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The Active Witness: Social Work Care of Children and Families at the Time of Child Death

Abstract

The Royal Children's Hospital, Melbourne, is a large tertiary paediatric hospital and primary paediatric trauma centre. One of the more difficult realities of this setting is that not all children survive. End-of-life and immediate bereavement care of families at the time of the death of their child is an integral part of hospital social work. The work draws on a variety of theoretical frameworks and skills, and requires nuanced, responsive reading of family cues as well as carefully crafted systemic work. The clinician listens and bears witness in the immediate aftermath of the death, intervening on multiple levels to foster connections and to facilitate the honouring and leave-taking of the child in the singular way that each family desires. This article describes the knowledge that informs acute bereavement care, and the principles that guide social work clinicians in enacting this knowledge with respect for the particularity of each family.

Unanticipated Child Deaths: Contexts and Impact

Despite the best endeavours of skilled and caring health professionals, in an acute paediatric hospital, some children die. It has been widely noted that the death of a child is one of the most significant losses that can happen in a family (Janzen, Cadell, & Westhues, 2004). A significant number of deaths are anticipated and children, families and staff have some opportunity to prepare for the inevitable. Other deaths are not anticipated and may result from a traumatic accident, nonaccidental injury, unexpected outcome of a known illness, or unexplained events such as an apparently well child collapsing and subsequently dying. When death is unexpected and traumatic the risk of prolonged grief, complicated grief, or posttraumatic stress disorder (PTSD) is increased (Janzen et al., 2004; Kaul, 2001). While all child deaths cause significant distress not only to family and friends but also to staff, the unanticipated deaths have a particular impact, and the work done to support children and families in these situations in the immediate period leading up to the death, the death itself and the time immediately postdeath is rarely described. This article explores the unique role of the hospital social worker in these highly distressing child deaths.

The Social Work Response

Hospital social work department clinicians at the Royal Children's Hospital, Melbourne (RCH), provide a 24-hour on-call service in addition to their usual work hours. This service responds to a number of crisis situations including end-of-life discussions and child deaths. All social work clinicians take part in the on-call roster. They receive training before participating and have a senior social worker available for phone back-up whenever they are on call.

Social workers are a valued and integral part of the health care team in most child death situations at the hospital. The presence of a skilled social worker brings a dimension of care not provided by any other multidisciplinary team member. Bereavement care is nuanced and sophisticated work that draws on a variety of theoretical frameworks as well as core social work skills and values. It can lay the groundwork for grieving families to make meaning from a tragic situation and, if done well, can assist in mitigating trauma (Janzen et al., 2004). The social work clinician can also provide a sense of safety and containment for the healthcare team who work initially to save the child but then, when this is not possible, to facilitate a "good death". While all health care professionals working in these situations endeavour to provide a compassionate and caring response to the child and family, it is the social worker who keeps the whole system in mind throughout the process, bearing witness to the tragedy of unfolding events and intervening on multiple levels to build and maintain connections for, and with, the child and family. The theoretical underpinning of systemic thinking so central to the social work knowledge base assists social workers in navigating this complexity.

Social work bereavement care also utilises many elements of psychological first aid and crisis intervention. However, the work cannot be easily prescribed, as it needs to be crafted according to the very specific needs of each bereaved family, reflecting that, as Silverman has observed: "There are no universal patterns for grieving or for dying and there is no fixed schedule" (2013, p. 223). Social workers are guided in their bereavement work by several principles, in particular, those of fostering connection, active witnessing and listening, following, and guiding.

Witnessing and Fostering Connection at the Time of Death

The on-call social worker is asked to come to assist with, for example, the family of a previously well 14-month-old boy who has apparently had a cardiac arrest at home. The social worker arrives to find the infant being given CPR by a fully involved resuscitation team of doctors and nurses in the Emergency Department resuscitation bay. Shocked parents and grandparents stand back, waiting for a response. After several minutes of concerted effort and no response from the monitors, the resuscitation is called off and the child pronounced dead.

How does the social worker enact the principle of fostering connection in such a tragic and alienating situation? For a time, the child seemed to belong to the medical team and his life was in their hands, now the parents have to find a way to reclaim their relationship with their precious and now deceased child. To see

the lifeless body makes the death real. To see the exhausted and now silent medical team brings home the reality even more. To hear the words confirming death is almost unbearable. For the social worker, to bear witness to this grief, to listen but not intervene in the wailing of the mother and sobbing of the grandparents, to watch and not interfere with their desperate clinging to the child, to allow the staff the humanness of their own grief at their perceived failure to revive this child, is skilled and active work. It may appear that the social worker is merely a presence in this tableau but in fact the worker is consciously listening, observing and responding to all that is going on, gently encouraging the grandmother to comfort her daughter and reconnect as her mother, facilitating staff to say their own goodbye to the child, acknowledging their efforts and reinforcing their connection to each other. The social worker supports the devastated young doctor in his explanations to the parents, assisting with reading family cues and knowing when to speak and when to simply remain present but silent. This is not passive work; it is skilled, dynamic and crucial intervention.

