A Qualitative Analysis of the Experiences of Heart Failure Specialist Nurses

Working with Patients with End Stage Heart Failure

Submitted to the University of Leicester,

Faculty of Medicine & Biological Sciences,

School of Psychology in partial fulfilment of the degree of

Doctorate in Clinical Psychology.

by

Lynnette Marie Clarke

School of Psychology- Clinical Section

University of Leicester

May 2009

Declaration

2

This research has not been submitted for any other degree and all of its contents are original.

Thesis Abstract

A Qualitative Analysis of the Experiences of Heart Failure Specialist Nurses
Working with Patients with End Stage Heart Failure

Lynnette Marie Clarke

Literature Review. This aimed to systematically and critically appraise, as well as synthesise, qualitative research exploring the psychological impact on nurses of working within palliative care. Eleven papers were identified. Studies presented a number of quality issues. The taxonomy suggested that nurses develop a palliative care persona as a way of being, both personally and professionally. This fostered nursing resilience. Further research could explore the notion of a persona, with training, practice and support implications for nurses.

Research Report. This aimed to identify and explore the experiences of heart failure specialist nurses who work with patients with end stage heart failure, to understand how such experiences affected nurses, how they approached their work, and how they were supported. A qualitative design was used, with semi- structured interviews undertaken and analysed using Interpretative Phenomenological Analysis. Three superordinate themes were elicited: *Keeping the Rhythm Going*, relating to aspects of routine care; *The Rhythm Peters Out (A Good Death)*, relating to tasks at end of life; and *Winding up the String*, relating to the impact of working with the dying. Participants appeared to profess a 'professional face', rejecting the emotional impact of working with the dying. The perpetual physical effort of caring for patients at end of life was articulated, as were high expectations of achieving a 'good death'. Being managed from an acute context seemed to undermine delivery of an alternative model of care within the community. Recommendations regarding training, supervision and bridging two approaches of care were made.

Critical Appraisal. This section offers a reflection upon the whole research process, with reference to the research diary. Implications in terms of being a researcher and a clinician were made.

Acknowledgements

I would like to thank all of the participants who agreed to take part in this research. It has been a really enjoyable experience to get to know the professionals who make up the service and they made me feel very welcome throughout the whole research process. I would also like to thank my field supervisor for his continued enthusiasm for the project.

I would also like to thank Dr Noelle Robertson for her time, patience and understanding. Setting deadlines and spurring me on to meet them has helped me throughout. I also give thanks to members of the qualitative support group for their continued help and support.

Finally, I could not have done this without the love and support from my partner Stuart, who has been extremely patient in letting me spend countless hours getting this written.

Word Counts

Thesis Abstract-301

Literature Review- 5,398

Research Report- 12,699

Critical Appraisal- 4,304

Total- 22,702

Reference Lists- 5,089

Tables, Figures, and Appendices- 3,507

Total- 8,596

Contents Page

Addenda
      For Transcripts see separate document

List of Tables

List of Figures

<u>Literature Review</u>

<u>Working in Palliative Care Settings: A Critical Review of Qualitative Research</u>

<u>Examining Psychological Impact on Nursing Staff</u>

Target Journal- Journal of Advanced Nursing (See Appendix A)

1. Abstract

Aim. This paper sought to systematically and critically appraise and synthesise qualitative research exploring the psychological impact on nurses of working within palliative care.

Background. Previous literature reviews appeared to lack rigour, systematic approach, and incorporated flawed quantitative research. Previous reviews highlighted that whilst nurses experience adverse effects of working within palliative care, staff remain in post. Previous reviews had not concentrated thoroughly upon nurses' experiences as they favoured quantitative literature.

Data Sources. A systematic literature search of qualitative literature was undertaken between November 2008- January 2009, spanning 1887- January 2009. Eleven papers were identified.

Review Methods. Studies were critically appraised and synthesised using established methods for qualitative literature, and a taxonomy of findings developed.

Results. Included studies presented a number of quality issues. The taxonomy suggested that nurses develop a palliative care persona, establishing a new personal and professional way of being. This persona emphasises resilience and an adaptive way of coping with death and dying, enabling nurses to continue to care. In- patient settings specifically appeared to encourage development and maintenance of the persona.

Conclusion. This review created a focus on phenomenological models to understand how palliative care nurses continue to care. Further research could explore the palliative care persona, with particular reference to the unique aspects of in- patient settings, with potential training, practice and support implications for nurses.

2. Introduction

There has been growing recognition that optimal healthcare delivery is reliant upon staff health and wellbeing (Department of Health 1999, 2000, Health & Safety Executive 2002, 2008). With nurses forming a large sector of the workforce (Department of Health 1999) and being particularly vulnerable to organisational and emotional stressors (Ekstedt & Fagerberg 2005), a substantial body of research has focused upon how the provision of care affects nursing staff. Indeed, nursing can be a demanding and challenging profession, with numerous studies defining nurses' distress, variously conceived of as 'stress' (Lambert 2001, McVicar 2003, Keil 2004, Evans, Pereira & Parker 2008, p.196), 'burnout' (McElroy 1982, p. 211), 'compassion fatigue' (Sabo 2006, p. 138), and 'emotional labour' (Kelly, Ross, Gray & Smith 2000, p. 952, Henderson 2001, Huynh, Alderson & Thompson 2008). Furthermore, labels have been constructed and applied to describe nurses' responses to death, including 'grief' (Saunders & Valente 1994, p. 319, Marino 1998, Wakefield 2000, Mead 2007), 'cumulative trauma' (Davidson & Jackson 1985, p. 7), and 'death anxiety' (Davidson & Jackson 1985, p. 4, Payne, Dean & Kalus 1998).

Palliative care promotes patients' 'physical, psychosocial and, often, spiritual well-being' (Department of Health 2003, p. 24). Consequences of palliative care nursing specifically have been identified, with previous reviews identifying stress, burnout, grief, death anxiety, and 'vicarious traumatisation' as adverse psychological consequences of working within such contexts (McElroy 1982, Cohen 1995, Vachon 1995, Corner 2002, McWilliams 2004, Sinclair &

Hamill 2007, p. 350). However, previous reviews also emphasised well- being (Cohen 1995, Vachon 1995, Corner 2002, McWilliams 2004), intrinsic rewards (Corner 2002, McWilliams 2004) and nurses' unique personal philosophies and coping mechanisms, with support at home and work (McElroy 1982, Cohen 1995, Vachon 1995, Corner 2002).

The equivocal nature of concepts caused the author to examine the literature and note that conclusions appear to have been drawn from reviews whose rigour was questionable. Of those examined, only one had a search strategy specified, with defined inclusion criteria (Sinclair & Hamill 2007), and this review only indirectly considered the impact on nurses with anecdotal suggestions of extrapolation to nursing contexts. None of the six reviews made attempts to systematically critically appraise the quality of included studies. Furthermore, conclusions from reviews often do not emerge from nurses' self- defined experience, with lack of exploration regarding nurses' perspectives of personal and professional impact.

The scoping review by the author exposed vulnerabilities within palliative care nursing literature undertaken quantitatively, including multiple definitions of negative outcomes, such as stress or burnout, and a variety of different measurement tools. Furthermore, terms appeared to be used interchangeably within different quantitative research papers, with a lack of clarity over their meaning (Keil 2004) such that undertaking comparisons of homogenous groups would be undermined by the number of disparate nursing populations, settings, countries, and patient groups researched. Quantitative research is arguably reductionist and deterministic, for example measuring levels of burnout using predefined

explanations with which nurses simply agree or disagree. Quantitative research operates from the assumption that palliative care nursing is toxic.

Given these perspectives and frailties, it was felt that a review of qualitative literature might redress assumptions made within quantitative literature. Interestingly, given the high preponderance of nursing studies utilising qualitative methodologies (Nordgren, Asp & Fagerberg 2008), no such qualitative review had been undertaken to date.

2.1. Aims

The review aimed to systematically critically appraise and synthesise published qualitative research exploring the psychological impact on nurses of working within palliative care.

3. Design

3.1. Design of review

Previous literature reviews in this area had been insufficiently systematic and explicit quality criteria to appraise studies had been notably absent. This review therefore aimed to adopt a systematic approach to both selection and inclusion of papers, and ensure a rigorous and transparent approach to quality assessment. While attempts to purely review qualitative research have been encouraged (Dixon-Woods *et al.* 2006), researchers have debated the value of guidelines for critically

appraising qualitative research, and their potential bias and rigidity given the variety of designs and theoretical approaches to be incorporated (Greenhalgh & Taylor 1997, Dixon- Woods *et al*. 2006). Consequently, the use of guidelines considering basic quality considerations that can be applied regardless of design or theoretical underpinning have been promoted (Greenhalgh & Taylor 1997, Elliott, Fischer & Rennie 1999, Meyrick 2006).

This review adopted one such framework by Meyrick (2006), to assess quality and rigour. It advances principles of transparency and systematicity as common criteria for identifying high quality research. Transparency refers to 'disclosure of all relevant research processes', while systematicity refers to 'the use of regular or set data collection and analytic process, any deviations in which are described and justified' (p. 803). A recent review of qualitative research examining the impact of miscarriage, stillbirth and neonatal death on a midwifery population (Wallbank & Robertson 2008) had successfully used this approach.

3.2. Reflexivity

The author had no explicit theoretical position prior to the review. As a trainee clinical psychologist working within a physical health setting, conducting research with nursing staff working with dying patients, and having conducted a scoping review, the author was aware of labels used within nursing literature related to psychological impact, and relevant models of bereavement, stress and coping.

4. Search methods

4.1. Search strategy

The following databases were accessed between November 2008- January 2009: CINAHL (1981- 2009), AMED (1985- 2009), BNI (1985- 2009), Medline (1950- 2009), PsychInfo (1887- 2009), and Web of Science (1970- 2009). Limits on searches within databases were placed where possible: English language, peer reviewed, exclude chapters in books, editorials, reviews, dissertations, and articles that have no experimental study.

Search terms were split into four categories: palliative care (palliati*/ end of life*/ dying/ terminal*/ death); nursing (nurs*/ hospice nurs*/ oncology nurs*/ district nurs*/ community nurs*/ palliative care nurs*/ clinical nurse specialist*); psychological impact (psycholog*/ stress*/ burnout/ distress*/ bereave*/ difficult*/ coping/ strateg*/ resilien*); and qualitative research (qualitative/ experience*/ interview*/ observ*/ focus group*). Subject and free text searches were undertaken and reference list and citation reference searching were also employed, consolidated by hand-searching of the following journals between 1997 and 2009: Journal of Advanced Nursing, Palliative Medicine, Journal of Palliative Care, and Cancer Nursing.

4.2. Inclusion/ exclusion criteria

Inclusion/ exclusion criteria for the title/ abstract stage are outlined and explained within Table 1.

5. Search outcome

A total of 337 abstracts were retrieved and the inclusion/ exclusion criteria discounted abstracts accordingly (see Figure 1). A total of 116 abstracts were retrieved in full. The same inclusion/ exclusion criteria were applied to full papers, with an additional criterion developed to ensure a homogenous group of papers (see Figure 2). Thus, eleven studies were included in the review.

6. Quality appraisal

Assessment of papers for transparency and systematicity was undertaken by analysing each component of the paper, namely 'researcher epistemological and theoretical stance, process and analysis (methods, sampling, data collection, analysis) and results and conclusions (applicability)' (Meyrick 2006, p. 804), thus establishing the quality and rigour of the included studies. Criteria included within this framework resonate with criteria used within other sets of guidelines (Mays & Pope 1995, Greenhalgh & Taylor 1997, Elliott *et al.* 1999, Mays & Pope 2000, Yardley 2000, Barbour 2001, Froggatt 2001, Barbour & Barbour 2003).

7. Data abstraction

A table, based on Meyrick (2006) and Wallbank and Robertson (2008), was developed for the purposes of data abstraction and summarising the quality appraisal of each paper (Table 2). This approach concords with Popay *et al.*'s (2006) 'preliminary synthesis', with 'textual descriptions' and 'tabulation' of included studies (p. 16- 17).

8. Synthesis

Data were synthesised on the basis of quality issues using Table 2, and then synthesised by 'translating data' using 'thematic analysis' (Popay *et al*. 2006, p. 18), adopting Wallbank and Robertson's (2008) table (Table 3). A 'taxonomy of findings' (Wallbank & Robertson 2008, p. 105) was used to exemplify the relationship between the papers' findings (Table 4). Such a synthesis embraces Popay *et al*.'s (2006) techniques of 'textual descriptions', 'groupings and clusters' (p. 16- 17).

9. Results

9.1. Overview of papers

Studies were conducted in Europe, Australia, and North America between 1993- 2007, using in-patient and/ or community settings. All studies used interview data. Five used additional data collection methodologies. Table 2 summarises each paper.

9.2. Researcher epistemological and theoretical stance

9.2.1. Theoretical stance

Only five papers explicitly discussed theory relating to rewards of palliative care nursing and resilience (McNamara, Waddell & Colvin 1995, Byrne & McMurray 1997, Dunniece & Slevin 2002, Georges, Grypdonck & Dierckx De Casterle 2002, Ablett & Jones 2007), with the remaining six papers appearing to assume adverse effects would be discovered.

9.2.2. Epistemological stance

Papers should state a clear epistemological position (Meyrick 2006). However, five papers stated no position (McConigley, Kristjanson & Morgan 2000, Newton & Waters 2001, Georges *et al*. 2002, White, Wilkes, Cooper & Barbato 2004, Ablett & Jones 2007). Others stated phenomenological (McWilliam, Burdock

& Wamsley 1993, Byrne & McMurray 1997, Dunniece & Slevin 2002, Barnard, Hollingum & Hartfiel 2006), an interpretative sociological framework (McNamara *et al.* 1995), and Ricoeur positions (Rasmussen, Sandman & Norberg 1997).

9.3. Reflexive/ objective stance

Objectivity should be maintained or reflexive position stated (Meyrick 2006). Four papers did not note reflexive or objective positions (McNamara *et al.* 1995, Rasmussen *et al.* 1997, White *et al.* 2004, Barnard *et al.* 2006). Two papers explicitly described methods used to maintain objectivity (McConigley *et al.* 2000, Georges *et al.* 2002).

Five papers specified reflexivity by noting the potential impact of their professional and research experiences (McWilliam *et al.* 1993, Byrne & McMurray 1997, Newton & Waters 2001, Dunniece & Slevin 2002, Ablett & Jones 2007). However in none of these papers was the position explored with regard to the impact on the research process or outcome.

9.4. Process and analysis

9.4.1. Methods

Meyrick (2006) identified that clear aims enable assessment of appropriate methodologies to answer research questions. Overall, the quality of analysis varied in methodological rigour. Six papers had clear aims, utilising appropriate methodologies for both data collection and analysis (Byrne & McMurray 1997, Rasmussen *et al*. 1997, Dunniece & Slevin 2002, White *et al*. 2004, Barnard *et al*. 2006, Ablett & Jones 2007). However, Georges' *et al.* (2002) research questions could have been more appropriately addressed using service evaluation. McNamara *et al.* (1995) had vague aims, and failed to specify a method of data analysis. Furthermore, McConigley *et al.* (2000) stated inappropriate reasons for utilising a modified grounded theory approach, and use of observation obscured theory development. Newton and Waters' (2001) use of survey meant the seven stages of Colaizzi were incomplete. The origin of the themes also became unclear, as data sources were separated and amalgamated at different points within the paper. McWilliam *et al.* (1993) did not present a coherent rationale for modifying an existing grounded theory.

9.4.2. Sampling

Sampling should be clearly articulated, with rationale for use (Meyrick 2006). All but three papers implemented appropriate sampling techniques. McWilliam *et al.* (1993) used purposive sampling with grounded theory, and White *et al.* (2004) and Barnard *et al.* (2006) relied on convenience samples.

Every paper omitted some sampling detail. Papers failed to adequately describe how nurses were recruited (McWilliam *et al.* 1993, McNamara *et al.* 1995, Rasmussen *et al.* 1997, Georges *et al.* 2002, Barnard *et al.* 2006, Ablett & Jones 2007) and five papers failed adequately to describe setting or nursing role, compromising transferability (Byrne & McMurray 1997, Dunniece & Slevin 2002, White *et al.* 2004, Barnard *et al.* 2006, Ablett & Jones 2007).

All papers reviewed had incomplete demographic data, particularly information on gender and ethnicity, although not unusual given a need to preserve confidentiality. Furthermore, lack of clarity within three papers regarding presentation of demographic information and incomplete descriptions of data collection methods, left residual questions regarding participant process through the research (McNamara *et al.* 1995, McConigley *et al.* 2000, Georges *et al.* 2002).

Three papers attempted comparisons within their analysis and interpretation considering different demographics of the sample relating to experience or setting (McNamara *et al.* 1995, Rasmussen *et al.* 1997, Newton & Waters 2001). However, other authors did not make such distinctions, so it remained unclear as to whether

such differences affected theme generation (McConigley *et al.* 2000, Dunniece & Slevin 2002, White *et al.* 2004).

9.4.3. Transparency

Papers were deemed to have adequate transparency when there was sufficient description of the interviewer, setting and duration of interview, interview schedule and amendments to schedule, and how data were recorded. Similarly, for observation data, detailing method of observation, length, aims, and how data were recorded implied transparency. Four papers showed sufficient transparency (Byrne & McMurray 1997, Rasmussen *et al.* 1997, Georges *et al.* 2002, Ablett & Jones 2007), with the remaining papers providing insufficient details.

9.4.4. Systematicity

Systematicity refers to clear analytic process, eliciting plausible theme generation, with any changes being articulated (Meyrick 2006). Systematicity was deduced when articles sufficiently detailed the analytic process undertaken (given constraints on article word length), provided clarity regarding stages of analysis and theme development, and possibly made reference to an audit method for analysis. Seven articles evidenced such features (Byrne & McMurray 1997, Rasmussen *et al.* 1997, Newton & Waters 2001, Dunniece & Slevin 2002, Georges *et al.* 2002, Barnard *et al.* 2006, Ablett & Jones 2007).

A further four papers lacked systematicity, with transparency and/ or reflexivity notably lacking, particularly regarding analytic process (McNamara *et al.* 1995, McConigley *et al.* 2000, White *et al.* 2004), detail regarding theme generation (McWilliam *et al*. 1993, McNamara *et al.* 1995) and theory development (McWilliam *et al.* 1993).

9.4.5. Internal validity and objectivity

Internal validity is implied by how data analysis moves towards conclusions (Meyrick 2006), and was deduced where papers had comprehensible themes, grounded in data, with quotes attributed to participants, and appropriate balance between description and interpretation, with links to previous knowledge and implications for practice (Elliott *et al.* 1999, Froggatt 2001, Wallbank & Robertson 2008). Three articles implied overall internal validity (Dunniece & Slevin 2002, White *et al*. 2004, Ablett & Jones 2007), with two articles not identifying quotes (McWilliam *et al.* 1993, Byrne & McMurray 1997).

Six articles did not imply sufficient internal validity, with lack of supportive quotes (Rasmussen *et al.* 1997), or failure to ground themes in data (McNamara *et al.* 1995, Georges *et al.* 2002). Absence of interpretation (McConigley *et al.* 2000, Barnard *et al.* 2006) and undue emphasis on one theme (Newton & Waters 2001, Georges *et al.* 2002) were also evident. McConigley *et al.*'s (2000) overall framework appeared simplistic, with inadequate exploration of the relationships between themes. Omission of links to extant literature (Georges *et al.* 2002) and lack of recommendations (Rasmussen *et al.* 1997) were also noted.

Objectivity is implied by methods used to distance self (Meyrick 2006). Objectivity was deduced when methods such as triangulation, having more than one researcher, or checking with participants or external researchers were undertaken (Mays & Pope 1995, Mays & Pope 2000, Meyrick 2006). One or more of these methods were used by the majority, with only three papers not detailing any methods to maintain objectivity (Rasmussen *et al.* 1997, Barnard *et al.* 2006, Ablett & Jones 2007).

9.4.6. Data omission and deviant cases

Only one paper identified that all data had been used, and that deviance had been incorporated within analysis (McNamara *et al.* 1995). However, some oblique reference was suggested since participant checking implied deviance had been actively sought and incorporated (McWilliam *et al.* 1993, Byrne & McMurray 1997, McConigley *et al.* 2000, Dunniece & Slevin 2002).

9.5. Results and conclusions

9.5.1. Applicability

Quality considerations in this domain assess whether studies provide
sufficient contextual detail to permit extrapolation (Meyrick 2006). Where
transparency, systematicity, reflexivity, and epistemological position appear lacking
or dubious, along with lack of clarity around sampling, transferring to the wider
nursing community becomes compromised, especially when considering
international relevance, extrapolating findings to different healthcare systems.

The majority of papers provided insufficient detail to assure transferability.
Five papers failed to detail contextual information (Byrne & McMurray 1997,
Dunniece & Slevin 2002, White *et al.* 2004, Barnard *et al.* 2006, Ablett & Jones
2007), and a further three studies obscured distinctive effects of context blending
data from different settings, so that unique research environments were lost
(McConigley *et al.* 2000, Dunniece & Slevin 2002, White *et al.* 2004). One paper
appeared specific to rural nurses within a particular healthcare system (McConigley
et al. 2000), and a further paper focused on research questions specific to the unit
studied, further undermining transferability (Georges *et al.* 2002).

10. Findings

Themes and conclusions are shown in Table 3, while Table 4 indicates a taxonomy of findings. Themes suggested construction and development of a persona enabling resilience and engagement with the philosophies of delivering palliative care.

10.1. Adjusting to an ethos of palliative care

Adjusting encompasses experience of emotional strain when continually exposed to physical and psychological patient suffering, and experiences of emotional depletion as a consequence of developing close relationships with patients and families (Rasmussen *et al.* 1997, Newton & Waters 2001, White *et al.* 2004, Barnard *et al.* 2006). Continual exposure to ending relationships, others' grief, and grieving oneself, and perceived need to maintain professional role, led to anger and guilt when own expectations were not met (McWilliam *et al.* 1993, McNamara *et al.* 1995, Byrne & McMurray 1997, Rasmussen *et al.* 1997, Newton & Waters 2001, Barnard *et al.* 2006). Many studies reported difficulty maintaining boundaries between work and home, and reflected on own mortality and meaning of life (McWilliam *et al.* 1993, McNamara *et al.* 1995, McConigley *et al.* 2000, Dunniece & Slevin 2002, White *et al.* 2004).

10.2. Developing a palliative care persona

This describes a self- identity evolving with experience, by accepting flaws, establishing a balance between closeness and distance to patients, and finding meaning in and accepting patient death (McWilliam *et al.* 1993, McNamara *et al.* 1995, Byrne & McMurray 1997, Rasmussen *et al.* 1997, Dunniece & Slevin 2002, Georges *et al.* 2002, Barnard *et al.* 2006). As nurses appeared to come to terms with own mortality (McNamara *et al.* 1995, Byrne & McMurray 1997, Ablett & Jones 2007) and seemed to adopt philosophies particular to palliation values including: inclusive holistic care; open honest communication; respect; empowerment; dignity; and provision of comfort (McWilliam *et al.* 1993, McNamara *et al.* 1995, Byrne & McMurray 1997, Rasmussen *et al.* 1997, Dunniece & Slevin 2002, Barnard *et al.* 2006, Ablett & Jones 2007). Nurses professionally and personally endeavoured to identify meaning in life and living in the moment (McNamara *et al.* 1995, Rasmussen *et al.* 1997, Barnard *et al.* 2006, Ablett & Jones 2007). To put philosophy into practice, skills such as acting on intuition and understanding verbal and non- verbal communication, became important (Byrne & McMurray 1997, Dunniece & Slevin 2002).

10.3. Maintaining the palliative care persona

Maintaining the palliative care persona seemed to imply 'giving self without losing self' by maintaining a healthy work- life balance (McWilliam *et al.* 1993, Rasmussen *et al.* 1997, p. 335, McConigley *et al.* 2000, Newton & Waters 2001,

29

Dunniece & Slevin 2002, White *et al.* 2004, Barnard *et al.* 2006, Ablett & Jones 2007). Working with patients became a 'privilege', with nurses maintaining motivation from the challenges and rewards of the role (McWilliam *et al.* 1993, McNamara *et al.* 1995, McConigley *et al.* 2000, Newton & Waters 2001, Dunniece & Slevin 2002, p. 17, Ablett & Jones 2007).

Organisational factors, such as team membership with informal colleague support offered validation, addressing any doubts about the palliative care ethos (McWilliam *et al.* 1993, McNamara *et al.* 1995, Byrne & McMurray 1997, Rasmussen *et al.* 1997, Newton & Waters 2001, White *et al.* 2004, Barnard *et al.* 2006, Ablett & Jones 2007). Yet sharing with colleagues was reported as draining (Rasmussen *et al.* 1997), so organisational factors such as team meetings, humour, and effective management became beneficial (McWilliam *et al.* 1993, McNamara *et al.* 1995, Rasmussen *et al.* 1997, Newton & Waters 2001, White *et al.* 2004, Barnard *et al.* 2006, Ablett & Jones 2007). Supervision offered reflection and new understanding, while counselling was suggested to address more significant difficulties (McWilliam *et al.* 1993, McNamara *et al.* 1995, Byrne & McMurray 1997, Rasmussen *et al.* 1997, Newton & Waters 2001, Georges *et al.* 2002, White *et al.* 2004, Barnard *et al.* 2006, Ablett & Jones 2007). Mentoring and training opportunities were suggested (McWilliam *et al.* 1993, Byrne & McMurray 1997, Rasmussen *et al.* 1997, McConigley *et al.* 2000, Newton & Waters 2001, Dunniece & Slevin 2002, White *et al.* 2004, Ablett & Jones 2007). Finally, appreciation from the wider community could facilitate continued motivation (McConigley *et al.* 2000).

