

**Staff Experiences of the Media Representations of
Paediatric Palliative Care: Implications for Wellbeing
and Career Longevity**

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ABSTRACT

This study examined representations of paediatric palliative care (PPC) available in the UK media. Furthermore, the study explored PPC nurses' experiences of these representations, with consideration of the impact of these on wellbeing and career longevity.

With research from the fields of media and cultural studies and medical sociology informing its theoretical basis, the study demonstrated how popularly held constructions of healthcare services and staff are influenced by media representations and come to shape the lived experiences of healthcare workers.

Furthermore, in drawing upon Social Representations Theory (Moscovici, 1988), the study proposed an explanation for how PPC is perceived and understood by the public. Moreover, the study offered a novel insight into the impact of media representations of PPC on nurses, an area which previously has not been explored in this way.

Utilising Critical Realist Discourse Analysis a review of representations of PPC available in the UK media was completed. Here, findings indicated PPC was often represented as controversial and hospice-based. Furthermore, media representations tended to position nurses in polarising ways (e.g. as "angels" or "baby-killers"). In addition, semi-structured interviews were used to explore nurses' experiences of media representations with a focus on the impact of these on wellbeing and career longevity. Data from the interviews was analysed using Interpretative Phenomenological Analysis. Three superordinate themes were developed; 'PPC: A Contentious Approach', 'The "Threat" of the Media' and 'Not the Whole Story: One-sided media representations'. In all themes nurses described the impact of media representations upon clinical practice. However, impact on wellbeing and career longevity were not identified.

Findings from the study are discussed in relation to existing literature and psychological theory, and consideration was given to the implications for clinical psychologists working in PPC and physical healthcare settings generally. Recommendations for future research are also given.

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1.0 INTRODUCTION

Radio, television, film, popular music, the Internet and social networking, and other forms and products of media culture provide materials out of which we forge our very identities, including our sense of selfhood; our notion of what it means to be male or female; our conception of class, ethnicity and race, nationality, sexuality; and division of the world into categories of “us” and “them”. Media images help shape our view of the world and our deepest values: what we consider good or bad, positive or negative, moral or evil. Media stories provide the symbols, myths, and resources through which we constitute common culture and through the appropriation of which we insert ourselves into this culture. Media spectacles demonstrate who has power and who is powerless, who is allowed to exercise force and violence and who is not. They dramatize and legitimate the power of the forces that be and show the powerless that they must stay in their place or be oppressed.

(Kellner, 2011 pg.7 Lines 1-11)

1.1 Overview

The aim of this research is to explore how paediatric palliative care (PPC) is represented in the media and how such representations are experienced by nurses in this field. Specifically, the study seeks to examine the impact of media representations on clinical practice and wellbeing, with the view that these may in-turn affect the career longevity of nurses in PPC.

Mindful of potentially identifying various different media representations, the study aims to avoid the assumption that these will necessarily be problematic. However, some assumptions do still underlie this research. These are outlined below;

- Representations of PPC are available within the UK media.
- These representations reciprocally underpin and come to be shaped by, the constructions of PPC held by the general public.
- Such representations therefore serve as a form of culturally-based knowledge, situated in a given time and place.
- The impact of media representations of PPC influence the clinical practice and wellbeing of PPC nurses.
- PPC nurses will seek to negotiate the impact of media representations to enhance career longevity.

In my introduction I explain how I have situated this research in terms of the existing literature, discussing its broader location within the work of medical sociologists. I develop this by examining how nurses and nursing as a profession are represented in the media, before introducing PPC in the UK and the media representations of palliative care. Furthermore, I consider how media representations of PPC might be experienced by nurses in the field and implications for their clinical practice and general wellbeing.

To conduct the literature search for this study, I began with a precise focus, using the search terms 'paediatric palliative care and the media' and 'paediatric

palliative care nurses and the media'. The specificity of the terms reflected how I had previously identified the phenomena I wished to investigate through discussion of my research interests with the Director of Studies. However, although a number of databases were trialled using this search term, including EBSCO PsychInfo, Science Direct and EBSCO CINAHL, no relevant journal articles were identified. Here, relevant articles were those deemed to discuss issues of *paediatric* palliative care, with reference to their representation in the media.

As there did not appear to be a literature base which pertained explicitly to the area I sought to investigate, I amended my search strategy to include related, albeit, broader areas of research. Here, I recommenced the literature search looking at 'health and the media' and also 'nurses and the media', before filtering down to the areas of 'paediatric palliative care' and 'palliative care and media'. The filtering process has been captured below under the subsequent headings within this chapter.

Furthermore, to maximise the possible number of articles to include in the literature review, I utilised additional databases covering articles from the fields of medical sociology and health sciences, namely; BioMed Central, PubMed and EBSCO Academic Search Complete and CINAHL Plus. The only inclusion / exclusion criteria used was that articles possessed validity by virtue of being relatable to the topic under investigation, as measured by their ability to offer some insight into how the media represents the treatment and care of those at the end of life, and / or how this is experienced by the individuals providing such care.

1.2 Health and the Media

There exists a substantial literature base within the field of medical sociology, which has explored how various health-related topics are represented in the media (Seale, 2003a). This literature has taken multiple sources of media as its focus, from newspaper reporting to social media and other internet-based commentary (for example, Facebook and Twitter – Moorhead et al., 2013).

The role of media in the construction of identity and experience, in the context of health and healthcare, is a particular topic which has been examined in the work of medical sociologists (Lyons, 2000). Utilising a social constructionist framework, these studies have highlighted how the influence of culturally-based knowledge, as represented and communicated through the media, plays a significant role in shaping lived experiences:

Systems of knowledge, or discourses, are promoted in mass media and influence audiences in various ways...we must, therefore, understand popular media if we are to understand experience ... (Seale, 2003b pg. 513, Lines 23-27)

With increasing access to the stories of those providing and receiving healthcare services using different forms of media, popularly held constructions of health and healthcare professionals continue to morph and multiply. Furthermore, such constructions are formed and exist across a multitude of contexts, indicating how interwoven ideas about health and health-care professionals have become in the social and political fabric of society (Turow, 1989, Karpf, 1988).

For example, at the time of writing, people across much of the western world have witnessed the efficacy of social media in publicising a means of raising money for, and awareness of, motor neurone disease charities, namely, the 'Ice Bucket Challenge'. This media coverage also served to represent particular ideas around acts of charity; including a sense of collective action, a coming together of people achieved in spite of multiple forms of difference - something which arguably has never before been achieved so quickly and efficiently through any other form of communication.

Again a timely, yet contrasting use of media representation was that illustrating the failings in care of those typically constructed as vulnerable in society; namely the Winterbourne View scandal. Here, ideas of blame, responsibility, and vulnerability are represented in the rhetoric of the media coverage, serving to position the various parties involved and constructing for them identities which are then fed-back into society:

Winterbourne View care home abuse reveals the 'criminal acts' nurses and carers are capable of, Health Minister warns.

(Daily Mail Headline, 29 October, 2012)

The quotation above is one example of how an identity can be constructed for nurses caring for people with learning disabilities. Here, a national newspaper represents the nurses as capable of “criminal acts”, which in turn serves to position them as potentially dangerous and a group which the public should be “warned” of.

The reach of media representations on the lived experiences of people transcends both those groups working within health care, and those who are recipients of its services. For example, we need only look to the NHS Constitution (DoH, 2013) for a representation of the ideals and values incumbent in the health service, and thus suggested as embodied in the people working therein. The constitution names its’ core values as;

Working together for patients

Respect and dignity

Commitment to quality care

Compassion

Improving lives

Everyone counts

Interpretations are often made on the basis of such representations. These interpretations then shape and inform expectations around care and those responsible for the provision of that care (Washer & Joffe, 2006).

1.2.1 Media Representations of Nurses

The research community has paid specific attention to media representations of the nurse. Moreover, of the representations discussed, most are argued to be

problematic and subsequently challenged. For example, Bridges (1990) identifies four common representations; the “ministering angel”, the “battle-axe”, the “naughty nurse” and the “doctor’s handmaiden”.

In Bridges’ (ibid) examination of the “ministering angel” stereotype, she draws upon the work of Hughes (1980), Salvage (1983) and Kalisch & Kalisch (1982), highlighting how synonymous nurses have become with the term “angel” within the media. Exploring the representation further, Bridges (1990) discusses the formal origins of nursing, proposing the religious affiliation probably stems from the historical practices of religious orders who were typically responsible for nursing the ill and infirm.

Bridges (ibid) goes on to describe how nurses are often represented to possess innate virtues; such as compliance, willingness, kindness and selfless dedication, and cites the former Department of Health and Social Security’s advertisement to potential nursing recruits; *“The best nurses have the essential qualifications before they go to school”* (Alderton, 1983). The advert suggests the qualifications needed for nursing are inherent, personality-based attributes, as opposed to skills which can be taught and learned. Drawing upon feminist critiques of this portrayal; that personality traits as opposed to mental ability and political shrewdness dominate popular ideas of good nurses (Salvage, 1983), Bridges (1990) argues that such representations perpetuate a negative stereotype of nurses. Namely, that they succeed in the profession by virtue of temperament, rather than academic achievement or skill.

Furthermore, Bridges (ibid) points to the typically female representation of the nurse, proposing this is likely compounded by media endorsed links between nursing and motherhood. This gendering of the nurse by the media is further examined by Stanley (2012), who looked at representations of male nurses within films. Here he found that again, predominately negative identities were constructed, however these appeared specifically linked to gender and included; effeminate, homicidal and corrupt. Furthermore, Stanley (ibid) hypothesised these popularly held negative identities were related to relatively low male nurse recruitment, and underpinned a negative public perception of the male nurse.

In a more recent examination of media representations, Kelly, Fealy and Watson (2012) looked at the ten most viewed You Tube videos depicting the nurse. Here they found three gendered identities were constructed; the nurse as “a skilled knower and doer”, a “sexual plaything” and a “witless incompetent”. This finding is particularly interesting as the authors highlight how a considerable number of these videos appeared to be posted online by nurses themselves. This raises interesting questions about how far dominant media representations are internalised and perhaps even sought by nurses, and whether nurses think that in order to be considered successful, they must uphold these dominant representations.

1.2.2 The Impact of Public Perception on Nurses and the Nursing Profession

With multiple representations of nurses available in the media serving to construct public perception of them, it is perhaps unsurprising authors have sought to explore the impact of public perception; and thus indirectly media representations, upon nurses’ lived experiences and the profession more widely.

Hughes (1980), has suggested that media representation of the nurse not only influences public opinion of them, but also affects the demand for nursing services, decisions about the allocation of healthcare resources, and recruitment and retention of nurses.

Salvage (1983), argues that the failure of the media to accurately reflect the changing professional conditions in which nurses work, and the continued assumption of derogatory traits such as limited academic potential, serve to undermine the confidence the public have in, and their respect of, nurses.

Other research has suggested school leavers are put off from entering into nursing as they believe it to lack academic challenge, a view which is directly underpinned by media representations which place an emphasis on personal attributes over and above intellectual ability (Rogers, 1984). Similarly, individuals who view themselves as lacking the humbling qualities typically perpetuated in media representations of the nurse also feel discouraged from entering the profession. Furthermore, Rogers (Ibid) has proposed that these views became so dominant, they underpinned the move to professionalise

nursing. As seen for example in the shift in nurses' training from the hospital to the university setting through the introduction of the BSc degree in General Nursing.

In a paper of particular relevance to the current study, Takase, Maude & Manias (2006a) compared nurses' perceptions of their public image with their self-image. Here, they found that nurses' self-image was generally more positive than their perceived public image. Namely, they believed the public viewed them more negatively than they saw themselves, and that this was due a discrepancy regarding perception of leadership skills. Specifically, nurses considered themselves to possess leadership and management qualities unrecognised by the general public, who they thought viewed them purely in terms of traditional caring roles.

Takase, Maude & Manias (*ibid*), propose nurses' perception that the public lack an accurate understanding of modern nursing may have contributed to an expansion into other healthcare roles, thus blurring the boundaries between nursing and other healthcare professionals. Indeed, we see this now in the 'Nurse-Consultant' and 'Nurse-Prescriber' roles within the NHS. Moreover, the authors comment on the persistence of more traditional representations of nurses in the media, suggesting these underpin the dominant caring aspect perceived by the public. They suggest the absence of media representations other than that of the doctor's handmaiden, or ministering angel, render alternative, arguably more realistic representations, invisible.

Furthermore, the authors examined how the relationship between self-image and perceived public image was associated with work-related performance and retention. Here, they found that when nurses perceived the public to hold their caring abilities in higher regard than they did themselves, they viewed their job performance negatively and were more likely to want to leave their role. It is possible this finding may have been a result of stress induced by thinking they were not achieving the high expectations of the public around ability to provide care (Hemsley-Brown & Foskett, 1999). Moreover, it highlights a possible connection between public perception, lived experience, and career longevity.

Consequently, when nurses rated their self-image more positively than their public image in terms of ability to provide care, they tended to perceive their

performance more positively. Here, the authors explain this finding by drawing upon Person-Environment Fit Theory (Edwards, Cable, Williamson, Lambert & Shipp, 2006). Specifically, they propose the nurses sought to manage the difference between self and public perception by working harder, in order to change their public image so that this was more in line with how they viewed themselves.

Overall, these findings suggest that nurses are affected by how they think the public perceive them, and this has a direct impact on their clinical practice and wellbeing. Takase, Maude & Manias (2005, 2006b) suggest that whilst incongruence between self-image and perceived public image may in the short term motivate nurses to display excellent performance, in the longer term, the self-correcting motivation arising from such incongruence becomes stressful to manage and maintain. Furthermore, it may actually turn into frustration and job dissatisfaction, which can ultimately lead to professional burnout and a shortened nursing career.

The salient point from this study is that, over time, nurses' perception of their public image as constructed in the media, can be detrimental upon their practice and wellbeing. Furthermore, this can have repercussions in terms of career longevity in that nurses' motivation can be affected and they may be more likely to consider leaving their role. In order to address these issues, the authors identify the need to improve the public image of nurses in the media, and support the "... cultivation of positive, personal self-esteem, to ward off the negative influences of public stereotypes on nursing practice" (Takase, Kershaw & Burt, 2002 pg.196 Lines 16-18).

1.3 Paediatric Palliative Care

As general nurses who have undertaken further specialist training to work in the field of PPC, such men and women are similarly subject to, and of, the dominant media representations discussed above. However, this study seeks to establish whether there are any representations more specifically related to

the PPC context which impact upon those nurses working in this field, and if so, what implications do these have on clinical practice and wellbeing.

Before examining the media surrounding PPC, I firstly provide an overview of the development, as well as the modern day context, of PPC services in the UK.

1.3.1 Definition and History

According to the Collins English Dictionary (2010), the term 'palliate' means "*to lessen the severity of (pain, disease, etc...) without curing or removing*". This definition indicates how palliative care therefore seeks to make comfortable and support seriously ill and dying patients, as opposed to providing active treatment aimed at cure.

Whilst reference to what we would today describe as palliative care being traced back to the 11th Century, it is arguably most notably associated in the UK with the hospice movement of the 1960s, which sought to care for people at the end of life outside of the hospital setting. Indeed, the first UK hospice was founded by Dame Cicely Saunders in 1967, and served to offer people a place where they could be made comfortable and ultimately die a dignified death.

The work of the hospice movement aimed to champion the importance of recognising the needs of patients where curative medicine was no longer of any benefit. Rather than continuing with aggressive and invasive interventions, or leaving the individual without adequate support, the hospice movement offered an alternative whereby the holistic needs of people at the end of life could be met. These needs might include the physical; such as pain relief and dietary management, but also extend beyond this to consider the emotional, spiritual and practical needs of the individual and their family.

Despite the emergence of palliative care services for adults within the hospice movement, similar services for children were not established until the 1980s (Cottrell et al., 2011). Indeed, the first UK children's hospice, Helen House, was opened in 1982. This event marked an appreciation of children's entitlement to quality palliative care, care which was later formally defined by the Association for Children with Life-Threatening or Terminal Conditions (ACT) as:

an active and total approach to the care of children and young people with life limiting conditions, embracing physical, emotional, social and spiritual elements through to death and beyond.

ACT (2004)

Moreover, in 2009 paediatric palliative medicine was recognised as a subspeciality of the Royal College of Paediatrics and Child Health (RCPCH, 2009).

The ACT and RCPCH further define four groups of children who are likely to require palliative care. These four categories of life-threatening or life-limiting conditions (LTLLCs) are;

- Life threatening conditions for which treatment is possible but may fail e.g. cancer
- Conditions where there may be long periods of intensive treatment aimed at prolonging life, but premature death is still possible e.g. cystic fibrosis
- Progressive conditions without curative treatment options where treatment is exclusively palliative and may extend over many years e.g. Batten Disease
- Conditions with severe neurological disability, which may cause susceptibility to health complications. Patients in this group may deteriorate unpredictably but conditions are not considered to be progressive e.g. severe cerebral palsy.

The ACT and the RCPCH, as well as the World Health Organisation (WHO, 1998) emphasise how palliative care is something which is offered to the child and their family at the point of diagnosis, and is not therefore limited to the final days of life. Mellor, Heckford & Frost (2012) suggest that the need to assert this point speaks to the common misapprehension likely stemming from popular ideas around adult hospice provision, that palliative care is something only appropriate at the end phase of life; indeed a place where people go to die. Rather, paediatric palliative care is a philosophy concerned with symptom control and maintaining quality of life from the time of diagnosis of a LTLLC (Ibid), and so is as much about living, as it is about dying.

1.3.2 Population

Quantifying the number of children and young people in the UK in need of palliative care services at any one time is a complex task and this is in part due to the heterogeneity of this group. However, a report produced in 2011 cited figures of 40,042, 4463, 3199 and 1307 children living with LTLLCs in England, Scotland, Wales and Northern Ireland respectively (Fraser, Miller, & Aldridge, 2011). Indeed, part of the rationale for producing this report was as a response to the lack of a current, national database of clinical and demographic information which could provide accurate figures. Additionally, the report also recognised PPC clinicians' anecdotal sense that previous figures were underestimating prevalence of LTLLCs and the burden of such diseases.

The Fraser et al. (2011) report also provides information around prevalence of LTLLCs in relation to gender, socioeconomic status and ethnicity, the general key findings of which are detailed below;

- In all four UK countries prevalence of LTLLCs in children aged 0-19 years was highest in children aged under 1 year and decreased through the age bands. The prevalence in the male population was significantly higher than in the female population across all age bands.
- In all four UK countries the highest prevalence of LTLLCs in children aged 0-19 years were accounted for by congenital abnormalities.
- Associations between higher prevalence and levels of deprivation were seen in all four UK countries (although in Scotland and Wales this was a more linear association with the highest prevalence in the most deprived areas).
- Ethnicity was strongly linked to variations in prevalence. In England, prevalence in 'South Asian', 'Black', and 'Chinese', 'Mixed' and 'Other' populations were all statistically significantly higher compared to the 'White' population.

1.3.3 Context in the UK

Since the 1970s, various models of PPC have developed throughout the UK, mostly in response to local need, local resources, existing service provision and the motivation of interested professionals in a given area (Mellor, Heckford & Frost, 2011). However, more recently, there have been observable efforts both regionally and nationally, to promote equitable and sustainable services across the UK. Such efforts are seen in the publishing of key policy documents, as well as changes to funding and commissioning arrangements which have influenced the development of PPC in the UK.

For example, ACT first published definitions of children's palliative care and the numbers and needs of LTLLCs (ACT, 1997). This was followed in 2003 by Big Lottery funding grants to support the development of specialist community nursing teams and hospice services. In 2006, the Secretary of State for Health committed £27 million over 3 years to support children's hospices and commissioned an independent children's palliative care services review, which was published a year later (Killen, 2007). In 2008 followed the first ever 'National Strategy for Children's Palliative Care' and in 2009 the RCPCH formally recognised Paediatric Palliative Medicine as a sub-specialty. In 2010, the Department of Health provided £30 million in funding for palliative care projects and in 2011 a further review of the current funding mechanisms for dedicated palliative care services for children and adults in England was undertaken. Since 2012, Together for Short Lives (TfSL), an charitable organisation which was formed through the unification of ACT and Children's Hospices UK, has spear-headed the campaign to develop and deliver quality children's palliative care services through both their 2012-2015 Strategic Plan and the identification of 8 key policy priorities for the next parliament which was presented to MPs at Westminster in November 2013. Specifically, TfSL calls for;

- Every child to have access to children's palliative care in the setting of their or their family's choice and whenever they need it - 24 hours a day, seven days a week

- Every child - and their family - to have access to palliative care services, including children's hospices, which are sustainable and fairly funded.
- Every child - and their family - to get a short break if they need one
- Services to be more integrated around the needs of children and their families
- Every young person to have a smooth transition from children's to adult's palliative care services
- Services which provide palliative care to children - including children's hospices - to be regulated fairly and proportionately
- Support for families of children who die with life-threatening or life-limiting conditions to be improved
- Families to receive help from the state to help mitigate the financial impact of caring for a child

http://www.togetherforshortlives.org.uk/about/policy_priorities

It is possible to see that currently, PPC in the UK is provided by both statutory and voluntary sector organisations. PPC takes place across a number of settings and in differing forms, including; hospitals, hospices, community services working within family homes, specialist nursing and outreach teams. Such variation exists despite the production of Best Practice Guidelines (ACT / RCPCH, 1997) and the introduction of a care pathways approach (TfSL, 2004, 2007, 2009 & 2011). Moreover, it is arguably fundamental to the currently inequitable, and in places, inadequate PPC provision across the UK.

1.3.4 Perception of PPC and the Death of Children in the UK

As discussed earlier, the development of PPC in the UK can be observed to have emerged from the advancements in adult palliative care throughout the 19th and 20th centuries and also the rise of the hospice movement in the 1960s. However, PPC is currently an evolving speciality within paediatric medicine, and whilst it is significantly different from adult palliative care, confusion exists around these differences; such as the specialist skills needed within PPC and the unique challenges posed in working with children and young people with LTLLCs and their families.

Within the UK, the term 'hospice' has come to be known as a place where people go to die, an understanding which likely stems from the world of adult palliative care. Here, individuals are typically offered palliative care for relatively very short periods of time; often only weeks or even days prior to death. This occurs for a number of reasons including the cause of death / dying (e.g. age-related illness such as cancers and dementias) and the availability of provision where adults can be cared for using palliation for longer periods prior to hospice admission (e.g. nursing homes).

However, within PPC, services are utilised in different ways, often for longer periods of time, and in order to care for children with a greater variety of complex needs. Many of the conditions children receiving PPC experience are rare if at all diagnosable. Furthermore, it is not uncommon for children to rehearse their death on a number of occasions before they actually die. Here, the child may appear to enter the final stages of life only to experience a remediation of symptoms which can then be controlled and stabilised (Mellor, Heckford & Frost, 2011). There are also specific issues to be considered around where the child is developmentally, and how this will influence how care is delivered.

As with all children and young people, a system surrounds the child utilising PPC services, and it is likely this system is an extremely large and complex one when including medical, educational and familial networks. It is therefore vital that those professions working most closely with the child and their family possess advanced communication skills to ensure clarity and consistency of care, and can achieve sensitive negotiation of difficult ethical dilemmas which may arise amidst the multiple parties involved in that child's care (Clark & Quin, 2007). In addition, Papadatou (1997) highlights the particular nature of the death of a child and how this event can impact upon many people, including professionals themselves. Furthermore, Papadatou (ibid) suggests how professional carers will likely develop their own unique philosophy around life and death in order to cope with multiple deaths of children, and therefore will be uniquely impacted upon by such loss (Rothaug, 2012).

The dominance of palliative care representations which pertain to adult care, coupled with Western Society's reluctance to engage in thinking about

childhood death and dying (Baum, Dominica & Woodward, 1990), as well as the small numbers of children and young people with LTLLCs, has resulted in a lack of accurate understanding about PPC. Moreover, PPC is a vague and unknown concept for most, often equated with adult hospice care. As such, there is a heightened potential for sources such as the media to influence and shape the ways in which PPC is represented in the public domain. For most, PPC remains something which is not personally experienced, thus, what we come to know of it, is largely dependent upon the constructions and representations provided to us, and which come to form culturally-based forms of knowledge. Ultimately, when we are asked to think about PPC, we are drawing upon sources of culturally-based knowledge, such as the media.

1.4 Media Representation of PPC

1.4.1 The Good, the Bad and the Ugly

When looking to examine media representations of PPC, there are several topics which are frequently commented upon. Whilst a more thorough exploration will be conducted in a media review later in this study, it is useful to provide some introduction to these topics upon which media representations of PPC are based. One such particularly high-profile area is that of publicity for charities linked to PPC, which often utilise quotations from families who have experienced services. For example;

*...I can honestly say it's an **amazing** place, and the provision of **love and care** by carers, staff and parents is **beyond dedication**...*

(www.rainbows.co.uk)

*Jill gave us the emotional support we needed to keep going. **She became our guardian angel** and I can say with hand on heart that **we couldn't have coped without her.***

(www.rainbowtrust.org.uk)

Butterwick House Children's Hospice is amazing.

All the nurses love Paige and she loves them.

(www.togetherforshortlives.org.uk)

*Harvey was just four years old but in that time we were given **the best care and opportunities** even knowing the outcome was him not living past childhood.*

(www.togetherforshortlives.org.uk)

Here, the quotations utilise language which serves to position PPC staff as crucial and highly valued, as achieved by the foregrounding of caring attributes and temperament. It could be argued these excerpts are deployed to portray the service as able to provide nursing which is congruent with traditional and widely-accepted stereotypes (Cunningham, 1999). If this is the case, such representations reinforce the idea that provision of care is the most highly valued role of the nurse over and above technical skill, medical knowledge or leadership quality.

Another issue widely publicised in the UK media entwined with end of life care is that of the Liverpool Care Pathway (Royal Liverpool University Hospital, 1999), and its use as a model for the care of dying children and babies through the Neonatal Care Pathway for Babies with Palliative Care Needs (TfSL, 2009). The Liverpool Care Pathway arose out of concern around end of life care of adults in the hospital setting. Specifically, the use of inappropriate medical interventions causing unnecessary pain and suffering to those in the final stages of life. The pathway aimed to provide a uniformity to how patients at the end of life were treated in the hospital setting, so to uphold their dignity and cause the least suffering. It sets out the withdrawal of medical treatment and fluids, and introduces a sedation and dehydration regime so to induce a comatose state.