Active Listening, Following and Guiding Postdeath

The roles of the other members of the team change as the focus shifts once the child has died, but for the social worker, the focus was always the family. The worker has had no active part to play in the efforts to save the life of the child. The worker is there to help the family navigate this minefield of emotion and guide them towards the long journey of grief ahead, always acknowledging the particularity of their grieving.

Families have no road map for this journey. Parents and other relatives do not know how to behave, what happens next or what their choices may be. To simply ask a parent “What would you like to do now?” is meaningless in this context. Parents cannot be expected to act in a rational and thoughtful manner at this time but need guidance, a sense of holding and the opportunity to speak of their child and strengthen the connection they fear they have lost. Some parents may want to talk about the events surrounding the child’s death and the social worker needs to be able to listen to this. As the initial shock, disbelief and outpouring of grief dissipates, the social worker may quietly assist the parent to decide what to do next – move to a more intimate and private space, call other relatives or friends, or seek spiritual guidance. The social worker also pays attention to the physical needs of the parent and may organise food and drinks, blankets for the parent, somewhere comfortable to sit down – basic principles of psychological first aid. The worker follows the family’s cues and gauges their readiness for further information not only about what the doctors understand of the causes of the child’s death but also about procedures to come – coroner’s processes, police involvement, etc. In a study of suddenly bereaved parents (Harrington & Sprowl, 2012), parents spoke of their need for “timely and concrete information”. In acute paediatric social work, it is the role of the social worker to ensure this information is given in a way and at a time that the parents can hear and make sense of.

Saying Goodbye

Families have reported that they felt they were not allowed to spend enough time with their child after death (Dent, Condon, Blair, & Fleming, 1996; Smeesters, 2013). The hospital social worker aims to facilitate families spending as much or as little time as they need with their child in an appropriate environment with the people they most want to be present. This time allows parents to carry out the final rituals of parenting for their child – to wash and dress the child, hold and speak words of love and farewell, aloud or silently, to gaze at the face and body of their child for the last time, and try to make sense of the fact that their child is now dead. The social worker plays a crucial role in facilitating these rituals and helping the family to find what is meaningful for them. Worden (2009) identifies accepting the reality of the death as an important task of mourning. The process starts here – recognising the death is real and beginning to find a new way to remain connected to the child. The importance of this ongoing connection has been extensively articulated through the concept of continuing bonds (Klass, Silverman, & Nickman, 1996).

Not all families wish or are able to spend time with their deceased child. Cultural beliefs and rituals, individual family differences, responses to the trauma of the death and simple practicalities may guide these family decisions. Such wishes need to be respected and the family given permission to leave or to stay, as is fitting for them.

If the death is reportable, another layer of grief may be added as families are unable to have all tubes and medical equipment removed from their child’s body, or to wash or dress their child. The child remains entangled in the medical process that failed to save his or her life, and is not yet able to be fully reclaimed by the family. It often falls to the social worker to explain to families in clear and honest language why their child will need to go to the coroner and what the process will involve. Knowing what will happen in the immediate future and why it will happen assists families who feel no sense of control to find some connection and grounding in a world that has been upended. The social worker in this situation also works to help the family look beyond the tubes and lines, to see their child, speak their farewells and their love and reaffirm their significant role in the child’s life.

Staff take great pride in their ability to create mementoes for families when their child dies – hand and foot prints, a lock of hair, a finger or hand print for jewellery. While it is generally nursing staff who create these mementoes, it often falls to the social worker to decide when and how to talk with the family about this and gain their consent or otherwise. When families do not wish to have mementoes created it is the social worker who may explore the meaning behind the family’s wishes and then pass this on to staff to ensure these are understood and respected. When families wish to be involved in memento making, the social worker must work sensitively with staff members and the family to enable parents to be included in a respectful manner.