10.4. Perpetual threats to the palliative care persona

Threats to the palliative care persona could occur from diverse sources: resistance to palliative care ethos from patients (not accepting mortality, experiencing unrelieved suffering, traumatic or sudden deaths); families (who had difficult or strained relationships with patients); or professionals (ineffective team-working) (McNamara *et al.* 1995, Rasmussen *et al.* 1997, Newton & Waters 2001). As a consequence, nurses experienced stress, frustration, guilt and impotence, dissipated by 'problematising' the patient, assuaging any guilt or responsibility nurses felt for not facilitating a 'good death' (McWilliam *et al.* 1993, McNamara *et al.* 1995, p. 238, Rasmussen *et al.* 1997, Newton & Waters 2001). Work- life imbalance could occur with personal losses, working in rural communities (McConigley *et al.* 1993, Newton & Waters 2001, White *et al.* 2004), overwork, caused by unmanageable caseloads, shift work, or by engagement in non- patient tasks (McConigley *et al.* 2000, Newton & Waters 2001, Ablett & Jones 2007).

The persona appeared most vulnerable in certain organisational contexts. Acute academically orientated care could be challenging as practices and philosophies contradicted the palliative care ethos (Georges *et al.* 2002). Multi-disciplinary working threatened to breech the persona if nurses felt overburdened, or disrespected by colleagues, or where other professionals impinged on or misunderstood their role (McWilliam *et al.* 1993, McNamara *et al.* 1995, Byrne & McMurray 1997, McConigley *et al.* 2000, Newton & Waters 2001, Dunniece & Slevin 2002). Inadequate resources, such as staffing, demanding caseloads and inadequate administrative support threatened the persona potentially creating

dissonance if only basic physical care could be provided (McWilliam *et al.* 1993, Rasmussen *et al.* 1997, Newton & Waters 2001, Ablett & Jones 2007).When organisational strategies highlighted above which maintain the persona were not present or inadequate, this threatened the persona (McConigley *et al.* 2000, Newton & Waters 2001).

11. Discussion

11.1. Implications of findings (theoretical and practical)

The taxonomy identified within this review (Table 4) would appear to resonate with previous reviews regarding resilience, maintenance of the persona, and adoption of palliative care philosophies (McElroy 1982, Wilkinson 1994, Cohen 1995, Vachon 1995, Hayter 1999, Payne 2000, Corner 2002, McWilliams 2004, Sinclair & Hamill 2007). Previous reviews however have not emphasised the notion of finding a palliative care persona, or notion of resistance, with the exception of Vachon (1995) who highlights the role of the good death, suggesting that this review has added new understanding to the impact of being a palliative care nurse. This review would undermine a pervading conceptualisation of the impact of palliative nursing as potentially malign, instead fitting a 'salutogenic paradigm' (Ablett & Jones 2007, p. 734), where nurses psychologically shift towards resilience and 'hardiness' (Bonanno 2004, p. 6, Jackson, Firtko & Edenborough 2007) using the persona as a way of coping when faced with stressful situations. Interestingly, the concept of a persona although highlighted within Webster and Kristjanson (2002a, 2002b), has not been emphasised within palliative nursing literature as a whole.

Adoption of a persona could be viewed as a maladaptive, 'emotion- focused coping' style (Folkman, Lazarus, Gruen & DeLongis 1986, p. 572), implying avoidance, akin to distancing (McVicar 2003, Sandgren, Thulesius, Fridlund &

Petersson 2006). The persona could also be viewed as a 'professional face' (Bolton 2001, p. 90), where nurses become 'social actors' (p. 86) in order to manage situations emotionally. However, it appeared that rather than simply being a strategy or mask, or even simply a 'work persona' (Mackintosh 2007, p. 988), the persona actually permeated personal and professional behaviours, feelings and thoughts, and thus could be viewed as an adaptive change to personality and way of being.

Maintenance of psychological well- being became important. The persona was maintained in different ways even when faced with threats, such as defining work as a privilege, use of humour, and removing any responsibility from self when resistance to palliative care ethos was present, as well as finding meaning in life and living in the moment, all of which maintained belief in the ethos of palliative care as a way of living. In this way, the persona appeared to offer a way of regulating emotions (Lopes, Salovey, Côté & Beers 2005), or a method by which nurses could engage in 'positive reappraisal' (Sears, Stanton & Danoff- Burg 2003, Taylor & Stanton 2007, p. 384) or 'benefit finding' and 'sense- making' (Davis, Nolen-Hoeksema & Larson 1998, p. 561- 562). These adaptive methods of coping centre on finding purpose and meaning in adversity, retaining a certain belief about the world. Furthermore, the persona encouraged nurses to find an emotional balance in their relationships with patients, rather than becoming emotionally distant, which relates to 'emotional intelligence' (McQueen 2003, p. 106) where emotions are acknowledged while self is retained.

Emerging from the review, the environment of in- patient settings appeared to facilitate adoption and maintenance of the palliative care persona, such that the hospice was a containing 'life- affirming place' (Rasmussen *et al.* 1997, p. 334), supporting Cohen's (1995) review. Academic environments were felt to be threatening (Georges *et al.* 2002) and community settings engendered isolation (McConigley *et al.* 2000, Newton & Waters 2001, Dunniece & Slevin 2002). The concept of 'person- environment fit' (Takase, Kershaw & Burt 2001, p. 821) appears relevant, suggesting that environment can enter the psyche and alter self-concept, which relates to this review with regards to adopting a persona by virtue of the palliative philosophies within the environment. By implication, adjustment might be more difficult for community nurses with physical and emotional distance from a palliative environment. Developing and maintaining a persona might also be more difficult. Thus, community nurses may have higher propensity for stress and difficulties. Not all papers within this review distinguished different settings making it difficult to substantiate this idea.

Specific practical implications have been identified by the review, in terms of the importance of personal and organisational strategies to maintain the persona, with an established relationship between social support and ability to cope (DeLongis & Holtzman 2005). Organisations need to be aware of the detrimental effects to well- being of withdrawing or providing inadequate support. Organisations should also be mindful of the detrimental effects of overwork, large caseloads, shift work, lack of staffing and administrative support, and lack of protected time for non- patient tasks. However, there could also be a role for palliative nurses with regards to multi- disciplinary working, by making colleagues

aware of the parameters of the role and expertise they have, as well as linking regularly with professionals to maintain collaborative relationships.

11.2. Conducting the review

Conceptualisation and understanding of palliative care has understandably focused largely on patient experiences, and a substantial nursing literature base focuses on nursing patients with cancer, underpinned by assumptive methodologies. Literature is dominated by specific geographical domains, with circumscribed international relevance. Excluded studies within this review from acute, general, or paediatric settings, and palliative care nurses with mixed caseloads, could form future review topics. Literature searching was hampered by inadequacies of search limits within nursing databases, exclusion of nursing journals within medical databases, and difficulties discerning relevance and methodology from titles and abstracts. Reference and hand searching was necessary due to difficulties yielding papers through databases alone, which compromises ability to replicate the review. This suggests that qualitative research is not integrated well into databases. Such critique of qualitative literature searching has been noted elsewhere (Barbour & Barbour 2003, Lloyd- Jones 2004, Dixon- Woods *et al.* 2006).

In contrast to previous reviews, the use of epistemologically robust techniques (Meyrick 2006, Popay *et al.* 2006, Wallbank & Robertson 2008) ensured a structured, systematic approach, embracing different approaches and stances, with transparency and objectivity. However, the reviewer adapted tabulation to highlight quality issues specific to the studies elicited within this review, and tried to be

explicit during the review about what would constitute sufficient quality for each consideration. This ensured a consistent approach to enabling meaningful study comparison, and future reviewers might find tailoring Meyrick (2006) to suit their own reviews helpful. Furthermore, Meyrick's (2006) approach did not emphasise positive aspects of papers, journal word counts compromised assessment of transparency and systematicity, and determining internal validity can become subjective. Future reviews could adapt the approach to take account of these issues.

11.3. Quality of included studies

Overall quality of included studies, as shown in Table 2, revealed marked limitations, with particular concerns regarding transferability of the findings and taxonomy to other palliative care settings. Particular recommendations for qualitative researchers arising from this review are for researchers to ensure that contextual information is provided to ensure transferability, clearly articulating sampling strategies, being clear on reflexive or objective stance, and including information about deviant cases and omitted data.

11.4. Further research

Further assessment of how palliative nurses develop resilience via a persona, and how this is maintained, could have implications for nursing practice and staff retention and burnout (Wren & Michie 2003). Understanding whether the persona develops predominately as a consequence of experience, or whether other factors facilitate or obstruct development, could be useful. Working environment was

highlighted in this review as one key factor in the development of the persona. Further research to understand the relationship between the palliative care environment and resilience, particularly exploring distinct community and in-patient experiences, and how environment facilitates or obstructs resilience could be enlightening.

Further research could also help to understand the adjustment element of the taxonomy, with regards to transition experiences of nurses, extending existing research (Rasmussen, Norberg & Sandman 1995, Rosser & King 2003). This may help palliative nurses to normalise the adjustment difficulties they may encounter, and training and support could be developed to ensure a smooth transition and retention of nurses within the specialty.

Furthermore, more detailed research could explore how nurses use palliative philosophies within practice, which has implications for training and education. Closer relationships with patients are encouraged within nursing (McVicar 2003), and further research expanding the notion of how nurses balance emotional involvement without psychological consequence could have implications for optimal nursing practice. Finally, further research could further define the types and structure of organisational supports that are most beneficial to palliative care nurses.

12. Conclusion

Overall, applying stringent and systematic appraisal to qualitative nursing studies will ensure standards of quality within the literature base are established and maintained. Furthermore, the concept of resilience could be viewed as important within nursing, for it helps celebrate the capabilities of nurses, identify how nurses cope even when faced with adversity, and promotes respect for nurses within our healthcare systems.

N.B Figures 1 and 2 emphasise the primary reason an article was excluded, however an article may have been excluded for more than one reason.

Figure 1 Process of applying inclusion/ exclusion criteria to abstracts

Titles screened for appropriate articles

↓

337 abstracts retrieved for assessment using inclusion/ exclusion criteria

↓

112 abstracts excluded as quantitative papers

↓

6 excluded as review papers, 7 excluded as discussion papers

↓

212 abstracts remain

↓

1 excluded as outcome of intervention 1 excluded as student nurse population 6 excluded as focus other health professionals in sample 13 excluded as patient focused, 17 excluded as paediatric patient population 6 excluded for not examining effects on nurse 45 excluded as not primarily palliative care nursing focused (35 intensive care, 10 acute/ general/ surgical) 7 excluded as too narrow on topic area (1 link nursing, 1 spirituality, 1 concept of good death, 2 communication with patients, 2 moral decisions)

↓

116 abstracts remained, with full papers retrieved

Figure 2 Process of applying inclusion/ exclusion criteria to full papers

```
┌─────────────────────────────────────────────────────────────────────┐
│                      116 full papers retrieved                        │
└─────────────────────────────────────────────────────────────────────┘
                                   │
                                   ▼
┌─────────────────────────────────────────────────────────────────────┐
│ 5 excluded as outcome of intervention                                 │
│                                                                       │
│ 5 excluded as discussion papers                                       │
│                                                                       │
│ 10 excluded as quantitative papers                                    │
│                                                                       │
│ 29 excluded as not palliative care setting (1 disease specific unit,  │
│ 18 general/ acute wards, 3 chemotherapy, 6 oncology with acute        │
│ treatment focus, 3 settings which included acute management, 1        │
│ nursing home)                                                         │
│                                                                       │
│ 11 excluded for not examining effects on nurse                        │
│                                                                       │
│ 11 excluded as patient focused                                        │
│                                                                       │
│ 17 excluded as too narrow on  topic area (1 good death, 1 wound care, │
│ 2 language of dying, 1 ethics, 2 testing model, 1 ward environment,   │
│ 1 nurse skills, 1 feeding, 1 supervision, 1 power relationships, 2    │
│ transition experiences, 1 palliative sedation, 1 education, 1         │
│ euthanasia)                                                           │
└─────────────────────────────────────────────────────────────────────┘
                                   │
                                   ▼
┌─────────────────────────────────────────────────────────────────────┐
│                           17 papers remain                            │
└─────────────────────────────────────────────────────────────────────┘
                                   │
                                   ▼
                    ┌──────────────────────────────────┐
                    │ 6 excluded as caseload not solely │
                    │ palliative care patients          │
                    └──────────────────────────────────┘
                                   │
                                   ▼
┌─────────────────────────────────────────────────────────────────────┐
│                      11 papers remain for review                      │
└─────────────────────────────────────────────────────────────────────┘
```

Table 1 Initial inclusion/ exclusion criteria

Criteria	Description
Topic	Articles with an unrelated topic were excluded
Empirical research	Discussion papers, reviews, editorials, opinion papers, single case studies, articles without empirical studies were excluded
Qualitative methodology	Quantitative articles were excluded. While it can be debated as to what constitutes qualitative research (Dixon-Woods *et al.* 2006), articles described as qualitative or those with 'non- numerical analysis of data gathered by distinctive methods' (Dixon- Woods, Fitzpatrick, & Roberts 2001, p. 126) were included.
Nursing population	Articles focusing solely on another professional group were excluded, or those focusing on nursing and another professional/ patient group were excluded.
Qualified nurses	Articles focusing on student nurses were excluded.
Patient focus	Articles focusing solely on the impact of nursing on the patient, and could therefore be described as having a patient focus, were excluded.
Topic area too narrow	Articles where the focus was not on palliative nursing generally, but a specific aspect of care, practice, or a specific effect on the nurse were excluded.
Palliative care nursing	Articles focusing on palliative care nursing were included. Whilst the World Health Organisation (WHO) definition of palliative care was adhered to (2002), bearing in mind that 'palliative care, supportive care, end- of- life care, and hospice care are frequently used interchangeably' Kuebler, Lynn and Von Rohen (2005, p. 7). Articles that included nurses who cared for dying patients as part of their usual caseload were included, articles including nurses who cared for a palliative care patient when this did not form a usual part of

	their caseload were excluded. For example, nurses working in acute settings, on general hospital wards, or nursing where patients are not necessarily palliative (for example intensive care) were excluded. Nurses must be offering an end of life care approach.
Setting	Articles focusing on palliative care settings were included, this could be community, hospital, clinic, hospice, for example. Setting must be identified as a palliative care setting, not a setting where palliative patients are being cared for but where the setting is not described as palliative care, for example general ward.
Patient population	Articles focusing on caring for terminal/ palliative/ hospice/ end of life/ patients were included. Paediatric nursing studies were excluded, so the focus of the articles included related to adult nursing.
Effect on nurse	Psychological impacts could be positive or negative. Studies must include focus on effects on nurse to be included.
Intervention	Studies where an intervention is explored are excluded, for example impact of a training course.
Funding	Articles with inappropriate sources of funding were excluded.

Table 2 Summary of quality appraisal of included studies

Author, Year, Country	Theoretical stance	Epistemological stance	Reflexive/ Objective stance	Method of data collection	Method of data analysis	Sampling	Data collection and analysis (Quality considerations)	Results and Conclusions (Applicability)
Ablett & Jones (2007), UK	Stress, burnout, distress, a salutogenic paradigm, resilience, and well-being	None	Reflexivity: Stated importance of reflexivity, identified stance, prediction of results, but no reflection of how reflexivity affected process or results	Semi-structured interviews, 35- 80 minutes duration	IPA, with common themes identified	Ten palliative care nurses from a hospice, purposive sampling. D R T	O U	NI

Barnard, Hollingum & Hartfiel (2006), Australia	Task orientated nursing, compassion, nurse-patient relationship, distancing, good death, and grief	Phenomenographical approach, with a hermeneutic perspective	None	Semi-structured interviews (duration not stated)	Phenomenography, with common themes identified	Ten nurses from a palliative care unit within a hospital setting, sampling was a convenience sample S D R T	T IV Q O U	QI NI
Byrne & McMurray (1997), Australia	Nurse-patient relationship, social transaction of caring	Phenomenological approach, within an interpretative paradigm	Reflexivity: Authors bracketed pre-suppositions, but did not state what the	Un-structured interviews, 60 minutes duration	Colaizzi method, with common themes identified	Nine nurses from one hospice. Purposive sampling employed. D	Q U	NI

			actual stance was or how reflexivity affected process or results			T		
Dunniece & Slevin (2002), Northern Ireland and Ireland	Personal growth, life experience, expert nursing and intuition	Phenomenological approach with hermeneutic perspective, with existentialist viewpoint.	Reflexivity: Stated importance of reflexivity, identified stance, method of tracking reflexivity, but no reflection of how reflexivity affected process or results	Semi-structured interviews, 60- 90 minutes duration	IPA, with common themes identified	Seven nurses from two hospices, with four in-patient and three community staff. Purposive sampling employed. D T	T U	NI

Georges, Grypdonck, & Dierckx De Casterle (2002), Netherlands	Moral practice, caring	None	Objectivity: Methods identified to maintain objectivity	Participant observation, with semi-structured interviews, 90 minutes duration NA	Constant comparative method (with software package), with common themes identified	Fourteen nurses from one palliative care unit within an academic hospital, with the majority being observed, and ten being interviewed, and a further three being asked for a second interview. Purposive sampling. D R	IV G Q U	QI LA

							C		
McConigley, Kristjanson & Morgan (2000), Australia	Limited theoretical perspectives in relation to nursing identified- Professional isolation	None	Objectivity: Methods identified to maintain objectivity	Interviews, 90 minutes duration, plus participant observation NA	Constant comparative method, along with software package, with common themes identified and attempt at developing a grounded theory	Six nurses, palliative care unit, hospice, integrated palliative care service, and community settings used. Theoretical sampling. D C	T S IV Q U	QI LA
McNamara, Waddell, & Colvin (1995), Australi	Resilience, efficacy, hospice philosophy, good death, stress,	Ethnographic and contextual approach, using sociological hermeneutics and an interpretative sociological framework.	None	Participant observation and interviews, 60 to 150 duration, followed	Analytic framework was not identified in the paper	22 nurses working within hospice and community settings, six of which	T S IV G	QI

a	cultural context of hospice nursing, as well as coping strategies			by second interviews, unknown duration		were retired. Eleven of the sample were interviewed a second time. Purposive sampling. D R C		
McWilliam, Burdock & Wamsley (1993), Canada	Stress, burnout, and coping strategies	Phenomenological approach	Reflexivity: Stated importance of reflexivity, identified stance, method of tracking reflexivity, but no	Analysis of nurses' diaries, as well as semi-structured interviews, one 120 minutes duration, followed	Grounded theory (extending existing model), with common themes identified Unclear why this method	Two palliative care support team nurses, working within the community. Purposive sampling employed.	T S Q U	QI

			reflection of how reflexivity affected process or results	by two 60 minute duration interviews	was chosen	S D R		
Newton & Waters (2001), UK	Stress, burnout, overload, emotional exhaustion, coping mechanisms	None	Reflexivity: Stated prior experience, method of tracking reflections, but no appreciation of importance of reflexivity or reflection of how reflexivity affected process or results	Survey with open-ended and tick- box questions, followed by interviews, 20 minute duration NA	Adapted Colaizzi method, with common themes identified	20 community palliative care clinical nurse specialists were surveyed, with 14 going on to interview. Purposive sampling employed. D	T IV Q U	QI

Rasmussen, Sandman & Norberg (1997), Sweden	Stress, burnout, spiritual dimension of nursing, coping, and preserving integrity	Ricoeur philosophy	None	Semi-structured interviews, 50- 100 duration	Phenomenologic-hermeneutic approach, with common themes identified	18 hospice nurses. Purposive sampling employed. D R	IV Q O U	QI
White, Wilkes, Cooper & Barbato (2004), Australia	Limited theoretical perspectives in relation to nursing identified- Suffering and unrelieved patient suffering	None	None	Semi-structured interviews, 40- 60 minutes duration	Software package, with common themes identified	Nine specialist palliative care nurses from community (5), hospice (5) and hospital (3) settings, with four nurses working in more than one setting. Sample was identified through	T S U	QI NI

					personal acquaintance and then snowballing. S D		

Key to Table 2.

Method of Data Collection

NA= Methods not appropriate to answering question

Methods of Data Analysis

NA= Methods not appropriate to answering question

Sampling

S= No clear rationale for use of sampling strategy
D= Missing demographic data
R= Unclear how sample were approached/ recruited
T= Description of sample (role/ setting worked in) was not described, making transferability more difficult
C= Overall, sampling not clearly articulated (confusing)

Data Collection and Analysis

T= Lack of transparency within data collection
S= Not systematic in analysis of data
IV= Lack of internal validity in analysis
G= Not grounded in data
Q= Quotes not identified
O= Lack of objectivity in analysis
U= Unclear whether or not all data was used and whether or not there were deviant cases

Results and Conclusions

QI= Quality issues would need to be taken into account before transferring findings to other populations
NI= Not enough information about setting, role of nurse or context to judge applicability (transferability) of findings
LA= Limited applicability/ transferability due to specific setting

Table 3 Summary of thematic content analysis

Author, Year	Stated aims	Themes	Conclusions
Ablett & Jones (2007)	• Understanding resilience and maintenance of wellbeing within a palliative care setting.	• An active choice to work in palliative care • Past personal experience influences care-giving • Personal attitudes towards care-giving, living and dying • Awareness of own spirituality • Job satisfaction and stressors • Ways of coping • Personal/ professional issues and boundaries	• Palliative care nursing can be rewarding, and resilience helps nurses to continue to care. • 'Hardiness and sense of coherence' (p. 738) are useful concepts, which could be incorporated into staff training. • Reflective practice encouraged.
Barnard, Hollingum & Hartfiel (2006)	• Understanding experiences of nurses and their journey within palliative care.	• Doing everything you can • Developing a closeness • Working as a team • Creating meaning out of life • Maintaining myself	• Relationships with patients can affect the nurse. • Rewards from setting. • Nurses' journey can parallel patient journey. • Team reflection and support recommended.
Byrne &	• Understanding	• Being transformed by the experiences (perspectives on dying,	• Importance of looking

McMurray (1997)	experiences of nurses who care for patients who are dying, and improve nursing practice and support as a consequence.	loss and own mortality changed) • The influence of the context of caring (effective team-working) • The embodiment of caring (making a difference, empowering patients, not over identifying with patients, and realising own limitations) • Caring for the family (offering emotional support, easing conflict) • Coping (caring for self and managing stress, keeping work in perspective, emotional distancing)	after the self, and importance of reflection to help identify extra support required. • Hospice environment contributes to nurses' resilience. • Death and bereavement education recommended.
Dunniece & Slevin (2002)	• Understanding how nurses' develop knowledge when caring for patients who are dying.	• Having a holistic view of patient • Past experience influences current practice (becoming confident practitioners) • Respecting patient autonomy whilst making difficult clinical decisions • Finding meaning in own life (work- life balance) • Use of intuition when responding to patient needs • The embodiment of "being with" (simply being with the patient) • Learning from the patient	• Informal colleague support can be helpful as a learning support. • Nurses embrace holistic nature of setting.
Georges, Grypdonck & Dierckx	• Research overtly aimed to understand nurses' experiences,	• The striving of nurses to adopt a well- organized, and purposeful approach in an academic setting ○ Developing a professional, rule bound attitude with	• Academic hospital environment inimical with caring role, and

De Casterle (2002)	and covertly aimed to understand reasons for nurses leaving their jobs.	objectivity
		  o Being task- orientated
		• Striving to increase the well-being of the patient
		  o Being available to patients
		  o Striving to adopt a humble and person- centred, caring attitude
		  o Trying to accept and cope with emotional strain
			nurses do not embrace the ethos of palliative care.
			• Reflective practice recommended.

McConigley, Kristjanson & Morgan (2000)	• Understand experiences of rural nurses in community.	• Work-life imbalance • Wearing many hats (number of clinical and non- clinical tasks) • Being the expert (burden of consultative role)	• Nursing within rural communities can be stressful and isolating, with limited organisational support • Need for accessible education and training.

McNamara, Waddell & Colvin (1995)	• Identifying sources of stress and coping within daily nursing practice.	• Threats to the good death value system as sources of stress for hospice nurses
		  o Societal values and reactions
		  o Organisation of the work environment
		  o Exchanges between nurses and the patients and their families
		  o Personally facing death
		• Coping and support: negotiated strategies and shared logic
		  o Reversing the discourse and definitions of failure
		  o Negotiating and validating support
		• Contextualising death
			• Nurses do experience stress.
			• The hospice environment supports the good death and a shared understanding of difficulties within nursing.

