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# Paediatric death and dying: Exploring coping strategies of health professionals and perceptions of support provision

## Abstract

Without question a child's death is a devastating event for parents and their families. Health professionals working with the dying child and family draw upon their expertise and experience to engage with children, parents, and families on this painful journey. A delicate and sensitive area of practice, it has strong and penetrating effects on health professionals. They employ physical, emotional, spiritual and problem solving strategies to continue to perform this role effectively and to protect their continued sense of well-being.

**Aim:** To explore health professionals' perceptions of bereavement support surrounding the loss of a child. **Methods:** The research was underpinned by social constructionism. Semi-structured interviews were held with 10 health professionals including doctors, nurses and social workers who were directly involved in the care of the dying child and family in 7 cases of paediatric death. Health professional narratives were analysed consistent with Charmarz's (2006) approach. **Results:** For health professionals, constructions around coping emerged as peer support, personal coping strategies, family support, physical impact of support and spiritual beliefs. Analysis of the narratives also revealed health professionals' perceptions of their support provision. **Conclusion:** Health professionals involved in caring for dying children and their families use a variety of strategies to cope with the emotional and physical toll of providing support. They also engage in self-assessment to evaluate their support provision and this highlights the need for self-evaluation tools in paediatric palliative care.

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## Introduction

Unfortunately, a number of children die each year due to congenital conditions, injuries and oncology related conditions (Australian Institute of Health and Welfare [AIHW], 2012). Health professionals caring for these children and their families provide care and support at an intimate and emotionally charged time and draw upon a range of coping strategies in order to manage the personal and professional impact of this care.

The death of a child “precipitates a cascade of existential emotions for families and thus multiple layers of loss within the family” (Cacciatore, DeFrain, Jones & Jones, 2008.p.352). Health professionals who provide care leading up to and following the child’s death are a supportive presence in the midst of providing end of life care and must traverse this situation carefully in order to ensure families are supported effectively. This is a heavy burden for health professionals who often experience physical, emotional and moral distress arising from this end of life care provision (Brazil, Kassalainen, Ploeg & Marshall, 2010; Keene, Hutton, Hal & Rushton, 2010).

Each health professional group within the team approaches end of life care with variations in philosophy, knowledge, experience and specific roles. Recent studies have highlighted the differences among health professional groups in relation to palliative care and its impact on health professionals and the need to consider the distinct needs of particular disciplines (Slocum-Gori et al., 2013; Zambrano et al., 2014). Professional differences have also been noted in relation to educational needs and priorities in paediatric palliative care (Amery, 2012). The present study found both areas of commonality and difference among health professionals, however, this article reports on the commonalities in relation to coping and

perceptions of support. The study findings are from a doctoral study which explored both parent and health professional perceptions of bereavement support surrounding the loss of a child.

### Study Design and Methods

The research was underpinned by the assumptions of social constructionism that acknowledge that meaning is shaped by our interactions with others and people construct knowledge between them in their daily interactions within the social world (Berger & Luckmann, 1966). The methodology for this qualitative study was based on obtaining, through semi-structured interviewing, the narrative accounts of a purposive sample of health professionals at a large tertiary paediatric hospital in Queensland, Australia. There were two participant groups: health professionals and parents. This article focuses on the first participant group of nurses, doctors and social workers who were involved in the care and/or support of a dying child and families around the time the child died. The second participant group were parents who lost a child and whose child was cared for by staff from the tertiary paediatric hospital, however this parent data is not reported in this article. The study gained ethical approval from the tertiary paediatric hospital ethics committee and the human ethics committee of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines.

Health Information Services at the paediatric tertiary hospital conducted a search of deceased patients each month during the data collection period and checked medical records for completion of the hospital's Privacy Consent Form. Health professionals were identified through the documentation in a child's medical record and were contacted approximately 12

weeks after the child's death, through an introductory letter delivered to their workplace. Consenting health professional participants were interviewed after parents had consented to be involved in the study and following parent interviews. To ensure confidentiality no data was revealed between the parent and health professional participants.

