their manager and caused (albeit temporarily) a change that was beneficial for the entire workforce.

Many studies highlight the prevalence of stress associated with nursing workloads; however, this is usually related to the type and amount of nursing work required when the nurses are on shift. This study revealed that, in this particular context, the uncertainty about when the nurses were going to work was their greatest concern. This concern led to the actions described above, which could also be considered an

improvement in communication and assertiveness as found by McDonald et al. (2013) whose series of workshops designed to improve resilience led to improved communication and assertiveness in the workplace generally.

6.6.3 PAR Cycle 3: Nurse Retention

The nurses in the CIG suspected that nurses who left the organisation were doing so due to organisational issues that were affecting resilience. There was a perception of a discrepancy between official and unofficial reasons stated for the nurses' leaving and the group wanted to identify any issues that could be addressed to enhance resilience in future. As reported in the findings chapter, the process of obtaining facts about why people left was useful as it further identified how not knowing was stressful for staff. Once staff knew the reasons staff had left, and trusted that information, this appeared to alleviate their concerns. This process further highlights the importance of this study's approach: linking perceived stressors with action focussed inquiry to identify how local situations can be improved. On the surface, it seemed there was a problem with nurse retention, and whilst this was true for a period before the study, there was no evidence it was related to resilience nor an ongoing problem.

6.6.4 PAR Cycle 4: Investigating how to respond to concerns about teamwork, feeling affected by patients and needing to tell their stories.

This cycle included a workshop for all staff at the hospice to explore thoughts about how best to address concerns related to identified stressors such as sub-optimal

teamwork, feeling affected by patients, and the need to tell one's story. Interestingly 15 staff attended the workshop, a higher number than anticipated and suggests the topic was of interest to other non-nursing staff in the unit. The workshop participants concurred with the findings from the literature review and agreed on factors that influence resilience and the need for support to be able to cope with the demands of their roles. The findings from this workshop were used to inform the final action cycle.

6.6.5 PAR Cycle 5: A Nurses' Meet and Chat (NMC) Group

The CIG decided upon a forum they believed would achieve the desired outcomes from the workshop in cycle four. This group, designed by nurses, for nurses (with consideration about the impact on non-nursing staff), was entitled the "NMC group", an acronym also shared with the Nursing and Midwifery Council. The CIG thought this would not be a deterrent and may emphasise the focus on trained nurses in particular. This intervention was eagerly implemented by the CIG, due to the perceived possibility that it could support staff with most, if not all, of the issues identified as adversities in their workplace.

Despite careful consideration, planning and implementation, the group appeared unsuccessful due to a lack of uptake from nurses. There was one meeting, which was well-received and evaluated but consisted entirely of Band Six nurses, as there were no Band Five nurses on duty at the time of the meeting. No staff attended the second meeting, and this could be due to a perception that it is only for senior staff, or because

it was considered part of a research project and, as above, nurses may be reluctant to participate in research. Also, upon further inquiry, it was seen by some as yet another meeting and more work to do. Implementation of research-based interventions in hospice and palliative care is poor, as it is in many areas of healthcare (Demiris, Parker Oliver, Capurro, & Wittenberg-Lyles, 2014). Nurses may be reluctant to implement changes, even when there is sound evidence to support changes to practice (Johnson, 2014). This reluctance may be for a variety of reasons, including the degree of support from senior staff, lack of time and unsupportive organisational cultures (Curtis, Fry, Shaban, & Considine, 2017).

Nursing staff are often stressed and busy. There is no doubt that there is more work than can comfortably be achieved at any given time in healthcare settings and a perception that an intervention such as the NMC group is more work rather than a source of support is worrying. Despite a workforce of 18 registered nurses, only five attended the NMC group (two of whom were part of the CIG). This lower than expected turnout was explored and revealed that nurses considered it to be 'yet another meeting' and made comments such as 'will I be paid for it?'. This suggests they perceived the group to be akin to work and therefore burdensome rather than rejuvenating. There is little in the literature to explain the reluctance of nurses to seek or avail themselves of support, but some suggest this may be due to fear of losing a registration, stigma, embarrassment and concerns about confidentiality (Cares, Pace, Denious, & Crane, 2015). It seems plausible that other factors may influence the ability

to take time away from the workplace for support, such as concern for patients, burdening other colleagues or perhaps a doubt that support may be beneficial.

6.7 Reflexivity

Reflexivity involves monitoring one's thoughts, feelings and actions throughout the research process. This reflexivity may contribute to a deeper understanding of any knowledge claims by reflecting on how the research was conducted and the nature of relationships with participants (Cassell et al., 2018). There are criticisms of the validity of reflexivity in research, largely connected to how language shapes our understanding of the world and can, therefore, be as limiting as it may be illuminating (Cassell et al., 2018). By acknowledging these challenges and acknowledging that social reality is constructed and influenced by the situated nature of knowledge, the importance of explicitly stating how particular interests have shaped the research process becomes apparent.

