

**Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the
Barriers and Levers Staff Report when Discussing Family Risk of BRCA 1
and BRCA 2 mutations**

Thesis submitted in part fulfilment of the degree of

Doctorate in Clinical Psychology

(DClinPsy)

By

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Declaration

I confirm that the research contained within this thesis is my own original work.

It was completed in part fulfilment of the degree of Doctorate in Clinical Psychology (DClinPsy) and has not been submitted for any other academic award.

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Barriers and Levers Staff Report when Discussing Family Risk of BRCA 1
and BRCA 2 mutations**

Lisa Ingleby

Abstract

Palliative care is a term which refers to the services provided to those with incurable, life-limiting illnesses. In addition, the specialism of clinical genetics is increasingly able to identify individuals who are genetically predisposed to illness, particularly Breast Cancer (BRCA) 1 and 2 mutations which increase the chance of developing breast or ovarian cancer. A range of preventative and screening interventions are available. These issues have the potential for psychological consequences for patients at the end of life, their families and for the clinicians raising these issues with them.

The review of the literature examined the qualitative evidence-base regarding the impact of caring for the dying on hospice nurses. A qualitative metasynthesis of 11 articles was carried out and identified two main themes and eight subthemes. These reflected what nurses' considered to be core elements of their work with patients and a primary driver to facilitate a 'good death'. Further to this, factors which either facilitated or impeded achieving this aim were identified to act to either replenish or drain nurses' resources. Recommendations for how to best meet these identified needs were made with potential benefit for both nurses and patients.

The research consisted of interviews with 13 palliative care staff to explore issues pertaining to the discussion of genetic risk in a palliative care setting. Thematic Analysis (TA) was used to develop four main themes and seven subthemes identifying the main considerations for participants regarding the inclusion of conversations about potential genetic risk of BRCA 1 and 2 mutations within their general practice. These formed the basis of recommendations which may be useful to services as they adapt to novel clinical interventions within their care for dying patients.

The critical appraisal provides a reflective account of the experience of undertaking research and limitations of the research are discussed.

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I would like to thank the 13 participants who took time away from their clinical responsibilities to participate in this research project. The reflective and honest accounts provided were both interesting and at times moving and I felt incredibly privileged to hear them. The investment, enthusiasm and support of the hospice site used for this research was an inspiration and a motivating force. I am truly thankful all of your help and for making me feel so welcome. You provide such a valuable service to your patients and your families and I feel lucky to have been part of it for a short while.

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Part 1
Literature Review

How is Caring for Dying Patients Experienced by Palliative Care Nurses?

Abstract

The hospice movement was conceived in 1967 to care for those in the terminal stages of illness, yet has grown in recent years to encompass those with life-limiting chronic conditions. The role of the hospice nurse within care provision is varied across both inpatient and community settings and is seen as integral to ensuring high quality care for patients and their families.

Managing uncertainty, tolerating distress and suffering in others and liaising with wide-ranging partner agencies are inherent to the role and a review of the literature two decades ago identified both protective and detrimental factors impacting on the emotional wellbeing of hospice nurses. Research in this area, particularly utilising experience-based qualitative approaches, has continued in the interim and thus an updated review was warranted.

The review systematically searched for qualitative research related to the experiences of hospice nurses in specialist palliative care services across four databases (PsychINFO, EMBASE, CINAHL and PubMed). 65 articles were initially identified and following application of inclusion and exclusion criteria, 11 articles were included in the review. Qualitative metasynthesis methods of reciprocal translation were used to analyse and interpret the data.

The synthesis highlighted two main themes and seven subthemes in the exploration of nurses' experiences. 'The Drive to Make Good' was key to the delivery of care and comprised personal experiences, acknowledgement of the perceived 'privilege' of the role and the nurses' desire to 'get it right'. This was seen as interacting dynamically with the second main theme, 'Replenishing and Draining Aspects of the Role'. This identified aspects of work that were either consonant with or antagonistic to the main driver to deliver excellent care. Similarities to previous reviews of the literature were noted alongside the context of an increasing care remit within fiscal constraints. Thus recommendations for intervention for this staff group are considered.

1. Introduction

The context of palliative care

Since the inception of the hospice movement in 1967, the values and practices of palliative care have significantly evolved. The term 'palliative care' has developed to include not only end of life care (deemed to indicate the last 6-12 months of life), but also care for those with progressive and incurable conditions, as well as those with life-threatening acute illnesses (National Institute of Clinical Excellence, 2004). The contexts in which palliative care is provided have also developed, from traditional hospice-based care to treatment offered within primary care, community and hospital settings (Faull, 2013).

This shift in ethos and delivery has been data-driven (Department of Health, 2002) and has been accompanied by development of national guidance outlining best practice (National Institute of Clinical Excellence, 2004), both drivers seeking to reduce inconsistencies in availability of palliative care. A Gold Standard Framework for palliative care has emerged to encourage improved organisational systems, communication and competence of healthcare workers to avoid care which is uncoordinated, inconsistent or reactive (Hansford & McChan, 2007). Guidelines have also highlighted the need for staff delivering quality palliative care to respond to the social, psychological and spiritual needs of an affected family as part of the care team. Thus, palliative care encompasses wide-ranging care needs for the patient and wider family system as well as addressing medical needs for diverse illnesses with variability in prognosis, course and duration. Despite these initiatives to enhance services for patients at the end of life, there remain high levels of unplanned patient

admissions in the last year of life, and patients unable to end their lives in their preferred place of death (Oxenham, Finucane, Arnold *et al.*, 2013).

The nurse's role within palliative care

Nurses are at the frontline of service delivery and this role is integral to delivering good outcomes in line with national guidance. The role encompasses many aspects of patient care common to all areas of nursing such as symptom management, working collaboratively with multi-disciplinary teams and advocating for patients (Brown, 2013) however, particular and distinct areas of emphasis are evident in this discipline. Awareness of the psychosocial dimensions of patient care is seen as key to best practice and nurses are said to rely on intuition which requires being present to the suffering of patients who are dying and their families' (Larkin, 2010). As Corner (2003) argues, talking about dying is seen as inherently stressful for healthcare professionals, yet this is an essential and recurring theme to be addressed by palliative care nurses. This requires a 'deep interest' in the dying patient, an engagement with the emotional aspects of caring and the development of relationships with patients to facilitate the finding of meaning for those who are dying and their loved ones. These challenges, alongside data suggesting that quality improvement initiatives are not yet improving patient care outcomes sufficiently well, indicates a need to focus on the experiences of palliative care nurses in the context of the rigours of their work.

Relevant Research

There has been a significant shift towards more explicit measurement and promotion of compassionate care within recent years in the National Health

Service, particularly in light of large scale enquiries such as the Francis Report (2013). There appears to be significant impetus to assess experiences of staff, and the impact these have on patient care, as research suggests that staff wellbeing is an antecedent of patient care rather than a consequence of good performance in key patient outcome indicators (Maben *et al*, 2012; DoH, 2012). Despite this, relatively few NHS innovations focus on improving the experience of staff and measures of experience are often interpreted from quantitative data such as rates of absenteeism and staff turnover (Dixon-Woods *et al*, 2014). These measures, although useful to enumerate general and broad ranging trends, lack the specificity and depth to truly offer insight into the lived experiences of staff as they deliver care.

Previous Reviews of the Literature

The experience of hospice staff as they deliver care has been examined through review (Vachon, 1995). This 20-year old review was wide-ranging in its scope examining all professional groups within international hospice settings, and included qualitative and quantitative methodologies. The review's aim was to provide an overview of palliative care from a historical perspective, charting occupational stressors from the early stages of the hospice movement to identify changes over time. A range of other factors were explored including whether palliative care professionals experienced more or less 'burnout' than other health professionals, factors which increased the experience of stress, and mechanisms which helped to manage stress responses. While themes relating to stress in hospice staff emerged and were discussed, a review of this age shows significant methodological weaknesses, notably in relation to the lack of transparency regarding search strategies, and the narrative synthesis of

diverse findings from diverse epistemologies did not allow a deeper exploration of context specific factors. However of note in recommendations for future research, Vachon highlighted a number of areas which appear to remain pertinent in the current context of hospice care, including the need to focus on the impact of providing staff with support in the context of increasing workload, and the impact of a changing hospice environment.

1.1 Aims of the Present Review

In the two decades since Vachon's review of the literature, the agenda of palliative care has developed significantly to encompass a broader range of disease processes over a longer period of time. There has also been an increasing focus on conducting research into lived experiences of the dominant profession, nurses, working in these environments. The present review will focus on qualitative papers relating to how nurses' experience caring for dying patients. It can be argued that qualitative research is best placed to explore these experiences, allowing for more personalised and richer accounts to be examined.

While qualitative research has been criticised for being context specific and lacking generalisability, methods of metasynthesis have become increasingly prominent to enable studies to be brought together to examine broader themes permeating studies in a way which goes 'beyond both narrative and systematic literature reviews' (Britten *et al.*, 2002). The present review will focus only on the experiences of nurses. Two primary reasons underpin this focus; firstly, nurses' have been shown to be integral to the process of care delivery and therefore can have a significant impact on patient experience of care. Secondly,

it is likely that the varied job roles of different professions would have a considerable influence on the experience of the staff member. For example, the roles taken by doctors and nurses may differ in terms of length of time with patient and thus may contribute to the resulting affect. Finally, in order to reflect the evolution of end of life care, it was decided that the review would focus on nurses providing care within specialist palliative care services. Given that research has revealed the impact of working with dying patients is likely to differ across settings, it was judged that those nursing patients in specialist palliative care are likely to have access to different resources and have different expectations to their counterparts in acute medical settings (Ewing, Farquhar & Booth, 2009). The review will thus include studies relating to both hospice and community-based settings to reflect the growing emphasis on home-based care, given that many palliative care services encompass both in and outpatient services (Finlay, 2001).

2. METHOD

2.1 Search Strategy

Four databases pertinent to the research area were selected for the systematic search; PsychINFO, EMBASE, CINAHL and PubMed. The Medical Subheading (MeSH) library was used to define the following search terms: (hospice OR palliative OR end of life OR terminal illness*) AND (doctors OR nurses OR clinicians OR physicians) AND (stress OR occupational stress OR stress management OR psychological stress OR physiological stress OR work related illnesses OR caregiver burden OR relaxation OR coping behaviour OR anxiety OR anxiety management OR anxiety disorder OR depression OR emotional states OR job satisfaction OR self-care skills).

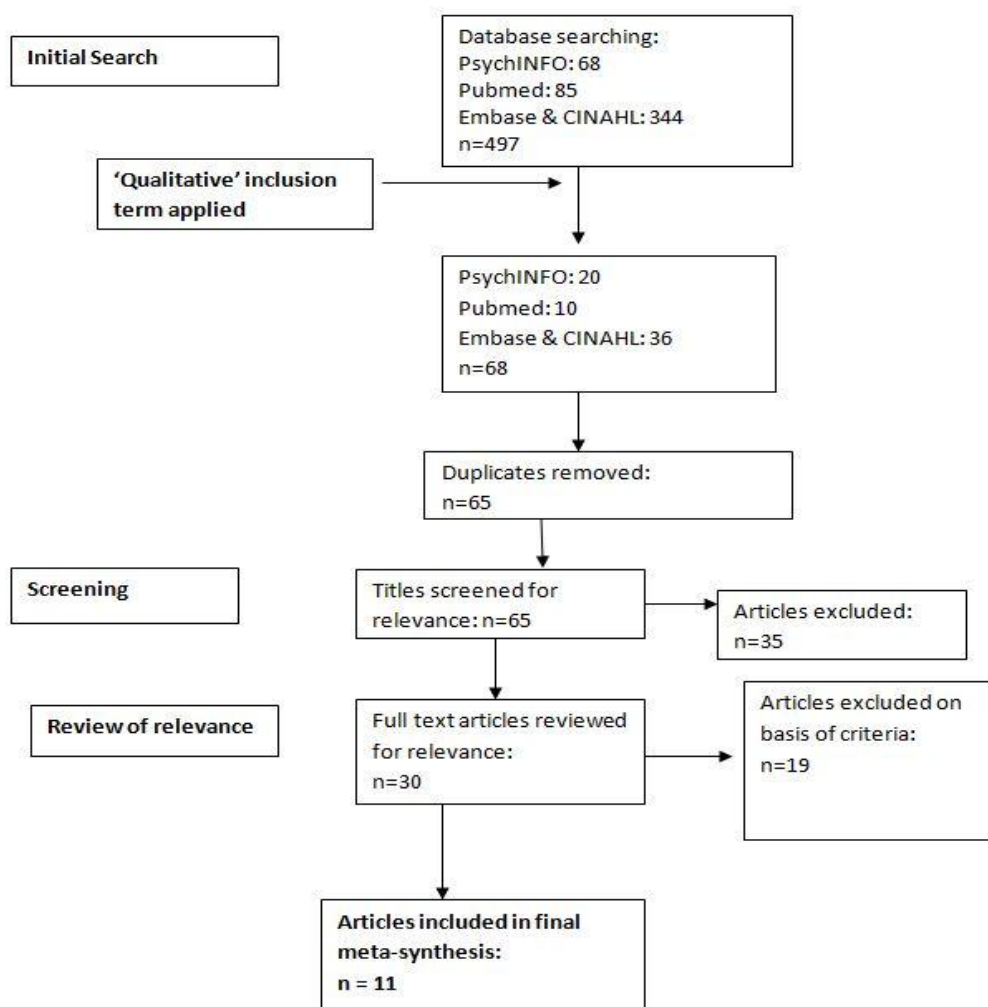
A search was conducted in September, 2014 and again in March 2015 with limits applied in order to provide greater focus to the research question. Articles published before 1995 were excluded given the extensive prior literature review (Vachon, 1995), and only articles employing a qualitative methodology were included ensuring a focus on nurses' own reporting of their experiences. Articles were excluded if they were not written in English, were not published in a peer-reviewed journal, had a quantitative design, or focused on care experiences in acute or emergency settings.

2.2 Identification of relevant papers

An initial search elicited 65 articles (three duplicates removed) and abstracts for each of these articles were obtained. These were hand searched by the reviewer to ensure relevance to the research question with 30 full text articles

obtained. A further 19 articles were excluded as they reported experiences of those working in acute or emergency services. Reference lists and citations for all papers were searched by hand; however, no further pertinent studies were found. Thus 11 articles were included in the final literature review and the process of filtering is noted in figure 1

Figure 1 – Literature Review Flowchart



2.3 Quality Appraisal

The quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) appraisal checklist (CASP, 2014), which uses a structural approach to sensitise the researcher to procedural elements of the research. However, weight is also given to the qualitative judgement of the researcher in relation to the importance of the findings. Application of the tool found no articles to warrant exclusion on the basis of quality and all studies offered rich descriptions of key findings (Dixon-Woods *et al.*, 2007). In addition, concerns have been raised that while quality appraisal tools may act as a useful way of screening papers for synthesis and may help to omit poor quality research, this may lead to intuitively good research with helpful qualitative findings being omitted (Atkins *et al.*, 2008).

To reduce subjective bias of one reviewer, papers were independently scrutinised by the trainee's supervisor with little divergence in opinion evident, and where discrepant views were held, discussion occurred until consensus was achieved.

2.4 Meta-synthesis using Reciprocal Translation

The present review has taken an interpretive rather than aggregative approach to synthesis, underpinned by the aspiration to develop concepts beyond the original papers thus cohering varied accounts given by nurses in relation to their experiences of caring for the dying. It has been argued that in order for qualitative research to produce cumulative knowledge and to aid theoretical development, it is important to develop syntheses which 'go beyond both narrative and systematic literature reviews' (Britten *et al.*, 2002). Meta-

ethnography is a means of presenting qualitative studies in an interpretive rather than aggregative way, to reduce data from multiple qualitative accounts in order to reveal social phenomena and identify common areas across multiple perspectives (Noblit & Hare, 1988). This method acknowledges the researcher's role in the construction of meaning across data, yet aims to maintain the context of the original interpretations through inclusion of detail from the synthesised studies (Weed, 2006). This enables the development of an interpretative account which identifies broadly similar themes while maintaining integrity of the original data; when the ideas examined are similar, Noblit and Hare (1988) argue that studies may be translated into each other to identify similarities across different accounts while maintaining key metaphors within an account via Reciprocal Translation, a means of translating studies into one and another when they are describing similar things. Noblit and Hare's seven steps of meta-ethnography were employed to synthesise the data in the current review:

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis.

Following the process of study selection described above, the chosen papers were carefully read to identify the main concepts and themes discussed. Due to the idiographic nature of qualitative research, varying methods of sampling, data collection and analysis were utilised across the studies. The majority used individual, face to face interviews (n=9) with only one questionnaire study and one utilising focus groups. The majority (n=8) utilised a thematic approach to data analysis and three used interpretative methods. Seven of the selected studies focused on the delivery of care to adults and with the remaining four based on the experiences of paediatric nurses. A more comprehensive summary is presented in Appendix B. A worked example of how emergent reciprocal translations were derived from the original studies is available in Table I.

Table I – Example of a reciprocal translation.

Study	Kaplan, 2000	Newton & Walters, 2001	Ekedahl & Wengstrom, 2006	Emerging reciprocal concepts
Key Metaphors and Concepts	<p>Being 'an actor' and 'wearing a mask to hide emotions'.</p> <p>Needing to 'connect' with grief. Emotions as central to the work.</p> <p>The idea of 'good grief'; not allowing it to overwhelm.</p> <p>Continuous presence of loss in context of continuous new patients and referrals.</p> <p>Needing to "balance emotional tensions".</p>	<p>A "constant stream of referrals" leaving little time to process emotions.</p> <p>Impact of other health professionals; "not giving patients the care they need"; "they don't understand"</p> <p>Pressures inherent to the system; "system produces stresses of its own".</p> <p>"Repeated strain" and "accumulation" of losses.</p>	<p>The death of young patients as a stressor; patients who "die to early".</p> <p>Impact of strong emotions on nurses.</p> <p>Lack of supervision; being "thrown in". Where to express emotions?</p> <p>Impact of wider system e.g. economy and cutbacks.</p> <p>Impact on ability to give good care and increases stress.</p>	<p>- Needing to 'make good', offering a 'good death'.</p> <p>Presence and impact of strong affect.</p> <p>Systemic issues outside of individual control. Economy, supervision, other health professionals etc.</p> <p>Cumulative nature of losses.</p>

2.5 Data Extraction

The reviewers (LI and NR) extracted original concepts from each study to facilitate comparison and translation between studies (Britten *et al.*, 2002). This

included the themes presented in each study, direct quotes from participants and the authors' comments presented in Appendix C.

2.6 Second-Order Constructs

In accordance with Britten *et al's* methodology, the term 'second-order constructs' refers to the constructions discussed by authors of the original papers. The first order constructs, that is, original material from the participants, are presented under the original themes in 'findings' (Appendix C). The second-order constructs ('Authors' comments' - Appendix C) represent the authors' observations and interpretations of the data. It emerged that key concepts such as emotional responses, individual and organisational processes and ideas around 'balancing' competing demands were similar across the papers.

2.7 Third-Order Constructs

Using the second-order concepts as 'building blocks' on which to build a synthesis (Britten et al, 2002), third-order themes were iteratively developed combining similar concepts from the original studies through moving between the original data and identified second-order constructs. This is summarised as 'conclusions' in Appendix C. This permitted construction of interpretative categories which summarised the key concepts while maintaining the individuality of the accounts in relationship to each other. Two main themes and eight subthemes were identified and are presented in table II.

3. Findings

The findings reported are represented in Table II. Themes were derived from the original material and authors' comments in the papers included within the metasynthesis. Comments used are taken directly from author and participant quotations with the included studies.

Table II. Theme Table

<p>The Drive to Make Good</p> <ul style="list-style-type: none">• Personal experiences• Privilege of the role• Getting it right
<p>Replenishing and draining aspects of the role</p> <ul style="list-style-type: none">• Cumulative effects and intense affect• Where and how to express intense emotions• Feeling heard and being validated• Tolerating uncertainty and need for control• Boundary maintenance and transgression

The Drive to Make Good

This theme encapsulates the reported motivations and impetus for working with life-limited and dying patients and was present in all but one of the papers reviewed (Reid, 2013b). Hospice nurses' desire to 'make good' was privileged in many of the reviewed papers and staff reported striving to 'make a difference'; "...only the best I can do for them is good enough really...I want it to be right for them..." (Ablett & Jones, 2007); "...We were going to do our very best for whoever travelled through the door" (Penz & Duggleby, 2012). This impetus encompassed elements of both commitment and responsibility; "...we have the responsibility to help them realise they are still very much a part of the life around them" (DeArmond, 2012) and appeared to override personal needs for sociable working hours or financial reward. Many nurses expressed an altruistic rationale for their work "...it has more to do with doing good and feeling that you can help" (Ekedahl & Wengstrom, 2007) although this generosity appeared to have diverse roots such as empathy related to their own experiences and a personal desire to get it right, as described by the subthemes.

Personal Experiences

This theme was present in four of the reviewed papers; and in three of these as a main theme (Ablett & Jones, 2007; DeArmond, 2012; Penz & Duggleby, 2012) and reflects a holistic focus in which broader aspects of nurses' lives were explored in relation to their work. A dominant drive in accounts was a need to mend previous breaches in personal experience, of their own or others' care, with a desire to replicate 'good' care or repair 'bad' experiences. "As

upsetting as it was...it sort of turned my dad's dying into a positive thing..." (Ablett & Jones, 2007). This might involve identification with a patient, for example, when a dying patient had children the same age (Ekedahl & Wengstrom, 2006). DeArmond (2012) and Penz and Duggleby (2012) described personal experiences and aspects of the self seemed integrated and informed delivery of care; "Now the experience of my mother comes back to me. I can say to some families that I have been on their side of the table".

Role as a 'Privilege'

The idea of privilege was commented on either directly by a participant or in the author's interpretations of accounts in five of the reviewed studies. Offering the best palliative care was seen not only as worthy obligation, but as an honoured and respectful position offering personal reward (Ablett & Jones, 2007). "It's a privilege to go into people's homes...It's their home and their inviting you into their life..." (Penz & Duggleby, 2012). The acknowledgement of the importance and intimacy of the role led participants to conclude "it was a very privileged place to be" (Reid, 2013a). Although not all accounts explicitly referred to the idea of privilege, there was a consistent theme throughout the accounts of a more general respect and appreciation of the relationships built with patients related to the high level of commitment shown by the nurses (Ablett & Jones, 2007).

'Getting it Right'

In recognition of the distress and suffering of patients and their families and the centrality of a good passing, nurses reported striving to give optimum care; "the family is stressed and you really want to alleviate that as quick as possible"

(McCloskey & Taggart, 2010); “I am not a perfectionist, I just like to be right, to the best of my ability...it’s about them, not me” (Ablett & Jones, 2007). To ‘get it right’, a complex range of factors were noted for negotiation; “we make sure that they’re prepared spiritually, physically and emotionally, and they’ve had someone who they can talk to openly about what they’re needs are” (Penz & Duggleby, 2012). Nine of the 11 accounts referred to aspects of getting it right, for example, the importance of being seen to be coping by patients (Kaplan, 2000), and optimum care as an important factor of job satisfaction (Newton & Walters, 2001). Where the desire to get it right was thwarted frustration was expressed, notably the impact on patients of rapid or ill-considered discharge planning (Reid, 2013a).