The participants were ten health professionals (two doctors, six nurses and two social workers) involved in the end of life care surrounding 7 cases of paediatric death in medical, oncology and paediatric intensive care settings at the tertiary paediatric hospital. The participants' ages ranged from 24 to 57 years and their years of experience in their particular specialty ranged from four to over 20 years.

### **Data Analysis**

The interviews were audio recorded and transcribed verbatim. The transcribed data texts were then entered into the QSR NVivo™ Version 7 software program and coded into nodes. The interview data was then subjected to a process of analysis consistent with Charmaz' (2006) approach. Charmaz' approach is grounded in social constructionism (2006) and has developed as a method of qualitative analysis which can be utilised in diverse areas and for varied purposes (Charmaz, 2012). The analysis included familiarisation with data, generation of initial codes, the search for themes, review and revision of themes, the definition and naming of themes, and this process was inductive, comparative, interactive and iterative (Charmaz, 2012).

### **Findings**

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Analysis of staff narratives revealed their constructions of meaning around coping with caring for dying children and families. Social workers, doctors and nurses constructed coping with their experiences in caring for children and their families at the time of a child's death in various ways including seeking out staff who shared the same experience, confiding in a supportive partner, using personal coping strategies such as compartmentalising or focusing on the positives and drawing upon their spiritual beliefs. Staff coping mechanisms were identified by all three types of health professionals interviewed: doctors, nurses and social workers. In keeping with the underpinning constructivist framework the researcher is a co-creator of meaning and therefore to present a meaningful analysis of the data, the findings and discussion of the insights drawn from these will be merged.

### Peer Support

The first way that coping was constructed by participants was confiding in peers and seeking peer support and was the most common coping strategy reported by staff. The sudden, unexpected death of a child was reported by staff as the stimulus for seeking out colleagues who had shared the experience in order to harness support and aid coping. Staff acknowledged that the impact on one health professional could also affect the other health professionals involved, as witnessing the shattering impact on others increased their own awareness of the shocking and unsettling nature of the experience.

Well you get affected by other staff as well. You know, you have other people around you as well. I mean, everyone was there trying to help. The girl from theatre kept coming back saying "Is there anything I can do?" and she just kept saying "Oh, this is

terrible”, because she had a small child as well. She was just, you know, not quite sobbing but she was really shocked by the whole scenario. (RN 5)

Health professionals expressed the need to discuss their experiences concerning patient death with each other. However, while the sharing and recounting of experiences among staff may be beneficial, they may also exacerbate feelings of shock and devastation concerning the experience. The literature regarding peer support following traumatic occupational experiences has identified the potential negative impact of such support, with it contributing to psychological distress and ineffective coping (Parkes, 1986; Stephens & Long, 2000). Some studies have reported a reverse buffering effect of social support where, instead of improving the effects of stress on the individual, social support may actually worsen these effects (Button, 2008; Glaser, Tatum, Nebeker, Sorenson, & Aiello, 1999). For example, in a survey of 212 midwives and nurses and the role of social support in moderating occupational stress, when nurses’ stress levels were high, higher levels of social support had a detrimental effect on psychological and physical health (Button, 2008).

The sharing of experiences between staff as a way of coping was not limited to cases of sudden and unexpected death, but also occurred among health professionals working in palliative care. Health professionals described the importance of sharing with other members of the health care team in order to cope with the experience of caring for dying children and their families in palliative care:

I probably could have found a psychologist or something like that to debrief but I think it was made harder because [RN] wasn’t here that last week, and she’s my support. We have been supporting each other through this very well. But she was just away at a pretty

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good time even though she kept telephone contact the whole time, two or three times a day and I talked with her. But she wasn't here; we had quite a good team relationship. I think that contributed to it a bit. (Doctor 2)

This finding of shared experience is consistent with existing research into physician reactions and ways of coping with patient death. In a study of 188 doctors in the United Kingdom into their reactions to patient death, Moores, Castle, Shaw, Stockton and Bennett (2007) found the majority of doctors coped with their experiences of patient death by talking with others. The source of support was weighted equally between other doctors and nurses and friends, family and loved ones (Moores et al., 2007). Redinbaugh et al. (2003) also found that doctors used coping strategies such as gaining emotional support from others, reframing and immersing themselves in work in an attempt to cope with the moderate levels of emotional impact experienced through encountering patient death.

