Supporting parents and children prior to parental death in an NHS setting

Catriona Macpherson
Children and Families Practitioner
Fife Specialist Palliative Care
Victoria Hospice, Victoria Hospital
Kirkcaldy, Fife
catrionamacpherson@nhs.net

The Children and Families Service in Fife Specialist Palliative Care adopts a psycho-educational model of support which offers advice and information to enable parents to prepare themselves and their children for parental dying, death and bereavement. The role of the Children and Families Practitioner is to support the family as early as possible, through each stage of their journey through bereavement, as far as possible. Working closely with school staff and other services ensures that everyone concerned has the information they need from us to support the children and young people concerned.

Preparing a child for parental death is undoubtedly one of the most overwhelming experiences for a parent. It is also one of the most challenging for healthcare professionals who aim to adopt a family-centred model of care to help patients, carers and families prepare for death and bereavement (The Scottish Government, 2011). It is often only at crisis moments, such as when given bad news about disease recurrence, that parents start to think about preparing their children. These may be the times when they feel least prepared to do so (Park et al., 2016; Sutter & Reid, 2009).

In Fife, Scotland, all specialist palliative care, including hospital, hospice and community care, is provided by the NHS. There are close working relationships with Oncology staff and our local Maggie's Centre which offers support for anyone affected by cancer at any stage of their journey. In practice, this should enhance the opportunity to provide seamless care from diagnosis through to bereavement care for family members. However, there are many factors that may interrupt the potential for family-centred care, and in particular, meeting the needs of children in the family. We might consider these in terms of each perspective.

The practitioner perspective

Practitioners have the responsibility to provide ethical, equitable, empirically proven, holistic, person centred care to patients, family/carers, both as individuals, and as a family, to prepare for death and bereavement (The Scottish Government, 2011). This is no small ask. Judging the timing during such an endeavour raises ethical conflicts and contradictions, even with families who appear to be collaborating well on decision making.

It has been argued, rightly, that practitioners provide overly adult focussed family services (Comben, 2011), and cite communication with families about their children's needs as an area of work about which they feel least confident (Fearnley, 2010). My role as a Children and Families Practitioner, with specific responsibility for supporting parents to prepare themselves and their children for parental death, and to support other practitioners to do likewise, is somewhat unusual, especially within the NHS.

However, it is clear that such practice needs to be seen as core to bereavement care, particularly with the advent of the *Carers (Scotland) Act 2016* (The Scottish Government, 2016). Positioning such services within health care is so important because of the shared knowledge of the patient's condition, possible outcomes and timescales. Whilst such information is not 'ours', we generally acquire it before the patient. We have then to negotiate how to share it, depending on its recipient's wishes. The pacing of information giving, whilst respecting the patient's rights not to know, can be enormously tricky and patients are well able to prevent the giving of bad news regardless of a practitioner's skill in communication (Hunt & Meerabeau, 1993).

Psychosocial care is deeply embedded in palliative care and includes both the aims of maximising individual psychological security and autonomy, and enhancing significant bonds in order to address the social meanings of a death within the family (Corr, 1992). In other words,

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a parent stays a parent when they are dying and we have a responsibility to facilitate the maintenance of that role.

Parents find it hard to raise the subject of anticipated death (Thastum, Munch-Hansen, Wiell & Romer, 2006), and if they expect professionals, such as oncologists, to be the ones to re-visit the topic of their prognosis (Park et al., 2016), we need to be finding ways in advance of more clearly setting a contract with patients about their communication wishes over time. This is all the more the case when we know that parental coping strategies include the avoidance of discussion about their illness as a method of compartmentalising anxiety. Communication about end of life is more likely to happen where clearer information regarding prognosis has been received, a core feature of hospice service provision (Park et al., 2016). Assessing the understanding of parents is complex, but important, because it is obvious that none of us can talk about our dying and death with our children until we have ourselves faced it.

It is also important to note that, assuming a patient has capacity, it is their right to make decisions about how details of their confidential information is shared with family (General Medical Council, 2009). This complication tends to be under-estimated in child bereavement literature (Macpherson, 2017), and it means that even when practitioners know most children want the information, and may perceive cues that it is wished, they are not at liberty to offer it. This is not simply resolved by changing legislation to accommodate children's needs (Karidar, Åkesson & Glasdam, 2016), and in any case, ethical practice entails facilitating parents to continue to see themselves as the best person to communicate with their child.