Replenishing and Draining

This theme encompassed the importance of maintaining equipoise in the workplace, and stressed the capacity of work to provide life-affirming and fulfilling experiences, yet tempered by aspects of work which could diminish and deplete physical and emotional resources. Many participants specifically focussed on stressful aspects of their caring role as well as working contexts construed as draining nurses’ resources and undermining best practice, for example, the tensions between different parts of a system; “the transition...produces stresses of its own...there’s always a bit of a mess in the middle” (Newton & Waters, 2001). However, many also reflected on aspects of the work which provided fulfilment and facilitated better care for patients and their families. The synthesis of findings suggested a dynamic process of balancing stressors and rewards exists for nurses providing palliative care (Kaplan, 2000). Context is key to this process; each nurse brings their own

unique set of personal factors which may influence coping and different parts of the system may offer positive *and* negative contributions to the hospice nurses' experiences of care.

'Balancing the emotional tension' (Kaplan, 2000) was deemed important as maladaptive ways of managing difficult emotions or stressors was associated with compassion fatigue or burnout and this link was explicitly explored by several authors (Kaplan, 2000; Newton & Waters, 2001; Ablett & Jones, 2007; Rose & Glass, 2010; Melvin, 2012; Penz & Duggleby, 2012; Reid, 2013b); "I do feel quite burnt out you know. How much compassion have I left?" (McCloskey & Taggart, 2010). Evidence for this main theme is discussed within the subthemes below.

Cumulative effects and intense affect

Strong affective responses were alluded to in all but one of the papers reviewed. Kaplan (2000) noted that 'emotionality' is central to the work of the hospice nurse and participants discussed needing opportunities to connect with grief. While understanding intense emotions was essential to understanding their work for nurses', these responses could be difficult to understand and process. It was acknowledged that "every death changes you" and that while 'intimacy with death' could be rewarding, inherent sadness surrounding death and dying was an inescapable feature of work; "death is a tragic experience and we are never ready to die" (DeArmond, 2012). Very strong affect was expressed in the context of the death of children; "dealing with the impact of a child's death can be awful, it's not that their nursing needs were terrible, but it is

the emotional intensity of it”, (McCloskey & Taggart, 2010); “young people affect you mightily more than somebody who has lived a full life” (Reid, 2013a).

Also acknowledged was the cumulative effect of caring for patients at the end of life and the impact of multiple losses. This element of the subtheme, while alluded to in other papers was most notable in Melvin (2012) “...it can eat also eat away at you – multiple losses. And how can you not get attached to people because they are just lovely...and then they die”. A participant in Melvin’s study also noted the challenges of hospice nurses’ need for self-reflection in relation to their patients’ distress stating that, “it takes a person being willing to be introspective to really understand and to be honest with themselves about what they are feeling and why they are feeling that”.

Strong affective responses were not limited to expressions of grief and loss. Intense anger and frustration were reported as expressed and received in liaising with and relating to multi-disciplinary team members who were perceived to inadequately understand palliative care, lack of trust in other health professionals could lead to taking on extra work or retaining responsibility for tasks (Newton & Waters, 2001).

Where and how to express intense emotions

Whilst intense affect was evident in all papers, seven explicitly discussed the need to be able to process such emotions. Staff appeared equivocal about giving voice to emotion, perceiving expression as both cathartic and showing human vulnerability and connection “it’s probably better that I feel a bit sad than just walk out the door and not think anything” (Rose & Glass, 2010), yet

threatening if ignored, “you need to talk it out because you don’t want to be taking it home” (Rose & Glass, 2010),

Tensions were also evident regarding the practicalities of expressing feelings with a lack of time or formalised spaces; “you have to be an actor, and just change your mask and put a smile on and go in and do it” (Kaplan, 2000).

Having a space to reflect on experiences was reported as helpful to practice, but was often lacking (Rose & Glass, 2010), as was formalised clinical supervision, “there was never any talk of supervision...you were thrown into it directly” (Ekedahl & Wengstrom, 2006). Given a lack of formal systems to express affective responses, respondents noted informal opportunities to meet this need, notably the integral role of colleagues’ reciprocal support; “I talk to colleagues and we do actually discuss how we feel” (Ablett & Jones, 2006). More opportunistic means of expressing emotions were sought through the rituals of death such as funerals and bereavement support (Reid, 2013b), in which distress was seen as legitimate; “the funeral didn’t give any sense of farewell...my picture is still of a very distressed family”. Reid also noted that funerals could be seen as appropriate places to ‘demonstrate personal grief’, perhaps suggesting that nurses may believe that their own grief response are not valid and should not be expressed. The need for a place in which to express these responses may be exacerbated by the relentlessness of loss, “I was going from the relatives of the person who had died, and then trying to be bright and sparkly to the next relative” (Ablett & Jones, 2006). With adverse reactions to emotional overload, “[when I am] unbalanced, everybody knows it...I’m teary, I’m emotional, I’m impulsive”, (Rose & Glass, 2010)

Feeling heard and being validated

In addition to nurses' appraisals of the legitimacy and validity of their emotional responses, they expressed broader concerns about the value and respect afforded them by other systems with whom they liaised. This theme was present in seven of the studies and difficulties pertaining to the multi-disciplinary team or navigating the 'professional road' were cited as main or subthemes in five of these (Newton & Walters, 2001; McCloskey & Taggart, 2010, Rose & Glass, 2010; Penz & Duggleby, 2012; Reid, 2013a). While it was acknowledged that collaborative working relationships could assist patient care, perceptions of nurses' roles by other health professionals could cause frustration and a sense that optimal care was being undermined (Rose & Glass, 2010) notably, when nurses' did not feel respected; "The GP kept me waiting about an hour...I felt he wanted me to give up and go" (Newton & Walters, 2001).; "they don't understand you have to do things quickly, because if you hang around you've missed it" (Newton & Walters, 2001). Lack of acknowledgment of the specialist skills possessed by palliative care nurses was also associated with frustration; "you do have that knowledge and skills and experience behind you... it's frustrating when people don't credit you for that" (McCloskey and Taggart, 2010).

It was acknowledged that sustaining care across multiple and complex care systems could be a challenge given the "huge" teams involved, most particularly evidenced when caring for children; "these child plans try and encompass school, social work and respite...team is actually so huge" (Reid, 2013b); "this chap belonged to everybody...I couldn't get one direct answer" (Reid, 2013a). Perceptions of inadequate managerial support were also

associated with feelings of frustration (Newton & Walters, 2001), and 'disempowerment or distress' (Rose & Glass, 2010). Increased and unacknowledged workloads left nurses' feeling 'unimportant and forgotten' (Penz & Duggleby, 2012), and such feelings were voiced more particularly in community settings where nurses felt less supported by management systems (McCloskey & Taggart (2010), attributed to physical distance from colleagues, from whom emotional support could be sought.

Tolerating uncertainty and need for control

Respondents noted uncertainty as an inherent part of their work (Ablett & Jones, 2006) and control, as a means of containing uncertainty, was evident in eight of the studies reviewed. Newton and Walters (2001) noted nurses' tendency to be rigid in self- expectations 'to be perfect, always to be in control, to make everything better', which could exacerbate feelings of stress. Control was expressed in relation to a reluctance to relinquish care to others if they seemed insufficiently expert and committed; "some district nurses not giving patients the care they need" (Ekedahl & Wengstrom, 2001). Exerting control/expertise also emerged when nurses were unable to respond to requests; "sometimes I don't know what to say and sometimes I'm crying just as much as they are" (Rose & Glass, 2010). Feeling excessively responsible for providing patients with perfect care could prevent stress reduction needed to 'switch off' at home (Melvin, 2012), as could inability to address stress at work. Failure to control stressors appeared to engender guilt if it compromised meeting patients' and families' expectations (Penz & Duggleby, 2012). External factors too could undermine control, especially the additional demands created by the shift from 'hospice' to 'palliative' care and the impact of financial

cutbacks; “we get told to take on more...but we don’t get resources” (Rose & Glass, 2010; Ekedahl & Wengstom, 2001; McCloskey & Taggart, 2010; Reid, 2013a). This was more prominent in community settings where resources were deployed across a wider area (Reid, 2013a).

Boundary maintenance and transgression

Maintenance of professional boundaries was discussed in all but one of the papers and was related to the emotional connection felt by nurses to their patients through which personal reward and fulfilment could be experienced; “I feel personally enriched by having dealt with the situation” (Reid, 2013a).

Despite the benefits of developing meaningful and deeply connected relationships, delimiting work served as a protective strategy; “you get involved in your job and what you need to do...but I think you have to protect yourself as well” (Ablett & Jones, 2006). Yet respondents expressed doubt about appropriate level of involvement to ensure good quality care; “the challenge is not to get too involved...but where do you cut off?” (Rose & Glass, 2010). Despite this ambivalence, setting boundaries was deemed a healthy coping strategy for nurses; “I think the boundaries make me not less of a compassionate person but I think it preserves me” (Melvin, 2012). Moving between ‘mechanical and holistic care’ could be helpful for nurses’ in maintaining their emotional wellbeing (Ekedahl & Wengstom, 2006).

Maintaining helpful boundaries was expressed differently by nurses in hospice settings and those based in the community, where less overt and immediate peer support appears available (Newton & Walters, 2001; McCloskey & Taggart, 2010; Penz & Duggleby, 2012; Reid, 2013a; Reid, 2013b). Both

groups noted boundaries between work and home life were difficult to maintain, and that their identities as care giver could be merged with extended family members (Penz & Duggleby, 2012). This appeared magnified in the community role where collision of role and persona was exacerbated by living and working in the same community; “there is one mummy I would see and she always says hello and the first thing she would tell me about is her sick child” (McCloskey & Taggart, 2010).

Close relationships with patients and their families could lead to ethical dilemmas. This was particularly challenging for nurses working in palliative care for children and young people, with significant challenges being faced when families and patients had conflicting ideas to the care team regarding treatment, this is described as walking a ‘fine line between advising, advocacy, empowering and intervening’ (Reid, 2013b).

4. Discussion

Metasynthesis of these 11 papers revealed that hospice nurses' experiences of caring for dying patients are various and influenced by a complex range of factors. Experiences were shaped and affected by motivations for the career chosen and key beliefs about a need to ensure and deliver high quality care to patients and their families. These motivating factors to 'make good' interacted with and influenced external factors, many of which existed beyond individual agency. It should be noted that the context of palliative care is somewhat different to traditional 'curative' approaches in medicine; while overlap exists regarding what constitutes good care, the palliative approach is more attuned to subjective experiences of patients. Thus patient preference is a key driver rather than reliance on the scientific skill and judgement of a clinician (Fox, 1997). When internal and external factors were felt to act synergistically to deliver high quality care, respondents reported a sense of fulfilment; however, when an intrinsic drive to provide excellent, time-limited care was thwarted, respondents reported distress that was emotionally sapping.

The current review, adopting a more focused exploration of nurse experience, had resonances with Vachon's (1995) earlier work despite differences in methodology and examination of professional group. Both reviews revealed nurses' experiences to be dynamically related to a range of personal and work related influences. Common to both was the finding that organisational changes, particularly imposed and unconsulted, exacerbated any staff distress and was felt to compromise nurses' ability to deliver care. Given ongoing contexts of economic uncertainty and fiscal restraint in conjunction with the broadening of the palliative care remit, it appears little has changed in two

decades to build resilience and mitigate what are now recognised as common stressors.

Understanding the experience of hospice nurses

Nurses' experiences as articulated in these studies appear consistent with other health professionals' experiences (Costello, 2006) and with current psychological perspectives on work-related distress and resilience. Particularly the theme of balancing replenishing and draining aspects of care resonate with demand resource models of distress such as the Person-Environment fit model (Caplan, 1984), and the Job Demands-Resource model (e.g. Bakker, Demerouti & Verbeke, 2004; Bakker, *et al.*, 2000). Both of these well-evidenced models emphasise resilience resulting from successfully balancing adversity at work with clear and supported benefits, congruent with personal values in synchrony with organisational values.

Beyond explicit reference to compassion fatigue (Melvin, 2012), nurses across studies described phenomena consistent with this emotional depletion, attributed to intense emotional engagement with patients and experienced as more acute in onset than burnout (Boyle, 2011). These descriptions of affective responses which may be 'cumulative and intense', sit more appropriately with compassion fatigue and go some way to explaining why incidences of burnout are lower for hospice nurses than for their counterparts in acute settings (Payne, 2001). The articulation of privilege and rewards described in the synthesised papers revealed not only fatigue but also compassion satisfaction (CS). CS can be negatively correlated with both CF and burnout (Alkema, Linton & Davies, 2008) and, offering protective function, again reflects

descriptions of filling and draining. Interestingly, in comparative research hospice medicals staff report higher CS than nursing colleagues (who score higher on CF) (Slocum-Gori *et al.*, 2013), perhaps suggesting differential impact of their work in palliative care

Making Good at the End of Life

The overarching theme of ‘the drive to make good’ revealed in the present synthesis suggests that nurses are driven not just by personal experiences of care and potential intrinsic reward, but also by a desire to ‘get it right’ possibly underpinned by the overt ethos of palliative care. Indeed, McNamara, Waddell and Colvin (1995) suggested that hospice workers are united by a common agenda, to provide a ‘better way to die’, with an emphasis on respectful, personal interactions with the patient or family member. Yet the striving to manage a ‘good’ death articulated by respondents is not value free and despite the patient-centred focus of palliative care, may be imposed by clinicians with frustration ensuing when patients and/or their families do not engage fully with tasks seen as important to achieving a ‘good’ death (Masson, 2002). More recent research has also suggested that hospice clinicians use narratives to support the ethos of palliative care, for example, how when a ‘bad’ death occurs, the focus of failure is often shifted to the patient or the family for not conforming to hospice expectations. (Semino, Denijen & Koller, 2014). Whilst this may serve a protective function for staff unable to achieve a positive outcome, the consequences for families are unexamined.

Patient Relationships and Boundary Maintenance

Nurses reported that the relationship with patient was central to their work, allowing them to anticipate and meet patient needs. This echoes previous research that suggests that relationships are particularly important with patients with complex and ever changing symptom control difficulties (Zerwekh, 1994). Privilege alongside the desire to facilitate a 'good death' and acknowledgement of the shift in focus from hospice to palliative care, may underpin their need to engage fully emotionally. However this brings with it costs. Sawbridge and Hewison (2013) noted that nursing practice has shifted from task-centred to holistic care exposing them to greater emotional engagement with the suffering of their patients and perhaps lacking the protective factors inherent in a 'mechanical' approach (Ekedahl & Wengstrom, 2006). However, as with respondents in this review, nurses may feel discomfort maintaining distance in relationships with patients.

The need to be heard and validated

This theme largely encapsulated nurses' experience of frustration when other professions did not appreciate the immediacy of their patients' needs or the complexity of their roles. The finding that nurses appeared particularly dispirited by perceptions of disregard for their specialist skills may magnify unhelpful 'territorial' behaviour over patient care and compromise collaboration (e.g. Street, 2001). Such a confrontational position may exacerbate stress where nurses' that they have to 'take on the system' to promote their patients' choices and autonomy (Zerwekh, 1994). A sense of validation appeared harder to achieve in community settings consistent with other findings that while the hospice is deemed a conducive setting for interdisciplinary collaboration (Kobayashi & McAllister, 2014), support may feel less tangible in the

community, magnifying isolation (Street, 2001). Respondents voiced these concerns most prominently when nursing children with terminal illnesses in the community as they also address broader societal pressures to protect children from harm (Morgan, 2009) and potentially undermine their role in helping families manage the transition from curative to palliative care. The interdisciplinary working context may also be more pronounced in paediatric palliative care, for example, the inadequate provision of education for children with terminal illnesses (Carroll, Torkildson & Winsness, 2007) making it harder to meet their patients' complex and multiple needs.

The experience and expression of affect

Nurses within the reviewed papers described doubt about the validity and appropriateness of their own grief responses when patients die, consistent with findings that nurses may feel a responsibility to induce or repress their own affective states in order to promote feelings of care and safety in their patients (Gray, 2009). This is likely to be societally sanctioned and colluded with given societal resistance and avoidance of talking about death and dying (McNamara, Waddell & Colvin, 1995).

Taken in the context of the wider literature, this review suggests that while the distress of patients is not in itself stressful (Arneart, 2009), the absence of venues for legitimate emotional outlets is. Nurses find informal opportunities to discuss their experiences with colleagues helpful, for example, in maintaining a boundary between work and home life (Ekedahl & Wengstrom, 2006) but their responses also argue for inclusion of safe and formal opportunities, such as clinical supervision, to support emotional processing and counter severe

distress. This seems particularly important given that respondents will frequently place patient before needs of self, possibly as an implicit, yet potentially damaging of quality care

4.1 Summary

The present review provides evidence to suggest that the task of delivering palliative nursing care is a complex yet rewarding undertaking. Nurses' need to balance several competing elements of care in order to meet their primary desire to facilitate a 'good death' for their patients. This is a goal which, when achieved, can mitigate the more negative aspects of care that might be manifest as CF or burnout.

4.2 Conclusions and Recommendations for Future Research

Nurses across all palliative care settings can experience negative affect as a consequence of the challenges inherent to caring for their patients. The results of the present synthesis highlight potential areas for intervention for services where these issues may be pertinent:

- Difficulties associated with palliative nursing appear to be more pronounced in paediatric settings. The findings acknowledge that already large care teams can be even more complex for children and young people due to additional considerations such as education provision. Providing specialist education and information to partner organisations regarding the role and remit of palliative care may facilitate more consistent working relationships and thus increase nurses' confidence in their colleagues from other settings.

- It appears that nurses working in the community may be more sensitive to the impact of affect in their work due to their comparative isolation from the team. While hospice based nurses acknowledged the importance of informal peer support in relation to their coping, these opportunities may be scarcer community nurses. It therefore seems important for those managing nursing teams to ensure that these opportunities are facilitated and embedded within the structure of the nurses' role.
- Delivering holistic, person-centred care to the patient and their family is firmly embedded into the hospice culture and appears consistent across a number of different settings, however, it appears that this ethos does not always extend to those delivering care. The results suggest that caring for one's self is seen as an integral part of the delivery of excellent care. Given that hospice teams often include formalised and planned multi-disciplinary meetings in which to discuss patients, this may be an appropriate place in which to consider and reflect on the impact of patient care on nursing staff. Discussion of emotional responses in such a way could communicate the importance of emotional responses and thus validate some of the experiences discussed within the present synthesis.
- Staff resilience and care quality will remain prominent in palliative care with fiscal restraints and greater demand for services. The development of models evident in other professions, for example, clinical psychology, such as reflective practice, may be helpful in addressing resilience with potential benefits for nurse and patient. Reflective practice has the potential to facilitate nurses' understanding of what conscious and unconscious drivers exist in their delivery of care and thus enable a structure in which to examine what constitutes a 'good' outcome, and a place to consider their responses when outcomes are

less positive. It may be helpful to consider that these groups are facilitated by an individual external to the team to promote honest and open discussion which may not always be possible should the facilitator have additional line management responsibilities. It is likely that Clinical Psychologists are well placed to offer this service. Further research may be necessary to explore how these could be practically adopted by services providing palliative care.

In addition to recommendations for services, the present review suggests that common themes exist across disparate settings which could provide the context for larger scale quantitative studies examining the factors which influence nurses' experiences of caring for the dying.

4.3 Strengths and Limitations

The present review provides a rich description of how palliative care nurses experience their roles. The inclusion of community, inpatient, adult and child-focused services has allowed exploration of diverse contexts and has revealed factors both internal and contextual that mitigate and exacerbate distress and satisfaction. Qualitative methods have been criticised for their low levels of generalisability, however, the present study aimed to address some of these difficulties by synthesising the results of multiple, related studies to contribute to the evidence base.

As the participants of these studies are most often self-selecting volunteers, the synthesis may comprise opinions of only those who are more confident discussing the emotional impact of their work. As with all qualitative and review methods, while great care was taken to ensure the context and detail of the individual accounts were kept, some elements will be less prominent in order to

construct a coherent narrative of findings. At the time of synthesis, the trainee was in the process of undertaking qualitative research with palliative care staff and thus it is possible that both research processes influenced each other to some extent as these narratives were developed; however, this was noted early in the process and separate reflective accounts were kept to ensure themes were rooted in the data from the selected studies. This should be considered when interpreting the presented results.

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* Denotes studies used within the synthesis

Part 2

Research Report

Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the Barriers and Levers Staff Report when Discussing Family Risk of BRCA 1 and BRCA 2 mutations.

Abstract

Clinical genetics is a medical speciality that offers genetic counselling and testing to those who may be at increased risk of developing a range of genetically related diseases. Of particular interest have been Breast Cancer (BRCA) 1 and 2 mutations which, when present, substantially increase the chance of developing breast and ovarian cancer. This risk can be significantly modified with increased screening and preventative interventions. A living tissue sample from an affected relative is required for the most successful identification of such a mutation, and thus palliative care settings represent a last opportunity to obtain this in order to inform future generations. While the literature has explored clinicians' ideas in relation to this area, relatively little has explored the context of palliative care specifically and this research aimed to contribute to this evidence.

Thirteen clinicians from a hospice-based palliative care service were interviewed and clinical vignettes formed a basis for discussion of what factors promoted or impeded discussion of genetic risk at the end of life. These were analysed using Thematic Analysis (TA) and four main themes were evident; Values and Ethos of Palliative Care; Concord/Discord; External Barriers Beyond the Self and Integrating Clinical Genetics into Practice. Subthemes explored the elements contributing to these themes in more detail.

Participants described the centrality of providing excellent care to their patients and illustrated how the process of integrating discussions about genetic risk into their practice was influenced by wide-ranging factors. A process of 'weighing up' the extent to which clinical genetics was consistent with their values and ethos was considered. The limitations of the research and potential clinical and research implications are discussed.

1.Introduction

Clinical genetics and the delivery of care informed by the discipline, is a rapidly expanding domain within the National Health Service. Its development and the services created, have significant implications for diagnosis and management of conditions wholly or partly determined by genetic anomalies and have shown considerable benefit for those able to access information regarding their genetic risk (e.g. American Society of Clinical Oncology, 2003; Watson *et al.*, 2004)). However whilst the biomedical benefits are focused upon, psychological consequences have been scrutinised rather less.

Whilst there are many diseases resulting from genetic frailties, risks for cancer have garnered most attention. There exist a range of syndromes which may accelerate cancer development (Economopoulou, Dimitradis & Psyrris, 2015), such as Li-Fraumeni Syndrome (LFS), most commonly associated with early onset soft tissue sarcomas and premenopausal breast cancer. However, the variability in how, when and where these genes are expressed in this condition means that targets for prevention and screening are limited (e.g. Malkin, 2011; Kamihara, Rana & Garber, 2014). By contrast, mutations of the Breast Cancer (BRCA) 1 and 2 genes when inherited, more definitively increase likelihood of developing breast or ovarian cancer at an earlier age. Limited data on men has suggests an increased risk of developing breast cancer and more aggressive prostate cancer (Pal *et al* 2013), but in women, such mutations account for the development of 5-10% of all breast cancers and 15% of ovarian cancers; presence of one of these mutations increases the chance of developing breast cancer from 12% to between 45% and 65%, and in ovarian cancer from 1.4% in

the general population to between 11% and 39% in those with a gene mutation (National Cancer Institute, 2014).

