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‘With every fiber of their being’- perspectives of healthcare professionals caring for children with non-malignant life-limiting conditions

Abstract

Background

Children with non-malignant life-limiting conditions (NMLLCs) constitute the largest proportion of children requiring palliative care. In part, due to technological advances, growing numbers of such children are experiencing improved survival. Care is mostly provided at home by the family, with significant professional input at different points in the child’s life trajectory. This study explored the experience of healthcare professionals caring for this cohort of children.

Methods

A qualitative descriptive study design using single-occasion one-to-one semi-structured interviews collected data from twelve healthcare professionals’ including nurses, social workers and doctors. Data were analysed using thematic analysis.

Results

The findings highlighted the unfailing determination and dedication of healthcare professionals who provided care despite challenges with what seemed like ‘with every fiber of their being’. Three key themes marked such strength and commitment those were: ‘Being there’, ‘Being focused’ and ‘Being strong’. ‘Being there’ explicitly highlighted expert

care that was individualized and responsive to the child and family's unique needs. The provision of such care was often threatened and potentially compromised by the intricacies and challenges associated with Children's Palliative Care (CPC) and service provision. 'Being focused' captured the sense that the healthcare professionals remained entirely focused on providing expert care despite these challenges. 'Being strong' epitomized the personal and professional impact on healthcare professionals who are working in this area and the manner in which they sustain themselves in 'being focused' and in 'being there'.

Conclusions

The healthcare professionals demonstrated their unwavering commitment to deliver quality care required by children and families, however against a background of issues relating to organizational constraints. The findings have implications for education/service providers such as the need for specific palliative care education at both pre-registration level and continuing professional development.

Key words

children, life-limiting conditions, children with medical complexity, palliative care, multidisciplinary

1 Introduction

There has been a significant increase in the number of children living with life-limiting conditions an increase which is forecasted to continue (Fraser et al., 2020). The term 'childhood life-limiting condition' encompasses children with non-malignant as well as malignant conditions with the range of conditions being extensive (Siden, 2018). Children with NMLLCs constitute the largest proportion of children requiring palliative care (Siden, 2018). Care is mostly provided at home by the family, with significant input from a range of health and social care professionals at different points in the child's life trajectory (Courtney et al., 2018). Interestingly, the evidence base to underpin care is stronger for children with cancer than for children with NMLLCs. There is a growing body of research that focuses on parents' experiences of caring for children with NMLLCs (Collins et al., 2016; Verberne et al., 2017). However, a limited body of information exists regarding the experiences of healthcare professionals. Many of the studies previously undertaken focused on a single care setting or a particular care environment such as a children's hospice or a community setting (Hunter, 2017; McConnell & Porter, 2017; Neilson, 2013). While these studies are informative they provide a distinctive perspective. Additionally, earlier studies almost exclusively focused on the experiences of nurses and doctors, with very little contribution of other relevant healthcare professionals (McConnell & Porter, 2017; Mitchell & Dale, 2015). Yet the multidisciplinary nature of CPC has been previously emphasized (Postier et al., 2018). Children and families often need considerable investment in time and call for a multidisciplinary action of a highly complex nature. This paper explores the experience of healthcare professionals caring for children with NMLLCs from a range of healthcare settings on the island of Ireland. Specific objectives include to: illuminate their views regarding what

is integral in the provision of such care, for instance, personal/professional qualities required; gain an understanding of the personal/professional effects of providing such care and explore their views with regard to current CPC service provision. This paper is part of a larger study which explored the experience of caring for children with NMLLCs including, accessing services and decision-making surrounding the child's care (Hurley et al., 2021).

2 Methods

2.1 Research design

A qualitative descriptive study design was adopted in order to gain a comprehensive insight into the experience of healthcare professionals caring for children with NMLLCs, including their experience of service provision.

2.2 Sampling

Purposive sampling was used to identify participants with particular expertise and experience in the care of children with NMLLCs. An Advisory Group, comprising of healthcare professionals and academics all involved in CPC practice/research on the island of Ireland oversaw the implementation of the research playing a key role in advising re recruitment. Following consultation, it was suggested that recruitment of healthcare professionals should be guided by parents who were part of the larger study. These parents were asked to reflect on the healthcare professionals that they regularly engaged with in the course of care and to identify the professionals that they felt represented their 'key

contact'. Four main groups were identified including nurses, social workers, doctors and psychologists. Parents repeatedly identified nurses as key. The decision to include representation from different service providers and geographical settings was made in an effort to learn about a diverse range of experiences and was in keeping with the larger study. The aim was to represent healthcare professionals from the four main groups identified and to include at least one healthcare professional from each organization where recruitment originally took place.