The use of the Liverpool Care Pathway is an issue that has been widely debated and labelled as contentious in the UK press. Whilst it is often said to be supported by the medical community, several national newspapers have run stories which appear to pit medical professionals' endorsement of the pathway

against the personal experiences of families whose relatives have been placed on it, only to experience agonising and protracted deaths. Often, such stories comment on; the length of time people are on the pathway prior to death (some articles citing up to 12 days - <http://noliverpoolcarepathway.com/the-peoples-page/relatives-speak-out/>), the lack of communication from medical teams informing families their relative has been placed on the pathway, and the subjective and sometimes mistaken decision to place someone on the pathway in the first instance – indeed, one woman made a significant recovery from the health issues which had led doctors to believe she was in the final stages of life (Daily Mail article, 26.10.2012).

Although pertaining to only a minority of individuals placed on the Liverpool Care Pathway, most stories around its use represent doctors and nurses as complicit in the euthanasia of patients, by embedding its practice within a context of NHS cost-cutting and bed shortages. In doing so, media reports create a suggestion the pathway is used as a means of bringing about premature death to cut costs (<http://www.dailymail.co.uk/news/article-2161869/Top-doctors-chilling-claim-The-NHS-kills-130-000-elderly-patients-year.html>). Moreover, a number of articles have reported what they describe as “financial incentives” given to NHS Trusts where the pathway has been used (<http://www.dailymail.co.uk/news/article-2223286/Hospitals-bribed-patients-pathway-death-Cash-incentive-NHS-trusts-meet-targets-Liverpool-Care-Pathway.html>). Such representations appear to further sensationalise the story by implying NHS Trusts are in fact financially rewarded for effectively euthanizing some patients.

With articles describing the pathway as killing off patients, clinicians are positioned as responsible for carrying out such an agenda. Thus, those members of staff said to be delivering the Liverpool Care Pathway; specifically palliative care nurses, come to be represented by more dangerous stereotypes such as the homicidal nurse identified by Stanley (2012).

Controversy has leaked into the field of PPC through media reporting which draws parallels between it and other fields of nursing represented in damaging ways e.g. neonatal and paediatric intensive care (<http://www.telegraph.co.uk/news/health/news/9710426/Children-placed-on->

[controversial-death-pathway.html](#)). The homogenising of nurses into a generic stereotype is achieved by failing to identify the different nurse specialisms and roles, blanketing all nurses who work with the seriously ill and dying in the central theme of a given media story.

For example, where reporting of the Neonatal Care Pathway has been depicted as paralleling aspects of the Liverpool Care Pathway, which is typically constructed in the media as deviant, this has served to represent neonatal care nurses in similarly harmful ways as those nurses working with adults at the end of life. Through association, these nurses too are positioned as complicit in suffering and protracted deaths. Moreover, these identities have the potential to become shared by all nurses working with dying children and / or using the Neonatal Care Pathway; namely PPC nurses.

Perhaps one of the most powerful aspects of the media is its ability to construct affiliations between groups of people and ideas so adeptly, to the point whereby such representations become a virtual truth; a taken for granted knowledge informing cultural and societal views (Kellner, 2003). The power of the media to do this therefore has the potential to render its subjects in polarised positions, as reflected in the dominant stereotypes of the nurse. Indeed, it would seem that within PPC, there are contexts in which the nurse can be represented as an angel, and yet there are also others where he/she may be portrayed as a baby killer. We must then ask, how do nurses in this field negotiate such representations and what impact, if any, do these have upon their clinical practice and wellbeing. Moreover, how do nurses manage the stress and strain we would assume them to experience in this negotiation, and is it possible to draw upon what we already know about how PPC nurses cope with stress to answer these questions?

1.4.2 Coping, Resilience and Wellbeing in PPC

1.4.2.1 *Stresses of Working in PPC*

Whilst numerous studies have looked at the various stressors staff working in PPC may encounter, very few have examined the contribution of media representations in this endeavour. Of the research base that does exist, there are several issues which are believed to contribute to stress of PPC workers

which are highlighted repeatedly. Of particular interest to this study is the issue of disenfranchised grief experienced by PPC workers (Liben, Papadatou & Wolfe, 2008). Namely, the experience of feeling unable to express grief in response to the death of a child, due to particular expectations of nurses arising from the ways in which they are represented in popular media and society more widely (Sapir et al, 2000).

As already discussed, media representations perpetuate an expectation that nurses should be unfaltering in their tireless dedication to the care of patients (Cunningham, 1999). Such representations leave little room for these professionals to publicly demonstrate their grief, which leaves it invisible, and ultimately unaddressed. Moreover, Davies et al. (1995) found grief distress to be a particular dilemma for PPC nurses, who commonly felt expressing their sadness at the death of a child conflicted with expectations of them as professionals. Ultimately, in these situations, the grief felt by the PPC nurse becomes compounded in an environment which does not facilitate the healthy expression and exploration of it, something which has been shown to directly interfere with the provision of care to children and families (Caine & Ter-Bagdasarian, 2003).

The work of Menzies-Lyth (1990) further elucidates the practice implications of the maladaptive processes nurses are expected to use to manage the emotional stresses of their work. She suggests that often, in an attempt to create distance between nurses and the anxiety evoked from their close and prolonged proximity to human suffering, attempts are made by institutions to avoid it, by dissecting nursing duties into impersonal elements and tasks (ibid). Consequently, to reduce the guilt and frustration associated with the stress caused by such working practices, nurses may come to avoid communication with patients. Ultimately, these processes can lead to feelings of dissatisfaction, and have been hypothesised as a causal mechanism of high rates of sickness, absenteeism and staff turnover, factors which all impact upon career longevity.

Further sources of stress identified in the work of PPC nurses have included communication with families of children with LTLLCs (Contro, Larson, Scofield, Sourkes, & Cohen, 2002), as well as the children themselves; particularly

around sharing information about diagnosis and prognosis (Hatano, Yamada & Fukui, 2011). In a study by Wooley, Stein, Forrest, & Baum (1989), the authors highlighted how threats to team cohesiveness are a source of conflict within staff teams and as such a major source of stress for workers. Such threats included conflicting ideas around treatment orders, with Davies et al. (1995) suggesting nurses are particularly vulnerable to stress in negotiating treatment orders administered by doctors when these conflict with their sense of duty to provide as comfortable and dignified a death as possible. Within PPC, such dilemmas and conflicts are arguably more common due to the prognostic uncertainty surrounding many children with LTLLCs. Furthermore, it is possible the stress associated with such dilemmas is heightened by media reports, and indeed the internal pressure generated by institutions themselves, where staff teams have been portrayed as failing to treat or are under pressure to provide active treatment.

Finally, McCloskey & Taggart (2010) found that palliative care nurses experienced ethical dilemmas related to the withdrawal of treatment and feeding. This undeniably very emotive issue was recently covered in the UK press which reported the concerns of a doctor adhering to a neonatal care pathway outside of the UK, which was similar to that endorsed by NICE and widely used within the UK (TfSL, 2009). Specifically, the report constructed a representation of staff as permissive of the stress and suffering of new born babies on the pathway, describing how they bear witness to the “shrinking and suffering” of babies who have had their feeding withdrawn (Daily Mail, 30.11.2012 and <http://www.lifenews.com/2012/11/29/doctors-haunting-testimony-uk-babies-put-on-euthanasia-pathway/>). Echoing reports of the stories of people under the Liverpool Care Pathway, this article foregrounds the doctor’s account of watching babies die protracted deaths over extended periods of time, quoting that in their experience, this takes an average of 10 days from the withdrawal of feeds (Anonymous, British Medical Journal, 2012).

1.4.2.2 Coping Strategies and Promoting Wellbeing

A number of studies have identified the importance for PPC staff to have opportunity to makes sense of, or give meaning to, the death of a child (Papadatou, 1997). To enable this to happen, staff must be encouraged to take

part in a dual process of exploring their grief so to make sense of the loss, and repressing their grief so to cope and adjust (Papadatou, Bellali, Papazoglou, & Petraki, 2001).

PPC staff may be supported in exploring their grief through various work-related strategies. For example, Maytum, Heiman, & Garwick (2004) have suggested the development of supportive professional relationships may be a useful resource for enabling the exploration of grief, whereas Papadatou, Papazoglou, Petraki, & Bellali (1999) have proposed informal support from fellow nurses is particularly helpful for sharing experiences of struggle.

Alternatively, Maunder (2006) has suggested the use of “dark humour” amongst work colleagues can also serve to protect them from the hurt of the death of a child. However, Maunder (Ibid) also points out that the use of this kind of strategy is something which requires skill and expertise and so is perhaps only available to more experienced staff. Benner (2000) too proposes experiential learning is a fundamental aspect of developing skills needed to manage issues such as grief and stress as a nurse. This would support the suggestion that use of complex protection strategies such as dark humour develop over time, and may not be at the disposal of nurses early into their careers.

The work of Keene, Hutton, Hall, & Rushton (2010) has highlighted the use of debriefing sessions for PPC staff following the death of a child, including the entire team involved in the care of that child. They suggest this collective exploration of the experience of the child’s death can be useful in sharing loss and thus reducing the sense an individual is alone in their grief. However, as Davies et al. (1995) point out, some team members may feel conflicted in sharing their beliefs and feelings due to expectations around professional conduct and relationships. Such expectations may reinforce the notion staff should be in control of their emotions and behave in ways which serve to maintain professional hierarchies.

Similarly, support groups utilising external facilitators such as clinical psychologists may serve a similar function to the debriefing sessions, and may be particularly useful in revealing and addressing distress which may otherwise be expressed unconsciously in staff members’ clinical work (Menzies-Lyth, 1990). Furthermore, providing PPC staff with psycho-education around typical

grief responses of families and fellow professionals, may help to reduce distancing and avoidance of communication with those experiencing distress.

1.5 Summary and Justification for the Current Research

1.5.1 A Qualitative Approach to Exploring Staff Experiences of the Media Representations of PPC

The reach of modern day media is far and wide with multiple forms available all around us in western society, from newspapers to television to social media. As a society we have almost constant access to the lives and experiences of others through the media, and are able to use the content of such coverage as a form of culturally-based knowledge about the world. What we come to know of the world in this way is essentially social construction; co-created and produced, a representation of others propagated on a huge scale through various forms of media and woven into the fabric of everyday life (Burr, 2003).

The current research study aims to elucidate the interactions between media representations, individual experience and clinical practise. It therefore serves as an opportunity to gather further information about what helps promote, or may threaten, career longevity of PPC nurses.

If these issues could be better understood, this knowledge may enable clinical psychologists working in paediatric settings to support the wellbeing and best practice of nurses in PPC. Furthermore, if PPC nurses were to experience more helpful support, this may have an impact on reducing work-related stress which may have otherwise led them to consider leaving their role.

As such, the study has potential to make a contribution to clinical psychology and broader medical systems, in that it may better our understanding of the kinds of media representations of PPC which are available to nurses, and how these hinder or enhance wellbeing and practice. The study may also allow consideration of how institutions such as the NHS engage with the media, so to negotiate representations which come to impact upon its staff and services.

1.5.2 Research Questions

A number of studies have examined the roles of clinical psychology within palliative care (Hudson, Remedios & Thomas, 2010, Strada & Sourkes, 2009). This study seeks to add to that contribution through its novel focus, exploring how PPC nurses experience media representations of them and their services.

It is hoped the study will develop our understanding of how media representations impact on PPC nurses' wellbeing and clinical practice. Furthermore, based upon this, suggestions will be made to inform the work of clinical psychologists supporting PPC staff and working in physical health setting more generally.

This study aims to add to the contribution of clinical psychology within PPC by addressing the following questions;

1. What representations of PPC are available in the UK media?
2. How are these representations experienced by PPC nurses?
3. What is the impact of such media representations on the clinical practice and wellbeing of nurses working in PPC?

2.0 METHODOLOGY

This chapter outlines the approach used to study the topic of interest and the methods used to do this. In describing the methodology, I give a rationale for adopting a qualitative approach to the research and the decision to use multiple methods. I then go on to provide an overview of the epistemological position of the study. I conclude the chapter by discussing the two qualitative methods utilised and attend to ethical issues within the research.

2.1 Methodology

2.1.1 Rationale for Adopting a Qualitative Approach

Of interest to this study was how knowledge about PPC and PPC nurses are represented in the media. Moreover, the study sought to explore not only the different representations of PPC available in the media, but how these are experienced by PPC nurses. As such, a qualitative approach, which aimed to describe events and experiences and allowed exploration of multiple and varying understandings of reality, was required (Willig, 2008). Furthermore, the use of a qualitative approach avoided the determinism inherent within quantitative methodologies, thus lending itself to more exploratory research like the current study.

2.1.2 Rationale for Utilising Multiple Methods

In developing the research questions for the study, it became clear that there needed to be a preliminary exploration of the kinds of representations of PPC available in the UK media. Such a question would aim to provide a contemporary and thorough account of media representations and prevent inaccurate assumptions being made about how PPC is constructed. Additionally, a critical examination of media representations was hoped to yield insight into how language is utilised to construct ideas about PPC and position nurses working in the field, with consideration to the wider political and social context. The findings from this question would also serve to complement and

contextualise the data gathered from PPC nurses about their experiences of media representations.

In order to answer a question about what kinds of media representations of PPC were available in the UK media, a qualitative methodology which enabled an examination of the constructive power of language in discourse was needed. This particular requirement would indicate the use of a methods such as Discourse Analysis (Potter and Wetherell, 1987) and Discursive Psychology (Edwards, 2005). However, to provide insight into the way media representations of PPC utilise specific discursive structures to reproduce or resist the socio-political context, the method would need to be situated within a critical framework. Hence, Critical Realist Discourse Analysis (Sims-Schouten, Riley & Willig, 2007) was chosen as the specific method of analysis.

The remaining research questions were interested in PPC nurses' experiences of media representations and how these impacted on practice and wellbeing. With the focus of these questions on lived experiences, phenomenological methodologies were indicated (Larkin, Watts & Clifton, 2006). However, combined with a recognition of the researcher's role in interpreting participants' lived experiences and thus the co-construction of data (hermeneutics), Interpretative Phenomenological Analysis – IPA (Smith, Flowers & Larkin, 2009) was selected for use in the research also. Furthermore, with PPC nurses being purposively and exclusively sampled for the study, as they were uniquely placed to offer relevant insights into the phenomena of interest, the sample formed a homogenous group, which also fitted with the commitment to idiography within IPA.

2.2 Epistemology – Critical Realism

Epistemology is concerned with the theory of knowledge describing what we can know and how (Barker, Pistrang & Elliott, 2002). Therefore, the epistemological position of a piece of research determines the assumptions held about the relationship between the data under exploration and the world. Furthermore, epistemological position guides the design and development of the research, by indicating methodology; the approach taken to gaining

knowledge about the world and methods; how the data is collected. So to ensure consistency between methodology and method, and the study's claims to knowledge implicit in the research questions, clarity regarding epistemological position was crucial (Winter, 2013).

The extent to which data is a reflection of reality varies across a continuum from a realist position at one end, to a relativist position at the other end (Harper & Thompson, 2011). A realist position suggests that there is a real world out there independent of whoever is observing it and that this is discoverable and can be directly measured (Bhaskar, 2013). A relativist position in the form of constructionism or constructivism, dispenses with the assumption there is an objective reality and instead posits that knowledge is socially constructed through peoples' interpretations of the world, which are situated within a historic and cultural context (Burr, 2003). As such, multiple knowledges of the same phenomena can exist as a result of differing perspectives, and these are constituted through discursive resources and practices (Willig, 2008).

Between both poles lies a critical realist position (Archer, Bhaskar, Collier, Lawson, & Norrie, 2013). Critical realists retain an ontological realism that there is a world that exists independently of our perceptions and constructions, whilst also accepting a form of relativism that our understanding of this world is constructed from our own perspective. This study adopts a critical realist stance whereby the physical and material dimension of people's lives and the influences of power are acknowledged and seen to be reflected in the use of language (Nightingale & Cromby, 1999).

2.2.1 Critical Realism and the Analysis of Discourse

Sims-Schouten, Riley & Willig (2007) identify three advantages of adopting a critical realist position to the analysis of discourse. Firstly, they contend; "critical realism enables an analysis that can consider why certain discourses are drawn upon, by proposing that the extra-discursive (*embodiment, materiality and institutional power*) provides the context from which the use of certain discourses is more or less easily enabled" (pg.103 Lines 35-38 text in italics added).

Secondly, the authors (Ibid) highlight how “critical realism can explore the impact of material practices on discursive practices” (pg. 103 Lines 38-39), something they argue is ignored elsewhere within discursive psychology.

Finally, it is argued that the approach does not only analyse the ways in which discourse is used to construct particular versions of reality, but it also positions such talk within the materiality that must be negotiated. The authors go on to discuss how such contextualising of participants’ talk within the material reality of their world forms an ethical stance, in that analysing discourse without considering material existence does not always do justice to participants’ lived experiences.

2.3 Methods

Two approaches were used to analyse data, Critical Realist Discourse Analysis (Sims-Schouten, Riley & Willig, 2007) and Interpretative Phenomenological Analysis (Smith, 2004).

2.3.1 Critical Realist Discourse Analysis

According to Sims-Schouten, Riley & Willig (2007) “an effective critical realist discourse analysis is produced through a multi-level analysis that draws upon discursive practice, Foucauldian discourse analysis and an examination of embodied, material and institutional practices that may be considered to have extra-discursive ontology” (pg. 107, Lines 7-11). As such, the action orientation of talk and discursive resources (Edwards, 1997) drawn upon in interactions to achieve interpersonal objectives can be examined, as well as the implications for ways of being that are structured by local dominant discourses and the given cultural context.

Furthermore, the authors argue that whilst an individual is able to choose from a number of discourses in any given interaction, those available to them is limited by “personal, psychological and social mechanisms that include embodiment, institutions and materiality” (pg. 107, lines 34-35). Therefore, both discursive practices *and* material resources shape the social constructions that structure our ways of understanding the world.

2.3.1.1 *Data collection and sample size*

A review of UK media stories related to PPC was conducted to critically examine representations of services and staff. This process involved selecting articles from UK newspapers and online texts. Before elaborating on the how the review was completed with further details of data collection, I firstly address some methodological issues, which are pertinent when utilising edited media texts and online data.

As pointed out by Winter (2013), it is important to recognise and respond to potential concerns related to the use of edited media and online texts. It is acknowledged that utilising such sources of media may not be representative of the wider population and are constructed with particular political and social ideologies in mind. Furthermore, such texts are often published without scrutiny as to technical accuracy and reference to official guidance or evidence base. As such, their reliability in terms of neutrality and accuracy of content becomes questionable.

However, this study is concerned with finding out what kinds of representations of PPC are available in the UK media, regardless of accuracy of content or underlying agenda. Therefore, in drawing upon edited texts in newspapers, I hope to access a sample of the available media, from which to examine the kinds of representations of PPC which are present in the public domain.

Moreover, in utilising critical realist discourse analysis, I am able to examine the text above and beyond the function of the language used (a discursive level of analysis), and look to the extra-discursive in terms of embodiment, materiality and institutional power (a material level of analysis). This additional level of analysis will allow a critical consideration of the political, social and material contexts within which the text is situated.

Ultimately, I am less interested in the credibility of the texts I examine. Nor is it my aim to produce generalizable findings from this research, as would be more fitting with a positivist approach. Rather, I intend to examine what a sample of available media texts are achieving in terms of representations of PPC, and how.

2.3.1.2 *Process*

The NEXIS database was used to find relevant newspaper articles for inclusion in the media review. The terms used to search for texts and numbers of articles found are given in Appendix E.

To ensure the data reflected modern day PPC services and nursing practices, a date-period was used to inform eligibility of texts (2004-2014). Furthermore, articles were only selected where their content made explicit reference to PPC services and staff. Therefore, a piece written solely about a fundraising event for example would be excluded. This criterion was implemented to ensure texts were relevant to the research questions.

A final criterion was that texts were taken from UK newspapers. This criterion was imposed in response to an assumption the author made that people residing within the UK, including PPC nurses who were interviewed, would be more likely to engage with articles from UK-based newspapers, about UK-based PPC services.

In addition to edited media texts from UK newspaper articles, stories of families who have used PPC services and blogs posted by staff were included also. The rationale for including online texts was a response to the growing phenomenon that is social media. Social media is one of the most popular and utilised forms of media available (Chou, Hunt, Beckjord, Moser, & Hesse, 2009) and so neglecting to include it in would be to neglect a potentially huge source of relevant data. Furthermore, and as with newspaper articles, online texts serve as forms of “naturalistic” data (Potter, 1997). Such naturalistic data is fitting with the discursive approach which is orientated to naturally occurring talk and text, as opposed to that co-constructed in interview data for example (Edwards & Potter, 1992). A list of websites used as data sources for the online texts is given in Appendix F along with the criterion for their use.

There are however potential challenges to using online texts. As with newspaper articles, online texts are subject to the same criticisms around neutrality and accuracy of content. Furthermore, one must consider the context of and limits imposed upon those authoring texts, such as posts made by staff working in the field. Here, staff members may be governed in what they can and cannot say, or rather “blog”, due to policies around use social media in

some NHS Trusts

(<http://www.leedsandyorkpft.nhs.uk/documentbank/CityWideSocMedGuidelinesOct13Final.pdf>). However, in utilising critical realist discourse analysis, there is scope to consider such factors.

In view of how the content and availability of online media continuously changes, the author decided an appropriate strategy for obtaining data would be to sample at discreet time points. As such, the websites in Appendix F were searched on a given date in November 2014, December, 2014 and January 2015. This strategy was also helpful in managing the volume of data that could potentially be included for analysis. Following this sampling strategy, 11 newspaper articles were included for analysis. Articles ranged from 342 to 2262 words in length. In addition, online data was retrieved from 9 of the 15 possible PPC websites listed.

2.3.1.3 *Analytic steps*

As outlined by Sims-Schouten, Riley & Willig (2007), I followed three analytical steps in the review of media representations of PPC. Whilst I deviated from the order in which these three steps were conducted, I make the argument my approach remained congruent with that of a critical realist discourse analysis. This was because I upheld the multi-level analysis required to enable an examination of both the discursive practices *and* material resources which shape the social constructions and representations of PPC.

The deviation in process to which I refer connotes the difference between the present study and that of Sims-Schouten, Riley & Willig (Ibid). Namely, the application of critical realist discourse analysis to naturally occurring media texts. As such, it was not possible to assess extra-discursive features in an individual participant's local context. Instead, I identified the key material factors which were likely to have an extra discursive impact by examining the broader PPC context in the UK. Specifically, I provided a description of PPC provision throughout the UK, with reference to material differences between hospital and hospice settings.

Once this was been completed, I moved on to steps two and three of the analysis which involved reviewing the extra discursive and discursive features *within* the texts. To achieve this, each text underwent preliminary coding to

identify the most commonly recurring themes. Preliminary coding was necessary to transform the data corpus into manageable “chunks”, whilst remaining as inclusive as possible (Potter & Wetherall, 1987). This enabled me to examine specific extracts of texts, which represented recurring themes.

Step two involved an examination of the *extra discursive* features within the text extracts (e.g. elements of embodiment, materiality and institutional power).

Step three involved an examination of the discursive features within the text extracts, and drew upon elements of Foucauldian Discourse Analysis (Wodak & Meyer, 2009, Hook, 2001) and Discursive Psychology (Edwards, 2005). Here, I looked to identify the use of local dominant discourses pertaining to PPC (such as discourses about the death of a child and end of life care), and attended to the presence of power relations and cultural context. I also examined the action orientation of the language and discursive resources used to achieve particular objectives in the texts. This aspect of the analysis therefore had a focus on both action and reality production (Hepburn & Potter, 2006).

2.3.2 Interpretative Phenomenological Analysis

According to Eatough & Smith (2006), Interpretative Phenomenological Analysis (IPA) is interested in the detailed analysis of individual human experience and how this is made sense of; an area they argue is neglected in much of psychology. As such, IPA is theoretically underpinned by phenomenology; the study of the way things appear to us in experience, and hermeneutics; the theory of interpretation.

According to Eatough & Smith (2008), to study individual life is to do so through a lens of cultural and socio-historical meanings. Jennings (1986), refers to this as an examination of a “factual existence”, meaning the study of experiences which appear to the individual in his / her own way – hence the relevance of hermeneutics and a focus on interpretation. However, IPA also recognises the researcher’s role in making sense of the participant’s experience, a double hermeneutic (Osborn & Smith, 1998), and so acknowledges that the account is co-constructed between participant and researcher.

In addition, phenomenology posits that human beings are in the world with things and others (Spinelli, 2005). The body therefore becomes central in this

interweaving of man, things and others, as it is through one's body that experience becomes particular to that individual. However, Eatough & Smith (2008) point out that IPA also maintains that "*the life-world of the individual is socially and historically contingent and contextually bound*" (Pg180, Lines 46-48). This is of particular relevance in the current study, as it illustrates how IPA is fitting with the critical-realist epistemological position of the research. Namely, that the physical and material dimension of people's lives are acknowledged, and seen to be reflected in, the use of language which structures our understandings of the world (Nightingale & Cromby, 1999).

2.3.2.1 Procedure

IPA advocates data collection methods which allow participants to provide first-hand accounts of their experiences (Smith, 2004). Semi-structured interviews facilitate this endeavour by providing access to richly detailed, subjective accounts of the individual's experiences of the phenomena under investigation. As such, semi-structured interviews were conducted with PPC nurses in order to gather data for analysis (see Appendix I). Furthermore, utilising an interview schedule enabled the researcher to interview participants around the topics of interest, with enough flexibility so to be non-prescriptive and remain fitting with the concerns of IPA.

Once the method of data collection was decided upon, the author sought to identify potential services to recruit participants. This was facilitated by the Director of Studies, who had an existing contact with the palliative care team at a London children's hospital. The author was able to form a link to this team and provide them with a brief presentation about the intended research. This resulted in the recruitment of four out of the five participants. Subsequently, the author was put in touch with a psychologist working for a children's hospice organisation. This contact led to the recruitment of the final participant.