This study sought to identify the nature of resilience according to hospice nurses and to understand influencing factors from individual, interpersonal and organisational perspectives. Whilst the summaries above accurately describe the experiences of the nurses and what the CIG did, they do not contain information about my experience of the process and subsequent reflections. As reported earlier, there are hundreds of ways to define and categorise action research in its various guises yet it is common (if not necessary) to include an element of critical reflection that demonstrates what the

researcher has learned about themselves or their professional practice as a result (Costello, 2003). Different levels of reflexivity may be referred to as first person, second person or third person action research (Coghlan & Brydon-Miller, 2014) or individual, societal/collective, or institutional levels (Cassell et al., 2018). My reflections on implications for my practice, that of the nurses who participated and for hospices and palliative care generally are outlined according to each level below.

6.7.1 First-person/individual level

As a senior manager in a large hospice, I learned enormously from my experience of conducting this study and collaborating with nurses and the organisation they work for. Multiple times during the CIG groups I experienced a desire to react and attempt to fix things and direct to solutions based on my own experiences. I reminded myself frequently that the nurses were the experts in their environment and how I needed to listen to their story and ensure their voices were prioritised and heard. A goal of first-person action research is to improve, rather than prove, something (Coghlan & Brydon-Miller, 2014). My practice as a manager will improve if I implement the following lessons from the study into my practice: adversity is what nurses say it is, not exclusively what the stress literature reports; nurses need time to reflect and learn from their experiences and to not feel bad for doing so; nurses need time together to share their stories and this should be encouraged; death and dying is not stressful per se, but some patients will affect nurses more than others; rotas must absolutely be

done with as much notice as possible; and finally, open, honest transparent communication is key.

6.7.2 Second-person/societal – collective level

The second-person or societal level of inquiry involves an exploration of how knowing is based on the relationships people have with others, usually in small groups who come together to investigate matters of mutual concern (Coghlan & Brydon-Miller, 2014). I was struck by several things during phase two of the study, where relationships with others were crucial elements of the process. Firstly, it was imperative that groups were well-facilitated and enabled everyone to have a voice. I noticed that some members spoke much more than others and how this was sometimes related to rank or position in the organisation. I was mindful that those who spoke the most did not necessarily have more to say. I was especially interested in encouraging a dialogue that elucidates the nature of adversity and how perhaps taken-for granted things might remain unspoken, especially where this is connected to the relationships the participants had with each other and their organisation. I paid attention to points of confluence as well as conflict, suggesting we notice where there was agreement, and just as importantly, where there was not. I learned the importance of conversation and dialogue between nurses and how this influenced the way they spoke about the challenges they face in their work. This observation undoubtedly contributed to the desire to establish a forum where this could happen regularly.

6.7.3 Third-person/institutional level

This level of inquiry considers the broader contribution to a society or system, often connected to processes where there is no direct contact between people with a view to elevating what is discovered locally, to larger level discourses (Coghlan & Brydon-Miller, 2014). There are several areas of reflection to consider regarding the findings from this study and relevance to a wider audience. Whilst there are inevitable limitations (discussed further later in this chapter) of this study, not least of which is that it was never intended to find universal truths, there are important considerations for the palliative care community.

There are over 200 hospices in the UK with inpatient facilities (Care Quality Commission, 2018) and therefore a large number of settings to which the findings from this study could apply. Whilst avoiding assumptions that the findings are inevitably relevant, it is my hope that this research raises awareness of the nature of resilience in hospice inpatient units and provides a platform to generate further discussion (at least) or more research (at best) that will influence the way we enhance resilience for nurses in this field. I hope organisations take greater responsibility and avoid asking nurses to tolerate greater levels of strain at the expense of addressing the issues inherent in caring for those approaching the end of their life.

6.7.4 Researcher background and influences

My childhood closely resembled that described in the earlier resilience literature, which focussed on how children who had experienced significant challenges in life tended to fare better than expected. The challenges I experienced were related to significant psychological and physical abuse, neglect and impoverishment. At its peak, this led to an absence from school for almost two years at a time when I should have completed GCSEs. I left school with very few qualifications and this no doubt contributed to a desire to prove myself academically later in life.

During my career as a paramedic, I became increasingly interested in how staff were able to cope with exposure to traumatic situations. I trained as a counsellor and subsequently taught counselling skills to colleagues as part of a successful peer support system. Shortly after I moved into palliative care as a counsellor, I was asked to provide resilience training as part of a suite of mandatory training for all staff. With the experience and knowledge I had, at that time, I developed training based on Cognitive Behaviour Therapy (CBT). CBT approaches assume that unwelcome thoughts and feelings can be changed to benefit the individual. Whilst the CBT label is new, this approach relates to the teachings of the early stoics who espouse that one is not disturbed by things in themselves, rather the views they take of them. Reflecting on that approach now, in respect of this study, I feel uncomfortable in my complicity that the stressors one faces at work are problematised at the level of the individual.

