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Long term nurse – parent relationships in paediatric palliative care: A narrative literature review

Abstract

Background: Paediatric Palliative Care (PPC) is an active, total approach to the holistic care of the child and family. Close, long lasting, relationships between healthcare professionals and parents in paediatric palliative care enhance quality, provide emotional support and can influence how parents' manage their role in the face of uncertainty. **Aim:** To present a narrative literature review of long term relationships between children's nurses and parents in PPC settings. **Methods:** Six databases (CINAHL, PsycINFO, ASSIA, Scopus, Medline and BNI) were searched, identifying 35 articles. A grey literature search produced 7 additional, relevant items. **Findings:** Four themes: - Bonds, attachments and trust, Sharing the journey, Going the extra mile, Boundaries and integrity. All themes revealed an element of tension between closeness and professionalism. **Conclusion:** Gaining a greater understanding of how closeness and professionalism are successfully managed by children's palliative care nurses could positively influence pre and post registration nurse education.

Key words

Paediatric palliative care

Nurse-parent relationships

Professional boundaries

Professional integrity

Reflective questions

How attached am I to the children and families in my care?

What is the difference between sympathy and empathy?

Do I sometimes work beyond my remit to benefit children and families?

What are my self-care strategies?

What do professional boundaries and integrity mean to me?

Introduction

Paediatric Palliative Care (PPC) is defined as an active, total approach to the holistic care of the child and family (WHO, 1998). Close, long lasting, relationships between healthcare professionals and parents in PPC are an important source of emotional support and can influence the way in which parents manage uncertainty (Rodriguez and King, 2014, Mooney-Doyle et al, 2017, Davies et al, 2017). Whilst these relationships can enhance quality (Klassen, 2012, Buder and Fringer, 2016) and job satisfaction, they often carry an emotional burden; hence managing them is a challenge (Rushton and Ballard, 2011). Nurse-parent relationships in PPC are explored in this narrative literature review which is drawn from a larger review, the latter being part of a doctoral study. This review is divided into four themes which were derived by an in-depth analysis of the literature:

- Bonds, attachments and trust
- Sharing the journey
- Going the extra mile
- Boundaries and integrity