Research into burnout and staff retention among health professionals has also pointed to the importance of peer support. Peer support has been found to provide health professionals with positive validation, a sense of shared experience, knowledge and opportunity for reflective practice, stress and coping strategies and enhanced self-confidence (Peterson, Bergstrom, Samuelsson, Asberg, & Nygren, 2008). Health professionals in the oncology setting have also gained information and emotional support from their peers, followed by supervisors, with the least amount of support coming from within the organisation itself (Barnard, Street, & Love, 2006).

### Personal Coping Strategies



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The second way that coping was constructed by health professionals was through the use of personal strategies. Health professionals described using a combination of emotion-focused coping where the experience was consciously blocked in the short term via compartmentalisation. Later, the health professionals could address the impact of the experience with problem-focused coping:

Yes, well, I think you have to compartmentalise it. I think you have to be able to . . . like you can't stop how you're feeling, you've just got to put that in to its own little place and go on with what you're doing and then you will work through that over the next hours, days, whatever. When I say compartmentalise I just mean that they are big things happen in your life and if you just thought about them till they were sorted out would paralyse you and you wouldn't be able to do anything. So you just have to have that ticking away, do your job and this just gets sorted out in time. It's a bit like your own personal experience of grief, which is completely overwhelming and initially you're completely paralysed and you can't do a thing. And after a while it's like this great big huge shape, it gradually sort of gets more and more contained, it's almost like it's in a little box and you can sort of open the lid and it comes out but then you can put the lid back on again. So I think that to a degree is happening all the time. And I think if you sort of say where you're just putting those emotions aside and all those experiences that you have about these deaths and ignoring them, I think that . . . I don't think that happens. And I think you would be quite robotic if you did that. (Doctor 4)

Compartmentalising may be a strategy used to be able to cope with treating dying children and supporting their parents. Similar perceptions have been found among oncologists when interviewed about their approaches to end-of-life care, including their ways of coping (Jackson et al., 2008). Nurses have also described 'boxing or curtaining off' their feelings

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when caring for dying patients in order to maintain a professional outward demeanour and to continue to perform their caring role (Gerow, Conejo, Alonzo, Davis, Rodgers, & Domain, 2010; Badger, 2005). Compartmentalising affords clinicians time to work through their emotions and conflicting feelings about a child's death at a later time.

### Family support

The third way that coping was constructed by staff was using family support. Health professionals described debriefing with a supportive partner at home and also mentioned the physical toll in providing support to families:

I have a very supportive partner who you know, understands a lot of that stuff, so I'm able to debrief when I go home. From a significant on-call one like that that's really useful, you know, that your family support you. And he's interested. Yes, I mean, it takes its toll at times, I have to say I'm probably not very good from a physical point of view. Sometimes in a long, intense session with a family I find I'm in pain somewhere because I've been holding my body in an attentive listening point of view or trying to make sure that I'm there and I'll go home and say "Oh, I need a long, hot shower". But I guess you develop some skills over the time to be able to do that. (Social Worker 1)

These comments highlight the role that family members play in providing an avenue for health professionals to discuss experiences in caring for dying patients and families. However, the notion of confidentiality remains an issue with this type of coping. Because health professionals are bound by confidentiality, the discussion of work experiences with those other than peers or team members may constitute a breach of confidentiality. Other studies have also identified that health professionals turn to family and friends to discuss

stressful work experiences (Moore et al., 2007). In a study of student paramedics, one of the reasons postulated for lack of self-disclosure to work peers and emotional expression concerning traumatic experiences encountered at work was the fear this would give the impression that they cannot handle their job and undermine their sense of security (Lowery & Stokes, 2005). Similarly, in a study of junior doctors working in palliative care, a third of participants reported they were reluctant to share feelings with peers for fear of being judged or perceived as weak (Feld & Heyse-Moore, 2006).