2.3 Inclusion criteria

Experts including nurses, social workers, doctors and psychologists were invited to participate. In order to gain quality data, it was considered necessary that the healthcare professionals would have a minimum of one-year experience in caring for children with NMLLCs on the island of Ireland.

2.4 Recruitment

Five organizations aided in the recruitment of participants, including a Children's hospital, two children's units within regional hospitals, a respite facility and a children's hospice. The organizations were situated in Ireland (two urban and two rural) and one situated in the north which covered a wide geographical remit. Two methods of recruitment were used. The researcher organized information sessions which were targeted for particular groups of healthcare professionals in the five aforementioned organizations. The second method of recruitment involved contacting healthcare professionals from the

organizations directly. Both verbal and written information was provided. After expressions of interest were received, appointments for the interviews were arranged.

2.5 Sample size and participant characteristics

Interviews were conducted with healthcare professionals until data saturation was reached. This culminated in a sample of twelve healthcare professionals. The healthcare professionals had a variety of roles in CPC service provision (Table 1). Additionally, they provided CPC in a variety of settings including hospital, respite and hospice settings on the island of Ireland (Table 2). All of the healthcare professionals were involved in the assessment and delivery of CPC in excess of five years.

2.6 Ethical approval

Approval was obtained from the Ethics Committee in the relevant University and also from the five organizations involved in recruitment.

2.7 Data collection

Data were collected using single-occasion one-to-one semi-structured interviews with healthcare professionals. The average length of the interviews were 54 minutes. An interview guide was developed to ensure all areas were addressed. The interview guide included a number of questions, a list of major topics of interest and a list of prompts to facilitate exploration of each area. The questions and topics were constructed from the

findings of the literature review and in line with the objectives of the study. The introductory question in the interview guide was designed to elicit information regarding the healthcare professionals role within CPC service provision and their experience of providing palliative care. The guide also contained a number of questions regarding current CPC service provision. Kallio et al. (2016) suggest that rigorous development of a qualitative semi-structured interview guide contributes to the objectivity and trustworthiness of studies. The author (F.H.) who conducted the interviews was known to a number participants professionally but was not in a position of power or authority. F.H. had prior experience of interviewing and had also received additional training.

2.8 Data analysis

Braun and Clarke's (2006) six-phase thematic analysis framework was used to guide data analysis. The recorded interviews were transcribed verbatim, checked for accuracy, and entered into NVIVO 10 for data storage and management. Initially open coding identified themes which were then refined, cross-checked, and adjusted as needed through discussion with the entire research team, each who independently coded the data, until reaching consensus. Finally, exemplars were identified and chosen through selective coding. To assure trustworthiness, the second author conducted all interviews and kept memos detailing interactions. Data collection and data analysis occurred simultaneously.

Table 1:

Participant characteristics

Roles in CPC service provision	n=12
Clinical Nurse Managers	3
Social Workers	2
Children's Hospice Nurse Specialists	2
Paediatrician	1
Neonatologist	1
Clinical Psychologist	1
Outreach nurse	1
General Practitioner	1

Table 2:

Participants organizations

Organizations	n=12
Children's Hospital	3
Children's Unit Regional Hospital	2
Children's Unit Regional Hospital	1
Respite facility	2
Children's Hospice	4

3 Results

Three key themes emerged charting the healthcare professionals' experiences of caring for children with NMLLCs, including their experience of service provision. During ongoing thematic analysis, it was apparent that a relationship existed between the three themes those were 'Being there', 'Being focused' and 'Being strong'. All three themes were intrinsically interlinked. For the purpose of clarity, the three themes are presented separately.

3.1 Being there

'Being there' captured a sense of determination, dedication, passion and empathy on the part of the healthcare professionals and appeared borne from their knowledge that families needed support amidst emotional and practical chaos. The healthcare professionals repeatedly spoke of the significance of 'being there' with many being present throughout the care trajectory from diagnosis through to end-of-life care and following the death of the child:

I find that being there is very important. I think sometimes it's not about sorting it out, it's about being there as a presence, as a listening ear, as a support and normalizing what parents are going through at any one time. [P11].