The patient perspective

There are many reasons why the preparation of children in a family is often commenced in the late stages of a patient's life. Patients with dependents are more likely to choose life-prolonging treatment over symptom relief in last 6 months of life, report significantly more anxiety and worse quality of life at end of life (as do their co-parents), and are less likely to engage in advance care planning (Park et al., 2016; Yopp, Park, Edwards, Deal & Rosenstein, 2015; Lovell & Yates, 2014, Nilsson et al., 2009; Siegel, Karus & Raevis, 1996).

We also know that family problems and communication breakdown are common causes of patient suffering (Cherny, Coyle & Foley, 1994), causing offspring unhappiness is a source of guilt (Bolmsjo, 2000) and that high rates of anxiety and depressive symptoms in parents are correlated with parenting concerns including the emotional impact of disease on their children and worries about being a 'good parent' (Park et al., 2016; Muriel et al., 2012; Kennedy & Lloyd Williams, 2009; Turner et al., 2007; Helseth & Ulfsæt, 2003). Worrying about managing to maintain your parental responsibilities and missing out on the joys and worries of the role has been shown to be a major influence on treatment decision making (Park et al., 2016). Worrying about the disruption to your children's daily routines, the potential harm emotionally of your death upon them and the quality of parenting your children will receive in your (irreplaceable) absence (Park et al., 2016) may understandably be something you do not wish to explore with health care professionals.

This is not to say that parents completely exclude planning for the future. Many will formalise care arrangements and engage with financial and legal concerns and Park et al (2016) found evidence that parents consciously chose to impart learning from their own life, including memories, values and decision making processes. However, the process of talking about advanced cancer, dying and bereavement seems far harder for parents to approach and there is some evidence that it is more likely to occur when the youngest child is older, and the patient is experiencing greater symptom burden (Hailey et al., 2018). This means that practitioners working with parents frequently encounter parents who will talk about what they wish to leave for their children but wish to delay conversations about what is actually happening for as long as possible.

The co-parent perspective

Patients may share their parenting with a number of different co-parents, including the other biological parent, stepparent, grandparent or sibling. Identifying who is significant to the children and who ultimately will have responsibility for them during a patient's period of treatment, hospitalisation or incapacity may be less straightforward than it sounds. Not all families are in agreement about these decisions and the treatment period is the time when it becomes crucial to clarify this. This is particularly the case because the coping, functioning and quality of the communication and parenting of the surviving parent is the most powerful predictor of a child's psycho-social functioning and adjustment to death of a parent (Haine, Wolchik, Sandler, Millsap & Ayers, 2006; Christ, 2000; Worden, 1996).

Even when family caregiving responsibilities are clear, the co-parent can be under enormous strain. Patient and co-parent are unlikely to be able to talk to children about what is happening until they are able to talk together, both about their shared parenting relationship and about the dying process (Macpherson, 2005). Assuming parents understand their children's need for information, they struggle to provide it for understandable reasons: they are afraid of frightening them and seeming to take away any sense of hope or of not doing it 'right" (Elmberger, Bolund & Lutzen, 2005; Barnes et al., 2000; Buxbaum & Brant, 2001) and they feel they don't have knowledge about reactions or how to respond to them (Helseth & Ulfsæt, 2003).

The co-parent is usually very worried about the patient and, in my experience, often traumatised by the side effects of treatments. They therefore wish to focus on how to help their partner, (and children) practically. They may often also wish to discuss practical preparation for the dying process, the funeral and how to be a single parent. Equally, they wish to avoid causing further pain to their partner by bringing up emotionally challenging decisions or losing control of their own feelings. I am often approached privately by co-parents anxious to start these discussions, but struggling with guilt for doing so.

So, each is aware that the other is distressed, neither wishes to burden the other with their concerns, and the co-parent is unlikely to go against the wishes of the dying parent, unless the decision is no longer perceived as shared (for example when the patient is unconscious) (Macpherson, 2005). Even when opportunities to actively focus on children's needs and to explore and rehearse communication with them are offered this process is emotionally demanding and time consuming, and the poignancy and preciousness of time and timing are ever present. Parents generally delay breaking this worst and final news for as long as possible, and usually, until the last possible moment. This means that practitioners are facilitating the maximum amount of decision-making achievable in the minimum amount of time possible.

