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The use of reflection in children's palliative care: a revised model

Abstract

The unique needs of children requiring palliative care and their families have been increasingly recognised on a global scale. The complexities of such care, the unpredictability of the illness trajectory and increased choice in terms of where care is provided has led to challenges for nurses/practitioners striving to provide optimal care for these families. Working in partnership with children and families and reflecting on practice are key issues in providing care and support. Reflective models are frequently used as a tool for two reasons – firstly to reflect on practice with the aim of quality improvement and secondly to help practitioners explore difficult or challenging aspects of care negotiated with families. Here we report on a specialised model that has been developed and updated for use within children's palliative care. For reasons of confidentiality, a fictitious case study is used to illustrate how this model could be used during a debriefing session following the death of a child. While more research is needed initial trials of the model by the authors suggests that using specialised reflective models and frameworks can help to facilitate such discussions in children's palliative care.

Introduction

Palliative care for children has continued to develop across countries in the past 2 decades where knowledge and understanding around the care needs of this specific group of children and their families has increased (Together for Short lives (TfSL), 2018). Globally there is recognition of the need to optimise care for children and their families across various settings with recognition of the need for partnership working (NICE, 2017). Developments within the speciality have included a focus on the particular needs of children and young people, for example, those undergoing the transition from child to adult services (Kerr *et al.* 2018) and a shift to include babies both before and immediately after birth within the neonatal palliative care pathway (Peacock *et al.* 2016). Palliative care is provided by a range of professionals across disciplines and organisations, with nurses playing a crucial role. Professionals may work in specialist palliative care settings, for example children's hospices or in areas where these children can be cared for at home or in acute children's wards. Hence levels of knowledge, skills, confidence and competence vary considerably (Royal College of Nursing (RCN), 2018). Whilst formal, specialist education and research based guidelines are viewed as central to the provision of quality care for infants, children and young people and their families (NICE, 2016), the experiences of both practitioners and families is a vital aspect of evidence based palliative care. Thus reflection on and in practice still remains crucial in the delivery of holistic, safe and effective palliative care in partnership with children, young people and their families. As such reflection is threaded throughout the recent Education standard framework for children's palliative care (Children's Palliative Care Education and Training UK and Ireland Action Group, 2020). It is generally accepted that Using a reflective model or framework can help foster critical thinking around care provision in

partnership with families, facilitate shared decision making and contribute to the quality improvement process.

The aim of this article is twofold. Firstly, we provide an updated version of a specialised model for reflection for use in children's palliative care previously published (McNeilly *et al.* 2006). Secondly, we provide an illustration, by way of a case example, of how it may be used in practice to reflect on the death of a child.

Background

Reflection has widely been used in education and clinical practice for many years. While there is no one definition (Nguyen *et al.* 2014), it is generally accepted that reflection can help professionals explore their feelings around challenging aspects of practice, promote critical thinking and problem solving and identify lessons learnt to inform future practice (Welp *et al.* 2018). The use of reflection has traditionally been seen as a personal activity and indeed this forms part of the current revalidation process for nurses registering within the UK (NMC, 2019); however, it can also be conducted in a group setting with the interdisciplinary/multiagency team. This may be particularly relevant for those working within palliative care where many challenges exist for families and practitioners, not least at the end of life phase (TSL, 2018). Previous authors have reported the benefits of multidisciplinary group reflection and debrief following the death of a child. For example, in a study by Keene *et al.* (2010), professional distress was cited as the most frequent reason for attendance at such debriefing sessions. Such distress was related to having a long term relationship with the family and witnessing parents' pain amongst other factors.

Numerous generic models have been devised in order to provide a structure or framework to facilitate the reflective process; for example, Gibbs (1988) and Johns (2000). Souter (2003) adapted the latter for use within adult palliative care. However, palliative care for children is unique in a number of ways and an increasing number of children are presenting with very specific and particularly complex needs. Clearly this can bring additional challenges for both families and service providers and as such a specialised model is warranted. Here we present a revised model of reflection in children's palliative care, first published by McNeilly *et al.* in 2006. The original model involved 5 key phases: a preliminary phase, phases 1-3, including a deductive phase and inductive phase and a final post reflection stage that focused on the outcomes of the reflection and further action required. While the model was used periodically in a local context in both education and practice, it became evident from anecdotal feedback that it would benefit from revision and further development. Firstly, some practitioners felt that it could be more streamlined and was unnecessarily detailed. Secondly, it became clear that palliative care provision had become increasingly complex, leading to multiple challenges for both families and practitioners across the hospital/community/ interdisciplinary/interagency interface.