The healthcare professionals identified the systemic impact of NMLLCs on parents and families:

it's their grief, their anticipation of what is going to happen. For some they have to grapple with this idea that they will have huge care demands potentially over a long

period. At the same time, they're terrified that they're going to lose their child so it's this rock and a hard place. [P10].

The healthcare professionals revealed the true value of 'being' as opposed to always 'doing'. They realized that their duty was not to solve every problem or complex situation, but to 'be there' to support parents and families through undoubtedly difficult, uncertain and frightening times.

'Being there' was, however incredibly complex and multi-faceted. A component of being there involved fully embracing their role of advocate in an effort to support children and families: *"we are very much an advocate, not just within the hospital and within the multidisciplinary team, we are their advocate in the community, we need to advocate for them"*. [P11]. As advocates, the healthcare professionals made every effort to ensure that the families' needs were met and that their best interests were respected. 'Being there' was therefore much more than just being there from a physical perspective; it incorporated many different aspects: *"it's much more than just talking. I could be in a house listening, talking, directing and there is so much more going on."* [P3]. In 'being there' the healthcare professionals frequently assumed numerous roles to varying degrees, including healthcare provider, case manager, educator and counsellor throughout the course of the care trajectory.

The close relationship that healthcare professionals developed with children, parents and their families were viewed as key to 'being there'. This appeared true irrespective of duration that they had to develop this relationship: *"such a big part of it is getting to know the families, which is the bit that's very hard to measure and yet it's the core."* [P3].

Certainly, caring for a child for a long period assisted healthcare professionals in getting to know the child which formed the basis of this relationship. It also helped them get to know

the parents' personalities which meant they had a better understanding of how to support them. In addition, trust was viewed as critical to the relationship. This relationship did not happen by chance but rather required a conscious effort on the part of the healthcare professionals' in establishing and maintaining it.

In some situations, there was limited time to develop a relationship with parents and families due to the nature of NMLLCs in children and the pattern in which they presented:

I recently had that issue, where I was referred a baby, in fairness, the baby was only six months, and she was referred three weeks prior to her passing. That was a challenge in that I was coming in where this baby was having worsening seizures and the neurologists were saying there's no more drugs to try. That was hard, because I was giving that information. Why should the parents trust you when you've only seen their baby for a few days? That's not the norm, but that can happen. [P4].

It was thus challenging for healthcare professionals to develop a rapport and establish trust over shorter periods. However, the healthcare professionals were experienced and had clearly developed expertise in the art and science of communication: *"so that's very skilled, you only have a short space of time and parents are so traumatized, they are so traumatized at that time."* [P1]. The healthcare professionals used their expertise to overcome such challenges so that they could provide the best possible individualized care and support for children and families.

3.2 Being focused

Regardless of professional role or setting in which care was delivered all healthcare professionals encountered many challenges in the delivery of such care. Despite these

challenges the provision of expert care was beheld by all as immensely valuable: *“if they are getting that support in the hospital and that support is extended to the community and to the home, I think we can make their burden a little easier.”* [P11]. Remaining focused on the care provided took precedence over any challenge encountered.

Although time was emphasized as an important factor in the provision of expert care the majority of healthcare professionals struggled with time constraints. As a result, they regularly pushed themselves by juggling their time to be there for all. Many healthcare professionals were of the opinion that appropriate support was not accessible for these families if they themselves were not available. While the healthcare professionals were touched by how parents managed and had a sense of admiration for them, they also articulated unease about the vulnerability of parents within this role as well as concern with regard to the level of recognition and support they received: *“some of them are taking care of the most complex of children in this country, in their own home and very often with limited supports.”* [P11]. The healthcare professionals emphasized the importance of providing a coordinated and collaborative CPC service in order to meet the needs of families: *“for those parents to survive and keep doing the job that they do every day, they need support.”* [P5]. Many healthcare professionals spoke of the efforts they had made in their service to provide a coordinated and comprehensive service: *“I provide support in a flexible way. I’ll see mothers or fathers by themselves or couples together. I am easily accessible.”* [P10]. Yet the frustration of the healthcare professionals regarding CPC service provision was evident throughout the narratives.

The healthcare professionals identified major gaps in service provision. Furthermore, different areas had different services, making it difficult to meet the needs of families depending on where they lived. Across all service areas and even within service

areas inequalities were highlighted. These inequalities were viewed as detrimental to care provision. Additionally, while the importance of working together was reiterated during the course of the interviews this was often tremendously complex. All healthcare professionals identified the need for improved communication in order to enhance care for children with NMLLCs and their families.