The children's perspective

The loss of parent is usually the loss of a primary attachment figure, a person uniquely able to foster feelings of security in a child. This individual cannot simply be replaced (Bowlby, 1980). The fear for many parents is intuitively that their loss will mean their child's sense of security will be affected for the remainder of their life and lead to later problems in developing close personal relationships. This is made all the more complex when insecurity of attachment has been a feature.

Emotional developmental stage is key to children's understanding, experience and expression of grief, which is further sculpted by the language they have available to them. In most families I have worked with, it is clear that children's understanding is somewhat ahead of their ability to express what they think is happening. This is demonstrated by behavioural change, an inevitable response to anxiety and changes within the family. Children have less control over their circumstances and need continuing staged information, at the right time, especially given that adjusting to parental bereavement will be a lifelong process.

Christ (2000) comprehensively explored the needs of children with a seriously ill parent. However, there is a dearth of research examining actual communication between young children and their parents at end of life, for obvious ethical reasons. However, it is equally argued that it is unethical *not* to be studying the interactions between parents and children before death because we miss building crucial understandings regarding the needs of especially vulnerable groups, such as children losing a single parent to death, and the effects of poverty on pre-bereavement (Christ, 2000).

Research with adolescents suggests that they tend to resist professional input (Dehlin & Mårtensson Reg, 2009), and like adults, are perfectly capable of evading illness related communication (Hailey et al., 2017). In a national Swedish study, teenagers retrospectively reported their experiences of parental death and only 60% reported having been told that the death was imminent. 44% realised that death was imminent only on the day of the death and 19% never realised it (Bylund Grenklo et al., 2013). Nearly all the participants thought that teenagers should be told when death was expected in order to be given a chance to say goodbye and prepare emotionally for the loss. A significant secondary finding in this study was that 'trust' in the care provided to their dying parent was highest when they had been told, which has obvious impact on their future relationship with care providers (Bylund Grenklo et al., 2013). Assuming experiences in the UK are not dissimilar, we still have some way to go in reaching our aspiration that children receive the right help at the right time (Scottish Government 2012, *Getting It Right For Every Child* (GIRFEC): http://www.scotland.gov.uk/gettingitright), and specifically 'information, guidance and support to enable them to manage the impact of death on their lives' (Child Bereavement Network, 2001).

Initiatives for working with families

The above perspectives point to the need to work with the family as a system comprised of individuals and relationships whose needs may overlap but not necessarily concur (Breen et al., 2018). Parents need help with grasping their children's comprehension of the situation in relation to their emotional maturity, but also within the context of the family's culture and religious beliefs. This all becomes far more challenging for professionals when they are dealing with complex family situations, such as single parents with no extended family, adversarial parents, families with pre-existing unresolved trauma or bereavement, families who cannot find a way out of chaotic functioning, or who are subject to powerful control by one individual (Macpherson, 2009).

Within our service we have for some years run regular, full day training for senior staff to focus on the needs of patients, co-parents and children. Palliative care practitioners are not family therapists, but they are able to make some baseline assessment which provides insight into the way a child is related to in their family, and in particular, understanding the ways in which the family safeguards and promotes the child's well-being. However, the recent emphasis on the provision of End of Life Care at home (The Scottish Government, 2015) may conflict with nurturing children (Turner & Almack, 2017), increase the practical and emotional demands on parents and young carers and require far more nuanced assessment and support packages for families.

We have recently set up a parents' advice clinic to which any patient diagnosed with advanced cancer, recurrence of disease, or palliative care needs (or their co-parent partners) may be referred. In addition, any patient or co-parent at any stage of their journey who is expressing difficulties with communication with their children or other family members about their disease, or resultant role changes, may be referred. Referrals come from oncology, palliative or primary care services.

Whilst offering psychosocial support as a routine part of care is desirable (Ernst et al., 2013; Inhestern, Haller, Wlodarczyk & Bergelt, 2016), considerable preparatory work is usually needed before parents agree to talk with someone like me about their communication with their children because they are often concerned that they will lose control over what their children know. My role is to establish a working relationship on their terms, find a shared understanding and establish where they are in their own understanding and communication, and other concurrent complexities affecting their lives. Only then might I start exploring what they think their children understand, what they have told them and reactions they have observed in their children. This offers the opportunity to reinforce resilience building, such as by emphasising the crucial role of at least one unconditionally supportive parent or parent substitute, the importance of routines and consistent boundary keeping (whilst identifying what might have changed), building strong social support networks, school and out of school activities and enhancing self-esteem by praising a child's efforts to make a difference when they help with simple tasks at home. Once we have established this baseline, questions around their memorialising wishes, end of life care wishes (if they are ready to discuss these) and sharing aspirations for parenting including the importance of continuing bonds (Silverman, 2000, Worden, 1996), are usually also raised.