McWilliam,	• Understanding	• Preserving own integrity through:	• Nurses find team

Burdock & Wamsley (1993)	nurses' experiences within palliative care.	○ Establishing a professional practice base (with values, motives and expectations)
		○ Sense of own worth
		    ▪ Supportive care to patients and families (gaining patient trust, offering practical support, empowering patients)
		    ▪ Facilitating other professionals' work (supporting, coordinating and managing)
		• Impediments to preserving own integrity
		    ▪ Limitations of the system (system constraints, intrapersonal conflict, interprofessional conflict, characteristics of setting such as round-the-clock care)
		• Secondary work effort
		    ▪ Role adaptation (maintaining emotional distance, facilitating patient autonomy)
		    ▪ Intrapersonal conflict management
		    ▪ Interprofessional conflict management
			communication stressful.
			• Self-esteem is compromised by patient deaths.
			• Maintain integrity by adapting their role and dealing with conflicts.
			• Reflection, peer support, and teamwork and addressing conflict encouraged.

Newton & Waters (2001)	• Identification of sources of stress and support within Community Palliative Care Clinical Nurse Specialists (CPCCNS).	• Pressure of workload ○ Staff shortages ○ Poor cooperation or accessibility of some health professionals ○ Did not trust the performance of some other health professionals ○ Insecurity arising from multiple organisational changes ○ Lack of management response or appreciation	• Stress did occur, and was individual and ever-changing. • Staff who were inexperienced or worked in the setting a long time were at risk of

		o Clients or professionals' misperceptions of the CPCCNSs role
		o Changing role and changing educational requirements
		o Erosion of normal support systems
		• Relationships with other health professionals
		• Impact of the sadness of the client group
		    o Identification with the client
		    o Skills were tested to the limit
		    o Prevention of optimum care
		    o Repeated strain and an accumulation of sadness
			stress.
			• Supervision, counselling, team away days, planned sabbaticals, and educating other health professionals about the role were recommended.
			• Nurses found the role rewarding.

Rasmussen, Sandman & Norberg (1997)	• Understanding experiences of being a hospice nurse.	▪ Pursuing meaningful hospice care
		    o Pursuing "good" nursing care
		        ▪ What it ought to be: Time to care consistent with hospice philosophy
		        ▪ The vitalizing experiences: Sharing life experiences; Serving on the premises of the family units; Caring in accordance with one's own values
		        ▪ The devitalizing experiences: Not caring in accordance with one's own values; Being in the midst of suffering; Not sharing life experiences
		        ▪ What is absent from the stories: Caring for
			• Nurses found to have death anxiety, and found rewards and stressors from doing the role.
			• Relationships with patients paramount.
			• Good deaths are important, spirituality and mortality are

		the body
		 o Pursuing "good" dying and death
		     ▪ What it ought to be: Living fully while dying and departing in peace
		 o Pursuing a supportive working environment
		     ▪ What it ought to be: Being contained and containing colleagues
		 o Pursuing personal and professional confidence and growth
		     ▪ What it ought to be: Enduring suffering; Giving of self without losing self; Increasing self- awareness
		 o Pursuing spiritual integrity
			addressed within the setting by the nurses themselves.
			 • Education, supervision, counselling, discussion considered beneficial.

White, Wilkes, Cooper & Barbato (2004)	o Understand nurses' experiences in relation to unrelieved patient suffering.	• Nurses perceive patients endure physical and psychological suffering
		 • Impact
		     o Perceptions of unrelieved suffering
		     o Feelings when faced with unrelieved suffering
		     o Invasion of personal space
		     o Relationship with patient, experience of nurse, and work-life imbalance impact on how suffering affects nurses
		 • Strategies to ameliorate the personal impact
		     o Support from work colleagues, family and friends
			• Unrelieved suffering does have a negative impact on palliative care nurses and can lead to stress, distress, and feelings of failure.
			 • Negative feelings exacerbated by close relationships with the patient.
			 • Sense of suffering as

		o Personal strategies	failure. • Recommend suffering is acknowledged and explored with patient and family, and reflect on the impact of suffering.

Table 4 Taxonomy of findings

Adjusting to an ethos of palliative care
- **Exposure to patient suffering**
- **Forming relationships with patients and families**
- **Exposure to grief and grieving oneself**
- **Need to be perfect**
- **Boundary maintenance**
- **Reflecting on own mortality**

Developing a palliative care persona
- **Growth from adjustment process**
  - *Accepting flaws*
  - *Developing safe relationships with patients and families*
  - *Coming to terms with patients dying*
  - *Coming to terms with own mortality*
- **Adopting palliative care philosophies**
  - *Values: holistic care, inclusion, open communication, respect, honesty, empowerment, dignity, comfort*
  - *Finding meaning in life*
  - *Living in the moment*
- **Putting philosophy into practice**

Maintaining the palliative care persona
- **Personal strategies**
  - *Maintaining work- life balance*
  - *Maintaining motivation for the role*
- **Organisational strategies**
  - *Being part of the team*
  - *Informal support from colleagues*
  - *Team meetings*
  - *Humour in the workplace*
  - *Effective management*
  - *Clinical supervision and mentoring*
  - *Counselling*
  - *Education/ training*
  - *Support from the community*

Perpetual threats to the palliative care persona
- **Resistance to palliative care philosophies**
- **Work- life imbalance**
- **Organisational threats**
  - *Working in an academic hospital*
  - *Multi- disciplinary working*
  - *Lack of resources*
  - *Strategies inadequate or lacking*

13. References

* Ablett J.R. & Jones R.S.P. (2007) Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work. *Psycho-Oncology* **16,** 733-740.

Barbour R.S. (2001) Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal* **322,** 1115-1117.

Barbour R.S. & Barbour M. (2003) Evaluating and synthesising qualitative research: the need to develop a distinctive approach. *Journal of Evaluation in Clinical Practice* **9** (2), 179-186.

* Barnard A., Hollingum C. & Hartfiel B. (2006) Going on a journey: understanding palliative care nursing. *International Journal of Palliative Nursing* **12** (1), 6-12.

Bolton S.C. (2001) Changing faces: nurses as emotional jugglers. *Sociology of Health and Illness* **23** (1), 85-100.

Bonanno G.A. (2004) Loss, trauma, and human resilience. Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist* **59** (1), 20-28.

* Byrne D. & McMurray A. (1997) Caring for the dying: nurses' experiences in

    hospice care. *Australian Journal of Advanced Nursing* **15** (1), 4-11.

Cohen M.Z. (1995) The meaning of cancer and oncology nursing: link to effective

    care. *Seminars in Oncology Nursing* **11** (1), 59-67.

Corner J. (2002) Nurses' experiences of cancer. *European Journal of Cancer*

    Nursing **11**, 193-199.

Davidson P. & Jackson C. (1985) The nurse as a survivor: delayed post- traumatic

    stress reaction and cumulative trauma in nursing. *International Journal of*

    Nursing Studies **22** (1), 1-13.

Davis C.G., Nolen- Hoeksema S. & Larson J. (1998) Making sense of loss and

    benefiting from the experience: two construals of meaning. *Journal of*

    Personality and Social Psychology **75** (2), 561-574.

DeLongis A. & Holtzman S. (2005) Coping in context: the role of stress, social

    support, and personality in coping. *Journal of Personality* **73** (6), 1633-1656.

Department of Health. (1999) *Making a Difference. Strengthening the Nursing,*

    Midwifery, and Health Visiting Contribution to Health and Healthcare.

    Department of Health, London.

Department of Health. (2000) *Improving Working Lives Standard: NHS Employers Committed to Improving the Working Lives of People who Work in the NHS.* Department of Health, London.

Department of Health. (2003) *Developing Services for Heart Failure*. Department of Health, London.

Dixon- Woods M., Bonas S., Booth A., Jones D.R., Miller T., Sutton A.J., Shaw R.L., Smith J.A. & Young B. (2006) How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research* **6** (1), 27-44.

Dixon- Woods M., Fitzpatrick R. & Roberts K. (2001) Including qualitative research in systematic reviews: opportunities and problems. *Journal of Evaluation in Clinical Practice* **7** (2), 125-133.

* Dunniece U. & Slevin E. (2002) Giving voice to the less articulated knowledge of palliative nursing: an interpretative study. *International Journal of Palliative Nursing* **8** (1), 13-20.

Ekstedt M. & Fagerberg I. (2005) Lived experiences of the time preceding burnout. *Journal of Advanced Nursing* **49** (1), 59-67.

Elliott R., Fischer C.T. & Rennie D.L. (1999) Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology* **38**, 215-229.

Evans A.M., Pereira D.A. & Parker J.M. (2008) Occupational distress in nursing: a psychoanalytic reading of the literature. *Nursing Philosophy* **9**, 195-204.

Folkman S., Lazarus R.S., Gruen R.J. & DeLongis A. (1986) Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology* **50** (3), 571-579.

Froggatt K.A. (2001) The analysis of qualitative data: processes and pitfalls. *Palliative Medicine* **15**, 433-438.

* Georges J.J., Grypdonck M. & Dierckx De Casterle B. (2002) Being a palliative care nurse in an academic hospital: a qualitative study about nurses' perceptions of palliative care nursing. *Journal of Clinical Nursing* **11,** 785-793.

Greenhalgh T. & Taylor R. (1997) How to read a paper: papers that go beyond numbers (qualitative research). *British Medical Journal* **315**, 740-743.

Hayter M. (1999) Burnout and AIDS care-related factors in HIV community clinical nurse specialists in the north of England. *Journal of Advanced Nursing* **29** (4), 984-993.

Health & Safety Executive. (2002) *Interventions to Control Stress at Work in Hospital Staff.* HSE Books, Suffolk.

Health & Safety Executive. (2008) *Management Competencies for Preventing and Reducing Stress at Work. Identifying and Developing the Management Behaviours Necessary to Implement the Health and Safety Executive Management Standards: Phase Two.* HSE Books, Suffolk.

Henderson A. (2001) Emotional labour and nursing: an under-appreciated aspect of caring work. *Nursing Inquiry* **8** (2), 130-138.

Huynh T., Alderson M. & Thompson M. (2008) Emotional labour underlying caring: an evolutionary concept analysis. *Journal of Advanced Nursing* **64** (2), 195-208.

Jackson D., Firtko A. & Edenborough M. (2007) Personal resilience as a strategy for surviving and thriving in the face of workplace adversity. *Journal of Advanced Nursing* **60** (1), 1-9.

Keil R.M.K. (2004) Coping and stress: a conceptual analysis. *Journal of Advanced Nursing* **45** (6), 659-665.

Kelly D., Ross S., Gray B. & Smith P. (2000) Death, dying, and emotional labour: problematic dimensions of the bone marrow transplant nursing role? *Journal of Advanced Nursing* **32** (4), 952-960.

Kuebler K.K., Lynn J. & Von Rohen J. (2005) Perspectives in palliative care. *Seminars in Oncology Nursing* **21** (1), 2-10.

Lambert V.A. (2001) Literature review of role stress/ strain on nurses: an international perspective. *Nursing and Health Sciences* **3***,* 161-172.

Lloyd- Jones M. (2004) Application of systematic review methods to qualitative research: practical issues. *Journal of Advanced Nursing* **48** (3), 271-278.

Lopes P.N., Salovey P., Côté S. & Beers M. (2005) Emotion regulation abilities and the quality of social interaction. *Emotion* **5** (1), 113-118.

* McConigley R., Kristjanson L. & Morgan A. (2000) Palliative care nursing in rural western Australia. *International Journal of Palliative Nursing* **6** (2), 80-90.

McElroy A.M. (1982) Burnout- A review of the literature with application to cancer nursing. *Cancer Nursing* **June,** 211-217.

* McNamara B., Waddell C. & Colvin M. (1995) Threats to the good death: the cultural context of stress and coping among hospice nurses. *Sociology of Health and Illness* **17** (2), 222-244.

McQueen A.C.H (2003) Emotional intelligence in nursing work. *Journal of Advanced Nursing* **47** (1), 101-108.

McVicar A. (2003) Workplace stress in nursing: a literature review. *Journal of Advanced Nursing* **44** (6), 633-642.

* McWilliam C.L., Burdock J. & Wamsley J. (1993) The challenging experience of palliative care support-team nursing. *Oncology Nursing Forum* **20** (5), 779-785.

McWilliams A.E. (2004) Stress in palliative care. *Progress in Palliative Care* **12** (6), 293-301.

Mackintosh C. (2007) Protecting the self: a descriptive qualitative exploration of how registered nurses cope with working in surgical areas. *International Journal of Nursing Studies* **44**, 982-990.

Marino P.A. (1998) The effects of cumulative grief in the nurse. *Journal of Intravenous Nursing* **21** (2), 101-104.

Mays N. & Pope C. (1995) Qualitative research: rigour and qualitative research. *British Medical Journal* **311**, 109-112.

Mays N. & Pope C. (2000) Qualitative research in health care: assessing quality in qualitative research. *British Medical Journal* **320**, 50-52.

Mead L.J. (2007) When nurses mourn: layered suffering. *International Journal for Human Caring* **11** (2), 47-52.

Meyrick J. (2006) What is good qualitative research? A first step towards a comprehensive approach to judging rigour/ quality. *Journal of Health Psychology* **11** (5), 799-808.

* Newton J. & Waters V. (2001) Community palliative care clinical nurse specialists' descriptions of stress in their work. *International Journal of Palliative Nursing* **7** (11), 531-540.

Nordgren L., Asp M. & Fagerberg I. (2008) The use of qualitative evidence in critical care. *Evidence Based Nursing* **11,** 4-5.

Payne, N. (2000). Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing* **33** (3), 396-405.

Payne, S. A., Dean, S. J. & Kalus C. (1998) A comparative study of death anxiety
in hospice and emergency nurses. *Journal of Advanced Nursing* **28** (4), 700-706.

Popay J., Roberts H., Sowden A., Petticrew M., Arai L., Rodgers M., Britten N.,
Roen K. & Duffy S. (2006) *Guidance on the Conduct of Narrative Synthesis
in Systematic Reviews.* ERSC Methods Programme, Manchester.

Rasmussen B.H., Norberg A. & Sandman P.O. (1995) Stories about becoming a
hospice nurse. *Cancer Nursing* **18** (5), 344-354.

*Rasmussen B.H., Sandman P. & Norberg A. (1997) Stories of being a hospice
nurse: a journey towards finding one's footing. *Cancer Nursing* **20** (5), 330-341.

Rosser M. & King L. (2003) Transition experiences of qualified nurses moving into
hospice nursing. *Journal of Advanced Nursing* **43** (2), 206-215.

Sabo B.M. (2006) Compassion fatigue and nursing work: can we accurately capture
the consequences of caring work? *International Journal of Nursing Practice*
12, 136-142.

Sandgren A., Thulesius H., Fridlund B. & Petersson K. (2006) Striving for
emotional survival in palliative cancer nursing. *Qualitative Health Research*
16 (1), 79-96.

Saunders J.M. & Valente S.M. (1994) Nurses' grief. *Cancer Nursing* **17** (4), 318-325.

Sears S.R., Stanton A.L. & Danoff-Burg S. (2003) The yellow brick road and the emerald city: benefit finding, positive reappraisal coping, and posttraumatic growth in women with early- stage breast cancer. *Health Psychology* **22** (5), 487-497.

Sinclair H.A.H. & Hamill C. (2007) Does vicarious traumatisation affect oncology nurses? A literature review. *European Journal of Oncology Nursing* **11,** 348-356.

Takase M., Kershaw E. & Burt L. (2001) Nurse- environment misfit and nursing practice. *Journal of Advanced Nursing* **35** (6), 819-826.

Taylor S.E. & Stanton A.L. (2007) Coping resources, coping processes and mental health. *Annual Review of Clinical Psychology* **3**, 377-401.

Vachon M.L.S. (1995) Staff stress in hospice/ palliative care: a review. *Palliative Medicine* **9,** 91-122.

Wakefield A. (2000) Nurses' responses to death and dying: a need for relentless self- care. *International Journal of Palliative Nursing* **6** (5), 245-251.

Wallbank S. & Robertson N. (2008) Midwife and nurse responses to miscarriage,

stillbirth and neonatal death: a critical review of qualitative research.

Evidence Based Midwifery **6** (3), 100-106.

Webster J. & Kristjanson L.J. (2002a) Long- term palliative care workers: more

than a story of endurance. *Journal of Palliative Medicine* **5** (6), 865-875.

Webster J. & Kristjanson L.J. (2002b) But isn't it depressing? The vitality of

palliative care. *Journal of Palliative Care* **18** (1), 15-24.

* White K., Wilkes L., Cooper K. & Barbato M. (2004) The impact of unrelieved

suffering on palliative care nurses. *International Journal of Palliative

Nursing* **10** (9), 438-444.

Wilkinson S. M. (1994) Stress in cancer nursing: does it really exist? *Journal of

Advanced Nursing* **20**, 1079-1084.

World Health Organisation. (2002) *National Cancer Control Programmes: Policies

and Managerial Guidelines, 2ⁿᵈ Edition*. WHO, Geneva.

Wren B. & Michie S. (2003). Staff experiences of the health care system. In

Handbook of Clinical Health Psychology (Llewelyn, S. & Kennedy P., eds),

John Wiley & Sons, Chichester, pp. 41-60.

Yardley L. (2000) Dilemmas in qualitative health research. *Psychology and Health* **15**, 215-228.

Research Report

A Qualitative Analysis of the Experiences of Heart Failure Specialist Nurses

Working with Patients with End Stage Heart Failure.

1. Abstract

Aim. To identify and explore the experiences of heart failure specialist nurses who work with patients with end stage heart failure, in particular to understand how such experiences affected heart failure specialist nurses, how they approached their work, and how they were supported.

Method. A qualitative design was used. Six heart failure specialist nurses participated in the study. Individual, semi- structured interviews were conducted and data were analysed using Interpretative Phenomenological Analysis.

Findings. Three superordinate themes were elicited: *Keeping the Rhythm Going*, relating to aspects of routine care; *The Rhythm Peters Out (A Good Death)*, relating to tasks at end of life; and *Winding up the String*, relating to the impact of working with the dying. Routine care centred on maintaining patient stability within their homes but as clients faced death, participants' use of an acute model of care was abandoned, and effort taken to ensure a 'good death', consonant with the ethos of palliative care. However, participants' perceived lack of efficacy in a palliative care approach seemed to underpin construction of the role of key- worker, adopting a task- orientated approach. They seemed to adopt a professional face, rejecting the emotional impact of working with the dying, which might lead to detachment, and burnout.

Conclusions. The perpetual physical effort of caring for patients at end of life was articulated, as were high self expectations of achieving a good death for those in their care. Caring for the dying whilst managed from an acute context appeared to undermine delivery of an alternative model of care within the community. Recommendations were made regarding training, supervision, and more effectively bridging two models of care.

2. Introduction

2.1. *Heart Failure Specialist Nurse Intervention for Patients with Heart Failure*

Heart failure, defined as the "end stage of all the diseases of the heart" (Davies, Hobbs, & Lip, 2000, p. 1) costs the National Health Service (NHS) some 625 million pounds every year, with patients' survival rates worse than many cancers (Healthcare Commission, 2007). Within recent years, patients with heart failure have responded well to multi- disciplinary interventions, showing improvements in key aspects of heart failure: quality of life; reduced hospital admissions; readmissions; and mortality (Blue, 2004a; Blue & McMurray, 2005; Grange, 2005; Healthcare Commission, 2007; Holland et al., 2005; National Institute for Clinical Excellence (NICE), 2003). Over the last decade, heart failure specialist nurse (HFSN) posts developed by the British Heart Foundation (BHF) have become central to such multi- disciplinary interventions, particularly in their support for patients with Left Ventricular Systolic Dysfunction (heart failure) enabling patients to self- manage their condition at home (Blue & McMurray, 2005; Holland et al., 2005; Pattenden, Lewin, Roberts, & Miles, 2004; Sargeant, Payne, Seymour, & Ingleton, 2008).

2.2. *Role of Palliative and Supportive Care for Patients with End Stage Heart Failure*

The disease trajectory within heart failure has been identified as more complicated than the straightforward decline noted with cancer, with recovery

periods as well as the threat of sudden death making prognostication difficult (Blue & Stewart, 2004; Gott et al., 2007; NICE, 2003). However, as patients reach end stage heart failure (ESHF) or New York Heart Association (NYHA) Class III or IV, professionals have been encouraged to consider delivery of end of life care (Blue & Stewart, 2004; Thompson, Spilsbury, Dowding, Pattenden, & Brownlow, 2008).

Within recent years, limited access to specialist palliative care input, and lack of supportive care at end of life for patients with heart failure has been heavily criticised (Aldred, Gott, & Gariballa, 2005; Boyd et al., 2004; Gibbs, McCoy, Gibbs, Rogers, & Addington- Hall, 2002; Healthcare Commission, 2007; NICE, 2003; Thompson, 2007; Ward, 2002; Zambroski, 2006). A new End of Life Care Strategy (Department of Health (DH), 2008) has suggested that assessment of need, Advanced Care Planning, meeting patient preferences, as well as "management of pain and other symptoms and provision of psychological, social, spiritual and practical support" should be standard care at end of life irrespective of diagnosis (DH, 2008, p. 47; Healthcare Commission, 2007). Initiatives such as the Macmillan Gold Standards Framework and Liverpool Care Pathway have outlined appropriate care and best practice for patients that are dying. It has been argued that such initiatives should no longer be confined to malignant conditions (DH, 2005).

2.3. *HFSNs' Role in End of Life Care*

The development of the HFSNs' role can be partially understood as an inadvertent consequence of perceived limited capacity and knowledge of heart failure within specialist palliative care services. There has been an expectation that

the HFSN role could be extended to offer end of life care, with joint working and liaison with specialist palliative care services as required (Bekelman, Hutt, Masoudi, Kutner, & Rumsfeld, 2008; Blue & Stewart, 2004; DH, 2003; 2004; Field & Addington- Hall, 1999; Flynn, Connolly, & Booth, 2008; Healthcare Commission, 2007). However, training in palliative and supportive care has formed only a small part of current HFSN development courses (Blue, 2004b; Blue & McMurray, 2005; Jaarsma et al., 2006; Ryder, 2005) and although HFSNs have continued to request such training when surveyed (Pattenden et al., 2004; Sargeant et al., 2008; The National Council for Palliative Care, 2006), there has not been formal consensus as to what should constitute adequate training for their role (Blue & McMurray, 2005). Suggestions have been made regarding the knowledge and skills HFSNs may require to provide end of life care, including: communication; Advanced Care Planning; symptom management; palliative care including spiritual and religious aspects; and bereavement care (Aldred et al., 2005; Anderson et al., 2001; Davidson et al., 2004; DH, 2004; 2008; Horne & Payne, 2004; Nordgren & Sörensen, 2003; Skilbeck & Payne, 2005).

2.4. *Psychological Consequences of Providing End of Life Care*

With limited preparation for delivering end of life care and growing recognition that working with patients who are dying can be emotionally draining and care for which professionals are often inadequately prepared (British Psychological Society (BPS), 2008; Flynn et al., 2008), HFSNs may be left vulnerable to aversive consequences of providing care, such as stress or burnout (BPS, 2008). Indeed, within nursing contexts where nurses specialise in caring for

the dying such as palliative care, the supportive context of the work environment as suggested by philosophies advocating open communication, acceptance of death, valuing honesty, respect, and dignity have been known to help palliative care nurses to develop resilience (Ablett & Jones, 2007; Byrne & McMurray, 1997; McNamara, Waddell, & Colvin, 1995; Newton & Waters, 2001; Payne, 2000; Plante & Bouchard, 1995; Rasmussen, Sandman, & Norberg, 1997; Sandgren, Thulesius, Fridlund, & Petersson, 2006; Webster & Kristjanson, 2002a; 2002b; Wilkes & Beale, 2001). By contrast, studies have identified that nurses caring for the dying within non- palliative care nursing specialities, without the same context or philosophy, have encountered psychological difficulties. Research has suggested that nurses working within acute settings, driven by rapid patient throughput, who had also provided some end of life care, found shifting between alternate models of care difficult and stressful, especially when they did not have support at work (Payne, Dean, & Kalus, 1998; Plante & Bouchard, 1995; Sandgren et al., 2006). Similarly, HFSNs undertake dual responsibilities as autonomous decision makers and prescribers within the community, with focus on preserving life, whilst being exposed to patients who are dying (Blue & McMurray, 2005; DH, 2004) thus shifting between alternate models of care with potential for adverse psychological consequences.

Indeed, research has identified that when palliative care nurses have cared for patients with ESHF, they have found such care easy to deliver (Brännström, Brulin, Norberg, Boman, & Strandberg, 2005), while nurses caring for dying patients in acute coronary care appeared frustrated by lack of knowledge and lack of time committed to those patients (Nordgren & Olsson, 2004). Cardio-respiratory

nurses within an acute setting reported "significant discomfort in dealing with death and dying, together with a lack of awareness of palliative care philosophies and resources" (Davidson et al., 2004, p. 71). Comparing nurses within acute coronary settings with nurses within palliative care settings, Wotton, Borbasi and Redden (2005) found that acute nurses struggled to provide "holistic patient- centred care" (p.21) due to lack of time. However, interestingly they felt best placed to offer care to cardiac patients as opposed to transferring patients to a palliative care team due to the specialist knowledge they had about heart failure.