3.3 Being strong

All healthcare professionals reported that they felt emotionally touched in different ways in caring for children with NMLLCs and meeting the needs of families. The healthcare professionals shared stories, frequently with heartfelt responses about parents and children who they cared for. Many healthcare professionals shed tears in the course of the interviews as they recalled situations and disclosed the lasting influence of their experiences on them personally and professionally.

The healthcare professionals described how they gained perspective with each palliative care experience. The perspective that they gained through their interactions with families appeared to give them the strength and energy to keep going and keep focused. The death of a child was regarded as an emotional experience by all healthcare professionals, but with experience came a level of comfort: *“she became very unwell and died very peacefully in her parents' arms at the age of nine months, so it all worked out ideally the way they wanted it.”* [P7]. In time the healthcare professionals developed the strength and resilience to deal with anguish and death. They felt rewarded that they were able to support and provide comfort to children and families.

Caring for children with NMLLCs and meeting the needs of families were described as both demanding and complex particularly when it involved insufficient resources. Yet most healthcare professionals described altruistic intentions and despite the challenges, they were able to derive self-motivation and value from their role. The healthcare professionals had the strength and vision to see that they had the ability to make a real difference in the lives of these children and families:

You're going in with just the skills that you have, to deal with that situation, to support the families, the professionals, and make sure the care is of a standard that – whatever length this life is, that it's valuable, and the child doesn't need to suffer. [P1].

The healthcare professionals strove to deliver quality care. They had strengths in developing others and found meaning in their experiences: *"it's unique work, because you have to have those conversations with professionals, they're dealing with something they're not used to, it's about supporting them and getting them to feel confident and understand what this care means."* [P1]. They reported feeling enriched from their work and felt they gained a new perspective on life in relation to what is most important and meaningful:

This kind of work is very grounding. It's very grounding around I suppose the value of life, of your experiences... I think sometimes, when you get more grounded, you can see the value of it in your own life. [P1].

Through their many meetings with parents and children the healthcare professionals appreciated and re-evaluated their lives.

The healthcare professionals felt that they were doing the best that they could to support families. However, they also felt a sense of powerlessness and lack of control over workload and patient care. They too needed support in providing expert care: *"I've never been finished at five ever, because lots of things happen in the evening. It's often in the*

evening when parents need support.” [P7]. The healthcare professionals often worried about sustaining the care. They were aware that they had to remain strong and thus it was necessary at times to hand over the care. However, the lack of resources made this extremely difficult.

4 Discussion

The collective findings provided an in-depth understanding of the experiences of healthcare professionals caring for children with NMLLCs. Such caring was multi-faceted and emotionally intensive. The findings demonstrated that the provision of expert palliative care across settings was grounded in the establishment of therapeutic relationships with children and families alongside others in the wider network of support. Furthermore, it was clear that the healthcare professionals understood and had empathy regarding the uncertainty and other worldliness in which families find themselves residing.

Such otherworldliness and the notion of being in limbo due to prolonged uncertainty was in keeping with the concept of liminality. Liminality, traditionally associated with transitions and thresholds reflects a position of being in ‘limbo’ or no-mans-land (Turner, 1967). The healthcare professionals acknowledged that the parents were regularly struggling to ‘find their place’. They alluded to how liminality was manifested in their everyday life and how they tried to organize a self that engaged with the liminal space between caring for their child and their impending death. Jordan et al. (2015) described how parents were in a state of liminality, an unsettling period of transition between one social state and another when caring for their dying child. The healthcare professionals in the present study reported that they supported and provided direction to parents as they

tried to organize themselves in this space. This was clearly evident in the themes 'Being there' and 'Being strong'. The healthcare professionals perceived that while being confined in the indeterminate state of existence can lead to a wide variety of existential and psychological concerns, the ability to experience autonomy appears to mitigate the anguish. The application of the anthropological concept of liminality has been made in adult palliative care (McKechnie et al., 2011). Additionally, Carter (2017) suggests that palliative care for infants, children and adolescents encompasses numerous transitions and thresholds of uncertainty that are challenging. Healthcare professionals have opportunities to be more comfortable amid such challenges, or perhaps even overcome them, if they are attuned to the unique times and places in which families find themselves. Liminality provides a framework for addressing the unbound spaces that families occupy: what is past is behind-the present place is tenuous and temporary and what is ahead uncertain. This place is where the healthcare professionals can offer families guidance (Carter, 2017). The healthcare professionals in our study found that conceptualizing care in terms of liminality offers a powerful framework for understanding the experiences and challenges faced by families as they negotiate this particular life change.