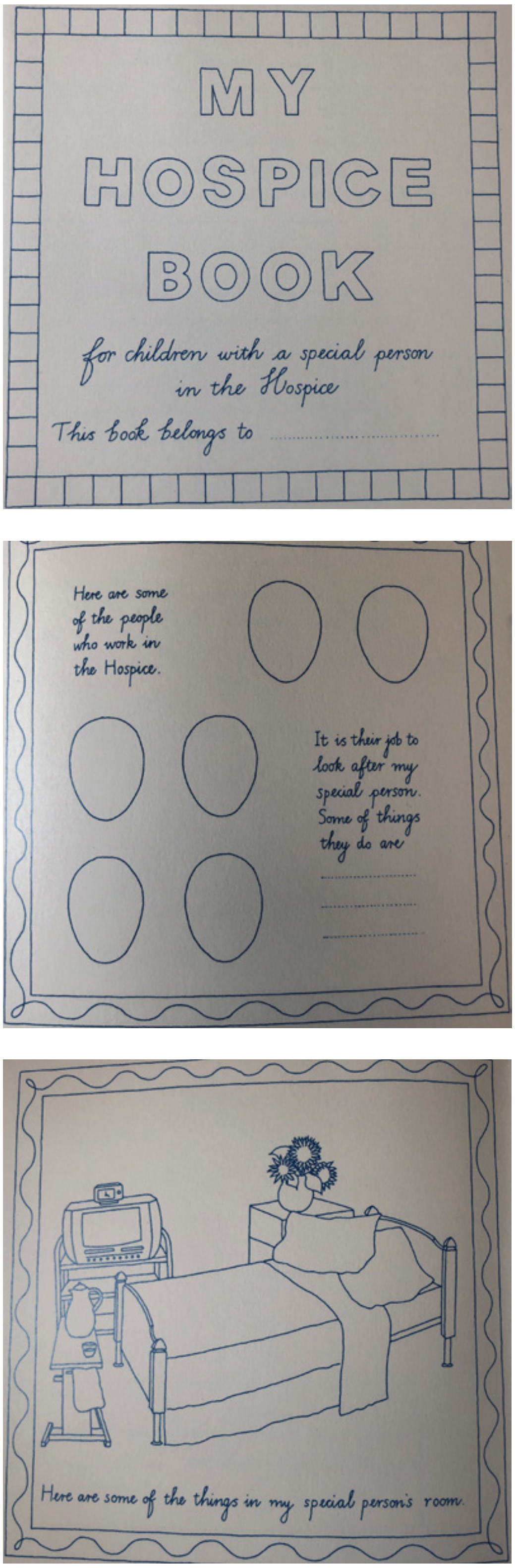
Parents worry about giving information if they believe that their child is 'too young to understand' or is unaware and 'doing fine'. They worry that older children will 'get too upset', and they often lack confidence in own ability, fearing that they themselves will be overwhelmed and make things worse for their children. Helping parents to consider the ways that their children are picking up on all sorts of cues including complex adult emotional responses, and see that distorted or incomplete information is likely to lead to feelings of confusion and insecurity is key. Most parents can be helped to understand that they need to give permission to their children to ask questions and explore their thoughts and feelings as part of learning how to manage painful loss. Most agree, in principle, that their children have the right to know about any situation which affects them, though this may conflict with the rights of others and emotional comfort of all. Finding language to discuss life limiting disease, dying and bereavement, is a major concern to parents. Helping them to plan ahead with each stage of information with a step-by-step approach is generally received with relief. The line between 'won't get better' and dying is one that requires particular care and attention and often requires more than one meeting.

When parents are really struggling to talk to their children my final 'card' is the position that honesty is not the same as openness. Children can be helped to understand that there are some things that we (the parents) are worried about, that these are not your (the children's) fault and when we have worked them out ourselves we will talk to you about them. Most parents do not want to lie to their children; they just don't yet feel ready to be completely open. There are some 'adult-only' family matters, and not everything can be explained. Being honest means acknowledging this.

