

A Parent's Worst Nightmare: Grief, Families, and the Death of a Child

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Jon was four years old: beautifully and impossibly precocious, engaging, taxing and loving. He was diagnosed with a serious form of leukemia which required very aggressive treatment. Jon was hospitalized and his parents of Chinese Vietnamese background struggled through the English that did nothing to bring clarity to their understanding of how their only son could have this disease that infiltrated his bone marrow. It was quickly decided that Jon needed a bone marrow transplant and Jon underwent the rigorous and demanding process of treatment and isolation. As the Family Support Nurse, I had the privilege of being with Jon every day. He told his mother that he wanted his hair to grow back "yellow" this time like "Auntie Nancy."

Jon, cured of leukemia — as a result of the transplant — developed a cerebral bleed — as a result of the transplant — and died on my birthday. After we all held him and let him go, his mother in a conversation that required neither English nor Vietnamese — a universal language of grief — guided me to the bathroom off of his room and pointed to a bird's nest that she had been monitoring on the ledge outside the window. The mother bird was gone and inside the nest lay a baby bird that died. Jon's mother had seen it that morning and knew it was coming. Like the unspeakable nature of a child's death, she bore this knowledge in her heart.

Grief is the most universal of human experiences; it is also one of the least understood. Layered in this argument is the complex reality that, although we expect to bury and grieve loved ones in our lives, we never anticipate that our children should die before us. The death of a child brings both the loss of a past and a future. I contend that those of us working in the health care system are obligated to understand this

human phenomenon in order to be able to effectively support children and families, as well as our peers and ourselves. This applies equally those of us that work throughout this system as child life workers, nurses, social workers, or members of any of the other professions that come into the "stop in the tracks" experience of the privilege of being alongside children who are dying and families who have to let them go.

Current Understandings of Grief

Grief, as an experience of mystery (Attig, 1996; Klass, Silverman, & Nickman, 1996) that "pervades our human condition" (Attig, 1996, p. 15), has prompted the call to understand, define, predict, and ultimately eradicate it. Within this call, there has been a distinct evolution of thinking of grief as a process of energy withdrawal involved in the psychic process of releasing

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and transferring energy and an association between unsuccessful mourning and melancholia (Freud, 1917/1947); to grief as a disease or pathology with predictable trajectories (Eliot, 1932; Engel, 1961); to grief as a process involving stages and expectations (Bowlby, 1980; Fulconer, 1942; Parkes, 1985; Rando, 1984; Schneider, 1984; Worden, 1982); to grief as requiring models of clinical practice that involves tasks and accomplishments in the work of letting go (Parkes, 1985; Rando, 1984; Schneider, 1984; Worden, 1982).

Shifts in understanding have opened the notion that grief is not something so easily defined or predicted, but rather is an unavoidable life experience that is not anticipated, in spite of any preparation; does not follow a temporal and limited sequence; and ultimately does not result in recovery, resolution, or successful elimination. Rather, it is more currently being regarded as a normal reaction to an event of loss, a response that becomes a part of living and relationships in unique, mutable, life-long, and life changing ways (Attig, 1996; Klass et al., 1996; Moules, 1998; Moules & Amundson, 1997; Moules, Simonson, Prins, Angus & Bell, 2004; Moules, Simonson, Fleiszer, Prins, & Glasgow, 2007; Neimeyer, 2001a, 2001b; Worden, 2000). Ultimately, grief does not result in a “recovery” as seen as a return to the familiar, but in an incor-

poration of the loss into living forward, and an ongoing connection with the deceased that allows one to continue to move ahead in living (Klass et al., 1996; Moules et al., 2004; 2007; White, 1989).

In spite of these shifts in our understandings, however, we have been left a pervasive legacy that finds its place in everyday experience of grief and loss. We are burdened with the idea that there is a right way to “do” grief, that this right way is measured by the absence of grief feelings, and that ultimately, to stray from these prescribed trajectories implants a stamp of failure, if not pathology, that takes shape in lives and relationships (Moules et al. 2004).

Dominant Discourses about Grief

Clinical practice and research (Moules et al., 2004; 2007) have allowed us to examine the kinds of discourses and beliefs that seem to arise in grief experiences. Some of these beliefs are about grief itself and the nature of grief, while others are related to the activities that occur in grief. Other beliefs that surface in grief seem to fall more in the domain of the particularities and complexities of the relationship with the deceased and the events preceding and following the loss.

Discourses about saying goodbye and disconnecting

The legacy left to us that viewed grief as a process of

energy withdrawal and the work of disconnection with the deceased often creates a belief in the bereaved that they ought to be working on “getting over” their loss and learning how to say goodbye to their loved ones. There is a part of grief that absolutely involves a departure, a physical absence, a loss, and ending to a relationship as it once was. We have learned however that, while simultaneously letting go of the deceased, the bereaved are also finding ways to remain connected, to redefine their relationship with the deceased. Michael White (1989) first described this as a process of “saying hullo again” in learning to “re-member” the deceased, to call the deceased back into membership in lives and relationships. The nature of this membership, of course, is changed, though often not the character of it. Silverman and Klass (1996) used the language of “continuing bonds” and staying connected by internalizing and incorporating aspects of the lost person such that a physical presence is no longer necessary for the relationship to exist.