2.5. *Lack of Research Focusing on HFSNs*

To date, research with HFSNs has attempted to understand the key components of their role (Davidson, Paull, Rees, Daly, & Cockburn, 2005; Jaarsma, Abu- Saad, Halfens, & Dracup, 1997; Sargeant et al., 2008), with nursing "presence", based on intuition and spending time with patients, identified as a central aspect (Anderson, 2007, p. 93; Wilson, 2008). Yet research on the effects of working with patients with ESHF remains largely absent despite end of life care being identified as a significant aspect of HFSNs' work (Sargeant et al., 2008). One study has highlighted as part of a larger evaluation of the role, that HFSNs had difficulties maintaining work- life balance, and felt "overwhelmed and burned out" (Pattenden et al., 2004, p. 36).

2.6. *Summary and Current Study Research Aims*

Overall, the role of the HFSN may be relatively new to cardiac care, but seems to have made a significant impact to the lives of patients with heart failure (Holland et al., 2005). Recent policy documentation refers to the potential role of palliative and supportive care within heart failure, with the primacy of the HFSN role in providing end of life care (DH, 2003; 2008; Healthcare Commission, 2007). Interestingly, research has not considered views and experiences of HFSNs as they engage with end of life care, the role that they should undertake, or the impact on them of the care they provide for patients with ESHF. The aim of the current research study therefore, is to identify and explore the experiences of HFSNs, with regards to the following main research questions:

- What are the experiences of HFSNs working with patients with heart failure?

- What are the experiences of HFSNs working with patients who have ESHF and their families/ carers?

- How do these experiences affect HFSNs?

- How do HFSNs approach their work?

- How do they feel they are supported?

Conducting this research with HFSNs should help to address the paucity of research conducted with HFSNs who care for patients at end of life, and may help contribute to greater understanding of what can form best practice delivery. The research should also increase our understanding of the rewards and challenges of the HFSNs' role as well as any support or training needs to maintain them in their role as effective practitioners.

3. Methodology

3.1. *Study Design*

3.1.1. *Rationale for using a qualitative design.*

HFSNs' views towards and experiences of end of life care had not been widely explored or voiced. A qualitative approach offered opportunity to investigate a novel research area thoroughly and with significant depth (Haverkamp & Young, 2007; Morrow, 2007). Furthermore the research aims, founded on exploration, were appropriate for investigation using a qualitative methodology (Maykut & Morehouse, 1999; Morrow, 2007), as was the concept of the emergent design, enabling participants to guide the research process (Morrow, 2007).

3.1.2. *Rationale for using interpretative phenomenological analysis.*

Interpretative Phenomenological Analysis (or IPA) was used for data collection and analysis (Smith & Osborn, 2003; 2008). With its origins in both "phenomenology and symbolic interactionism" (Brocki & Wearden, 2006, p. 87), it focuses on participants' own accounts of experiences, and the meanings those experiences have for the participant within their particular context. IPA invites the researcher to attempt to understand (interpret) the meaning the participant is trying to make while being conscious of their own reflexive position and what this brings to the interpretation (Brocki & Wearden, 2006; Smith, 1996; Smith, Jarman, & Osborn, 1999; Smith & Osborn, 2003; 2008; Willig, 2008).

IPA was chosen given this research aimed to understand the meaning of being a HFSN working with patients who are dying of heart failure (Willig, 2005). This was particularly important given the lack of research exploring HFSNs' experiences, enabling HFSNs to describe their own perceptions and experiences. Furthermore, the current study had purposefully chosen a small number of homogenous HFSNs specifically to help understand the phenomena, which suited the idiographic approach of IPA (Brocki & Wearden, 2006; Smith & Osborn, 2003; 2008). IPA has been increasingly used within health psychology to explore healthcare professionals' experiences (Brocki & Wearden, 2006; Jarman, Smith, & Walsh, 1997; Murray & Chamberlain, 1999; Seymour & Clark, 1998; Smith, 1996; Smith, Flowers, & Osborn, 1997). Grounded Theory shares some methodological characteristics with IPA (Willig, 2008), but was not selected for reasons outlined in the Critical Appraisal.

Semi- structured interviews were used within the current study, consistent with IPA (Brocki & Wearden, 2006; Smith & Osborn, 2003; 2008; Willig, 2008), and considered to be a medium through which thoughts and feelings could be obtained (Maykut & Morehouse, 1999; Willig, 2008). The format was also consonant with an emergent design, enabling the participant to guide data produced (Morrow, 2007; Shaw, 2001; Smith & Osborn, 2003) and important for investigating a new topic area, where existing theoretical frameworks might not be present (Brocki & Wearden, 2006).

3.2. *Participants*

Twelve community based HFSNs were approached as a purposive sample, working within a Heart Failure Service within the Midlands. The HFSNs formed a homogenous group, by virtue of working with patients with ESHF, with experience of working with patients who had died and/or patients who were dying. The Heart Failure Service accepts referrals of patients who have a diagnosis of Left Ventricular Systolic Dysfunction (LVSD), with their main clinical problem being heart failure, they must be under the care of a General Practitioner (GP) within the area covered by the service, and the patient must be willing to accept the support of the service. Patients would be excluded from the service if they have good left ventricular function despite having symptoms of heart failure, if the patient declines the support from the service, if the patient has another immediately life threatening illness, or is under the age of 18.

Primary care within the United Kingdom (UK) refers to the first point of contact with health services and usually refers to services within the community (DH, 2006). Within heart failure care, primary care professionals equate to district nurses, practice nurses, GPs, community matrons, intermediate care teams, or diabetes specialist nurses. Secondary care refers to specialist medical services, usually based within hospital settings, where patients are referred following primary care contact (DH, 2006). Within heart failure care, secondary care professionals/ services would equate to cardiology services, medical wards, accident and

emergency departments, medical assessment units, and other services based within hospitals. The HFSN bridges primary and secondary care, with the main aim of the service being to optimise management of the patient with heart failure within the primary care setting. The goals of the service include improving post discharge management, improving quality of life, and avoiding unnecessary hospital readmissions of patients with heart failure. The service also aims to provide seamless care between primary and secondary care, working closely with other professionals, and providing support at each stage of the disease process. The intervention of the HFSN is split into three levels, reflecting the severity of heart failure according to NYHA classification.

A total of six participants agreed to take part in the current study. To maintain confidentiality, only salient summary demographics are presented here. Five of the participants were female, with one male. Three of the participants were in their thirties with three being in their forties. Participants had worked in a variety of contexts, most notably acute coronary care settings prior to their HFSN post. All participants had been registered nurses for over ten years, with some more experienced in the HFSN post than others. The participants were employed across the locality in urban and rural areas.

3.3. *Materials for Recruitment and Consent*

An Introductory Letter was used to recruit participants (Appendix B), an Information Sheet used to explain the research to participants (Appendix C), and a Reply Slip (Appendix D) was attached to the Information Sheet, to indicate interest

in the research. Participants signed a Consent Form (Appendix E) before being interviewed and completed a Demographic Information Sheet (Appendix F).

3.4. *Interview Schedule*

The researcher constructed an Interview Schedule (Appendix G) with broad areas of questioning initially developed, then broken down into questions around the broad area with prompts (Smith & Osborn, 2003). The schedule was designed to move from general questions to facilitate rapport to more in- depth and potentially difficult questions.

The interview schedule was designed to offer structure and guidance, but retained flexibility so that participants could explore their own areas of interest, with no requirement for every question on the schedule to be asked (Brocki & Wearden, 2006; Burman, 2001; Owens & Payne, 1999; Smith & Osborn, 2003; 2008). The first two interviews were used to pilot the schedule. No alterations were deemed necessary, with all interviews being included within the analysis. The Critical Appraisal considers further the process of developing and implementing the interview schedule.

3.5. *Ethical Approval*

Application to ethics focused upon informed consent, confidentiality and potential for distress as particular ethical issues. Ethical approval (Appendix H) for the current study was granted by the local Ethics Committee and appropriate

Research and Development (R&D) departments. For a Chronology of Research

Process see Appendix I.

3.6. *Procedure*

The researcher issued information packs either during HFSN team meetings

or via post. Packs contained the Introductory Letter (Appendix B), Information

Sheet (Appendix C) and Reply Slip (Appendix D). HFSNs had two weeks in which

to return Reply Slips within pre- paid envelopes. The researcher arranged interview

dates with those HFSNs confirming their wish to participate via return of Reply

Slips.

Data collection involved semi-structured interviews conducted at the work

place of each participant, lasting between 50- 85 minutes. Prior to interview,

participants were asked to sign a Consent Form (Appendix E) and fill in a

Demographic Information Sheet (Appendix F). Before switching on the Dictaphone,

the researcher read out a pre- amble (see Interview Schedule, Appendix G). The

same researcher conducted all of the interviews, and used the Interview Schedule to

guide the interview. At the end of the interview the researcher de- briefed each

participant (see Interview Schedule, Appendix G). Interviews were transcribed by

the researcher using transcription guidelines (Appendix J), anonymised and labelled

numerically in order of interview.

3.7. *Analysis of Interviews*

While it was recognised that there is no definitive IPA data analysis method, the researcher followed general guidelines developed by Smith and Osborn (2003). Analysis began idiographically, analysing one transcript to develop one person's story, moving on to find commonalities between the remaining transcripts, to develop a number of "superordinate" themes with sub- themes (Reid, Flowers, & Larkin, 2005; Smith et al., 1999; Smith & Osborn, 2003, p. 71; 2008; Willig, 2008).

The first transcript was read and re- read a number of times to engage with and become familiar with the text (Smith & Osborn, 2003). The left margin was used to record interesting thoughts regarding content or process, with some parts of the transcript analysed more than other parts, and with the intention of coming to an understanding of what the participant was trying to say (Smith & Osborn, 2003). The right margin was then used to note "emerging theme titles" (Smith & Osborn, 2003, p. 68), the intention being to begin to understand the meaning behind what the person was saying, with interpretation, which could include psychological understanding (Smith & Osborn, 2003).

Following this process, the themes within the right margin were lifted from the transcript and connections made, with themes clustered together (Smith & Osborn, 2003). The transcript was checked to ensure themes were grounded within the data, forming an "iterative" process (Smith & Osborn, 2003, p. 72). Supportive quotes for each of the themes were noted, using a page and line number, and thus a table emerged which identified the clustered themes and supportive quotes

alongside one another (Smith & Osborn, 2003). Each cluster of themes was given a title, which represented each superordinate theme, with sub- themes beneath (Smith & Osborn, 2003).

The second transcript was then analysed using left and right margins. The table of themes from the first participant was referred to and, where possible, emerging themes were mapped onto the theme table. The researcher also remained open to new themes being present and added these to the existing table (Smith et al., 1999; Smith & Osborn, 2003). Analysis of the remaining transcripts continued in this vein and when completed, the transcripts were scanned again for further supporting evidence to corroborate themes (Smith & Osborn, 2003). During the final stages of analysis, the table of themes was synthesised and reduced so the final table encapsulated an "essence of the phenomenon under investigation" (Willig, 2008, p. 66), not necessarily implying prioritisation of those themes cited most frequently by participants (Smith & Osborn, 2003; 2008; Willig, 2008). Thus, a final master list was developed, with superordinate themes and sub- themes, with supportive quotes from each participant (Smith & Osborn, 2003). All analysis was completed manually. An example of the analytic process is included within Appendix K.

3.8. *Epistemological Position*

The researcher's epistemological position was that of a "critical realist" (Madill, Jordan, & Shirley, 2000, p. 3), explored within the Statement of Epistemological Position (Appendix L). The Critical Appraisal reflects upon this position.

With regards to therapeutic stance, the researcher favoured systemic and psychodynamic approaches within therapeutic work. However, the researcher was familiar with cognitive behavioural therapy, resembling IPA in focus on thoughts and feelings (Smith et al., 1999; Smith & Osborn, 2003).

3.9. *Reflexivity*

As outlined within Appendix L, the researcher appreciated the importance of reflexive position when undertaking research, and was mindful of the "double hermeneutic" within IPA (Smith & Osborn, 2003, p. 51; 2008), which emphasises the role of the researcher within the research process and analysis. As such, the researcher was keen to outline a reflexive position.

Prior to commencing the research, the researcher was a 27- year- old, white British female, living with a partner of six years, with no children. The researcher had not encountered anyone personally or clinically with heart failure, and knew very little about heart failure as a medical condition. The researcher had had personal experience of losing a grandparent to cancer in 1998, with the grandparent receiving support from palliative care nurses at home. Clinically, the researcher commenced a placement within a health psychology department in November 2008.

The researcher had read widely about heart failure, the need for palliative care for non- malignant conditions, as well as studies articulating patient experiences of heart failure, and the role of the HFSN as part of a multi-

disciplinary team. The researcher also shadowed two HFSNs in their role, meeting patients and their relatives/ carers in the home. The researcher also completed a literature review on the psychological effects on nursing staff of working within palliative care.

The researcher had not undertaken qualitative research before coming on to the training course, though received teaching about qualitative methodologies, and read extensively about their potential. The researcher also attended a one- day training course on IPA.

The researcher used the research diary to monitor reflexivity, record ideas, thoughts and feelings throughout the research process and reflected upon reflexivity within the Critical Appraisal.

3.10. *Quality Measures*

Guidelines for assessment of basic quality within qualitative research have been developed (Yardley, 2008) and the researcher's critical realist epistemological position suggested that credibility and objectivity should be incorporated within assessment of quality (Madill et al., 2000). To this end, guidelines developed by Elliott, Fischer, and Rennie (1999) were incorporated, ensuring that credibility, validity, and rigour were maintained during the research process. Such guidelines were also chosen as they fitted application to "phenomenological- hermeneutic" research studies (Willig, 2008, p. 152). The guidelines are noted below, alongside the researcher's attempts to meet them.

3.10.1. *Owning one's perspective.*

The researcher ensured that reflexive, epistemological and theoretical positions were stipulated, and used a research diary to monitor these positions. The Critical Appraisal was used to reflect upon these positions.

3.10.2. *Situating the sample.*

The researcher provided demographic information and background to the HFSN role, to provide a context, and to enable readers' decisions regarding transferability.

3.10.3. *Grounding in examples.*

The researcher endeavoured to provide quotes from participants within the Analysis of Data section. The researcher also provided information about the analytic stages of the research (Appendix K) to show the links between the data and interpretation.

3.10.4. *Providing credibility checks.*

The researcher used sessions with colleagues from a qualitative support group to analyse data, check coding and theme generation. In particular, two members of the group helped the researcher to collapse the emerging themes into a

smaller number of superordinate themes, with sub- themes, by drawing the themes out together onto a large piece of paper and drawing connections between the different themes, and coming to an understanding of which themes appeared to be most important. The group members also looked through the quotes used to support each theme to make sure they appeared appropriate. The group members also checked a few of the transcripts to identify the plausibility of the codes. The researcher also sought assistance from both the research and field supervisors, who had clinical and research interests with cardiac populations, offering triangulation of perspectives on the data (Yardley, 2008).

3.10.5. *Coherence.*

The researcher shaped the Analysis of Data section to tell a clear and coherent story, explaining each theme, with supportive examples from the transcripts.

3.10.6. *Accomplishing general v[ersu]s specific research tasks.*

The researcher aimed to offer transparency and systematicity during the Methodology section by explicating the participant characteristics, data collection and analysis methods, to help readers to identify whether the findings may be transferable to different contexts. The researcher also addressed transferability within the Discussion section, with emphasis on theoretical as well as clinical transferability (Smith & Osborn, 2003).

3.10.7. *Resonating with readers.*

The researcher checked whether the master theme list resonated with the research and field supervisors, as well as a colleague within the qualitative support group who had experience within palliative care.

4. Analysis of Data

The master list of themes is shown below in Figure 3, with three superordinate themes, with associated sub- themes.

Figure 3. Master list of themes

KEEPING THE RHYTHM GOING • Keeping patients well • Stability versus decompensation • Keeping patients at home
THE RHYTHM PETERS OUT (A GOOD DEATH) • Certainty and honesty • Meeting patient preferences • Making life comfortable • Being a key- worker • Staying until the end (providing continuity)
WINDING UP THE STRING • Just dealing with it • End- stage overload • Giving your all • Good death failure

4.1. *Keeping the Rhythm Going*

Imagine a yo-yo. The yo-yo incorporates a tightly coiled string which, by holding its end, the person can release, while simultaneously establishing a rhythmic action such that the yo-yo gains enough momentum and pace to return to the hand. The yo-yo will be released again and again, with the holder of the string becoming more comfortable with the momentum they have created and expectant that the yo-yo once released will return to them.

The superordinate theme *Keeping the Rhythm Going* relates to HFSNs' role with patients prior to ESHF. The HFSN establishes a relationship (rhythm) with a patient (yo-yo) upon referral, endeavouring to achieve stability (*Keeping Patients Well* and *Keeping Patients at Home*) in order that the patient (yo-yo) can be released into primary care. However, upon decompensation (deterioration in condition) the HFSN brings the patient (yo-yo) close to them again until they regain stability and can be discharged (*Stability versus Decompensation*). Over time *Keeping the Rhythm Going* becomes routine case management, with the HFSN comfortable with the relationship (rhythm), expectant that the patient will bounce back to them when they decompensate, and assured that they can continue to stabilise the patient.

4.1.1 *Keeping patients well*.

Keeping Patients Well was felt to require a multi-faceted approach and engagement with other professionals. Participants liaised with GPs and cardiologists, monitored clinical status and medications, and provided education to patients and the family to encourage self- management, as the extract below exemplifies:

> *it's being a a bit of an all- rounder, educator, supporter, facilitator, (pause 1) er, (pause 1) and* <u>*also*</u> *someone who's there to* <u>*monitor*</u> *the patients' conditions and symptoms* (P5. 3. 55- 58) [1]

4.1.2 *Stability versus decompensation*.

Stability of patient condition, with no "*heart failure drug change for two months or a hospital admission for three*" (P2. 15. 365- 366) appeared to be welcomed, easing pressure on caseload enabling the delegation of responsibility for the patient back to primary care, as P1 explained:

> *we just cannot physically continue seeing every patient we've got (pause 1), erm [HMM] and therefore we do have to sort of decant these patients down to, you know,* <u>*other*</u> *members of the multi- disciplinary team* (P1. 4. 78- 81).

---

[1] Participants have been numbered in order of interview, and are referred to by the initial "P". Supportive quotes are identified in parenthesis by participant number, page number, and line number within the transcript.

Stable patients were less demanding and sent "*off on their merry way*" (P1. 1. 23) back to primary care management. HFSNs retained identity and status as specialists, dealing with patients who were unmanageable and had deteriorated, patients "*bounce back to me as and when, (pause 1) you know, the situation, (pause 1) you know, they they decompensate*" (P1. 3. 71- 72). P2 identified status as a specialist as important:

> *the role itself has, erm, has quite a lot of, well an advanced practitioner role, has got quite a lot of, erm, sort of kudos if you like [HMM] attached to it…I mean I've friends that are specialists in other areas and it it sort of, almost like a sort of a handmaiden type (pause 1) role, you know, it's like the doctors' told you what the problem is, now you can go and talk to the nurse about it [HMM] you know, and it's it's not like that* (P2. 35. 863- 865. 867- 871).

4.1.3 *Keeping patients at home.*

The HFSN role was developed specifically to avoid hospital admissions and readmissions, with respondents articulating strong belief in the importance and benefits of being cared for at home, within the community:

> *patients erm, certainly, er, are less likely, to pick up infection, er, they eat better, they sleep better, they generally they do much better when they're at home* (P1. 13. 315- 317).

Hospital admissions appeared to imply failure, the last resort as patients *"end up in <u>hospital</u>"* (P2. 26. 631) when HFSNs efforts were insufficient to control the condition permitting stability at home.

4.2 *The Rhythm Peters Out (A Good Death)*

Routine management (*Keeping the Rhythm Going*) could continue for many years. However, the relationship (rhythm) eventually becomes harder to maintain, the patient not recovering (bouncing back) from decompensation, with the HFSN acknowledging that the patient has reached ESHF. *The Rhythm Peters Out* as the HFSN lets the string become loose and a new role, as provider of *A Good Death,* becomes prominent. Each sub- theme below outlines implicit beliefs to *A Good Death* which the HFSN used to negotiate the complexities of end of life care.

4.2.1 *Certainty and honesty*.

Certainty emerged as a central focus in end of life care. Respondents grappled with patients' understandable lack of comprehension or acceptance of ESHF, with a need to develop *Certainty* from uncertainty. This appeared staged with HFSNs pursuing leads from patients to have conversations about the reality of their approaching death, as the extract below explains:

you sort of (pause 3, tut) use your own intuition and your own experience
with that patient to answer their probing questions that they <u>have</u> (sigh),
delve into them a bit more or, and come to the stage of <u>prompting</u> them to
say well, you know, "you're not responding as well as to your treatment as
you are, I think you're moving into another phase of your condition" (P5.
10- 11. 248- 253).

Accompanying *Certainty* was *Honesty*. There was a strong belief in being
honest with patients and families regarding prognosis from referral onwards,
enhancing acceptance of end of life when it was reached. The extract below
illustrates how honesty regarding the possibility of sudden death had helped a
family to understand and accept the loss of their loved one who did die
unexpectedly:

we'd already talked about sudden death, erm, so when it <u>did </u>happen (pause
1) not that we could predict it his <u>wife </u>although very much shocked to find
him lying on the bathroom toilet in the early <u>hours,</u> and the paramedics
came and tried to resuscitate him. In the back of <u>her</u> mind, she always knew
that could happen (P6. 23. 563- 567).

By being honest, the researcher felt that respondents believed that they built
a relationship of unquestionable trust with their patients, with the HFSN being held
in high regard by the patient and family:

I think we're in a <u>very very</u> privileged position in the fact that they <u>trust</u> us

so much you know, and they they, (pause 2) you know, sometimes you think

if they if you say jump they say how high (P1. 26. 635- 638).

I've gotta say I- it's just the the appreciation that the patients do have for ya

(P5. 7. 169- 170).

4.2.2 *Meeting patient preferences.*

There was a sense that *Certainty and Honesty* were purposeful, goal-orientated phases of end of life care, for participants appeared to feel that following *Certainty and Honesty* they could then open dialogue with the patient and family about preparing for death. This ensured that another goal could commence, that of fulfilling end of life wishes:

you have to say, you know, "you're not <u>going</u> to get better", or or not not

directly as that, but try and get to that point because, the patients are

waiting to get better, they they're never gonna do what they wanted to do

(P4. 18. 443- 446).

Meeting Patient Preferences was conveyed to the researcher as key to the HFSNs' role at end of life, and an aspect of care undertaken with enthusiasm, as the extract below suggests:

I think <u>my role</u> at <u>that</u> stage is definitely, to, erm, do some advanced care

planning, work out, you know, <u>where</u> they want to die, <u>how</u> they want to die,

if they're <u>aware</u> of how it's <u>actually</u> going to <u>be</u> for them when they die (P2.

5. 121- 124).

4.2.3 *Making life comfortable.*

Within the accounts, end of life care was understood to be somewhat

different to care previously provided during *Keeping the Rhythm Going*, with this

former type of care more akin to that delivered in acute contexts. The suggestion

that invasive, intervention focused care be discontinued, to focus on *Making Life*

Comfortable, giving patients a quality of life, is illustrated in the following extract:

By the <u>time</u>, you know, patients reach <u>end of life</u> it's about (pause 1) I think

individuals and how individuals <u>react</u> with patients rather [HMM] than you

know, throwing a bi- ventricular pacemaker at somebody that really isn't

going to benefit from it, do you know what I mean? It's about making that

<u>life</u> the <u>best</u> of the <u>rest</u> of their lives (P1. 28. 688- 693).

This new focus, "*looking at the <u>holistic</u> thing rather than treating one part*

of that patient" (P4. 11. 267- 268) appeared to draw respondents away from their

acute practitioner roots, towards an appreciation of the value and benefits of

palliation, as "*another <u>approach</u>*" (P2.12. 280), suggesting willingness to

incorporate a different philosophy of care within their approach towards patients:

makes you realise how important (pause 1) the role of palliative care is, you

know, within a <u>Heart </u>Failure Nurse role (P6. 11. 267- 269).

However, while this suggested tacit acceptance, the researcher felt that participants could not relinquish their referent model of care altogether. When faced with patients' psychological and social issues, such as anxiety, fear of dying and isolation, they did not appear comfortable with simply sitting with the patient and listening to their emotional distress, but rather felt compelled to resolve the distress practically, again exerting a sense of control over the situation:

the person that (pause 1) is is going to- to make themselves available needs

to <u>act on </u>what they <u>say</u>, if they want them to, so, you know, I think it's no

good just sitting there being a good listener and then walking away and

(pause 1) writing it all in your notes and then going back the following week

and having (laughs) the same conversation (P2. 9. 215- 219).