In the presentation given to both services, potential participants were invited to contact the researcher if they were interested in taking part in the study. Both teams were also issued with Information Sheets (see Appendix C) outlining the aims of the study and the methodology involved, and there was opportunity to ask questions and offer feedback on the proposed study. Interviews were then arranged through email contact with prospective participants. Prior to interview,

participants were issued with an additional copy of the Information Sheet and a Consent Form to sign (see Appendix D).

2.3.2.2 *Research participants and sample size*

Consistent with IPA's orientation, purposive sampling was used to recruit a homogenous group of individuals who all had experience relevant to the topic under investigation. The study imposed only one inclusion / exclusion criterion; that participants must have been practising as PPC nurses for at least twelve months. This was to ensure authenticity to the phenomenological approach being used and familiarity with the topic under investigation.

As an expression of the commitment to idiography within IPA, many studies use a single-case design (see Bramley & Eatough, 2005). Where studies use data from multiple cases, these are kept small in number, so to facilitate cross case analysis at the within and between levels (Brocki & Wearden, 2006). Smaller sample sizes also speak to practical restrictions of conducting IPA (e.g. the ability to recruit participants to form a homogenous group), the richness afforded through individual-case analysis, and the strength of commitment to a case by case approach (Smith & Osborn, 2003). As such, a sample size of between 4 and 6 participants was sought for the current study. This number was also influenced by practicality, with an awareness of the need to limit sample size in view of the additional analyses being conducted through the review of media representations.

All those who participated in the study were female. This reflected the all-female working environments of each service and may speak to a gendering of the nursing role as commented upon by Stanley (2012). Length of practise as a PPC nurse varied from 3 to 16 years. No further demographic data was collected.

Table 1: *Participant Demographics and Type of Service Recruited From*

PARTICIPANT No.	GENDER	LENGTH OF PRACTICE (YEARS)	SERVICE TYPE
1 Jane	F	14	Hospital
2 Maxine	F	16	Hospital
3 Katie	F	3	Hospital
4 Louise	F	9	Hospital
5 Suzi	F	15	Hospice

As mentioned, four out of five participants were recruited from the hospital setting, with the fifth participant being recruited from a children’s hospice. Numerous attempts were made to recruit more participants from the hospice setting. These attempts included visiting several hospice sites and presenting the research proposal at each in staff meetings. Furthermore, the author sent regular follow-up emails to the Managers at each site requesting they remind nurses of the study and encourage those that may be interested in participating to contact the author.

The decision to recruit from both the hospital and hospice settings reflected the researcher’s intention to explore multiple experiences of the media representations of PPC. It also spoke to findings from the literature review which suggested differences existing in the representation of hospital and hospice-based palliative care services. For example, that hospice-based media representations tended to focus upon charity work and fundraising and consequently were more positively framed compared to that of hospital-based services. Thus, recruiting nurses from both settings may have influenced the research findings by introducing some variability and avoided the assumption that media representations would have been necessarily experienced as problematic.

2.3.2.3 *Methodological practice of IPA*

Eatough & Smith (2008) propose it is possible to observe patterns across the growing corpus of published IPA studies. They suggest such studies are typically concerned with the concepts of identity and sense of self, and tend to focus specifically on participants’ meaning making and interpretation, whilst

holding an attention to bodily feeling within that lived experience. In keeping with this orientation, the author developed a particular methodology for practising IPA in the current study, which is outlined below. Particular detail has been provided on the use of semi-structured interviews within an IPA study;

- Semi structured, audio recorded interviews with individual participants were used as the means of data collection.
- Semi structured interviews involve the use of a set of questions which serve to guide the interviewer, and allow him / her to pursue what are experienced as interesting and relevant areas of inquiry.
- Semi-structured interviews allowed for the data collection process to be dialogical, and afford participants a significant role in exploring their lived experience and deciding what it was they wanted to say.
- The questions utilised within interviews with participants were directed towards aspects of lived experience.
- A small, homogenous sample of participants was selected as an example of the study's commitment to idiography fostered by IPA.

2.3.2.4 *Transcription and analysis*

Once each interview was completed, an informal engagement with the data began by reflecting upon what had been said and how, and also the feelings evoked in the researcher, noting these in a reflective diary (see Appendix P for an extract). The author was particularly mindful here to consider how her assumptions and existing ideas might have influenced deviation from the interview script to explore other areas of inquiry, and how this may have shaped participants' responses. This process was assisted through the author's participation in an IPA forum where data gathering and analysis could be discussed within a group setting and critically explored with others utilising the method.

Each interview was transcribed following a complete 're-listening' of it, which served as a means of re-familiarising the author with the interaction. As the author was interested in the subtleties of each interaction, it was important to transcribe not only the words spoken in each interview, but also how these were spoken. As such, interviews were transcribed verbatim and a convention which allowed for the coding of pauses and overlapping speech was applied (Potter,

1997). The convention also noted inaudible speech and included supplementary of clarifying information (see Appendix J for full details of the transcription convention used).

Each transcript was analysed individually before themes from across all transcripts could be integrated. The complete set of analytic steps taken are summarised below;

- Preliminary notes which indicated interesting points or use of language were made on the right hand margin of the transcript.
- Following a re-reading of these and the transcript in its entirety, these preliminary notes were transformed into initial themes and noted on the left hand margin of each transcript (see Appendix K for a worked example of IPA coding).
- Once the initial themes had been listed, attempts were made to form connections between these by developing cluster themes (Smith, 2004) – see Appendix L.

The levels of interpretation described above represent the inductive and iterative nature of the analysis and are in-keeping with the IPA approach. They speak to the aim of producing a rich, experiential description of the phenomenon under investigation, and also the hermeneutic or interpretative element of the approach which aims to build an alternative narrative from the participant's original words. As a further validity check, one interview was analysed by both the author and the Director of Studies. This aimed to establish that the author was following the correct analytical procedure, and that a degree of similarity in terms of findings could be reached to demonstrate coherence which served as a form of inter-rater reliability.

- The above steps were then repeated for all transcripts, resulting in the development of four further lists of initial and cluster themes. At this point, any divergent points were noted so that difference across transcripts could be recognised and explored.
- Cluster themes were then integrated to develop a set of superordinate themes, which were accompanied by additional notes to describe their possible meanings (see Appendix M).

- The final stage of analysis was to develop a consolidated list of superordinate and subordinate themes representative of the entire data set (see Appendix N).

2.3.3 Reflexivity

Within both discursive approaches to qualitative research and IPA, there is need to attend to the position of the researcher and their contribution to the co-construction of the research findings. This is because all qualitative methods are subjective in nature, and thus the values, experience and assumptions of the researcher will inevitably come to bear upon how data is gathered and ultimately made sense of (Willig, 2001). As such, reflexivity serves as an important part of the research process, which in the case of the current study, entailed regularly revisiting the author's personal and professional identities. This was in-terms of both her position to the phenomenon under investigation, and also what she anticipated the experience of PPC nurses to be.

Primarily, I would identify myself as a white woman, of working class background. I am in my early thirties and am a parent to two step-daughters. I am a Trainee Clinical Psychologist, but am also the main carer for my twin sister with learning disabilities and autism.

In reflecting upon my personal experiences, there are two which stand out as particularly relevant to making sense of how I have approached the current study. Firstly, is my own experience of physical illness and hospitalisation. At the age of twelve years I became acutely unwell with what was suspected to be viral meningitis. Following this, I developed a form of juvenile arthritis which resulted in my being admitted numerous times to Great Ormond Street Hospital for intensive treatment and rehabilitation. During my admission, I did co-habit with young people with life threatening conditions, such as systemic juvenile arthritis. Indeed, I was a patient on the ward when two children died of complications connected with their chronic illnesses.

At the time, these experiences of death were difficult to make sense of in terms of concrete knowledge about the 'hows' and 'whens', but I believe now on reflection, this was in part due to how they were managed and communicated by the nursing team. These particular children were located in closed rooms on the ward, perhaps to keep the seriousness of their condition separate to that of

the other, relatively healthier children. To me, the discreet segregation of these children served to only amplify how unwell they were.

Therefore, when as a cohort the rest of the ward was formally addressed by a senior nurse to inform us of the children's deaths, it was not as shocking a disclosure as might have been anticipated. For me, it felt as though the nursing team had nursed these children in such a way as to expose the rest of us to their likely deaths, preparing us for the loss of life that ensued.

My experience of nurses working with seriously ill children, felt considered and subtle. What I mean here is that despite the needs of these seriously unwell children dominating the time and duty of the nurses, there was still space to communicate to the rest of us on the ward, albeit perhaps unconsciously, that we too were being thought of and considered in how the inevitable deaths would be shared with the wider group. My sense was that both my emotional and physical health was being taken care of by the nurses at these times, and I valued being held in mind in this way.

Whilst I might be criticised for my rather egocentric and romanticised experience of 'the nurse', this construction has nevertheless stayed with me and throughout my life I have often returned to it when considering nurses and their work in various contexts. As such, I hold nurses in high regard but what I particularly foreground here is an assumption that all nurses possess the same kindness and compassion shown to me in my experiences of a) being unwell as a child and b) an observer to the death of another child.

Secondly, and intrinsically linked to the experience I have discussed above, is what I would describe as my sensitivity to how people talk about nurses who work with seriously ill children. Having a chronic health condition has afforded me many opportunities to listen to the talk of others regarding their own experiences of care. Here, I have often heard for myself how nurses are positioned as "angels", "completely devoted" in the care of those they nurse. I have also heard parents and family members talk of how "they couldn't do it", referring to the 'job' of being such a nurse. This notion of being 'unable' to nurse seriously unwell children suggests it can only be achieved by those who possess some innate virtue, qualities which cannot be taught or gained through the learning of technical skills alone.

I have often wondered what the implications are for nurses who are positioned as caring for their patients in such a tireless and selfless way, and how it might feel if they do not share the same ideas about themselves. Perhaps again, my experience here is the result of how I may selectively attend to positive narratives of the nurse, as these are the narratives congruent with my own reality.

However I have come to experience talk of nurses who work with seriously ill children, I cannot deny I am biased in my assumption that this is generally representative of nurses. It is positive and tends to privilege caring attributes as opposed to technical skill or medical knowledge. It serves to construct the nurse as an altruistic, selfless, almost self-sacrificing being who can put aside their own needs to tend to those of others. With such a strong construction of the nurse in mind, I have needed to be reflective and remain critical, so not to impose this idea onto the data before me or disregard that which challenges my own views and assumptions.

2.4 Ethics

UEL ethical approval was sought and given for the current study (see Appendix B). NHS ethical approval was not necessary in this instance, however, the author did follow the procedures outlined by the research departments of both services where PPC nurses were recruited.

All participants were given access to an information sheet outlining the aims and methodology involved. Within this, participants' right to withdraw was made explicit, as were details of how the data would be managed and anonymity maintained.

A particular ethical issue that the author anticipated arising was around participants re-joining their colleagues after taking part in the study. As such, the author remained mindful of the importance to ensure confidentiality. This was achieved by giving thought to where and how frequently interviews took place, contacting participants through individual work email addresses, and also by asking interviewees to refrain from discussing their interview with colleagues who might also go on to take part. Furthermore, the need to ensure

confidentiality amongst team members informed the choice to use individual interviews, as opposed to a focus group, in order to gather the data.

3.0 ANALYSIS

In this chapter I discuss the findings of the current study in relation to the specific research questions. To begin, I present the results of the critical realist discourse analysis which was conducted to answer the question; '*What representations of PPC staff are available in the UK media?*' I then go on to present the findings of the interpretative phenomenological analysis of interviews conducted with PPC nurses to answer the questions; '*How are these representations experienced by nurses?*' and '*How do nurses describe the impact of such media representations on their practise and wellbeing?*'

3.1 Critical Realist Discourse Analysis

3.1.1 The 'Extra Discursive' and its Impact on How PPC is Talked About

As per Sims-Schouten, Riley & Willig's (2007) seminal paper on critical realist discourse analysis, I started by examining the "extra discursive" in my analysis of how PPC is talked about. To focus this part of the analysis, I chose to examine the NHS England 2013/14 Standard Contract for Paediatric Medicine: Palliative Care (NHS England, 2013). This document is publicly available online and arguably provides the most current and comprehensive overview of PPC provision across England.

3.1.1.1 *Materiality*

In utilising the 2013/14 Standard Contract for Paediatric Palliative Care (Ibid) it was possible to identify examples of materiality; such as physical resources, service structures and professional networks, which may have an effect on the ways in which PPC is represented. Firstly, the document describes how PPC services should be commissioned and configured so to provide the most efficient and cost-effective service. Specifically, the document states each PPC service should aim to serve a population of between 1-2 million people although acknowledges that due to the relatively small numbers of children and young people requiring palliative care within a population of 250,000, and the specialist

nature of such services, it may be advisable to plan services for a larger population of up to 4 million.

With these figures in mind, it is understandable that people may talk about PPC services as being scarce compared to other NHS services; an idea which is compounded by their lack of visibility to the public relative to the observable presence of GP surgeries or general hospitals for example. Consequently, ideas about PPC are heavily influenced by those limited representations which *are* available in the public domain, even if these constitute only one type of PPC service. Indeed, children's hospices are arguably the most common type of PPC service represented publicly due to the fact they actively aim to establish a public presence to attract the charitable funding needed for their survival. In contrast, the relative absence of hospital based PPC service representations in the public domain render these types of services somewhat enigmatic by virtue of the fact many members of the public will never even see one, let alone experience it.

Furthermore, in view of how PPC services are geographically widespread, challenges may exist around accessibility, particularly when a family requires the use of public transport to get to and fro the service. Therefore, where PPC services are located outside of the hospital setting, where one would assume there to be better transport links, it is possible to see how members of the public might construct representations of them as being largely absent or difficult to access.

The Standard Contract also describes the different forms of PPC services available including; inpatient care; such as that offered within acute hospitals, outpatient care; including reviews held within the family home or at the child's school, hospice and short term respite provision. With these multiple and varied forms of specialist PPC provision, it is difficult to construct a constant and clearly identifiable mental image of what the PPC setting looks like. As such, the concept of PPC is intangible and abstract to many unless they have individualised experience of a particular service, and this may further contribute to the idea of PPC as distant and unfamiliar.

In addition, the Standard Contract (ibid) specifically highlights the need to provide specialist PPC within a setting as close to the child's home and of the family's choice in so far as is practicably possible. Therefore, whilst PPC appears to be rather obscure and unknown to most, there is also a sense of it being available whenever and wherever it is needed. As such, it is not bound to fixed locations and static; rather it is a service which aims to follow and meet the needs of the child. Whilst other NHS services might aim to achieve such flexibility and person-centeredness, it is arguably uncommon and so this again may add to an idea PPC is something specialist and dependable.

The lacking physicality of PPC services within the public domain, coupled with the multiple forms that PPC services can take, arguably serves to construct a representation of PPC as something uncommon and abstract. Moreover, the ambiguity over what PPC is may lead people to lack confidence when talking about it, or even avoid talking about it at all. However, there may also be a sense that whilst PPC services are often impalpable, they are still available for people when they are at their most needy which arguably creates a somewhat magical feel to services and those working in them. It seems the default material representation of PPC is that of the hospice setting, and as such, hospice-based representations may dominate popular understandings of PPC.

3.1.1.2 *Embodiment*

As clearly defined in the NHS England 2013/14 Standard Contract for Paediatric Palliative Care (NHS England, 2013), specialist palliative care for children is provided to those with LTLLCs up until their 19th birthday. Whilst there are four broad categories of LTLLCs, as discussed in the Introduction chapter, Wood, Simpson, Barnes & Hain (2010) highlight the extremely wide range of diagnoses which may potentially be included (in excess of 300 ICD-10 diagnoses). As such, it is not possible to identify the appropriateness of specialist PPC services by diagnosis alone, rather care will follow the child's illness trajectory and be responsive if and when the child becomes in need of palliation.

Here, the Standard Contract (ibid) advises consideration be given to the spectrum and severity of the child's disease, subsequent complications that may arise, the

needs of the child and their family, and the impact of the disease when making the decision a child is in need of PPC. However, ultimately, the provision of specialist PPC is dependent upon the clinical judgement of the team around the child, and as such is variable and assessed on an individual basis, although clinical tools such as the Spectrum of Children's Palliative Care Needs (Shaw et al., 2014) may be used.

Detailed within the Standard Contract (NHS England, 2013) are also descriptions of some of the specialist PPC interventions that should be provided by services. Much of these descriptions centre around assessment and management of symptoms; for example, assessment of pain, pain management, non-drug symptom management. Furthermore, reference is made to the equipment that might be needed by some patients; such as syringe drivers for end of life care delivered at home.

The noting of these particular features speaks to the embodied experience of having a LTLLC and / or receiving PPC. They may serve to construct an idea such an experience is extremely intense in nature, heavily medicalised and dominated by pain and pain management. However, little is said here about alternative experiences of PPC such as it's more holistic and developmental approach, which attends to emotional and spiritual wellbeing as well as the physical. Furthermore, the dominating influence on representations of PPC here appears to be one focussed on the individual child with a LTLLC, as opposed to the embodied experience of parents, carers and siblings.

Such features may also influence ideas constructed around the embodied experience of nurses and other staff members working within the field of PPC, where they are responsible for managing such pain on a daily basis. Specifically, consideration might be given to the qualities and attributes needed by PPC professionals to work with children in pain and requiring the use of specialist medical equipment such as syringe drivers. Qualities such as a thick skin perhaps, or a heroic and dedicated disposition that can cope with and endure a child's suffering.

These representations of PPC therefore serve to position staff in the field in particular ways. For example, PPC nurses might come to be thought of as heroic or selfless when they are assumed to put aside the feelings evoked in them to work with children they know will not live into adulthood. Alternatively, staff, and particularly nurses, might be viewed as more caring and compassionate compared to other health professionals. This might occur when their fundamental role is constructed to be around pain and symptom management and thus contrasts to roles of nurses in other fields. Finally, the person-centred, need-driven 24/7 approach of PPC may serve to construct staff as tirelessly dedicated to supporting the child and their family whenever, wherever this is needed.

3.1.1.3 *Institutional Power*

Acknowledged within the NHS England 2013/14 Standard Contract for Paediatric Palliative Care (NHS England, 2013) are inequalities across PPC provision. The Standard Contract highlights for example; the differences in service funding with hospices largely depending upon charitable donations rather than that provided through clinical commissioning groups. In addition, the Standard Contract notes the role of ethnicity and also social deprivation on the prevalence of certain LTLLCs, and speaks of the difficulties of physically accessing some services when reliant on the use of public transport.

Such inequalities signal the presence of institutional power and how this may be used to gate-keep and regulate services. For example, the Standard Contract (ibid) describes how service provision is often decided using figures of service activity, referral rates and the level of health needs in the PPC setting. However, such indicators can often lead to gaps in provision, particularly when services are not commissioned according to the needs of the local population, or do not take into consideration material challenges which are impacting upon accessibility, such as poor transport links and bed shortages.

Moreover, identifying children in need of specialist palliative care services is often done through clinical judgement rather than objective means. Alternative methods of identification, such as prognostication, are often considered inadequate as they are inaccurate for various reasons. For example, healthcare

professionals may be reluctant to give a child a poor prognosis and some conditions are so rare, little is known about the child's expected illness trajectory. With this in mind, it is likely referral rates to PPC services underestimate clinical need. Therefore, access to services may not be consistent or equitable, and the decision to refer to specialist PPC services may be made by a limited number of highly powerful clinicians.

The sense that access to specialist PPC services may be controlled by a powerful few may serve to position those making such decisions as experts over and above the individual child and their family. This notion is perhaps compounded when the structure of PPC clinical networks, with their top-down hierarchical arrangement, are examined. Namely, the Standard Contract sets out how local PPC services will be linked into a PPC network. This network receives advice from a specialist PPC team which is overseen by a Lead Consultant Paediatrician. The Lead Consultant Paediatrician holds clinical responsibility for the child and coordinates their care.

With a clinical network comprised of multiple teams and professionals, it is important to recognise the potential for power differentials and the impact these may have on decision making and the ability to accommodate the choices and preferences of the child and family. Furthermore, safeguards against the impact of such power differentials are found in the Standard Contract in the form of recommended outcomes for PPC services. These outcomes include the specification that:

“children, young people and families must be able to engage in discussions around the child's future care and develop anticipatory care plans and that these are delivered effectively”

(NHS England 2013, pg. 10 Lines 7-9).

Such outcomes aim to ensure that decision making and delivery of care remains collaborative and inclusive of families and the child themselves where appropriate. Therefore, it is not subject to the authority of a limited number of clinicians who, by virtue of the structure of PPC clinical networks, may be geographically and relationally removed from the child and their family.

3.1.2 The 'Extra Discursive' *within* Talk about PPC and the Impact of the 'Discursive'

As discussed previously steps two and three of the critical realist discourse analysis have been combined. To synthesise the data, I followed a process of coding each media text to identify the most recurrent themes (see Appendix G). Extracts of text from each media source were then grouped according to these themes, upon which the remainder of the analysis was carried out (see Appendix H). Findings are presented below for each theme.

3.1.2.1 *Theme 1: Positioning of PPC nurses*

This theme captured three features which appeared to recur frequently across the online texts and newspaper articles; specifically, the roles of nurses working in PPC settings, parents' experiences of PPC nurses, and also nurses' own experiences of working in PPC.

Descriptions of the roles of nurses within PPC appeared to vary depending upon who was providing the account, a parent or PPC nurse themselves. For example, parent reports tended to position nurses' roles within the domain of providing emotional and practical support:

(Nurses) were there to talk us through the worst days of our lives.

They made phone calls, dealt with about 200 visitors, brought us tea, sandwiches, crisps, cakes, they never grumbled.

They organised everything, it was astounding.

www.demelza.org.uk

Here, the text serves to construct a representation of the role of the PPC nurse, drawing upon what would be considered more generic and practical nursing duties, such as providing meals / feeding, and contrasting this with a more specialist and emotive aspect of the role; namely counselling the family through the death of their child. Specifically, the use of rhetorical devices focussed on reality production, such as vivid description (Hepburn & Potter, 2006), serves to invoke a powerful category of the PPC nurse, which in this case is of someone providing practical and emotional care.

In addition, from a Foucauldian stance, the inclusion of the description; “they never grumbled” perhaps perpetuates a more historic westernised representation of the nurses as subservient and humble, placed to receive and carry out duties rather than act under their own volition. This idea is substantiated in the way the speaker describes the nurses’ organisational skills as “astounding”, possibly implying it is difficult to believe they were capable of acting with such autonomy and efficiency. The implication here is that what the nurses were doing was not expected based on commonly represented nurses’ subject positions; especially in relation to more powerful medical professionals. By positioning their work as unexpected given their role, the text keeps nurses grounded in such a professional hierarchy.

Parental descriptions of their experiences of PPC nurses further served to position the nurses in particular ways. Specifically, there appeared to be a strong sense that parents’ experienced the nurses providing compassion and even love in their care:

The (nurses) looked after us with love and kindness, they helped us plan his funeral and say goodbye to our beautiful boy ... the (nurses) played him nursery rhymes and talked to him every day.

www.TogetherforShortLives.org.uk

PPC is constructed here as something compassionate and loving, through the use of rhetorical devices including vivid description (Potter & Hepburn, 2008) and dispositional formulation (Edwards, 1995). The use of vivid description serves to conjure a strong representation of the PPC nurse as a person who can navigate the barriers of professionalism to offer love and compassion to those they work with. Furthermore, the use of dispositional formulation serves to describe the actions of the PPC nurses as motivated by them as individuals and their disposition, rather than as something done out of duty or chore. Use of this device may therefore serve to strengthen the popular discourse that nurses do what they do for emotional, as opposed to material or professional gain.

A final aspect of this theme centred on PPC nurses own descriptions of their role and experience. In contrast to parental views, nurses appeared to talk of

their role in more formal terms, for example as being responsible for symptom management:

During my time as a young nurse not all was good. I found myself caring for many patients facing the end of their life in side rooms, not always with their symptoms well managed. This started my passion for working with patients at the end of their life.

www.keech.org.uk

Here, the nurse implies that what attracted her to the role was the opportunity to bring about change in the care of people facing the end of their lives.

Furthermore, the suggestion that PPC nurses have the power to bring the dying out from side rooms and into view, could also be understood more metaphorically. For example, the speaker here may be suggesting that the role is highlight issues of death and dying in the public domain. Such an idea forms a representation of the PPC nurse as an advocate for the dying, seeking to champion and meet their needs. The nurse achieves this by packaging actions within description (Edwards & Potter, 1992), specifically, she embeds the notion of achieving change in her talk of what attracted her to being a nurse in PPC.

Furthermore, the reference to symptom management may serve as a categorisation (Billig, 2001) of PPC nurses as specialist medical professionals, as the activity is medically oriented and implies the need for specialist knowledge those outside of the field would unlikely possess. This aspect of the nurse's description of her role appears to challenge that constructed in the talk of parents by focussing more on the professional. However, that the dominant discourse about the roles of nurses remains closely bound to constructions which tend to be put forward by parents, for example those which centre on care and love of patients (Cunningham, 1999), suggests nurses' voices are not as well heard in the public domain. In taking a Foucauldian stance, one might argue this particular positioning of nurses, as medical specialists, is negated by a dominant discourse that nurses are there solely to care, as the former position would pose a challenge to the power of other professionals such as doctors. Moreover, if one were to consider gendered representations of nurses and specifically that nurses tend to be female (Bridges, 1990), denying the nurse power in this way may then also add to subjugation of women in society more broadly.

3.1.2.2 *Theme 2: PPC in the hospice setting*

The vast majority of media texts included in the review were in some way based upon the hospice setting which would appear to support the assertion made earlier that the most available media representations of PPC are those based upon hospice, as opposed to hospital provision. Furthermore, in analysing this dominant representation of PPC, it was clear to see the abundance of vivid description pertaining to resources within the hospice, such as:

In the messy craft area, which is stuffed with rainbow pots of paint, Jessica's 18month old sister is cheerfully smearing colours on a piece of paper...more youngsters are whooping enthusiastically in a playroom filled with plastic balls and squashy foam obstacles for climbing over. The corridors are lined with books and bright drawings.