The time a family can spend with their deceased child is precious and lays the foundation for future memories that do not include only the horror of the death. The social worker observes what is happening and what they can see of the relationship with the child and reflects this back to the family in a powerful therapeutic intervention: "What a beautiful, strong-looking boy he is". This statement triggers a conversation about the child as a living, vibrant person. Maybe his dad is a wrestler and the child was going to follow in his father's footsteps; maybe the child loved the food his grandma prepared for him; maybe the family were proud of his size and robust appearance. In this way the relationship between the child and his family is recognised and he is brought to life for those who never knew him. The love the family felt for him is acknowledged and validated by the observations the social worker makes. The family may share photos and stories with the social worker, inviting the worker into their world. When the child is a very young infant these observations are particularly important, as the family do not have a wealth of memories to draw on and have not had time to discover their child's emerging personality. In these instances comments such as "Look at that little nose – do you think he has his dad's nose?", "You have dressed her so beautifully", or "The nurse told me how she always settled much more easily when you were in the room" reinforce the significance of the parents' relationship with this tiny baby.

This is hard and purposeful work. When it is enacted well, the family feel they have time to begin to integrate their loss, to say farewell to their child and to reconnect to the memories of their living child.

Leave Taking

Although families need time to be with their child it is also important for staff to understand that parents may need assistance with the process of leave taking. Leaving the child in the hospital for the final time is perhaps the hardest thing a parent has to do. To facilitate this leave taking the social worker may ask the family if they would like to know more about what comes next – funeral arrangements, coroner's processes, what will happen to the child's body and so forth. If they have not done so already they may start to talk about likely reactions of other children, and about how grief may feel and be expressed by those closest to the child. The social worker may explore who else needs to be told and who could tell them. They may offer information on support services and common grief and trauma responses, and discuss the immediate practicalities of how the various family members are going to get home. Often the social worker becomes an advocate for the parents with well-meaning others who wish to protect them from the overwhelming pain of returning to a house empty of the vitality of the now dead child. In short, the worker starts to prepare them for the coming hours, days and months outside the relatively safe walls of the hospital. The worker may also identify particular individuals who are most able to receive this information and may play key roles in supporting the family in coming days.

The social worker attempts to understand how the family wish to say goodbye to the child. Do some relatives need to be told gently that the couple need to have the opportunity to spend time alone with their child? Does the mother need to relinquish the child into the arms of the father for a time? Has anyone not had the opportunity to express their grief and to say their farewell? Have any children present been included, had the opportunity to ask questions and have them answered, to be present or absent as they need, to be hugged, included, played with, or fed? All family members need to be given recognition of their singular relationship to their child and the particularity of their loss.

Many families cannot bear the thought of their child being left alone and may request that someone stay with the child until the undertaker comes. Some families wish to wait until the undertaker arrives and want to see their child placed in the undertaker's vehicle. Some want to see their child placed in the mortuary. It is the social worker who attempts to understand the meaning of these requests from the family and does their best to facilitate them. At times this requires advocacy with other members of the care team. Whatever the family needs to be able to leave their child should be, if at all possible, accommodated. It is important, however, to ascertain what the parents understand of what they will see before, for instance, going to the mortuary. Social workers are not always comfortable to hold a dead body if the parents have asked for this, but words and actions can be found to make this better, for example, "Why don't you wrap your baby up snugly and put her in the cot and I will stay with her until the undertaker comes"? Alternatively, perhaps a nurse is able to hold the child while the social worker walks the family out of the hospital. However it is done, this is a crucial and incredibly painful time for the family, and the role of the social worker in making this as good as it can be is significant.

Conclusion

The role of the hospital social worker in the care of a family experiencing the unexpected death of a child is unique in the health care team and requires specialised training and skilled use of self. The social worker supports the family from the beginning through to the time they leave the hospital and beyond. The social worker is not involved in the endeavours to save the child's life and the role does not change when these efforts eventually fail. While nurses may change shifts and doctors move in and out, also tending to living patients, the social worker remains present with the family. Not only must the social worker be present with the family to guide them through this most unexpected and unwelcome of experiences, they must be constantly assessing risk. The worker must be cognisant of the tasks that families are faced with if they are to be able to go on and form a new relationship with their child, must understand trauma responses, grief reactions, cultural needs, support systems, the complexity of a hospital system, and the legal requirements around unexpected deaths. Most of all, the social worker must know how to be an active witness, fostering connections between the family and their child, different family members, parents and surviving children, family and their community, and

members of the health care team. If all this is well attended to, the family are likely to begin on their path of grieving feeling that their child's death was managed by a caring and compassionate team. Nothing can ease the immense and long lasting pain of the death of a child, but good intervention at the time of death may allow the possibility of an investment in living, while carrying the loss.

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