A lot will, erm<u>, panic</u> in the middle of the night, and, you know, that's <u>one</u> of

the things that we do with them, we talk to them about breathing exercises

(P1. 14. 336- 338).

4.2.4 *Being a key- worker.*

There was a real sense that "*rather than actually doing the sort of hands <u>on</u>*

care" (P2. 2. 40) that might imply emotional engagement, participants preferred to

take a more distant role of key- worker, acting as a lynchpin to "*coordinate and call*

in all the other community services <u>required</u> if that patient so wishes to be nursed at home" (P5. 1. 20- 21). Involving community matrons, district nurses and macmillan nurses where appropriate, with individualised packages of support, appeared to be a task with advantages for the HFSN, permitting them to define and retain a specific identity as a HFSN and overview of end of life care without providing it, being involved:

> *just to sort of make sure that the management plan is being, you know, sort of is being, er, adhered to but that's it's still meeting the patients needs* (P2. 2. 37- 39).

Yet, *Being a Key- Worker* could feel "<u>*superfluous*</u> *to the situation*" (P3. 14. 327) reflecting again the tensions from familiarity and comfort with an acute, intervention- based ethos which could induce a sense of redundancy:

> *you think well "I'm not doing anything", but I think that's the real medical model that we're in that you think well "I don't <u>need</u> to be doing anything, I just need to be there for <u>support</u>"* (P6. 8. 178- 180).

Trusting relationships built with patients and families appeared to be particularly significant within the last weeks of life, as the HFSN introduced patients to other professionals, mitigating any distress this might cause:

I personally feel they need that reassurance that there's someone there who they have <u>built</u> up the confidence with and <u>built</u> up a rapport with who they can still have that contact with (intake of breath) to help them with any enquiries and also to, <u>build</u> up (pause 1), erm, the relationships with other <u>members</u> of the community team (pause 1) over a short period of time, because very often that patients going to be dead within a week or two of you calling them in (P5. 19. 451- 457).

There was a sense that the liaison implicit in the key- worker role permitted professional burden to be legitimately shared, trying "*not to take everything on board myself and realise there's other people out there to do it*" (P6. 11. 258- 259) and other professionals' involvement seemed to provide reassurance and comfort that the patient was receiving optimal care:

you've <u>talked</u> about it, you've <u>all</u> agreed the <u>pathway</u> with the patient, (pause 1) it doesn't <u>really</u>, sort of, cause you too many concerns. It's the ones where you sort of go it <u>alone</u> that tend to be the ones that (pause 2) cause you more <u>stress,</u> yeah, so a team is invaluable (P2. 18. 437- 440).

4.2.5 *Staying until the end (providing continuity).*

HFSNs remained involved in care until the death of the patient, as a consistent professional who can offer:

continuity for the family, it's continuity for the patient, it's also <u>support</u> for

the primary healthcare teams (P6. 8. 176- 177).

Discharge before death appeared unprofessional, arguably an act of betrayal, potentially detrimental for the patient and family, and reflection of the dependency felt to exist between patient and nurse:

but if I <u>suddenly</u> backed off <u>completely</u> he <u>knows</u> that whenever he starts to

decompensate that up to <u>now</u> we've always managed to get him up and and,

you know, and sorted, erm. And I <u>suppose</u> it's a (sigh) you just know that's

there's somebody that that, is, you know, au fait with what you know, with

<u>your</u> condition, that you want around when you're not feeling very well I

suppose [HMM] erm, and if you suddenly say <u>well</u>, it's over to, you know,

[HMM HMM] so and so now, that can be <u>quite</u> (pause 1) distressing, for

some of the patients <u>and the</u> relatives (P1. 21. 515- 522).

Interestingly, the benefits of staying involved were framed in relation to the patient and family rather than the benefits for the HFSN themselves. This quote reinforces participants' perceived their role as integral, emphasising their value and contribution. This could be viewed as narcissistic, or could reflect a need for validation.

4.3 *Winding up the String*

When the yo-yos' momentum has dissipated, the string is carefully re-wound and the yo-yo is put away. Following the death of a patient (yo-yo), the HFSN engages in *Winding up the String* with that relationship ended, and the process must start again with a new patient (yo-yo). This superordinate theme describes factors that contributed to the HFSNs' capacity and ability to keep *Winding up the String*, and continue to care for patients.

4.3.1 *Just dealing with it.*

When asked how working with the dying affected them, participants appeared blasé, noticeably curtailing this focus, and being emphatic that the work had little affective impact, with the repeated notion of being able to just "*deal with it*" (P1. 25. 623) and "*just learn to (pause 4) put it behind you in a way*" (P4. 30. 742), with "*it*" not being defined. It appeared there was little time afforded for reflection or emotional processing, with the sense of simply moving on to the next patient, reflected within doctrine from managers within acute settings, encouraging nurses to "*just get on with it*" (P6. 38. 935).

Work- life balance was conveyed as important, achieved by spending time with family and friends, having interests outside of work, and trying to block out thoughts about work, sometimes "*combined with a lot of alcohol*" (P3. 15. 369-370). The following extract conveys the need to dispense with the burden of the role,

with the perceived simplicity of a swift removal of the uniform when home from work functioning as an effective cut off point:

> *I-I can switch off (intake of breath), you know, the uniform comes off and when I'm at home and I (intake of breath), I tend not to or try not to think about work in that way* (P5. 22. 544- 546).

Just as winding up a yo-yo would be easier for somebody more experienced, competence in *Just Dealing with It* also emerged over time in the role. There appeared to be three tasks or processes to master in order to deal with it, the first two related to learning to be a specialist within heart failure and becoming a nurse prescriber:

> *perhaps a few years ago I'd take things home things like worrying about somebody's blood test results because I'd prescribed them a new drug that day (pause 1), I suppose at the time that's because I was a new prescriber, erm, I suppose when I started as a Heart Failure Nurse I would go home and just worry about the job itself* (P2. 31. 761- 765).

The third task related to proficiency in dealing with patients with ESHF and end of life care. Prior to being HFSNs, participants came from backgrounds in acute care, appearing unaware that end of life care would form a major part of their role, as the extract below illustrates:

I-I-I thought that (pause 1) being able to visit people at home, and assess

them, provide a, (pause 1) erm, (tut) their treatment plan, and follow things

through and things would would get better and then you'd move on to the

next patient. But really I didn't actually have much of an idea of what heart

failure was about before I actually (laughs) got into seeing patients [HMM].

It's been a steep learning curve really (P3. 1. 19- 25).

Learning about the specialism and becoming a prescriber appeared to take

precedence when new in post, consonant with previous roles and experience, with

limited capacity left over to acquire end of life care skills. Nonetheless demands

were still made on them to care for patients with ESHF, making "*the palliative side*

of this role extremely difficult in the beginning" (P5. 19. 469- 470).

Even some years into the role, there was expression that learning to care for

patients at end of life was an ongoing challenge, "*It is a skill I feel that I am always*

learning more and more about" (P5. 20. 480- 481), with suggestion that continued

learning and updating knowledge was an accepted part of being in a specialist nurse

role, with end of life care being no different. An Advanced Communication Course

had certainly helped incorporation of a palliative model of care, with suggestion the

course "*changes your whole approach*" (P6. 11. 266). However, proficiency in end

of life care felt more effortful than learning to become a specialist or a prescriber,

requiring greater informal support from colleagues when trying to deal with end of

life care experiences:

we'll talk to each other everyday, erm, normally, and <u>certainly</u> if there's any

of us have <u>got</u> end stage patients on our caseload we tend to ring each other

quite frequently just to get some support with that (P2. 23. 573- 575).

so it (pause 2) so it is informal, it is the fact that, you know, you cry on

someone's shoulder really (pause 3) (P4. 29- 30. 720- 721).

Supervision and informal advice from professionals at a hospice, who provided this support out of goodwill, had been particularly helpful in building confidence and expertise in end of life care, as P6 explained:

I think without that (pause 1) I'd probably be sitting here and saying is "I'm

frightened of palliative care", where, you know, <u>now</u> (pause 1) I'm not, I

can deal with it (P6. 11- 12. 273- 276).

4.3.2 *End- stage overload.*

Working with patients with ESHF was conveyed as intense, despite proportionally few patients within a caseload of 70 approaching end of life, "*but those <u>four</u> will actually take up (laughs) half of your time*" (P2. 20. 499). Thus, HFSNs did not have to be holding many patients (yo-yos) to become overwhelmed, with end of life care seemingly physically and emotionally draining:

all you ever seem to be doing is going in and sort of, erm, expecting that the next time you get a phone call that, you know, you're going to, somebody's going to say that they've passed away (P1. 23. 568- 571).

they take up so much time and effort, personal effort you know, it's, erm, it's hard work looking after people that are dying (P2. 21. 519- 520).

I think it's, it's draining [HMM], and, er, emotional. Even if you're (pause 1) not involved (pause 1) from day to day if if you're if you're seeing them once a fortnight (pause 2) they tend to be the ones that you wake up at 3'o clock in the morning and think "oh, I wonder I wonder how they are" (P3. 15. 355- 358).

Interestingly, the above quotes suggest depersonalisation of patients, using "they" or "them" to refer to patients. However, this could have been done to protect the identities of their patients.

Unremitting intensive caseloads may affect capacity to continue to care over time, with P2 hinting:

you know, the burnout rate potentially amongst Heart Failure Nurses I'm sure, is is soon to start being seen (P2. 17. 416- 417).

Organisational issues, such as lack of administrative support, as well as increased pressure on target and activity monitoring were noted by the researcher. It appeared that such pressures may be inimical to the original intention of delivering person- centred care:

We're an expensive service, we're high grades, paid high grades, we're experienced members of the team (intake of breath), and if we're not getting the results that are required or showing that we are reducing hospital (pause 1), erm, (pause 1) admissions for the heart failure patients then (pause 1) we will be seen as not being productive enough I suppose (P5. 35. 850- 855).

Targets appeared to relate to routine aspects of the role, with care at end of life not accounted for within such activity monitoring, with implication that such care was not validated by the organisation. This held particular poignancy for P4 who expressed incredulously how bereavement visits were not viewed favourably by managers:

I'm not keeping somebody out of hospital on that visit am I? [HMM] so from [HMM] a cost point of view am I cost effective at that point [HMM] (pause 2). No (P4. 24. 588- 591).

However, despite such challenges, it became clear during the interviews that working with patients with ESHF was a rewarding aspect of their role, with the variety and challenge of end of life care important for their overall job satisfaction:

So, it's very variable really. Erm, but I <u>think</u> that's wha- that's what makes

it a challenge. I think if it was <u>just</u> mundane, you know, sort of up- titrating

medicines then, the challenge, I thrive on challenges and erm, [HMM] it

would be gone really (P1. 22. 543- 546).

4.3.3 *Giving your all.*

A significant contributing factor to *Just Dealing with It* appeared to be

achieving *A Good Death* for the patient, enabling respondents to feel they were

"*making a difference*" (P6. 4. 91) to that patient and family. By putting plans in

place and working towards *A Good Death,* the HFSN and patient could exert some

control over death, which by its nature defies control, which could be inherently

rewarding for the HFSN when plans went as expected:

How does it affect me personally? [HMM] It is, I suppose if you do it <u>right</u>

and you get it right it's quite rewarding in a in a (pause 1) and that isn't

meant that death's rewarding it's meant that the <u>good</u> death is rewarding

[HMM] erm, so how do I cope with that? How do I feel? [HMM] I feel if it's

gone well that it's actually quite a positive thing (P4. 25. 615- 620).

Closure for the HFSN also appeared to come from knowing that everything

had gone as planned, everything possible done for that patient, with the added

bonus of the family valuing the HFSNs' input and role at end of life, appreciating

everything they had done, as illustrated by the extracts below:

it also (pause 1) assists <u>me</u> I suppose in putting <u>closure</u> on that patient's

episode of care too (pause 1). In the fact that, well you know, it's nice to

know you did everything you could do and coordinated all the services in

the most appropriate way, and deliver a a quality (pause 1) of service

(intake of breath) within the end stages of their condition (P5. 19. 458- 463).

it's the appreciation that the the the patients [HMM] have for you, the

patients and their family members (P5. 7. 154- 155).

By working hard and placing energy into achieving *A Good Death*, the researcher also felt that the death itself became less daunting, and was not emphasised as a source of emotional distress, with vehement denial of any aspects of grieving for patients, because everything had been achieved prior to death:

I sort of put <u>double</u> effort [HMM] into sort of getting it right before (P2. 26. 648- 649).

you do get people who are <u>always</u> crying with the families and that

afterwards but to <u>me</u> (pause 1) you need to do everything <u>you</u> can do before (P4. 27. 668- 670).

However, whilst trying to provide *A Good Death*, there appeared to be an unwritten rule of *Giving Your All,* placing high expectations on themselves to do all they could for the patient, with a sense that there was no second chance to get things right, and thus trying to achieve *A Good Death* itself became a source of stress:

> *I find it <u>very</u> draining and the reason being that I want to make sure I get everything <u>right</u> because it's not like you're gonna get another chance* (P2. 24. 596- 598).

Giving Your All might appear detrimental to self with its potential to create burnout. During the interviews there appeared to be an understanding that loosening boundaries between home and work at times was a virtuous, accepted part of the role rather than something to be resisted:

> *because they're coming to their end stages, that they're not gonna be around very long so you trying to provide the best quality care you can (pause 1) for them (intake of breath). And if that <u>means</u> me staying over a bit later (intake of breath) or having a bit more demands placed upon my time within my working day (intake of breath), erm (pause 2), I'm content to (pause 1) do that* (P5. 25- 26. 621- 626).

I see it very much as a 24/ 7 job it's <u>not</u>, it's not a 9 to 5 job, never has been, never will be, erm, and (pause 1), you know, if you've got somebody dying at home who you've looked after for two years, you don't switch your phone off at 5'o clock [HMM] you know, if the relatives need you, they need you. Erm, you know, we work <u>flexibly</u>, you take a couple of hours <u>back </u>some other time, erm [HMM], but, you know, we need to be able to provide that service and work [HMM] flexibly for these people (P2. 17- 18. 423- 430).

4.3.4 *Good death failure.*

Giving Your All to provide *A Good Death* may be successful when end of life care goes according to the plans made. However, achieving *A Good Death* could become complicated, interrupted or prevented, resulting in *Good Death Failure*. For example, patients referred to the HFSN when already at end stage, appeared to create difficulties as they had not established a prior relationship, *"they haven't got to trust me as well"* (P3. 3. 72- 73), suggesting that control exerted by implementing the rules of *A Good Death* became jeopardised.

Similarly, sudden deaths also appeared to sever the completion of an episode of care, and thwarted the careful planning between the HFSN and patient, with death reasserting control. This left participants questioning whether they had done their best for the patient, preventing adequate closure:

yeah it has gone <u>well</u> and it's, I suppose it's because you've had time to plan it, whereas I think sometimes it doesn't go well because everything's <u>suddenly</u> oh <u>suddenly</u> we've gone from lots of activity to oh you're dying [HMM HMM] so you haven't got time to put all those things in place (P4. 20. 487- 491).

I think every patient that dies suddenly or more unexpected, I still have the same thing I think (pause 1) "right, have I done everything? Was everything done possibly? Should I have done this, should I have seen them a week before?", erm. And (pause 1) it's <u>always</u> been, you know, the same (pause 1) and you just think "well (pause 1) erm, and then you think "well, I'm never going to see that patient again so you don't know (pause 1) erm (tuts), you know, if everything <u>could</u> be achieved", so you sort of question yourself (P6. 21. 501- 508).

Where this had occurred, closure had been sought from bereavement visits or informal colleague support, reassuring the HFSN that they had made a difference, and their role had been valuable.

Whilst caring for patients at end of life, HFSNs retained links to an acute setting. At times, *Good Death Failure* occurred when practitioners within the acute context undermined the HFSNs' rules for *A Good Death*. This occurred when patients were admitted to hospital at the weekend or out of hours, with patient preferences being ignored, and the patient dying in hospital, leaving participants feeling powerless, angry and frustrated:

sometimes you feel quite <u>powerless</u> I think is probably what it is…when I sort of look back at those sometimes you can <u>really</u> see that's it's, erm, quite angry some of it, erm, and it's about, erm, <u>if,</u> er, it's <u>normally</u> if the patient died in hospital, erm, having (pause 1) sub- optimal care, er, sub- optimal <u>palliative</u> care, erm, <u>against</u> their wishes, er, and <u>I</u> feel quite <u>strongly</u> about that but I think that <u>upsets</u> me if somebody, you know, has gone to the effort to make advance care plans, put things in <u>place</u>, you know, you've spent a long time with a patient trying to get their wishes, erm, put in place, and then for <u>whatever</u> reason they end up in <u>hospital</u> (P2. 25- 26. 617. 623- 631).

Good Death Failure could also occur when GPs or cardiologists failed to acknowledge the terminal nature of the condition, contravening the principles of *Certainty and Honesty*, and again potentially thwarting *A Good Death*, leaving feelings of frustration:

some Cardiologists would say "how on earth can you talk about death and dying when this patient is actually only got, sort of, minimal LV dysfunction?". Well (pause 3) you don't say to a patient "you've only got a little bit of cancer" do you? (P1. 15- 16. 374- 377).

the way he put the conversation was, "well, we'll treat things as they come <u>up</u> and although we'll manage to keep on top of things", and he didn't <u>really</u> come out clearly with with what I was hoping that he would say that,

you know, this is <u>all</u> that we can manage and we're not treating, we're not

making your your heart any better (P3. 10. 240- 245).

A further barrier to providing *A Good Death* occurred when there were inadequate resources for patients to be cared for at home, with P5 identifying the need for:

more palliative care teams, more equipment, such as beds, bed cradles

(pause 1), syringe- drivers, for example, erm (tut, pause 1), and bigger

amounts of staff to help provide this basic nursing care (P5. 15. 360- 363).

There were also still inequities in resources when compared to patients with cancer, with P4 expressing angrily:

A lot of the <u>hospice</u> (pause 2), er, things, so sort of life the, erm (tuts) you

know, their the <u>counselling</u>, or the, er, <u>aromatherapy</u> or the <u>massage</u>, or

(pause 1) they're all paid for by the <u>cancer</u> charities (pause 1) so heart

failure patients can't access those, and some of the day care they can't

access because it's paid for out of cancer charity money (pause 1) and I

think that's a very famous thing with erm, with, erm, (tuts) Esther Rantzens'

husband, who actually said if he'd had cancer he'd have had a far better

death, and I think that still is very true (P4. 13. 302- 310).

5. Discussion

5.1 *Theoretical Implications*

The findings from the current study articulated the experiences of HFSNs in providing end of life care for patients with ESHF. The metaphor of the yo-yo was used to encapsulate the dynamism and differences between offering routine care (*Keeping the Rhythm Going*) and end of life care (*The Rhythm Peters Out- A Good Death*), as well as identifying the ways in which end of life care affected HFSNs (*Winding up the String*).

5.1.1 *Keeping the rhythm going.*

Routine care appeared to be focused upon monitoring clinical status and medications, liaising with GPs and cardiologists where necessary, and supporting patient self- management (*Keeping Patients Well, Keeping Patients at Home*). Such tasks have been identified as important to the HFSNs' role in other studies (Jaarsma et al., 1997; Sargeant et al., 2008). Also evident in this maintenance was the definition of role. HFSNs felt they had achieved status within their healthcare community as specialists who are relied upon when patients deteriorate (*Stability versus Decompensation).* This need to define a clear position and relationships is perhaps not too surprising given the infancy of their role (Pattenden et al., 2004).

5.1.2 *The rhythm peters out (a good death).*

As patients within the current study moved towards end of life there appeared to be a pronounced shift from intervention focused care towards a palliative approach. The sub- themes *Certainty and Honesty*, *Meeting Patient Preferences*, *Making Life Comfortable*, and *Staying until the End* resonate with definition of a 'good death' within palliative care literature, with its emphasis upon open communication, patient preferences, comfort and being involved until death reinforced as evidence of their good practice at end of life (Brännström et al., 2005; Mok & Chiu, 2004; Payne, 2000; Webster & Kristjanson, 2002a; 2002b; Wilkes & Beale, 2001). By incorporating maxims of *A Good Death*, participants could be construed as wresting some control from death's inevitability, enhancing internal locus of control (Conner & Norman, 1996) and increasing self- efficacy (Schwarzer & Fuchs, 1996), perhaps their own as well as their patients. Control has been understood within palliative care literature as an adaptive coping mechanism (Ablett & Jones, 2007; Johnston & Smith, 2006). Patients with heart failure have been identified as feeling powerless over their condition and life at times (Thornhill, Lyons, Nouwen, & Lip, 2008), and implementation of such maxims of *A Good Death* offers patients empowerment.

Participants also emphasised within *Giving Your All* that by providing *A Good Death* they felt they could make a difference. This appeared to guard against any adverse effects such as grief, because everything possible had been achieved prior to the patient's death. As such participants appeared to reappraise death as an

achievement, finding purpose and meaning in death. Positive reappraisal can be viewed as an adaptive "emotion- focused coping" style (Davis, Nolen- Hoeksema, & Larson, 1998; McVicar, 2003, p. 639; Taylor & Stanton, 2007) and finding purpose relates to resilience literature around the concept of hardiness (Jackson, Firtko, & Edenborough, 2007).

The remaining sub- theme, *Being a Key- Worker,* suggested that participants became coordinators of care rather than providing 'hands- on' care themselves. Such task orientation with its emphasis on "doing for" rather than "being with" (Anderson, 2007, p. 90) contradicts a palliative care ethos, where focus shifts to relational care and being with the patient (Barnard, Hollingum, & Hartfiel, 2006; Barthow, 1997; Cronqvist, Theorell, Burns, & Lüzén, 2004; Dunniece & Slevin, 2002). This may well reflect their prior work experiences and styles and necessary defences.

While HFSNs have been expected to undertake a pivotal role in providing end of life care (Blue & Stewart, 2004; DH, 2003; 2004; Healthcare Commission, 2007) it was clear within *Just Dealing with It* that participants had found end of life care a difficult area to address, especially given the competing demands of becoming a nurse specialist and nurse prescriber when new in post. An Advanced Communication Course appeared to be the only frame of reference participants had to implement end of life care, consistent with literature highlighting the lack of formal training for HFSNs regarding palliative care (Blue, 2004b; Blue & McMurray, 2005; Jaarsma et al., 2006; Ryder, 2005).

Participants were also clear within *Just Dealing with It* that they had not

expected that end of life care would form such a large part of their role, and that

given their backgrounds in acute contexts, offering a different model of care was a

novel experience for which they often required additional informal colleague

support. Nurses within cardiac contexts are familiar with monitoring patient

condition and often rely on objectivity rather than emotional closeness with patients

(Svedlund, Danielson, & Norberg, 1999). Nurses from acute contexts are known to

be inadequately prepared for end of life care, with the shift to a different model of

care being difficult (BPS, 2008; Marino, 1998).

Psychoanalytically, participants' reactions are an unsurprising response to

threat creating anxiety and activating defences to dispel anxiety and adapt to the

situation (Salander & Windahl, 1999). Given the lack of expertise, unfamiliarity

with sustained contact with those dying and palliative care, it is perhaps

understandable that participants adopted a key- worker role. This would be similar

to the goal- orientated role implicit in the acute contexts from which they came and

who continue to manage their service.

5.1.3 *Winding up the string.*

Participants denied that working with the dying affected them, with little

evident emotional processing or reflection within the interviews, and an overall

rhetoric of *Just Dealing with It* becoming prominent. *Just Dealing with It* could be

viewed as a defence mechanism and would relate to literature around denial or

"detachment" from affective components of nursing (Menzies Lyth, 1960, p. 445).

Such defences have been highlighted within the literature as maladaptive coping

strategies, leading to burnout and "cumulative grief" (BPS, 2008; Ekstedt &

Fagerberg, 2005; Hopkinson, Hallett, & Luker, 2005; McVicar, 2003; Marino, 1998,

p. 103; Menzies Lyth, 1960; Sandgren et al., 2006). By maintaining emotional

restraint (Menzies Lyth, 1960) nurses control their feelings and maintain a

professional persona (Bolton, 2001) enabling nurses to care for patients while

remaining emotionally distant. The professional face can offer illusory coping,

particularly important for HFSNs who are keen to be seen as competent specialists

(*Keeping the Rhythm Going*). Participants may well have declined to consider

emotional corollaries of work given their limited access to supervision for their end

of life cases.

Within the current study, participants alluded to managing emotions by use

of alcohol and removal of work uniform. Sandgren et al. (2006) suggested that

nurses often hide behind their profession, the uniform enabling the nurse to use

their professional dress as a shield, with removal of the uniform once home being

"like cutting off emotions and lifting the problems away" (p. 85). This would be in

contrast to palliative care nurses, reporting an infusion of palliative care ethos into

their professional as well as personal life to enhance resilience (Webster &

Kristjanson, 2002a; 2002b).

However, participants did articulate awareness of the burden of caring for

the dying in terms of at times feeling overwhelmed by the effort such patients

required (*End- Stage Overload*). Organisational issues, such as lack of

administrative support and activity monitoring for routine elements of care also undermined participants' attempts at offering quality end of life care. Stress can result when the demands of work and control over work become imbalanced (BPS, 2008), with P2 suggesting that unremitting caseloads may affect capacity to continue to care over time.