6.7.5 Reflection on the research process

Proponents of PAR sometimes appear evangelical in their approach, pitching PAR as the panacea for change, especially where there is a degree of oppression in a group or community (Benjamin-Thomas, Corrado, McGrath, Rudman, & Hand, 2018). Furthermore, Benjamin-Thomas et al. (2018) note a lack of author reflexivity in published papers which, in their view, serves to undermine the credibility of the research process. Reflections on particular aspects of the process in this present study are described with respect to Grant, Nelson, and Mitchell (2008)'s identified challenges: relationships, power, participation, change and credibility.

6.7.6 Relationships

Building relationships with the CIG members was a priority for me as I doubted the research would be possible otherwise. Grant et al. (2008) highlight the need for transparency, openness and honesty in communication, with expectations navigated at the outset. Additional time invested to describe the proposed research, explain roles and levels of commitment and the nature of the study to participants in advance was well spent. I reflected on my internal challenges with participants which I found emanated from different aspects of myself; on the one hand, as a manager, I wanted to influence, lead and coach participants to reach certain conclusions, yet on the other, I appreciated the value in approaching challenges in keeping with my professional training as a counsellor, where emphasis is placed on creating the right conditions for people to process their thought and feelings with a view to better understanding their

options and choices. The length of this project coupled with regular monthly meetings contributed to the relationships that were successfully built.

6.7.7 Power

Issues with power and control are inevitable in PAR studies, to varying degrees and must be considered as part of the research process (Grant et al., 2008). Power may come from being the more informed researcher in the group or may also come from participants, without whom the research could not exist. Key to the process for me was acknowledging honestly, in advance, the nature of the process and what this may mean for all concerned. For example, I explained carefully that the project was part of my PhD study and would hopefully culminate in an academic award. This necessitated a clear explanation of which parts of the process belonged to me, and which elements were shared. We agreed, as a group, to take shared ownership and responsibility for the second phase of the study, which also meant acknowledging that any future publications arising from this aspect of the study would involve shared authorship.

One of the nurses in the CIG was of a higher grade than the others, and this inevitably influenced the nature of discussions. I was very aware of the need for careful facilitation at times when rank appeared to influence contributions, views and opinions; finding that reminders about the group's shared values and aims supported us to consider discordant views as valuable data for us to learn from.

6.7.8 Participation

As mentioned above, there are degrees of participation in PAR studies. Even within the CIG group, there was variability in involvement and commitment from the individual members. Grant et al. (2008) note the importance of addressing barriers to participation and in this study, there are some examples of how this was addressed, such as one participant's pregnancy and the group's response to ensuring meetings were arranged at suitable times. Similarly, when the participant had her baby, the group were willing to accommodate the baby in the meetings so as not to prevent full participation from this member. Other ways in which participation was considered was through initial negotiation with senior managers who agreed that the meetings could happen during paid time, and if staff attended outside of their working hours, they could be paid or take this time back. This agreement, symbolically, reinforced the organisation's endorsement of the study.

6.7.9 Change

The desire for change was strong from all members of the CIG group, in addition to my hope that the project would bring about change for the better for the nursing workforce in the study. Change, however, may be a slow process and there may not always be tangible outcomes (Grant et al., 2008). Whilst I was disappointed that we did not discover *the* answer to resilience in the nursing workforce we did, however, identify that change is possible. We also identified that change can be instigated by nurses themselves in response to the challenges they face.

6.7.10 Credibility

Grant et al. (2008) argue that credibility in PAR studies is based on the extent of participants' voices. An example of a threat to credibility is how researchers may sacrifice local knowledge from community members in place of more generalisable knowledge production (Grant et al., 2008). Throughout this study, I sought clarification from participants on my understanding of the knowledge generated. During phase one, I analysed the data myself and then brought it into phase two for scrutiny. The CIG members agreed with the themes and used them as a basis for addressing the issues they identified as particularly problematic. There were times during the assessment of the challenges they faced that I had other ideas about what may be more interesting or practical to pursue, however, I recognised that these were my preferences rather than theirs. At times I described my views yet strived, insofar as it was possible, to offer my views/interpretations but, in keeping with the ethos and methodology of the study, I was keen to know how the nurses themselves wanted to conceptualise and address the challenges they faced.

Results in action research are considered authentic when they are recognisable and of importance to those in the study rather than relying on traditional views of validity and reliability (Zuber-Skerritt & Fletcher, 2007). I reminded myself frequently that the nurses' views were of primary relevance in keeping with the aims of the study. Furthermore, in the methodology chapter, the importance of addressing the elements

in Table 6-1 (adapted from Zuber-Skerritt & Fletcher, (2007)) was acknowledged and each was self-assessed as covered in this study:

Table 6-1 Essential elements of an action research thesis

Action research theses should be:		Achieved?
1	Be practice-oriented	Yes
2	participative	Yes
3	focussed on issues of relevance to the wider community/organisation/world, not just themselves	Yes
4	Use multiple perspectives of knowing	Yes
5	Demonstrate rigour in methodology to contribute new theory and practice	Yes
6	Be explicit about assumptions	Yes
7	Be reflective, critical, self-critical and ethical	Yes

6.8 Limitations

Limitations of this study relate to both design and methodology that influenced how findings were interpreted. Whilst every care was taken, including the support of a specialist librarian, there were small numbers of peer-reviewed, primary research papers on resilience in palliative care available to synthesise in the literature review.