Search strategy

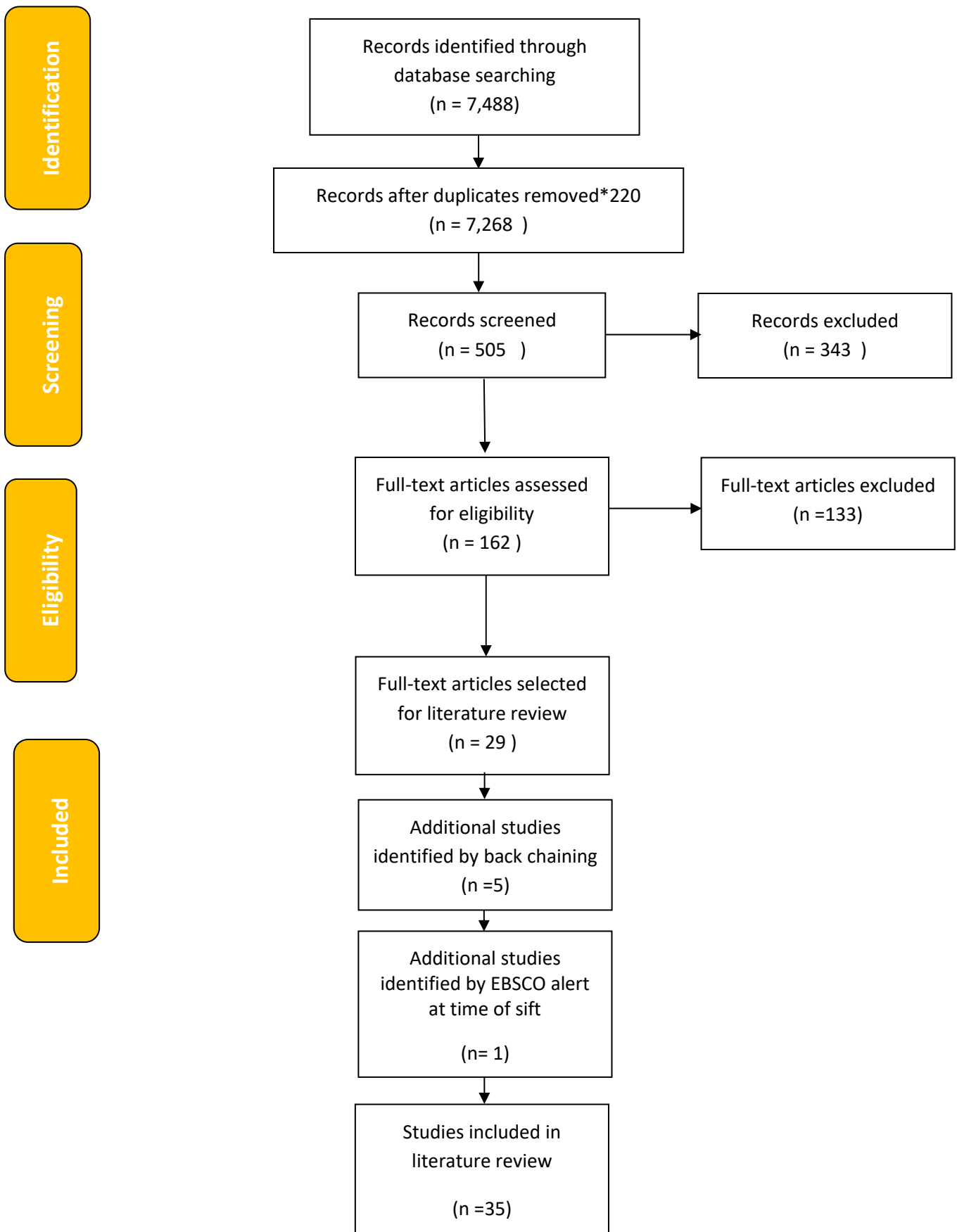
An initial search on nurse-parent relationships in PPC elicited few hits so it was necessary to conduct an expansive search. Subject headings and key words (Table 1) were used with Boolean operators to search the CINAHL, PsycINFO, ASSIA, Scopus, Medline and British Nursing Index databases. Year of publication parameters were 1982 – 2019. The rationale for choosing 1982 was the opening of the world’s first children’s hospice, an environment where nurse-parent relationships are often lengthy (Grinyer, 2012).

Child	Palliative care	Family	Nurse
(MH "Child+")	Terminal care (subject heading)	Parents+ (subject heading)	Nurs*
Child*	Palliative care (subject heading)	Caregiver	Healthcare provider*
Paediatric*	Terminally ill patients (subject heading)	Care N1 giver	Healthcare professional*
Pediatric*	Hospice	carer	“Health care provider*”
Adolescen*	Eol	Father	“Health care professional*”
Youth*	End N5 life	Mother	Nurses+ (subject heading)
Teen*	Terminal* N2 care	Mum*	Nursing staff+ (subject heading)
Young* N3 people	Dying N2 child*	Dad*	healthcare worker*
Young* N3 person	Terminal* N2 ill*	Guardian	“health care worker*”
Kid	“Life limit*” (illness / condition?)	Legal guardianship+ (subject heading)	Nursing care+ (subject heading)
Juvenile*	“Life threatening”	Professional family relations (subject heading)	
Boy*	Hospice and palliative	Parent*	

	nursing (subject heading)		
Girl*	Critical illness (subject heading)	Parental attitudes (subject heading)	
(MH “Minors (Legal)”)	LTI		
Baby			
Babies			
Infant*			

Studies which focused on PPC in areas where nurse-parent relationships were likely to be long term were included, e.g. oncology, hospice, community, as were those involving complex, chronic illness as care delivery and length of relationship is similar (Whiting, 2014). As the focus of the review is relationships during palliation but pre end of life, studies covering this phase of care were excluded. Studies in which the main focus was not nurse-parent relationships, but where the subject arose, were included. The initial search produced a total of 7488 hits. The PRISMA Flowchart (Figure 1) maps the process of identification through to inclusion.