Stress can be mitigated by self- care and efforts to ensure that life exists beyond work (Ablett & Jones, 2007; Barnard et al., 2006; Newton & Waters, 2001). Participants did emphasise the importance of work- life balance within *Just Dealing with It*, however they were equally emphatic that patients should achieve *A Good Death*, even if this meant loosening the boundaries between work and home life. Within *Giving Your All* participants believed that there were no second chances to get things right, and placed high expectations on themselves to do all they could for each patient. Participants seemed fixed upon knowing they had done a good job regardless of cost to self, a notion understood within nursing literature as "confirmation seeking" (Sandgren et al., 2006, p. 86). They also appeared to pursue a purpose as virtuous carers (Bernard & Creux, 2003; Burt, Shipman, Addington-Hall, & White, 2008; Newton & Waters, 2001), which has been conceptualised as "maladaptive perfectionism" (Taylor et al., 2002, p. 325). This particular objective may have arisen for participants as they engaged with end of life care feeling less familiar with, and less equipped for, what was demanded of them. Paradoxically, although the boundaries constructed for themselves as key- workers may appear safe and defined, the key- worker role appeared to cause a sense of redundancy and fraudulence. Only by *Giving Your All*, with its attendant risks for health could

participants confirm that the role they had undertaken at end of life had been worthwhile and of essential benefit to patients.

Furthermore, the sub- theme *Good Death Failure* suggested that even when participants gave their all, other factors obstructed validation. One such factor was sudden death, with participants finding that when a patient died unexpectedly this left them questioning their role and the care they had provided, threatening the image of the 'good carer'. When this occurred, participants sought confirmation from relatives or colleagues that they had still done a good job, which has been found in previous research (Borbasi, Wotton, Redden, & Chapman, 2005; McNamara et al., 1995; Rasmussen et al., 1997).

Lack of clear prognosis information from GPs and cardiologists, patients dying on acute wards contravening patient preferences, as well as lack of community resources could all conspire against the model of care participants were attempting to deliver. Transactional theories of stress and person- environment fit models emphasise the importance of the interaction between environment and the individual for job satisfaction (Hopkinson et al., 2005; Palmer, 2006; Takase, Kershaw, & Burt, 2001), with a shared value system being key (Brännström et al., 2005). While this appears evident in palliative care and arguably mitigates stress for staff (McNamara et al., 1995), acute care contexts are notably devoid of such a shared cultural understanding (Georges, Grypdonck, & Dierckx De Casterle, 2002; Thompson, McClement, & Daeninck, 2006). Nurses working in acute care sometimes struggle to offer palliative care within a culturally inimical environment (Cronqvist et al, 2004; Davidson et al., 2003), consistent with difficulties articulated

by participants who appeared to experience stress when switching between conflicting models of care (Nordgren & Olsson, 2004; Payne et al., 1998; Plante & Bouchard, 1995).

Menzies Lyth (1960) suggested that when discrepancies occur between the individual and the system, the nurse can no longer be a member of the system, and must find others with whom their values correspond. Within attachment theory, secure bases offer a safe environment (Byng- Hall, 1995; Garrett & McDaniel, 2001; McWilliams, 2004). For participants within the current study, links to a hospice in terms of supervision and advice were appreciated and in this way could offer participants a safe base and an anchor from which they could offer end of life care absent from their own system. They could return to the hospice when difficulties arose or they required containment, advocated within palliative care when nurses working within the community retain links to palliative care teams to avoid isolation (Dunniece & Slevin, 2002; Newton & Waters, 2001). This could be particularly important in helping participants in the current study to continue to care.

5.2 *Clinical Implications*

The current study has emphasised that while HFSNs are keen to be involved in end of life care, taking on such a role has not been without consequences for the HFSNs' themselves, in terms of well- being and ability to provide such care. With a burgeoning agenda for HFSNs to offer end of life care (Blue & Stewart, 2004; DH, 2003; 2004; Healthcare Commission, 2007), the following findings from the current

study suggest certain clinical implications. These may help ensure that HFSNs can offer end of life care without adverse consequence to self.

5.2.1 *Developing competence in end of life care.*

Participants expressed that they had not expected end of life care to form a significant part of their role. It would be recommended that adverts for HFSN posts clearly outline a role at end of life to avoid misconceptions. While participants attended Advanced Communication Courses, they lacked formal training. It is recommended that a formal training course in end of life care for HFSNs is developed and standardised. When new in post, participants expressed that learning to become a specialist and prescriber took precedence. It is recommended that HFSNs new in post spend time shadowing HFSNs with end of life cases, with delay in assigning patients at end of life at first where possible. HFSNs could also be given ongoing mentoring when new in post to help with role transition (Rosser & King, 2003) and understanding what end of life care involves. Such initiatives may help to prevent isolation within the community. Participants also noted that simple things such as lists of local contact numbers and resources for end of life could be helpful when new in post.

5.2.2 *Dealing with and containing emotions.*

Participants appeared reluctant to engage with emotions arising from working with the dying, and had limited access to supervision where they could process emotions safely. Formal, funded links to specialist palliative care services

may be helpful to HFSNs, to offer advice, consultation, as well as individual and peer supervision. This could be valuable in terms of offering a secure base, closure, enabling emotional processing, encouraging work- life balance, and setting realistic targets as opposed to placing high expectations on the self. HFSNs could also feel validated for their role in end of life care with difficulties achieving this validation within their referent context of care. Supervision can be preferable to reliance on informal colleague support, offering a designated space for reflection, and has been identified within palliative care nursing as a key component to maintaining emotional well- being (BPS, 2008; Jones, 2001; McElroy, 1982; McWilliams, 2004; Von Klitzing, 1999). However, it should also be remembered that denial and avoidance can be effective coping mechanisms (Chodoof, 1997; Salamon, 1994) and as such may be adaptive for HFSNs at times, given that caseloads can be demanding with frequent losses.

5.2.3 *Developing a team philosophy.*

The current study testifies to the importance to participants of validation for their role in end of life care, with the referent model of care often undermining satisfaction from their role. Managers may need to be made aware that bereavement visits offer closure (Birtwistle, Payne, Smith, & Kendrick, 2002) and administrative support could help HFSNs to be more effective with time. Targets relating to routine management of cases as opposed to end of life care devalue the HFSNs' work with patients with ESHF and appear to impinge on HFSNs' sense of validation for their role in end of life care. Developing a shared understanding of end of life care with practitioners within acute settings would also be beneficial

(BPS, 2008). Supporting GPs and cardiologists to align more with HFSNs in terms of offering *Certainty and Honesty* to patients in terms of prognosis, would be significant in terms of bridging the two models of care and offering HFSNs a better sense of cohesion between different aspects of their work.

5.3 *Future Research*

The current study offered an initial exploration of HFSNs' experiences of end of life care, as well as beginning to understand the complexities of providing end of life care, its potential impact and emergent need for support. Further research to extend understanding of the unique role HFSNs undertake could be developed within the following areas:

- Further research in other services concerning the experiences of HFSNs in terms of end of life care would be helpful in terms of reinforcing or challenging the findings from the current study.

- Further research to understand whether the maxims of *A Good Death* predominate within other services and whether they make a positive difference to patients' lives would be useful. Both nursing and patient-focused studies could be conducted to enable greater understanding and policy development for end of life care for patients with ESHF.

- Longitudinal or case series research into transition experiences, HFSNs' experiences when new in post and how knowledge is acquired most effectively regarding end of life care would be useful. Finding out what training HFSNs would value when new in post and in terms of ongoing

training needs would also be useful to help start the process of developing nationwide training programmes.

- Further research into the benefits of clinical supervision for HFSNs, and whether this should be provided from those imbued within a palliative care ethos would be useful in understanding the support needs HFSNs require to provide end of life care.

- Further research with other professionals working with patients with ESHF would be enlightening in terms of defining roles and developing pathways for end of life care.

5.4 *Limitations*

The current study employed a self- selecting sample, which may have implications in terms of the findings. Qualitative studies are limited in terms of generalising to other contexts (Smith & Osborn, 2003). However, it would be expected that given the care taken to meet quality measures for qualitative studies (Elliott et al., 1999), the findings could be transferred to other community based heart failure services with HFSNs.

6. References

Ablett, J. R., & Jones, R. S. P. (2007). Resilience and well- being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-Oncology, 16*, 733- 740.

Aldred, H., Gott, M., & Gariballa, S. (2005). Advanced heart failure: Impact on older patients and informal carers. *Journal of Advanced Nursing, 49* (2), 116- 124.

Anderson, J. H. (2007). The impact of using nursing presence in a community heart failure program. *Journal of Cardiovascular Nursing, 22* (2), 89- 94.

Anderson, H., Ward, C., Eardley, A., Gomm, S. A., Connolly, M., Coppinger, T., et al. (2001). The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliative Medicine*, *15*, 279- 286.

Barnard, A., Hollingum, C., & Hartfiel, B. (2006). Going on a journey: Understanding palliative care nursing. *International Journal of Palliative Nursing, 12* (1), 6- 12.

Barthow, C. (1997). Negotiating realistic and mutually sustaining nurse- patient relationships in palliative care. *International Journal of Nursing Practice, 3*, 206- 210.

Bekelman, D. B., Hutt, E., Masoudi, F. A., Kutner, J. S., & Rumsfeld, J. S. (2008). Defining the role of palliative care in older adults with heart failure. *International Journal of Cardiology, 125*, 183- 190.

Bernard, M. F., & Creux, F. (2003). Suffering- A problem that also affects nurses. *European Journal of Palliative Care, 10* (2), 77- 81.

Birtwistle, J., Payne, S., Smith, P., Kendrick, T. (2002). The role of the district nurse in bereavement support. *Journal of Advanced Nursing, 38* (5), 467- 478.

Blue, L. (2004a). Glasgow heart failure liaison service: A model for future services. In S. Stewart & L. Blue (Eds.), *Improving outcomes in chronic heart failure- Specialist nurse intervention from research to practice* (pp. 69- 84). London: BMJ Books.

Blue, L. (2004b). Appendix 1: Profile of the specialist heart failure nurse: Qualifications and training. In S. Stewart & L. Blue (Eds.), *Improving outcomes in chronic heart failure- Specialist nurse intervention from research to practice* (pp. 201- 203). London: BMJ Books.

Blue, L., & McMurray, J. (2005). How much responsibility should heart failure nurses take? *The European Journal of Heart Failure, 7*, 351- 361.

Blue, L., & Stewart, S. (2004). New frontiers in specialist nurse management of

heart failure. In S. Stewart & L. Blue (Eds.), *Improving outcomes in chronic*

heart failure- Specialist nurse intervention from research to practice (pp.

187- 197). London: BMJ Books.

Bolton, S. C. (2001). Changing faces: Nurses as emotional jugglers. *Sociology of*

Health and Illness, 23 (1), 85- 100.

Borbasi, S., Wotton, K., Redden, M., & Chapman, Y. (2005). Letting go: A

qualitative study of acute care and community nurses' perceptions of a

'good' versus a 'bad' death. *Australian Critical Care, 18* (3), 104- 113.

Boyd, K. L., Murray, S. A., Kendall, M., Worth, A., Benton, T. F., & Clausen, H.

(2004). Living with advanced heart failure: A prospective, community-

based study of patients and carers. *The European Journal of Heart Failure,*

6, 585- 591.

Brännström, M., Brulin, C., Norberg, A., Boman, K., & Strandberg, G. (2005).

Being a palliative nurse for persons with severe congestive heart failure in

advanced homecare. *European Journal of Cardiovascular Nursing, 4*, 314-

323.

British Psychological Society (2008). *The role of psychologists in end of life care*.

Leicester: The British Psychological Society.

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of

   interpretative phenomenological analysis (IPA) in health psychology.

   Psychology and Health, 21 (1), 87- 108.

Burman, E. (2001). Interviewing. In P. Banister, E. Burman, I. Parker, M. Taylor &

   C. Tindall (Eds.), *Qualitative methods in psychology. A research guide* (pp.

   49- 71). Buckingham: Open University Press.

Burt, J., Shipman, C., Addington- Hall, J., & White, P. (2008). Nursing the dying

   within a generalist caseload: A focus group study of district nurses.

   International Journal of Nursing Studies, 45, 1470- 1478.

Byng- Hall, J. (1995). *Rewriting family scripts: Improvisation and systems change*.

   Surrey: Guildford Press.

Byrne, D., & McMurray, A. (1997). Caring for the dying: Nurses' experiences in

   hospice care. *Australian Journal of Advanced Nursing*, *15* (1), 4- 11.

Chodoff, P. (1997). The holocaust and its effects on survivors: An overview.

   Political Psychology, 18 (1), 147- 157.

Conner, M., & Norman, P. (1996). The role of social cognitions in health

   behaviours. In: M. Conner, & P. Norman (Eds.), *Predicting health

   behaviour* (pp. 1- 22). Buckingham: Open University Press.

Cronqvist, A., Theorell, T., Burns, T., & Lüzén, K. (2004). Caring about- caring for:

    Moral obligations and work responsibilities in intensive care nursing.

    Nursing Ethics, 11 (1), 63- 76.

Davidson, P., Introna, K., Daly, J., Paull, G., Jarvis, R., Angus, J., et al. (2003).

    Cardiorespiratory nurses' perceptions of palliative care in nonmalignant

    disease: Data for the development of clinical practice. *American Journal of*

    Critical Care, 12 (1), 47- 53.

Davidson, P. M., Paull, G., Introna, K., Cockburn, J., Maree Davis, J., Rees, D., et

    al. (2004). Integrated, collaborative palliative care in heart failure. The St

    George heart failure service experience 1999- 2002. *Journal of*

    Cardiovascular Nursing, *19* (1), 68- 75.

Davidson, P., Paull, G., Rees, D., Daly, J., & Cockburn, J. (2005). Activities of

    home- based heart failure nurse specialists: A modified narrative analysis.

    American Journal of Critical Care, 14 (5), 426- 433.

Davies, R. C., Hobbs, F. D. R., & Lip, G. Y. H. (2000). History and epidemiology.

    In C. R. Gibbs, M. K. Davies & G. Y. H. Lip (Eds.), *ABC of heart failure*

    (pp. 1-4). London: BMJ Books.

Davis, C. G., Nolen- Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology, 75* (2), 561- 574.

Department of Health. (2003). *Developing services for heart failure*. London: Department of Health Publications.

Department of Health. (2004). *Supportive and palliative care for advanced heart failure*. London: Department of Health Publications.

Department of Health. (2005). *The coronary heart disease national service framework. Leading the way. Progress report.* London: Department of Health Publications.

Department of Health. (2006). *Our health, our care, our say: A new direction for community services.* Norwich: The Stationary Office.

Department of Health. (2008). *End of life care strategy. Promoting high quality care for all adults at the end of life.* London: Department of Health Publications.

Dunniece, U., & Slevin, E. (2002). Giving voice to the less articulated knowledge of palliative nursing: An interpretative study. *International Journal of Palliative Nursing, 8* (1), 13- 20.

Ekstedt, M., & Fagerberg, I. (2005). Lived experiences of the time preceding burnout. *Journal of Advanced Nursing, 49* (1), 59- 67.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215- 229.

Field, D., & Addington- Hall, J. (1999). Extending specialist palliative care to all? *Social Science and Medicine, 48*, 1271- 1280.

Flynn, M., Connolly, M., & Booth, K. (2008). Philosophy and principles of supportive and palliative care in heart failure. *British Journal of Cardiac Nursing, 3* (5), 193- 198.

Garrett, D., & McDaniel, A. (2001). A new look at nurse burnout: The effects of environmental uncertainty and social climate. *Journal of Nursing Administration, 31* (2), 91- 96.

Georges, J. J., Grypdonck, M., & Dierckx De Casterle, B. (2002). Being a palliative nurse in an academic hospital: A qualitative study about nurses' perceptions of palliative care nursing. *Journal of Clinical Nursing, 11*, 785- 793.

Gibbs, J. S. R., McCoy, A. S. M., Gibbs, L. M. E., Rogers, A. E., & Addington- Hall, J. M. (2002). Living and dying from heart failure: The role of palliative care. *Heart*, *88*, 36-39.

Gott, M., Barnes, S., Parker, C., Payne, S., Seamark, D., Gariballa, S., et al. (2007). Dying trajectories in heart failure. *Palliative Medicine, 21*, 95- 99.

Grange, J. (2005). The role of nurses in the management of heart failure. *Heart, 91*, 39- 42.

Haverkamp, B. E., & Young, R. A. (2007). Paradigms, purpose, and the role of the literature: Formulating a rationale for qualitative investigations. *The Counseling Psychologist, 35*, 265- 294.

Healthcare Commission (2007). *Pushing the boundaries. Improving services for people with heart failure.* London: Commission for Healthcare Audit and Inspection.

Holland, R., Battersby, J., Harvey, I., Lenaghan, E., Smith, J., & Hay, L. (2005). Systematic review of multidisciplinary interventions in heart failure. *Heart, 91*, 899- 906.

Hopkinson, J. B., Hallett, C. E., & Luker, K. A. (2005). Everyday death: How do nurses cope with caring for dying people in hospital? *International Journal of Nursing Studies, 42*, 125- 133.

Horne, G., & Payne, S. (2004). Removing the boundaries: Palliative care for patients with heart failure. *Palliative Medicine*, *18*, 291- 296.

Jaarsma, T., Abu- Saad, H. H., Halfens, R., & Dracup, K. (1997). 'Maintaining the balance'- Nursing care of patients with chronic heart failure. *International Journal of Nursing Studies, 34* (3), 213- 221.

Jaarsma, T., Strömberg, A., De Geest, S., Fridlund, B., Heikkila, J., Må̊rtensson, J., et al. (2006). Heart failure management programmes in Europe. *European Journal of Cardiovascular Nursing, 5*, 197- 205.

Jackson, D., Firtko, A., & Edenborough, M. (2007). Personal resilience as a strategy for surviving and thriving in the face of workplace adversity: A literature review. *Journal of Advanced Nursing, 60* (1), 1- 9.

Jarman, M., Smith, J. A., & Walsh, S. (1997). The psychological battle for control: A qualitative study of health- care professionals' understandings of the treatment of anorexia nervosa. *Journal of Community and Applied Social Psychology, 7,* 137- 152.

Johnston, B., & Smith, L. N. (2006). Nurses' and patients' perceptions of expert palliative nursing care. *Journal of Advanced Nursing, 54* (6), 700- 709.

Jones, A. (2001). Some experiences of professional practice and beneficial changes derived from clinical supervision by community macmillan nurses. *European Journal of Cancer Care, 10*, 21- 30.

McElroy, A. M. (1982). Burnout- A review of the literature with application to cancer nursing. *Cancer Nursing, June*, 211- 217.

McNamara, B., Waddell, C., & Colvin, M. (1995). Threats to the good death: The cultural context of stress and coping among hospice nurses. *Sociology of Health and Illness, 17* (2), 222- 244.

McVicar, A. (2003). Workplace stress in nursing: A literature review. *Journal of Advanced Nursing, 44* (6), 633- 642.

McWilliams, A. E. (2004). Stress in palliative care. *Progress in Palliative Care, 12* (6), 293- 301.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*, 1- 20.

Marino, P. A. (1998). The effects of cumulative grief in the nurse. *Journal of Intravenous Nursing, 21* (2), 101- 104.

Maykut, P., & Morehouse, R. (1999). *Beginning qualitative research. A philosophical and practical guide*. London: Falmer Press.

Menzies Lyth, I. (1960). Social systems as a defense against anxiety. An empirical study of the nursing service of a general hospital. In: E. Trist, H. Murray, & B. Trist (1990) (Eds.), *The social engagement of social science: A tavistock anthology. Vol 1: The socio- psychological perspective* (pp. 439- 462). Baltimore: University of Pennsylvania Press.

Mok, E., & Chiu, P. C. (2004). Nurse- patient relationships in palliative care. *Journal of Advanced Nursing, 48* (5), 475- 483.

Morrow, S. L. (2007). Qualitative research in counseling psychology: Conceptual foundations. *The Counseling Psychologist, 35*, 209- 235.

Murray, M., & Chamberlain, K. (1999). Health psychology and qualitative research. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology. Theories and methods* (pp. 3- 15). London: Sage.

National Institute for Clinical Excellence. (2003). *Chronic heart failure. Management of chronic heart failure in adults in primary and secondary care*. London: National Institute for Clinical Excellence.

Newton, J., & Waters, V. (2001). Community palliative care clinical nurse specialists' descriptions of stress in their work. *International Journal of Palliative Nursing*, *7* (11), 531- 540.

Nordgren, L., & Olsson, H. (2004). Palliative care in a coronary care unit: A qualitative study of physicians' and nurses' perceptions. *Journal of Clinical Nursing, 13*, 185- 193.

Nordgren, L., & Sörensen, S. (2003). Symptoms experienced in the last six months of life in patients with end- stage heart failure. *European Journal of Cardiovascular Nursing, 2*, 213- 217.

Owens, R. G., & Payne, S. (1999). Qualitative research in the field of death and dying. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology. Theories and methods* (pp. 148- 163). London: Sage.

Palmer, S. (2006). Stress management and prevention programmes. In: R. Woolfe, W. Dryden, & S. Strawbridge (Eds.), *Handbook of counselling psychology* (pp. 572- 591). London: Sage Publications.

Pattenden, J. F., Lewin, R. J. P., Roberts, H., & Miles, J. N. V. (2004). *The british heart foundation heart failure specialist nurse. Evaluation of a new service. April 2002- December 2003.* York: British Heart Foundation Cardiac Care and Education Research Unit, University of York.

Payne, N. (2000). Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing*, *33* (3), 396- 405.

Payne, S. A., Dean, S. J., & Kalus, C. (1998). A comparative study of death anxiety in hospice and emergency nurses. *Journal of Advanced Nursing*, *28* (4), 700- 706.

Plante, A., & Bouchard, L. (1995). Occupational stress, burnout, and professional support in nurses working with dying patients. *Omega: Journal of Death and Dying*, *2*, 93- 109.

Rasmussen, B. H., Sandman, P., & Norberg, A. (1997). Stories of being a hospice nurse: A journey towards finding one's footing. *Cancer Nursing, 20* (5), 330- 341.

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring the lived experience. *The Psychologist, 18* (1), 20- 23.

Rosser, M., & King, L. (2003). Transition experiences of qualified nurses moving into hospice nursing. *Journal of Advanced Nursing, 43* (2), 206- 215.

Ryder, M. (2005). Is heart failure nursing practice at the level of a clinical nurse specialist or advanced nurse practitioner? The irish experience. *European Journal of Cardiovascular Nursing, 4*, 101- 105.

Salamon, M. J. (1994). Denial and acceptance: Coping and defense mechanisms. *Clinical Gerontologist, 14* (3), 17- 25.

Salander, P., & Windahl, G. (1999). Does 'denial' really cover our everyday experiences in clinical oncology? A critical view from a psychoanalytic perspective on the use of 'denial'. *British Journal of Medical Psychology, 72*, 267- 279.

Sandgren, A., Thulesius, H., Fridlund, B., & Petersson, K. (2006). Striving for emotional survival in palliative cancer nursing. *Qualitative Health Research, 16* (1), 79- 96.

Sargeant, A., Payne, S., Seymour, J., & Ingleton, C. (2008). Heart failure nurses' experiences of specialist palliative care. *End of Life Care, 2* (3), 55- 60.

Schwarzer, R., & Fuchs, R. (1996). Self- efficacy and health behaviours. In: M. Conner, & P. Norman (Eds.), *Predicting health behaviour* (pp. 163- 196). Buckingham: Open University Press.

Seymour, J., & Clark, D. (1998). Phenomenological approaches to palliative care research. *Palliative Medicine, 12*, 127- 131.

Shaw, R. (2001). Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update, 10* (4), 48- 52.

Skilbeck, J. K., & Payne, S. (2005). End of life care: A discursive analysis of specialist palliative care nursing. *Journal of Advanced Nursing, 51* (4), 325- 334.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, *11*, 261- 271.

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material discourses and health* (pp. 68- 91). London: Routledge.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 218- 240). London: Sage.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 51- 80). London: Sage.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 53- 80). London: Sage.

Svedlund, M., Danielson, E., & Norberg, A. (1999). Nurses' narrations about caring for inpatients with acute myocardial infarction. *Intensive and Critical Care Nursing, 15*, 34- 43.

Takase, M., Kershaw, E., & Burt, L. (2001). Nurse- environment misfit and nursing practice. *Journal of Advanced Nursing, 35* (6), 819- 826.

Taylor, B., Bulmer, B., Hill, L., Luxford, C., McFarlane, J., Reed, J., & Stirling, K. (2002). Exploring idealism in palliative nursing care through reflective practice and action research. *International Journal of Palliative Nursing, 8* (7), 324- 330.

Taylor, S. E., & Stanton, A. L. (2007). Coping resources, coping processes and mental health. *Annual Review of Clinical Psychology, 3*, 377- 401.

The National Council for Palliative Care (2006). *A national survey of heart failure nurses and their involvement with palliative care services.* London: The National Council for Palliative Care.