There is an ongoing debate about optimal numbers of participants in qualitative studies (Dworkin, 2012) and whilst seven participants in phase one may be considered reasonable, only four participants were recruited for phase two (the CIG). Furthermore, all participants (excluding me) were female and therefore may be subject to gendered bias. Finally, all participants were self-selecting, and it may be that their views are not representative of all nurses working in hospice inpatient palliative care. Participants were recruited from one organisation and therefore findings are not necessarily generalisable to other hospices or settings. Understandably the participants in this study described issues that were recent, relevant and contextually located in this one organisation. Issues that influenced the way the participants experienced the nature of adversity may change over time and this should be borne in mind when interpreting findings.

PAR as a research approach has inherent limitations as well as values. Mackenzie et al. (2012) highlight the following issues to be considered: clarity of roles and responsibilities; resource requirements; sensitivity to stakeholder needs versus research needs; and confusion regarding whether the researcher is indeed a researcher, or a facilitator of research. Such issues were present in this study, including the omnipresent need to monitor how roles, responsibilities and relationships were influencing the research process. One of my internal conflicts, for example, was striving to balance how I could contribute to the study as a participant, without imposing my views on the nurses. Furthermore, PAR requires a larger time

commitment than many other types of research, with high degrees of personal investment of the researcher. This investment involved forming relationships over time and facilitating groups carefully to ensure stakeholders were supported to engage in the project in meaningful ways. Finally, PAR poses challenges to traditional methods of assessing scholarship such as a PhD award in this case. The need to own much of this work myself influenced the design of the study and it may well have been conducted differently had this influence not been present.

This study did not find that exposure to death and dying affected resilience, despite claims that this is often a cause of significant distress for those who confront the existential limitations of life (Wagner et al., 2016). Similarly, humour and faith were not reported as resilience facilitators, contrary to findings in other studies (Cameron & Brownie, 2010; Pinna et al., 2018).

Biron and Karanika-Murray (2014) claim there appears to be little progress in stress intervention research and caution against a repetition of offering more of the same, whereby interventions are designed to be methodologically robust rather than pragmatically relevant. This study sought to make a difference to and for participants, but the impact of the study is hard to determine given the apparent lack of reach. Only four (of a possible 18) nurses participated in the second phase of this study and it is unclear why some may be motivated/willing whilst others are not. One possible explanation could be a lack of readiness to change (Biron & Karanika-Murray, 2014). It

may well be that the four who chose to participate, as self-selected, willing participants, are not entirely representative of the whole nursing group.

Of particular concern is the risk that the final intervention was seen as a failure; this may deter people from participating in future interventions to improve stress in the workplace (Biron & Karanika-Murray, 2014). This was mitigated in the study by emphasising the nature of the research and testing ideas to see what works and what does not. With this attitude in mind, all results are useful regardless of the outcomes of the interventions. Another way to consider outcomes is to explore whether the intervention is in itself ineffective, or whether the outcome has been unduly influenced by issues with implementation (Biron & Karanika-Murray, 2014). Of note, the CIG believed the intervention to be sound, although not at this time with this particular staff group.

6.9 Implications for research policy, and practice

Resilience research is often complex, multi-faceted and frequently makes assumptions about the construction of the concept and its generalisability to multifarious settings. To the best of my knowledge, this study is the first to work collaboratively with registered nurses in hospice inpatient care to define resilience, understand the challenges they face from their perspective and then work with them to develop strategies to enhance resilience in the face of the particular adversities they identified.

Future research could explore further the extent to which resilience is affected by particular settings and how participants themselves could identify optimal strategies to enhance it. The findings from this study suggest this is a feasible approach and may encourage researchers to look beyond the typical mindfulness-type approaches to generalised resilience enhancement, towards a more individualised, specific approach depending on the demands of the particular environment where adversity is experienced. Resilience is, and will likely continue to be, a complex construct. There is just one study published to date that used Participatory Action Research (PAR) to attempt to better understand resilience from the perspectives of nurses themselves (Liang, Wu, Hung, Wang, & Peng, 2019) to enhance resilience in student nurses in their final year of training. PAR appears to be more commonly applied to the study of resilience in industries such as agriculture (Apgar et al., 2017) or ecology (Campos et al., 2016), for example. Future research may benefit from a focus on the extent that meaning-making processes or interventions influence resilience. Such interventions have proven efficacious in patients facing their death (Wagner et al., 2016) and may benefit professional caregivers.

In terms of policy, the assumption that resilience training (using mindfulness or CBT approaches) might influence nurses' ability to tolerate increasing levels of adversity in healthcare provision is challenged. An example of this is the study by Pipe et al. (2011, p. 11), based on the notion that

“increasing the ability of healthcare providers to perform more efficiently under conditions of stress is a realistic way of adding to the value of healthcare”

Policymakers are encouraged to consider how best to consider resilience from a systemic perspective rather than concentrate efforts towards problematising adversity as the individuals' responsibility. Furthermore, demands on the healthcare system, and consequently those who deliver it, are predicted to increase significantly in future. It seems that doing more of the same, or worse, doing nothing to support nurses in stressful working environments, will threaten the ability to cope with present and future need.