Relational practice was also integral to the experiences of healthcare professionals in supporting parents navigating their liminal space. The concept of relational practice refers to the art of authentically being with people and includes reciprocity (Bjornsdottir, 2018). Relational practice was unveiled in the three themes, 'Being there', 'Being focused' and 'Being strong'. Schwind and Manankil-Rankin (2020) suggest that healthcare professionals' relational work articulates a reality that exists but is not realized. However, in this study it was the awareness of this reality that led to the discovery of where the healthcare professionals held their professional value. They experienced that the relationship they

built with children and families was key and it was a major source of both personal and professional fulfilment. They evidently acknowledged the uniqueness of each family and their situation. The healthcare professionals' relational practice was regularly strengthened in scenarios where relationships existed over a longer period. The findings also illustrate the complexities that healthcare professionals encounter in striving to develop a close relationship with the child and family in what can be a short period. Clearly trusting relationships could be formed within a shorter period. The healthcare professionals' engagement with families included not only the initial joining with a family, but also reflected a commitment to continuing and fostering a relationship to care for the child and the family after the child's death. The significance of the relationship between healthcare professionals and families of children with life-limiting conditions has been previously emphasized (Mitchell et al., 2020). The relationship capacities found in this study are consistent with those described in the literature, which show that relating to children and families is a caring process that involves values, intent, knowledge, commitment and actions. Bergsträsser et al. (2017) described the experiences of healthcare professionals providing end-of-life care to children in Switzerland. Similar to the findings of the present study the key aspect in end-of-life care provision was identified as the capacity to establish a relationship with the child and family. Bergsträsser et al. (2017) suggested that trusting relationships could likewise be formed even in highly acute situations within a shorter period, for instance on a Paediatric Intensive Care Unit (PICU).

In conjunction with relational practice were the philosophy and core concepts of family-centred care (Banerjee et al., 2018; Coyne, 2015). Unveiled across the three themes, 'Being there', 'Being focused' and 'Being strong' healthcare professionals respect of the parents' knowledge concerning their child was pivotal. Recognizing parental expertise was

viewed as fundamental in supporting families. Professional participants outlined that they did not view themselves as 'experts' with specialized knowledge and skills to solve problems, but as companions to 'be there' to support families. As alluded to earlier the healthcare professionals described the necessity of finding out what was important to the family and not focusing simply on what they perceived as important. The concept of family-centred care and relational practice are closely associated (Foster & Whitehead, 2017). A key element in both family-centred care and relational practice is a partnership formation with the child and family in order to best support their needs (Brødsgaard et al., 2019; Magen & DeLisser, 2017). The healthcare professionals in the present study identified compassion primarily as a disposition requiring action. Being dedicated to the context of the child and family's situation afforded them opportunities to be hopeful, to be honest and assess how they could best provide care to address the specific needs of the child and family. Similarly, in the literature, family-centred care was described as not focusing on tasks alone, but including families in consultations and attending to their concerns, fears and hopes (Dudley et al., 2015). The healthcare professionals in this study experienced family-centred care and relational practice as a dimension of quality healthcare and as a holistic approach to care.

The aforementioned concepts of relational practice, family-centred care and liminality were clearly apparent within the healthcare professionals' stories and appeared to give rise to the practice of a very clinically competent expert within CPC. All three concepts played out in conjunction with each other. Whilst the healthcare professionals appeared to view the parents as expert in their child's care, they also recognized their own knowledge and expertise in care provision. Their aim was to actively and tangibly address the needs of children and their parents and family. Ghanem et al. (2018) suggest that experts differ from

novices with respect to both their knowledge base and the epistemic activities in which they engage. The healthcare professionals use of expert knowledge to provide anticipatory guidance, approach problems with creative solutions and recognize that planning is needed before a crisis occurs was evident across the three themes 'Being there', 'Being focused' and 'Being strong'.