A burgeoning evidence base revealing predicted risk from genetic anomalies and mutations has been paralleled by growth of genetic counselling. This is defined as a process of interpreting family and medical history in order to gauge chance of disease occurrence or reoccurrence, promoting informed decision making in patients, and helping those affected to adapt to potential medical, psychological and familial sequelae (Resta *et al*, 2006). Given the potential vulnerability of individuals seeking information about genetic risk, counselling emphasises that any information provided is offered in an emotionally congruent way (Middleton, Hall & Patch, 2015). The impact of genetic testing has been evaluated in a systematic review with regard to testing in patients with newly diagnosed breast cancer (Meiser *et al.*, 2008), in which its influence on patient management was appraised and synthesised. The review authors noted that confirmation or presence of a BRCA 1 or BRCA 2 mutation permitted patients to benefit from genetics-informed treatment options in relation to potential severity and reoccurrence of a cancer. This also allowed treatment options to be discussed and tailored to mitigate further likelihood of disease, for example, through prophylactic, risk-reducing mastectomy.

As the discipline of clinical genetics has evolved, there has been not only scrutiny of its potential clinical benefits, but also consideration of anticipated detriments, notably the psychological impact of being told that genetic anomaly may confer increased risk of disease and subsequent behavioural impacts on patients. As patient participation has become part of the formal NHS agenda, with NICE guidance specifically advising involvement of patients and their

families in shared decision making (NICE, 2012), there is greater onus on clinicians to accurately communicate risk (Naik, Ahmed & Edward, 2012). Debates about the most appropriate way in which to communicate risk pre-date evolution of clinical genetics in diverse procedures and consultations such as consent for surgery (Bhandari & Tornetta, 2004), radiation imaging such as CT scans (Dauer *et al.*, 2011), presenting risk of venous thrombosis in contraceptive pill use (Baglin, 2005) or risks associated with hormone therapy use in menopausal women (Fenton & Panay, 2014). Given the impact that such communication can have on treatment adherence and health outcomes (Street *et al.*, 2009) clinicians need to shape messages and their delivery as well as discerning the 'pseudo-compliant' who give socially desirable response yet do not instigate risk-reducing behavioural change (Honey *et al.*, 2015)

Risk communication has been examined in clinical genetics, with evidence suggesting most benefit is accrued through genetic counselling when there is clear information provision and a patient's active role (Metcalf, Werrett, Burgess & Clifford, 2006). These authors also demonstrated patients' need for ongoing support and engagement in the process to enhance their perceived self-efficacy and reduce avoidance or anxiety behaviours in response to information about risk. Awareness of these consultation features, and the skills required to effect risk communication, are likely to be required by more health professionals as genetic bases of disease are more fully understood and explored (Middleton, Hall & Patch, 2015).

Given the growing evidence base regarding the extent to which clinical genetic counselling may benefit individuals with a genetic cancer mutation, there has been an increasing focus on how individuals can be encouraged to access

services. This has been informed by a context in which routine annotation of detailed family histories does not form part of standard medical procedure and with an onus on the patient to raise any concerns in this area (Lim *et al*, 2011). Indeed, a significant proportion of the population remain unaware of their potential genetic vulnerability to disease, the relevance of their family history or, even when informed, are unlikely to discuss concerns with health professionals; despite high profile media cases (Evans *et al*, 2014). Opportunities to enhance engagement with services are increasingly being examined to optimise availability of screening and prophylactic interventions that might mitigate future disease. Audit data, notably retrospective case review of patients referred to regional cancer genetics units, has revealed suboptimal service access (Lakhani *et al* 2013). Approximately two thirds of 508 patients audited could have been referred at an earlier point in their illness trajectory. Less than a third of referrals were made for individuals with an existing cancer diagnosis, reducing opportunity for direct genetic testing and increasing uncertainty for unaffected individuals with a significant family history of the disease. In reviewing these findings the authors identified an opportunity to enhance access to genetic risk information where opportunities were missed earlier in a care pathway within palliative care - “the last opportunity to identify the affected individuals where storing DNA would help to clarify risk for family members, but referrals from this discipline were remarkably low” (p. 1354).

To date the role of palliative care and staff within these services has been little examined with regard to their engagement with clinical genetics, and staff perceptions have been explored only indirectly. A large questionnaire study of 328 nurses from 40 different hospices across England and Wales examined

their confidence in conveying information about genetic risk to patients, and how importantly they prioritised clinical genetics within their practice (Metcalf, Pumphrey & Clifford, 2010). Although reported as an important aspect of clinical work, staff expressed ambivalence about the hospice setting as an appropriate place to discuss genetic cancer risk and low confidence in addressing clinical genetics issues more generally. However, the quantitative nature of the study precluded detailed exploration of the factors affecting confidence and ambivalence about the appropriateness of integrating this area into standard practice. In a further circumscribed study, Lillie, Clifford and Metcalfe (2011) used a phenomenological approach to explore experiences of a small sample of hospice nurses eliciting concerns about missed opportunities to gather information from previous generations to inform care of successive generations. Although this study provides some insight regarding these concerns in end of life care, it is largely descriptive in nature and only explores experiences of nursing staff. Taken together this limited data tentatively suggests that, for nurses, engagement and confidence in addressing clinical genetics is lacking in end of life care and a more nuanced approach may be required to understand potential levers and barriers staff experience in relation to its inclusion in the day to day care of the dying. Previous studies may offer some general data on staff caution and uncertainty when asked to consider genetic referral, thus a more detailed examination of hospice clinicians' views and experiences of applying genetic counselling could permit systematic exploration of information-rich data to identify subtleties, which may be significant barriers or levers to further implementation of discussing family risk.

1.1 Summary

The scope and predictive abilities of clinical genetics services and their partner organisations are evolving, and with them increased awareness and knowledge of the role of genetic mutation and anomaly in disease presentation and progression, notably cancers. Services aim to increase identification of potentially affected individuals, and to increase confidence in broaching this potentially emotive area to improve patient access to options to modify their risk. Approaches to date appear to have been informed by research suggesting that identification of genetic risk can inform patient-professional discussions surrounding treatment choices, empower affected individuals in decision making, and underpin public health intervention strategies to reduce numbers of affected individuals. Further examination of factors influencing palliative care clinicians' decisions to pursue information suggestive of genetic risk is warranted as the evidence-base regarding this area is very circumscribed. Palliative care settings represent a final opportunity for those in end of life care to provide genetic material needed to offer prediction of genetic risk for successor generations; referrals from hospice care clinicians appear low relative to community prevalence rates of genetic susceptibility and final opportunities may be being missed.

1.2 Aims and Objectives

The proposed study aims to gain an understanding of the awareness of hospice staff regarding genetic testing and pathways to clinical genetics, and to explore potential barriers and levers to discussing genetic risk with families in a hospice context.

In doing so, the research seeks to develop an understanding of what promotes or prevents staff discussions regarding familial risk with patients during end of life care. A qualitative approach will gather rich data from all professional groups delivering palliative care to help develop implementation strategies that may facilitate discussions and referrals to clinical genetics.

2. Method

2.1 Study Design

Qualitative approaches are increasingly used, particularly in health settings permitting broad exploration of under researched areas, such as use of clinical genetics in palliative care. Qualitative research is particularly helpful to examine impacts of organisational or policy change (Mays & Pope, 1995) and thus it appeared a useful method to explore changing practice in light of the evolving field of clinical genetics. The methodology also acknowledges the pragmatic capacity of qualitative research to provide practical insights to enhance delivery of quality, evidence-based care (Sandelowski, 2004). Given discussion of clinical genetics within the context of palliative care might be relatively novel to many participants, a qualitative approach was felt able to examine of the complex accounts of health care workers with divergent opinions and experiences (Sofaer, 1999).

Thematic analysis (TA) was chosen as the most appropriate method by which to analyse data. Braun and Clarke (2006) describe TA as 'a method for identifying, analysing and reporting patterns (themes) within data' and states that in order for research to be evaluated effectively, it is essential to explicitly articulate what ideas influenced analysis of data and what methodology was utilised. The method utilised in this study addressed a broad research question in a relatively under-researched area and thus the analysis aimed to provide a rich description across the entire data set rather than focussing on narrower questions within the individual interviews.

2.2 Ethical Approval

Prior to commencing data collection, ethical approval was sought and obtained from the University of Leicester Psychology Research and Ethics Committee and the relevant NHS Trust Research and Development Committee (Appendix D).

2.3 Semi-Structured Interview Schedule

A semi-structured interview (Appendix E) was designed to gather information regarding the participants' exposure to a clinical genetics service, the perceived value of the service offered to them as professionals, in addition to patients and their families, and participants' appraisals of barriers and facilitators to discussion of genetic risk. Since the author's familiarisation with the palliative care service suggested some potential participants might have had little or no contact with the service, five short vignettes were utilised to stimulate discussion and provide a context for the questions. Research interviews ranged between 33 minutes and 67 minutes in length, with an average interview length of 43 minutes.

2.4 Vignettes

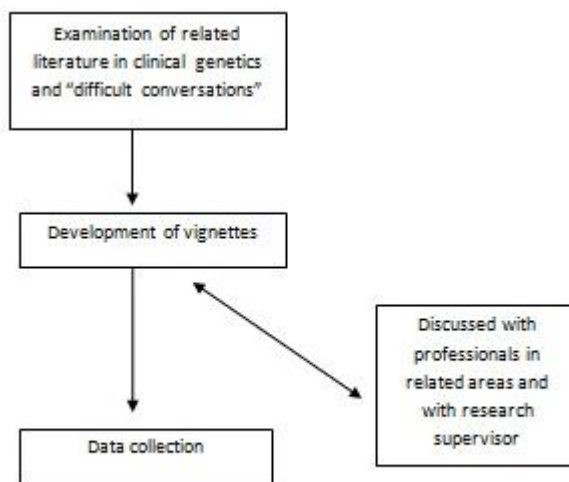
Vignettes, "short, descriptive sketch[es] of an incident" to "elicit their opinions and reactions to its contents". (Schoenberg & Ravdal, 2000) were utilised, mindful of the potential sensitivity of this topic area and to permit respondents a level of abstraction to mitigate social desirability bias (Gourlay *et al.*, 2014). The vignettes afforded three main benefits: allowing modification of information to be consistent with the specific research questions/ topics; potentially reducing

feelings of being 'overburdened' by the research interview; and finally permitting an element of depersonalisation and abstraction. Whilst acknowledging that direction of research might be influenced by the introduction of written material, vignettes were also considered to stimulate reflections of an experience to create a mediated account of the 'truth' (Spalding & Phillips, 2007) while also avoiding some of the ethical and practical problems of conducting direct observations (Wilks, 2004).

Four vignettes were devised to encompass these anticipated difficulties (see Appendix E) and were created after discussion with key professionals with expertise in clinical genetics and hospice/palliative care (Wilson & While, 1998). Design of vignettes was also informed by the published research evidence on areas in which discussion of risk appeared to be problematic for clinicians: possible concerns regarding the emotional responses of patients (Metcalf, Werrett, Burgess & Clifford, 2006; Heiniger, Butow, Price & Charles, 2013; Vos *et al.*, 2014); anxieties regarding the dissemination of relevant information to families (Ormondroyd *et al.*, 2008); and lack of patient awareness of the issue (Quillin, Bodutha, Simonoff & Smith, 2010). It was also noted that anxieties inherent in palliative care, such as uncertainty regarding prognosis and difficulties addressing emotionally charged issues with physically unwell patients may be relevant to the topic of clinical genetics (Barclay & Maher, 2010). There is also evidence that it may be more difficult to discuss clinical genetics with families who are in conflict and issues of shame and guilt associated with leaving a legacy of 'inherited' cancer may be problematic (Parkey & Lucassen, 2003). Minor amendments were made to the wording and proposed changes to the order in which the material was presented were

addressed. A further vignette was added to reflect the reported clinical experience of receiving increased referrals following media exposure of the issue and enhanced public awareness. The process of decision making is illustrated in figure 1.

Figure 1. Vignette Decision Flowchart



2.5 Epistemology and Methodology

Theoretical elements were present in the design given the research question aimed to explore a particular clinical issue, that is, what influences staff members' thinking regarding the use of clinical genetics in this setting. This informed the questions asked of participants; the nature of the vignettes thus provided a focus for the discussion of the subject in question. However, the process of conducting and transcribing interviews revealed a wide range of data with differing material given prominence and emphasis and it was therefore decided to take an inductive approach to data analysis to allow the themes to emerge from the data themselves rather than being coded on pre-prescribed

categories of interest. A fuller account of the researcher's epistemological position can be found in Appendix F.

2.6 Recruitment and Participants

Initial contact with the participating hospice was made through their research and development team. Recruitment was encouraged via poster display (Appendix G) in communal staff areas, email dissemination containing study information to all staff members, and via trainee attendance at team meetings to describe and publicise the research. The research project was also featured in the hospice research newsletter.

Participants were recruited from a hospice which provided inpatient, outpatient and community based specialist palliative care services.

2.7 Recruitment Procedure

Prospective participants volunteered their involvement via email in response to advertising material. A convenient time for interview was arranged within the participant's working hours to avoid unnecessary impact on patient care.

Participants were sent detailed information regarding the study at least 24 hours prior to their interview (Appendix H). They were presented with this information again immediately before the interview and given the opportunity to ask questions. Written consent was obtained and interviews were audio recorded (Appendix I). During the interview, participants were read each vignette and also given a written copy to refer to. A series of prompts were developed to help participants to elaborate their answers and process notes

were made by the researcher as soon as possible after completion (Appendix J).

2.8 Analysis

Analysis was undertaken in accordance with Braun and Clarke's stage model of thematic analysis (2006)

1. Familiarisation with the data

All interviews were conducted by the researcher and thus some knowledge of the data was obtained through this process. The researcher transcribed each interview and made further process notes of initial thoughts and reactions to the data (Appendix J). Following this, the transcripts were read and re-read several times to ensure immersion in the data and were also checked against the audio recordings to ensure accuracy. Initial ideas about the data were generated and noted.

2. Generating initial codes

A list of potential codes was generated by making notes on the transcribed data and identifying units of meaning (Appendix K). Braun and Clarke identify that it is important to consider whether coding at a semantic or a latent level, that is, whether codes are identified at explicit level or aimed at identifying underlying assumptions respectively. The interviews were constructed in such a way that they gathered both factual and descriptive information about the amount of contact had with the clinical genetics service and also hypothetical discussion around vignettes. Therefore, data was coded according to the 'best fit'; information giving responses at the semantic level and vignette responses at

the latent level. The data set was coded manually, with colours representing each code used to ensure the entire data set was included in the process (Appendix K). Following this, key quotes were taken and tabulated transcript by transcript.

3. Searching for themes

As recommended by Braun and Clark, the initial list of codes from individual analyses of the transcripts were represented visually on separate pieces of paper, allowing the researcher to move them around to identify emerging relationships and broader themes across the data set (Appendix L). From this, the initial themes and subthemes were identified.

4. Reviewing themes

The themes were reviewed initially in relation to the coded quotations obtained from the transcripts to ensure that data formed a coherent picture which was consistent with the theme. Following this, these themes were considered in relation to the entire data set and all transcripts were re-read to ensure that the themes accurately captured the data as a whole. The validity of the thematic analysis was aided by independent review of sections of the transcripts. Points of difference were discussed and integrated into the final analysis (Appendix M).

5. Defining and Naming Themes

The themes identified during the previous stage of analysis were then compared to collated extracts of coded data. This was to ensure that each theme told a coherent story that was consistent with both the question of

interest and accurately represented the narratives told within individual accounts. This process also involved checking for areas of overlap, ensuring important areas were not omitted (by ensuring that data were coded comprehensively) and through discussion between trainee and supervisor to define names of themes which accurately encapsulated the 'story' of each theme. Subthemes were added or removed as part of this refinement and examples can be found in Appendix M.¹

¹ A full chronology of the research process can be found in Appendix N

3. Results

Challenges to Changing Practice

Participants' comprised 13 hospice staff members of whom 12 were female. A broad range of professional disciplines were represented (see Table I). Experience of working in the hospice ranged from six months to 23 years. Due to the relatively small team working at the hospice, it was deemed inappropriate to collect more detailed demographic information in order to preserve participant anonymity.

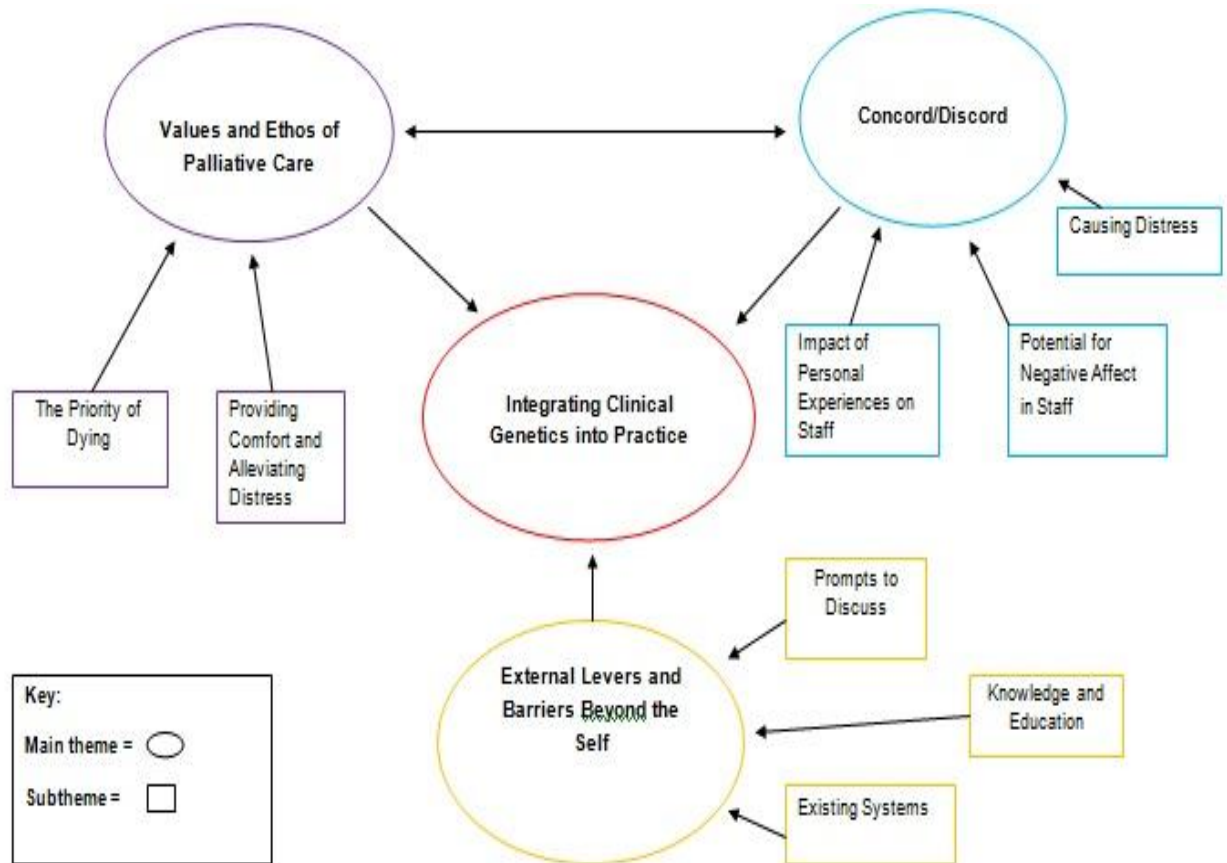
Table I. Participant Demographics

Job Title	Number of Participants
Clinical Nurse Specialist (Community)	4
Consultant (Palliative Care)	2
Health Care Assistant	1
Specialist Palliative Care Registrar	2
Staff Nurse (Day Unit)	1
Staff Nurse (Ward)	2

Four main themes and eight subthemes emerged as palliative care clinicians reported efforts to integrate a genetic perspective into end of life patient care (Figure II). The subthemes were identified as related to the main theme, yet held internal consistency as smaller themes within the broader overarching title. For example, within the 'values and ethos of palliative care' theme, participants focussed on both the priorities of their patients as individuals nearing the end of life, yet also discussed their own drive to provide comfort and alleviate

suffering, so these became subthemes which stood alone and also complemented each other within the same theme.

Figure II – Interaction of Main and Subthemes



The theme of ‘*Values and Ethos of Palliative Care*’ was characterised by participants’ awareness and respect for the realities facing patients who are dying and also of the focus of their care to provide comfort and alleviate distress. Secondly, participants discussed the extent to which clinical genetics was seen as consonant with the values of palliative care. This theme focused on concerns relating to potential to cause patients and families distress. Participants also considered their personal experiences of those with cancer as well as considering their views regarding what they would wish to know. Some participants also described a desire to avoid negative affect which was

associated with not having sufficient knowledge to help or concern about 'getting it wrong'.

A further sub theme comprised external barriers to engagement with clinical genetics; participants reported a reliance on external prompts to think of and discuss clinical genetics with a patient. Perceived deficits in knowledge and education and the impact of external systems were also considered. Finally, participants discussed the process of becoming convinced of the use of clinical genetics as a key factor in the implementation of this area into a palliative care setting.

Values and Ethos of Hospice Care

The values and ethos of palliative care were evident within this theme with all participants raising their working context to contextualise the appropriateness of raising genetic issues in a hospice setting. These values were predominantly patient-focused, with emphasis given to the pressing needs of patients with limited time in which to make things 'right' in relation to both their level of pain and discomfort, and with regards to relational tasks with family members.

Participants gave consideration to what they saw as their primary responsibilities and duties. Each participant, irrespective of professional discipline, either focused explicitly on or alluded to the immediacy of care which appeared to be central to their work; "you're talking about dealing with the here and now, primarily we're here to look after that patient"; "at the end of life it can become quite insular because it's about the here and now" (Participant A). The data suggested that the drive to focus on the present was driven by two main

areas of concern; the priority of dying and the need to provide comfort and alleviate distress within a circumscribed temporal window.

The priority of dying

Most participants emphasised and acknowledged their role in managing the primacy of emotional and practical aspects of dying, and working with the potential stresses both for the patient and for their families; “we’re looking after people that are looking after people who are terminally ill, it’s quite a stress on the patient and the family”. “[patients] are often quite scared of me being there and the connotations of having a hospice nurse in their home...”; “most people who die aren’t scared of dying, they’re not scared of death...they’re scared that they’re not here anymore to support the family” (Participant C). In addition to intense affect experienced and expressed by their patients, there appeared to be consideration of the limited scope of the health professional relative to the enormity of caring for a dying relative, both emotionally and practically; “families and other carers are often really important...[the] health professional role is often quite limited in the grand scheme of day to day living” (Participant K); “if they’re nursing their loved one at the end of life...it’s the practicalities of arranging the funeral and...having to sort out the family, financially” (Participant D). Given the immediacy, potency and overwhelming size of the task at hand, it may be that hospice clinicians may not feel that clinical genetics forms part of their primary duties.