(Mail on Sunday, May 1, 2011)

The use of these descriptions serves to construct a representation of hospice PPC which is materially-based and arguably embodies an idealistic childhood, from the enthusiastic whooping of the children through to the descriptions of play and toys. This particular article contrasts these opportunities for an idyllic childhood within the hospice to the experiences that might be had within hospital services:

We try to avoid a hospital atmosphere...the staff want it to be a home from home and a place for families to relax and recharge, and not simply a place where children come to die.

(Mail on Sunday, May 1, 2011)

Here, an inference is made that the hospital environment is one where such a homely atmosphere cannot be found and it is not as possible to relax and recharge. Such contrasts serve to give the hospice an added edge over hospital provision, and therefore make the hospice setting more appealing to families. Moreover, in view of how children's hospices are funded, it is necessary to their survival to attract service-users in order to warrant greater government and charitable funds.

Finally, it could be argued there is a need to represent children's hospices in ways which construct them as joyful, happy, and full of life, to counter common misconceptions that hospices are just places where people go to die. This is an

idea which was referred to frequently across the media texts, and often, appeared to be deliberately juxtaposed with the kinds of vibrant descriptions examined above:

*When the family were told about the hospice, they were wary.
We had a friend whose child had died and just assumed that
hospices were for dying children...*

(Mail on Sunday, May 1, 2011)

Here, the speaker uses stake inoculation (Edwards & Potter, 1992) to construct their talk as coming from someone whose stake in that talk, as the parent of a child with a LTLCC, is counter to what would be expected when making the claim. In other words, the speaker acknowledges the dominant construction that hospices are places to die and therefore are commonly feared, but uses their position as someone who now has first-hand experience of the setting to counter that claim.

3.1.2.3 *Theme 3: Controversies in PPC*

This theme captured issues reported in the media sample which were considered by the author to pose difficult ethical or social dilemmas.

One such inequality represented in the media was that of access to PPC, particularly for Asian communities:

Forty percent of all babies born in Bradford are to Asian parents yet disproportionately few terminally ill Asian children have been receiving specialised care services available to them. Attributing the poor uptake to linguistic and cultural misconceptions, Bradford Hospital NHS Trust appointed psychology graduate Rahila Mughal 12 months ago to liaise between health professionals and Asian families to clarify misunderstandings that have prevented sick children from gaining optimum care.

(The Guardian, October 11, 2006)

Here, the media represent PPC as a service which is often not accessed by Asian communities due to “linguistic and cultural misconceptions”. This explanation of the lack of service uptake by Asian communities serves to place responsibility with that community and their “misconceptions”. This is opposed

to locating the problem with services and their potential shortcomings in reaching out to different ethnic communities or ability to work with non-western beliefs around LTLLCs. Whilst the hospital Trust upon which this particular article is based does appear to be trying to improve access to its PPC services for Asian communities, there is still a sense those communities must be liaised with by an NHS professional, rather than consulted with, or referred to for advice. This positioning of the Asian community subjugates the difference they embody and serves to substantiate current UK based PPC practices and understandings as most valid.

Decision-making was another issue which appeared to be represented in a controversial way in the media sample. Here, a number of data sources pertained to the cases of Ashya King and Charlotte Wyatt, both children with LTLLCs where differences in opinion existed in the decision-making around ongoing treatment. In both cases, there appeared to be a reluctance by parents to accept doctors' views that active treatment should be ceased and the children would be better managed with palliation. The stories illustrate the inherent power of the medical profession compared with that of parents, and demonstrate how this is upheld by forces such as the media. For example:

The hospital trust has supported the stance taken by its medical experts and said it will seek a court ruling if the parents insist on 10 month old Charlotte Wyatt being resuscitated in an intensive care unit.

(The Daily Telegraph, August 28th, 2004)

Using category entitlement (Potter, 1996) the text achieves a positioning of doctors as "experts", and serves to substantiate their knowledge over and above that of her parents. The text therefore implies doctors' credibility outweighs that of parents. Consequently, there is a strong suggestion that decisions about a child's care should be in line with medical recommendations, and not the insistence of their parents.

What is controversial here is not necessarily the difference of opinion between doctors and the child's family, it is the positioning of the medical team as more credible and essentially right in their views compared to the parents.

Furthermore, what doesn't appear to get questioned is the basis upon which doctors are positioned as right and parents wrong. Rather than the issue being

one of ethics with the child's best interest taking precedence, it becomes one of who has the greatest power and best endorsement which, in this case, and in western society generally, is the medical profession.

3.2 Interpretative Phenomenological Analysis

This section of the chapter discusses the findings of the analysis of interviews with five PPC nurses. To begin, I explain how themes were arrived at before presenting these in a table (see Table 2). The themes are then discussed in detail throughout the remainder of the chapter.

Each interview was analysed individually before themes from across all transcripts could be integrated. Further detail on the process undertaken to develop themes is given in Chapter 2. However, of note, was the transformation of preliminary notes to initial themes (see Appendix K), which were then examined to identify connections and develop cluster themes (see Appendix L).

Lists of cluster themes were developed for all interviews, and any divergent points were noted so that difference could be recognised and explored. Here, it appeared the experiences of the media varied according to the setting from which the participant worked. Specifically, Susi spoke about her experiences of media representations of hospice-based PPC, with a focus on its utility in raising money and the general public profile of the hospice.

Cluster themes were then integrated to develop a set of superordinate themes, which were accompanied by additional notes to describe their possible meanings (see Appendix M). The final stage of analysis was to develop a consolidated list of superordinate and subordinate themes representative of the entire data set (see Appendix N / Table 2).

Table 2: *Super-ordinate themes and corresponding sub-ordinate themes*

SUPER-ORDINATE THEMES	SUB-ORDINATE THEMES
PPC: A Contentious Approach	<ul style="list-style-type: none"> • Perceived as abnormal • In need of “defence”
The “Threat” of the Media	<ul style="list-style-type: none"> • “Surviving the Profession”: Impact on professionals • Managing the media
Not the Whole Story: “One-sided” Media Representations	<ul style="list-style-type: none"> • Lack of understanding • Sensationalism • Positioning of nurses: The “Angels of Death”

3.2.1 PPC: A Contentious Approach

This theme conveyed nurses’ experience that the media represented PPC as a contentious subject. Moreover, the theme captured the notion that PPC was constructed as something abnormal and in need of “defence”, hence it’s positioning as a contentious subject. As such, the nurses’ accounts appeared to suggest that PPC was not always easily accepted by families, or the wider public.

3.2.1.1 *Perceived as abnormal*

Nurses’ accounts suggested that the media tended to represent PPC in the context of children’s fight for life, rather than focusing on their care as children with a LTLLC:

Um, I think from my experience it, media tends to portray a fight against disease in children to the very end even though those children in a clinical setting may be receiving palliative care (2) I would say things (.) in the media always tend to talk about the child fighting for life...

(Katie, Lines 22-27)¹

¹ The names given for participants throughout the thesis are fictional so to protect anonymity.

This construction of children within the media as fighters seemed to speak to dominant social and cultural beliefs that the death of a child must be fought against and prevented as it is abnormal:

...I think there's a very you know, negative, view of it [PPC]...that partly comes from things that people see on the TV or hear about, and because obviously you're working with something that shouldn't, that people feel shouldn't happen everyone expects that when you have a child you will die before your child, that's the normal way of things, so when it's that, the fact that a child is going to die before their parents, before what people view is their time, I think, um people find it very difficult to accept and to understand... (Louise, Lines 21-33)

Here, Katie and Louise may be alluding to the idea that it is more socially acceptable to position children as fighting for life rather than dying, as the care of dying children is often not portrayed in the media. Moreover, they suggest the death of a child is not the “normal” way of things, and therefore caring for a child going through this is perhaps abnormal.

Not only does this representation demonstrate how the nurses' experience of the media fails to correct commonly held misconceptions of PPC (that it is only about the care of children at the end of life), it may also position PPC as having no place in the public domain. Katie goes on to elaborate on this point, speaking about how the true “nature” of PPC is never accurately represented in the media:

...although the media talks about children dying, it never would (2) truly talk about the nature of palliative care like... [which] is about enabling this child to be as comfortable as possible ...

(Katie, Lines 112-116)

In Katie's description of how the aims of PPC, as “enabling” children to be “as comfortable as possible”, are not reported in the media, she may be suggesting it is something that the wider public do not want to hear and think about. Indeed, she goes on to qualify this, explaining how she thinks PPC is something

inconceivable for most people as to them, it is represented as something which happens when the child is no longer fighting:

...I think that, possibly is because in the general population and through the media, it, it, it's perceived as giving up, palliative care is unable, giving up. (Katie, Lines 181-184)

This construction of PPC thus positions individuals caring for the child as having given-up on them, something which perhaps is significant to Katie, as demonstrated through her repetition of the words "giving up". Furthermore, Katie stops herself from completing her sentence; "palliative care is unable". This could indicate that she recognises the public perception that PPC is unable to save children, and therefore may have disdain for the profession and those that work in it. Such a thought may be experienced as difficult to process for Katie, as she struggles to verbalise it.

3.2.1.2 *In need of "defence"*

Many of the nurses interviewed talked about PPC being represented in the media in ways which led them to feel protective of it, as though it was in need of defence. Rather than this sense resulting from PPC being positioned as precious or prized, it appeared to come from their experience of it being the victim of attack in the media. Furthermore, some nurses spoke of feeling offended and insulted by how PPC was being portrayed, as though such attacking representations extended to them personally:

...I think it tends to be if, if there's any negative media coverage...you tend to get quite protective and quite sort of, um defensive about it and um, um (2) take it personally as a personal insult and stuff...

(Suzi, Lines 414-420)

These reactions to media representations of PPC would suggest the nurses often experienced them as negative, as though these representations had wronged the profession and those that work in it. Implicit in this interpretation is the need to defend against the wounding sustained in being wronged in this

way, a wounding that is conveyed in Suzi's repetition of the word "personal". Moreover, Suzi goes on to discuss this in her talk about social media. Here, she explains how comments made in these particular forums may be experienced as critical, suggesting such media can have a detrimental impact on wellbeing:

...I know that um there have been instances where there has been some sharing of opinions between service users on Facebook and that has had a very negative impact on the staff here because they have all taken it very personally... (Suzi, Lines 425-429)

Whilst Suzi points to the personal impact of social media on nurses' experience, Maxine speaks of how national newspapers can represent PPC in ways which are disparaging also. Here, she talks about how, due to the nature of PPC, there is no one available to 'advocate' for it, which in her view, perpetuates one-sided and perhaps even harmful media representations:

... I think its scandal, it is something that is going that's going to sell newspapers... Um, and actually that's not helpful, when you're delivering care it's the opposite ... the majority of parents will say this is not our experience but how are you going to search those parents out and when they are at their most vulnerable, even before or just after a child has died, so who is going to be the advocate for palliative care, those parents and the children themselves but they're vulnerable and you're not going to expose them to the press so that's why it's usually just one sided.

(Maxine, Lines 235-253)

Here, Maxine alludes to the power of the media agenda and speaks of the need to scandalise representations of PPC in order to sell newspapers. She elaborates by drawing on her perception of parents' experiences of PPC, suggesting they hold a different view to that portrayed in the media which could have the potential to counter such scandalised representations. However, she explains that despite the power of their voice, by virtue of their contact with PPC services; as parents of a child with a LTLLC whom may have died, they are not in a position to use that voice. She implies that the grief for their child makes

them vulnerable and so unable to speak of a more positive experience of PPC. As such, she suggests that scandalous and negative portrayals of PPC continue to pervade and dominate popular discourse, and representations remain one-sided.

Additionally, Maxine talks about not exposing parents at a time where they are at their most “vulnerable”. The use of the word exposing implies Maxine perceives the media as potentially threatening or harmful, and therefore something which parents who have used PPC services must be defended against. This need to defend parents may serve to construct the media as predatory. Thus, not only PPC, but parents themselves, are positioned as vulnerable and in need of defence against the media.

3.2.2 The “Threat” of the Media

This theme captured nurses’ accounts of media representations of PPC which were experienced as threatening in some way. Specifically, nurses spoke of the impact of media representations on professionals working in the field, the impact on clinical work, and also their experience of needing to manage the media so as to minimise potential threats.

3.2.2.1 *“Surviving the Profession”: Impact on professionals*

Many of the nurses interviewed spoke of their experience of social media and how they had often felt this to be critical and exposing of them:

...I’ve been aware of families who really document their journey throughout curative treatment and palliative care on social media. Um and I think that has a really, really big effect on care.

(Katie, Lines 282-285).

...I suppose there’s always things like online blogs that families put up...families share an awful lot of stuff...but they’ll talk “oh you know they came to see me, this happened that happened, I didn’t like what she said about this” so it can be quite (.) um you feel, you feel, it can be quite personal...

(Louise, Lines 40-74)

Here, both Katie and Louise speak of how families' use of social media can be experienced as negative and personal by nurses. Moreover, Louise seems to suggest that families utilise social media to voice their disagreement and dislike of what nurses may have said to them. Families' use of social media to voice disagreement in this way may be experienced as particularly threatening due to the accessibility and reach of social media. Putting such critical comments on social media exposes nurses to a potentially vast audience, leaving them and the care that they provide vulnerable to scrutiny.

Katie goes on to talk about the impact of families' use of social media on clinical decision making. She describes how some nurses might experience self-doubt as a result of their work being discussed and scrutinised so publicly. Furthermore, she implies what makes this experience difficult is that social media enables individuals who may not have a full understanding of or connection with the situation, to have access to such comments:

... if that was happening and I knew it involved me I don't think I would read it so much so because I think it would really effect how I interacted with that family so, if (2) a decision that I would confidently stand by and, you know, evidence-based decision I would make for any family, I think I would question (.) ten times more if the day before I'd been reading about every clinical decision that I'd made and the family's musings and opinions on that on a public site...I don't think there is anything wrong with opening up decisions to scrutiny of families in and other members of your team but I think on social media it it's very, it it's people seeing that who are not involved in that situation either professionally or emotionally, you know and I think that makes it much more difficult.

(Katie, Lines 338 – 361).

With professionals' clinical decisions and thus treatment of patients vulnerable to criticism, nurses may feel a need to justify their practice. Maxine appears to allude to this in her talk of how negative media reporting of adult palliative care in the UK, in her view, came to impact on how professionals were regarded in other countries in her experience of setting up a children's palliative care service abroad:

...so even on Sky News [deleted text] it would come up as a big problem in the UK that we were trying to kill people so that had a detrimental effect on what we were trying to do in the [deleted text]... the global media exposing what was happening in the UK, bumping people off, they didn't want us to set up a hospital here and do the same thing ... it made them question what we were doing... (Maxine, Lines 48-65)

For Maxine, such media representations implicate nurses in the death of patients which led to her and colleagues' decisions and practice to be called into question. Furthermore, it is implicit in Maxine's talk how nurses are vulnerable to being positioned as at best lacking in competence, and at worst murderous.

Finally, it appeared some nurses managed the potential threat of the media by disengaging with it or avoiding it:

...I think the media is always trying to do the emotive side of things, I mean ... I don't do social networking um especially with any families, I don't discuss palliative care in social networking forums, um I haven't watched the news in ages so, um I haven't read a newspaper in ages, um so this is just the things that you know that I have seen and come across... (Jane, Lines 66-73)

Here, Jane describes what might be interpreted as her active avoidance of the media. She reels off a list of different forms of media which she appears to have chosen to disengage with, perhaps so to disconnect from any potential threats she may experience. This interpretation is qualified somewhat later in Jane's interview, where she talks of the negative ways in which families and NHS professionals can be positioned by the media:

...I think the massive problem I have with that portrayal of the story is um, they portray it in a very black and white way, and, one moment it was the family that was criminals and the next moment it's the NHS that are culpable... (Jane, Lines 110-114)

Jane speaks of her experience of how those working in the NHS generally are vulnerable to vilification in the media, being positioned as “culpable” for whatever storyline is being represented. With nurses experiencing the media in these ways, it is possible their disengagement serves as a form of self-care, protecting them from any emotional or professional consequences. Suzi develops this idea in her talk of how she has experienced the media. In particular, she draws attention to the notion nurses may feel wary of the media, and perhaps fear being caught-out by it in some way:

...I'm very cynical about media stories because I think they twist them and, and then they want to suit the message they want to give...if somebody wanted to spin something, to create negative um publicity, for their benefit then, then, yeah you are mindful of that ... because yeah you might just say something completely, especially me I'm a bit, bit, run away with myself sometimes and it could be twisted ... (Suzi, Lines 695-716)

Here, Suzi describes a wariness of the media. This appears to arise in the context of her experience of a media agenda which seeks to catch-out nurses through twisting what they say to suit their message. Suzi's use of spatial metaphors to describe this really achieves a sense of the media distorting reality for their own agenda.

With the media being experienced as a threat in the ways discussed above, coupled with the additional challenges specific to working in the field, it is possible to understand why nurses might describe their careers in PPC as a threat to their survival:

... it's not just about the job and someone being in a position to deliver a service it's about how they survive the profession particularly those that might be at the beginning of their career...(Maxine, Lines 501 – 504)

Here, it is possible that Maxine is that implying the demands and challenges of working in the field of PPC have the potential to threaten one's survival; not only professionally, but also personally. Such an interpretation suggests the

potential threat to wellbeing of working in PPC is one of some magnitude, to which media representations appear to contribute significantly.

3.2.2.2 *Managing the media*

Many nurses spoke about their view of how the media needed to be managed, which seems to have been a response to their experience of it as intrusive or threatening. Here, they gave examples of forms of management that were already available to them, and talked of additional measures which they believed could be implemented in the future:

...I think we need to learn to be skilled at how we manage it I think... we need to learn to get better about how we utilise it ... with the instance of all these things starting to develop and growing and changing and evolving, um we're finding that professional bodies are putting guidelines in so I think that will become clearer, so um you know there's professional, so the NMC, the Nursing and Midwifery Council are supposed to be giving guidance on, um, your relationship with people online... (Jane, Lines 337-355)

I think there are mechanisms to discuss and and, sort of share about how that pressure affects everybody really, but I, and I also think that it's something that is going higher up the hospital about, as, as an organisation how we think about how this affects our staff and ways that we respond to this as well... (Katie, Lines 378 – 384)

... if there's any chance that somebody might be ringing us up for a story, we have a, you know we can refer it, refer it on to our PR people. (Suzi, Lines 710-713)

Here, Jane, Katie and Suzi all refer to mechanisms which are already in place for managing the media. Jane speaks of guidance issued by a national body; the Nursing and Midwifery Council, Katie speaks of decisions that are being made “higher up in the hospital” suggesting the issue is being considered at a Trust level, and Suzi describes a department where she works which is

dedicated to managing press and PR. All three accounts suggest that the impact of media on staff and clinical practice is a very real issue for providers of PPC as it is recognised and being responded to at various levels.

Whilst nurses often appeared to speak of managing the media in the context of potential threat, they also described a need to learn how to engage with it in ways that could be useful. For example, the nurses spoke of the potential utility of media to communicate with families and one nurse also spoke of utilising it in order to fund raise:

...sometimes we will look at blogs that have been put up just to see what a family are doing, what they're feeling just because sometimes it gives you a bit of an insight into (.) where they're at ...

(Louise, Lines 42-46)

...there was a lot of media coverage through the local newspaper, the local radio when we were fundraising to build the new hospice. Um and that was all very much geared around fundraising... it was more about celebrating the fact that all this money had been raised and it heightened our profile quite considerably within paediatric palliative care world, not just here in England but internationally as well.

(Suzi, Lines 22-31)

Here, the nurses' talk suggests there forms of media that may actually work in the favour of PPC. However, even with these examples, nurses still appeared to be wary of possible dilemmas that could arise:

... trying to do a programme about what paediatric palliative care is, um you maybe (2) having some of these talk pieces these popular talk shows that people have and having a conversation there ... but (.) I'm not convinced ... it almost needs like (.) a celebrity pushing it but they you kind of think that's sensationalising it again...

(Jane, Lines 225-236)

Jane describes one such dilemma in utilising the media to explore PPC. She highlights how in her view, PPC would need some form of celebrity endorsement as to attract an audience. Her comments may illustrate a concern that PPC is an issue that is not of interest to people, which may make it difficult to talk about honestly in the public domain. In addition, she appears to suggest that in promoting PPC through the experience of a celebrity, there is a risk of “sensationalising” it; something she seems to want to avoid.

Suzi talks about dilemmas that can arise in utilising media in the context of fundraising for PPC. Again, her example draws upon the notion of media incorporating some kind of celebrity presence to attract an audience:

...but that in itself, causes a knock on effect because um, obviously, you know, it's a need to know basis when these people [celebrities] are visiting, um and if families get to hear that they've been to visit then of course they assume that everybody knew about it; "oh why didn't you get me in, why didn't you invite us down to the hospice to see?" ... (Suzi, Lines 488-494)

Here, Suzi describes practical implications on utilising celebrities in this context in terms of the impact on families and their reactions to missing out on seeing the celebrity. Suzi explains how some families react negatively if they are not included when celebrities are invited to the service, and this is something which then needs to be managed by PPC staff.

In describing what appear to be dilemmas for them in utilising the media, PPC nurses continue to demonstrate their concerns around it. Furthermore, talking about these dilemmas may too support the notion many nurses experience or perceive the media to be a potential threat to either themselves, or their practice.

3.2.3 Not the Whole Story: One-Sided Media Representations

The final theme was named ‘Not the whole story: one-sided media representations’. The theme encapsulates nurses’ experience of media

representations of PPC as incomplete or unbalanced, stereotypical and sensationalist.

3.2.3.1 *Lack of understanding*

Many of the nurses expressed the view that they didn't feel the public had an accurate understanding of PPC and that one-sided and incomplete media representations perhaps underpinned this:

... the difference with palliative care is services are built around the child so services should follow the child and um...I don't think that gets picked up by the media... they don't pick up on that because...the popular press view is palliative care is end of life care it is somebody who is physically dying in bed and not somebody who is living. (Maxine, Lines 346-362)

Moreover, the nurses spoke of how the media tended to focus on adult palliative care, hospice-based stories, oncology and end of life care in talking about PPC. For example:

...I think the main thing that would affect your day to day clinical things will be more adult based palliative care storylines so (.) families being aware of hospices cos they're portrayed quite awful, well not awful but quite often, a lot more than paediatric hospices in the media (.) and they're not portrayed as very nice places um... (Katie, Lines 226-232)

...oncology nursing and the oncology nurse's role at the end of life is a very big (2) figure in the media and things like that, um but I, I just don't think there is any recognition that palliative care nurses exist really. (Katie, Lines 419-423)

...I still think there's a huge thing around the term 'hospice', um and the fact that the hospice is the place where you go to die, um, I still think there's an awful lot of that, the public perception is very

much around um (.) it is a very sad place to work... (Suzi, Lines 46-51)

In limiting media representations of palliative care to these particular issues, nurses appeared to suggest the public were unable to access more balanced and informative portrayals of PPC. Furthermore, they also spoke of how fellow professionals shared similar one-sided, limited understandings of PPC, and the consequences of this on referrals to services:

I think there's a poor understanding within professionals about what palliative care is so I think it's understandable that the media doesn't portray it um, as well as it could be portrayed...

(Jane, Lines 22-28)

...a lot of our oncology children don't get referred to us until the end of their lives, and I think a lot of that is around the fact that um (2) oncologists...don't like to introduce the idea of a hospice at that stage because it brings that idea, that element of doubt.

(Suzi, Lines 198-205)

However, the nurses also seemed to acknowledge that they perhaps had a role in perpetuating one-sided and unbalanced representations of PPC, by not challenging these or providing more informative accounts themselves:

Yeah I don't think there is very much positive written from us about us, if you see what I mean, there's a lot about how people experience palliative care, but I think there's really little out there about this is what palliative care is actually about and this is what we do.

(Louise, Lines 136-142)

3.2.3.2 Sensationalism

Connected to the previous sub-ordinate theme was also the notion that media representations tended to be sensationalist in content:

...I think where people are given a voice in the media to express their story, um (.) it is a really wonderful thing but I think the media can sensationalise things and pervert it almost. (Jane, Lines 161-163)

Here, the nurses often appeared to hypothesise about the underlying agenda of the media, assuming this to be about intentionally provoking as great a reaction in the public as possible. With this in mind, nurses were able to propose a rationale for making media representations of PPC sensationalist, even though in their view, PPC was not a sensational subject:

I think it, I think it's scandal, it's something that is going that's going to sell newspapers...you know the Daily Mail is always gonna to bash the NHS ... so I think it's about sensationalism, how it's, how it's going to sell and almost create um, a reaction I think. (Maxine, Lines 235-243)

Um I think because it [PPC] wouldn't have been very newsworthy. It wouldn't have made a sensational headline. Um if they had portrayed it with the balanced argument it wouldn't have been news anymore. (Suzi, Lines 130-134)

Furthermore, the nurses were able to deconstruct the ways in which they perceived the media to portray PPC as sensationalist. For example, Suzi spoke of how media representations of PPC use emotive language and images to provoke a reaction in the public:

I think (3) they're very heavily loaded towards oncology ... um because I think that's, it's a very emotive topic, lots of children with bald heads and nasogastric tubes, are very (.) photogenic you know they create this image of sort of vulnerability which creates emotions in people that are watching the programmes... (Suzi, Lines 258-264)

Finally, the nurses appeared to suggest such sensationalist representations of PPC persisted partly because they were unable to access the media to give a

counter view. Moreover, many of the nurses spoke about how there was no “recourse” for them or the NHS generally, and that in their view, only the most powerful were able to access the media to get their voice heard:

...they think we said we would but we didn't actually say that but there's no recourse for it, it's alright being like; "I've seen what you've written on Facebook about me and it's not true" so there's this whole thing of, whereas normally you wouldn't know about that, you'd be completely unaware of them moaning about it to their friends and family, whereas suddenly you get a bit of an insight and I think that's quite hard...

(Louise, Lines 607-617)

And they're, they're people that have the greater readership etcetera, the greater distribution, they are the exact same people that will sensationalise ...and again they never get their facts quite right, and (.) the NHS is in a position where it can't correct those facts ...

(Jane, Lines 243-252)

Nurses' accounts seem to suggest they experience the media as something they are unable to utilise to get their voice heard. This again supports their claim that media representations of PPC are usually one-sided and fitting with a particular agenda.