In practice, individual nurses are likely to manage adversity better when there is a supportive work environment, where they can both give and receive support as required. The findings from this study show that it is feasible for nurses to have a voice and influence change in their workplace. Managers should consider how best to respond to the challenges their staff face by creating opportunities for reflection and honest discussion of workplace adversities. Furthermore, it appears there is not a one size fits all approach when identifying solutions; but through a process like PAR, nurses could develop opportunities to enhance resilience in the workplace.

In the final weeks of writing this thesis, Covid-19, a global pandemic, challenged the world in ways usually confined to fiction. The impact of the disease will be felt for

many years to come. Of relevance to this study, is the impact on healthcare and its providers. Covid-19 is highly contagious with an estimated fatality rate of approximately 1.4% of those infected (Wu et al., 2020). Rates of death will change according to variables such as age or underlying health conditions and means countries are having to reorganise the way healthcare is delivered in radical ways. The UK, for example, has adopted a particular approach to 'flattening the curve' of rates of infection by implementing a lockdown policy, asking people to stay at home to reduce the risk of contracting the disease. This approach is designed to protect the NHS and ensure there are enough critical care beds available for those who need them.

Makeshift hospitals are opening at commercial sites to increase the capacity to care for thousands of Covid-19 patients with calls for volunteers and staff to join the workforce. It seems inevitable that staff in the healthcare system, throughout the world will now be exposed to death, dying and suffering at rates familiar to palliative care staff. Resilience may not be the only answer to the challenges the healthcare workforce faces, but certainly warrants further attention in this context.

6.10 Conclusion

Nurses in inpatient palliative care settings are exposed to adversities, many of which are similar to workplace stress that many other professionals may experience. However, this study sought to identify the particular adversities faced in one setting; finding that the key adversities likely to undermine resilience were related to

particular patients, feeling kept in the dark and when teamwork was sub-optimal. Furthermore, in facing these adversities, resilience is enhanced through a process of meaning-making. Meaning-making helps nurses to make sense of their experiences in such a way as to prepare them to more effectively deal with similar situations in future. The process of meaning-making involves particular mindsets, team support and the ability to develop a coherent narrative about one's experiences. There was a strong desire for this coherent narrative to be developed with a group of peers, however this strategy was not sufficiently tested during the time constraints of this study.

Generating greater understanding of both the adversities in palliative care inpatient nursing and the nature of resilience in the face of such adversities enabled a collective sense of strategies that could be employed by nurses themselves to enhance overall resilience in the workplace. The final cycle of action in this PAR study was the creation of a 'Nurses Meet and Chat' (NMC) group, which the CIG hoped would provide the level of support required when nurses face the adversities identified in this study. Whilst the NMC group was not considered successful it was discovered that nurses could collectively identify ways in which resilience could be enhanced through a process of PAR and not rely solely on previously empirically tested interventions such as mindfulness or CBT principles, where the aim is to increase resilience at the level of the individual rather than the system.

The finite time constraints of the study meant the official process stopped after cycle five, but it is hoped that the nurses will continue to plan, act and reflect on resilience enhancement strategies for the better of their workplace, themselves and their patients.

There are gaps in the extant literature that this present study was designed to address, each of which are now stated in turn below. Resilience is often poorly defined in research studies and used interchangeably between different people, professions and settings. A definition of resilience was offered in chapter one to situate this present study based on extensive reviews of literature and published concept analyses. Resilience is typically measured at the level of the individual and is rarely linked to particular adversity. Intervention studies that report self-assessed measures of resilience may use validated scales/tools, but these are subjective and not directly connected with adversity. Rather, they tend to ask individuals to evaluate how they believe they would behave in challenging scenarios, whereas the investigative work during the literature review phases of this study highlighted that resilience only occurs as a consequence of adversity. Therefore, predicting how people believe they will behave without exposure is hypothetical in nature.

Published resilience studies in healthcare workers or systems usually assume that resilience is the same regardless of discipline or setting, whereas this study originated from concerns about nurses in particular. During the research it became clear that the targeted, nursing-specific endeavour was appropriate and worthwhile and generated

findings that may be relevant to other professionals, but this should not be taken for granted.

Finally, interventions in the resilience literature are typically designed to improve individual tolerance for adversity, rather than designing interventions that could improve resilience at the system or organisational levels. Furthermore, these interventions are almost always based on mindfulness or stress reduction approaches and therefore do not empower or encourage nurses to challenge the systems within which they work. The nurses in this study demonstrated they are keen, willing and able to make a difference for themselves, their workplace and the patients they care for through a participatory research process.