Providing comfort and alleviating distress

Allied to participants’ prioritisation of their need to empathise and address difficulties experienced by patients and their families at the end of life, was the

paramount need to give care which could alleviate distress to “make [patients] last few weeks as good as possible” (Participant I). “The patients that we’re looking after, they have a lot, with dying, a lot of things on their mind and a lot of worries...I like to think that we’re there to try and alleviate them”. This need was appraised as something desired by patients; “they just want to be comfortable...just want to be pain free” (Participant G). All of the participants discussed the “pressing need” for symptoms control to be “prioritised” (Participant A). Allowing patients to reduce their level of physical pain was explicitly linked to better outcome; “when someone comes for symptom control...you want to make the quality of life and appointments they make as useful as possible and as good as possible” (Participant M). It was noted that clinicians’ had their own ideas regarding what constituted a positive experience for patients, for example, “I’m realistic but I like to be idealistic, I like everybody to die comfortably, peacefully, without worrying about their family” (Participant C);

Alleviation of distress appeared linked to pressure to be omniscient and omnipotent, offering patients reassurance to their pressing questions irrespective of topic; “that’s really important that they feel calm, relaxed and confident that you know what you’re doing...we all strive to be competent in as many [areas] as possible” “they do kind of look at you and hope that you know or that you can give them information about everything” (Participant H); “they look up to you don’t they? They almost think that you know *everything* about everything” (Participant G); “if you’re somebody’s nurse, you have to instil confidence...if they don’t have confidence in what you do it’s very difficult to care for somebody” (Participant C).

It was also apparent that while the hospice aimed to deliver holistic care to patients and their families, it was the *patient's* pressing concerns and needs that were vital; "our motto is 'caring for you and your family' and so the family is very much in there with the patient, but the patient is essential to everything" (Participant A); "our first focus is always the patient" (Participant H). To ensure the centrality of patient need, nothing was deemed irrelevant or unimportant if expressed by a patient; "I think that staff should be able to explore people's worries and concerns...it doesn't necessarily matter what that topic is" (Participant M) suggesting that at least some participants felt that concerns should be addressed regardless of the clinician's perceived level of competence in the area. While many participants endeavoured to be led by patients' expressed needs they also acknowledged that more difficult conversations and topics could be broached if potentially beneficial for the patient; "[if] they're not wishing to discuss it [death] we have to tread very carefully...we can't really necessarily grant their wishes in the sense of where they want to be cared for" (Participant F). However, subject matter considered more threatening was understood to need careful management in order to sustain an authentic, therapeutic relationship; "it's about balance...between maintaining a relationship with her and not putting that relationship at risk by talking about something she doesn't want to talk about" (Participant E).

Concord and Discord

Expressions of the central values of hospice and palliative care seem valuable in understanding the next overarching theme, concord and discord. This theme encompasses responses in which clinicians construe clinical genetics as in harmony with, or antagonistic to, their values and their perceived levels of

competence. In summary, Participant K described the range of difficulties encountered by clinicians as they contemplated the question of raising genetics; “[reluctance to discuss clinical genetics may be caused by] their own feelings and competence around understanding family genetics, some of it may be around any personal vulnerabilities...some of it may be handling strong emotions that the patient may show if they get upset...they may feel...that it’s someone else’s job”. This overall theme appeared to have three distinct but inter-related subthemes of; fear of causing patients and families’ distress, the impact of personal experience, and potential for negative affect in staff.

Causing Distress

Fear of discussing the area clumsily was associated with anxieties about doing harm to someone perceived as already profoundly vulnerable; “it might come out wrong and cause the patient more distress than they were in in the first place” (Participant I). Some participants considered possible discussions about genetic legacy as provoking issues and affect that could not be controlled or addressed, for example, “one of our concerns is that we’re opening up a can of worms and who will look after them, particularly as a family after the person’s died?” (Participant B).

All participants expressed a belief that raising genetic issues would undermine an explicit role to provide succour and relief, “... *particularly* at the end of life, we feel we’re there to...give comfort and ease distress, so it does feel like you’re *adding* distress...[and that’s] contradictory to what you aim at” (Participant N). The deep and empathic understanding that the participants strove to offer their patients was evident in most accounts which expressed

such apprehension about how discussions about genetic anomalies may further burden a patient; “I think if somebody’s dying they’ve got enough on their plate with dying” (Participant C); “you don’t want her to have anxieties and extra worries on top of everything else” (Participant D); “they’re quite stressed without you throwing another firework in” (Participant E). Mentioning clinical genetics was thought to be particularly difficult if a patient had neither instigated discussion nor had previous overt conversations; “if they haven’t considered it then *broaching* the subject I think I would find quite hard” (Participant F). If families were to be alerted to increased risk of developing cancer, the potential for mindfully engaging with dying in a way that could be healing and calming was felt to be jeopardised; “it can become a *huge* component for the family if they’ve never considered it before...you’re kind of watching how you might die in a very much more focused way” (Participant B).

Almost all participants considered that patient equilibrium would be disturbed through inducing guilt in relation to discovery of a genetic link; “...if no one’s thought of that before, and potentially opens up a range of thinking and emotional response around am I passing things on? Am I blaming people in previous generations? What kind of legacy am I leaving for my family? There’s potential for that to disturb people’s coping” (Participant K). It was also apparent that participants anticipated increased anxiety for family members, for example in relation to what could happen to them and to future generations “it brings about all your fears about your own mortality, about what could happen to your children” (Participant A).

The timing of these conversations was also seen as a key factor in the potential for distress; “doing it in the last few weeks of life is potentially

traumatic to the family members who have other things going on and it's not helpful for that patient" (Participant M). Discussing genetic risk *at this time* appears to influence clinicians' as they question the appropriateness of this subject for their patients. Several participants, were concerned that the hospice was not the correct part of the 'system' to be addressing patients' potential genetic risk and many assumed that this would be raised earlier in the patient's cancer journey; "when someone is in the last few week of life, I don't know how helpful it is to do that [discuss genetics]" (Participant M); "people...assume it will have been done previously by the surgeon or the oncologist" (Participant N); "I definitely think it's probably something that should be discussed in the early stage" (Participant G).

Impact of staff's own experiences

All respondents were either explicit or alluded to framing decisions about discussing clinical genetics with reference to personal and anticipated experiences. This appeared to be expressed to two ways: firstly through empathy or identification, expressing what they would value if dying; "if it was *you* in that situation...I'd want my daughters to have the possible chances in the future" (Participant E); "staff put themselves in a position which empathises with that patient and then they might think, if I got that information how would I cope with that" (Participant M). Secondly personal experience was filtered via views of the clinical genetics service derived through work, with one participant explicitly giving precedence to this anecdotal experience in contrast with formalised knowledge from research findings; "I think like lots of people I probably attribute more...value to personal experience than to raw data" (Participant K). For others who had experienced liaison with the clinical

genetics service, positive experiences were associated with appraisals that hospice staff could use services for benefit; “it was a very thorough assessment of her genetic risk...it felt like that *really* worked” (Participant N). By contrast, a negative experience appeared to be associated with doubt about the merits of clinical genetics; “[when] there’s no timely response, it does put you off really” (Participant M); “when you’ve sent someone and it works badly...you feel quite differently about the risks and benefits to somebody” (Participant K).

Potential for negative affect in staff

Some participants expressed anxieties about raising clinical genetics as they believed their position as a healthcare worker may unduly influence them for example; “I wouldn’t feel that I should really have too much influence because I might try and push something that would be the *wrong* decision...I wouldn’t want to be blamed” (Participant F). Perceived risk of error and eliciting distress appeared to be linked to a lack of confidence in their knowledge of clinical genetics; “it makes you feel unsettled...incompetent isn’t the word but you feel a bit lost because you haven’t got that information”; “you just feel a bit deflated because you can’t help” (Participant H). ‘Self’ as seen by patients could also be adversely affected in relation the participants’ perception of competence in providing emotional containment; “[if you know a patient well] you’ve already proved yourself in other areas so they’re not going to think you’re a complete duffer...it’s about confidence” (Participant D). Other participants focused on the potential impact of raising a conversation that they then couldn’t adequately address, “you’re always a bit kind of on your guard because what you say could be something that that person remembers for the rest of their life....things stick with people don’t they?” (Participant J). Anticipating causing a vulnerable

patient distress seemed to be a powerful disincentive to discussion, “maybe I’m protecting myself as well because...I don’t want to think I’ve caused anybody those anxieties and I can’t resolve it” (Participant D).

External levers and barriers beyond the self

There were a number of issues discussed which focused on perceived realities of introducing, implementing and embedding clinical genetics into routine practice. While a number of barriers were discussed, there were also suggestions of where existing systems could facilitate discussions about clinical genetics and areas for development which might assist integration of genetics into routine care. These were grouped into three subthemes which although describing distinct areas were again related to each other; prompts to discuss, knowledge and education, and existing systems.

Prompts to discuss

All participants expressed a sense that genetic issues and use of diagnostic and intervention services was seldom raised and discussed within the context of end of life care; “we tend to see them...more in the terminal phase of their disease...it’s not something we come across on a regular basis” (Participant E); “I can’t say we’ve actually had regular contact with them. It comes in fits and starts” (Participant A); “it happens so rarely I haven’t got on board with it really” (Participant E). This absence or limited discussion of genetics rendered it peripheral and “fading from memory” (Participant K). Genetic discussions seemed to be capricious and related to clinicians’ own pre-existing areas of interest; “there are a few people who it’ll be really strongly on their agenda because they’ll have read something or know about it” (Participant K); “doctors

are quite variable [in thinking about clinical genetics], we have our own interests, some probably wouldn't do it unless there was a prompt" (Participant M).

The 'prompts' that made it more likely that a clinician would discuss genetics were consistently noted by participants; if patients were younger, experienced multiple incidence of familial cancer, and initiated discussion; "[prompts are] things like patients where there's a very clear history of multiple cancers, multiple young relatives...there's kind of common clinical things that make me think about it...and if the patients bring it up *themselves* are probably the two main prompts in my mind" (Participant N); "it has to be *glaringly* obvious to me...it's probably something a person would bring up with *me* probably more than something I would straight away think of in my own head" (Participant D). If patients were deemed to be 'younger' (for example, those with young children) or had large, extended families, there appeared to be additional factors which promoted clinicians' likelihood of considering clinical genetics, for example, the visibility of the next generation who could benefit from risk information; "[the family] are your reminder...it's there in front of you and it's that generation" (Participant A).

Many participants discussed the importance in assessment of taking a thorough family history and developing a family genogram. While this could identify other family members who had died of related cancers, the genogram did not appear to be directly related to identifying genetic risk; "it's normally not asking your family's medical history, it's normally about trying to gain a picture about who's around and who's important to you" (Participant C); "[the genogram is] to see where the support network's coming from" (Participant D); "Vignettes had

stimulated focus on the communication with patients' who do not speak the same language as their health care professional. Linguistic differences raised concerns not just about omitting genetic risk but all cues from patients; "how do you pick up cues that aren't in your first language? Do you rely on the interpreter?" (Participant B); "when you talk to somebody in your own culture, there's similar cultural norms...you don't know how they think" (Participant I)

Knowledge and Education

All participants directly raised their knowledge of genetics and available services as a factor that could help initiate discussion and mitigate a lack of confidence in raising genetic issues; particularly striking was the apparent impact that this had on the clinician's confidence in broaching the area; "my discomfort would be the knowledge behind it...if I was to be asked specific questions on genetics I would not have an absolute clue" (Participant C); "it's definitely the lack of knowledge that stops you...talking about it...I wouldn't even *think* about it" (Participant G).

Several participants expressed a desire for greater knowledge and learning more; "a lot of people...don't know the referral criteria or might not feel confident in the actual knowledge of what they need to ask" (Participant M); although it was unclear who should be responsible for initiating learning "we're lacking in education...who should we be referring? When should we be referring? Have they been referred?" (Participant A). Some participants sought protocols to aid discussion; "I would possibly benefit from having some sort of guidelines just on how to *broach* the subject and whether it is a subject that should be broached" (Participant F). Where participants had received training

and education from the clinical genetics service, this was seen as a helpful addition to their practice. and an important reminder of its role in a palliative care role; “we’ve had...quite a lot of education really...and I think just that reminder...that that is there even if we feel we shouldn’t have to be addressing it as much” (Participant N).

Existing Systems

Many of the participants discussed pre-existing systems which facilitate integration of clinical genetics into practice, for example, “we have a handover every morning...the team doctor sees the patients everyday so hopefully...some of this would have come forward already” (Participant A).

Many raised the important role of protected and allocated time to discuss patients, to facilitate decision making regarding complex patients with multiple competing needs; “we have team meetings, we have handovers...if something, anything crops up then that’s where I’d discuss anything that was concerning to me” (Participant J); “we only have a small window of opportunity...but we can talk to the medical staff in an MDT meeting” (Participant I); “part of having a discussion at MDT is...we’re all kind of collectively trying to figure out the issues” (Participant K). Scope for enhancing integration of genetic dimensions to care appeared to be influenced by team communication and safety. Some participants described being relaxed about discussing new initiatives which were unfamiliar to the wider team; “We’re all open and that’s the good thing here, I would feel really comfortable...you can talk to anyone and we’re open-minded” (Participant E). However, some participants noted concerns about process of communication, particularly if they worked in community settings; “the medical and the nursing profession as a whole have a very poor history of

communication, I do think it's better here [than previous job]...I think as the community team we *are* a little bit out of the loop, because the hospice has its own inpatient things" (Participant C). Concerns about communication were also expressed in relation to reliance on translators and the level of trust required within this working relationship; "it does worry you if you've got a limited resource of people to come and help you translate and get information over" (Participant A); "In addition to potential benefits and difficulties associated with discussions between different professions, some practical issues were raised regarding access to patient information and records from other service providers; "we've gone onto a paper light system here so all our patient records are on computers and the one thing we haven't got there is a genogram" (Participant A); "training doctors come through every four months...we've done [training] but it doesn't necessarily pass into established practice...partly because our electronic notes system may need a template...to make things embedded in practice" (Participant B); "often we have quite limited information...oncology notes are in a separate folder to the main notes" (Participant M).

Three participants suggested that the changing and expanding role of the hospice, and staff roles, could be significant in considering the potential role of clinical genetics in the hospice; "there's lot more acute and palliative care here [than there used to be]...things have changed...it's not always quiet and you're not always holding hands" (Participant H); "we see people earlier on probably now than we did 10 or 15 years ago" (Participant M); "often people progress very rapidly and there isn't time...there might be a whole swathe of patients that are being missed" (Participant N).

Integrating Clinical Genetics into Practice

The final theme encapsulates participants' consideration of factors which facilitate the likelihood that genetic foci may be integrated into standard practice. Participants considered this likelihood largely via the perceived utility of clinical genetics for their patients; "they can feed the knowledge into us that it makes a difference and...you can stop people getting it...and that's a *huge* revelation!...You'll save lives really" (Participant B); "you're giving them the chance aren't you? That they might not have to go through what *you're* going through" (Participant G); ". Yet genetics could raise uncertainty and be detrimental; "it's not like getting a diagnosis of Huntington's where you know you're going to get it, there...isn't an absolute guarantee that you are going to get that" (Participant M); "it's *chance* and risk isn't it rather than certainty so it leaves people with still a lot of not knowing when what they're trying to seek is...some certainty....It can make it emotionally *more* difficult to be seeking answers" (Participant B) which might preclude integration.

Many participants linked the idea of potential initial distress with eventual benefit and reassurance and thus increased the likelihood of clinical genetics being integrated into their practice; "if it caused distress for the patient initially, it might be that over time, they are actually reassured by it" (Participant F). This could also be seen in the context of other difficult conversations that are had within the hospice setting; "similar with many difficult conversations, we....*rightly* worry about the effect this is gonna have on our patient but if they're handled in a sensitive and appropriate manner, most of the time that's ok" (Participant N). A potential conflict was seen when raising an issue that was potentially not a concern for the patient thus leading to a sense of dissonance

between the clinician's goals and the potential impact of discussing genetic risk; "when you're highlighting things that aren't an existing concern to the patient or family...what's the likelihood that it's going to be of benefit for them?"

(Participant K). However, one participant highlighted the process of weighing up pros and cons expressed by many clinicians; "sometimes it's easier to...push a slightly difficult conversation when you think there's going to be a benefit"

(Participant K).

A further factor that influenced participants' consideration of integrating a genetic perspective was a lack of clarity about what happened to genetic material.; "if we didn't get any feedback from genetics it's one of the things that it becomes something else to do, and when it's something else to do it's always a bit laborious" (Participant M). One participant discussed how they felt the hospice and the clinical genetics service needed to work together routinely to remain mindful of genetics; "it's got to be collaboration on this...they need to understand the sort of care the hospice provide...and we need to understand the sort of care and role that they have and the potential that they have in order for it to work well" (Participant B) and to ensure it became rooted in practice "I think it becomes embedded in the culture if it happens enough and becomes the norm...I think it increases everyone's confidence to talk about those issues and see it as something...we do talk about in the hospice" (Participant N).

Professional Differences

The inclusion of nursing and medical professionals permitted consideration of differences emerging between participants' accounts. All participants were asked about their current level of direct contact with the clinical genetics

service. Whilst all medically trained participants had direct experience of referring to or working with patients affected by diseases with genetic mutation/anomaly, no nurse described having worked with these issues directly. Furthermore all medical professionals interviewed had attended educational events related to clinical genetics whereas only two nurses had either attended a talk given by a clinical genetics nurse and one had instigated contact with a genetics professional as part of their continued professional development. Participant quotes are presented here with different participant codes based on profession to preserve anonymity.

Themes elicited appeared largely universal irrespective of professional background; every participant noted potential for patient or family distress as a result of discussing a potential genetic component to their illness. All participants discussed their reliance on external *prompts* to discuss the genetic issues, whether this emerged from a patient or was cued by history of multiple cancers across generations. However, doctors seemed more likely to talk about needing to raise the issue in circumstances where the patient had not identified the need for themselves, for example; “if someone’s not initiated it, then you might bring it up to see if that’s something they’re thinking about” (Medic 3).

Professional differences did appear evident in relation to *knowledge and education*; all nursing staff interviewed expressed a need for further information, education and training. Although medical staff did describe their specialist knowledge of genetics was circumscribed, they felt knowledge was sufficient to feel confident in seeking advice or making a referral. Furthermore, no medical staff discussed the potential emotional impact to themselves as result of discussing clinical genetics with a patient, whereas seven nurse participants

discussed the potential for feeling shamed - 'rubbish' (Nurse 3), 'blamed' (Nurse 5), 'a fool' (Nurse 6), and as though they had 'let patients down' (Nurse 7). By contrast medical participants reported feeling sufficiently assured to reveal less knowledge, "I'm quite comfortable at admitting my ignorance really" (Medic 1); "I'm happy saying I don't know enough about that...I don't have an issue revealing that to people" (Medic 2).

4. Discussion

The expansion of the discipline that is clinical genetics may now permit identification of those whose risk of cancer is increased through genetic mutation. Treatment options for those affected have also developed allowing for the modification of cancer risk. Despite this, the present study suggests that a gap remains between this knowledge and its consistent application in a palliative care setting. The results within this study indicated areas which could perhaps be expected in relation to staff acquisition of practical knowledge regarding the genetic bases of conditions. This was particularly in relation to who and how to refer, as well as how existing systems may impact positively or negatively on the likelihood of referring to clinical genetics. However, of perhaps more interest were themes which related to perceived core values of palliative care and its delivery, and the extent to which clinical genetics was appraised as being in harmony or discord with these values. The 'weighing up' of these two elements was represented in a theme which concerned the integration of this relatively novel area into clinical practice and participants described the process of becoming engaged with, or deterred from acting.

These results support previous research which has suggested that as people die, hospice nurses believe that clinical genetics should have been explored prior to the terminal phase of their illness (Metcalfe, Pumphrey & Clifford, 2010). The qualitative findings also echo those of Lillie, Clifford and Metcalfe (2011) who found that nurse participants described missed opportunities to intervene and concerns that the hospice was an inappropriate setting in which to discuss clinical genetics. The present study develops these ideas further, not only through the additional perspective of medical and community nursing

viewpoints, but also by using vignettes to allow for a richer understanding of the areas in which it would be helpful to target in order to make clinical genetics a more obvious area of attention for specialist palliative care staff. At the time of writing, the author was unaware of any research exploring the perspectives of doctors regarding the appropriateness of discussing genetic risk at the end of life.

The Unique Context of Palliative Care

Permeating the themes were the key values that govern palliative care, which emphasise special meaning created between patient and clinician in the context of the patient's limited time as paramount (Mok & Chiu, 2004). Whilst the study included members of the community team, all participants came from the same hospice and were based there. Hospices themselves have unique status, many receiving some funding from the NHS, but most run as charities and are independent entities (Fennemore, 2009). While NHS philosophy has increasingly promoted patient choice and active participation in care decisions, the terminally ill are particularly vulnerable and otherwise competent individuals may be effectively disabled by a hospice environment or indeed, the experience of being terminally ill itself. This is therefore somewhat at variance with the NHS ethos of patient choice (Scott, 1999). The social context of the hospice may thus affect decision making to pursue genetic counselling or testing.

Respondents noted concerns that their views may unduly influence those in their care, and there is recognition of the implications of illness on cognitive function and the vulnerability of seriously ill patients to 'mindlessly adopt' the views of their clinicians (Epstein & Street, 2011) Introduction of genetic-based

discussions may need to be tempered by explicit recognition of patient and family vulnerability.

Respondents also emphasised difficulties addressing clinical genetics in association with complexity of care. Indeed the shared social context of hospice care may affect novel developments given its complex relationships with multiple partnerships with community organisations and large multidisciplinary teams (Kobayashi & McAllister, 2014). Locating responsibility for where and who should raise these sensitive issues may be diffuse.

The relational focus of palliative care

Respondents, in their emphasis on the primacy of dying and the intimacy and intensity of this experience, stressed also relationships with patients that were mindful of distress and focused on the alleviation of suffering. Concerns about raising genetics unsurprisingly focused on potential to do harm, counter to Hippocratic tradition. The literature regarding clinician-patient relationships in end of life care describes the 'fleeting but intense' nature of these interactions (McNamara, Waddell & Colvin, 1995) which may explain why clinicians experience feelings of wanting to protect their patients from areas that could increase distress at an already difficult time.

Clinicians in this environment gave some sense of how they respond to the existential suffering they witness, often, deploying skills beyond scientific and technical knowledge (Boston *et al.*, 2011), to negotiate boundaries of relationships with patients. These specialist staff may be amongst the first people to honestly discuss the likely progression and prognosis of the patient's condition complicating the patient-clinician relationship (Zambrano *et al*, 2014).

This has implications for introduction of further sensitive topics such as clinical genetics when staff may already feel a burden of responsibility for breaking bad news and have concerns that discussion of genetic risk may be construed as a further threat or burden. Clinicians in the present study also expressed concern about prompting poor decisions which could be the focus of regret. These findings have been demonstrated elsewhere (Lee, Kristjanson & Williams, 2009), however, it was also noted that the relationships formed facilitated greater engagement of the patient in the decision making process and were a positive influence.