3.2.3.3 *Positioning of nurses: The “angels of death”*

Nurses often spoke of how media representations of PPC positioned them as professionals working in the field. Specifically, the nurses found themselves being portrayed in polarised positions as either a perfect angel, or an angel of death responsible for euthanizing patients:

I think nurses are portrayed in the media in a in a very black and white way we're either the angels of death or angels and I'm neither...

(Jane, Lines 368-371)

...starving, um, um, uh speeding up death, syringe drivers, meds escalating doses, almost inferring that you're, you're escalating drugs to help end life... (Maxine, Lines 42-44)

Furthermore, nurses' accounts described how their positioning in the media had implications for clinical practice. For example, they spoke of the impact on conversations with families entering services, how nurses were reacted to by families, and even on the kinds of people that applied for jobs:

So I suppose the Liverpool Care Pathway was quite um, negative towards nurses and doctors, I think a lot of families felt "does this mean you're going to starve my child to death?" that was the biggest thing and families would often ask you about that or you know, "are we not feeding, are we not giving my child", and so you need to know how to deal with that. (Louise, Lines 252-259)

...it can put an enormous pressure on us and it's because ... people look at us and think "oh I'd really like to work there", um but (.) but also you get people who really want to work here for all the wrong reasons... and you have to sometimes question peoples' motivation to come and work here. (Suzi, Lines 634-644)

In addition, nurses spoke of how dominant representations based on the angel stereotype failed to recognise nurses' clinical skills and the complexity of the work they do. Here, Louise talks about how instead, typical reactions to her as a PPC nurse tend to imply her role is all about providing tea and sympathy; something she experienced as derogatory:

...I suppose that the biggest thing that we talk about as nurses would be...the old head tilt so like people talk about you know; "ah palliative care, ooh" and they do a lot of nodding of the head ... yeah it feels quite derogatory. I think people, like I think often you'll get doctors outside of the team who assume that what we do is make tea... We do do that but we do that alongside symptom management you know, really complex symptoms and trying to

unpick family dynamics and trying to help people make decisions about what their child wants... (Louise, Lines 198-231)

Louise also makes the point that even other health professionals lack an accurate understanding and appreciation of the role of a PPC nurse, again assuming they are just there to undertake menial duties.

Some nurses also discussed their experience of how the media portrays hospice and hospital PPC nurses differently:

I think hospices are painted within the media as fun places... and that the sort of people that work there are angels ... whereas I think hospital palliative care team ... in the media would probably be depicted a lot more as a clinical team very related to active treatment...possibly not seen in such a positive light...

(Katie, Lines 59-70)

Here, Katie suggests that perhaps PPC nurses experience greater acceptance when they are based in the hospice setting, and that this is directly linked to representations in the media.

Finally, several of the nurses spoke of how they experienced the media as ignoring nurses' personal agendas for wanting to work in the field. They may be implying here that the media fail to report this issue, as an honest exploration of it may not fit with preferred representations of PPC nurses as perfect angels:

it attracts all sorts of professionals...who come into it because they need to be needed or um, ... it's just managing that in terms of um, you don't develop a Messiah complex and you, you've got to keep it in check ...

(Maxine, Lines 387 – 397)

Here, Maxine suggests that in some cases there may be a potential for nurses to become rather narcissistic through their role, whereby they might come to think of themselves as a saviour of the children and families they work with. This potential appears to overlap with Suzi's experience which she talks about

in Lines 640-644 (see quotation on page 70). Here, Suzi highlights the need to question the motives of those applying for jobs in paediatric palliative care, which may be due to how she perceives there is a possible risk that they are doing so in order to serve their own needs, for example to develop a 'heroine' identity for themselves.

It seemed that overall, nurses experienced media representations to position them in ways that were not accurate or complete, and in some cases, offensive. Furthermore, nurses appeared to challenge these polarising representations by talking about the complexities of their roles and alternative accounts of why individuals may enter the profession.

4.0 DISCUSSION

This chapter begins by summarising the analysis before discussing the findings in relation to the research questions. I then examine implications for the clinical practice of psychologists, before making recommendations for future research. The chapter concludes with a critical review and personal reflections.

4.1 Summary of Analysis

Throughout the study there was an assumption that the impact of media representations on PPC nurses' wellbeing and clinical practice would have implications for career longevity. This arose from the examination of literature around the impact of public perception on general nurses' wellbeing, practice and retention to the profession (Takase, Maude & Manias, 2006a). However, in the current study, nurses did not identify a direct impact of the media representations of PPC on their wellbeing, although they did acknowledge a number of implications for clinical practice. As such, the findings would suggest media representations of PPC alone do not pose enough of a challenge as to threaten career longevity of nurses.

Another salient finding was that nurses experienced media representations of PPC as one sided and sensationalist. They suggested this was in part achieved through a media focus on the issue of end of life care. Whilst the nurses seemed to suggest end of life care was only one aspect of PPC, they somewhat contradicted this by repeatedly talking about their role in managing symptoms when a child is dying. This emphasis may speak to how in practice, end of life symptom management takes precedence in a resource limited field such as palliative care. Furthermore, it may also point to the roles of others in the system around the child; such as family members, clinical psychologists, social workers and play therapists, who may be more responsible for promoting quality of life for the child.

4.1.1 Media Review

Materiality, embodiment and institutional power were all considered to be extra-discursive factors impacting upon representations of PPC. Specifically, an examination of material factors demonstrated why services were commonly represented as abstract and unfamiliar and based on the hospice setting. Examination of the embodiment of PPC showed how media representations constructed PPC as medicalised and a response to the pain and suffering of individual children. As such, dominant media representations failed to portray the holistic nature of PPC, and could neglect the experience of family members. Moreover, embodiment appeared to have implications for how nurses were positioned in media representations. Specifically, nurses were portrayed as heroic and selflessly dedicated in their care of seriously ill children. Finally, the examination of institutional power highlighted the presence of inequalities in PPC and how these often came to be represented in the media. Here, the power held by medical professionals was portrayed as was the issue of inequitable access to services for particular minority ethnic groups.

In the analysis of discursive factors, three themes emerged. The first theme; 'Positioning of PPC nurses' discussed the various subject positions PPC nurses can hold in the media. Specifically, parental reports were used to represent nurses as providing emotional and practical support, whereas nurses' reports sought to construct a more skills-based identity. The theme highlighted how media representations based on parental reports appeared to deny PPC nurses power by grounding them in professional hierarchies and failing to portray their specialist clinical skills. The second theme; 'PPC in the hospice setting' described how the most commonly available media representations of PPC were those based on the hospice setting. Furthermore, such representations portrayed hospices as able to offer an idyllic childhood experience with lots of resources and a homely atmosphere. The theme discussed how these representations of PPC served to position hospital based services negatively by comparison, and were possibly used to counter common misconceptions that hospices were just places individuals go to die. The final theme; 'Controversies in PPC' discussed the representations of ethical dilemmas in PPC, such as inequalities and decision making. In its representation of inequitable access to PPC services for some communities, the media appeared to substantiate UK-

based, westernised PPC practices and understandings. Furthermore, the media represented doctors working in PPC as holding the most power, over and above parents and nurses. As such, they were constructed as best placed to make decisions regarding care, even if this opposed parental views.

In summary, PPC was represented in the media in the following ways;

- PPC is largely absent in most people's everyday lives.
- PPC is relatively abstract and unfamiliar.
- PPC is flexible and person-centred, and available whenever and wherever it is needed despite being largely unknown.
- The most accessible representations of PPC are based on the hospice setting:
 - Here, representations drew on descriptions of material resources and notions of an idyllic childhood.
 - The representation of hospices as places where people go to die was deliberately countered and positioned as a common misconception.
- Common representations of PPC centre on an intense and heavily medicalised phenomena.
- Associated representations of PPC nurses were largely based on parental views and experiences:
 - Parents' representations centred on nurses' disposition for managing grief and suffering, and ability to offer care and compassion.
 - PPC nurses were most often represented as heroic, self-less and dedicated by others.
- Nurses' representations of their role was different to that constructed by parents, and was organised more around their identity as medical professions and advocates for children with LTLLCs.
- Access to PPC services was regulated by powerful clinicians who were constructed as best placed to make decisions about the child's care over and above the child or their parents.
- Representations of PPC positioned westernised practices and understandings as most valid and credible.

4.1.2 Interviews with PPC Nurses

The theme 'PPC: A Contentious Approach' illustrated nurses' experiences of the media as representing PPC in ways that were considered contentious. Moreover, nurses described media representations positioning PPC as an abnormal practice, due to how as an approach, it challenges dominant social and cultural beliefs around the death of children. Specifically, the theme explored how media constructed child death as something which must be fought against and prevented. Such constructions therefore positioned an approach like PPC, which accepts and aims to facilitate the comfortable death of children, as one which was not normal.

Furthermore, the theme captured nurses' views that, because of such media representations, PPC is in need of defence. Here, nurses explained how media representations were often attacking of PPC, and in some cases, of those working in the field. As such, nurses felt a need to advocate for and defend PPC. This need to defend PPC also seemed to extend to the families using services. Here, nurses spoke of families being in a vulnerable position, which implied they needed defending against some media representations which were considered harmful or threatening.

'The "Threat" of the Media' was another theme constructed from nurses' talk about how PPC is represented in the media. Here, nurses described how media representations of PPC threatened to impact on their wellbeing and clinical practice. Specifically, nurses described how some forms of media published exposing and critical accounts of nurses' work. Consequently, such representations had an impact on nurses' confidence to make clinical decisions and deliver care to patients. It also appeared to impact upon communication between families and PPC professionals, whereby nurses felt they were unable to confront problematic media representations with families. As such, nurses felt there was no recourse for them to challenge negative media representations, which left them having to find other ways to deal with these experiences.

The theme also captured nurses' views that media representations of PPC needed to be managed, so to prevent harmful impact upon professionals and practice. Here, nurses described mechanisms which were already known to

them, such as adherence to guidance from professional bodies on their engagement with social media. However, nurses also discussed the potential utility of the media to PPC, although they recognised engaging with it did present with challenges. For example, nurses spoke of the dilemma of using the media to represent PPC more positively, without it becoming sensationalised.

The final theme constructed from interviews with PPC nurses was 'Not the Whole Story: "One-sided" Media Representations'. This theme captured nurses' views that media representations of PPC were often limited and unbalanced, and contributed to a lack of understanding by the wider public and other medical professionals. Specifically, nurses described how media representations tended to focus on adult palliative care, hospice-based stories, oncology, and end of life care. However, nurses also spoke of how they may have some responsibility in perpetuating these limited media representations of PPC. Here, they acknowledged that there were few accounts written by PPC nurses about their role and the profession, which may have challenged one-sided representations.

Furthermore, the theme captured nurses' views that media representations of PPC were often sensationalist in nature, and aimed to provoke an emotional response in the public. Again, nurses discussed how such representations may persist as they considered themselves unable to counter these. Specifically, they alluded to lacking the power to access the media.

Finally, the theme discussed the positioning of nurses in the media and how this was often polarising. Namely, nurses experienced the media to represent them as either perfect angels or responsible for euthanizing patients. Such contrary and powerful representations had implications on clinical practice; for example in terms of managing families' expectations and concerns about PPC. Moreover, both portrayals failed to acknowledge nurses' specialist skills and knowledge, and as such could be experienced as derogatory. The theme also highlighted how in positioning nurses in these ways, the media often failed to represent personal agendas for pursuing a career in PPC. Here, nurses appeared to suggest that in some cases such personal motives for entering the profession were not represented as they did not fit with preferred portrayals of the PPC nurse.

Overall, the findings indicate coherence (Yardley, 2000) across the two sets of analyses, whereby the media review identified representations of PPC which were congruent with nurses' experience. Such coherence adds to the quality of the current piece of research, which is further discussed later in this chapter.

4.2 Addressing the Research Questions

This study was concerned with identifying the ways in which the media represents PPC, and how such representations are experienced by nurses working in the field. Furthermore, the study sought to find out whether media representations of PPC had any impact on nurses' wellbeing and clinical practice. Each of the research questions will now be discussed with reference to the existing literature base and relevant psychological theory.

4.2.1 What Representations of PPC are Available in the UK Media?

The study showed that a variety of representations of PPC were available in the UK media. These representations portrayed not only PPC services, but also nurses working in the field. Drawing upon social constructionist ideas that social and linguistic processes bring into being psychological phenomena (Burr, 2003), it becomes apparent why examining media representations, as forms of such social and linguistic processes, is needed to make sense of nurses' experience and also popular understandings of PPC more generally.

Furthermore, research from the field of media and cultural studies has also explored the power of the media in shaping public opinion and individual experience (Kellner, 2011). There is a substantial literature base which has responded to the vast media interest in health related topics in particular. Media coverage of advancements in cancer research serves as one such topic.

For example, Benelli (2003) discusses the provision of a new cancer treatment in Italy. Here, she describes the impact of media coverage on the supply and demand of services and families' awareness and expectations around access to treatment. Furthermore, she suggests the absence of specialist medical journals in the popular press has led to a media focus on sensationalism rather than accuracy. Indeed, Ooi & Chapman (2003) discuss how media portrayals

of cancer research often represent exciting, viable treatment options. However, of the 31 reports examined in their study, only 8 detailed interventions which went on to be incorporated into practice.

Arguably then, media coverage of specific treatments and interventions can be seen to pervade popular culture and influence how such issues come to be thought of and perceived by the public. Hodgetts & Chamberlain (2006) discuss how the media processes used to achieve this are not just an issue of concern for sociologists and media analysts. Rather, they represent an area of great potential interest for psychologists also. Specifically, the authors highlight again the role of the media in constructing shared understandings, particularly in the field of healthcare.

For example, Judge, Soloman, Miller, & Philo (1992) discuss the changing media agenda and media representations of political debate. Furthermore, they comment on how this influences public perception and thus explains fluctuating ideas about the NHS. Their findings may be helpful in explaining why polarised representations of PPC services and nurses are able to co-exist in the media. Namely, that differing and sometimes extreme representations illuminate the vastly different media agendas being served.

From a Foucauldian perspective, one might suggest the media then serves as a means of social control, by virtue of mediating the relationship between power and knowledge. Specifically, the media is something underpinned by political and economic forces, through which discourse in society and knowledge about various topics evolves.

Media representations can similarly shape public knowledge and perception of nurses. In their study, McGillis-Hall et al. (2003) explored media portrayals of nurses in the SARS epidemic in Toronto, Canada. They provide some interesting insights into the varying ways nurses came to be thought of by the public during this crisis. Moreover, they suggest that the media's representation of the nurses as leaders in delivering complex medical interventions was beneficial for recruitment to the profession, and contributed to a more realistic portrayal of modern nursing roles. However, the authors also suggest media reports may have simultaneously reinforced an "image of invisible, masked

hardworking victims of the health care system” (pg. 215), a contradictory and polarised view compared to that presented previously.

As in the current study, it would seem that media representations of nurses can help to inform public knowledge of nursing roles and portray nurses in ways which are experienced as useful on a professional level e.g. representations which increase nurse recruitment. However, representations may also portray nurses in ways which are detrimental to their collective identity, by grounding them in subject positions which deny them power or worse, hold them responsible for the deaths of patients.

4.2.2 How are These Representations Experienced by PPC Nurses?

It appeared that the majority of media representations of PPC were experienced negatively by those nurses involved in the study. Moreover, the nurses explained that of the available representations, most were limited by virtue of being inaccurate, sensationalist or unbalanced. As such, it appeared nurses tended to disengage with the media by avoiding it.

In drawing upon the idea of internalisation, one might propose that nurses are vulnerable to internalising the negative identity constructed for them through media representations. Specifically, nurses may integrate the attitudes, values and opinions portrayed in the media into their sense of self. In the case of this study, nurses were at times portrayed as murderous, responsible for the euthanizing of patients. Therefore, it is possible that nurses’ disengagement from media, and particularly social media, served as a form of defence against the internalisation of such a negative identity.

Alternatively, nurses’ withdrawal from the media may have been a response to a lack of control over how their collective identity was presented. The idea of self-presentation (Goffman, 1959), whereby individual’s interactions have the purpose of trying to control other’s perceptions of them, is rendered obsolete when it is another person representing the individual to others. In some instances, nurses experienced families’ representations of them through social media as critical and exposing. Moreover, the nurses described being unable to challenge these representations, and thus, were unable to present preferable accounts of themselves.

To explain both these accounts of nurses' disengagement with the media I have drawn upon Self Determination Theory (Ryan & Deci, 2000). Here, it is posited individuals have innate psychological needs; namely competence, autonomy and relatedness, which influence the integration of self-motivation and personality. However, there are social contexts and environmental factors which may threaten to thwart the person from meeting these needs. Such social contexts may then hinder motivation, social functioning and personal wellbeing.

The theory is particularly useful in the context of this study as it offers an explanation as to why nurses may disengage with the media. Whether this might be the result of internalising a negatively constructed identity, or to preserve self-presentation, social determination theory would suggest that overall, the nurses are seeking to avoid social contexts and environmental factors which hinder their wellbeing. In managing their experience of media representations in this way, the nurses are demonstrating resilience towards a potential threat to their wellbeing, a finding which has been echoed elsewhere in the literature (Ablett & Jones, 2007).

Whilst the majority of media representations of PPC appeared to be experienced negatively by nurses, some did identify portrayals which might offer utility to PPC. For example, several interviewees spoke of families' use of the media to document their journey through PPC services. Here, they suggested that these representations could serve to attract positive media attention leading to a greater public awareness of PPC and charitable donations to hospices. However, nurses still showed reticence at endorsing use of the media to represent PPC. This reticence appeared to stem from concerns that the media could distort and sensationalise stories. Overall, PPC nurses seem to experience dilemmas regarding use of the media to represent PPC, and this perhaps offers another explanation as to why they may have preferred to avoid engaging with it.

4.2.3 What is the Impact of Media Representations on the Clinical Practice and Wellbeing of Nurses Working in PPC?

Findings from the study demonstrated that there were media representations available to nurses which impacted upon their clinical practice. For example, representations of patient and families' dissatisfaction with PPC professionals had the potential to increase nurses' self-doubt leading them to question their decision making. Furthermore, when families used social media in this way, nurses often felt as though they had no opportunity to address this with the family, and as such needed to find other avenues for exploring the impact of it on their wellbeing and practice.

In addition, nurses spoke of how media representations of PPC influenced the preconceived ideas of families entering services, which often resulted in the need to engage in conversations to address possible misconceptions. An example which several interviewees gave was around media headlines which portrayed PPC practices as "starving" children to death. Here, nurses explained how media coverage of the Liverpool and Neonatal care pathways were instrumental in affecting the ways in which new service users thought of PPC. As acknowledged elsewhere (Moorhead, Hazlett & Hoving, 2013), social media was recognised as particularly powerful in communicating ideas around healthcare and impacting on clinical practice.

Another example of the impact of media representations of PPC on clinical practice centred on professionals' misconceptions and how these affected referrals to services. As identified by Twamley et al. (2014), knowledge and attitudes of healthcare professionals pose a major barrier to accessing PPC services. Moreover, the limited, and often sensationalist portrayals of PPC services as only for those at the end stage of life, may underpin professionals' misunderstandings and misconceptions. Hence, this may explain the vast differences in referral rates across PPC services and why certain groups of children do not get offered palliative care as early as they could be (e.g. children with malignancies are often not referred to PPC until curative treatment has failed).

Finally, media portrayals of PPC often represented services as flexible with a person-centred orientation. Constructing PPC in these ways may impact on clinical practice in terms of being able to say “no”. For example, several of the nurses touched upon this in their talk of how the public, families and referrers often had unrealistic expectations of what PPC could provide. Consequently, media representations of PPC may be fundamental in setting up unrealistic precedents in services where nurses and other professionals feel unable to say “no”; a tendency that is perhaps compounded by nurses’ positioning in the media as angels or heroes, where no duty or task is too much.

The impacts on clinical practice described above are proposed to be mediated through media representations. Whilst the processes through which the media comes to shape lived experiences were discussed earlier in the chapter, Social Representation Theory (Moscovici, 1988) may add some further insight. Social Representation Theory parallels Social Constructionism (Burr, 2003) in its contention that values, ideas, beliefs and practices are shared amongst communities. Moreover, in its processes of anchoring and objectification, the theory explains how the unfamiliar can become known and collective meaning making is achieved.

Specifically, Moscovici (1988) proposed social representations serve to establish an order which enables individuals to orient themselves in the world. Social representations also enable communication to take place by classifying aspects of the world. Here, Moscovici (*ibid*) describes what he calls the ‘consensual universe of social representation’, whereby the lay public circulate forms of knowledge which come to constitute common sense understandings. As such, the media is viewed as a communication process, with the use of Social Representations Theory demonstrating how it can serve to link individuals and society. Essentially, the media is able to “naturalise social thinking and generate collective cognition” (Hojjer, 2011).

Despite the numerous implications for clinical practice discussed above, the nurses interviewed did not readily describe an impact of media representations of PPC on their wellbeing. This was an interesting finding in that it was

somewhat counterintuitive given their talk of how the media could position them in ways which threatened their clinical practice. Moreover, nurses' view that at times their role was in need of defence, due to media representations which portrayed them as "angels of death" for example, further challenged this finding.

It may be that nurses' responses sought to minimise any potential impact of media representations on their wellbeing, as they believed admitting to this may have undermined their professional identity. The threat to professional identity is something discussed by Gordon (2005). Here, she describes how dominant media portrayals of nurses, positioning of nurses within the typical hierarchical structure of western healthcare settings; particularly as subordinate to doctors, and the demands of the hospital environment, all serve to threaten the identity of nurses as autonomous, competent medical professionals. Furthermore, she suggests these factors impact on nurses' ability to function, as they constrain their roles and reduce their identity to something much more menial and basic.

4.3 Implications and Recommendations

4.3.1 Implications for Clinical Practice

The study findings suggest opportunities for reflection and exploration of the impact of media representations may be useful. Specifically, nurses spoke of the need to discuss negative impacts of the media within their team. With their experience of consultation, supervision and reflective practice, combined with their knowledge of paediatric psychology, clinical psychologists working in paediatric settings are well placed to facilitate such discussions, bridging the gap between physical and psychological health (Jacobs, Titman & Edwards, 2012).

However, facilitating groups which tap into this reflective style of thinking with staff, particularly around issues they do not readily identify as threats to wellbeing, may be challenging for psychologists. This consideration is particularly relevant in the current study, where it was unclear how much nurses were consciously or unconsciously defending against their own self-care in

denying any impact on wellbeing, or other processes which were mediating impact of the media were at play. For example, the nurses may have already developed a resilience to experiences and influences that were critical or positioned them in potentially harmful ways.

To aid reflective practice, it may be of use for psychologists involved in this work to draw upon the ideas of Connelly et al. (2010), who have specifically looked at facilitating reflective practice groups within palliative care settings. Here, their development of the 'Sage and Thyme Model' (ibid), which aims to enhance the communication skills of staff so that they can better address the emotional concerns of patients and colleagues, may be applied. Moreover, utilising the model may serve to develop the confidence, competence and willingness of PPC nurses to discuss the negative impacts of media representations on both their personal wellbeing and clinical practice.

Clinical Psychologists may also be well placed to work with PPC nurses on developing strategies which support them to recognise their value, improve self-esteem and generally empower them. Again, reflective practice groups might be a useful forum for working collaboratively to develop such strategies. Specifically, ideas from narrative therapy could be used here such as outsider witness practices (Carey & Russell, 2003). Here, PPC nurses could work alongside the clinical psychologist and indeed other clinicians from neighbouring fields of medicine, in a therapeutic and reflective conversation, so that preferred stories and accounts can be listened to and heard. Such practices would aim to make the experiences of PPC nurses more meaningful and foster a community of appreciation both within the team and the wider institution.

In addition, the study indicates a bridging role for clinical psychologists between services and families, which focuses on managing the impact of media representations of PPC. This role might involve exploring families' concerns around treatment with PPC staff. Alternatively, it could be used to facilitate discussions around use of social media, something which the current study indicates some nurses may feel unable to do. In both examples, use of the 'Sage and Thyme Model' (Connelly et al., 2010) would again be helpful.

Finally, the study indicates a role for clinical psychologists to provide consultation around some of the uses and challenges of media representations of PPC. Taking a systemic perspective, one might argue this role could be located across various levels of the healthcare system. For example, it might take the form of reflective practice with groups of nurses, through to consulting in the development of policies and guidance for utilising the media. The role of clinical psychologists at this organisational level makes use of their skills in leadership, consultation and education, and speaks to the more systemic practice they can offer within teams (Onyett, 2007).

In terms of policy recommendations, the findings from the study indicate a need for PPC services to actively engage with the media, so to promote more accurate understandings of it and also help construct more positive representations of nurses in the field. One way of achieving such engagement might be through the development of policies which specifically give guidance to the use of media departments within hospitals and hospice organisations by staff members.

Media departments in particular may serve as a useful interface between services and the public, playing a vital role in shaping how PPC comes to be represented. Moreover, the use of online and social media may be a particularly useful in facilitating nurses' voices to be heard in this endeavour. Specifically, nursing blogs may provide an insight into the work of PPC nurses, detailing some of the challenges and rewards they experience. Social media may also prove a useful means for communicating messages about the clinical practice of those in the field including some of the decision making processes which are followed by nurses delivering care to those with LTLLCs.

Another aspect of online and social media use speaks to its capacity for educating the general public and also colleagues outside of palliative care. As Taubert, Watts, Boland & Radbruch (2014) highlight, social media can be utilised to raise awareness of issues such as death and dying, and may serve as a platform for enabling those affected by LTLLCs to come to know what to expect of services, treatment and clinicians.

4.3.2 Recommendations for Future Research

This study sought to examine media representations of PPC and explore how these were experienced by nurses in the field. Whilst critical realist discourse analysis and IPA were used in this endeavour, they are not the only possible approaches to design and analysis which could have been used.

Indeed, it could be argued taking a different approach may have been beneficial in exploring other processes which may have shaped the research findings. For example, using focus groups to explore nurses' experiences of media representations may have been more likely to illuminate areas of difference. Specifically, this may have been achieved through the use of a group dynamic, whereby participants may have been more stimulated to discuss the topic in greater depth.