Figure 1 : PRISMA Flowchart (Adapted from Moher, et al, 2009)



Inclusion of grey literature, including strategic documents, can give a broader perspective (Hopewell et al, 2007). The subject of this review particularly lends itself to this approach as views of emotive topics may be more fully revealed through less formal avenues. Godin, et al. (2015) states that searching for grey literature in a systematic manner is difficult and requires specific search methods, i.e. grey literature databases, customised Google searches, targeting specific websites and consulting subject experts. Therefore, the sources listed in Box 1 were searched, producing 7 relevant items.

Box 1: Unpublished and grey literature search	
British Library Conference Proceedings Institute for Health & Social Care Research (IHSCR) NIH Re-PORT New York Academy of Medicine Grey Literature Report Open Grey ProQuest International Children’s Palliative Care Network Website	Together for Short Lives website E-Hospice website Hospice UK website Local children’s hospice website European Association for Palliative Care website The Worldwide Hospice Palliative Care Alliance website Google

Bonds, attachments and trust

McCloskey and Taggart (2010) and Pearson (2013) identified that longstanding relationships increased the intensity of mutual attachment between nurses and families, making PPC a ‘unique’ type of nursing. ‘Connectedness’ between healthcare professionals, particularly nurses, and families in PPC was highlighted by Clarke and Quin (2007), Erikson and Davies (2017), Davies et al (2017) and Beaune (2018).

Doe and Katz (2016) used case studies to explore emotional attachments with a client or patient. This has been identified as an issue in PPC, which increases stress (Maytum et al, 2004). Doe and Katz (2016) found that when asked about emotional

attachments, experienced PPC professionals strongly refuted this. Nevertheless, the case studies revealed evidence of strong emotional involvement with children and families, particularly when the nurse identified closely with them. Interestingly the first named author used the pseudonym 'Jane Doe' because she felt she would be labelled as unprofessional for admitting her emotional involvement. The fear of being seen as unprofessional for becoming emotionally involved with children and families seems evident in the emphasis placed on professionalism in a video blog promoting the work of children's hospice nurses, i.e.

"We are professional nurses, the care that we give is professional but you can't help but take them to your heart"

(Ty Hafan, 2018a)

The actions of nurses can have a profoundly positive affect on parents, as demonstrated in the personal parental accounts by Nahra (2008) and Dolan (2013). In Nahra's (2008) account the nurses' attachment and love for the child was deemed to be as important as clinical competence (Nahra, 2008). Further, having a 'good day' was dependant on a nurse, with whom they had a strong bond, being on duty (Nahra, 2008). Similarly this quotation, from a father's social media post, gives his perception of the relationship between his family and hospice nurses.

"It's not just about a professional duty but a desire to give as much of themselves as is humanly possible ... alongside compassion, support , understanding and most of all love"

(Ty Hafan, 2018b)

Neal's (2015) exploration of staff experiences of media representations of PPC also found that 'love' for children in the nurses' care was prevalent in parental

perspectives. Likewise Konrad's (2008) phenomenological study found that mothers often used the word 'love' to describe how they perceived the professional caregiver felt about their child. The word 'love' is commonly used in everyday language but when used to describe positive feelings about a child it usually relates to something deep, long lasting and unconditional. It is doubtful that this is, in fact, what nurses are feeling. Furthermore, this is not the role of the professional nurse (Buder and Fringer, 2016).

Commonalities between nurses and particular children or parents, such as similar background, life experiences, or ages of their children have been found to intensify connections on the part of the family (Woolley et al, 1991) and the nurse (Doe and Katz, 2016, Erikson and Davies, 2017). Furthermore mutual respect and nurses recognition of parental instinct and expertise, strengthened trust and reciprocal bonds (Steele, 2002, Konrad, 2008, Whiting, 2014, Rodriguez and King, 2014 and Beaune et al, 2018).