Consequently, the opportunity arose to consider what could be provided to support practitioners working with children and families requiring a palliative approach to care and potentially lead to quality improvement and practice development.

The revised model

The revised model was developed by the authors (with representation from one local Health and Social Care Trust, the local children's hospice and 2 educational institutions) over a series of meetings. It was anticipated that it could be used on an individual or on a group basis to:

1. reflect on positive and negative experiences in a given situation and in so doing provide some level of catharsis and mutual support.
2. assess and review the quality of care provided to the child and family.
3. identify learning from the situation
3. identify if further action is required on an individual or wider basis.

It has undergone small scale testing by the guiding team during debriefing with community children's nurses and is presented in Figure 1. Accompanying guidance notes for use have been developed and are available from the first author.

A case study presented below, based on a fictional team brief, describes the model stages and its potential application to practice.

Case study

Sarah was the first and only child of Claire and Martin. She experienced hypoxia at birth and as a consequence had complex health needs. She had cerebral palsy, dystonia, seizures, feeding difficulties, visual impairment and developmental delay. Sarah loved being held by her mum and dad. She loved music and being in water. She loved being out in fresh air. While frequent chest infections, seizures and dystonia related pain limited her time in school, she enjoyed being with her classmates and the new experiences the school day brought. Unfortunately, Sarah's health deteriorated over a period of months and she was six years old when she died.

Sarah was referred to the Community Children's Nursing CCN team at birth and the team had been highly involved in her care. She had a care package and healthcare assistants within the team provided three hours of support and one overnight sit per week. The nurses not only responded to Sarah's medical and nursing care needs, they also were an important source of support to Claire after she and Martin separated. Sarah's final 5 weeks were spent at home with a high level of involvement from the team. During this time, Sarah's seizures were difficult to control and she was in a state of agitation despite much intervention and ongoing review of her symptoms. She was unable to tolerate feeds and

was producing increasing secretions. Following input from the paediatrician, the CCN and children's hospice team, feeds and fluids were withheld for the last 7 days of her life. Following this decision, Sarah was more settled and slept for long periods of time. The hospice community nurse was present when Sarah died late into the evening. The team leader requested a debriefing session as several months had passed since Sarah's death as they continued to visit Claire every week but were struggling to support her through her grief.

Preparatory activity

The debriefing session was led by the bereavement co-ordinator and took place with six members of the team, four nurses and two healthcare assistants. Participants received a copy of the model and the guidance notes beforehand to familiarise them with the model and to provide an opportunity to identify the aspects most pertinent to them before the session. Ground rules were set at the beginning of the session which included maintaining confidentiality, the scope of confidentiality and the agreed response and aftercare should individuals become distressed.

Stages of the model

The model is comprised of 7 steps which prompt reflection. It acts as an aid memoire to facilitate discussion according to the elements relevant to a specific case rather than as a structured template where every element needs to be systematically followed (see Figure 1).

1. Family story

In keeping with the first element in the model, the session began by providing a space for participants to tell the family story. This was not rushed as, in keeping with Drumm (2013), it was evident that telling the individual and team story was, in itself, therapeutic. Essentially it facilitated personal understanding, assisted individuals to reframe the story where appropriate and engendered collective empathy.

2. Contextual factors

According to Rolfe (2002) additional factors, such as the socio-cultural context are important in reflective practice. Questions to be considered here include: What was important to understand about the child/family's situation and what factors led up to the circumstances under discussion? Examples include:

- a. Situational constraints such as single parent families, financial pressures, work pressures, scope of family support, other physical or mental illnesses within the immediate or extended family.