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APPENDICES

Appendix 1 Literature review search terms and databases

CINAHL Search Strategy			
Sequence	Search items	Limiters	Results
S13	S4 AND S9 AND S12	None	(721)
S12	S10 OR S11	None	(50,208)
S11	TI (hospice OR palliat* OR end of life care OR terminal care) OR AB (hospice OR palliat* OR end of life care OR terminal care)	None	(35,778)
S10	(MH "Hospice Care") OR (MH "Hospices") OR (MH "Terminal Care") OR (MH "Palliative Care")	None	(37,879)
S9	S5 OR S6 OR S7 OR S8	None	(91,240)
S8	TI (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment) OR AB (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment)	None	(72,978)
S7	(MH "Coping")	None	(20,845)
S6	(MH "Adaptation, Occupational") OR (MH "Adaptation, Psychological")	None	(16,189)

S5	(MH "Hardiness")	None	(4,505)
S4	S1 OR S2 OR S3	None	(405,301)
S3	TI nurs* OR AB nurs*	None	(384,087)
S2	(MH "Nurses")	None	(45,822)
S1	(MH "Hospice and Palliative Nursing")	None	(3,845)

Academic Search Ultimate Search Strategy			
Sequence	Search Items	Limiters	Results
S12	S3 AND S7 AND S10	Language: English	(299)
S11	S3 AND S7 AND S10	None	(310)
S10	S8 OR S9	None	(43,463)
S9	TI (hospice OR palliat* OR end of life care OR terminal care) OR AB (hospice OR palliat* OR end of life care OR terminal care)	None	(43,285)
	((DE "HOSPICE care" OR DE "HOSPICES (Terminal care facilities)") OR (DE "PALLIATIVE treatment")) AND (DE "TERMINAL care" OR DE "TERMINAL care -- Psychological aspects")	None	(2,436)
S7	S4 OR S5 OR S6	None	(345,682)
S6	TI (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment) OR AB (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment)	None	(341,470)
S5	DE "ADJUSTMENT (Psychology)"	None	(16,882)

S4	(DE "RESILIENCE (Personality trait)") OR (DE "ORGANISATIONAL resilience")	None	(6,068)
S3	S1 OR S2	None	(238,536)
S2	TI nurs* OR AB nurs*	None	(235,485)
S1	DE "NURSES" OR DE "NURSES -- Job stress"	None	(45,660)

PsycINFO Search Strategy			
Sequence	Search Terms	Limiters	Results
S12	S3 AND S7 AND S10	Language: English	(276)
S11	S3 AND S7 AND S10	None	(291)
S10	S8 OR S9	None	(20,896)
S9	TI (hospice OR palliat* OR end of life care OR terminal care) OR AB (hospice OR palliat* OR end of life care OR terminal care)	None	(17,289)
S8	(DE "Hospice" OR DE "Palliative Care") OR (DE "Terminally Ill Patients")	None	(15,480)
S7	S4 OR S5 OR S6	None	(233,794)
S6	TI (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment) OR AB (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment)	None	(223,366)
S5	((DE "Adjustment") OR (DE "Adaptation")) OR (DE "Coping Behavior")	None	(65,070)
S4	DE "Resilience (Psychological)"	None	(10,389)
S3	S1 OR S2	None	(88,231)
S2	TI nurs* OR AB nurs*	None	(86,275)

S1	DE "Nurses" OR DE "Nursing"	None	(37,057)
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Medline Complete Search Strategy			
Sequence	Search Options	Limiters	Results
S16	S3 AND S8 AND S14	English Language	(811)
S15	S3 AND S8 AND S14	None	(885)
S14	S9 OR S10 OR S11 OR S12 OR S13	None	(115,188)
S13	AB (hospice OR palliat* OR end of life care OR terminal care) OR TI (hospice OR palliat* OR end of life care OR terminal care)	None	(82,689)
S12	(MH "Terminally Ill")	None	(5,978)
S11	(MH "Terminal Care")	None	(24,357)
S10	(MH "Palliative Care") OR (MH "Palliative Medicine")	None	(46,726)
S9	(MH "Hospice Care")	None	(5,480)
S8	S4 OR S5 OR S6 OR S7	None	(386,713)
S7	AB (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment) OR TI (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment)	None	(337,946)
S6	(MH "Adaptation, Psychological")	None	(83,890)
S5	(MH "Emotional Adjustment")	None	(254)
S4	(MH "Resilience, Psychological")	None	(3,123)
S3	S1 OR S2	None	(430,378)

S2	AB nurs* OR TI nurs*	None	(393,245)
S1	(MH "Hospice and Palliative Care Nursing") OR (MH "Nurses") OR (MH "Nursing")	None	(82,517)

Scopus Search Strategy		
Sequence	Search terms	Results
S1	(ABS (nurs*) AND ABS (hospice OR palliat* OR terminal*) AND ABS (coping OR cope OR resilien* OR hardiness OR adaptation OR adjustment)) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (LANGUAGE , "English"))	340