Physical contact, i.e. social touch and embracing between those who have an emotional bond or attachment is commonplace (Suvilehto, et al, 2015). Such physical contact has been found to be beneficial to patients and families in palliative care (McPherson and White, 2015). Pearson's (2013) UK wide phenomenological study of paediatric oncology nurses identified that the length and depth of the relationship between nurses and families influenced whether nurses would use physical contact as a means of comfort. Further, Maunder's (2013) study of children's nurses delivering hospice and community based palliative care found that they were engaged in warm interactions, and close personal contact such as hugging colleagues, children and parents. Appreciation of this is demonstrated by parental accounts such as Nahra (2008) who recalls being regularly physically

comforted by nurses during her emotional outbursts. However, McPherson and White, (2015) acknowledge that this level of emotional closeness, interpersonal intimacy and engagement may be unfamiliar and uncomfortable for some in respect of professional boundaries. Conversely, Maunder (2013) found that children's hospice nurses who did not hug their peers, children and families were seen as transgressing the expected 'norm'.

Trust is also an important factor in relationships between parents and PPC healthcare professionals (Contro, et al, 2002). For example Steele (2002) and Klassen (2012) identified that trustworthiness was fundamental to nurses being seen as 'part of the family'; in that healthcare professionals working with life-limited and life-threatened children recognised the trust parents placed in them and felt privileged to be welcomed into their lives. Clarke and Quin (2007), Konrad (2008), Korzeniewska-Eksterowicz et al (2010) and Buder and Fringer (2016) discuss the role of good communication, honesty and authenticity in building relationships in PPC and as pre-requisites for a trust. Konrad (2009), Rodriguez and King (2014), Davies, et al (2017) and Mooney-Doyle et al (2017) identified that parental trust in healthcare professionals extended to reliable advice or even trusting them make a decision on their behalf if they were overwhelmed and felt unable to do so.

Sharing the journey

Woolley et al (1991), Rodriguez and King (2014) and Davies et al (2017) found that parents greatly appreciated healthcare professionals who would take the time to be with them, just getting to know them, talking and listening. O'Shea and Kanarek (2013) offer a case study written from a parental perspective. The major issues identified are the importance of really listening to families; effective, open, sensitive

communication across all aspects of care; helping families to maintain hope – not necessarily for a cure but for comfort, for good things to happen to their child, the family and others; and working in partnership with families. These themes, for an adapted type of hope and helping families navigate their journey are supported by Smith et al (2018). Similarly Mooney-Doyle et al's (2017) study found that a major parental expectation of the healthcare professional was to empower them to carry on with their everyday lives and maintain their family relationships.

As well as featuring in empirical studies, journeying alongside families and a sense of shared history is a prevalent theme in grey literature, such as video blogs. For example:

*“making a real difference for families and accompanying them on their journey” ...
“for me, is where the reward is”*

(Together for Short Lives, 2016)

Being part of the family is a common theme across the literature. For example Steele (2002) identified that becoming ‘just like part of the family’ was a result of being seen as trustworthy thereby permitted to accompany the family on their journey. A recruitment campaign for children’s hospice nursing also highlights this notion of becoming part of the family (Together for Short Lives, 2016) as does Johnson (2016).

This is an aspect of the nurse-parent/child relationship that needs careful management in terms of the journey belonging to the family and not the healthcare professional (Davies et al, 2017), however much they may empathise (Papadatou, 1991). Davies et al (2017) undertook a 3 year prospective grounded theory study

which explored parental and healthcare professional perspectives of best practice in provider / parent interaction. A major finding was that healthcare professionals who demonstrated best practice empathised rather than sympathised with parents. They defined empathising with parents as a shared experience, in which they entered the parents' story to try to understand their perspective. These 'best practice' practitioners felt that differentiating their own experiences and feelings from that of the family was integral to empathy; described as the ability to become a 'fellow traveller' without becoming overwhelmed by their own feelings.