### The Physical Impact of Support

Caring for dying children and their families also has a physical impact on health professionals. Maintaining an attentive posture during a long and intense period with parents and families left the social worker feeling physical pain. Similar physical impacts were mentioned by other health professionals in the study, and some described needing to take sick leave in order to cope with the physical toll that arose from working with dying children and families.

Certain occupational groups, for example, health professionals and those involved in counselling, have been identified as being at risk for stress or for exacerbation of existing stress (Christopher et al., 2011). The importance of self-care for health professionals has been discussed in the literature and comprises both physical and psychological self-care in order to circumvent the adverse effects of job-related stress (Christopher et al. 2011). Caring for dying patients and their families is considered a significant contributor to stress among health professionals and has been found to manifest in physical health problems among doctors and nurses (Aycock & Boyle, 2009; Isikhan, Comez, & Danis, 2004). In their study

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of 109 doctors and nurses working in oncology settings the predominant physical signs of stress experienced were headaches, gastrointestinal problems, increased nervousness and sleep problems (Isikhan et al., 2004). A recent Australian study into the support needs among community palliative care nurses acknowledged the physical and emotional impact of working in palliative care (Lobb et al., 2010). In this study, 71% of participants reported that they would like therapies such as massage, reflexology and aromatherapy to be available to assist them to cope with the physical and emotional impact of caring for dying patients and families (Lobb et al., 2010).

### Spiritual beliefs

In addition to peer support, personal coping strategies and family support, the spiritual beliefs held by health professionals may also enable them to cope with dealing with the experiences of child death encountered at work.

I guess it's partly about your world view and what your spiritual beliefs are and you know, I don't have this view that you know, there must be a horrible God, or there must be no God because why would he do things like that to little children, I guess my spiritual beliefs allow me to deal with that sort of stuff. (Social Worker 1)

Spirituality is thought to be significant in circumstances of bereavement and may prompt a reconsideration and re-evaluation of assumptions about the world and life's purpose which are often grounded on religious or spiritual beliefs (Tedeschi & Calhoun, 2006). Health

professionals encountering loss and bereavement may engage in existential questions that may assist them to find meaning and to cope with their experiences. Studies into health professional coping when caring for dying patients and their families have found that nurses may use religious beliefs and resources as a way of coping with patient death (Peterson et al., 2010). Desbiens and Fillion (2007), in their study of palliative care nurses who encounter bereavement frequently, suggest there is a link between meaning making strategies such as turning towards religion and spiritual quality of life. Such strategies may aid coping and mediate stress for those working with dying patients and families.

### Perceptions of Support Provision

Staff constructions of their ability to provide support to the dying child and family was influenced by their perception that they received limited feedback on this directly from parents. Rather than constructing a positive or negative view regarding their ability to provide support, staff narratives turned to their perceived lack of education regarding providing support and the resultant learning through experience and through consultation with their peers.

When staff reflected on their ability to provide support to families they referred to not knowing how parents felt about the support they provided. They described considering how they or someone close to them would like to be cared for, as well as the relationship they had developed with families over time, as their ‘yardstick’ for measuring their ability regarding

support provision. They also described sometimes muddling through the process due to a lack of educational preparation concerning the best way to provide support.

I guess we don't really get taught exactly. No one can prepare you for that situation. You're just sort of thrown into that situation and you've just got to sort of bum your way through it in the best way that you can. So yeah, I don't know. I don't know whether I did it right, whether I did it wrong, what [parents] thought of me. I know that I got on with them really well when he was quite well but I don't know how they felt the experience went because you don't sort of get that feedback. They went home at the end of the day and I went to his funeral and that's it. You don't see them again. So yeah, I really don't know. (RN 6)