Appendix 2 Characteristics of included studies

Article	Setting	Aim	Methodology (if/as described by author)	Methods: Data collection	Methods: Data analysis	Participants	No of Participants
Ablett, J. R. & Jones, R. S. 2007. (UK)	Palliative Care Unit (independent hospice)	To describe hospice nurses' experiences of work	IPA	Interviews	Thematic Analysis	Nurses	10
Alexander, D. A. & Ritchie, E. 1990. (UK)	Palliative Care Units (setting unspecified)	To define which features of palliative care are stressful and establish the influences on nurses' attitudes towards death		Interviews	Thematic analysis	Nurses and Care Assistants	61
Barnard, A. et al. 2006. (Australia)	Palliative Care Unit (within hospital)	To describe how nurses understood their experience of being a palliative care nurse	Phenomenological	Interviews	Familiarisation, condensation, comparison, grouping, articulating, labelling and contrasting	Nurses	10
Georges, J.-J. et al. 2002. (Netherlands)	Palliative Care Unit (within hospital)	To elicit the way nurses working on a palliative care ward in an academic hospital perceive their role and gain insight into the problems they encounter	Qualitative	Interviews	Constant Comparison	Nurses	10
Huang, C. C. et al. 2016. (Taiwan)	Hospice settings (unspecified)	Explore the transformative process that occurs in nurses because of the spiritual suffering and conflict associated with caring for dying patients	Qualitative	Interviews	Reflective analysis	Nurses	8

Peters, L. et al. 2013. (Australia)	Palliative Care Unit (within hospital) & Emergency Department	To compare levels of death anxiety between Emergency Department and Palliative Care nurses and understand how they cope with exposure to frequent deaths	Mixed methods	Interviews	Thematic analysis	Nurses	56
Shimoinaba, K. et al. 2015. (Japan)	Palliative Care Units (unspecified)	To explore the nature of nurses' resilience and how it is developed	Phenomenological	Interviews	Grounded theory	Nurses	13
Wu, H.-L. & Volker, D. L. 2009. (Taiwan)	Hospice settings (unspecified)	To explore and describe the experiences of Taiwanese nurses who care for dying patients in hospices, a relatively recent healthcare option in Taiwan.	Phenomenological	Interviews	Thematic analysis	Nurses	14

Appendix 3 Ethics approval letter



Applicant: Martin Powell
Supervisor: Katherine Froggatt and Sabir Giga
Department: Health Research
FHMREC Reference: FHMREC16052

28 February 2017

Dear Martin

Re: Using Participatory Action Research (PAR) to develop an understanding of resilience in hospice inpatient nursing.

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

As principal investigator your responsibilities include:

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

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 4 Participant information sheet

Participant Information Sheet

Using Participatory Action Research (PAR) to Develop an Understanding of Resilience in Hospice Inpatient Nursing.

My name is Martin Powell and I am conducting this research as a student of the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to understand hospice inpatient nurses' perspectives on resilience and how it may be influenced by individual, interpersonal and organisational factors. Participants (as co-researchers) will develop their understanding of resilience using a Participatory Action Research approach. This will involve collaboratively identifying areas where resilience could be influenced, designing actions that are likely to make a difference, implementing such actions and evaluating the effectiveness of the actions.

Why have I been approached?

You have been approached because the study requires involvement from the nursing workforce who understand the nature of hospice inpatient units and how resilience is influenced in this setting.

Do I have to take part?

No. It's completely up to you to decide whether to take part. There are no negative consequences to non-participation.

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

There are 3 ways in which you could participate in this study:

- 1) A 90-minute individual interview with the researcher, to explore the concept of resilience in hospice inpatient nursing. It is hoped that participants will identify any actual or potential problem areas in relation to resilience in hospice inpatient nursing.
- 2) Join a co-operative inquiry group of between four and twelve nurses, meeting monthly for up to 1 year (90 minutes each time). The group will examine the problem areas identified during the individual interviews, generate new ideas for actions that are planned, acted, evaluated and reflected upon as part of the Action Research Cycle process. This phase of the study requires participants to keep a reflexive journal throughout (to capture information about your thoughts, observations and ideas about the impact of the study) and a willingness to critically engage in a process designed to bring about change for the better.
- 3) Participate in both 1 and 2 above

Should you wish to withdraw at any time during the study you may do so without negative consequences. Individual interview data will be removed from the study if the researcher is notified within 2 weeks of the interview taking place. Data from group meetings cannot be disaggregated at any point and will be included even if participants subsequently withdraw.

Will my data be Identifiable?

The raw data collected for this study will be stored securely and may only be accessed by the participants, the researcher, his research supervisors and transcriber.

- Audio recordings will be destroyed after the project has been examined
- Hard copies of generated material will be kept in a locked cabinet in the researcher's home for 10 years after the PhD is awarded and then destroyed by the researcher.
- The files on the computer will be encrypted (that is no-one other than the researcher and research supervisors will have access to them) and the computer itself password protected. These files will be kept for 10 years after the PhD is examined.
- The typed material will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from our

meetings may be used in the reports or publications from the study, and our names will not be attached to them.

- All our personal data will be confidential and will be kept separately from our responses.
- Transcripts, meeting notes and journal data will be stored anonymously by the university for bona fide secondary data analysis by bona fide researchers in future

There are some limits to confidentiality: if what is said in the interview makes us think that someone is at significant risk of harm, we must break confidentiality and speak to a member of staff about this. If possible, I will tell you if I must do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal, or presented visually or orally at conferences.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

As co-researchers in the project we will learn together about resilience in the nursing workforce and how to conduct and participate in action research. Interested

participants will learn how these principles could be applied to other areas of their practice.