Another area of potential enquiry would have been to review the research findings in relation to postmodern feminist ideas (see Huntington & Gilmour, 2001). Such a critical approach may have offered useful insights into issues such as power and agency briefly touched upon throughout the study. For example, a feminist approach to the finding that nurses often felt their voices were subjugated within the public arena; particularly in relation to media representations that positioned them as complicit in the harm of patients with LTLLCs, may lead to new understandings of why nurses do not or cannot get their voices. Moreover, this approach may better identify the resilience and robustness of nurses working in PPC. Engagement with PPC nurses' embodied experience through a feminist approach may lead to new representations of this group, which are typically marginalised by dominant discourses propagated by the media. This endeavour would also aim to help support self-esteem and protect against threats to wellbeing and clinical practice.

Additionally, future research may choose to utilise a different group of participants to explore their experience of media representations of PPC. For example, it would be interesting to see how doctors or parents of children using PPC services may have responded, and to establish points of similarity and contrast with the findings obtained from nurses.

4.4 Critical Review

4.4.1 Methodological Considerations

Whilst this research achieved its aim of providing an analysis of data in relation to the research questions using critical realist discourse analysis (CRDA) and interpretative phenomenological analysis (IPA), there are inevitably limitations to any methodology employed in a given study.

Moreover, of concern to all qualitative research is the issue of ensuring quality. This issue arguably represents a vast epistemological debate. On one hand is the antirealist position which posits that qualitative research is a distinctive paradigm and as such it cannot be judged by conventional measures such as validity, generalisability and reliability (Lincoln & Guba, 1990). On the other hand, naïve realists would argue that there is single, unequivocal reality independent of the researcher which can be measured objectively against definitive criteria. However, there is also a third position, the critical realist position, which proposes that all research involves subjective perception, but that there is an underlying reality which can be studied (Mays & Pope, 2000). As such, I have examined the current study according to Yardley's (2000) criteria for assessing the validity of qualitative research.

4.4.1.1 *Sensitivity to context*

The current study sought to provide an overview of the theoretical and empirical context in which the research is situated in the Introduction Chapter. Here, detail was given of the relevant literature about media representations of healthcare services and professionals with a particular focus on nurses. This was developed to look at media portrayals of palliative care. In addition, an overview of the development of PPC in the UK was provided as well as a commentary on current service provision. However, the focus on UK-based PPC neglected to attend to international systems and literature. In addition, it was not possible to draw upon other comparable studies to situate the research more specifically, as it appeared other work on the media representations of PPC had not been conducted.

4.4.1.2 *Commitment and rigour*

Arguably, this was an area of relative strength in the current research as an in-depth engagement with the topic was achieved through the use of two analytical methods. The inclusion of checks such as the coding of one interview by both the author and Director of Studies served to further validate the analytical process followed. The description of the methods of data collection aimed to demonstrate competence and skill, to further support the robustness of the findings drawn. However, the limits imposed by the word count of a professional doctoral thesis meant the study may be criticised for not achieving the same depth of analyses for both methods as might have been obtained if just one had been used.

4.4.1.3 *Transparency and coherence*

Throughout the research process I aimed to provide transparency around how findings were reached. This has involved a thorough explanation of the fit between theory and research methods and the inclusion of an audit of theme generation for both the CRDA and IPA provided in Appendices G and K. The presentation of the findings in the Analysis Chapter sought to provide clarity and order to the data whilst demonstrating coherence across both analyses. Furthermore, the study aimed to demonstrate reflexivity throughout, something which was addressed specifically in the Methodology Chapter and the inclusion of an extract from the reflexive journal kept throughout the research process (Appendix P). Reflexivity was also embodied in the author's attendance at an IPA forum where the research could be discussed critically with others knowledgeable about IPA.

4.4.1.4 *Impact and importance*

Finally, the study aimed to demonstrate the impact of findings in terms of the implications or clinical practice of psychologists working in the field of PPC and in health care settings more widely. In addition, attention was given to the importance of the study in terms of elucidating nurses' experience of the media representations of PPC and the impact of this on clinical practice, wellbeing and ultimately career longevity. Furthermore, the study contributes novel insights

into a previously unexplored area, drawing upon research from the fields of medical sociology and media and cultural studies.

4.4.1.5 *Further Critique*

Whilst it can be argued the study generally meets Yardley's (2000) criteria for quality in qualitative research, further critique can be offered around the use of IPA specifically. Firstly, one might contend the sample of PPC nurses did not satisfy the commitment to homogeneity as previously inferred. This was due to how it consisted of 4 PPC nurses from the hospital setting, and 1 from the hospice setting. Indeed, this difference was reflected to a degree in the participant's interview data; specifically around the discussion of utility of the media.

In terms of general critique of purposive sampling in IPA, the commitment to homogeneity inevitably reduces variability and potentially generalisability of the findings. Indeed, all participants were White British and female. Furthermore, the sample were self-selecting, which may indicate the presence of particular biases in the data.

Researchers using IPA are also vulnerable to critique around how explicit they are about their interpretative role in making sense of the data. Moreover, Brocki & Wearden (2006) point out the difficulty in firmly assessing reflexivity of the researcher and demonstration of an adequately interpretative role. Whilst Smith (2004) identifies different levels of interpretation, there is still some ambiguity as to what constitutes good enough interpretation and which of these levels is the most fundamental to a robust IPA.

4.4.2 Alternative Explanations

It is possible the finding that nurses did not appear to link any impact of media representations with their wellbeing, represents an underlying assumption made by myself and perhaps psychologists more generally. Within my own clinical training, there has been a focus on linking the personal and professional to develop reflexive skills and advance clinical practice. However, this may not be something that comes as naturally for staff in other healthcare disciplines,

where perhaps there is more of a trend to shy away from thinking about the personal consequences of our professional roles for example. Additionally, the burden and duty of care doctors and nurses are faced with on a daily basis may lead them to create a defence or persona that is less aware of personal wellbeing.

This notion is somewhat reminiscent of the work of Menzies-Lyth (1990) in her analysis of how nurses managed anxiety evoked in their role caring for seriously ill patients. Here, nurses were found to utilise the hospital organisation to develop socially structured defence mechanisms, in an attempt to externalise their characteristic psychic defences. Menzies-Lyth (ibid) proposes that through subconscious collusion and agreement, the socially structured defence becomes part of nurses' external reality. Moreover, the defence is made up in part by the denial of feelings, so to facilitate the development of professional detachment. Furthermore, Menzies-Lyth (pg. 7) suggests nurses used "interpersonal repressive techniques" to deal with emotional distress that may have proven problematic in the work context. Indeed, perhaps the emotional demands are so high for PPC nurses as they are dealing with the extremes of life and death as a matter of course, suggesting repression and denial of threats to wellbeing is the only accessible way to function in the role;

...anyone who works in palliative care has to love it, you have to really enjoy this work, you see the very best and you see the very worst of humanity ... not everybody has that exposure to such happiness and sadness all at the same time... (Maxine, Lines 530-536)

4.5 Reflections

4.5.1 Assumptions and Biases

In conducting this research I have aimed to be honest and transparent about the assumptions and biases I hold that may have come to bear on the research findings presented. I believe of particular relevance are my personal experiences of being nursed and the ways I have come to position nurses as a consequence. Indeed, there were times when I quizzed myself as to whether I

might have been interpreting the data in light of my own preferences and opinions.

At such times it was helpful to write down my beliefs and assumptions so I could consider whether they were coming through in the analysis or if I had successfully managed to remain true to the data. In addition, I regularly met with other trainees to discuss my research and its findings. This was particularly useful in lifting my analysis from the level of description to that of interpretation in the interpretative phenomenological analysis of nurses' interview data.

Engaging in these steps reinforced my belief people can never really separate their experience fully from the sense they make of the world. Moreover, it was this view that attracted me to conducting a piece of qualitative research in the first instance. For me, it is this potential for multiple meaning making that renders qualitative research so rich and valuable.

4.5.2 Changes throughout the Research Process

At the start of this project, I had wanted to conduct a piece of research that sought to explore nurses' experiences of the media representations of PPC. However, I quickly realised this would not be possible unless I investigated the kinds of media representations that were available to begin with. Therefore, recognising the need to carry out a review of the media, led me to employ two analytical approaches; CRDA and IPA.

Finally, throughout the study, I often questioned whether the title of my research tapped into and did justice to, the phenomena I was really interesting in; namely nurses' experience of the media and the impact of this on their wellbeing and clinical practice. On reflection, I realise this concern has been evident in the write up through my attempts to explicate the relationship between wellbeing, clinical practice and career longevity. As such, I think there was a degree of shift in the aims of the study as it progressed. However, I would argue this is something which can be an effect of the process of doing research and represents a form of evolution from initial ideas to the completed work.

4.5.3 Final Thoughts

Whilst the process of undertaking this research has at times been rather stressful, it has also advanced my knowledge of PPC and views of how the media comes to shape lived experience. Moreover, the insights into nurses' experience has led me to wonder about the utility of further research to explore how the media can be used to construct more accurate and thorough understandings of PPC. Furthermore, if PPC nurses were to be involved in this, it may provide them with an opportunity to voice their views; something the study suggests they felt they were currently denied.

Furthermore, I also have thought how PPC seems to underuse the media, particularly social media; something authors elsewhere have commented upon (Kleszcz & Campbell, 2013). Moreover, with the potential for social media to provide the public with education and information about PPC services, it is of interest to consider why it is not used more and if better usage could enhance interactions between clinicians and patients.

A final point is around the term 'palliative care' and what this means to people. The study supports the notion the term is seen as synonymous with death and dying, indeed even PPC nurses described it in this way, whilst also recognising the more holistic meaning. Perhaps the dominance of this lay understanding has resulted in the term becoming forever changed and as such, a new term is needed to describe the holistic care of children with LTLLCs and their families. Furthermore, this lay understanding has made me wonder how difficult it must be for families and professionals to hold multiple possibilities in mind when facing the reality of a LTLLC. Perhaps the term 'palliative care' evokes an emotional reaction which means it is too complex to hold different possibilities in mind, and because it represents what people fear the most (death), people are unable to acknowledge other possible meanings.

5.0 REFERENCES

Ablett, J. R., & Jones, R. S. P. (2007). Resilience and well-being in palliative care staff: a qualitative study of hospice nurses' experience of work. *Psycho-Oncology*, 16(8), 733-740.

Alderton, J. (1983). The Best Nurses Have the Essential Qualifications Before They Go to School. Or do They? *Nursing Times*, 79(10), 12

Anonymous. (2012). How does it feel to withdraw feeding from new-born babies? Retrieved from:

http://www.bmj.com/content/345/bmj.e7319?ijkey=196d9b170fbfbb725323782436587a6256dc3d87&keytype2=tf_ipsecsha&linkType=FULL&journalCode=bmj&resid=345/nov01_1/e7319 12th, May, 2015

Archer, M., Bhaskar, R., Collier, A., Lawson, T., & Norrie, A. (Eds.). (2013). *Critical realism: Essential readings*. Routledge.

Association for Children with Life-Threatening or Terminal Conditions and their Families / Royal College of Paediatrics and Child Health (ACT / RCPCH). (1994). *A guide to the development of children's palliative care services: Report of the joint working party*. Bristol: ACT / RCPCH

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT). (2004). *A framework for the development of integrated multi-agency care pathways for children with life-threatening or life-limiting conditions*. Bristol: ACT

Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology*. Chichester: Wiley.

Baum, J. D., Dominica, S. F., & Woodward, R. N. (Eds.). (1990). *Listen: My Child Has a Lot of Living to Do: the Partnership Between Parents and Professionals in Caring for Children with Life-threatening Conditions*. Oxford University Press, USA.

Benelli, E. (2003). The role of the media in steering public opinion on healthcare issues. *Health policy*, 63(2), 179-186.

- Benner, P. (2000). The wisdom of our practice. *AJN The American Journal of Nursing*, 100(10), 99-105.
- Bhaskar, R. (2013). *A realist theory of science*. Routledge.
- Billig, M. (2001). Discursive, rhetorical and ideological messages. *Discourse theory and practice: A reader*, 210-221.
- Bramley, N., & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health*, 20(2), 223-235.
- Bridges, J. M. (1990). Literature review on the images of the nurse and nursing in the media. *Journal of advanced nursing*, 15(7), 850-854.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and health*, 21(1), 87-108.
- Burr, V. (2003). *Social constructionism*. Psychology Press.
- Caine, R. M., & Ter-Bagdasarian, L. (2003). Early identification and management of critical incident stress. *Critical Care Nurse*, 23(1), 59-65.
- Carey, M., & Russell, S. (2003). Outsider-witness practices: Some answers to commonly asked questions. *International Journal of Narrative Therapy & Community Work*, 2003(1), 3.
- Chou, W. Y. S., Hunt, Y. M., Beckjord, E. B., Moser, R. P., & Hesse, B. W. (2009). Social media use in the United States: implications for health communication. *Journal of medical Internet research*, 11(4).
- Clarke, J., & Quin, S. (2007). Professional carers' experiences of providing a paediatric palliative care service in Ireland. *Qualitative health research*, 17(9), 1219-1231.
- Connolly, M., Perryman, J., McKenna, Y., Orford, J., Thomson, L., Shuttleworth, J., & Cocksedge, S. (2010). SAGE & THYME™: a model for training health and social care professionals in patient-focussed support. *Patient education and counselling*, 79(1), 87-93.

- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of pediatrics & adolescent medicine*, 156(1), 14-19.
- Cottrell, S., Edwards, F., Harrop, E., Lapwood, S., McNamara-Goodger, K., & Thompson, A. (2011). *A care pathway to support extubation within a children's palliative care framework*. Bristol: ACT
- Cunningham, A. (1999). Nursing stereotypes. *Nursing Standard*, 13(45), 46-47.
- Davies, B., Clarke, D., Connaughty, S., Cook, K., MacKenzie, B., McCormick, J., O'Loane, M., & Stutzer, C. (1995). Caring for dying children: nurses' experiences. *Pediatric nursing*, 22(6), 500-507.
- Department of Health (2013). *The NHS Constitution: The NHS belongs to us all*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf 12th May, 2015
- Dictionary, C. E. (2010). Harper Collins Publishers. *The University of Birmingham, UK*.
- Eatough, V., & Smith, J. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, 97(4), 483-498.
- Eatough, V., & Smith, J. (2008). Interpretative Phenomenological Analysis in C. Willig & W. Stainton-Rogers, (Eds.). *The SAGE handbook of qualitative research in psychology*. (pgs. 179 – 194) London: Sage.
- Edwards, D., & Potter, J. (1992). *Discursive psychology* (Vol. 8). Sage.
- Edwards, D. (1995). Two to tango: Script formulations, dispositions, and rhetorical symmetry in relationship troubles talk. *Research on language and social interaction*, 28(4), 319-350.
- Edwards, D. (2005). Discursive psychology. *Handbook of language and social interaction*, 257-273.

- Edwards, J. R., Cable, D. M., Williamson, I. O., Lambert, L. S., & Shipp, A. J. (2006). The phenomenology of fit: linking the person and environment to the subjective experience of person-environment fit. *Journal of Applied Psychology*, 91(4), 802.
- Fraser, L. K., Miller, M., & Aldridge, J. (2011). Life Limiting and Life Threatening Conditions in Children and Young People in the United Kingdom; National and Regional Prevalence in Relation to Socioeconomic Status and Ethnicity. *Final Report for Together for Short Lives. Division of Epidemiology, University of Leeds and Together for Short Lives, Bristol.*
- Goffman, E. (1959). *The presentation of self in everyday life*. United States: Anchor
- Gordon, S. (2005). *Nursing against the odds: How health care cost cutting, media stereotypes, and medical hubris undermine nurses and patient care*. Cornell University Press.
- Hall, L. M., Angus, J., Peter, E., O'Brien-Pallas, L., Wynn, F., & Donner, G. (2003). Media portrayal of nurses' perspectives and concerns in the SARS crisis in Toronto. *Journal of Nursing Scholarship*, 35(3), 211-216.
- Harper, D., & Thompson, A. R. (Eds.). (2011). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. John Wiley & Sons.
- Hatano, Y., Yamada, M., & Fukui, K. (2011). Shades of truth: cultural and psychological factors affecting communication in pediatric palliative care. *Journal of pain and symptom management*, 41(2), 491-495.
- Hemsley-Brown, J., & Foskett, N. H. (1999). Career desirability: young people's perceptions of nursing as a career. *Journal of Advanced Nursing*, 29(6), 1342-1350.
- Hepburn, A., & Potter, J. (2006). Discourse analytic practice. *Qualitative Research Practice: Concise Paperback Edition*, 168.
- Hodgetts, D., & Chamberlain, K. (2006). Developing a critical media research agenda for health psychology. *Journal of health psychology*, 11(2), 317-327.

- Höijer, B. (2011). Social Representations Theory. *A New Theory for Media Research. Nordicom Review*, 3-16.
- Hook, D. (2001). Discourse, Knowledge, Materiality, History Foucault and Discourse Analysis. *Theory & psychology*, 11(4), 521-547.
- Hudson, P. L., Remedios, C., & Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC palliative care*, 9(1), 17.
- Hughes, L. (1980). The public image of the nurse. *Advances in Nursing Science*, 2(3), 55-72.
- Huntington, A. D., & Gilmour, J. A. (2001). Re-thinking representations, re-writing nursing texts: possibilities through feminist and Foucauldian thought. *Journal of Advanced Nursing*, 35(6), 902-908.
- Jacobs, K., Titman, P., & Edwards, M. (2012). Bridging psychological and physical health care. *Psychologist*, 25(3), 190-193.
- Judge, K., Solomon, M., Miller, D., & Philo, G. (1992). Public opinion, the NHS, and the media: changing patterns and perspectives. *BMJ*, 304(6831), 892-895.
- Kalisch, P. A., & Kalisch, B. J. (1982). The image of the nurse in motion pictures. *The American Journal of Nursing*, 82(04), 605-611.
- Karpf, A. (1988). *Doctoring the media: The reporting of health and medicine* (pp. 222-230). London: Routledge.
- Keene, E. A., Hutton, N., Hall, B., & Rushton, C. (2010). Bereavement debriefing sessions: An intervention to support health care professionals in managing their grief after the death of a patient. *Pediatr Nurs*, 36(4), 185-189.
- Kelly, J., Fealy, G. M., & Watson, R. (2012). The image of you: constructing nursing identities in YouTube. *Journal of Advanced Nursing*, 68(8), 1804-1813.
- Kellner, D. (2011). Cultural studies, multiculturalism, and media culture. *Gender, race, and class in media: A critical reader*, 7-18.
- Killen, S. (2007). *Palliative care services for children and young people in England: an independent review for the secretary of state for health*. Department of Health.

- Klein, S. M. (2009). Moral distress in pediatric palliative care: A case study. *Journal of pain and symptom management*, 38(1), 157-160.
- Kleszcz, E., & Campbell, C. (2013). P43 The use of social media by UK Hospices: review and discussion. *BMJ Supportive & Palliative Care*, 3(Suppl 1), A25-A25.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology*, 3(2), 102-120.
- Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: challenges and emerging ideas. *The Lancet*, 371(9615), 852-864.
- Lincoln, Y. S., & Guba, E. G. (1990). Judging the quality of case study reports. *International Journal of Qualitative Studies in Education*, 3(1), 53-59.
- Maunder, E. Z. (2006). Emotion work in the palliative nursing care of children and young people. *International journal of palliative nursing*, 12(1), 27-33.
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *BMJ: British Medical Journal*, 320(7226), 50.
- Maytum, J. C., Heiman, M. B., & Garwick, A. W. (2004). Compassion fatigue and burnout in nurses who work with children with chronic conditions and their families. *Journal of Pediatric Health Care*, 18(4), 171-179.
- McCloskey, S., & Taggart, L. (2010). How much compassion have I left? An exploration of occupational stress among children's palliative care nurses. *International journal of palliative nursing*, 16(5), 233-240.
- McNamara-Goodger, K. (2007). *The ACT Care Pathway: Transition*. Retrieved from:
<http://www.eapcnet.eu/LinkClick.aspx?fileticket=EAet4jZd TI%3D&tabid=608>
 12th May, 2015
- McNamara-Goodger, K. (2009). *A neonatal care pathway for babies with palliative care needs*. Retrieved from:
http://www.togetherforshortlives.org.uk/assets/0000/7095/Neonatal_Pathway_for_Babies_5.pdf 12th May, 2015

- Mellor, C., Heckford, E., & Frost, J. (2012). Developments in paediatric palliative care. *Paediatrics and Child Health*, 22(3), 115-120.
- Menzies-Lyth, I. (1990). Social systems as a defence against anxiety (revised). *The Social Engagement of Social Science*, 1, 222-235.
- Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of medical Internet research*, 15(4).
- Moscovici, S. (1988). Notes towards a description of social representations. *European journal of social psychology*, 18(3), 211-250.
- NHS England (2013). NHS Standard Contract for Paediatric Medicine: Palliative care. Retrieved from: <http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med-pall.pdf> 12th May, 2015
- Nightingale, D., & Cromby, J. (1999). *Social constructionist psychology: A critical analysis of theory and practice*. McGraw-Hill International.
- Ooi, E. S., & Chapman, S. (2003). An analysis of newspaper reports of cancer breakthroughs: hope or hype?. *Medical journal of Australia*, 179(11/12), 639-643.
- Onyett, S. (2007). New ways of working for applied psychologists in health and social care: Working psychologically in teams. *Leicester, England: British Psychological Society*.
- Osborn, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology*, 3(1), 65-83.
- Papadatou, D. (1997). Training health professionals in caring for dying children and grieving families. *Death studies*, 21(6), 575-600.
- Papadatou, D., Papazoglou, I., Petraki, D., & Bellali, T. (1999). Mutual support among nurses who provide care to dying children. *Illness, Crisis, & Loss*, 7(1), 37-48.

- Papadatou, D., Bellali, T., Papazoglou, I., & Petraki, D. (2001). Greek nurse and physician grief as a result of caring for children dying of cancer. *Pediatric nursing, 28*(4), 345-353.
- Potter, J. (1996). *Representing reality: Discourse, rhetoric and social construction*. Sage.
- Potter, J. (1997). Discourse analysis as a way of analysing naturally occurring talk. *Qualitative research: Theory, method and practice*, 144-160.
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. Sage.
- Potter, J., & Hepburn, A. (2008). Discursive constructionism. *Handbook of constructionist research*, 275-293.
- Rogers, R. (1984). The Image Makers. *Senior Nurse, 1*(6), 10-11
- Rothaug, E. R. (2012). *An Exploration of the Dilemmas Encountered by Staff Working in Paediatric Palliative Care* (Doctoral dissertation, University of East London).
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American psychologist, 55*(1), 68.
- Salvage, J. (1983). Distorted Images. *Nursing Times, 79*(1), 13-15
- Seale, C. (2003a). *Media and health*. Sage.
- Seale, C. (2003b). Health and media: an overview. *Sociology of health & illness, 25*(6), 513-531.
- Shaw, K. L., Brook, L., Mpundu-Kaambwa, C., Harris, N., Lapwood, S., & Randall, D. (2014). The Spectrum of Children's Palliative Care Needs: a classification framework for children with life-limiting or life-threatening conditions. *BMJ supportive & palliative care, bmjpspcare-2012*.
- Sims-Schouten, W., Riley, S. C., & Willig, C. (2007). Critical Realism in Discourse Analysis A Presentation of a Systematic Method of Analysis Using Women's Talk of Motherhood, Childcare and Female Employment as an Example. *Theory & Psychology, 17*(1), 101-124.

- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1(1), 39-54.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretative Phenomenological Analysis. In J.A. Smith (ed.). *Qualitative Psychology: A practical guide to research methods* (pgs. 51-80). London: Sage
- Spinelli, E. (2005). *The interpreted world: An introduction to phenomenological psychology*. Sage.
- Stanley, D. (2012). Celluloid devils: a research study of male nurses in feature films. *Journal of advanced nursing*, 68(11), 2526-2537.
- Strada, E. A., & Sourkes, B. M. (2009). Psychotherapy in the palliative care setting. *Primary psychiatry*, 16(5), 34-40.
- Takase, M., Kershaw, E., & Burt, L. (2002). Does public image of nurses matter?. *Journal of professional Nursing*, 18(4), 196-205.
- Takase, M., Maude, P., & Manias, E. (2005). Nurses' job dissatisfaction and turnover intention: Methodological myths and an alternative approach. *Nursing & health sciences*, 7(3), 209-217.
- Takase, M., Maude, P., & Manias, E. (2006). Impact of the perceived public image of nursing on nurses' work behaviour. *Journal of Advanced Nursing*, 53(3), 333-343.
- Takase, M., Maude, P., & Manias, E. (2006). The impact of role discrepancy on nurses' intention to quit their jobs. *Journal of Clinical Nursing*, 15(9), 1071-1080.
- Turow, J. (2010). *Playing doctor: Television, storytelling, and medical power*. University of Michigan Press.
- Twamley, K., Craig, F., Kelly, P., Hollowell, D. R., Mendoza, P., & Bluebond-Langner, M. (2014). Underlying barriers to referral to paediatric palliative care services Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom. *Journal of Child Health Care*, 18(1), 19-30.

- Washer, P., & Joffe, H. (2006). The “hospital superbug”: social representations of MRSA. *Social Science & Medicine*, 63(8), 2141-2152.
- Widdas, D., McNamara, K., & Edwards, F. (2013). *A core care pathway for children with life threatening and life limiting conditions*. Retrieved from: http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE_.pdf 12th May, 2015
- Willig, C. (2001). *Qualitative research in psychology: A practical guide to theory and method*. Buckingham: Open University Press.
- Willig, C. (2008). *Introducing qualitative research methods in psychology*. Buckingham: Open University Press.
- Winter, H. (2013). *ADHD: ‘Because You’re Worth It’: The Marketisation of ADHD to Adult Women* (Doctoral dissertation, University of East London).
- Wodak, R., & Meyer, M. (Eds.). (2009). *Methods for critical discourse analysis*. Sage.
- Wood, F., Simpson, S., Barnes, E., & Hain, R. (2010). Disease trajectories and ACT/RCPCH categories in paediatric palliative care. *Palliative Medicine*, 24(8), 796-806.
- Woolley, H., Stein, A., Forrest, G. C., & Baum, J. D. (1989). Staff stress and job satisfaction at a children's hospice. *Archives of disease in childhood*, 64(1), 114-118.
- World Health Organization. (1998). *WHO Definition of Palliative Care for Children*. Retrieved from: <http://www.who.int/cancer/palliative/definition/en/> 12th May, 2015
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, 15(2), 215-228.