There is often a lack of formal feedback received when providing care to the dying child and family. Health professionals are not likely to seek feedback from parents and family member who are in the midst of grief. The comment above also alludes to the perceived abrupt end to contact with the child and family following the child's death. This seems to be in contrast with other experiences in caring for children and families where there may be ongoing contact that may provide opportunities to better assess one's performance and parents' satisfaction with care. Although studies have been conducted that have assessed family perceptions concerning their loved one's end-of-life care (Stajduhar et al., 2011), the comments made by staff in this study suggested they must rely on their own assessments to evaluate the quality of the care they provided to the dying child and family. Health professionals in this study described carefully reading cues from parents and assessing the way parents were interacting with their child and each other as a way of evaluating their performance. One social worker, for example, discussed how he assessed how the parents

were interacting at the time of the child's death and this gave him a sense that his preparatory work with the family had enabled them to experience their loss in a supportive environment. Such comments point to the way in which health professionals reflect upon their practice to ascertain whether they have performed the kind of end-of-life care needed and desired by families.

Two Canadian nurse academics developed a palliative care nursing self-competence scale: Desbiens' Palliative Care Nursing Self-Competence Scale (Desbiens & Fillion, 2011). They argue the importance of self-assessment of one's ability to provide quality of care to dying patients and families because of the limited professional training in this area (Desbiens & Fillion, 2011). This tool contains ten dimensions of care that the nurse can self-assess, including dimensions relating to providing psychological support to the patient and family and providing 'authentic presence' during the patient's last hours of life (Desbiens & Fillion, 2011).

More recently, this tool has been adapted for use in paediatric end of life care to recognise the unique needs of children and their families (Hafiz, 2013). Table 1 lists the paediatric items developed by Hafiz (2013).

**Insert Table 1 here**

Self- evaluation tools have also been developed for medical professionals however standardised instruments that measure competence are limited and therefore researchers have developed their own surveys (Mulder et al., 2009). Mason and Ellershaw (2008 and 2010) used the Self Efficacy in Palliative Care Scale to examine the palliative care self efficacy among undergraduate medical students. Weismann et al. (1998) developed a self report tool

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The Palliative Medicine Comfort- Confidence Survey to investigate competence and concerns in relation to end of life care among medical students, interns and residents.

When providing support, health professionals may experience uncertainty due to their feelings of inadequacy, fear of doing harm, or lack of knowledge regarding how to provide effective support (Main, 2000; Main, 2002; Shumaker & Brownell, 1984). In this study, staff perceptions concerning their ability to provide support to dying children and their families have shown that health professionals sometimes find it difficult to gauge their ability in this area and this uncertainty may impact on their support provision. Assisting health professionals to evaluate their practice in end-of-life care can provide them with clarity concerning their capabilities and reveal areas that need development.

Staff perceptions concerning their ability to support dying children and their families was also linked to the importance of experiential learning. Health professionals mentioned never having been taught how to manage supporting a bereaved family at the time of child death and described gaining experience as they gained seniority within the medical profession.



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Pretty comfortable, unfortunately from experience. Nobody teaches you these things. I can remember as a junior doctor, as a registrar, you don't get any experience as a resident but as a registrar where we pulled the plug on some kid in intensive care—very uneasy, awkward, but I've now got close to 30 years experience up my sleeve and having been there, I'm confident in my own mind that what we're doing is the best care for the child.

(Doctor 2)

These findings bring to light the experiential nature of learning to support families of dying patients. For health professionals experience with dying children and their families is often gained after years of clinical practice when the role may be allocated to them, for example, to registrars or nurses with a few years post graduate experience. The perception of limited educational preparation for such roles is consistent with Moores et al.'s (2007) study where two thirds of doctors surveyed reported that they had received little or no undergraduate or postgraduate education and preparation for how to cope with patient death and over half agreed that further education and training would be beneficial. Similarly, nurses have expressed being unprepared to cope with patient death (Meyer, 2014; Wah Mak et al., 2013) and the need for better educational preparation in this area has been highlighted.