Furthermore, participants described multiple relationships with other stakeholders beyond the specialist hospice environment, not all of which were felt to be adequate or helpful. The findings echoed other exploration of interactions between generalist and specialist palliative care workers (Gardiner, Gott & Ingleton, 2012) in which communication could be asynchronous, inappropriate or irrelevant. As with the current study poor mutual understanding of roles could adversely affect team working and lead to territorialism over patients. This latter response may exacerbate workloads if specialist staff feel others are less driven to provide what they deem excellent care. As clinical genetics is likely to become a more integral part of a care pathway to optimise 'last opportunities' to obtain genetic material and to inform decisions about genetic risk (Lakhani *et al*, 2013), greater thought should be given to how its benefits are conveyed and framed within working relationships given these are likely to influence its successful uptake (Koboyashi & McAllister, 2014). While formal spaces were valued and important, the creation of informal relationships with collaborators also promoted goodwill between clinicians and strengthened

partnership working (Mahmood-Yousef *et al*, 2008). This is consistent with data in the present study suggesting that positive or negative interactions, and their perceived outcome for patients, acted as a powerful reinforcer for future referral behaviour. This suggests that not didactic information, but also the development of relationships with clinical genetics staff would be an important factor in promotion of this area, which is mirrored in participants' accounts of how positive and negative experiences influence their decision making in the discussion of genetic risk.

The role of affect

Dominant in many nurses' narratives was the reported avoidance of negative affect, particularly in relation to being unable to answer patient's questions (lack of genetic knowledge), a sense of letting patients down and feeling blamed in relation to decision making. This theme was elicited only from nurse participants despite common themes across professional groups in other elicited themes, and may reflect the intense and consistent nursing role in direct, continuous patient care.

Affective responses of hospice staff, especially negative emotions, is under-researched (Boston *et al.*, 2011), yet they are indirectly referred to in evidence that hospice staff attempt to reduce the emotional impact of their work through creating opportunities for 'good deaths'. These are defined as when patients are calm and prepared for death (McNamara, Waddell & Colvin, 1995). If staff fail to manage a good death, as many noted in this study, care is construed as compromised which may breach staff's need to do good (Semino, Denijen & Koller, 2014). Indeed in this study raising genetic issues appeared to be

associated with unsuccessful interventions, and may be marginalised in attempts to ensure the good death and allay staff concerns (Kamau *et al.*,2014)

Staff may be at risk of distress in hospice care with negative emotional end points; however the focus of education has remained on tasks of care rather personal coping strategies. There is a dearth of literature relating to the emotional coping of medical staff, however, Zambrano *et al.*, (2014) found that doctors were affected both positively and negatively by their work with dying patients. While affect was acknowledged, the reactions to patient death were reported as being short-lived and a tendency to play down the emotional impact was noted. These results suggest that there are differences between nurses and doctors in relation to how readily able they are to express and manage the affective demands of their work. Given that clinical genetics has the potential to interfere with clinicians' main aim to reduce or eliminate distress in their patients, this could be an important area for consideration of how to integrate this more fully.

Integrating into practice

Considering both the appraisals of staff expressed here, the unique setting of palliative care and evidence base on what can enhance implementation, there are a number of areas in which to focus the development of clinical genetics. This study and the as yet limited research base, suggests staff have legitimate concerns about the emotional impact of discussing genetic risk with both positive and negative impacts (Vos *et al*, 2013). Clinicians may be concerned not only for the patient, but also regarding the support needs of their families as they are left to manage uncertainty at an already difficult time and the potential

additional impact of having a lived experience of a loved one dying from the disease in question (Middleton, Hall & Patch, 2015). It has been noted with other genetic conditions such as Huntington's Disease, that medical and ethical dilemmas are often entwined and complex (Anderson *et al*, 2013). It seems likely that clarity and reassurance from the clinical genetics team regarding responsibility for the psychological implications for families would be helpful in allowing clinicians to not feel burdened in a system where resources may already feel scarce. Parallels could be drawn with other similar conversations, for example, regarding prognosis, which are described as 'difficult'. In fact, several participants in the present study drew these parallels themselves and described areas which they thought were similar and/or specific to the idea of discussing genetic risk.

Staff may be exposed to evidence regarding those who had accessed genetic testing for breast cancer after developing the disease, in which the majority wished that they had known earlier and were focused on their families (Vadaparampil *et al*, 2008). Framing the benefits of engaging with patients as 'late for the patient but early for the family' may help develop scripts to use in discussions (Quillin, Bodurtha & Smith (2008). Balanced discussion in which legitimate ethical concerns can be aired, may enable clinicians to understand benefits of genetics as part of the palliative agenda. Given that many participants discussed the need to focus on the patient's family as part of their delivery of holistic care, this appears to be an important consideration for how knowledge about genetics is delivered to clinicians.

Understanding Implementation of Clinical Genetics

Introducing discussion of clinical genetics was described by participants as a complex process with evidence of some resistance to implementation. This can be understood with reference to psychological models used to understand health professional behaviour in other contexts, such as the Theory of Planned Behaviour (TPB) (Ajzen, 1985). This argues that behaviour change is influenced by intention to perform an action, which is mediated by attitudes towards the intervention, the perception of others' attitudes (subjective norms) and the perceived level of behavioural control over the situation. However, more recently, the limited predictive capabilities of the model as well as a focus on more rational elements of decision making over affect and emotional-based factors have led to criticism of the model (Ajzen, 2011). Indeed the respondents in this study expressed more emotionally-driven behaviours in their fear of eliciting patient distress and revealing themselves to be incompetent. This suggests that the TPB does not provide a comprehensive model with which to understand the complex interplay of systemic and affective factors in understanding the application of clinical genetics.

The limits of the TPB model have been acknowledged elsewhere and extended versions have been utilised to explore intention to obtain genetic testing in the general population, with attempts to address more affective components (Wolff *et al*, 2011), however, a detailed exploration of staff perceptions and attitudes has not been carried out in the area of clinical genetics. Frameworks exist to conceptualise how new practices are implemented in health settings to ensure that research is translated into meaningful patient care outcomes, for example, Damschroder *et al.*, 2009. These may have some relevance for staff

experiences reported herein, particularly whether the task of eliciting genetic material has 'good fit' with the individual's belief about self and working context which may reflect some of the dilemmas faced by the present study's participants in deciding the relevance of clinical genetics for their work. Also consistent with Damschroder's (2009) findings, current participants' alluded to organisational networks and cultures, such as formal MDT meetings and their interaction within these, that may be seen to affect adoption of clinical genetics. In addition, the importance of the individual and how they interact with the organisation are considered.

Any intervention to enhance the reference, use and application of genetic knowledge to request material should be mindful of the diverse barriers and levers to change articulated by study participants. Consistent with review regarding implementation of best evidence into practice, multifaceted interventions sensitive to the hospice setting, incorporating audit and feedback regarding current practice, decision making tools and 'opinion leaders' to champion integration of genetic dimensions will be needed to promote change (Boaz *et al*, 2011).

4.1 Strengths and Limitations

While previous studies have explored nursing perspectives on the integration of clinical genetics in a palliative care setting, this study has sought to understand a more complete range of clinical staff. It has also been mindful to use vignettes as a tool to elicit data in a potentially sensitive area for discussion, considering their scope to provide explicit contextual information for answers elicited, and ensuring that they are rooted in the clinical setting to ensure credibility. The

vignettes were therefore deemed both a strength, by allowing exploration of areas suggested by the literature, but also a weakness as they, by their nature may have influenced participants to consider areas which may not have occurred naturally.

Though the present results seem to fit with the limited available evidence to date, clinical genetics is a comparatively new domain of care and its application of this in a palliative care setting more so. The current sample were recruited from the same hospice, likely to be exposed to similar culture with a strong emphasis on research and may not be representative. The study also used a self-selecting sample of volunteers in which those more interested or familiar with genetic counselling may have been more likely to participate, although in fact participants varied in their knowledge and familiarity recorded. A need to protect the participants' anonymity precluded use and analysis of fuller demographic details (such as age, ethnicity or gender) in this small system.

4.2 Clinical Implications and Recommendations for Future Research

While exercising appropriate caution regarding the methodological limits of the present study, some useful areas for development have been revealed:

- **Addressing Intervention at Multiple Levels.** First of all, the wider evidence regarding implementation of novel areas suggests that the complex and at times ethically challenging area of clinical genetics should be addressed at multiple levels to become successfully integrated into palliative care.
- **Increasing the Knowledge Base.** Concerns about lack of knowledge and education in relation to the area of clinical genetics was apparent across all

professional groups and this appears to be one area where clinical genetics services could provide training to increase confidence in knowing who, when and where to refer potentially affected patients. This could assuage concerns about making errors in discussions with patients. It may be helpful for this additional factual knowledge to be linked to other areas of practice where difficult topics are broached such as discussing preferred place of death.

- **Building Relationships between Services.** The relational context of delivering palliative care appears to be as significant to the multi-disciplinary team as it is to patient care. The results of the present study indicate a need to promote and nurture the more relational aspects of collaborative working to encourage more informal exchanges between clinical genetics and palliative care staff.
- **Keeping Clinical Genetics Prominent in Palliative Care Agenda.** To ensure continued awareness of genetic issues, regular training as well as promoting opportunities for colleagues from different teams to ‘shadow’ each other are potentially useful. Services may find it helpful to include clinical genetics as an agenda item during multi-disciplinary team meetings to ensure this is considered and discussed alongside other routine care objectives. It appears that interventions which are seen as consistent with the aims of palliative care are adopted successfully so therefore framing clinical genetics within the wider aim of delivering holistic care to the patient and their family may be helpful.
- **Involving all Professions in Training Opportunities.** It has been noted that nurses and healthcare assistants spend a great deal of time interacting

with their patients and the intimacy of care tasks often develops close and trusting relationships within which patients discuss their hopes and fears. A familiarity with clinical genetics would allow more opportunities for concerns to be identified and taken further as part of a whole team approach.

- **Further research.** The present study identified a number of areas for future investigation. Differences between professional groups in relation to the expression and experience of affect related to their patient interactions does not appear to have been comprehensively researched and focus here could give valuable insights into how multi-disciplinary teams function in practice. The present study was also restricted to discussions regarding BRCA 1 & 2 mutations, however, the capacity of clinical genetics to identify a wide range of genetic frailties is ever expanding and raises ethical dilemmas ethical implications, for example, regarding what information to share and with whom. While there are clear pathways for those identified as carrying BRCA mutations to modify their risk of cancer, this is not the case in all areas and could have implications for whether patients would wish to be privy to such information.

While research regarding clinical genetics in the area of palliative care is relatively in its infancy, this appears particularly pertinent for those from diverse cultural backgrounds. While this is touched upon in the present study, it would be helpful for future research to more fully investigate the acceptability and interest of people from minority ethnic backgrounds in discussing potential genetic risk, in order to promote equity of accessibility for patients from all backgrounds.

As a profession, Clinical Psychology appears well-placed to support the implementation of many of these recommendations, with specific skills in working with and managing complex systems. This may be pertinent to not only staff teams but also to the family systems that palliative care clinicians routinely engage with. Psychological ways of thinking about how to respond to and manage strong affect may also be helpful, along with the introduction of models of reflective practice in order to give clinicians a well-defined and containing space in which to consider their responses to their clinical work. Clinical Psychologists may also be able to offer expertise in the development of further research and the evaluation of patient outcomes as this area becomes more embedded within routine practice.

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Part 3

Critical Appraisal

3. Critical Appraisal

3.1 Introduction

The following critical appraisal is based on a reflective journal and field notes which were kept throughout the research process. It is not intended to provide a comprehensive description of the research process, but will focus on key reflections and experiences.

3.2 Development of the research area

It has been noted that in order to produce high quality qualitative research, it is necessary for the researcher to understand their own values and norms while remaining mindful of the pressures of the institutional context in which the research is carried out (Malacrida, 2007). As such, reflections on how I came to choose my research area are valuable in the critical appraisal of the thesis project.

Although I came to clinical training with a broad range of clinical experience and some confidence in my ability to engage and work with clients in a clinical capacity, I was somewhat more ambivalent regarding the research process. I had been fortunate in that I had been given opportunities within previous clinical roles to contribute to service related research, however, I was uncertain that these experiences would have furnished me with the necessary skills to undertake a doctoral level project. I also came to the idea of research with some cynicism given that within my previous roles I had experienced some resistance to the findings of research from other stakeholders and a sense that the hard work undertaken had been 'lost'.

In addition to this, I reflected on my experiences as an undergraduate psychology student which was my only other 'formal' experience of carrying out research. I had enjoyed the process, however, I was aware that I was 'juggling' significantly more in terms of roles and responsibilities as I embarked on my second degree. My undergraduate dissertation had focussed on neurodevelopmental conditions, specifically Autism Spectrum Disorder, something which I have personal experience of within my immediate family. While I was aware that my personal perspective had in some ways enhanced my engagement with my research, I was keen to, for the present thesis, pursue an area which was not so personally relevant in order to broaden my research skills and experience.

My first year placement was in a medical psychology service. This was a new area to me and one which I found interesting which undoubtedly influenced my thinking as I developed research ideas. My initial idea had been regarding the experiences of fathers who had been present during their partner's traumatic birth, which was prompted by clinical encounters. Through liaison with colleagues in the research area, I discovered early in the process that my research question was already being investigated at a different university. I recalled a project that had been presented to us during our cohort research fair; it was prompted by noted low referral rates from the local hospice to the clinical genetics service. Although this area was novel, I was interested in the idea of developing my knowledge and skills in a new area and given my previous research experiences, I was particularly taken with the idea that my research would have the potential to benefit local services and service users.

Following meetings with the hospice in question and with the clinical genetics service, I was further convinced that this area was one worthy of investigation. While there was a large amount of research looking at the impact of genetic counselling, particularly in relation to cancers, I was struck by a dearth of literature regarding its application with patients at the end of life. My deepening understanding of the importance of obtaining a living tissue sample from an affected relative in order to most definitively assess the risk of cancer mutation for successive generations further convinced me that this was a worthwhile research project. I was also aware of recent media interest in the area as an internationally recognised film actor had undergone risk-reducing mastectomy as a result of the Breast Cancer (BRCA) gene mutation. I was moved by accompanying narratives in the area where, predominantly women, were able to reduce their risk of suffering in the same way as preceding generations. Although I did not have personal experience in this area, I empathised as a woman in a similar age range to those often affected and considered my personal opinions regarding the options presented to affected individuals such as mastectomy or hysterectomy.

During initial meetings at the hospice I was struck by two things; first I noted that clinical genetics was not a high priority for those I spoke to which I concluded was understandable in the context of looking after patients at the end of life with complex needs. Second, I was impressed by the strong focus on research, with a dedicated research department existing on site. I found myself contrasting this with NHS services, where research is often harder to carry out due to a range of complex factors, not least of all the management of extensive

waiting lists. I believed that this would be an essential element of successfully recruiting participants and thus producing a useful research paper, a belief which proved to be correct. In addition, I had noted that the work of the clinical genetics team was, understandably, focussed on quantitative data and auditing and was very medical in its focus. Developing a research project which met the needs of the genetics service in terms of information, yet was true to principles at the heart of clinical psychology were therefore important to consider. I was also conscious that although the project was rooted in a local service, it was important that the research project have wider applicability. Extensive reading in this area suggested to me that while the local context is undoubtedly important, similar issues were present across the literature, including international papers from Australia and America.

3.3 Developing the Method

As the research question was related to the consistent adoption of discussion about genetic risk in the hospice, it appeared that staff would be the most appropriate target in relation to selecting participants. It also seemed, given the relative lack of research in the area, that a qualitative method would be most suitable to gain rich data about the clinicians' experiences. I had noted from the existing literature that although hospice nurses had been recruited for research in this area, I could not find any information relating to the experiences of doctors and I was therefore keen to include this perspective. By utilising staff members as participants, I was also aware that this would pose fewer ethical challenges than recruiting service users and thus was consistent with the

academic demands of the research which had specific expectations regarding the deadline for completion of research.

Deciding on methodology proved challenging. I had some experience of using qualitative methods and wanted to develop my rigor and skills in relation to this area. I had developed an interest in Grounded Theory (GT) as a method and initially pursued this as an option. The process of seeking feedback from university academics was invaluable here as it allowed me to understand why this method was unsuitable despite my interest. The research question was too specific and had set parameters which were at odds with the underlying assumptions of GT. The method also involved the concept of reaching 'saturation' and the uncertainty involved in this method of sampling meant that I could not work within pre-prescribed time slots for data collection (Charmaz, 2006). This prompted me to spend more time examining the relative merits and pitfalls of a variety of qualitative methods including Interpretative Phenomenological Analysis and Discourse Analysis.

Thematic Analysis (TA) was a method I was aware of, yet knew little about and Braun and Clarke's 2006 paper was instrumental in convincing me that this was a method which would not only adequately address the research question, but would allow some flexibility in relation to my epistemological position. I was yet to fully understand where I located myself on the positivist – constructivist spectrum and I was drawn to the idea that this method would allow me to develop my ideas within it. I was also aware that in order to elicit discussion in this area, I would not be able to rely purely on a semi-structured interview technique. I would be discussing elements of clinical care that were not

necessarily part of the clinicians' existing repertoire and I appreciated that TA and its associated flexibility would allow me to be creative in response to this challenge.

I initially investigated 'emotional touchpoints' as a means of achieving this, which had been used with some success in exploring patients' experiences of inpatient care (Dewer *et al.*, 2010). This intrigued me as I believed it would allow participants some distance from the subject matter and may elicit more 'honest' responses as it moved the focus from them and would allow me to pursue a more affect based agenda. I was concerned that previous research has highlighted the tendency of participants to give socially desirable responses, particularly in relation to their clinical practice (Nederhof, 1985). This method of data collection did not seem to adequately address this issue and I found it difficult to conceptualise how this would work in the context of my study. Further reading led me to the idea of vignettes; I was aware from conversations with clinicians in hospice care and from the existing literature, that there were a number of issues which may make it easier or more difficult to raise genetic risk as an issue and believed that using these a basis of discussion would allow the 'depersonalisation' effect that I was drawn to from emotional touchpoints, but would also allow the research to be more focussed in relation to the area (Schoenberg & Ravdal, 2000). From a personal point of view, my experiences of being a trainee participant in formal teaching where vignettes were often used as a basis for discussion, gave me some insight into how useful this can be, particularly when knowledge of the area is limited.

3.4 Recruitment and Data Collection

The process of data collection was facilitated enthusiastically by the research site in question and I am certain that the overall philosophy of the site contributed to recruiting a respectable number of participants. Practical elements such as ensuring room bookings for interviews, having access to desk space and general support from the team were invaluable. In order to recruit participants, I attended several team meetings at various points throughout the recruitment and data collection process. This not only encouraged participation but also allowed me to familiarise myself with the context of the research site. It was a point of interest in reflective journaling that I was not so aware of the emotional impact of stories being told about patients in earlier sessions. I felt overwhelmed in the face of the complexity of the clinical situations and the often unfamiliar medical terms being used. I also felt more external to the setting than at earlier points in the process and this afforded some distance and enabled me to intellectualise more about the subjects of discussion. However, at later points, having conducted some research interviews and joined staff members on home visits and ward rounds, I noticed that I connected much more readily to the accounts given in MDT meetings and was moved on a number of occasions, particularly when the patients were younger and their young families were discussed.

The reflective journaling process was essential as part of managing and processing the emotional aspects of conducting the research. Despite never having experienced these issues directly, I was struck by the level of empathy that I felt, particularly in relation to nurses' accounts of their work with people

who are dying. I used both my journal and academic supervision to examine my responses and to attempt to be mindful of how these could impact on how I conducted interviews and analysed data. I also noted that, through feedback from my supervisor, I was able to refine and develop my interview technique. It was important to maintain my stance as a researcher when the role of clinician was more familiar to me. Initial interviews bore many features of clinical practice with paraphrasing and reflections evident in many of my responses. I was also aware that I had missed some opportunities to press participants further in relation to their affective responses, unsure of my remit and wishing to avoid causing negative affect in the participant. I became aware that although in clinical practice a first encounter marks the start of a longer term relationship, rapport needs to be established quickly in a single event such as a research interview.

I reflected on how my desire to be 'likeable' to the participant and to promote a positive view of psychology had the potential to interfere with data collection, a factor potentially exacerbated by my knowledge that the site did not employ a psychologist as part of the team. Later transcripts showed a marked improvement in my ability to listen more and talk less, with a better balance between maintaining a respectful rapport with the participant while still pursuing interesting themes within the interview. I was encouraged by the literature regarding qualitative research which emphasised the development of qualitative research skills as a 'lifelong endeavour' (Roulston *et al*, 2008) which enabled me to reflect more on my personal development in the area rather than aiming to achieve a 'perfect' interview.

3.5 Data Analysis

I decided early on in the development of the research that I would transcribe my data myself. I considered my options in relation to having this done by an outside agency but this did not sit well for two reasons; I wanted to maintain ownership of my data and to some extent felt protective of my interviews. I also believed that this would allow me to become more fully immersed in the data and thus aid analysis. The time consuming nature of this job was frustrating at times; I had not fully considered the impact of practical issues, such as air conditioning systems that interfered with sound recording, on the level of difficulty associated with transcribing. Transcribing each interview as quickly as possible afterwards allowed me to address these issues early on. However, I believe the increased level of familiarity gave me greater confidence in having ideas about potential themes as I came to coding the data. I kept notes regarding my initial impressions following the interview and also following transcription. I was surprised to note that my affective responses to the interview material would often be one of the more memorable elements of the interview.

I was initially concerned by my affective responses, particularly in relation to how this may influence my interpretation of the data. A research paper by Malacrida (2007) was particularly helpful in understanding this. This described the traditional view of research as taking a 'disinterested, distanced and objective' stance which serves to promote and perpetuate the interests of the researcher and the wider academic system, rather than focussing on the desires and needs of those participating. This paper was particularly interesting

as it placed this dilemma within the perspective of feminist critique of conventional positivist paradigms which view emotions as contradictory to the pursuit of knowledge and thus support paternalistic, patriarchal institutions which exclude vast proportions of the population. Malacrida argued that emotional responses are unavoidable and thus need to be acknowledged. This, along with the researcher's consideration of their own biases, motivations and privilege can enhance the quality and reflexivity of qualitative research. It can also make research more accessible to those who have participated and thus be more applicable in 'real world' settings. I found these ideas interesting as a female researcher with an interest in feminist approaches. I also believe that the resonance I experienced in relation to these ideas encouraged me to acknowledge my responses as an important factor to be examined and not avoided as part of analysis.