Going the extra mile

PPC staff, particularly nurses, often feel obliged to work beyond the remit of their role in relation to hours, tasks and contact with colleagues/families after the end of their shift (Kushnir et al, 1997, Erikson and Davies, 2017). Despite the personal cost of stress, work/life imbalance, home conflict, burnout and compassion fatigue, these additional duties were found to be undertaken with a sense of conscience and willingly (Rodriguez and King, 2014). Both staff and parents felt that these actions strengthened their relationship (McCloskey and Taggart, 2010, Pearson, 2013, Rodriguez and King, 2014, Davies, et al, 2017). However once these bonds were developed nurses often felt they needed to take on even greater responsibility for the family, so these additional activities became the 'norm' (McCloskey and Taggart, 2010, Pearson, 2013, Rodriguez and King, 2014). Undertaking these additional duties sometimes fulfilled the nurses need to be needed (Cargill, 2014) and gave rise to feelings of indispensability (Lattanzi-Licht, 1991). This perpetuated the behaviour but eventually led to serious effects such as compassion fatigue and burnout (Maytum et al, 2004). Further, if this meets the nurses need rather than that of the child or family it is outside the bounds of the therapeutic relationship (Roberts, 2015).

Maguire and Price (2007) reflect on how involvement should be fluid and adaptive, depending on the families' needs. Further professionals need to beware of taking over when the family may just need a little support, i.e. becoming the 'omnipotent rescuer' (Benner and Wrubel, 1989).

A number of studies identified that additional duties were also expected by parents. This was usually couched in terms of availability and flexibility (Woolley et al, 1991, Steele, 2002, Rodriguez and King, 2014, Whiting, 2014) or a greater level of commitment (Dolan, 2013), but in essence meant that parents wanted healthcare staff to be available whenever they were needed. This was recognised by parents as 'going the extra mile' and staff who did so were highly valued (Konrad, 2008, Nahra, 2008, Rodriguez and King, 2014). Witnessing the huge difference these actions made to families and the appreciation shown by parents further perpetuated staff self-expectation to operate at over and above their designated duties.

McCloskey and Taggart (2010) found that this often led to a very intense relationship between one nurse and a family, particularly for hospice nurses and community children's nurses. Such intense relationships increase stress and it is unlikely that any one person can fulfil all the needs of a child and family (Woolley et al, 1991, Rodriguez and King, 2014).

Boundaries and integrity

Maintaining the balance between over-involvement and distancing oneself from families as a protective measure is an issue in nursing generally (Griffith, 2013) and has been identified in nurses working in a range of paediatric areas (Totka, 1996, Pearson, 2013, Roberts et al, 2015). Since involvement, caring and interpersonal connections form the basis of nursing, Benner and Wrubel (1989) identify that the

path between over - involvement and distancing oneself is a narrow one which often requires experience to navigate. Nevertheless Cargill's (2014) qualitative exploratory study, involving six experienced paediatric oncology nurses, identified that even for this knowledgeable and skilled population there was an increased risk of violating professional boundaries, due to the length of involvement and the emotive nature of their role.

Maintenance of professional boundaries is essential in upholding the reputation of the nursing profession (NMC, 2018). Definitions of professional boundaries vary but most include reference to a line or an edge which should not be crossed. Most authors agree that the focus of nursing relationships must be on care and treatment (Griffith, 2013) and what is therapeutic for the child and family (Roberts, 2015). Some term this as the 'zone of helpfulness' existing between the extremes of over and under involvement (NCSBN, 2018). The importance of finding the right level of professional involvement in PPC is underlined by Maguire and Price (2007). They describe this as 'connected', which they define as compassion, conscience and commitment alongside the professionalism required by the NMC Code (2018). This is a significant challenge for children's nurses working in this field (Erikson and Davies, 2017) and one which has been termed as an occupational hazard (Cargill, 2014).

Woolley et al (1991), Kushnir et al (1997), Maytum et al (2004) and Rodriguez and King (2014) highlight that facilitating the parental expectations of flexibility, availability and emotional strength over long periods of time can result in healthcare professionals becoming overinvolved and overstepping boundaries. However, from Nahra's (2008) personal parental perspective, rather than interfering with the nurses' professionalism this higher level of commitment enhanced it. Further Dolan's (2013)

personal account of her children's ten year healthcare journey uses phrases such as 'girlfriends of mine', 'surrogate aunts, advisors and confidants' to describe nurses. She also recounts attending nurses' weddings. Dolan (2013) describes her experience as truly holistic care and clearly what occurred was highly beneficial to her and her family. Yet, it does raise the question of where work ends and personal life begins.