CPC was depicted in this study as a dialectical experience. The healthcare professionals revealed relational practice and family-centred care patterns such as making time and connecting with families. 'Being there' and spending time with the family gave healthcare professionals an opportunity to create trust and provide comfort care. They expressed professional satisfaction in caring, because the situation afforded the opportunity to provide compassionate care during this critical time. Despite this the majority of healthcare professionals struggled with time constraints. Many of the healthcare professionals recounted the unpredictable nature of their working day, the juggling of competing demands and the constant need to reprioritize their caseload. This at times generated feelings that they were providing impersonal or inadequate care. The findings from a number of studies likewise revealed demanding workloads with implications such as stress and fatigue for healthcare professionals (McCloskey & Taggart, 2010; Quinn & Bailey, 2011; Whiting et al., 2020). However, the healthcare professionals in the present study seemed to 'find' time, knowing perhaps the way to 'create' time was by being fully engaged with each family in the moments that were available. Within this study, healthcare professionals across all settings reflected on the consequences of developing deep relationships and attachments with children and families. This often generated a sense of grief when the child died, mirroring the findings of previous research (McConnell & Porter, 2017). Psychological self-care was identified as an important coping strategy. Finding

meaning and closure were important strategies for helping healthcare professionals cope and to diminish some of the anguish experienced. Additionally, reconciliation with the concept of child death was enhanced through the use of comparable stories regarding several care episodes.

4.1 Practice implications

The findings bring to light many pragmatic considerations for healthcare professionals and service providers. The healthcare professionals in this study were experienced and reported that they felt confident and competent in almost all aspects of their professional role. The necessity of foundational and specialized knowledge emerged throughout. Relational practice emerged as important to the healthcare professionals' ability to be with a family and provide support throughout the care trajectory from diagnosis through to end-of-life care and following the death of the child. Relational practice, in conjunction with family-centred care and liminality should be taught as foundational concepts in CPC curricula to all healthcare professionals in both undergraduate and postgraduate training. The findings indicate that caring and supporting children and families at end-of-life has a pervasive emotional impact on healthcare professionals. At a personal level, the development of positive coping strategies, including learning through reflection is essential. Organizational attention should be given to opportunities for support including peer support, critical incident debriefing and clinical supervision. There are tangible issues that could be addressed including the need for system level measures to standardize the approach to care for children with NMLLCs whilst also acknowledging the unique needs of children and families. The healthcare professionals highlighted the

detrimental consequences of the current ad hoc provision of services, a situation that typically leaves parents vulnerable and they themselves feeling overburdened/inadequate.

4.2 Strengths and limitations of the current study and future research

The findings provide a rich insight relating to how healthcare professionals experience the delivery of care required by children with NMLLCs and their families. In addition, the findings provide new insights regarding clinical expertise and the concept of the healthcare professional as expert. The healthcare professionals in this study had a variety of roles in the delivery of CPC service provision. Previous studies almost exclusively included nurses and doctors, with very little involvement of other relevant healthcare professionals (McConnell & Porter, 2017; Mitchell & Dale, 2015). It was important to include a variety of healthcare professionals in this study given the multidisciplinary nature of CPC (Basu & Swil, 2018; Postier et al., 2018). However, the findings are limited to the twelve healthcare professionals and this potentially limits representativeness. Additionally, while all four groups of healthcare professionals were represented the sample mostly comprised of nurses, which makes it less representative of all healthcare professionals. Additional research is essential to ascertain additional perspectives and to contribute to the optimal care and well-being of these children and their families. Other professional groups outside of the healthcare sectors such as priests/chaplains and teachers may bring new insights and perspectives.

5 Conclusion

The healthcare professionals experienced that the diagnosis of a NMLLC creates a complex, systemic, life-changing experience that propels families along uncertain trajectories. The healthcare professionals perceived that they have opportunities to mitigate suffering and to find relationship, space and language that works in synergy with families to participate in a reality that is unthinkable and yet undeniable. The healthcare professionals spoke of a willingness to enter into conversations with parents/families in which the outcome was unknown. They reported that fostering conversations among family members and between the healthcare professional and the family expanded possibilities for new understandings to emerge. Organizational barriers to relational practice certainly emerged as an issue in the interviews. The healthcare professionals coped by being mentally focused and emotionally prepared, maintaining boundaries with compassion and reminding themselves that they cannot fix everything all of the time.

Key messages

- Regardless of professional role or setting in which care was delivered all healthcare professionals encountered challenges in the delivery of palliative care.
- The perspective that healthcare professionals gained through their interactions with families gave them the strength and energy to keep strong and keep focused.
- The healthcare professionals felt that by 'being there' they were doing the best that they could to support families. However, they also felt a sense of powerlessness and lack of control over workload and patient care.
- The concepts of relational practice, family-centred care and liminality appeared to give rise to the practice of a very clinically competent expert within CPC.

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