Thompson, D. R. (2007). Improving end- of- life care for patients with chronic heart failure. *Heart, 93*, 901- 902.

Thompson, C., Spilsbury, K., Dowding, D., Pattenden, J., & Brownlow, R. (2008). Do heart failure specialist nurses think differently when faced with 'hard' or 'easy' decisions: A judgement analysis. *Journal of Clinical Nursing, 17*, 2174- 2184.

Thompson, G., McClement, S., & Daeninck, P. (2006). Nurses' perceptions of

    quality end- of- life care on an acute medical ward. *Journal of Advanced*

    Nursing, 53 (2), 169- 177.

Thornhill, K., Lyons, A. C., Nouwen, A., & Lip, G. Y. H. (2008). Experiences of

    living with congestive heart failure: A qualitative study. *British Journal of*

    Health Psychology, 13, 155- 175.

Von Klitzing, W. (1999). Evaluation of reflective learning in a psychodynamic

    group of nurses caring for terminally ill patients. *Journal of Advanced*

    Nursing, 30 (5), 1213- 1221.

Ward, C. (2002). The need for palliative care in the management of heart failure.

    Heart, 87, 294- 298.

Webster, J., & Kristjanson, L. J. (2002a). Long- term palliative care workers: More

    than a story of endurance. *Journal of Palliative Medicine, 5* (6), 865- 875.

Webster, J., & Kristjanson, L. J. (2002b). But isn't it depressing? The vitality of

    palliative care. *Journal of Palliative Care, 18* (1), 15- 24.

Wilkes, L. M., & Beale, B. (2001). Palliative care at home: Stress for nurses in

    urban and rural new south wales, australia. *International Journal of Nursing*

    Practice, *7*, 306- 313.

Willig, C. (2005). *Introducing qualitative research in psychology. Adventures in theory and method.* Berkshire: Open University Press.

Willig, C. (2008). *Introducing qualitative research in psychology. Adventures in theory and method. Second edition.* Berkshire: Open University Press.

Wilson, M. H. (2008). "There's just something about ron": One nurse's healing presence amidst failing hearts. *Journal of Holistic Nursing, 26* (4), 303- 307.

Wotton, K., Borbasi, S., & Redden, M. (2005). When all else has failed. Nurses' perceptions of factors influencing palliative care for patients with end- stage heart failure. *Journal of Cardiovascular Nursing, 20* (1), 18- 25.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 235- 251). London: Sage.

Zambroski, C. H. (2006). Managing beyond an uncertain illness trajectory: Palliative care in advanced heart failure. *International Journal of Palliative Nursing, 12* (12), 566- 573.

Critical Appraisal

1. Background to Study

I had limited knowledge of heart failure prior to commencing the research, but did have clinical interests within health psychology, and a supervisor within the department suggested that research within the area of heart failure would be timely. My research supervisor wanted to aim a research project towards HFSNs, as she had noticed that there were clear gaps within the literature, and had been curious within her own clinical work about the role of the HFSN in cardiac care and whether palliation would be something they would be able to offer without consequence to the self. When scoping the literature base, clear gaps within the literature did emerge, relating to the experiences of HFSNs and their role in end of life care.

When reading about the area I was struck by the inequities of palliative care provision for non- malignant patient groups, and watched a video about the discrepancies within patient care between patients with cancer and heart failure. This was a particularly significant experience for me, as I had not realised the difficult lives patients with heart failure experienced, and the lack of resources they had available to them to live decently and comfortably until death. It held particular resonance for me when I reflected upon my grandmother's death. She had been nursed within the home, and had all manner of resources and opportunities for palliation available to her as a cancer sufferer. She had also died at home, peacefully and with her family present. It felt wrong to me that someone else, albeit with a different condition, could have a totally different experience towards end of

life. One of my own personal values is a belief in fairness, and I felt that this was decidedly unfair. Thus, my interest within the topic area grew and I could not wait to get started.

2. Study Design

A qualitative design was felt to be appropriate for the current study. However, there were a variety of methodologies to consider and after reading about the potential of different methodologies, both IPA and Grounded Theory could have been appropriate for the current study. IPA and Grounded Theory appeared to share characteristics such as understanding a participants' view of the world, theme development, and constant comparison (Willig, 2008). Grounded Theory also had a particular strength, in that it could be used to develop a theory (Charmaz, 2003), which appeared to confer particular advantage given that the research area was new and the consequent theory could have been applied to other services.

However, I did not favour the notion of bracketing theory and reflexive position (Charmaz, 2003). I did not feel that this would be possible, and felt that separating oneself from the research would not be something I would be able to do. I also started to wonder about theory development, and whether this was a priority for me. Upon discussion with my research supervisor as well as debate as part of the peer review process, I came to the position that I was more interested in finding out experiences as opposed to developing a theory. I felt that rather than wanting to explain by adopting a theory, I wanted to be able to describe experiences. I also found that I started to question whether techniques such as theoretical sampling and

saturation (Willig, 2008) were appropriate, as the research was going to be focused upon a homogenous group of nurses, who had been purposefully chosen to take part in the research and offer their experiences of a phenomenon. The more I read about IPA, the more I felt that the aims of the research fitted more closely with an idiographic approach, concentrating on each person's subjective experience, and trying to understand the phenomenon (Smith & Osborn, 2003). Given that HFSNs' voices were unheard within the literature, I felt it was important to stay with understanding the experiences of this group of nurses. I wanted to know what it was like to be a HFSN, and what it meant to be a HFSN working with the dying, and felt that this could be accessed using IPA. I also felt that IPA valued flexibility, and would enable me to follow the stories of the participants, which would be important given this was a new area without pre- conceived ideas about what might be found.

3. Ethical Approval

Applying for ethical approval was a new experience for me. I have learnt new skills in terms of how to make an application, consideration of ethical issues, and attendance of an ethics panel. Local R&D approval created a delay which I had not anticipated. The timetables of R&D approval did not appear to cater for the limited timescales of the DClinPsy thesis. I have learned that applying well in advance is particularly important. I was also interested by the different requirements for the separate R&D departments, with one R&D department requiring me to attend a basic training course in ethical issues as part of the process. Interestingly, medics do not have to attend this course. Given our therapeutic and research backgrounds, mandatory attendance for our profession may not be appropriate. I

have since reflected upon the place of clinical psychologists within the NHS, and the potential for lack of understanding of our capabilities as professionals. I wondered whether we promote our skill base enough to our healthcare colleagues.

4. Recruitment

Recruitment was more difficult than I had anticipated. Two monthly team meetings used to recruit were cancelled at the last minute. This created delay as I had to inform the relevant ethical committees of my intention to post the information packs. In the future, I would try and protect myself more by including alternative methods of recruitment within the original ethics application, so that back- up plans for alternative methods of recruitment have already been agreed and can be carried out without delay. In future, I would also think carefully about who I am relying on to help with recruitment, and try and ensure that my reliance on others is minimal.

The service consisted of twelve HFSNs, however two HFSNs were off long-term from work at the time of recruitment. Six took part, appropriate for an IPA study (Smith & Osborn, 2003). I felt that having a small sample size was favourable, for this gave me appropriate time to spend with each transcript. I also noticed that I could hold each interview in mind during analysis, thinking about the connections between the transcript I was analysing at the time and other interviews. When using qualitative methodologies in the future I would feel more confident in pursuing studies where sample sizes may be considered small, and have altered my perceptions about the primary importance of representation within research.

Sometimes it can be rewarding and useful to concentrate on small numbers of participants.

5. Designing the Interview Schedule

Developing the interview schedule was a long process. I felt that I wanted to provide a structure to the interviews, so that each participant would be asked similar topic areas, in- keeping with Maykut and Morehouse (1999). Although the aims of the research were clear to me, I agonised over the questions used to cover each aim. I spent time drawing together the literature I had read, my discussions with both research and field supervisors, and my experiences of shadowing two members of the service, as well as other examples of interview schedules, and began drawing something together. It was difficult to decide on the final number of questions and also to ensure that questions had appropriate openness, flexibility, and depth.

I also noticed in earlier drafts that I was asking leading questions, highlighted by Smith and Osborn (2003) as a potential difficulty. Taking out such pre- conceptions helped to offer participants the opportunity to guide the interview. I tried to ensure that I had developed prompts. However in practice I found that I barely used them. It was an interesting process, and I found that although I had read guides on developing interview schedules, I felt that in the end I followed my own instincts and ideas of what I wanted to achieve during the interview rather than thinking too technically, for when I did I felt it constrained my creativity with the schedule.

6. Interview Process

Interviewing was an enjoyable yet exhausting process. I had anxieties prior to the interviews about whether I would gather enough data for a 'rich' analysis. I was also anxious over whether participants would talk for an hour. The first two interviews were used to pilot the schedule, and no alterations were felt to be necessary. Initially, I felt when interviewing that I did not know how much to direct the interview and keep to the schedule. Smith and Osborn (2008) suggest that the researcher needs to decide beforehand how much movement from the schedule would be permissible, but I don't think that I actually had a real sense beforehand of what I would do. Within the first few interviews I felt that I leaned towards trying to cover the schedule. I reflected in my research diary that I needed to get a "balance struck between asking all the questions and still ensuring the participant told their story".

Following the first two interviews I did not feel as pressured to stick to the schedule, and also found that I had a template in my mind of the topic areas on the schedule, so I did not need to physically refer to it. I found this improved the flow of the consequent interviews. I felt I was more able in later interviews to let the participant lead their own story telling, and felt confident that valuable information would result. I also found that participants only needed a nudge to start talking and could use the space well. Smith, Flowers and Osborn (1997) talk of the importance of a "one- sided conversation" (p. 86), where the researcher does not say much in order that the participant can tell their story. This would contrast to a therapeutic

interview, where the therapist may interject at times and help to guide the content and structure of the session. I have learned the importance of viewing interview schedules as an aid and not a rigid set of guidelines.

In addition, I found that running interviews back to back was not helpful as it became difficult to concentrate on the individual's story within the second interview, as I seemed to recall things said within the first interview and found myself pursuing similar angles. Interestingly, within my therapeutic work experience has taught me to try and have space between sessions where possible. Upon reflection, I wondered whether when conducting the research I placed my clinical experience to one side, while actually the two processes do mirror one another at certain points. I have learned that skills developed as a clinician can be applied to the research setting and do not have to be seen as distinct entities.

During the interview process, I also found that even though I had specified in the information pack and when I confirmed the interview how long the interviews would last, on the day of the interview many of the participants constrained the time they could meet for. This can be viewed as a difficulty when interviewing clinicians, who may have demands placed upon them which are out of their control. Perhaps interviewing out of office hours may have formed advantage in providing a longer time frame for the interview, however this could have impacted on participants' willingness to take part.

7. Analysis of Interviews

Transcribing interviews was an interesting process in terms of learning about the way in which I interviewed. During transcription I noticed how sometimes I asked long, convoluted questions, which I have since tried to reflect upon within my clinical work, and I have endeavoured to monitor the ways in which I phrase questions during sessions. The transcription process made analysis easier for me, as I could recall the content of the transcripts during analysis, remembering certain quotes I had found significant, or the ways in which things were said. For example, when developing the theme *Just Dealing with It*, I remembered back to transcribing and being surprised by how long participants had paused when asked how working with the dying had affected them and how they had avoided this line of questioning. In future, I will endeavour to transcribe my own data, where this is possible.

With limited knowledge and experience of qualitative methodologies, the prospect of analysing interviews daunted me. I also recalled the teaching we had had on qualitative analysis and from a course I had attended on IPA which suggested that a good analysis would rely on the richness of the interview data. While I felt that I had some rich data, that confidence left me when I sat down to analyse my first transcript. I felt that I was unsure about what was important, how much detail to go into, whether to analyse line by line, and all the time felt there was a burden to make the right hand codes interpretative and psychological.

Perhaps the burden to be psychological was particularly pronounced given my role as a trainee clinical psychologist.

During the analysis, I felt that there was not much written upon IPA to draw from during analysis, and felt I needed a 'how- to' guide. My difficulties regarding the need to follow guides when writing my interview schedule and a guide for IPA analysis have some parallels with my journey as a trainee clinical psychologist over the three years. When new to something, I have realised that I am often in search of guidelines for how to do things. When I first came onto the course I was always in search of 'how- to' guides for therapy, and would make long, detailed session plans, which I tried to stick to during sessions and felt uncomfortable when a client wanted to move away from the plans I had made. However, with clinical experience I have been able to stop searching for such a guide, and appreciate the client sat in front of me, their own agenda, and how 'being with' the client is essential not only for rapport but also to gain an understanding of that persons' world.

Indeed, the more I engaged with the analysis, the more thoughts about the 'right' way to analyse the data left me. I also came to view the guidance on IPA analysis as constraining at times. For example, I constructed a table to cluster themes because the guidelines suggested to, however I did not find that I gained much from constructing the table. I had a growing sense that IPA could be adapted to the requirements of the researcher and the research itself and that there was no single way to carry out the analysis. The analysis became encapsulating once underway, and I felt I was a detective trying to make sense of the material,

searching for leads in terms of possible themes. I have also learned the value of holding back on urges to press on past the initial coding stages, as it felt important to stay with the transcripts before moving onto theme tables.

There was a sense in which developing a theme table following P1 may have impacted upon the final themes chosen. I did notice that when choosing quotes I often went back to P1. However this may have been due to other factors, such as P1 being more articulate or capturing more of the essence of the phenomenon. However, I did not feel that I could have placed each transcript completely aside and start afresh with the next transcript, which is the other technique for IPA analysis (Smith & Osborn, 2003). Once I had analysed a transcript I did not feel that it left me. Moreover, themes are not supposed to be chosen based on the number of participants supporting that theme (Smith & Osborn, 2003). However, in practice this was difficult at times due to the frameworks of representation and generalisation I am used to operating from.

The process of writing was particularly difficult in terms of deciding on a master theme list, merging previous themes, and trying to write a coherent story within tight word limits. At times, it felt as though the individual stories of the participants became lost, and I remember re- drafting my initial Analysis of Data section because there appeared to be distance between myself and the participants' stories, due to constraints of word limits. I also re- worded some of the theme titles as I realised that I had almost tried to intellectualise the titles, which removed the participant's own words and indeed my own interpretative phrases from the list of themes.

Throughout the research process, but most especially while analysing transcripts, two members of the qualitative support group became important to me. They helped me to understand the different stages of analysis, and talking over theme development with them helped to shape the master list of themes, and was something I felt I would have struggled to do totally alone. Being close to your own analysis, it helps to have outsiders to question your interpretation and ideas. In future, I would continue to ensure access to independent researchers to discuss theme development and analysis when conducting qualitative research.

8. Reflexivity

Use of the research diary became an important tool in terms of monitoring reflexivity throughout the research process. When reflecting back on the entries within the research diary, there were entries which resonated with the master list of themes. Throughout the diary I have found reflections upon how HFSNs fitted within a medical, acute model, how participants appeared to be well respected by patients and relatives, how they appeared to hold status as specialists, how they acted professionally at all times, and the tensions between their acute referent model of care and the care they were trying to offer within the community. When shadowing I reflected how their role appeared to be about "monitoring and mending", and remarked "everything was geared towards making things stable". Entries prior to the interviews talked about whether the participants would be able to use the interview space given that "reflection and introspection may be alien to them". Following an interview, I also reflected within my diary about feeling

"coldness" from one of the participants, reflecting upon the control the participant had over the interview, and how the participant avoided talking about emotions.

Another thread I have found within the research diary related to feelings I had of being intimated, viewing the participants as confident, mature professionals. For example I noted being in awe of the "passion, commitment and drive" of the participants. I felt in comparison that I was younger, junior within my own profession, with less confidence in my abilities to do my job. This was not an unfamiliar experience for me, as during training I have often felt a lack of confidence in my abilities clinically and academically, and supervisors have commented that I tend to undersell my abilities. Such perceptions may have created a dynamic which affected the process of the interviews as well as the analysis.

Overall, I have definitely felt that my position as a researcher and therapist have impacted upon the research process. It would have been impossible to separate my preconceptions, and developing conceptions from the analysis. There was also a sense during the process that I had altered my views about the topic area. I have found myself feeling angry towards coverage of cancer within the news and other media, wondering why heart failure does not get the same amount of attention. I have also found myself questioning the NHS in terms of ongoing support for professionals, and also the damage that activity and target monitoring can have upon professionals working within the organisation.

In future, I will continue to make use of research diaries, due to the influence this can have over the process and analysis. It felt clear to me that a

different researcher may have brought other factors to the interviews and analysis, and thus developed alternative findings (Brocki & Wearden, 2006). This is really interesting, and suggests the need for quality measures within research. Also, given my developing conceptions upon HFSNs and heart failure, any piece of research I move onto with a similar sample or indeed nurses in general, has now been influenced by my knowledge gained from the current study. This is fascinating when thinking about experienced researchers who publish, and in future I will consider the reflexive position of the researcher when reading published work.

9. Epistemological Position

At the end of the process I have retained my critical realist position, and felt confident that the data produced was a good reflection of the phenomenon and what experiences the participants have had. However, I was also conscious of the co-construction of data between the participants and myself as researcher (Smith et al., 1997). My reflexive position for example may have affected the data that was constructed.

There were also certain points which suggested that the participants themselves had decided upon the content they shared with me, and thus there could be limitations regarding whether the data accurately reflects the phenomenon. For example, often participants would refer to me as a student, which to me has a different connotation to being a trainee clinical psychologist. They may have not felt safe enough to reveal certain aspects of their emotional experiences to a 'student' and this may have therefore accounted for some of the denial during the

interviews. I was also an outsider to the service, which may have affected the interview material. The Dictaphone also created barriers at times. One participant talked freely when I turned the Dictaphone off at the end of the interview, and I asked to put it back on again to capture what was being said. The field supervisor works closely with the participants, and there were times during the interviews where participants expressed that they would be identified and thus they may have been conscious of what they were saying on tape. One participant commented that they would have said more if they were not on tape.

Furthermore, a participant expressed that they did not want to see the transcript in case they could see any points where they had not been professional, suggesting that remaining professional was of concern. There was also a participant who appeared to use the interview as an opportunity to vent some frustrations about organisational issues, which could question how much participants use interviews as an opportunity for their own gain. One participant also asked me whether they were saying the "right" sorts of things during the interview, which again suggests a dynamic where participants may have selected the information shared based on what they thought I wanted to hear.

Thus, as a whole, there were certain points during the research where participants may well have selected the amount and type of information they shared with me, and therefore questions whether the interviews reflected the phenomenon under investigation. Indeed, Willig (2008) suggests that one of the limitations of IPA could be the reliance on the "representational validity of language" (p. 66), in that the words used to describe an event may be carefully chosen, and the same

event could be described in a number of ways, thus limiting the extent to which the account tells us something about the experience.

10. Quality Measures

When I wrote my literature review, I became familiar with critiquing qualitative literature and thinking about methodological flaws within qualitative work. As such, I was keen within my own research to ensure that I included quality measures so that I could monitor the quality of my research, to help to ensure that the findings would be transferable and publishable. On the whole, I felt that each aspect of Elliot, Fischer, and Rennie's (1999) guidelines were adhered to. I did find 'Situating the Sample' difficult, in that to protect the identity of the service and individuals that took part, I felt my ability to describe demographics was compromised. 'Grounding in Examples' was also difficult due to the word limits for the section. I felt that 'Providing Credibility Checks' and 'Resonating with Readers' were particularly important, and I made good use of supervision and sessions with colleagues from the qualitative support group to help me to become confident in my analysis. I will continue to use quality measures in the future when completing qualitative research.

11. Concluding Remarks

Overall, I have thoroughly enjoyed conducting this research project, and hope that I have empowered a group of HFSNs to have their voices and opinions heard and am very keen on trying to get the research known within the locality, but also within the wider research community. I have learnt a lot as a researcher, which will be of use to me within future projects, and I have also been surprised that some aspects of being a researcher can be taken back into therapeutic practice also. Thinking about my next step to becoming newly qualified, I have come to a different standpoint regarding research. Before conducting the research I did not have much interest within research post- qualification. However, I have been mindful during our teaching this year and core competencies upon placement that skills such as leadership and research will be important skills to be able to offer in terms of being unique, and that therapy will not become the primary focus of my career within the NHS. I have come to appreciate that any additional skills I can offer will be very important, and research may well become something I would like to pursue as an additional skill that I can offer as a clinical psychologist.

12. References

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21* (1), 87- 108.

Charmaz, K. (2003). Grounded theory. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 81- 110). London: Sage.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215- 229.

Maykut, P., & Morehouse, R. (1999). *Beginning qualitative research. A philosophical and practical guide*. London: Falmer Press.

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (Ed.), *Material discourses and health* (pp. 68- 91). London: Routledge.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 51- 80). London: Sage.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology. A practical guide to research methods* (pp. 53- 80). London: Sage.

Willig, C. (2008). *Introducing qualitative research in psychology. Adventures in theory and method. Second edition.* Berkshire: Open University Press.

Appendices

Appendix A

Journal Guidelines

Review Papers

Journal of Advanced Nursing publishes high quality traditional literature reviews, aggregative and interpretive reviews, qualitative, quantitative and mixed method systematic reviews, meta-analyses, meta-summaries and meta-syntheses.

Review papers should not exceed 5000 words for the main text, excluding the abstract, summary statement, tables and references.

The following headings should be used:

- **Title**
  Should end with a descriptor that best describes the type of review, such as: literature review, qualitative, quantitative or mixed method systematic review, meta-summary, meta-synthesis or meta-analysis.
- **Abstract**
  The 250 word abstract should use the following headings: Aims (of the paper), Background, Data Sources, Review Methods, Results, Conclusion.
- **Summary Statement**
  Please see the **Summary Statement guidelines** for further information.
- **Keywords**
  Should include 'literature review' and other MeSH headings appropriate for the specific review, such as 'systematic review', as well as subject-specific keywords.

Introduction

As for empirical papers – should include rationale, conceptual or theoretical context, international relevance of topic.

The Review

Aim/s

- Of the review
- Include research topic/ objectives / questions / hypothesis(es)
  For example, *"The aim of the (type) review was to…"*

Design

Should identify type of review, methods used and sources of reference, such as the Cochrane Handbook, Centre for Reviews and Dissemination Handbook, EPPI approach, Joanna Briggs Institute approach, or other rigorous systematic review methodological approach.

Should identify and adhere to relevant gold standards for the reporting and conduct of systematic reviews such as the QUOROM statement for meta-analyses of RCTs (see **http://www.consort-statement.org/?o=1065**) or, for example, ESRC guidance on Narrative Synthesis.

Search methods

Should include: search strategy, inclusion/exclusion criteria, databases searched, keywords, languages and inclusive dates of the literature searched.

Search outcome

Search outcome and audit trail if appropriate - application of inclusion/exclusion criteria, retrieval and selection of references and handling. Summarise included and, if appropriate, excluded studies in separate tables.

Quality appraisal

Should include approaches used and audit of discarded studies. For qualitative and traditional reviews, include a statement as to whether included studies were quality appraised or not and a supporting rationale.

Data abstraction

Systematic reviews should include a description of the process(es).

Synthesis

Should include description of process(es) used.

Results

With appropriate **subheadings** and should adhere to the relevant standard(s) of reporting (eg QUOROM statement for systematic review of RCTs).

Where appropriate, identify the conceptual or theoretical context of each definition or discussion of the concept found in the literature.

Discussion

Start with limitations and strength of the evidence.

Draw out the applicability, theoretical and practical implications of the findings.

Conclusion

Real conclusions, not just a summary/repetition of the findings.

Recommendations for practice/research/education/management as appropriate, and consistent with the limitations.

Where appropriate, consider whether one or more nursing conceptual or theoretical frameworks could guide future research about the topic of the review.

Links to useful resources

(Links open in a new window)

- Moher D, Cook DJ, Eastwood S, Olkin I, Rennie D, Stroup DF, for the QUOROM Group.
  Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. Lancet 1999; 354:1896-1900. **www.thelancet.com**

- Popay J, Roen, K, Sowden A, Rodgers M, Roberts H, Arai L, Pettigrew M. Baldwin S. (2006)
  Developing Methods for the Narrative Synthesis of Quantitative and Qualitative Data in Systematic Reviews of Effectiveness. ESRC Research Methods Programme. **http://www.ccsr.ac.uk/methods/projects/posters/popay.shtml**
- Centre for Reviews and Dissemination - **http://www.york.ac.uk/inst/crd/**
- Cochrane Collaboration – **http://www.cochrane.org/**
- EPPI Centre - **http://eppi.ioe.ac.uk/cms/**
- Joanna Briggs Institute - **www.joannabriggs.edu.au**
- National Institute for health and Clinical Excellence - **www.nice.org.uk/**
- Social Care Institute for Excellence - **www.scie.org.uk**
- Journal of Advanced Nursing - **Guidelines for reporting clinical trials**

Guidelines for References

How should I present my references?