The initial stages of coding at times felt overwhelming; this was evident in both my review of the literature in relation to hospice nurses' experiences of caring for the dying and in my own research. Undertaking two pieces of qualitative research posed challenges which I had not anticipated, not least of all how to maintain a coherent narrative which accurately captured the nuances of individual accounts. I was acutely aware of the time given by participants and was keen to 'do justice' to their accounts, not wishing to over simplify their accounts of their lived experience. This was a useful learning point which encouraged me to continually re-focus on the research questions and aims in order to not lost sight of the overall agenda. Again, I found myself contrasting this to the role of clinician, where individual accounts and experiences must be

balanced with information from the over-arching evidence base. I believe these experiences have improved my skills as a clinical psychologist in both clinical and research settings as I have been able to reflect on how one can be drawn into the detail while missing the 'bigger picture'.

During the coding process, it was useful to discuss these issues in supervision, particularly in instances where I had 'fell in love with' particular themes or ideas which were not consistent within the wider narrative. This need to account for my choices, for example, why I had chosen a particular title for a theme or had highlighted particular quotes as useful, was essential in the development of my research skills. I believe this encouraged me to engage more reflexively with the data and I noted that asking myself these questions started to become second nature as I progressed through the analysis.

3.6 Lessons Learned

Reflecting on the research process more generally, I have considered how these new skills will be translated and developed post-qualification. I believe the process of research as part of a doctoral thesis has encouraged me to develop practical skills in organisation and also my ability to switch between the different 'modes' often required as a clinical psychologist. Despite this, I am aware that psychologists are increasingly working in settings which do not promote research or protect time to do this with a greater focus on patient outcomes and throughput than in previous years. I have also been able to observe examples of how psychologists in clinical settings have continued to contribute to the evidence base and that this often requires considerable investment of personal time. This has encouraged me to consider how important it is that psychologists

continue to invest in research post-qualification, both as part of personal and professional development and also to promote the variety of competencies acquired throughout the process of training. This strikes me as essential in promoting the profession outside of traditional ideas about psychologists working purely in a therapeutic capacity.

Undertaking training on a clinical psychology course has undoubtedly been the most considerable challenge of my career to date and the research component has been a significant contributor to this. I hope that the skills I have acquired in balancing competing demands and working under pressure to tight deadlines will continue to develop throughout my career. An essential component of this has been the challenge of maintaining relationships and roles outside of the training environment and I have reflected on my tendency to become more 'insular' at times of stress. Relationships with fellow members of the cohort, academic staff and clinical supervisors have been integral to managing these demands, and I am mindful of how important collegial relationships will continue to be as I continue to develop and grow into the role of qualified clinical psychologist.

I am aware that this particular process of training is in many ways very distinct to other experiences and that this can sometimes lead to misunderstandings in personal relationships; the idea of being 'good enough' has featured as a theme throughout training. As I progress to the next stage, I will take the lessons learned and continue to apply them. The need to maintain and develop skills as a researcher and a therapist will also need to encompass elements of self-care. Undertaking research has taught me a considerable amount regarding a

number of issues, for example, knowing when to take a step back, understanding when it is important to ask for help, acknowledging that research is, by its very nature, always flawed to some extent. I have come to believe that these flaws, whether part of research, clinical practice or related to me personally, are not problematic in themselves. Flaws are not a problem to be solved, rather, they are important points to reflect on. I have grown more comfortable in acknowledging which areas can be targets for improvement and which must be accepted and worked around. I have also come to believe that self-care is about more than work-life balance and exercise but is a much broader concept, of which the ability to show kindness to myself is not self-indulgent but is integral to my ability to manage the demands of the profession.

Finally, confidence has been a concept which has been a source of much reflection. I have undoubtedly grown in confidence as a researcher as the project progressed and acknowledging that I am capable of producing work with significance and relevance for the wider scientific and clinical community has become easier. I have come to understand that acknowledging that I have areas in which to progress and develop does not need to be at the expense of accepting the value of my knowledge and experiences thus far. I am aware that there are limitations to the work produced as part of my doctoral thesis, yet I have become increasingly convinced that, when these are acknowledged and reflected upon, they do not diminish the value of the finished product.

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APPENDICES

Appendix A: Guidelines to Authors for Journal Targeted for Literature Review*

Guidelines retrieved on 26th June, 2014 from

<http://www.sagepub.com/journals/Journal201823/manuscriptSubmission>

Due to lengthy guidelines, a summary is presented. Full text can be found on the above link.

Palliative Medicine is a highly ranked, peer reviewed scholarly journal dedicated to improving knowledge and clinical practice in the palliative care of patients with far advanced disease. It reflects the multi-disciplinary and multi-professional approach that is the hallmark of effective palliative care. Papers are selected for publication based on their scientific excellence, contribution to knowledge, and their importance to contemporary palliative care. We welcome papers relating to palliative care clinical practice, policy, theory and methodological knowledge.

Palliative Medicine is an international journal, and is the official research journal of the European Association for Palliative Care and a journal of the Association of Palliative Medicine. Whilst we acknowledge that many papers will focus on palliative care issues within particular countries, it is important to our readers that authors reflect on how these issues might be relevant to a wider audience, present the study in the context of the existing international research on the topic, and discuss how this knowledge contributes to the international knowledge base.

1. Peer review policy

Palliative Medicine operates a conventional single blind reviewing policy in which the reviewer's name is always concealed from the submitting authors. All

submitted manuscripts undergo a two stage review process. The initial review is undertaken by three editors and a decision is made either to send the paper for external review or to reject it without review. We undertake to make the decision whether or not to send for external review within three weeks of submission. In this initial review the editors ensure that only those papers that meet the scientific and editorial standards of the journal and fit within the aims and scope of the journal will be sent for external review. Within 10 weeks of sending the paper out to external review we will make a final decision. Papers accepted for publication following external review usually require some modification before final acceptance. Generally, due to the high volume of submissions, we are able to accept only about 30% of papers submitted to us.

2. Article types

Palliative Medicine publishes original research and review articles on all aspects of palliative care.. The Journal considers the following kinds of article for publication:

1. Review Articles – 5,000 words.
2. Original Articles – 3,000 words with up to six tables or figures. For papers reporting qualitative methods participants' quotations may be excluded from the word count. We still prefer, however, that these quotations are succinct and carefully chosen – it is rare that more than one quote is required to illustrate the point being made. All research papers should follow relevant reporting guidelines such as CONSORT for trials, COREQ for qualitative research etc. Please see <http://www.equator-network.org/resource-centre/library-of-health-research-reporting/> for up to date information on reporting guidelines, and fuller instructions below on constructing different aspects of the paper.

3. Short reports – 1,000-1,400 words.
4. Case reports – 1,000-1,400 words with one table or figure.
5. Audit and Service Evaluation. 1 000- 1,400 words..
6. Research letters. We occasionally publish short research letters (750 words, no abstract required, no more than 3 references).
7. Letters to the editors. We welcome correspondence relating to issues of general interest to our readership, or in response to a publication. Such letters should be succinct, and generally no more than 500 – 750 words.

NB: word count excludes references, tables and figures references

2.1 Review Paper

These should generally follow the structure below, with reference to relevant review reporting guidelines such as PRISMA.

Background: Identify the issue to be addressed, current knowledge on the topic and some indication of its relevance and importance to clinical practice, theory or research methodology.

Aim: A clear statement of the review aim(s).

Design: A statement about the review strategy/methods adopted

Data sources: State the data sources used (including years searched). Include a statement about eligibility criteria for selecting studies and study quality appraisal

Results: Report the main outcomes(s) /findings of the review.

Conclusions: Identify how the aims have been met, and the relevance of the findings for clinical practice, theory or research methodology.

2.2 General instructions to authors relevant to all paper types

We wish papers published by *Palliative Medicine* to adhere to the highest publishing standards possible. We want to ensure that the key messages for our readers are explicitly articulated. We also want you to consider the following issues: authorship; multiple publications; ethical approvals; research design; and presentation of discussion.

Key Statements

Palliative Medicine has a system where all papers are required to clearly state what is already known about the topic, what their paper adds, and implications for practice, theory, or policy. You are required to give these at the start of the manuscript. Please use these three specific headings (see below), with 1-3 separate bullet points for each heading. Please use clear, succinct, separate bullet points rather than complex or multiple sentences. Each bullet point should be one sentence only.

What is already known about the topic?

Short statement(s) here about state of knowledge in this area.

You may highlight both what is known and what is not known.

Be specific rather than broad or sweeping statements. Avoid statements such as 'Little is known about ... x or y' in favour of statements specifying exactly what is known.

What this paper adds?

Short specific statement(s) here about what this paper adds.

These should be styled in terms of outcomes where possible (This study demonstrates that x intervention has a (specific) impact on y outcome) rather than study aims or process. (This study considers whether x intervention has an impact of y outcome).

Be as specific as possible please here. Avoid broad statements such as 'New Knowledge is added about ... ' but rather be specific about exactly what this knowledge is. So for example rather than 'We add to the knowledge base on x' we would prefer the specific such as 'x variable was found to increase the experience of y outcome (by z amount)'.
Ensure that these statements clearly relate to the findings of the study.

Implications for practice, theory or policy?

Short specific statement(s) here on the implications of this paper for practice, theory or policy. These should clearly draw from the findings of the study, without over stating their importance.

Where possible please make these internationally relevant

Appendix B: Study Characteristics Table

Study	Research Aims	Theoretical Framework	Sampling/ Population	Methodology	Analysis	Ethical Considerations	Reflexivity
Kaplan (2000) UK	To understand and define emotional reactions to loss for paediatric nurses, how reactions are expressed and how nurses are able to form and relinquish relationships with terminally ill patients	Not reported	15 Paediatric nurses: 14 female Age: 28-52 years - Nursing for ≥ 2 years - Primary client group; children with terminal illness	Face-to-face structured interviews	Thematic analysis implied, not stated.	None discussed	Not discussed
Newton & Walters (2001) UK	To analyse stories of Community Palliative Care Clinical Nurse Specialists' stress in the course of work to explore the meaning, and gauge what would help.	Not reported	Questionnaires to 20 community palliative care clinical nurse specialists : 18 female Interview of 14 CPCCNS's. Age: 31-50+ years - Nursing for ≥11	Non-validated questionnaire exploring perceived stress and useful coping strategies Interviews – structure not explicitly stated	Colaizzi approach – thematic.	Confidentiality since a potentially known group of specialists	Researcher noted mentor role of other researcher - Field notes kept re: atmosphere, body language and own feelings to inform analysis

Ekedahl & Wengstrom (2006) Sweden	To study the stress of health care staff, specifically oncology nurses.	Not reported	15 Swedish nurses working in hospices (n=5), oncology wards (n=6) & outpatient services (n=4): 13 female Age: 30-60 years	Semi-structured interviews based on four predetermined themes (demographics, stress in interactions, collaboration and personal networks).	Data analysis throughout Kvale's method for structuring, clarifying and developing new meaning	None discussed	Participants given opportunity to read their interviews to reflect and give opinions. No discussion of researcher's own reflexivity.
Ablett & Jones (2006) UK	To describe hospice nurses' experiences to understand factors that help to promote resilience and mitigate effects of workplace stress and processes by which nurses continued to work in palliative care/maintain a sense of well-being.	Phenomenology	10 palliative care nurses from one hospice: Nine female - majority of working time providing direct care to patients receiving palliative care	Semi-structured interviews	IPA	None discussed	Statement of researcher position at time of data collection
McCloskey & Taggart (2010)	1. To explore the experience of occupational stress	Not reported	18 children's palliative care nurses	Focus group discussions (4 focus	Thematic content analysis	Local permissions and informed	None discussed.

UK	within nurses working in the three district young people's palliative care services 2. to examine the consequences of such stress on the nurses' lives		- Working in children's hospice (9), children's hospital (2), community team (7)	groups).		consent sought	
Rose & Glass (2010) Australia	To explore and investigate the concept of emotional well-being, the relationship between emotional work, emotional well-being and professional practice and strategies used by the nurses promoting emotional well-being	Critical feminist emancipatory methodology.	16 palliative care nurses: all female	Semi-structured interviews/storytelling and reflective journaling	Thematic analysis	Informed consent Sensitivity to potential harms to participants	Reflective journaling and critical conversations between authors
DeArmond (2012) USA	To explore the impact of end-of-life care on the personal life of hospice workers and to focus on the holistic nature	Case study	17 hospice employees (including nurses(n=10), pharmacists (n=1), social	Life story telling (guided by schedule)	Phenomenological hermeneutic model	None discussed	Hermeneutic study to encourage reflexivity

	of their experience		workers (n=3), hypnotherapists (n=1) and therapeutic harp practitioner (n=1) and psychologist (n=1)) With ≥ 2 years experience				
Melvin (2012) USA	Are nurses whose job it is to deal with death and dying on a continual basis at risk of developing professional compassion fatigue? What are the physical and emotional consequences of hospice and palliative care nurses continually dealing with death?	Descriptive (phenomenologic al)	Six hospice/palliativ e care nurses: all female with 10 or more years of experience	Semi- structured interviews	Content and thematic analysis	Study approval via ethics committee	Not discussed
Penz & Duggleby (2012) Canada	To explore aspects of palliative care nurses' work lives that may contribute	Grounded theory	14 RNs who provide palliative care in rural/urban	Telephone interviews (x2 per participant)	Thematic analysis	Informed consent	Not discussed

	to their overall well-being and the overall context in which community nurses provide palliative care to understand the burden of care and factors contributing to resilience		community settings, deemed 'experienced'	Nine participants kept personal journals			
i) Reid (2013) UK	To highlight challenges perceived by rural adult community nurses when delivering palliative care to children and young people and their families at home	Phenomenologica l	Six district nurses Four adult community palliative care Community Nurse Specialists with 15-42 years experience	Semi-structured interviews	Inductive content analysis Thematic analysis	Ethical approval Informed consent	Not discussed
ii) Reid (2013) UK	To elicit lived experiences of children's nurses delivering palliative care in the community. To understand personal, contextual and interprofessional	Grounded theory	Seven nurses: Four Children's Community Nurses, three children's respite nurses	Semi-structured interviews	Thematic analysis	Ethical approval	Not discussed

	challenges faced by these nurses and the consequent influences of these on personal grief.						
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Appendix C: Data Extraction Table

Study	Aims	Themes	Authors Comments	Conclusions
Kaplan (2000) UK	To understand and define emotional reactions to loss for paediatric nurses, how reactions are expressed and how nurses are able to form and relinquish relationships with terminally ill patients	<p>Balancing/managing the “Emotional Tension” “you have to be an actor, and just change your mask and put a smile on and go in and do it”. “I’ve built into my profession these opportunities to connect with my grief so it doesn’t come out sideways”</p> <p>Grief-like Reactions “It’s a good grief as opposed to getting you emotionally, physically, totally bound up in it”. “You don’t get a day off and you don’t get to schedule an early vacation or something... you have to be like an actor, and just...put on a smile”.</p>	<ul style="list-style-type: none"> • Emotionality as central to the work. • Many described emotional experiences as a form of grief. • No formalised system exists to express feelings – where/with whom to share. • Various coping mechanisms relied on to protect self and retain emotional balance. • Children on the ward become integral so death feels like losing of a member of the unit. • Loss always present as staff return to the ward after the death to look after a new patient. 	<ul style="list-style-type: none"> • Palliative care is characterised by intense emotional responses, understanding the work but too difficult to process. • ‘Balance’ is important and this is achieved by drawing on diverse coping strategies but when there is insufficient time to ‘cope’, nurses have to ‘put on a mask’ to convey they are coping. • It is important to be seen to be coping by patients.
Newton & Walters (2001) UK	To analyse stories of Community Palliative Care Clinical Nurse Specialists’ stress in the course of	<p>1. Pressure of Workload “Constant stream of referrals” exacerbated by...</p> <p>- Staff shortages</p> <p>- Poor cooperation or accessibility of some health professionals “The GP kept me waiting about an hour ... I felt he wanted me to give up and go”</p> <p>-Not trusting the performance of some other health professionals “some district</p>	<ul style="list-style-type: none"> • No prospect of improved staffing levels led to a rising stress and decreased performance. • Organisational issues led staff to feel stuck and failing to improve things despite hard work. • Lack of trust in others led to taking on extra work/retaining responsibility. 	<ul style="list-style-type: none"> • Nurses feel frustration and demoralised when the system is unresponsive. • Nurses find it hard to relinquish responsibility as they

	<p>work to explore the meaning, and gauge what would help.</p>	<p>nurses not giving patients the care they need...”</p> <ul style="list-style-type: none"> - Insecurity from multiple organisational changes “the transition from one system and another system produces stresses of its own” - Lack of management response or appreciation - Clients/professionals’ misperceptions of the CPCCNS role “we’ve seen the posters in the tube stations... it isn’t what happens, it isn’t the reality”. - Changing role and changing educational requirements - Attitudes to work <p>2. Relationships with other health professionals “whether this is a female thing, a cultural thing or just “Doctors knows best” I don’t know, but it’s at the expense of the patient and this is what was so frustrating”. “They don’t understand you have to do things quickly, because if you hang around you’ve missed it”.</p> <p>3. Exposure to impact of sadness of the client group</p> <ul style="list-style-type: none"> - Identification with the client - Skills tested to limit - Prevention of optimum care “It’s knowing I can make a difference but not being able to” - Repeated strain/accumulation of sadness/Support Mechanisms 	<ul style="list-style-type: none"> • Poor management linked to cynicism, resentment and feelings of helplessness and worthlessness. • The pressure of educational requirements was felt by all. • Erosion of normal support (particularly at home) undermined coping and managing role. • Rigidity and inflexibility “to be perfect, always to be in control, to make everything better”, exacerbates difficulties. • Perceived lack of interprofessional respect led to nurses feeling they had to change their behaviour to benefit patients. • Knowledge of core professional boundaries did not prevent them from emotional entanglement, bringing joy and sadness. • Difficult patients with difficult to control symptoms and dysfunctional families, exacerbated isolation in being unable to provide solutions. • Providing optimum care important for job satisfaction but prevented by family culture, systems, lack of cooperation by others, denial of access to patient and stress. • Nurses loved and were motivated by their job. More experienced nurses lost initial enthusiasm but stability 	<p>fear others will not do as good a job.</p> <ul style="list-style-type: none"> • Nurses have high expectations of themselves prompting work overload and inflexibility driven by fear of failure. • Nurses place a high level of importance on their role and when not acknowledged, engendered anger and frustration. • Professional boundaries acknowledged but frequently blurred by community settings, achieving what considered to be best care. • Nurses are isolated in their work and feel a pressure to have all the answers. • Sometimes nurses need to distance themselves to maintain wellbeing.
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			would keep them going. <ul style="list-style-type: none"> • Team members can be supportive and source of stress. 	
Ekedahl & Wengstrom (2006) Sweden	To study the stress of health care staff, specifically oncology nurses.	<p>Four levels of stressors</p> <p>1. Related to the profession When young patients “die too early”. “For several years when I was there...and it was cancer...they all seemed to die”. “We are trying to make time; when we are with patients that are the focus”. “I was alone...with severely ill patients”. “You have to take anger from many people too”.</p> <p>2. The private life “Sometimes it’s impossible to cope with the transitions [between home/work]. At times, the contrasts are so big that it is impossible to live in the normal world”.</p> <p>3. The group level “There was never any talk of supervision... you were thrown into it directly”.</p> <p>4. Cultural level “We have been hit...with bad economy and cutbacks... it has increased the stress tremendously”. “Sometimes we are almost sure that this not going to help, but we give the treatment anyway”.</p>	Stress engendered by... <ul style="list-style-type: none"> • Identification with patients and not being able to alleviate suffering. • Time and isolation. • Expectations of workplace not matching reality experienced as ‘taxing’. • Ethical stress – balancing needs of patient and family. • Managing transitions between work and ‘real life’ are problematic, e.g. stress triggered by deaths in own family or own illness. • Culture clashes between health professionals cause stress and interface between private and public care. • Old vs. new nurses – new nurses go through ‘the school of hard knocks’. • Change from hospice to palliative care creates additional demands. • Cutbacks affected ability to give good care and increase stress. • Expectations of nurses differ at work – mechanical vs. holistic care paradigms in opposition – both can be integrated and going back and forth between them can help coping. 	<ul style="list-style-type: none"> • Hospice nurses care about caring for their patients and are stressed by factors preventing them from delivering care they expect of themselves. • Providing holistic care for patients <i>and</i> their families cause stressful ethical dilemmas. (Trying to make everyone happy?) • When work and home life contradict, the task of caring for the dying is more difficult. • Different professions’ focus may generate stress. • Nurses can rely on becoming more ‘mechanical’ in their care to protect themselves and cope emotionally.
Ablett &	To describe	1. An active choice to work in palliative	<ul style="list-style-type: none"> • There was a high level of 	<ul style="list-style-type: none"> • Palliative care seen

<p>Jones (2006) UK</p>	<p>hospice nurses' experiences of their work to understand factors that help to promote resilience and mitigate effects of workplace stress, and processes by which nurses continued to work in palliative care and maintain a sense of well-being.</p>	<p>care "I find working in palliative care to be a privileged post to have really" 2. Past personal experience influences caregiving "as upsetting as it was...it sort of turned my dad's dying into a positive thing" 3. Personal attitudes towards care-giving "only the best I can do for them is good enough really" 4. Personal attitudes towards life (and death) "life is for living". "I just think, today is today and I'm going to enjoy it!" 5. Awareness of own spirituality "I think that until a person is comfortable with their own spirituality...I don't see how they can be comfortable with the patients" 6. Personal attitudes towards work "I like to be in control of what I'm doing" 7. Aspects of job satisfaction "I get great satisfaction out of the job, great personal reward, my colleagues...that I'm really close to" 8. Aspects of job stress "I was going from the relatives of the person who had dies, and then trying to be bright and sparkly to the next relative" 9. Ways of coping "you have to have a good support system at home". "I talk to colleagues and we do actually discuss how we feel". 10. Personal/professional issues and boundaries "You get involved in your job and what you need to do...but I think you</p>	<p>commitment...they viewed it as a privilege to nurse people at the end of their lives</p> <ul style="list-style-type: none"> • Own experience of a loved one dying (either good or bad) led to desire to provide good quality care • Nurses wanted time to provide better quality care than able to as a ward nurse • Believing only their best was good enough for patients and relatives, nurses felt they had to give 100% at work. • Those that considered issues of mortality for themselves reflected on the concept of a 'good death' • Those who did not mention existential issues spoke of the need to possess a good sense of humour. • Nurses need to perceive themselves as being in control and that tasks are manageable. More important in palliative care as uncertainties exist. • Several factors underpinned job satisfaction (supportive work colleagues, a manageable workload with time to listen and talk to patients, pleasant working environment). • Stress linked to workload feeling less manageable and communicating that a loved one had died to relatives. • Range of behavioural coping 	<p>as intrinsically rewarding, drawn to repeat or repair positive/negative experiences of loved ones being cared for.</p> <ul style="list-style-type: none"> • Giving 100% at work is important and only the best is good enough. • Threat of existential issues prompted using humour as a coping strategy and caused nurses to re-evaluate their beliefs and values. • Feeling in control mitigates feelings of stress. Tolerating uncertainty is difficult. • Job satisfaction is derived from both work and home. • Protecting against negative affect important to maintain ability to work and boundaries help to achieve this.
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		have to protect yourself as well”.	strategies used both during and at the end of shifts. <ul style="list-style-type: none"> • Maintaining professional boundaries have defensive/protective function. 	
McCloskey & Taggart (2010) UK	1. To explore experience of occupational stress within nurses working district young people’s palliative care services 2. to examine the consequences of such stress on the nurses’ lives	<p>1. Demands</p> <p>Emotional Load “Dealing with the impact of a child’s death can be awful”</p> <p>Ethical Conflicts “There is this ethical challenge, what we are asking parent to do and how difficult it is for them to carry that through”.</p> <ul style="list-style-type: none"> • Constraints to the delivery of good care “I don’t have time to interact with the child...our job is more to do with personal care...our job is more than that and I feel we are not doing it”. • Limited Resources “There is the added stress when thinking – where is the family going to get practical hands-on support over the weekend?” • Administration “Everything is about paperwork...and meeting criteria” • Living and Working in the Same Community “There is one mummy I would see and she always says hello and the first thing she would tell me about is her sick child”. <p>2. Nurse-child/family relationships “as you get to know them more and more you feel you are taking on the world”</p> <p>3. Maintaining control</p>	<ul style="list-style-type: none"> • Deep-seated attachments to children and families lead to a sense of loss when the child died. • Bereavement support as mutually beneficial or emotionally draining. • Living in the same neighbourhood means being ‘the nurse’ constantly. • Developing relationships with families is satisfying, but absence of a good relationship is stressful. • Intense relationships between family and one nurse common. • Juggling competing demands, being the key decision maker and lone working seen as stressful. • Hospice nurses felt better supported by managers than those in the community. • Other health professionals do not always acknowledge skills and specialist knowledge. • Difficulties encountered with being able to ‘switch off’. • Cumulative impact of working in palliative care experienced across all groups. 	<ul style="list-style-type: none"> • Desire to ‘get it right’ leads to nurses developing close relationships with patients and families, which can exacerbate sense of loss and grief when a patient dies. • Working in isolation contributed to feelings of excess responsibility and increasing stress pressure to deliver perfect care. • Living in the same community intensifies relationship and prevents closure of professional role with families. • Stress exacerbated when nurses not supported/valued by understanding management/culture. • Balancing home and work is important for