- b. Cultural values that may have impacted on the family's perspective, such as gender roles.
- c. Religious values that impacted on the family's perspective in terms of illness related beliefs and the impact of faith on how illness is perceived and its contribution within the family's support structure.
- d. Spiritual values: how the impact of the child's illness was considered in existential terms such as the meaning, value and vulnerability of life.
- e. Professional issues such as accountability, advocacy, duty of care, duty of candour.
- f. Legal issues; e.g. issues related to mental capacity and the rights of the child (UNCRC).
- g. Ethical issues such as truth telling, withholding fluids and doctrine of double intent.
- h. Social/political issues: the impact of political and strategic decisions on the family, e.g. the availability of support services or the physical environment.

When considered in the team debrief, participants specifically identified that Claire's stress increased when she became a lone parent following her separation from Martin, and this was compounded by the absence of supportive relationships within her wider family and social networks. The relationship with the CCN team members grew in significance at this time as they offered emotional and practical support as well as clinical expertise. Additionally, Claire was experiencing financial problems following marital breakdown and she was having increasing mental health issues. Symptom management was a real challenge approaching the end of life phase as were efforts to provide 24-hour care at home.

3. The situation

This step explores the situation in more detail. Questions to be considered here include:

- a. Who was involved and what was their role?
- b. What, on reflection, went well?
- c. What didn't go so well, or what challenged you?
- d. How did you feel about the situation and how did this situation impact on you emotionally?

Reflecting on the team's involvement with the family there was consensus that despite the challenges, the care provided prior to and at the time of Sarah's death was good. In particular, those present felt that there had been optimal multi-professional/multi-agency working leading up to and during the end of life phase. While issues around symptom management were challenging, those present felt that the right decisions had been made at the right time. Nevertheless, the provision of 24-hour care at home over the last weeks and the unpredictability of the final phase

had been emotionally exhausting. Additionally, the staff were finding supporting Claire through her bereavement equally challenging. She was feeling sad, isolated and fearful about the future.

4. a,b,c - Additional factors

In this section it is important to explore whether or not the child and family wishes and the professional goals were aligned, or whether there were areas of variance between them that impacted on the child and family's care.

Questions to be considered here include:

a. **Personal factors:** Did your personal values impact on the situation? This may relate to your personal value base and/or ethical principles. There may be personal biases that impact negatively on the situation, such as your personal belief systems and those of others. How did your current level of knowledge, relating to what you have learnt (empirical) and what you have gained through prior experience (experiential), contribute to this event? Was this sufficient? Can you identify a gap in your knowledge?

In relation to Claire and Sarah's case, each participant was invited to reflect upon the personal factors of note to themselves. While those present felt that they had been well supported, they varied in their experience and level of additional training around providing palliative care at home. Two of the staff felt they needed more training around symptom management and actions required around the certification of death and care required immediately after. For example, the collection of mementos and funeral arrangements in cases where wider family support was not available. Additionally, the intensity of the relationship with Claire before and after Sarah's death, personal feelings of grief and a desire to further develop skills in relation to supporting Claire through grief well also came to the fore.

b. **Child and family factors:** Did you know i) the child's, and ii) the parents' wishes/expectations? Did these align with professionals' goals?

Applying the framework led the participants to identify that, in terms of advanced care planning, Claire had not been ready to discuss plans and expectations around the end of life care that the team could provide. This was influenced by previous periods of time where Sarah's health had deteriorated and then she recovered. Hence, an end of life care package was developed at a late stage and this had proved challenging. Claire's wishes for a home death were upheld, at least to some extent, because of the commitment and dedication of the healthcare team who provided care over and above what might have been expected of them.

c. **Professional factors** -What were your professional goals for this child and family?

- Were there differences of opinion between professionals?
- Were there differences of opinion between the child and/or their parents and/or professionals?
- Was your scope of practice, or your goals of care challenged in this situation?

Those attending the debrief shared goals in terms of the provision of best care for the family whilst working in partnership with Claire. However, the provision of 24-hour care in the last weeks was particularly challenging for the community team.

5. Outcomes

This section relates to the outcomes of the event. Key questions in this section include:

- a. What were the perceived outcomes for the child and family?
- b. What were the outcomes for the professional team?
- c. What was the outcome and how did this impact on you?

While the team acknowledged that Claire was unable to engage meaningful in end of life planning that may have helped to plan for Sarah to die from home and provide further support in terms of 24-hour care. Discussion followed around advanced care planning, who might take a lead role and what training might be needed around this area.