- References within the text should cite the authors' names followed by the date of publication, in date order, e.g. (Lewis 1975, Barnett 1992, Chalmers 1994). Where there are more than two authors, the first name followed by et al. will suffice, e.g. (Barder et al. 1994), but all authors should be cited in the reference list. Page numbers should be given in the text for all quotations, e.g. (Chalmers 1994, p. 7). All references should be cited from primary sources.
- References follow the Harvard style, i.e. they are listed in alphabetical order of first authors' names.
- References in Articles: We recommend the use of a tool such as **EndNote** or **Reference Manager** for reference management and formatting.

  EndNote reference styles can be searched for here:
  http://www.endnote.com/support/enstyles.asp

  Reference Manager reference styles can be searched for here:
  http://www.refman.com/support/rmstyles.asp

- The reference list should include all cited authors' surnames and initials, date of publication, title of paper, name of journal in full, volume number (and issue number where volume pages do not run on), and first and last page number.
- When a book is cited, the title should be stated, followed by the publisher and town, county/state (and country if necessary) of publication, and first and last page numbers.
- Where a chapter in an edited book is cited, details of author and editors should be given as well as publisher, place of publication, and first and last page numbers. The edition (where appropriate) of all books should be identified.
- References stated as being 'in press' are only acceptable if accompanied by proof of acceptance.
- We encourage you to refer to existing literature published in JAN.

See also **http://www.nurseauthoreditor.com/article.asp?id=61**. Please note that you will need to register with the site to view the article

Taken from:

http://www.journalofadvancednursing.com/default.asp?file=authorguidelines

<u>Appendix B</u>

<u>Introductory Letter</u>

University *of* Leicester

Date:

Re: Research Opportunity
                <u>Experiences of Heart Failure Specialist Nurses</u>
                <u>Working with Patients with End Stage Heart Failure</u>

As part of my training at Leicester University to become a Clinical Psychologist, I am planning to conduct some research with Heart Failure Specialist Nurses within xxxxx.

I am interested in hearing the experiences of Heart Failure Specialist Nurses regarding the role of Heart Failure Specialist Nurses in end of life care.

I am writing to you to invite you to take part in this research. Enclosed is an Information Sheet, which describes what the research would involve. I would be extremely grateful if you could read the information and consider taking part.

The results from the research will help to address the lack of research in the area of Heart Failure Specialist Nurses caring for end of life patients. The research will help to increase our understanding of the unique role that Heart Failure Specialist Nurses play in the care of their patients, and the strengths and challenges of the role.

Participation is entirely voluntary. If you would like to take part, then please complete the reply slip attached and send it to me in the pre- paid envelope provided. If you do not want to take part, it would be helpful if you could indicate this on the Reply Slip and send it back to me. It would be helpful if you could return the reply slip by (*two weeks from the date of the letter*).

If you would like to speak to me about the research then please leave me a message at the university on 0116 223 1639, and I will return your call. Alternatively, you can email me: **lmc30@le.ac.uk** and I will get back to you.

Thank you for your time, and I look forward to hearing from you soon.

Yours sincerely,
Lynnette Clarke
Trainee Clinical Psychologist
School of Psychology- Clinical Section
University of Leicester
104 Regent Road
Leicester
LE1 7LT

Version 3- Page 1 of 1- 06/11/2008

Appendix C

Information Sheet

University of Leicester

Contact: Lynnette Clarke (Trainee Clinical Psychologist)
School of Psychology- Clinical Section, University of Leicester, 104 Regent Road, Leicester, LE1 7LT. Messages can be left for me on 0116 223 1639. Email: lmc30@le.ac.uk

Information Sheet

What are the Experiences of Heart Failure Specialist Nurses Working with Patients with End Stage Heart Failure?

This Information Sheet has been designed to answer some of the questions you may have before deciding whether or not you would like to participate in the above research. If you would like further information then please contact me using the details above. Please complete the Reply Slip to indicate whether or not you would like to take part and return this to me in the pre- paid envelope. You are free to change your mind at any time. Thank you for reading the Information Sheet.

Who is conducting the study?

My name is Lynnette Clarke. I am a Trainee Clinical Psychologist at the University of Leicester, employed by the Leicestershire NHS Partnership Trust.

This study will be written up as part of my Doctorate in Clinical Psychology. I will be supervised by Dr. Noelle Robertson (Consultant Clinical Psychologist and Research Supervisor) and Dr. xxxxxxx (Consultant Physician and Field Supervisor).

What is the purpose of the study?

I am interested in finding out the experiences of Heart Failure Specialist Nurses who are caring for patients with end stage heart failure, and patients that have died. This research will help to increase our understanding of the unique role that Heart Failure Specialist Nurses play in the care of their patients, and the strengths and challenges of the role.

Why have I been chosen?

I am looking to involve all of the nurses that make up the xxxxxxx Heart Failure Service.

What will be involved if I take part in the study?

Before the interview you will be asked to sign a consent form and asked for some basic demographic information. The interview will take place at a convenient time and place, and last up to ninety minutes. I will follow a set of questions, but it is up to you which questions you answer and you can bring up topics that interest you too. I will record your interview on a Dictaphone.

Following the interview, I will identify themes within the interviews, and write these up as a thesis. The results will then be fed back to those who took part in the interviews and the service. I will also aim to get the results published in an academic journal and identify conferences where the results could be presented.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to take part. If you decide to take part I will contact you and arrange an interview time and venue that are convenient to you. You will be asked to sign a consent form before being interviewed.

If you decide to take part you can still withdraw from the study at any point without giving a reason. A decision to withdraw, or not to take part, will not affect the conditions of your employment.

Will information obtained in the study be confidential?

Throughout the research process, your identity will remain anonymous. All participants will be given a number, for example participant one, and will be referred to by this number in the thesis. If another person's name is mentioned during the interview, their name will be given a pseudonym in the transcript. Direct quotes may be used in the thesis. If I decide to use a quote from your interview I will contact you to check you are happy for me to do this, and that you cannot be identified from the quote. My Research Supervisor, Field Supervisor, and fellow Trainee Clinical Psychologists may want to look over the transcript from the interviews, to help me with writing the report. All transcripts will have been labelled numerically and pseudonyms given to names mentioned in the transcript when this occurs.

The interview recording will be labelled numerically in order of interview, and saved onto compact disc (CD) and computer file, the file being password protected. The transcription file will also be password protected and labelled numerically. All data and identifiable information such as Consent Forms, will be stored in a locked cabinet at the University of Leicester in a locked cupboard when not in use. All data will be destroyed five years after the research has taken place.

If, during the interview, I am concerned about anyone's safety or practice, then I have a duty to act on this and may need to disclose your identity to my Research Supervisor. I will be able to let you know if I need to do this.

What happens if I do not wish to participate in this study or wish to withdraw from the study?

If you do not want to take part then please indicate this on the reply slip and return it to me. I will not contact you again. If you decide to take part, but later decide not to take part, then I will not use any information collected up to that point, and I will destroy the information. You are free to withdraw from the study at any point, and I do not need a reason for your withdrawal.

What are the possible disadvantages and risks of taking part?

You will be involved in an interview where you can choose which questions you want to answer, and how much information you want to share with me. During the interview, there is a possibility that you may become emotionally affected due to the subjects we are talking about. If this happens, we will take a break in the interview, and may even stop the interview. You may wish to withdraw at this point.

I will have a short de- brief with you following the interview. Dr. Robertson is a Consultant Clinical Psychologist, and will be available to offer extra support to anyone that would like this. The Occupational Health and Counselling Services could also be contacted.

What happens if something goes wrong?

If you have reason to complain about any aspect of the study, the NHS complaints mechanisms are available to you. In addition, this research is subject to normal reimbursement if something goes wrong. You may also contact my Research Supervisor, Dr Noelle Robertson, at the University on 0116 223 1639, or Field Supervisor, xxxxx, at xxxx on 0xxxxx.

What are the possible benefits from taking part?

There are no direct benefits from taking part. However, the opportunity for a de-brief with me, a Trainee Clinical Psychologist, following the interview, and also continued support from Dr Robertson, Consultant Clinical Psychologist following the interview offers a benefit to the study.

The research provides you with an opportunity to share your experiences of being a Heart Failure Specialist Nurse. This may help to improve services or the training and support offered to nurses. Taking part will also help to add to the scientific literature around Heart Failure Specialist Nurses and patients with end stage heart failure.

What will happen to the results of this study?

The results will be written up and submitted as my thesis for the Doctorate in Clinical Psychology. A copy of the thesis will be stored at the University of Leicester. The results will be written up as an executive summary, and circulated to those who took part in the research and also to the service. I will also attend team meetings to present the findings. The research will also be submitted to scientific journals, the British Heart Foundation, and presented at conferences.

Who is organising and funding the research?

The research is organised and funded by the University of Leicester and Leicestershire NHS Partnership Trust.

Has the study been approved?
Yes. This study has been approved by the initial research panel organised by the University of Leicester, my Research Supervisor, plus formal peer review. The study has also been approved by xxxxxxx Research Ethics Committee.

Appendix D

Reply Slip

University *of* Leicester

Reply Slip

What are the Experiences of Heart Failure Specialist Nurses Working with Patients with End Stage Heart Failure?

- I am *interested/ not interested* in taking part in the above research (Please delete as appropriate).

    If you *are* interested in taking part please complete the following:

- I give my permission for Lynnette Clarke (Trainee Clinical Psychologist) to contact me to arrange an interview.

- I understand that taking part in the study is voluntary.

Name……………………………………….................

Daytime telephone number…………………………………………………….

Work telephone number (if different)……………………………………….

Date………………………………..

Version 3- Page 1 of 1- 06/11/2008

Appendix E

Consent Form

University *of* Leicester

School of Psychology

DClinPsy

Consent Form

What are the Experiences of Heart Failure Specialist Nurses Working with Patients with End Stage Heart Failure?

Interviewer: Lynnette Clarke (Trainee Clinical Psychologist)
School of Psychology- Clinical Section, University of Leicester, 104 Regent Road, Leicester, LE1 7LT

Thank you for agreeing to take part in my research. Please read this consent form, and ask any questions you would like to about the research. If you would still like to take part in the research, please sign the form.

Consent

- I have read the Information Sheet (Version 3, 06/11/08) and I have had the opportunity to ask questions.

- I understand that my participation is voluntary and that I can withdraw from the study at any point, without giving a reason.

- I understand that I will be interviewed, and that the interview will be recorded using a Dictaphone, and will be transcribed.

- I understand that my identity will remain anonymous throughout the study and that if quotes are used from my interview, that my identity and the identities of others I may mention will remain anonymous.

- I understand that if the interviewer is concerned about anyone's safety or practice during the interview, that the interviewer has a duty to break confidentiality.

- I understand that data from the interview will be kept securely at the university, and destroyed after five years by fire.

- I understand that my interview will be written up as part of a thesis, and the results will be published in academic journals, and fed back to participants and the service.

- **I agree to take part in this study.**

…………………………   …...…………………………..   ……………

Participant's signature   **Name of participant**   **Date**

I confirm that I have explained the nature of this study, as detailed in the Information Sheet, and it is my judgement that the participant has understood what is involved in participation.

…………………………   …...…………………………..   ……………

Researcher's signature   **Name of researcher**   **Date**

Appendix F

Demographic Information Sheet

Experiences of Heart Failure Nurses- Demographic Information Sheet

University of Leicester

Demographic Information Sheet

Before commencing with the interview, please answer the following questions. The purpose of asking these questions is so that in the introduction to the research report, a summary of the demographics of those who took part in the research can be given.

1. Into which age band do you fall?

   - Teens and Twenties ☐
   - Thirties ☐
   - Forties ☐
   - Fifties ☐
   - Sixties ☐

2. How many years have you been in the nursing profession?

   - Under five years ☐
   - Between six and ten years ☐
   - Between eleven and twenty years ☐
   - Between twenty- one and thirty years ☐
   - Over thirty years ☐

3. What other contexts have you worked in other than your current post?

   …………………………………………………………………………………

   ………………………………………………………………………………

4. How many years have you been working specialising with patients with heart failure?

   …………………………………………………………………………………

Version 2- Page 1 of 1- 13/06/2008

<u>Appendix G</u>

<u>Interview Schedule</u>

Experiences of Heart Failure Nurses- Interview Schedule

Interview Schedule

The participant will be welcomed to the interview, and the participant will be informed that the interview can last up to ninety minutes, and that will show the participant the recording equipment and inform the participant when this is switched on. The participant will be reminded of their rights to withdraw at any time, and that the interview can be stopped and tape recording suspended for a break if necessary. The participant will be reminded of the limits of confidentiality.

The participant will be reminded that they can choose whether or not to answer a question, and are in control of the amount and type of information they want to share with me. The participant will be asked whether they have any questions.

The researcher then orientated the participant to the interview by explaining that the research was concerned with the experiences of being a Heart Failure Specialist Nurse, and in particular about working with patients who have died or who are dying. The participant was reminded they did not need to rush, and that saying what comes to mind was OK, even if this did not seem relevant, and the researcher explained that there was a set of questions to work through, however it was OK if these topics were not covered and other avenues were explored, and that there was plenty of time so no. The researcher also suggested that examples were helpful.

1. Can you describe your role as a heart failure nurse?

2. What do you bring to your role?

3. How have you come to work with heart failure patients?

4. What do you do when a patient reaches end stage heart failure?

5. What do you think these patients need when they approach end of life?

6. What are your experiences of specific types of care for end stage heart failure patients at the end of life?

7. What is it like to care for a patient with end stage heart failure?

8. How does caring for dying patients affect you?

9. What helps or hinders you in doing this work?

10. How are you supported at work?

11. How do you achieve a balance between work and home life?

12. How would you describe your approach to mortality?

13. What personal philosophies are important to you?

14. What would help you to improve the service you offer?

Phrases to facilitate the interview may include:

- Can you give me an example?
- Can you tell me more about….?
- What does that mean to you?
- What makes you say that?
- What do you think about that?
- How did you feel about that?

Following the interview, the interviewer will have a de- brief with the participant asking them how they found the interview, whether they have any thoughts or concerns about the interview or how it has left them feeling, and whether they have any questions. The interviewer will explain that there is support available following the interview. The interviewer will ask if the participant would like a copy of their transcript. The interviewer will explain when the results of the research will be available.

Appendix H

Ethical Approval

(Pages 195- 201)

Appendix I

Chronology of Research Process

Chronology of Research Process

- Attend course in IPA (Completed by November, 2007)

- Amend research protocol (Completed by November, 2007).

- Write Information and Consent Forms (Completed by December, 2007).

- Complete Peer Review (Completed by December 2007).

- Submit Ethics Form (Completed by end of April, 2008).

- Ethics approved (Completed by August, 2008).

- Approach participants (Completed by November, 2008).

- Interviews (Completed by January, 2009).

- Transcribe and analyse data (Completed by March, 2008).

- Literature Review (Completed by February, 2009).

- Write Report (Completed by May, 2008).

- Submission (Completed by May, 2008).

- Disseminate findings (Due to be completed by November 2009 to participants and the service, dissemination to journals and conferences may involve a longer deadline).

<u>Appendix J</u>

<u>Transcription Guidelines</u>

Transcription guidelines

The researcher used the following principles when transcribing the interviews, which were taken from a tutor's own transcribing guidelines within the department. These ideas are supported by Maykut and Morehouse (1999).

- Interview transcribed verbatim, including speaking difficulties, with stammers (*hear- heart*), placeholders (*he was erm, ill*).

- Words spoken with emphasis underlined.

- Non- speech sounds, such as laughing are included in brackets.

- Names and places are anonymised (e.g hospital name)

- Interviewer speech is in capital letters.

- Each major speaking turn is given a new line.

- Any speech made by the other speaker during a speaking turn is indicated in square brackets (I was not happy [HMM] with that).

- Transcribing notes are written in brackets, in italics (*can't hear two words*).

- If the transcriber cannot hear, the period of time is noted in brackets.

- If the transcriber cannot decide which word is spoken this is indicated in brackets with a question mark (It was his (*failure?*) to act)

- Misspoken words and mis- speaking is included.

- The rhythm of speech is attended to, and artificial punctuation is not added.

- Pauses are included, with the amount of time in brackets (pause 6)
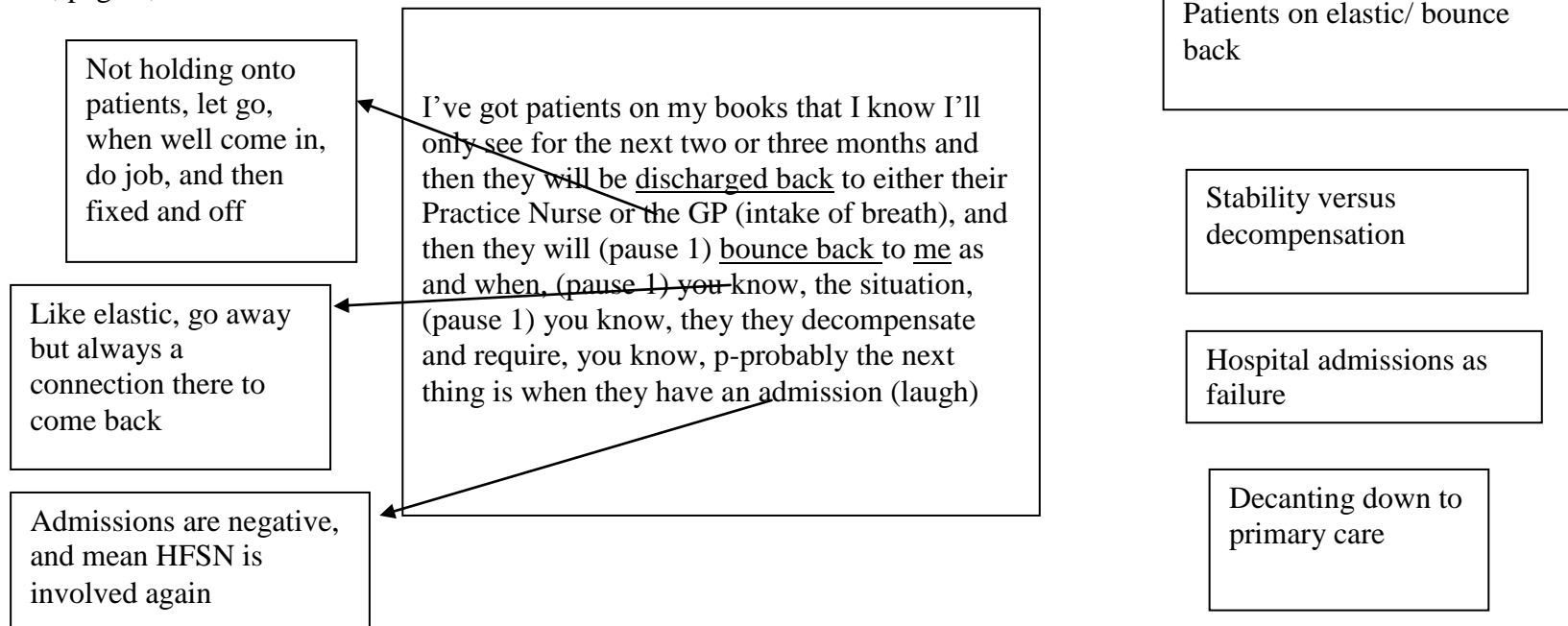
Appendix K

Example of Analytic Process

Example of Analytic Process

The following is an attempt to show each stage of analysis as outlined in the methodology, and does not represent all of the analysis, or even all of each stage of analysis, and is merely showing examples of the work done at each stage. Figure 4 below shows the process of analysing the left and right hand margins.

Figure 4. Left and Right Hand Margin Coding

Excerpt from P1, page 3, lines 68-73:

Not holding onto patients, let go, when well come in, do job, and then fixed and off

Like elastic, go away but always a connection there to come back

Admissions are negative, and mean HFSN is involved again

I've got patients on my books that I know I'll only see for the next two or three months and then they will be discharged back to either their Practice Nurse or the GP (intake of breath), and then they will (pause 1) bounce back to me as and when, (pause 1) you know, the situation, (pause 1) you know, they they decompensate and require, you know, p-probably the next thing is when they have an admission (laugh)

Patients on elastic/ bounce back

Stability versus decompensation

Hospital admissions as failure

Decanting down to primary care

As an example of the movement between data and interpretation, Table 5 below, shows an example of how the final super-ordinate theme "Keeping the Rhythm Going" was created using different participants' transcripts, with the three sub-themes illustrated. The Table shows the development from text, to margin coding, to sub- theme within overarching superordinate theme.

Table 5. Example of movement from data to interpretation.

Transcript data	Margin code (left)	Margin code (right)- Emerging Theme	Sub- theme	Superordinate theme
I'm there to educate them about the condition (P5. 1. 10)	Educative role again	Educative role	Keeping patients well	Keeping the Rhythm Going
Refer them to the <u>hospital</u>, er, for any investigations or to see a Cardiologist (P2. 1. 9- 10)	Liaison role	Liaison role		
Titrate the medications for them because (pause 1) that's a big part of the role (P5. 1. 10- 11)	Medication role again	Diagnostic and prescriber role		
A patient can be trotting along quite nicely, erm, and then suddenly they decompensate (P1. 2. 34- 35)	Movement from positive (trotting) to serious, change can be sudden, unexpected changes	Stability versus decompensation	Stability versus decompensation	
If they've not had a- a heart failure drug change for two months or a hospital admission for three months then we discharge them (pause 1), erm, basically to, obviously, you know, maintain our caseloads (P2. 13. 315- 318)	Decanting down to primary care, only dealing with the severe end	Decanting down to primary care		
Historically always gone into hospital when they're poorly, and come out and felt <u>better</u> (pause 1) and those patients continue to <u>do</u> that (P4. 13. 311- 312)	Sense of patients always been going backwards and	Patients on elastic		

	forwards, revolving door customers			
But you're giving something (pause 1) <u>back</u> to the person but in their home. Whereas in the <u>hospital</u> setting it's very much a throughput, you know, but you <u>really</u> get to know the patient, you know, from diagnosis really to <u>death</u> (P6. 4. 93- 96)	Importance of caring for patients in their homes, and developing relationships over time, until point of death	Community approach	Keeping patients at home	
Part of our role is to <u>prevent</u>, you know, unnecessary hospital re- admissions really (P1. 2. 27- 28)	Acting before, preventative role, admissions as unnecessary, as waste, stupid admission, end point is admission failure of HFSN is admission, process from education to admission	Hospital admissions/ readmissions as failure		
I don't think I've ever, ever, had anybody that actually <u>wanted</u> to die in hospital [HMM HMM] but <u>half</u> of the patients <u>do</u> still die in hospital [RIGHT] erm (pause 1) which is (pause 1) quite sad really (P2. 12. 292- 294)	Acute care failure, not wanting to die in hospital, hospital versus community again, hospital as not a good place to be, from HFSN's point of view and from	Acute/ hospital care as failure		

	patients' point of view, synchronised in approach, neither want to have care in hospital			

Appendix L

Statement of Epistemological Position

Statement of Epistemological Position

Willig (2008) suggests that when trying to identify "epistemological roots" (p. 12) three epistemological questions can be asked. The researcher asked herself the three questions to determine a position. The first question related to "what kind of knowledge does the method aim to produce?" (p. 12). The researcher felt they aligned themselves with a "critical realist" position (Madill et al., 2000, p. 3), endeavouring to "gain a better understanding of what is 'really' going on in the world with the acknowledgement that the data the researcher gathers may not provide direct access to this reality" (Willig, 2008, p. 13). The second question related to ontological position, or "what kinds of assumptions does the methodology make about the world?" (p. 13), with the researcher ascribing to a "relativist" position where the "world is not the orderly, law- bound place that realists believe it to be...emphasises the diversity of interpretations that can be applied to it" (p. 13).

The last question related to the "role of the researcher in the research process" (p. 13), where the researcher felt more inclined towards a "relativist" (p. 13) position, understanding the importance of the researcher in constructing what is found, with a different researcher potentially developing a completely different piece of research with the same participants (Willig, 2008). The researcher felt that reflexive position had much to offer the process of research, and would become important in terms of the data collection and analysis process.

The researcher's previous research experiences were within a positivist framework, and the researcher felt naive with regards to qualitative approaches, and as such felt that a "critical realist" (Madill et al., 2000, p. 3) position fitted overall. However, the researcher also appreciated the importance of reflexivity and co-construction of data, which would be seen more within a "contextual constructionist" (Madill et al., 2000, p. 9) or "relativist" (Willig, 2008, p. 13) position. Indeed, the researcher felt Smith (1995) reflected the researcher's own position, who stated that:

> *what respondents say does have some significance and 'reality' for them beyond the bounds of this particular occasion, that it is part of their ongoing self- story and represents a manifestation of their psychological world, and it is this psychological reality that one is interested in. The talk will probably also have some relationship to a world outside, though that is not the crucial point, but it will also be affected by the requirements of this particular interaction* (p. 10).

The researcher felt that this epistemological position was also reflected within IPA's epistemological underpinnings, such that IPA would align with a critical realist approach with assumption that the transcript tells us about the participant's inner world (Willig, 2008), while also appreciating that transcripts are a "joint product of the reflection by both participant and researcher" (Smith, Flowers, & Osborn, 1997, p. 68), with the researcher then interpreting that reflection. Thus, the researcher can affect that reflection made by the participant and the interview co- constructed.