6.0 APPENDICES

6.1 Appendix A: UEL Registration Document



Anna Neal
19 Clarendon Court
The Terrace
Gravesend
Kent DA12 2DT

9 May 2014

Student Number: 1236148

Dear Anna,

Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

Title of Professional Doctorate: Professional Doctorate in Clinical Psychology

Director of Studies: Neil Rees

Supervisor/s: Nimisha Patel

Registered Thesis Title: Staff experiences of media representations of Paediatric Palliative Care: Implications for wellbeing and career longevity.

Expected completion: According to your actual date of registration, which is **1 October 2013**, the registration period is as follows:

Minimum 18 months maximum 48 months (4 years), according to a full time mode of study.

Your thesis is therefore due to be submitted between:

1 April 2015 - 1 October 2017

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

A handwritten signature in black ink that reads 'James J. Walsh'.

Dr James J Walsh
School Research Degrees Leader
Direct line: 020 8223 4471
Email: j.j.walsh@uel.ac.uk

Cc: Neil Rees, Nimisha Patel

6.2 Appendix B: UEL Ethical Approval

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



6.3 Appendix C: Information Sheet

UNIVERSITY OF EAST LONDON

School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator(s)

Anna Neal, Trainee Clinical Psychologist, University of East London

U1236148@uel.ac.uk

Consent to Participate in a Research Study

The purpose of this sheet is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Professional Doctorate Degree in Clinical Psychology at the University of East London.

Project Title

Staff Experiences of the Media Representations of Paediatric Palliative Care: Implications for Wellbeing and Career Longevity

Project Description

The aim of this study is to explore how nurses working in paediatric palliative care (PPC) settings experience how the media portrays their services. It also asks what impact, if any, these media portrayals have on professional identity and wellbeing.

If you choose to participate, you will be asked to take part in a 20-30 minute audio recorded interview about your experiences of media representations of PPC, and the impact these have had on you.

Confidentiality of the Data

The content of interviews will be kept strictly confidential within the research team. The research team comprises of the main researcher – Anna Neal, the Director of Studies – Dr Neil Rees, University of East London and the Field Supervisors – Dr Zoe Berger, [DELETED TEXT] and Dr Rachel Marfleet, [DELETED TEXT].

All data from participant interviews will be stored securely by the researcher in password-protected files, on computers which require a password to access. Interviews will be anonymised to maintain confidentiality, with pseudonyms used within transcriptions. Access to transcriptions will be restricted to the research team as outlined above, and the assessors of the research.

The only circumstance under which confidentiality may be broken and the content of interviews shared would be if the research team were to have legitimate concerns over the welfare of participants or members of the public.

Audio recordings of the interviews will be destroyed following completion of the research. However, electronic transcripts of the interviews will be securely kept for five years after completion of the study, as per the Data Protection Act (1998).

Location

Interviews will be carried out at your convenience. This is likely to be at your workplace at a date and time that suits you. Should you prefer to be interviewed off-site, there is the option of meeting at the University of East London, Stratford Campus.

Disclaimer

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you are free to do so without any obligation to give a reason.

Please feel free to ask any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this information sheet for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr Neil Rees, School of Psychology, University of East London, Water Lane, London E15 4LZ.

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you.

6.4 Appendix D: Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Staff Experiences of the Media Representations of Paediatric Palliative Care:
Implications for wellbeing and Career Longevity

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date

.....

6.5 Appendix E: Media Text Search Terms

The table below shows the terms used to search for relevant media texts from the NEXIS database along with the number of articles returned on each search.

TERM	Nov 2014	Dec 2014	Jan 2015
<i>Paediatric palliative care</i>	20	20	23
<i>Paediatric palliative care nurses</i>	0	0	0
<i>Children's hospices</i>	>2900	>3000	> 3000
<i>Paediatric palliative care fund-raising</i>	0	0	0
<i>End of life care</i>	0	0	0
<i>Paediatric end of life care</i>	0	0	0
<i>Children's end of life care</i>	1	1	1
<i>Children's end of life symptom management</i>	0	0	0
<i>End of life symptom management</i>	0	0	0
<i>Life threatening and life limiting conditions</i>	30	31	31
<i>Paediatric palliative care staff</i>	0	0	0
<i>Paediatric palliative care workers</i>	0	0	0

Articles were then subject to the additional criteria discussed in the methodology chapter to arrive at the final number of texts included for review.

6.6 Appendix F: List of Websites Used to Obtain Online Data

www.rainbows.co.uk

www.havenhouse.org.uk

www.rainbowtrust.org.uk

www.togetherforshortlives.org.uk

www.acorns.org.uk

www.claire-house.org.uk

www.each.org.uk

www.chsw.org.uk

www.noahsarkhospice.org.uk

www.demelza.org.uk

www.teenagecancertrust.org

www.shootingstarchase.org.uk

www.keech.org.uk

www.martinhouse.org.uk

These websites were selected as data sources as they are associated with the majority of children's hospices and / or PPC charities in the UK. As such, it was assumed they are amongst the central sources of PPC related media available in the UK, and would therefore offer some of the most widely accessed representations of PPC services and staff.

As with the newspaper articles selected for inclusion, a similar inclusion / exclusion criteria was applied in the online search across the websites named above. Again, only texts published between 2004 and 2014 were used and the content of these needed to make reference to PPC services and / or staff.

6.7 Appendix G: Worked Example of Media Data Coding

PEACE OF MIND

Kiran says: "For the first two years after Ruby-Mo was born, I didn't smile. I felt deflated. I had to take each day as it came and couldn't plan anything. Ruby-Mo was on oxygen 24/7 and every time she went into hospital I thought I would lose her. Everything was a constant worry and I couldn't see how things would get better."

In November 2012, a home care nurse told Kiran about Haven House and the support it could provide. It took a while for the family to come round to the idea of visiting the hospice, fearing it was a place where children came to die, but Kiran now realises this is far from the truth. She says: "Ruby-Mo looks so happy when she is at Haven House and I know the nurses are brilliant so I have peace of mind. I was able to go away for my 30th birthday for five days and totally relax. It really was the best birthday present; having some 'me time' knowing that Ruby-Mo was in expert hands."

ZEST FOR LIFE

Ruby-Mo has been coming to Haven House for day visits and overnight stays for more than two years now and Kiran has her zest for life back. While the demands of a child with such a condition mean life will never be easy, Kiran is proud of Ruby-Mo and credits her daughter for making her the person she is today. Ruby-Mo thrives in her music therapy sessions at the hospice and loves the switch-adapted toys that she borrows through the hospice's toy home loan service. Kiran says: "Support is so important and that is what the Haven House nurses and other mums have given me. We truly

Complex health needs
fear the worse
hopeless

→ death
hospice misconception

brilliance - ~~brilliant~~ ~~brilliant~~ ~~brilliant~~ ~~brilliant~~ ~~brilliant~~

rejuvenated

resources

nurses = support network

would be lost without the respite care as it gives us the chance to have some kind of normality for a few hours. Please donate to an amazing charity, to enable other families to experience the hope and stability Haven House has given us, so we can keep smiling."

essential
provides normality

Themes

2 of 17 DOCUMENTS

MAIL ON SUNDAY (London)

May 1, 2011 Sunday

GLITTER BALLS, BUBBLE MACHINES AND ROOMS RINGING WITH LAUGHTER THIS ISN T JUST WHERE CHILDREN COME TO DIE

- the unexpected... more to PIC than death

BYLINE: BY ALICE SMELLIE

LENGTH: 1680 words

INSIDE THE HOSPICE THAT'S A WONDERLAND FOR SICK YOUNGSTERS AND THEIR DEVOTED FAMILIES

Little Bridge House reverberates with the shouts and laughter of happy children. It is early in the morning and in the vast, toy-strewn garden 5-year-old Jessica Parsons is squealing with joy as she hurles round the pathways in the front seat of a specialty adapted buggy-bike.

happiness/joy

Inside the pretty red-brick building, every brightly coloured room is like a child's most fantastic dream.

prettiness dreamlike

in the messy craft area, which is stuffed with rainbow pots of paint, Jessica's 18-month-old sister Ruby is cheerfully smearing colours on a piece of paper with her hands.

More youngsters are whooping enthusiastically in a playroom tiled with plastic bats and squashy foam obstacles for climbing over. The corridors are lined with books and bright drawings.

well-resourced

This is the type of place I imagine my own three children, aged three, five and six, would love.

same as other children

But, in reality, as wonderful as it is, I hope they never need to be here. For Little Bridge House is a hospice. And the families who stay here have children who are not expected to survive into adulthood.

LT&LGs

The condition that Jessica suffers from is so rare no one knows quite what is wrong. It is referred to as a syndrome without a name, or simply swan. Until she was six months old she was fine, but then she started to have fits, over and over again. Last year we were in hospital for a month because Jessica was so ill and had almost constant seizures, says her mother, Carly. Because of the lack of diagnosis, doctors can't give a prognosis. But at any moment she could have a fatal fit. Every time we go into hospital we are warned of the possible out-come, adds Carly.

rarity / unknown

fits+seizures

uncertainty

The family were referred to Little Bridge House in January 2009. Last year they came every month to the hospice, near Barnstaple in Devon, and the whole family stay over on their visits.

family provision

Far from being depressing, Little Bridge House is a haven where parents exhausted by the 24-hour demands of very sick children can have a break, and the mundanities such as cooking and washing are done for them. There is enough room for families to stay, and talk to and parents wish to leave their children. Jessica is autistic, which

demands of caring

proximity + availability of staff

GLITTER BALLS, BUBBLE MACHINES AND ROOMS RINGING WITH LAUGHTER
THIS ISN'T JUST WHERE CHILDREN COME TO DIE MAIL ON SUNDAY (London)

May 1, 2011 Sunday

means she has no concept of danger. She also has violent tantrums, so needs constant supervision, says Carly.

supervision

When the family were first told about the hospice, they were wary. We had a friend whose child died and just assumed that hospices were for dying children, says Carly. We didn't realise that we'd be eligible but it has been a lifeline for the whole family.

fear of unknown (hospice)
hospice = death
hospice = lifeline
relief

Jessica is happy here. We literally walk through the door and breathe a sigh of relief, adds her mother.

She looks fondly at her two daughters who are now both playing with paints. This is the best moment we've had in a long time. It is the first time I've seen the girls playing together in what feels like forever. Carly, 30, who works in catering, and the girls father, Neil, 32, a transport manager, are unequivocal about how much difference the service has made. Had we not come here I think Jess would be in care by now. As her mother, this is heartbreaking for me to admit.

keeps families together

Last year the family had a very difficult year. Jess was very violent. She kicked, bit and thumped us. She is up so much at night. When we come here, not only do we have a night's sleep, but we get to do things as a family normal things, like going to the beach and I can even go food-shopping without Jess. At the moment I can't take both children out by myself because

managing aggression
normality

Jess needs watching the whole time and Ruby has just learnt to walk.

There is a dedicated team at Little Bridge who look after the well siblings of sick children, which is why Ruby is here.

extended care to siblings =

If you are fortunate enough not to be in this situation you won't as I didn't have considered how hard it must be for the whole family. Siblings meet other children in the same situation and come on their own for special weekends, says Julie Stanway, Little Bridge House's head of care.

siblings

There are an estimated 23,500 children and young people in Britain with what doctors now term life-limiting illnesses. Little Bridge House, run by Children's Hospice South West, was founded in 1991 by Eddie Farwell and his late wife Jill, who had two children with life-limiting conditions.

It is one of 45 such centres operating in the UK, supporting about 5,000 families. We try to avoid a hospital atmosphere, says Julie. The staff want it to be a home from home and a place for families to relax and recharge, and not simply a place where children come to die.

difference to hospital
(hospice = home)
(hospital = death?)

Many areas are communal, and comfortable-looking. The kitchen is vast but wouldn't look out of place in a normal home, and everyone including the care team and families eats around a huge table. But it is not a forced situation. If people want to be on their own, they can, says Julie.

normality / family choice

Hospices have nursing staff, doctors and state-of-the-art medical equipment. Little Bridge House and Charlton Farm, the charity's hospice in Wraxall, Somerset, is currently able to support about 400 children across the South West of England.

resources

The service is free for the families but relies heavily on donations. However, it was close to Prime Minister David Cameron's heart: his own severely disabled son has needed extensive care before his death in 2009 at the age of six. One of the key Conservative pledges in the run-up to the General Election was to provide more funding for respite care services, including children's hospices. Currently about 10 per cent of funding comes from the Government.

[Redacted text]

Families are sometimes referred by their GP but the first approach may come from a consultant, a relative or even from the families themselves.

GLITTER BALLS, BUBBLE MACHINES AND ROOMS RINGING WITH LAUGHTER
THIS ISN'T JUST WHERE CHILDREN COME TO DIE MAIL ON SUNDAY (London)
May 1, 2011 Sunday

Hospices like these support all children with life-limiting and life-threatening conditions, from severe epilepsy and muscular dystrophy to cancer. They allocate annual time to each family, depending on their individual needs generally a few nights a year for short breaks.

conditions (respite)
needs-based provision

It also offers emergency care. If there is a crisis at home such as a sick parent, or the child needs recuperation after a hospital stay, it will try to help. All hospices have emergency beds. **Sam taken to meet seven-year-old Sam Walter, who is lying in the sensory room - a darkened room with a warm water bed, a glitter ball, bubble machines and bundles of LED fibre-optics to play with. This is a very calm room for children who need more peace and quiet than others, says Julie.**

emergency care

mood

Sam has neurological conditions that affect his physical and mental skills. He cannot walk or talk and although he experiences pain he is unable to communicate what is wrong.

conditions

He needs round-the-clock care, his health problems are complex, and even the slightest cold can quite quickly spiral out of control.

complexity, danger

unknown/uncertain

Again, he has no prognosis.

Sam's life expectancy is unknown. His mother Jo, 36, and father Jon, 42, who works for the local council, have been bringing him here for weekend respite stays for just over a year.

Because they live close by, on their first visit they came for a weekend. **The service is for the whole family. If you are the carer of an ill child sometimes you need someone to look after you, too, says Jo.**

care for parents

Sam is tube-fed overnight and wakes frequently. Like most of the children, he has a regimented medication routine that has to be adhered to. As yet, they haven't left Sam on his own but say it is something they may consider in the future. Last year he contracted meningitis. We thought we'd lost him, says Jo, her voice breaking. He as a very ill in hospital that he became totally unresponsive. When we brought him here to recuperate, he started to react again and make eye contact. We had a week at Little Bridge and it gave us the physical strength to take him home and pick up our lives again.

brought back?
recuperation? life
restorative

Down at the far end of the hospice is a lilac-painted room filled with soft chairs. At one end is a tree. Rather than real leaves, it is festooned with paper leaves in bright colours on which are handwritten notes. This is the multi-faith chapel and the messages are to children who have died.

faith

Next door to the chapel is a room called Star Room. It could be any child's bedroom, but when there is a death the child's body can be laid on the bed for as long as the family likes.

place to be

The room has a special cooling vent so the child can stay until the funeral, which gives a grieving family time to say goodbye as they wish. They can decorate the room, talk to their child and take as much time as they like saying goodbye, says Julie.

time to say goodbye

Finally, I meet Jo Chinnock-Schumann, 43, whose daughter Bethany, 11, was brought here from hospital after she died of pneumonia. Bethany had visited the hospice from the age of four with her sister, Amelia, who is two years younger.

contact & service several years

Bethany was born with a unique chromosome abnormality and with her bladder outside her body. After emergency surgery as a newborn, it became clear that her kidneys didn't work and that she was suffering from a host of other health problems including near blindness.

complex health conditions

Page 7
GLITTER BALLS, BUBBLE MACHINES AND ROOMS RINGING WITH LAUGHTER
THIS ISN'T JUST WHERE CHILDREN COME TO DIE MAIL ON SUNDAY (London)
May 1, 2011 Sunday

When her little body finally gave up, Bethany spent a week in Star Barn. Her father, Paul, couldn't bear to leave his little girl, and so he camped there overnight. The staff didn't question us, says Jo, who works with the families of special needs children. They could see Jo wanted to be with his daughter and simply came up with a practical solution. It is so cold in there that they suggested putting up a tent.

Pictures of Bethany show a tiny girl with a mass of fizzy curls and an intent face.

Her family came from all over the country to say goodbye and kiss her one final time. We made her beautiful, says Jo. They decorated her coffin and filled it with all her precious possessions. We couldn't bear for her to be at the hospital. We had such happy times here, as a family, so it seemed natural to be here at the end.

To find your nearest children's hospice, visit childhospice.org.uk. A fundraising week for children's hospices is running from May 14 to 21. For more details about Little Bridge House, go to CHSW.org.uk.

LOAD-DATE: May 1, 2011

LANGUAGE: ENGLISH

PUBLICATION-TYPE: Papers

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6.8 Appendix H: Themes and Supporting Extracts from Media Data

THEME	SUB-THEMES	EXAMPLE MEDIA EXTRACT	DATA SOURCE
POSITIONING OF NURSES	Roles of Nurses	<i>'I can talk to Jayne about anything. The support she offers is emotional as well as practical.'</i>	www.rainbowtrust.org.uk
	Parents' experiences of PPC Nurses	<i>'Demelza came to our rescue when we needed someone to put perspective back into our lives, I do not know how we would have got through it without them.'</i>	www.demelza.org.uk
	Nurses' experience of working in PPC	<i>'The patients and families I have cared for have taught me everything I know about what good care is, and also some very important lessons about life.'</i>	www.keech.org.uk
PPC IN THE HOSPICE SETTING	Material resources	<i>'More youngsters are whooping enthusiastically in a playroom filled with plastic balls and squashy foam obstacles for climbing over'.</i>	Mail on Sunday, May 1, 2011
	A homely place	<i>'The feel is of a home from home; the kitchen staff are as involved as the nurses and food is a serious affair.'</i>	Mail Online, December 16, 2012
	Hospice misconceptions: Not just a place to die	<i>'It took me a while to get my head around the idea. There is something about the word hospice...People assume that hospices exist only to provide care in the very last months of life.'</i>	Mail Online, December 16, 2012

CONTROVERSIES IN PPC	Inequalities in PPC	<i>'It costs on average £7000 a day to run a children's hospice...some get up to 30% of their funding from Government but for others it is a lot less so they are hugely dependent on the generosity of the public and volunteers.'</i>	Sunday Express, April 28, 2013
		<i>'Next month, the whole family is spending its first weekend away at Martin House children's hospice...this is a major breakthrough as hospice care...is a concept unfamiliar to south Asian cultures.'</i>	The Guardian, October 11, 2006
	Decision making in PPC	<i>Mr Lock told Mr Justice Hedley that the court had the "unenviable task" of deciding Charlotte's treatment. "Both the clinicians and the parents want the best for Charlotte but there is divergence about what would be in her best interests".'</i>	The Daily Telegraph, October 1, 2004

6.9 Appendix I: Interview Schedule

Questions were structured around the specific area of interest, but were kept open ended to promote conversation and allow participants to express what was most pertinent to them. The ordering of questions was flexible to allow further investigation of particular items when relevant.

Introduction

- Recap aims of interview
- Re-visit consent to record, right to withdraw and confidentiality.

Audio Test

I would like to begin by asking a test question to check the audio recording is working, so;

1. Could you tell me your profession and the number of years you have worked in the field of paediatric palliative care?

Main Interview – Media Representations of PPC

I will now begin the main interview by asking you about your experiences of how PPC is talked about in the media. In using the term media, I am not only referring to the stories we see on the television or read about in newspapers or magazines, but also social media such as Facebook, internet blogs and Twitter.

2. What is your experience of how the general public talk about PPC services and the staff working in them?

Prompt: What kind of language / phrases have you heard being used to talk about PPC amongst families / colleagues from other disciplines / colleagues within PPC / in the news and media?

3. How does the language and images used in media coverage about PPC make you as PPC nurse think / feel? Can you describe what it is about how PPC is portrayed that makes you think / feel this way?

Prompts: Can you give an example of a media representations of PPC which particularly struck you? What was the context?

Why do you think the media portrays PPC in the ways that it does?

In you experience, what are the main messages the media is trying to give out about PPC? How do you think it achieves this?

4. How would you describe the accuracy of media representations of PPC?

Prompts: How true to your own experiences are media representations of PPC?

How might the media over or underplay the aspects of care given to patients / the role that PPC nurses have?

Main Interview – Experience of Media Representations of PPC

I would now like to move on to ask you about when media representations of PPC might have been present in, or impacted upon, your clinical work.

5. Can you tell me about an example from your clinical work where media representations / popular ideas about PPC have arisen?

6. Can you give examples which you experienced as positive and negative?

Prompts: How are you (or other staff / services) referred to and regarded by the children and families you have worked with?

How do children and families speak about you as a PPC nurse / the service?

For what purposes do children and families talk about PPC nurses and services?

7. How does the language used by children and families using PPC services compare to that in the media?

Prompts: Have you noticed any similarities or differences in the ways the media talks about PPC compared to the ways in which children and families might talk about it – in what ways?

Main Interview – Staff wellbeing, career longevity and burnout

I would now like to move on to the final section of the interview which is about the ways in which media representations of PPC might impact upon the wellbeing of those working in the field.

8. Can you tell me whether you think you have been affected by the ways in which people talk about PPC?

Prompts: How does the way in which children and families talk about PPC make you, as a professional working in the field, feel?

How do you think nurses more generally are affected by representation of PPC in the media?

Is there any association between how PPC nurses and services are represented in the media and how nurses actually view themselves?

9. How do media representations of PPC impact on your perception of yourself as a nurse?

10. How do media representations of PPC impact upon your personal life, values and commitments?

11. How do you think PPC could be spoken about through the media, in order to support nurses working in the field?

Prompts: Are there particular media representations that are more or less helpful to nurses? What are those / what are the features of such talk?

What isn't said / represented in the media about PPC that you think could be relevant to nurses working in the field?

12. Can you tell me about the factors you think are related to burnout amongst PPC nurses?

13. Do you think any of these factors might be impacted upon or related to popular media representations? If so, how?

Prompts: What are common stressors for PPC nurses?

Which of these stressors are talked about / represented in the media?
What role might media representations of PPC nurses and services have in contributing to stress and burnout?

14. How do you think the way in which PPC is talked about in the media affects length of time it is possible to stay in this area of work? Do media representations generally support or get in the way of career longevity for staff?

Prompts: Could there be ways in which the media represent PPC which impact on how staff make sense of their professional experiences?

15. Are there any aspects / forms of media representation of PPC which you would consider to be protective for nurses working in the field?

Prompts: What things enhance career longevity for PPC nurses and are any of these available / evident in the media?

Closing

- Review confidentiality
- Ask how the participant is feeling about having taken part
- Explain how and when research findings will be made available
- Thank participant for agreeing to take part and for their time.