6. Considering the above stages:

This section relates to reviewing the previous stages. Taking the above into consideration:

- a. What have you learned?
- b. Has this altered your initial perspective of the situation?

Use of the model as a framework for debriefing helped the team to think critically about the situation and the care provided. Overall they concluded that a high standard of quality care had been provided. Challenges of providing 24-hour care were identified as an ongoing key issue and the decision was made to form a

regional group to explore this area further. While some parents may never be willing to engage in advanced care planning, some members of the team felt that they needed further training in this area. In terms of wider learning, the discussion revealed a great concern for Claire and a desire to continue a supportive relationship with her. Letting go was personally challenging yet they acknowledged that other services were better skilled to provide bereavement support. On reflection, participants acknowledged that while they outline the nature of their role when they first engage with families they currently do not articulate or plan with families for their withdrawal. While this may not be necessary in many cases, there are times when they have had a long established relationship with families when discussing and planning for this change would be worthwhile

7. Action plan

The last section is about determining whether or not action should be taken to influence the outcome in a similar situation again. Questions to be considered here include:

- a. Does anything need to change?
- b. Who do you need to discuss this with?
- c. Make a plan for your identified actions.

In concluding the session, the team identified a number of actions which included:

- Clarifying Claire's wishes and expectations as regards ongoing input from the CCN team
- Liaising with the specialist nursing service providing bereavement support
- Agreeing a plan for a gradual withdrawal of the CCN team over the coming months
- Developing a plan to access further learning around advanced care planning, grief and bereavement.

Those present agreed to share the plan with their team leader.

Reflection on the model

While the model shares many similar elements with Gibbs (1988) and Johns (2000) the added value lies within the prompts associated with the 4th element. These reflect the unique elements associated with caring for children and families where working in partnership requires the practitioner to respect and take account of the child's autonomy (where appropriate) and the expertise and responsibilities which lie with parents. Collaborative working requires a shared understanding and a sense of parents and practitioners being 'on the same page'. Exploring these factors enabled

participants to distil important perspectives that influenced their learning and action plan which may have been missed through the aforementioned models.

Discussion

With advancements in technology, treatments and medical expertise many children are now surviving with complex, life-limiting, life-threatening conditions and living for longer than would previously have been possible (DH, 2016). Palliative care for these children has increased in complexity and this can bring additional challenges for families and service providers. As previously stated, previous authors have developed models for use in adult palliative care (see for example, Souter, 2003; Kenny, 2003; Fook and Kellehear, 2010). The authors are unaware of similar models that have been developed or adapted for use in children's palliative care. In this article we have presented a specialised, revised model that can be used to reflect on caring for children and families requiring a palliative approach to care.

While reflection has traditionally been a personal activity there is increasing emphasis on its potential use in group reflection and debriefing after a significant clinical event. However, further research is needed. A review by Anderson *et al.* (2019) reported that the published literature around group reflection following the death of a patient was mainly descriptive with no comparative studies. Nevertheless there was some evidence that the process of team based reflection following the death of a patient by healthcare professionals led to improved emotional well-being and learning for future quality improvement.

Key to successful group reflection is the need for an experienced facilitator to assist in the reflective process and deal with difficult issues that may arise. Previous research has highlighted barriers to open group discussions such as feelings of vulnerability and fear of exposure that can result in participants being unable to openly and honestly discuss their practice in a critical way (Platzer *et al.* 2000). Thus, it is equally imperative that the facilitator follows up any specific difficulties on an individual basis and provides nurture and support (Bulman *et al.* 2014). They should also be aware of local support mechanisms for practitioners, for example, in relation to support from occupational health or an appropriate counselling service, if appropriate. TSL (2018) point out that the team caring for children and families should receive ongoing support and have the opportunity to feedback and discuss care provided. Group debriefing, as described here, is one way of contributing to this process.

Conclusion

The model presented here has been initially trialled in practice with nursing staff. Future work will involve securing funding to evaluate the model to explore its effectiveness as a framework for use in practice in terms of benefits, identify any

possible drawbacks and amend it if necessary. Finally, it is anticipated that the model could be more widely used by the interdisciplinary, interagency team when debriefing following the death of a child as a mechanism for emotional support, developing critical thinking and ultimately improving outcomes for families.

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