Who has reviewed the project?

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

Where can I obtain further information about the study if I need it?

If you have any questions and/or would like to participate in the study, please contact the researcher:

Martin Powell,

Student for the award of PhD in Palliative Care

Email m.powell3@lancaster.ac.uk

Supervisor:

Professor Katherine Froggatt

Professor of Ageing and Palliative Care

International Observatory on End of Life Care

Faculty of Health and Medicine

Lancaster University

Lancaster LA1 4YG

k.froggatt@lancaster.ac.uk

0044 (0)1524 593308

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Steven Jones

Director of Research

Tel: 01524 593382

Email: sjones@lancaster.ac.uk

Department of Health Research

Lancaster University

Lancaster

LA1 4YG

or if you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746

Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YG

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

Resources in the event of distress

Should you feel distressed either because of taking part, or in the future, the following resources may be of assistance:

- Insert EAP provider contact detail of participating organisation here
- The Samaritans:

Telephone 116 123 (free from any phone).

Email jo@samaritans.org

- British Association for Counselling and Psychotherapy (BACP):

BACP House
15 St John's Business Park
Lutterworth LE17 4HB

tel: 01455 883300
email: bacp@bacp.co.uk
text 01455 560606

Appendix 5 Consent form

Study Title: Using Participatory Action Research (PAR) to develop an understanding of resilience in hospice inpatient nursing.

Before you consent to participating in the study please read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the researcher, Martin Powell.

Please Initial each box to confirm each statement below:

1. I have read the information sheet and fully understand what is expected of me within this study ☐
2. I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that phase one interviews will be audio recorded, transcribed verbatim, analysed and summarily reported to the participating hospice. ☐
4. I understand that phase two group meetings will be audio recorded and summarised into anonymised written notes ☐
5. I understand that audio recordings, transcripts, meeting notes and reflexive journals will be kept by the researcher until 10 years after the research project has been examined. ☐
6. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without negative consequences. ☐
7. I understand that should I withdraw, my data from individual interviews will be removed only if requested no more than 2 weeks after the interview and that removal of data from group meetings is not possible. ☐
8. I understand that the information from my participation will be pooled with other participants' responses, anonymised and may be published ☐
9. I consent to information and quotations from my participation being used in reports, conferences and training events. ☐
10. I understand that any personal information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will need to share this information accordingly. ☐
11. I consent to Lancaster University keeping written records of my participation for 10 years after the study has finished. ☐
12. I consent to anonymised data generated during the study being kept in a central repository at the university indefinitely for secondary analysis by researchers in future ☐
13. I consent to take part in both Phases of the above study ☐
14. I consent to take part in Phase One only (individual interviews) of the above study. ☐
15. I consent to take part in Phase Two only (Participatory Action Research) of the above study. ☐



Name of Participant	
Signature	
Date	
Name of Researcher	
Signature	
Date	

Appendix 6 Interview topic guide

Interview topic guide

Date	
Q1	General Introduction, encourage participant to feel at ease, clarify consent, opportunity for questions
Q2	Demographics, brief career history, explore understanding of resilience
Q3	Thoughts about resilience in inpatient palliative care specifically
Q4	Examples of problems/areas where resilience could be improved. How did this affect individuals/teams/organisation?
Q5	Suggestions for improving resilience in hospice inpatient care
Q6	Opportunity to explore any other relevant thoughts
Q7	Conclusions, wind down, check-in and ensure participant is as comfortable as possible. Further opportunity to ask any questions.

Appendix 7 Transcriber confidentiality agreement



Confidentiality Agreement for the Transcription of Qualitative Data

Name of Study:	Using Participatory Action Research (PAR) to Develop an Understanding of Resilience in Hospice Inpatient Nursing.
Researcher	Martin Powell (PhD Student)

In accordance with the Research Ethics Committee at Lancaster University (UREC), all participants in the above-named study are anonymised. Therefore any personal information or any of the data generated or secured through transcription will not be disclosed to any third party.

By signing this document, you are agreeing:

- not to pass on, divulge or discuss the contents of the audio material provided to you for transcription to any third parties
- to ensure that material provided for transcription is held securely and can only be accessed via password on your local PC
- to return transcribed material to the researcher when completed and do so when agreed in password protected files
- to destroy any audio and electronic files held by you and relevant to the above study at the earliest time possible after transcripts have been provided to the researcher, or to return said audio files.

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Your signature _____

Date _____

Transcriber_Confidentiality_Agreement
Version: 1.0
Date: 31st December 2016

Appendix 8 Action research cycle template

Action Research Cycle Title	
Democratically agreed?	
Ethical Issues (including verbal consent)?	
WHAT will be done?	
WHO will be involved?	
WHERE will it take place?	
WHEN will each stage happen?	
HOW will we do this?	

Appendix 9 Example of early codes