		<p>“something acute happens and the child is stressed, the family is stressed and you really want to alleviate that as quick as possible”.</p> <p>4. Support and role related stressors</p> <ul style="list-style-type: none"> • Managerial support • Role ambiguity “You do have that knowledge and skills and experience behind you...it’s frustrating when people don’t credit you for that”. <p>Consequences of stress “I do feel quite burnt out you know. How much compassion have I left?” “It’s not that their nursing needs were terrible, but it is the emotional intensity of it”.</p>		<p>emotional wellbeing. Insufficient time to care ‘properly’ and process emotions contributes to ‘leaking’ into home life and ability to ‘switch off’.</p> <ul style="list-style-type: none"> • The cumulative emotional impact of working in palliative care increases stress over time.
Rose & Glass (2010) Australia	To investigate the concept of emotional well-being, the relationship between emotional work, emotional well-being and professional	<p>Pervasive Interconnectedness</p> <p>Interwoven nature of themes</p> <ul style="list-style-type: none"> • The concept of emotional well-being “[when I am] unbalanced, everybody knows it...I’m teary, I’m emotional, I’m impulsive’ • Emotional work “you’ve taken some of the load off the clients’ shoulders and put it on yours. You walk out feelings like a ‘rung out rag”’. • Organisational and workplace issues “We get told to take on more, we get told to do more but we don’t get 	<ul style="list-style-type: none"> • Emotional wellbeing was multifaceted, remaining in a perpetual process of fluidity. • Emotional work involved capacity to restore/maintain energy levels using inter- and intrapersonal forces creating a dialectical tension. • Promoting/enhancing emotional wellbeing through healing and self-care. • Demands related to emotional burden and the need to enhance relationships. 	<ul style="list-style-type: none"> • Emotional wellbeing fluctuates over time and is influenced by a range of factors. • Good relationships with patients enhance care, but can leave nurses feeling burdened. • Nurses feel ‘balanced’ when they feel they are competent. • Feeling heard,

	<p>practice and strategies used by the nurses promoting emotional well-being</p>	<p>resources”</p> <ul style="list-style-type: none"> • Communication with health professionals GPs placing own “ego and how they look” above clients’ needs. • Professional Boundaries “...The challenge is not to get too involved...but where do you cut off?” • Education and professional development “sometimes I don’t know what to say and sometimes I’m crying just as much as they are”. • Strategies used to promote emotional well-being “you need to talk it out because you don’t want to be taking it home”. “It’s probably better that I feel a bit sad that just walk out the door and not think anything”. 	<ul style="list-style-type: none"> • Palliative care as rewarding (making a difference). • Feeling able to meet client’s needs helped to avoid burnout. • Collaborative relationships with other professionals could be helpful but also contribute to difficulties. • Nurses felt that their education was ‘inadequate’ but standard of care was good. • Lack of support of professional development led to feelings of disempowerment and distress. • Nurses regarded work as a privilege, valuing relationships with clients. • Nurses engaged in strategies to help emotional balance (self-validation, emotional support and assertiveness). • Clinical supervision could enhance professional practice through self-reflection but this was often absent. 	<p>validated and acknowledged is important for nurses wellbeing.</p> <ul style="list-style-type: none"> • Providing good care mitigated against stress. • Lack of acknowledgement and investment in their development by managers led to nurses feeling disempowered and helpless. • Nurses do not have an adequate space to reflect on their work and instead rely on themselves and colleagues for support to stay in balance.
<p>DeArmond (2012) USA</p>	<p>To explore the impact of end-of-life care on the personal life of hospice workers and to focus on the holistic nature of</p>	<p>Personal growth in hospice workers</p> <p>1. Process of reflection “The experience of being with the dying is calming, authentic, intimate and loving”. “Every death changes you”.</p> <p>Approach to Death & Dying “I am not scared by death anymore”.</p> <p>Awareness & strength “Working at the hospice helps me to get balanced; it gives me strength; it is grounding”.</p>	<ul style="list-style-type: none"> • Interconnectedness <ul style="list-style-type: none"> - participation, empathy and compassion - changes to personality (e.g. becoming more empathic) - intimacy with death (rewarding) -overcoming fear of death and dying - changes in spirituality • Suffering, sacrifice and 	<ul style="list-style-type: none"> • Hospice work is rewarding and leads to personal growth by developing empathy and overcoming own fears. • Nurses see themselves as central to compassionate patient care.

	their experience	<p>Lifestyle & outlook “I have a more positive outlook. I work less. I am less hard on myself”.</p> <p>2. Progressive acceptance & integration of personal experiences & aspects of the personality “Sometimes at the hospice, I think of them. I would like to go back to this time because, now, I better understand the experience”. “I feel nobody should die alone. We did not come to this world alone. Death is a tragic experience and we are never ready to die”.</p> <p>3. Integration of personal experiences into a larger reality “When you work in a hospice you realise you are not the centre of the universe. You see wonderful people struggling and you realise you are just a small piece of the puzzle”. “We are all interconnected. It gives meaning to your life. Joy and sadness complement each other”.</p> <p>4. Sense of connection with the life of the Spirit “I have images, flashbacks, of people who died. It makes me feel peaceful. I carry with me a little bit of each of them”.</p> <p>5. Presence of epiphanies or numinous experiences “I think hospice increases spirituality if you already have some”.</p>	<p>redemption</p> <ul style="list-style-type: none"> - compassion and identification with the dying - dying person as symbol of suffering and sacrifice - offering ‘a cradle’ to the experience of the dying person <ul style="list-style-type: none"> • Birth and rebirth <ul style="list-style-type: none"> - hospice workers transformed and experience a form of rebirth - guiding the dying and guiding themselves 	<ul style="list-style-type: none"> • Nurses provide expertise and care to patients, but learn from them also. • Personal beliefs about how the dying should be cared for influence practice. • Interconnected nature of relationships with patients helps nurses to attribute meaning to their work. This enriches rewarding aspects of the work for nurses and enhances patient care.
Melvin	Are nurses	Risk for Professional Compassion	<ul style="list-style-type: none"> • Hospice nursing as a privilege but 	<ul style="list-style-type: none"> • Nursing is a privilege

<p>(2012) USA</p>	<p>whose job it is to deal with death and dying on a continual basis at risk of developing Professional Compassion Fatigue? What are the physical and emotional consequences of hospice and palliative care nurses continually dealing with death?</p>	<p>Fatigue “I think that hospice and palliative care nursing is very challenging...it takes a person being willing to be introspective to really understand and to be honest with themselves about what they are feeling and why they are feeling that”. “We do develop a separation...an abstraction”. “I was starting to feel it was who I was instead of what I do and I felt like I was starting to lose a bit of me”. Physical and emotional costs of caring “It can eat away at you – multiple losses”. “If you don’t do something in your life to make better or cope with that, then eventually you burn out”. Setting boundaries/healthy coping strategies “I think the boundaries make me not less of a compassionate person but I think it preserves me”.</p>	<p>also causing symptoms of PCF.</p> <ul style="list-style-type: none"> • Nurses needed to put deaths into perspective and not let it consume them. • Feeling responsible could lead to thinking about patients at home. • Boundaries important to manage ability to work in end of life care and each had key strategies to manage. 	<p>but must maintain some distance to avoid being consumed by sadness.</p> <ul style="list-style-type: none"> • Increased feelings of responsibility influenced ability to ‘switch off’. Professional boundaries increased ability to maintain wellbeing.
<p>Penz & Duggleby (2012) Canada</p>	<p>To explore aspects of palliative care nurses’ work lives that may contribute to their overall well-being and the overall context in which</p>	<p>1. Who I am “Even in this potentially horrible situation, I think because I was actively participating in doing something that might contribute to a positive outcome, I could reassure her”. 2. Resigning myself to the system “I gave up hope of the system changing”. “We were basically told, if we needed any more time, we should do it on our own time”. 3. Feeling valued and respected “I really feel I get a lot back from people. It’s very rewarding”.</p>	<ul style="list-style-type: none"> • Sense of who they were contributed to professional identities. • Reflection on past experiences helped them understand selves and complexities of caring. • Importance of being strong advocates, having compassion, flexibility, resilience, going with the flow and working independently. • Sense of humour, optimism and realism important. • Occupational stressors made them feel powerless and made it difficult to 	<ul style="list-style-type: none"> • Nurses’ sense of self and past experiences influence what they believe is important in patient care. • It is important to be realistic, optimistic and maintain sense of humour to defend against and cope with sadness of the work. • Feelings of powerlessness,

	community nurses provide palliative care to understand the burden of care and factors contributing to resilience	<p>“That’s the thing about knowledge too...it’s a comfort to them to know that somebody knows what they’re talking about”.</p> <p>4. Managing grief and loss</p> <p>“If you don’t search for meaning in your losses, then you’re trapped by the hopelessness. And then you go into despair”.</p> <p>“I just hoped that it would, that he would go fast and that he wouldn’t suffer, that, you know, that he would know that everybody around him loved him”.</p>	<p>meet the expectations/preferences of client and families.</p> <ul style="list-style-type: none"> • Lack of management support and overwhelming workloads made them feel unimportant and forgotten. • Rewarding aspects of work helped offset negative aspects. • Presence of suffering can take an emotional toll, particularly in close knit communities. • Lines blur between being a palliative caregiver and a friend/family member. • Managing grief and loss confounded by numerous losses happening concurrently and in rapid succession. • Nurses try to find meaning in losses to continue working in the area. 	<p>unimportance and of feeling forgotten influenced by an unsupportive system and impacted on ability to provide optimum care.</p> <ul style="list-style-type: none"> • Being able to make a difference to patients makes feelings of stress more manageable. • Feelings of grief and loss exacerbated by blurred professional boundaries with patients and cumulative impact of concurrent losses.
i) Reid (2013) UK	To highlight challenges perceived by rural adult community nurses when delivering palliative care to children and young people and	<p>1. Emotional preparedness</p> <p>“young people affect you mightily more than somebody who has lived a full life”. “I felt I was floundering...you’re flying by the seat of your pants”</p> <p>2. Navigating the ‘professional road’</p> <p>“We could have been more use earlier on...[instead of] coming late in the day... paddling fast to build a relationship...at a critical stage”. “This chap belonged to everybody... I couldn’t get one direct answer”.</p>	<ul style="list-style-type: none"> • Those without a child nursing qualification struggled to reconcile themselves with the concept of a child death. • Perceptions of professional expertise and self-confidence clearly differed between those who were registered children’s nurses and those who were not. • Discharge planning could be too late, too rapid or ill-planned. • Communication pathways between 	<ul style="list-style-type: none"> • Specific experience with children helps nurses to understand and manage child deaths. • The wider system affects ability to do a satisfactory job and exacerbates feeling unheard. • It is hard to maintain boundaries and not

	their families at home	<p>3. Becoming part of the family “A lot of relatives involved in the families...all looking to you for an answer...it is more stressful”. “It was a very privileged place to be”. “I feel personally enriched by having dealt with the situation”.</p> <p>4. It’s everybody’s business “The whole village reverberated...every single person is affected by that young person”.</p>	<p>hospital teams were a challenge.</p> <ul style="list-style-type: none"> • All described challenges with maintaining professional boundaries with some portraying themselves as a ‘pseudo-member’ of the family. • Children’s nurses demonstrated greater confidence in adapting communication styles to age of child. • Rewarding to provide care at a ‘private, personal and devastating time’. • Resources limited due to geographical spread of the teams. • Difficulties arose from working in tightly communities, making issues such as breaches in confidentiality and lack of nurses’ anonymity more problematic. • Working in rural settings makes it difficult to access face to face support from others (colleagues). 	<p>become part of the family. Feeling isolated increases nurses likelihood of blurring the boundaries.</p> <ul style="list-style-type: none"> • Support is more difficult to attain in the community due to geographical distance from colleagues.
ii) Reid (2013) UK	To elicit the lived experiences of children’s nurses delivering palliative care in the community and to understand the personal,	<p>1. Service Delivery “care environments have different rules”. “These child plans try and encompass school, social work and respite... team is actually so huge”.</p> <p>2. Nurse-family relationships “You get sucked into the family dynamic...found it quite difficult to stay neutral”.</p> <p>3. Nurses’ grief “Death is the most under-talked about subject...it was drummed into you, don’t</p>	<ul style="list-style-type: none"> • Challenge to initiate and sustain care plans across a range of contexts. • Delivery of care to families affected by variability in degree and quality of interprofessional working. • 24 hour care not formally provided but delivered on an impromptu, goodwill basis. • A ‘fine line’ between advising, advocacy, empowering and intervening. 	<ul style="list-style-type: none"> • Working across different settings and professional groups is complex and reduces consistency for the patient. • There is careful balancing act between providing appropriate care to different family

	<p>contextual and interprofessional challenges faced by these nurses and the consequent influences of these on their personal grief.</p>	<p>cry...it continually happens... so hard to keep dealing with it".</p> <p>4. Funeral rites and bereavement support</p> <p>"The funeral didn't give any sense of farewell...my picture is still of a very distressed family".</p>	<ul style="list-style-type: none"> • Difficult to gain open communication with the child as conversations go through parents. • Difficult family dynamics and ethical dilemmas caused nurses difficulties. • Nurses reconciled to child death but experienced strong feelings of fearful anticipation, emotional wrestling and cumulative effects. • All found reflective practice useful but some found it hard to disconnect from intrusive thought outside work. • Funerals offered opportunity to legitimately demonstrate personal grief. • Nurses acknowledged the mutual benefits for grief resolution but were conscious of having to maintain a clear, professional and family-orientated stance. 	<p>members.</p> <ul style="list-style-type: none"> • Child palliative care is complex due to the different systems around children (e.g. parents, school etc). • Sadness is cumulative and it is hard to know where to express this and whether it is appropriate. Nurses may not feel that their sadness is valid. • It is important to maintain professional boundaries to protect oneself from distress. • Reflecting on practice can be helpful but is not always easy due to a lack of formal supervision.
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Appendix D: Ethical Approval and Letter of Access*

Received electronically on 29th of November, 2013

To: L INGLEBY

Subject: Ethical Application Ref: **lji2-5490**

(Please quote this ref on all correspondence)

29/11/2013 09:09:19

Psychology

Project Title: Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the Barriers and Levers Staff Report when Discussing Family Risk

Thank you for submitting your application which has been considered.

This study has been given ethical approval, subject to any conditions quoted in the attached notes.

Any significant departure from the programme of research as outlined in the application for research ethics approval (such as changes in methodological approach, large delays in commencement of research, additional forms of data collection or major expansions in sample size) must be reported to your Departmental Research Ethics Officer.

Approval is given on the understanding that the University Research Ethics Code of Practice and other research ethics guidelines and protocols will be compiled with. The following is a record of correspondence notes from your application **lji2-5490**. Please ensure that any proviso notes have been adhered to:-

Nov 22 2013 3:50PM Thank you very much for your application. It is thorough and well-written. Please upload to the online system either an email or copy of a letter on letterhead from the gatekeepers at the hospices where you intend to collect data to confirm that you have permission to recruit staff.

In your consent for you indicate that data will be anonymised. Can you please briefly describe the procedures for this in section 4?

Nov 22 2013 5:20PM Thank you for your feedback - I have included additional information about anonymisation of transcriptions in section 4 and hope that this is satisfactory. I have requested confirmatory emails from the hospices and will upload when they are available.

Nov 25 2013 4:47PM Please hold onto the application until you obtain the approvals. (if the application stays with me, you can't upload them.) We cannot approve the application until you have them. Thank you.

Nov 27 2013 2:07PM Please find attached emails from both hospices confirming permission pending ethical approval.

Many thanks.

--- END OF NOTES ---

Ref: CF/IG
Date: 9th May 2014



Private and Confidential
Lisa Ingleby
Trainee Clinical Psychologist
University of Leicester
104 Regent Road
Leicester
LE1 7LT

Dear Lisa

Re: Letter of Access for Research

Study Title: Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the Barriers and Levers Staff Report when Discussing Family Risk

Sponsor: University of Leicester

Chief Investigator: Lisa Ingleby

Principal Investigator for [REDACTED]

This letter confirms your right of access to conduct research through [REDACTED] for the purpose and on the terms and conditions set out below. This right of access commences on 9th May 2014 and ends on 26th September 2014 unless terminated earlier in accordance with the clauses below.

The research to be carried out is detailed in Study protocol version 2, November 2013 (REC Exempt). Any amendment to the protocol can only be made in discussion with [REDACTED]

The information supplied about your role in research at [REDACTED] has been reviewed and you do not require an honorary research contract with [REDACTED]. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by [REDACTED] to employees and this letter does not give rise to any other relationship between you and [REDACTED] in particular that of an employee.

Cont'd.../



While undertaking research through [REDACTED] you will remain accountable to your current employer (the University of Leicester) but you are required to follow the reasonable instructions of [REDACTED] or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to cooperate fully with any investigation by [REDACTED] in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you on request, and the NRES research Governance Framework.

You are required to cooperate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the [REDACTED] policy 8.1.3 'Confidentiality required of staff (& volunteers) and contractors' and the Data Protection Act 1998. Furthermore, you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution. You should sign the [REDACTED] confidentiality agreement. You should sign in on arrival and out on departure from [REDACTED] on every occasion.

You should ensure that, where you are issued with a security card, this is returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that [REDACTED] accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of [REDACTED] or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Cont'd.../

██████████ will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager at ██████████

Yours sincerely



Director of Care Service



**Consultant in Palliative Medicine
& Lead for Research**

Signed: *L. Ingleby* Date: *20/05/14*

Lisa Ingleby

CC: ██████████ Human Resources Manager, ██████████
██████████ RM&G Facilitator & Team Leader, ██████████

Appendix E: Semi-Structured Interview Schedule and Vignettes

Version 2 (1st May, 2014)

Research Interview Schedule

1. Can you tell me about your job at the hospice and how long you've been working here?
2. What contact, if any, have you had with the clinical genetics service?
3. What do you understand about the role that clinical genetics can play in your clinical work with those affected by breast or ovarian cancer?

Prompts

What could clinical genetics do for patients and/or their families?

What could clinical genetics offer you as a staff team?

Vignettes

1. You are working with a new member of staff at the hospice and they recently started working with a new patient. Their patient recently saw the news of Angelina Jolie's preventative surgery as a result of a genetic cancer mutation and has asked your colleague whether her own cancer might be genetic.

How do you think you would respond to her question?

How do you think you might feel?

What things do you think influence your decision or discussion?

2. You are caring for a woman who has ovarian cancer. You have noticed from her visitors that she has several close female relatives, including two young daughters. The patient's early age of onset and information about her aunt's death from breast cancer make you consider that her cancer may have a genetic component.

- Do you think you would consider genetic counselling for this lady?

- What things influenced your decision?

3. You are working with a lady who is receiving palliative care after living with breast cancer for a long time. She has a number of risk factors which suggest her cancer may have a genetic component; however you are aware that she is estranged from all of her family members.

Do you think you would discuss genetic risk with this lady?

What things influenced your decision?

4. You are caring for a lady with breast cancer who you suspect has a few weeks to live. During a visit, the lady's daughter pulls you to one side and tells you that she's worried about her future risk.

What do you think you would say and do in that situation?

What feelings do you think you'd have?

What factors influenced any decisions you made?

5. A lady has recently been admitted to the hospice who speaks very little English. She tells you through a translator that her mother died of a related cancer and she herself developed breast cancer at a young age.

What do you think you might do with that information?

What things did you think about when making your decision?

How do you feel about this situation?

6. What things make you more or less likely to flag up or have a discussion with the team regarding a referral to the clinical genetics service?

Prompts

- Are there things about you as an individual that have an impact?
- How does the hospice support you to make clinical genetics referrals?
- Are there any organisational issues that make things easier or harder to refer?
- How do you feel about making referrals to clinical genetics?

7. How comfortable/confident are you in discussing genetic risk in breast/ovarian cancer?

Prompts

- What makes you feel that way?
- Can you give any examples?

Appendix F: Trainee's Statement of Epistemological Position*

Epistemologically, the researcher adopted a critical realist position in relation to the data, which can engender a greater inclusiveness of perspectives not afforded by a positivist or a purely social constructionist stance (Bhaskar & Danermark, 2006). This also allowed the researcher to take a position that acknowledged that observable phenomena are both produced by existing mechanisms while simultaneously being constructed through the eyes of the observer. In the present study, this translates to a reality of external forces on the hospice staff (for example, clinical guidelines, the existence of patients' responses to imminent death, and other instances of organisational and service structure) while also allowing recognising that the accounts in the data represent a 'reality' constructed by the participant's language, beliefs and attitudes. This enables a fuller appreciation of the data as comprising 'real' (structural and institutional features), the 'actual' (observable events) and the 'empirical' (how this is experienced by an individual) (Bergin & Wells, 2010).

References;

- Bergin, M., Wells, J.S.G. & Owen, S. (2010). Relating realist meta theory to issues of gender and mental health. *Journal of Psychiatric and Mental Health Nursing*, 17 (5), 442-451
- Bhaskar, R. & Danermark, B. (2006). Metatheory, interdisciplinarity and disability research: A critical realist perspective. *Scandinavian Journal of Disability Research*, 8 (4), 278-297.