This is further complicated by the informality desired by some parents (Steele, 2002, Davies et al, 2017) and encouraged by some philosophies or environments of care (Woolley et al, 1989, 1991, Martinson, 1995). Woolley et al (1991) identified that a sense of humour and sharing a joke with children and families was an important means of forming relationships within the hospice setting. More recently Maunder (2013) found that the homelike environment of the hospice and home visiting led children's nurses working in these PPC environments to assume informal, non-traditional professional personas in order to make families feel more comfortable.

Informality does pose risks for the care relationship to be misunderstood by families, e.g. they may perceive the relationship to be a friendship with all the closeness and personal exchanges this brings. Similarly healthcare professionals may unwittingly become drawn into conversations and situations which sit outside the therapeutic relationship outlined by Roberts et al (2015). This was evident in the study by Erikson and Davies (2017) which identified that some nurses' perceived some 'extra mile' activities and contact with parents outside work as a violation of professional boundaries, whilst others felt that this was an extension of their role and a valuable source of support. Even those who clearly identified some of their behaviours as boundary violations felt that this couldn't be helped due to their attachment to the

family. Participants in this study who successfully managed professional boundaries adopted behaviours which 'buffered' them from the emotions surrounding their work, such as keeping a distance and strict separation of personal and work life. This included careful limitation of personal disclosure and always keeping the focus on the child and family.

The enhancement of bonds due to commonalities between nurses and particular children or parents, identified earlier, (Woolley et al, 1991, Erikson and Davies, 2017) can also pose a risk for losing perspective, erosion of a clear sense of one's role and transgression of professional boundaries (Lattanzi-Licht, 1991). Healthcare professionals can easily identify commonalities with parents as they have access to much of their personal information. However, personal disclosure on the part of the healthcare professional needs to occur for the parent to identify a commonality. Self-disclosure is a recognised part of initiating, developing, maintaining and terminating therapeutic relationships (Ashmore and Banks, 2002) and is appreciated by parents of life-limited and life-threatened children (Steele, 2002, Davies et al, 2017).

However this reciprocity requires careful management and skill to discern what is appropriate and inappropriate (Lussier and Richard, 2007).

This brings one to the concept of professional integrity which, in essence, means engaging with the values of your profession by being both "self-regarding and other-regarding" (Rushton and Ballard, 2011). Brown (2007) and Pearson (2013) found that the uniqueness of each family and their situation meant that nurses continually reconstructed their approach to achieve holistic, bespoke care whilst attending to their own emotional labour and integrity. Similarly Erikson and Davies (2017) found that maintenance of integrity is achieved when nurses integrate two competing but essential aspects of the nursing role, i.e. behaving professionally and connecting

personally. When nurses were skilful at this they were able to provide high-quality care within a clearly defined therapeutic relationship. The process was highly individualised to each nurse and each family. Unsuccessful mitigation of tensions led to compromised integrity, characterised by boundary breaches, compassion fatigue and burnout. Further, a nurse's professional registration may be at risk if a boundary breach is deemed worthy of sanctions by their professional body.

Professional boundaries are complex and, as shown from the literature discussed here, particularly relevant to PPC nursing. Seeing them as straightforward, 'black and white' or a defined line is unrealistic (Erikson and Davies, 2017). Both Cargill (2014) and Buder and Fringer (2016) stress that understanding and managing professional boundaries is something which cannot really be taught but is learnt from role models, experience and a sense of one's own vulnerabilities and resilience.

Summary

This review has brought together two of the parties involved in the PPC journey; parents and nurses. The literature reviewed focused on studies in which nurses made up a substantial proportion of the sample and where the parent participants were caring for a life-limited child rather than bereaved, i.e. currently in the long term nurse-parent relationship.

The major themes arising from this review are bonds, attachment and trust, sharing the journey, going the extra mile, boundaries and integrity. It appears that the very things which enhance the nurse-parent/family relationship are those which pose the greatest challenges. This merits further exploration, particularly in the hospice setting as contemporary studies undertaken exclusively in this environment are rare.

Gaining a greater understanding of how professional integrity and emotional labour are successfully managed by children's nurses working in palliative care could positively influence pre and post registration nurse education.

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