Taking the approach that parents are able to identify their own family needs (Asbury, Lalayiannis & Walshe, 2014), we plan to gather data on the issues they raise, and use this to develop guidelines for simple practitioner led approaches offering support as early as possible. Where greater complexity of need is identified, families are referred to Child and Adolescent Mental Health Services.

Working in the hospice setting makes taking an active partnership approach with parents more straightforward. The staff team may form, for a period of time, membership of a range of people in children's lives who have an influence upon their attachment relations and emotional development. As such we have some responsibility to help parents offer consistent parenting which enables their children to feel that their environment is structured and relatively predictable (Burns, 2009). We can help children and young people to settle in, advise on visiting and staying over arrangements and encourage private time for individual children with their parent. In addition, staff are modelling behaviours by giving words for what children can see, explaining what they are doing and why, listening, and giving the opportunities to ask questions, and where appropriate allowing children to help with simple patient care tasks, using that as an opportunity to praise achievement. Helping parents to interpret behaviour that reflects a child's confusion or distress empathically can also make a big difference to family communication. It is part of my role to routinely liaise with school staff, for which parents are usually relieved to give consent.

A simple hospice initiative has been the introduction of a Children's, Young person's and Parent's Quiet Corner. Conscious that parents or carers are often torn between spending time with their terminally ill loved one and supporting and occupying their children, we have always tried to provide some facilities (such as art and craft



MY HOSPICE BOOK

for children with a special person in the Hospice

This book belongs to ....

Here are some of the people who work in the Hospice.

It is their job to look after my special person. Some of things they do are

....

....

....

Here are some of the things in my special person's room.

Samples from simple workbooks developed as part of support and communication with children who have a 'special person' in the hospice. The workbooks encourage them to find out names of staff in the team, to become familiar with the hospice, and to explore questions they might like to ask.

materials), to make regular or protracted visiting for children a more enjoyable experience.

The Quiet Corner was proposed as a safe, child-centred corner with the therapeutic purpose of allowing reflective time, supporting the adjustment to a potentially worrying environment and enabling the assimilation of new information and experiences. We do not 'staff' this space, but encourage parents or family members to facilitate their children using it, and where possible to use it with them.

The Quiet Corner is a simple space enclosed with a hinged book trolley, floored with sensory rugs and beanbag cushions. It includes a range of literary books, reflecting diversity and covering pre-school to adolescence. These include stories about the life cycle and life experiences such as 'The very hungry caterpillar' and 'The story of Tracy Beaker' and non- fiction books, such as talking about your feelings, life events, coming into hospital and interesting facts about the human body. We also have a small range of toys for role-play such as finger puppets and hospital Playmobil. We find that some of our children's books are profoundly helpful to adults, offering the kind of child-centred language that can be so difficult to locate at times of high emotional intensity. We have also developed some simple workbooks about having a special person in the hospice which encourage children to find out names of staff in the team, explore questions they might like to ask or messages they wish to be given (Macpherson & Clark, 2016)

However, there are still occasions when we fail to find a way of working with a parent (Macpherson, 2017). Some will resist working with us, despite our attempts to be 'person-centred'. Sometimes, collectively, we reach limits in language, verbal or non-verbal, to communicate through the depth and complexity of suffering in this situation. Then we have to try and find ways after the death to help the family make meaning. This is work that can *only* be approached by facilitation in individual ways (Innes & Payne, 2009), and sometimes not knowing and inadequate communication *is* part of our professional experience.

Conclusion

Health care practitioners understand the need to support parents to prepare themselves and their dependent children for parental death. However, such preparation is often started very late for a variety of complex and inter-related reasons. Parents who feel more confident at an earlier stage in the disease process about talking to their children, listening to their concerns and answering their questions may be better prepared to deal with the palliative and end of life phase of parental illness and able to parent in the longer term. Priorities for discussion include helping parents to identify their individual and shared emotional needs, their wishes regarding preparing themselves and their children, life review and memorialising wishes. However, there will be some parents who are unable to engage with this process until they are facing end of life, and whilst we need to offer a variety of ways to reach people, we need also to be able to engage quickly and flexibly when time is short. ■

ORCID

Catriona Macpherson http://orcid.org/0000-0002-8256-7507

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