Appendix G: Research Poster

Version 1 (27th January, 2014)

Research Participants Needed

Project Title: Clinical genetics in a palliative care setting: A qualitative exploration of the barriers and levers staff report when discussing family risk.

Research Aim

The aim of this research is to explore what makes talking to patients and their families about genetic cancer risk easier or more difficult.

Why?

Clinical geneticists are now able to identify those who are carrying the Breast Cancer (BRCA) 1 or 2 mutations which put them at increased risk of developing breast or ovarian cancer. Preventative treatments are available for those affected. Many people only ask for genetic testing after the death of their last affected relative making genetic testing impossible. In addition, very few referrals for genetic testing come from clinicians working in hospice care. The purpose of this research is to explore what helps and hinders this process from a clinician's point of view.

Who?

Any clinician working in the hospice who regularly cares for those with breast and/or ovarian cancer. It is not essential that you have had discussions about genetic risk with your patients and their families as this study is exploring thoughts and feelings about the subject.

What will happen if I take part?

You will be given more information about the research in order to make an informed choice about participating. The research involves being interviewed by the chief investigator for approximately one hour. Your interviews will be audio recorded and all data will be subject to NHS confidentiality and data protection policies. Interviews will take place in your place of work with agreement from your line manager. All steps will be taken to ensure minimal disruption to your services.

How do I find out more?

Please contact me (Lisa Ingleby – Chief Investigator) with any questions you may have or to request further information. You can contact me by email at [REDACTED] or by telephone at the University of Leicester on 0116 223 1639.

Thank you for your time.

Appendix H: Participant Information Sheet*

Printed on headed paper - Version 2 (27th January, 2014)

PARTICIPANT INFORMATION SHEET

Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the
Barriers and Levers Staff Report when Discussing Family Risk

Chief Investigator – Lisa Ingleby, Trainee Clinical Psychologist – University
of Leicester.

Academic Supervisor – Dr Noelle Robertson, Clinical Psychologist.
Research Director – Clinical Psychology Doctorate, University of
Leicester.

Field Supervisor – [REDACTED]

You are being invited to take part in a research study. Before you decide whether or not to participate, it is important for you to understand why the study is being done and what it will involve. Please take the time to read this information.

What is the purpose of the study?

The field of clinical genetics is a growing discipline, particularly in the speciality of cancer care. Geneticists are now able to test and identify patients who are carriers of the Breast Cancer (BRCA) 1 and 2 mutations, who are therefore highly susceptible to developing breast or ovarian cancer. The number of treatment options available to those identified as carrying BRCA 1/2 mutations means that patients are in a better position to make informed choices about any preventative treatments they may wish to undertake.

Clinical genetics services frequently receive referrals for individuals wishing to undergo genetic testing, for whom their last affected relative is deceased. This demonstrates a lost opportunity to collect genetic material to enable genetic testing for remaining family members. Clinical genetics services receive relatively few referrals from clinicians working in end-of-life care and this study aims to explore this in more detail.

Who is doing the research?

This research is being carried out as part of a doctoral thesis in clinical psychology at the University of Leicester. The research will be completed for submission by April, 2015.

What is the research for?

The purpose of the research is to better understand the things that make discussing genetic risk with patients and their families easier or more difficult. The research will be submitted to a peer reviewed journal to contribute to the existing evidence base. The results will also be presented to participating hospices. It is hoped that the results will identify areas for development to facilitate higher identification and referral of those who may be affected by cancer with a genetic component.

What will happen if I choose to participate?

In this study, you will be asked to contact the chief investigator to express an interest in participating. The interview will be arranged within your working hours in partnership with your line manager to ensure minimal disruption to your service. The interview should take no longer than an hour and will involve discussing your thoughts and feelings about discussing genetic risk with your patients and their families, as well as your confidence and knowledge around referral procedures. It is not necessary that you have discussed these issues with your patients before, or that you have had contact with the clinical genetics service as the research is exploratory in nature. You will be asked to give written consent for the interview to be recorded and will be given a copy of the consent form and participant information sheet to keep. There will be an opportunity after the interview to discuss with the researcher any questions or concerns you may have.

What will happen to my data?

You will be ascribed a participant number to keep your name confidential, should you wish to withdraw your data following the interview, this number will allow the chief investigator to identify and remove your data. Your interview will be audio recorded and transcribed by the Chief Investigator for analysis and any identifying information will be removed at this point. Your data will be kept on encrypted computer hardware and will be destroyed five years following the study.

It is possible that the sponsor of the study and/or host organisations may request access to the research data for monitoring/audit purposes.

PARTICIPANTS' RIGHTS

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed up to three months after taking part in the research. The time limit is required to ensure analysis of the data can be completed for submission as part of a doctoral thesis.

You have the right to omit or refuse to answer or respond to any question that is asked of you and to have your questions about the procedures answered. If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins.

BENEFITS AND RISKS

There are no known risks associated with participating in this study. The aim of the research is to work collaboratively with participants to understand barriers and levers to discussing genetic risk. The aim is to develop a model which will inform any future implementation of this area and thus provide benefits for patients for whom genetic risk may be a pertinent issue.

ANY QUESTIONS?

If you have further questions about this study, you may contact me at [REDACTED] or on 0116 223 1639. This study was reviewed by the University of Leicester Psychology Research Ethics Committee (PREC) and the [REDACTED] Research & Development Committee. You may contact the Chair of PREC [REDACTED] at [REDACTED] if you have any questions or concerns regarding the ethics of this project.

Appendix I: Participant Consent Form

Printed on headed paper - Version 3 (27th January, 2014)

Clinical Genetics in a Palliative Care Setting: A Qualitative Exploration of the Barriers and Levers Staff Report when Discussing Family Risk.

CONSENT STATEMENT	Please initial each box to indicate consent
I confirm I have read and understood the participant information sheet (version 2, dated 27-01-14). I have had the opportunity to ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I may withdraw from the research at any time up until three months after the interview without giving any reason.	
I consent to my interview being audio taped with possible use of quotations, which will be anonymised, in the write-up of the research.	
I consent for my data to be stored on encrypted computer software on University of Leicester computers.	
I understand that transcripts collected during the study will be anonymised and may be looked at by supervisors from the University of Leicester. I give permission for these individuals to have access to my transcripts.	
I understand that access to the research data may be required by the sponsor and/or the host organisations for the purpose of monitoring and audit. I give permission for these individuals to access my data.	
The overall findings may be submitted for publication in a scientific journal, or presented at scientific conferences, which may include anonymised quotations.	
This study will take approximately 18 months to complete.	
I agree to take part in the study.	

Participant's signature: _____ Chief Investigator Signature: _____

Participant's name (please print): _____ Chief Investigator Name: _____

Date: _____

Date: _____

Please note that this form will be kept separately from your data

Appendix J – Reflective Diary – Process Notes Examples

15th July, 2014
Research Participant [redacted]

- This was a tricky interview - it's so difficult to push the hesitance & uncertainty I'm not sure if it's specific to a particular profession but it feels difficult to challenge.

I've also noticed a tendency of participants so far to start to say something quite unguarded & affect driven, before retreating very quickly into the 'party line' about patient care. I can understand this defensiveness (is that what it is?) from a clinician's point of view, however, it's very frustrating when I can tell there's something under it. The psychologist in me wants to open it up by offering interpretation or metaphor to help them out, but all I've got to rely on is that's interesting, can you tell me more about that?

This interview was necessarily [redacted]

[redacted]

Interesting interview - repeated attempts to ask about her response were met with answers about how patient's would feel. Many answers very focused on facts (getting it right?) but some gems!

- Opening cans of worms' - causing distress for people who have already full plates & potential impact of preventative treatment for affected relatives
- Personal & professional experiences of this being helpful seem to have ↑ awareness & confidence in the subject
- Lack of knowledge again raised as an issue
- Lots about "burdens of guilt" for patients (this being hard for nurse to manage vaguely alluded to).
- Giving patients options.
- Lack of certainty ↓ confidence but having a good r/shp c patient helps
- Younger patients harder but unclear if that's because they are more distressed or because it causes more distress for nurses

[redacted]
- After some initial anxiety that the recording equipment wouldn't work I finally settled into the interview quite quickly. I was aware that the participant was very

[redacted] at
she was doing as much to put me at ease as vice versa. There was very little hesitation in her answers & she was very confident. I was impressed by her enthusiasm for her role and interest in developing technology & how this would positively impact on her patients & their families.

The flow of the interview was good but felt more like a conversation as we went on, however, I became aware I was perhaps getting answers that were very policy driven and I'm not sure much of the way of affect was

discussed I wondered whether

[redacted]
Overall, it's good to have the first one out of the way!

Appendix K: Coded Transcript Examples

Interview C

326 C - [I think there's] I think if somebody's dying they've got enough on their plate with dying

327 L - ok... What would your concerns be, if you did have that conversation with her? What

328 what do you think might happen?

329 C - that, erm, she would die with the worry that she's passed something on to her daughter

330 and that her daughter might be at risk...

331 L - ok

332 C - and I wouldn't want her... to die with that weight on her

333 L - mmm

334 C - if that, if that wasn't gonna be helpful

335 L - what would that mean for you as a nurse? If, if that was to happen? If she was to die

336 worrying about something?

337 C - ... it would, it would stay with me for a little bit but then (quietly) I would get over it

338 L - mmm and when you say it would stay with you what sort of feelings (would you...)

339 C - just the fact that she didn't die at peace. I like, you know, ... I'm realistic but I like to

340 be idealistic I like everybody to die comfortably, peacefully, without worrying about things

341 family and you know, knowing that everybody else is going to be ok cos I think it's very hard,

342 most people who die aren't scared of dying, they're not scared of death, they're scared of

343 what happens, they're scared that they're not here anymore to support the family

344 L - mmm

345 C - that's the biggest thing, I'm not gonna see somebody anymore... (sigh) so I wouldn't

346 want them to die with the worry that, some, that you've passed something on...

347 L - mmm

348 C - even though it wasn't your fault as a mother you would feel that it was your

349 responsibility and you'd done something and I wouldn't want... to add... to that...

350 L - yeah, that makes sense

351 C - and I don't think er, erm, I don't think it would be at all helpful because I could probably

352 get a history from her daughter

353 L - mmm, yeah... and erm... I mean, I was going to ask about what factors influenced your

354 decision, so you kind of, you've answered that I think, to some extent about...erm,

355 something about not leaving worry

They've got enough on their plate

Dying with worry

"Weight" of it for patients

Avoidance of -ve affect at end of life

It would stay with her

wanting people to die at peace

worried

Fears of patient

Nurses don't want patient to be worried

Responsibility

What would I do - assumptions

Interview H

125 H - and I think it's just like a service that could see the family so they could go through those tests,
126 you know what I mean?

127 L - yeah

128 H - but I haven't had anything to do with it, so I don't know how it would work

129 L - yeah

→ Doctors as the people with the knowledge

130 H - you know what I mean? Like I say, the doctors I think certainly have you know, or they've
131 certainly helped them, guided them through what tests to have you know, so, but it's not something
132 I would know

133 L - yeah... have you got any ideas about it, if there's anything they could offer you as a staff team?

134 H - education

wanting education from C.G. service

135 L - yeah

136 H - yeah, I think it would be great to actually know, what conditions we were looking for, you know,
137 what tests there are... scenarios, what likelihood there is of someone you know carrying that gene
138 and you know what I mean? And how we would support them through that

→ Wanting specific facts about usefulness

139 L - yeah, yeah

140 H - you know and I think, it's really tough when you don't know how to support them, you can sit
141 and listen, listen to their fears, but you know, you know, you know, you know, you know, you know,
142 know, because you don't know, you know, so...

→ Wanting to reassure → difficult when unable to help

143 L - yeah

144 H - so yeah, education would be great, I think it would be really useful to have training sessions here
145 on that

146 L - mmm, what sort of influence do you think it would have on your practice if you'd had some
147 education about it?

148 H - it would make me more aware I think, if I knew more about what conditions have a genetic
149 predisposition I would be more aware and perhaps would enable me to have those conversations
150 with families

→ Knowledge would allow conversations to happen

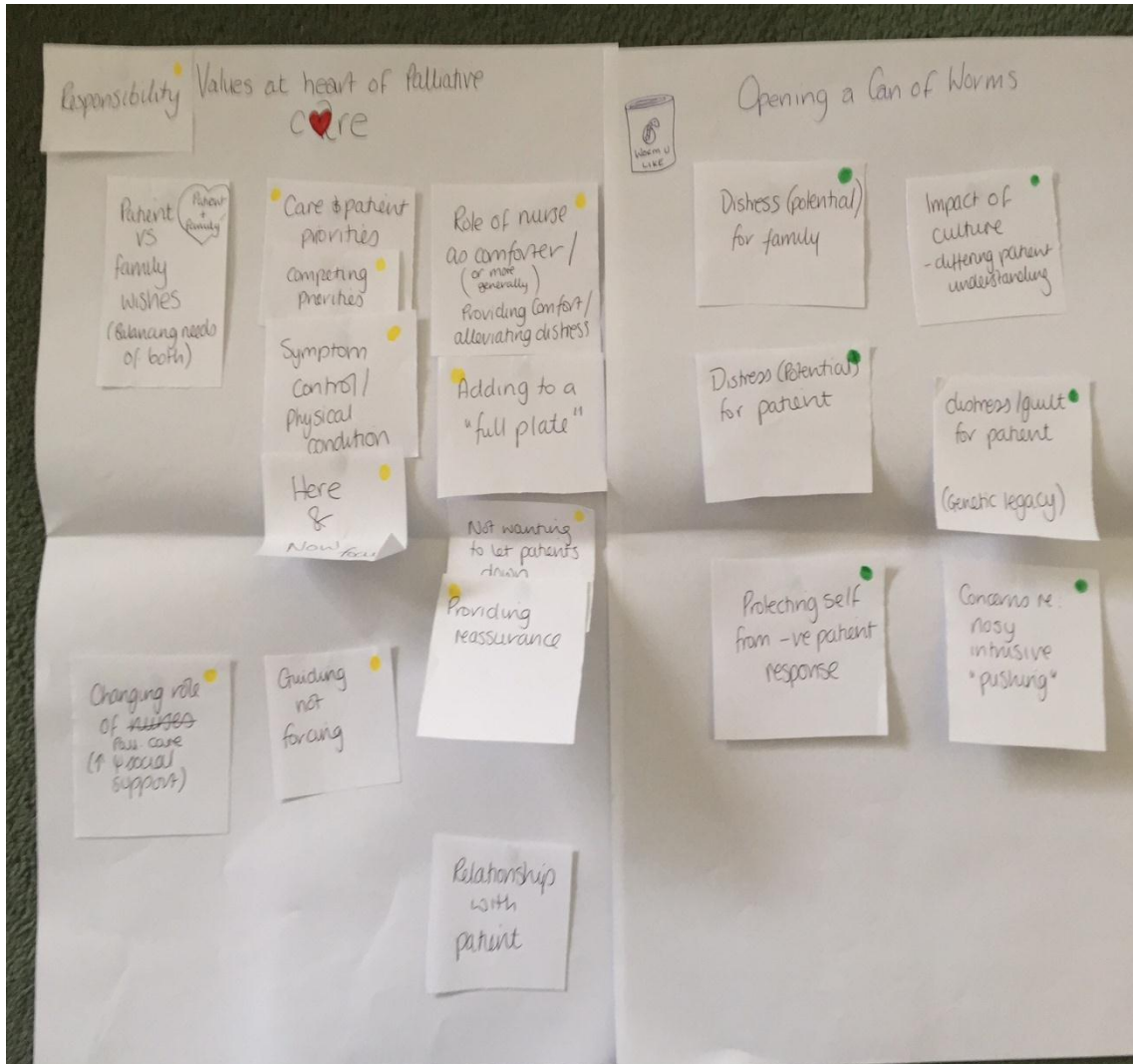
151 L - mmm

152 H - you know because, when they're traumatised, a lot of people don't think to, ooh, is it going to
153 be? You know? I mean, my best friend's got cervical cancer and she's quite poorly at the minute
154 although, I mean there's hope there, and I was thinking about her daughter, and I was thinking, has
155 she had the, you know, the immunisation? I don't know, we'd not even thought about it, because
156 we've been so wrapped up in that, and I think, I think that about our patients, they come in and they
157 are so wrapped up in what's happening to them, it's often the mother or you know, who will bring it

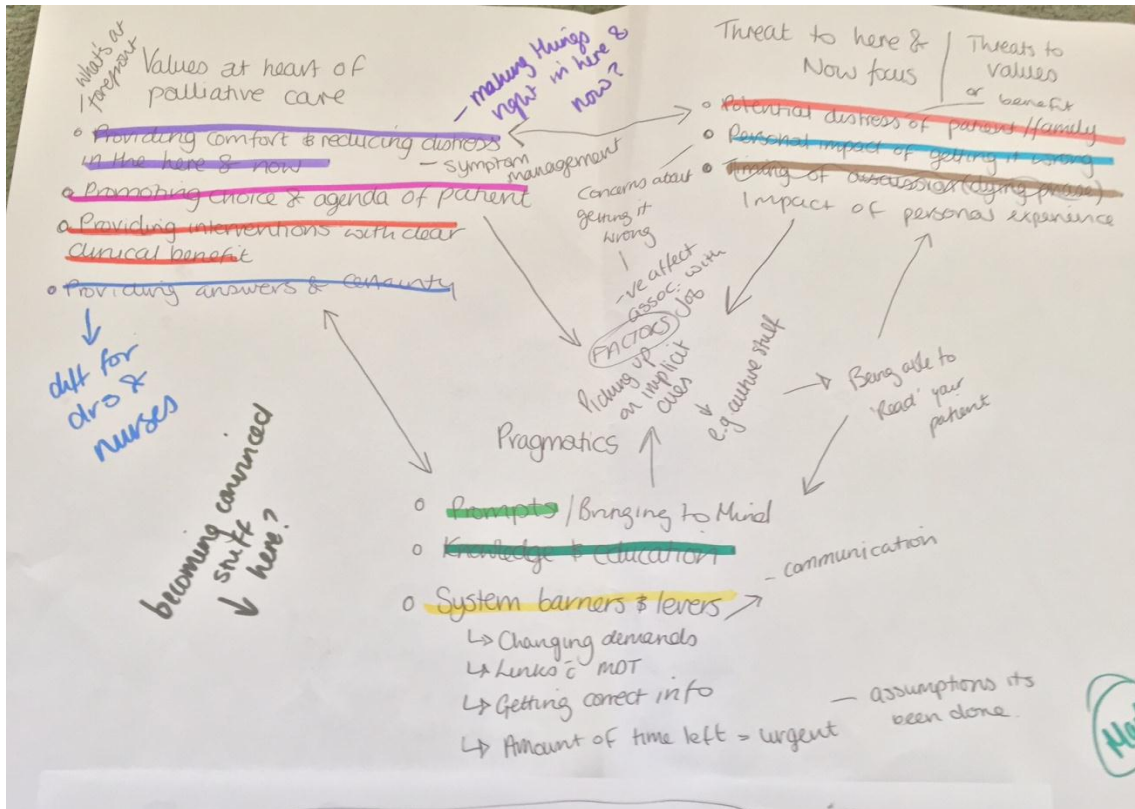
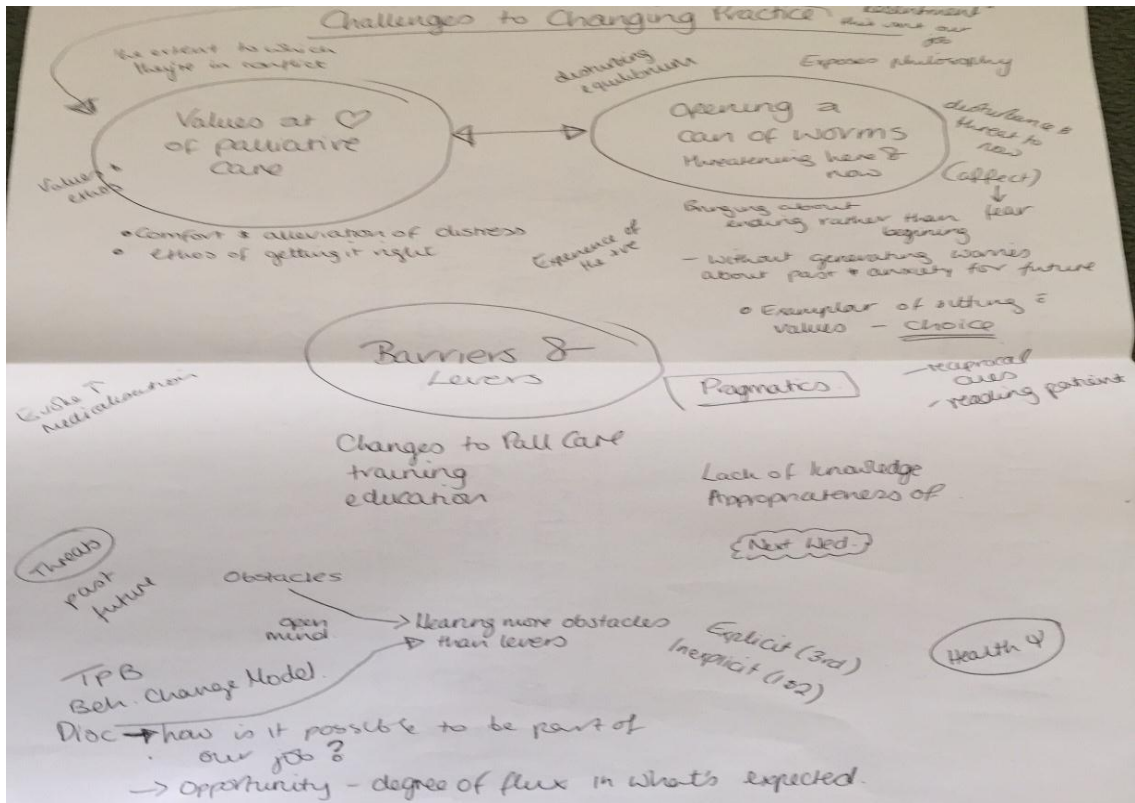
Personal experience

→ Patients are so wrapped up in what's happening, ∴ can't raise it themselves (no head space).

Appendix L: Examples of Theme Mapping



Appendix M: Process of Defining Themes – Example



Appendix N: Chronology of the Research Process*

Date	Research Activity
December 2012 – May 2013	Development of research ideas
May, 2013	Submission of research proposal for internal peer review
June, 2013 – November, 2013	Internal peer review obtained (June, 2013) Further refinement of research protocol and development of methodology Paperwork for university ethics and research and development approval completed
September, 2013 – November, 2013	Discussions with research site Ethical approval sought and obtained (November, 2013)
May, 2014	Approval obtained from research and development department Site specific approval obtained and letter of access granted
May, 2014 – November, 2014	Interviews carried out Transcription of interviews completed
January, 2015 – March, 2015	Analysis
March, 2015 – April, 2015	Write-up period
May, 2015	Thesis submitted
May, 2015 – July, 2015	Preparation for VIVA
July, 2015 – September, 2015	Preparation of manuscript for publication Dissemination of research Participation in trainee research conference