More recently, multi-professional programs for palliative care education at both undergraduate and post graduate levels have been implemented to enhance health professional preparation for palliative care practice. In Australia, the Palliative Care Curriculum for Undergraduates project (PCC4U) has been developed and trialled in ten undergraduate health courses in seven universities (Yates, 2007). (PCC4U) aims to promote the principles of palliative care for all health care providers (PCC4U, 2013). In Europe, the International Paediatric Palliative Care Course has been offered to health professionals across

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35 countries wanting to further their knowledge and skills in paediatric palliative care (Wager et al., 2013).

Health professionals recounted gaining comfort with the role of supporting dying children and families over time. However, despite many years of experience in working with dying children and their families, health professionals also acknowledged still feeling uncertainty at times.

I guess you're trained to save lives, you're not trained to take lives and palliative care is all about taking lives. You can think about it that way, it's keeping people comfortable while they die but the things you use to keep them comfortable, there's no doubt that they speed up their terminal phase of life. I think the big difference was in intensive care; the intensivist starts up the drugs, not me; whereas this time I was starting up the drugs in a situation that I was totally unfamiliar with. (Doctor 2)

Health professionals described making links with other health professionals in palliative care in order to gain insight regarding new or unfamiliar elements of end of life care practice. These links were made with formal professional organisations as well as colleagues. Although health professionals initiated contact with other colleagues to address their need for more information and skills in paediatric palliative care, and there was no specific mention made of mentoring within their existing roles. This may point to a need for mentoring in paediatric palliative care for both doctors and nurses currently working in clinical areas where the care of dying children and their families may be encountered.

## Conclusion

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Health professionals caring for dying children and their families use a variety of strategies to cope with this aspect of their role including seeking out staff who shared the same experience, confiding in a supportive partner, using personal coping strategies such as compartmentalising or focusing on the positives and drawing upon spiritual beliefs. This study's findings indicate that caring and supporting children and families at this time has a pervasive emotional and physical impact on health professionals who need peer support, mentoring and strategies for managing this impact in order to continue to provide this much needed end of life support and care. The findings indicate that most health professionals develop the skills for supporting children and families in end of life care through experience. Undergraduate education can equip beginning health professionals with communication and coping skills needed in providing paediatric end of life care and this focus on educational preparation continues to grow across the health disciplines internationally. Clinical simulation may also play a role in preparing undergraduates so that they begin to develop their experiences early and learn to anticipate and manage their own responses to situations of loss. Lastly, tools that enable clinicians to self evaluate their end of life care practices are also needed in paediatric end of life care and the Desbiens' Palliative Care Nursing Self Competence scale (Desbiens & Fillion, 2011) which has been adapted for paediatrics by Hafiz (2013) is a positive step towards the development of resources to assist nurses to evaluate their care. Further research is needed to develop paediatric specific self-evaluation tools for all health professionals involved in the end of life care for children.

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Table 1 Paediatric items developed by Hafiz (2013) from Desbiens' Palliative Care Nursing Self

Competence scale that specifically target children's and families' needs

1	Involve family in assessing child's pain and effectiveness of pain relieving methods.
2	Assess family preferences in engaging their child in end of life care decision-making.
3	Alert family members to the imminence of death and provide a quiet time and privacy during last hours and days.
4	Assess sibling's needs for psychological support.
5	Assess sibling's needs for spiritual support.
6	Assess grandparents' needs for psychological support.
7	Assess grandparents' needs for spiritual support.
8	Involve family in final nursing care after the child death.

9	Assess pain with age appropriate instruments/tools.
10	Ensure care plans reflect previous successful therapeutic interventions and meet the child's communication and coping styles.
11	Develop awareness of the child's expectations and needs through open discussion of their specific thoughts, feelings, hopes, wishes, fears and memories.
12	Identify and incorporate psychological interventions according to child's developmental level.
13	Identify and incorporate spiritual interventions according to child's developmental level.
14	Consider parent and child needs and preferences and facilitate necessary developmentally appropriate discussions about illness, death and dying.
15	Encourage children to maintain 'normal' activities of daily living,



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	and involvement in school, family and social activities.
16	Incorporate child's values, wishes and beliefs during end of life care.