6.10 Appendix J: Transcription Convention

(Adapted from Potter, 1996)

SYMBOL	EXAMPLE	EXPLANATION
(.)	<i>Um, so well I suppose (.) I'm trying to think really,</i>	Pause of 1 second
(2)	<i>I think my experience is that it (2) that in general society doesn't even recognise paediatric palliative care...</i>	Pause of more than 1 second with number of seconds in the bracket
(inaudible)	<i>Um, and they don't seem to pick up on that, it's not, they still don't (inaudible) but when there are any...</i>	Notates inaudible speech
(overlap)	<i>What was the kind of language being used?</i> <i>(starving), um, um, uh, speeding up death...</i>	Positioning of brackets indicates overlapping speech
[supplementary info]	<i>[gives an exaggerated facial expression and tilts head to</i>	Supplementary information given in square brackets e.g. gestures

	<i>one side – appeared to be mimicking sympathy]</i>	
[...]	<i>Um how it's going to be managed and whether being an (...) Facebook page ...</i>	Text has been deliberately omitted to maintain anonymity

6.11 Appendix K: Worked Example of IPA – Jane’s Interview

Jane's interview

<p>Media as a tool to explore / educate</p>	<p>218 I</p> <p>219</p> <p>220</p> <p>221</p> <p>222</p> <p>223</p> <p>224</p> <p>225 J</p> <p>226</p> <p>227</p> <p>228</p> <p>229</p> <p>230</p> <p>231</p> <p>232</p> <p>233</p> <p>234</p> <p>235</p> <p>236</p>	<p>yeah yeah, no that's</p> <p>great. Um, I was thinking about um, perhaps ways in which</p> <p>(.) the media can talk about paediatric palliative care in a</p> <p>way that was, that you thought might be more helpful or</p> <p>more accurate, um, and I I was wondering of that would</p> <p>happen, what were the kinds of things the media would be</p> <p>talking about?</p> <p>I think (.), I think it sort of, trying to explore or trying to do a</p> <p>programme about what paediatric palliative care is, um you</p> <p>know maybe (2) having some of these talk pieces these</p> <p>popular talk shows that people have and having a</p> <p>conversation there that sort of (2) but (.) I'm not convinced</p> <p>that people do cos it seems to be that the talk shows that</p> <p>people tend to watch are ones that are interested in</p> <p>celebrity, um and (.) celebrities don't really talk about the</p> <p>impact on their children, if they've, you know, if they've got</p> <p>a child's that's dying, but it almost needs like (.) a celebrity</p> <p>pushing it but then you kind of think that's sensationalising</p> <p>it again</p>	<p></p> <p></p> <p></p> <p></p> <p></p> <p></p> <p>popular + v ... media vehicle</p> <p>dilemma - need celebrity to raise profits but want to avoid sensationalism</p>
<p>Dominant media readership + sensationalism</p>	<p>237 I</p> <p>238 J</p> <p>239</p> <p>240</p> <p>241</p> <p>242</p> <p>243</p> <p>244</p> <p>245</p> <p>246</p> <p>247</p> <p>248</p> <p>249</p> <p>250</p> <p>251</p> <p>252</p> <p>253</p> <p>254</p> <p>255</p> <p>256</p>	<p>(yeah, yeah)</p> <p>It's not having a <u>deep and</u></p> <p><u>meaningful</u>. I think the <u>deep and meaningful</u> conversations,</p> <p>um, and the media portrayal of deep and meaningful</p> <p>conversations in palliative care will only be watched by a</p> <p>small, few people anyway so they're not going to reach the</p> <p>wider group. And, they're, they're people that have the <u>who / what is most</u></p> <p>greater, readership etcetera, the greater distribution are the <u>powerful</u></p> <p>exact same people that will sensationalise, so no, the Sun</p> <p>newspaper and things like that you know, how many</p> <p>campaigns do they do about different things and again they</p> <p>never get their facts quite right, and (.) the NHS is in a <u>inaccurate reporting</u></p> <p>position where it it can't correct those facts, um so I don't, I <u>no recourse for NHS</u></p> <p>don't know I think (.) you know, it's almost that you <u>want a</u></p> <p>media that's <u>going to be brutal and truthful</u>, um (.) but <u>almost contradictory</u></p> <p>actually can <u>give an empathic ear</u> and sort of a give a <u>a</u></p> <p>chance, an opening to explore these things and I think <u>opportunity to explore</u></p> <p>without families being able to promote that themselves <u>PPE through the</u></p> <p>think we don't move forward so it has to come from <u>stones of families</u></p> <p>families. <u>responsibility of families</u></p>	<p></p> <p>people not interested / avoidance of deep + meaningful</p>
<p>No recourse</p>	<p>257 I</p> <p>258</p> <p>259</p> <p>260</p>	<p>Do you, do you have any thoughts about, I know you said</p> <p>you don't necessarily um, read them or look at them but, do</p> <p>you have any thoughts around when families post blogs or</p> <p>set up pages around their, their story?</p>	<p></p>
<p>the nature of media</p>	<p>261 J</p> <p>262</p>	<p>There's been, now I know that um there's been a couple of</p> <p>families that have done blogs there was one family um that I</p>	<p></p>
<p>Media as a platform to explore</p>	<p>261 J</p> <p>262</p>	<p>There's been, now I know that um there's been a couple of</p> <p>families that have done blogs there was one family um that I</p>	<p></p>
<p>Families and the media</p>	<p>261 J</p> <p>262</p>	<p>There's been, now I know that um there's been a couple of</p> <p>families that have done blogs there was one family um that I</p>	<p></p>

	Jane's Interview				
<i>Impact of media on clinical work</i>	263	looked after that did a blog, um and I (...) don't read it	<i>impact of blogs on relationships</i>		
	264	because I feel that it might have an impact on my			
	265	relationship with them.			
<i>Patients' use of media</i>	266	Okay, that's quite interesting,			
	267	(yeah)			
	268	can you			
	269	talk a bit about sort of what, how you, thinking it might			
	270	impact if you were to look?			
<i>Professionals' engagement with media</i>	271	I think, um (2) I think sometimes that's something where (2)	<i>we of some forms of media to make some (distancing) of experience</i>		
	272	the person that's writing the blog wants to have a forum to			
	273	discuss in a in a way that is <u>distant</u> , and I think if I read their			
	274	blog and then went and met them and talked to them face			
	275	to face about what they'd written in their blog, that feels to			
	276	me <u>intrusive</u> , even though they've put it in a social media		<i>confrontational / intrusive to read</i>	
	277	context, they've put it in a social media context that is may			
	278	or may not invite commentary, um (...) and but they can		<i>take away choice by addressing blog</i>	
	279	choose whether they, whether they're going to listen to that			
	280	commentary or not, if I then take that and come back to		<i>receptive to discussion but not initiating</i>	
281	them, they're not given a <u>choice</u> about that commentary, if				
282	they want to discuss their blog with me that's fine, I've had				
<i>Disengagement to protect self</i>	283	a position where um I had a young girl who was using her	<i>avoidance</i>		
	284	blog to actually (...) um, (...) criticise people that were caring			
	285	for her um and um that was <u>real</u> , that made her care very			
	286	difficult she didn't criticise me on it, I didn't read it, so she			
	287	didn't criticise me it didn't make a difference but we had a			
	288	relationship where she could tell me she wasn't happy with			
	289	something. But she was criticising other professionals in		<i>implications for work even when not the subject of media</i>	
	290	another institution, and (...) I was being called on to try and			
	<i>Impact of media on professional relationships</i>	291		sort that, um and so I was having professionals from from	<i>both sides of the experience</i>
		292		the other institution telling me how upset they were cos all	
293		these things were being written on this blog, um and um she			
294		was telling me she was that she was writing these things on			
295		this blog because she was upset, um and both things were			
296		valid, um and my only commentary was you shouldn't be			
297		real, you shouldn't be reading her blog you have a	<i>professional responsibility to create opportunity for feedback of experience</i>		
298		<u>professional relationship</u> with her, it's a <u>personal account</u>			
<i>Boundaries of professional relationships</i>	299	that she's writing, if she wants to tell you that she should be	<i>using media in moments of distress (regret?)</i>		
	300	able to tell directly, and you need to provide an opportunity			
	301	for her to do so, um, but you also need to be aware of			
	302	where her distress is coming from and people write things in			
	303	moments of <u>distress</u> , especially on blogs and they then			
<i>Timing of use of media</i>	304	might regret later so (...) that's the reason why I don't follow	<i>indirect contact with families through social media</i>		
	305	them, um. We had another instance, um with one of the			
	306	nurses on our team who um, through social media, has um			
	307	mutual friends with a family that she's looking after, mutual			
<i>Contact with families</i>	307	friends so she's not directly involved with them this was			
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Jane's Interview

the threat of media (to professional relationships)

underhand use of media to argue

threat of media to professionals

learning to manage impact of media

manipulation of media

professional response

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long before she became a patient and that can compromise your professional relationship, so she, you know, would occasionally look on the blog to see (.) where she, you know, how they were doing but wouldn't address the blog with the family, so you can't use that within your relationship with the family I feel.

compromising the professional r'ship + boundaries
check on the family but no recourse, can't be used --> sneaky?

Yeah yeah,

And then there was a another patient that we found that had put their argument so, that they didn't want input from palliative care um because they were seeking further treatment, um and we were informed that the child died, um by their local team because they'd read it on a blog (2).

use of media to argue for treatment
passing on info through media

Right ok

I know and I just think, if you're doing this it can kind of, it can sometimes stop you from making those phone calls that need to happen anyway, and I possibly have an old fashioned view I don't like blogs, I, I just don't um it might be that they are good things that can be used and maybe we have to learn how to use them in a proper way but I think until we can make sure our professional relationships aren't compromised with families I think we should steer clear of them.

can shut down communication
maybe perceived as a threat to professionals?
avoidance

Yeah, do you think, I, I, I'm guess, I'm assuming that, you know before the rise of social media these kinds of issues wouldn't have existed or perhaps they they existed in different forms but um, I I just wondered do you think that this is an issue that will continue and probably grow um?

Yes. I think (.) I think we need to learn to be skilled at how we, manage it I think (2) I think there'll probably be impetus but I also think that these are fad things as well I don't mean that the social media is a fad but I mean that aspects of soc, aspects of social media are a fad so you know Facebook was big but it's started to die a death, Twitter started to be in fashions, others will come in, and I think they serve people's purposes um, and (.) um some people will be addicted to them but I'm, you know, I'm twenty years passed the generation that uses them and um, so I kind of think it's (2) we need to learn to get better about we utilise it, whilst maintaining our professional boundaries um and what's happening is, with the instance of all these things starting to develop and growing and changing and evolving, um we're finding that professionals bodies are putting guidelines in so I think that will become clearer, so

need to learn to manage and engage with (social) media
social media serve people's agendas
need to respond to media impact on clinical work
guidelines to assist nurses

6.12 Appendix L: Initial and Cluster Themes – Jane’s Interview

Initial Themes

1. Lack of public recognition of PPC (Lines 10-12)
2. Polarised portrayals of PPC (Lines 13-16)
3. Misconceptions about PPC (Line 17, Lines 180-185, Lines 189-193, Lines 436 - 437)
4. Palliative care component overlooked in the media (Lines 18-19)
5. Lack of understanding of PPC (Lines 20-23, Lines 432 - 435)
6. Accurate representations of PPC don’t make the “final cut” (Lines 29-35)
7. Families’ use of the media (Lines 37-39, Line 261, Lines 316 - 321)
8. Anti-PPC, pro curative treatment (Lines 44-45)
9. Media simplification (Line 49, Lines 110-112, Line 121)
10. Hospices synonymous with death (Lines 50-53)
11. Emotion-focussed reporting (Lines 66-67)
12. Disconnect with the media (Lines 68-73, Line 120, Lines 283-286)
13. Power of families stories (Lines 74-83)
14. No place to praise nurses (Lines 84-88)
15. Embodied experience and the media (Lines 92-98)
16. Vilification in the media (Lines 112-114)
17. Sensationalist reporting (Line 114, Line 121, Line 135, Line 164, Line 194, Lines 426 - 427)
18. Pitting parties against one another (Lines 115-118)
19. Media serves to provoke debate (Lines 128-130)
20. Inaccurate media representations (Line 131, Lines 247-248)
21. Intrusive media representations (Line 132)

22. Dilemmas in using the media (Lines 132 – 136)
23. Media corruption of PPC stories (Line 164)
24. Relationships to counter media (Lines 171-175)
25. Influence of media representations of families (Lines 176-177)
26. Media constructs ideas about PPC in a subtle way (Lines 203-206)
27. Practise more powerful than media (Lines 207-213)
28. Media as a tool to explore PPC (Lines 225-229, Line 253)
29. Readership and sensationalism (Lines 239-245)
30. No recourse for the NHS (Lines 248-249, Lines 313 – 314)
31. Impact of the media on nurses (Lines 263 – 265)
32. Professionals' engagement with social media (Lines 273 – 277)
33. Patients' use of social media (Lines 283 – 285, Lines 302 – 304)
34. Impact of media on professional relationships (Lines 289- 293, Lines 309-310)
35. Media and the professional relationship (Lines 297 – 301)
36. Contact with families through social media (Lines 305 – 308, Lines 311 – 314)
37. Threat of the media (Lines 326 – 331)
38. Learning to manage the media (Lines 337 – 338, Lines 347 - 348)
39. Professional response to media (Lines 351 – 356)
40. Polarised portrayals of PPC nurses (Lines 369 – 371)
41. Vilification of PPC nurses (Lines 375 – 376)
42. Media politicising the NHS (Lines 406 – 411)
43. Access to the media (Lines 418 – 420)
44. Unheard voices; families and clinicians (Lines 438 – 441).

Cluster Themes – Jane’s Interview

A: Patient and families’ use of the media

- 7. Families’ use of the media (Lines 37-39, Line 261, Lines 316 - 321)
- 8. Anti-PPC, pro curative treatment (Lines 44-45)
- 13. Power of families stories (Lines 74-83)
- 15. Embodied experience and the media (Lines 92-98)
- 33. Patients’ use of social media (Lines 283 – 285, Lines 302 – 304)

B: Professionals’ use of the media

- 28. Media as a tool to explore PPC (Lines 225-229, Line 253)
- 32. Professionals’ engagement with social media (Lines 273 – 277)
- 36. Contact with families through social media (Lines 305 – 308, Lines 311 – 314)

C: Positioning of PPC Nurses in the media

- 14. No place to praise nurses (Lines 84-88)
- 18. Pitting parties against one another (Lines 115-118)
- 31. Impact of the media on nurses (Lines 263 – 265)
- 40. Polarised portrayals of PPC nurses (Lines 369 – 371)
- 41. Vilification of PPC nurses (Lines 375 – 376)

D: Threat of the Media

- 2. Polarised portrayals of PPC (Lines 13-16)
- 8. Anti-PPC, pro curative treatment (Lines 44-45)
- 16. Vilification in the media (Lines 112-114)
- 18. Pitting parties against one another (Lines 115-118)
- 19. Media serves to provoke debate (Lines 128-130)
- 21. Intrusive media representations (Line 132)
- 22. Dilemmas in using the media (Lines 132 – 136)
- 23. Media corruption of PPC stories (Line 164)
- 34. Impact of media on professional relationships (Lines 289- 293, Lines 309-310)
- 35. Media and the professional relationship (Lines 297 – 301)
- 37. Threat of the media (Lines 326 – 331)

- 40. Polarised portrayals of PPC nurses (Lines 369 – 371)
- 41. Vilification of PPC nurses (Lines 375 – 376)
- 42. Media politicising the NHS (Lines 406 – 411)

E: Sensationalism

- 2. Polarised portrayals of PPC (Lines 13-16)
- 6. Accurate representations of PPC don't make the "final cut" (Lines 29-35)
- 11. Emotion-focussed reporting (Lines 66-67)
- 17. Sensationalist reporting (Line 114, Line 121, Line 135, Line 164, Line 194, Lines 426 - 427)
- 18. Pitting parties against one another (Lines 115-118)
- 19. Media serves to provoke debate (Lines 128-130)
- 29. Readership and sensationalism (Lines 239-245)
- 40. Polarised portrayals of PPC nurses (Lines 369 – 371)
- 41. Vilification of PPC nurses (Lines 375 – 376)

F: Lack of understanding of PPC

- 1. Lack of public recognition of PPC (Lines 10-12)
- 3. Misconceptions about PPC (Line 17, Lines 180-185, Lines 189-193, Lines 436 - 437)
- 4. Palliative care component overlooked in the media (Lines 18-19)
- 5. Lack of understanding of PPC (Lines 20-23, Lines 432 - 435)
- 9. Media simplification (Line 49, Lines 110-112, Line 121)
- 10. Hospices synonymous with death (Lines 50-53)
- 20. Inaccurate media representations (Line 131, Lines 247-248)
- 26. Media constructs ideas about PPC in a subtle way (Lines 203-206)

G: Accessing the media

- 22. Dilemmas in using the media (Lines 132 – 136)
- 30. No recourse for the NHS (Lines 248-249, Lines 313 – 314)
- 43. Access to the media (Lines 418 – 420)
- 44. Unheard voices; families and clinicians (Lines 438 – 441).

H: Engagement with the media

- 12. Disconnect with the media (Lines 68-73, Line 120, Lines 283-286)
- 22. Dilemmas in using the media (Lines 132 – 136)
- 27. Practise more powerful than media (Lines 207-213)
- 32. Professionals' engagement with social media (Lines 273 – 277)
- 38. Learning to manage the media (Lines 337 – 338, Lines 347 - 348)
- 39. Professional response to media (Lines 351 – 356)

6.13 Appendix M: Super-ordinate and Sub-ordinate Themes with Explanatory Notes

PPC: A Contentious Approach

Perceived as “abnormal”

Nurses’ accounts suggested they experienced the media to represent PPC in ways which were often incongruent with the fundamental basis and aims of the approach (such as enabling the child to die a comfortable death). Moreover, nurses reported they had often experienced representations which positioned children and their families fighting for treatment and ultimately life. The media’s focus on the battle for further curative treatment appeared to leave nurses feeling as though PPC had no place in the public domain, and as such was unaccepted socially and culturally. Some nurses spoke of the media representing PPC in terms of “giving up” on the child, and as such, suggested representations like these served to construct PPC as abnormal.

In need of “defence”

With nurses’ experience that the media tended to position PPC as “abnormal”, appeared to come a desire to want to defend it to the wider public. Furthermore, nurses spoke of a need to advocate for PPC, as though to counter dominant media representations that were often experienced as negative and one-sided. Examples given here included newspaper headlines around the Liverpool Care Pathway, where nurses were positioned alongside other health professionals as implicated in bringing about premature death. Nurses also spoke of feeling defensive personally, and described experiencing some media representations as personally insulting.

The “Threat” of the Media

“Surviving the profession”: Impact on professionals

Here, nurses spoke of their experience that media representations of PPC could be threatening to them as professionals working in the field. For example, nurses described the impact of their experience of social media and how this often felt critical and exposing when families used it to voice their disagreement

with or dislike of advice given to them. Here, it appeared nurses were wary of such comments being so widely accessible by virtue of them being in such a public forum, as this potentially left them open to scrutiny and judgement. Furthermore, the potential to be scrutinised publicly appeared to impact on nurses' clinical decision making, whereby nurses doubted their decisions and advice more than when the family they were working with did not use social media.

Nurses' accounts also described the impact of their positioning by the media, particularly when this was experienced as negative. For example, nurses spoke of being portrayed as responsible for the premature death of patients in certain cases. Such representations had implications in terms of how nurses were perceived by families using PPC services, but also in how nurses were thought of more generally. Here, nurses spoke of being vilified and portrayed as culpable in the media. Nurses also talked about feeling wary of the media due to these kinds of representations. Furthermore, they described what appeared to be active avoidance of the media, perhaps as a form of self-care to protect against the impact of such negative representations. Ultimately, the nurses appeared to describe their engagement with the media as a challenge which had the potential to affect them personally and professionally, and as such, compared their experience of their careers in PPC as a survival.

Managing the media

Here, nurses spoke about their view of how the media needed to be managed, which may have been a response to their experience of it as intrusive or threatening. They gave examples of forms of management that were already available to them, and talked of additional measures which they believed could be implemented in the future. The nurses also spoke of managing the media in terms of their engagement with it. This appeared to be in response to their recognition that engagement with the media could have some utility, if it were structured and guided in such a way as to preserve professional relationships with patients. However, nurses still seemed to have concerns around engaging with the media, describing dilemmas they might face in doing so; such as the risk of sensationalising PPC and also practical issues which might arise.

Not the Whole Story: “One-sided” Media Representations

Lack of understanding

Nurses' accounts often expressed their view that they didn't feel the public had an accurate understanding of PPC and that one-sided and incomplete media representations perhaps underpinned this. Here, they gave examples of dominant media representations of PPC which may have contributed to misconceptions and misunderstandings about it; such as the hospice solely being a place to die, PPC just being about the care of oncology patients at the end of life. The nurses also spoke of how fellow professionals seemed to lack an accurate understanding of PPC, and the implications of this on referrals to PPC services. Finally, nurses' accounts suggested they may have a role in perpetuating one-sided, inaccurate representations of PPC, by not challenging these or providing more informative information themselves.

Sensationalism

Nurses appeared to experience media representations of PPC as often being salacious and sensationalist in content. Here, they described a belief that the media aimed to represent PPC in these ways so to provoke as great a reaction in the public as possible, and achieved this through use of language and images. Furthermore, nurses' appeared to suggest that such sensationalised representations of PPC persisted, in part, due to their experience of being unable to access the media, so to provide a counter view. Here, the nurses spoke of being in a position where there was no recourse of them, as though their voice would not be represented in the media and so heard by the wider public.

Positioning of Nurses: The “Angels of Death”

In this final sub-ordinate theme nurses spoke of their experience of how media representations of PPC positioned them as professionals working in the field. Specifically, the nurses found themselves being portrayed in polarised positions as either a perfect angel, or an angel of death responsible euthanizing patients. The nurses also talked about their experience of the implications of such polarised portrayals on their clinical practise, and how such representations

often did not attend to the clinical skills of PPC nurses and the complexity of the role they do. In addition, nurses described their experience of how the media can represent hospice and hospital based PPC nurses differently, linking this to an idea that hospice nurses may be more readily accepted by society, as the hospice is most commonly associated to palliative care in the public domain. To conclude, nurses' accounts suggested the media tended to ignore individual's personal agendas for becoming a PPC nurse. Here, nurses speculated such motivations were not represented in the media as they may not fit with the preferred portrayal of nurses as perfect angels.

6.14 Appendix N: Table of Final Themes

Table of Super-ordinate Themes and Corresponding Sub-ordinate Themes

SUPER-ORDINATE THEMES	SUB-ORDINATE THEMES
PPC: A Contentious Approach	<ul style="list-style-type: none">• Perceived as abnormal• In need of “defence”
The “Threat” of the Media	<ul style="list-style-type: none">• “Surviving the Profession”: Impact on professionals• Managing the media
Not the Whole Story: “One-sided” Media Representations	<ul style="list-style-type: none">• Lack of understanding• Sensationalism• Positioning of nurses: The “Angels of Death”

6.15 Appendix O: Example of an Edited Quote

Original Quote:

Um (3) I think (2) I think it's, um I think it tends to be if, if there's any negative media coverage, whether it be the hospice here or [...] or whether it's a wider children's hospice if it's negative, you tend to get quite protective and quite sort of, um, defensive about it and um, um (2) take it quite personally as a personal insult and stuff ...

(Suzi, 414-420)

Edited Quote:

...I think it tends to be if, if there's any negative media coverage...you tend to get quite protective and quite sort of, um defensive about it and um, um (2) take it personally as a personal insult and stuff... (Suzi, 414-420)

6.16 Appendix P: Reflective Journal Extract

The following extract is taken from a reflective journal kept throughout the course of the research. A journal was used as a space for critical thinking; to reflect upon events at different stages of the research process. It was most useful for noting down my assumptions and views, to see where these might have impacted upon the research process. The journal was also a helpful outlet for anxieties and concerns I may have experienced, which I later had the opportunity to reflect upon and reconcile. The extract given here was written early in the research process whilst I was trying to recruit participants to the study. Specifically, it details my thoughts, feelings and learning points following a presentation I gave about the then intended study, to a potential groups of participants.

29.7.14

Today I met with the [deleted] Team at the hospital. I gave a short presentation about the proposed study and was able to get some feedback from the team on their thoughts about it.

Initially, I was quite apprehensive going in to meet the team. Over and above the typical anxieties one might feel about giving a presentation to a group of strangers, I also felt somewhat concerned by information that had been given to me about the team prior to our meeting. Specifically, my field supervisors had told me about the pressures currently facing the team in terms of their commitments to other projects. I had been told they were already being filmed for a documentary about their work as part of a series about the wider hospital. I thought perhaps this might be a useful 'way in' to speaking with them if they were quiet and had no feedback about the study. I wondered if perhaps I could raise the issue of them partaking in the filming, to get a sense of how they thought the footage might be used to represent PPC in the media, as a tangible example of what my project is about. However, I was also mindful that my project might be experienced as research overload; particularly as perhaps at first glance, it wouldn't be seen as massively different to what the nurses were doing with the filming.

Secondly, I had been told two nurses had recently left the team and it was intimated to me this was due to stress and burnout issues. This information left me wondering if the team really had the resource to take part in my research and whether activities such as research could be thought about and engaged in. I suppose this thought reflected an insecurity that my project wouldn't be considered important enough, interesting enough, or relevant enough. I'm not sure where this worry comes from, I think maybe it links to a broader worry I have that other trainees are doing better than me generally and as such, their research must be far more valuable than my own! I also wonder if my worry speaks to the selling aspect of research, getting people to buy in to my project, give me their time and knowledge when I don't really have much to offer in return ... I'm not sure I am much of a salesperson!

Thirdly, my supervisors had told me about their experience of feeling quite separate to the team at times, perhaps being perceived as rather precious about their role as clinical psychologists. They had wondered if this view of psychology might have come about as a result of the team being two nurses down. Moreover, my supervisors reported how they had seen the team adopt a 'chip in' attitude, whereby everybody was helping everyone else and getting stuck in to the work. As such, when psychology said "no" or was boundaried in what they would and would not do with the team, this seemed to be perceived as being precious and as though psychologists weren't real team players. This worried me quite a bit because I thought the team might be reluctant to help me, if I represented a group that they experienced not to help them; even though in my rational mind this was probably quite unlikely.

However, I am pleased to note the presentation went rather well from my perspective. I put on my smiley face and looked people in the eye and they seemed interested in what I had to say. Most of the team actually smiled back at me and some even gave comments and suggestions! On a serious note, the feedback was really useful; the team manager spoke about the Liverpool Care Pathway – something I am only vaguely familiar with through my work with older adults with dementia nearing the end of their lives. Whilst the pathway comes from the world of adult palliative care, the team manager described how media coverage of it often positioned nurses negatively and in her view, was full of controversy. She thought it probably would have an impact on nurses working

in palliative care generally, and suggested I do some further reading around it. This seems like a really interesting avenue to explore, one that maybe I chose not to consider as negative representations of nurses don't really fit my own assumed idea that all nurses are wonderful! Following her comments, a doctor from the team really flattered my ego by saying she would have loved to be involved! She also very helpfully went on to talk about the neonatal care pathway and how quoted newspaper headlines such as "killing babies". These suggestions / feedback have made me think carefully about my media review and how easy it would be for my own views and assumptions to dictate what I search for. I really want the media review to be honest and accurate, something that will capture a spectrum of media representations of PPC, if there is such a range available.

The team also gave me some helpful critique, points that will be useful to reflect upon in my discussion. For example, they asked about the representativeness of the media included for review and wondered how I might address this in the study. Specifically, they spoke about the need to highlight where media excerpts came from and what the agenda behind the text might be – these should be things I can address in my methodology chapter, perhaps discussing the limitations of my review. They also posed a question about capturing what you don't hear about in the media – I thought this was somewhat counterintuitive at first considering my project is about the media representations of PPC which are available, however on reflection I think the nurses have a point. Perhaps they were suggesting I stay receptive to alternatives and be critical about how accurate or representative media portrayals really are. Their comments here also made me wonder about whether they might think what they have to say is subjugated by the media, whether they experience the media to silence them?

The final critique raised was one about homogeneity of the sample. I felt like my knuckles were being wrapped (albeit gently) here because apparently I hadn't acknowledged in my presentation, that whilst I claim my sample to be homogenous (they are all nurses working in the field of PPC), in truth, nurses working in PPC may have very different backgrounds and roles. I think this is a point for my own learning and probably speaks to my dilemma of needing the project to meet methodological criteria (homogeneity of IPA), but knowing that

this probably can only be partially realised. I suppose I have to be pragmatic about the sample of participants I get – I don't feel I can turn potential participants away, indeed I feel I may struggle to recruit 6 nurses! I think though, again, this is something I can talk about in the discussion chapter.

Overall, I realise it was actually meeting the team that I was more apprehensive about rather than the presentation of the project itself. I suppose I wanted some reassurance that what I am doing is worthwhile and could be useful, and thankfully, they gave this in spite of some critique and question. Furthermore, I now have a much better appreciation of how research active the team are so probably feel a little less guilty for asking the nurses to participate – it seems research is a routine and valued part of their role. Indeed, two nurses signed up to take part today which has really spurred me on and laid my doubts and concerns to bed ... for now. I think their agreeing to participate has really countered the worry I had after I found out both my supervisors will be on maternity leave for the majority of the research. I suppose now it's a case of getting on with the media review and booking in more interviews – I'm excited, it is now starting to feel very real!