One family member seen in my work expressed her fear that she was losing her memory of her son. The work of staying connected and “re-membering” is also the work of nurturing memories. The beliefs about saying goodbye and letting go are perpetuated and sustained through popular literature, culture, and even some of our



therapeutic practices. Experiences of grief, however, contradict these culturally sanctioned beliefs and, in the contradiction, many people find themselves subscribing to a sense of personal failure, incompetence, and sometimes even pathology when they believe that their continued experience of feeling connected and in relationship is wrong.

Discourses about the time-limited, sequential nature of grief.

Over 100 years of theory, literature, and clinical practice has somehow created a culture of beliefs that grief is a process with a trajectory that is limited and that successful achievement of this enormous process is measured by the absence of grief. My clinical work and research has led me to a different belief that grief is a life-long and life-changing experience marked by shifts in intensity over time but not measured as successful by the evidence of its absence (Moules, 1998; Moules, Thirsk, & Bell, 2006; Moules et al., 2004; 2007).

The contradiction of bereavement experiences suggests this: Grief remains, not with the same intensity of deep, unrelenting sorrow but with aspects of memory, joy, love, connection, celebration and, yes, even pain. As one family member expressed: "We need steps to get on with life, not over him...we're never going to get over his death; we

don't want to." Another family member from our research project (Moules et al., 2007) stated "I wish that people understood that it wasn't a short-term process, and that it is a life-long change." A third member pointedly reminded us that:

How long does it last? I hate that question. But if you really, really insist, I would say if after 2 years and you're still where you are now, then you need to be concerned. But the real answer is never...it's not going to be like this forever, but it's not going to go away either.

The possible damage done by stage model theories of grief have left an imprint that there is a correct sequencing of actions and affect that, if followed correctly, result in the resolution of grief or, in other words, its ending, and in the "recovery" of the bereaved. The bereaved, however, have contradictions where experiences belie and defy these ideas: "recovery" is impossible. Life, as it was known before the death of the loved one, cannot be recovered, and although aspects of it can be reclaimed, there is no absolute recovery. Rather, we are moved into a life-long process of constructing meaning, re-authoring narratives, and relearning the world, our relationships, and often even our identities (Attig, 1996; Klass et al., 1996; Moules et al., 2007; Neimeyer, 2001a, 2001b; White, 1989). Stage model theories perpetuate the

discourse that there is a "right" and "wrong" or a normal way, or at least parameters to experiences and expressions of grief. As a result, some people believe they are not grieving enough or some too much; some move into a protectiveness in shielding their own grief from other family members; some view seeking support as a weakness; some believe that all family members should suffer the same amount at the same time; some believe that grief emotions should be controlled and managed (Moules, 1998).

Beliefs about events connected to the loss.

In the very normal process of reliving, recalling, and reflection that occurs after the death of a loved one, many family members struggle with beliefs around their relationship, their roles, and their responsibilities. These beliefs often arise as beliefs about something they could have done differently in life that may have prevented the death or the nature of the death, around things said or left unsaid prior to the death, about unresolved conflicts, or around concerns about how the dying member may have suffered. At times, these beliefs take the shape of guilt and often this guilt remains unspoken and in its unexpressed containment can become toxic and unrelenting (Moules & Amundson, 1997).

Beliefs about identity.

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al., 2007), a well-seasoned grief counsellor identified that there are three “red flags” that he is vigilant in watching for in his clients who present around grief experiences. These markers are bereaved people who present with guilt that is so overwhelming that it dominates and obscures other emotions of grief, with unrelenting anger that takes on an embitterment or resentment that casts other aspects of grief into the shadows, and finally when the person who has died was so significant to the identity of the bereaved that there is a feeling of complete loss of self. Very often this identity of being a parent is one of the most powerful of identities. If the bereaved person believes that she/he has no identity in the absence of the deceased family member, then this belief can block all of the courage, wisdom, and adventure required of the bereaved, where one enters into an engagement with the loss that is strong enough to sustain it.

Ameliorating Grief: Healing Conversations with Bereaved Families

Wright, Watson, and Bell (1996) suggested that it is the identification of beliefs that are constraining and beliefs that are facilitating that form the core of healing conversations. The work that occurs with the bereaved involves an excavation of the beliefs that may be creating, fuelling, or exacerbating the suffering that is already inherent in grief. In the

uncovering of such beliefs and the gentle and directed challenging of them, lies the possibility of healing conversations.

“To enter the world of one who is grieving, we must choose to listen to the pain behind the words” (Gibbons, 1993, p. 599). The death of a child is oft embodied in many narratives — - narratives of lives lived; of illness, anticipated or sudden; of death; of other losses; of complicated relationships; of joys, regrets, remorse, and guilt, and of continued love in presence and in absence. The context for healing in grief work is solidly rooted in this engagement with families as they begin to realize that their suffering is heard, honoured, and acknowledged. In grief work, recognizing suffering is a means of remembering and joining families in their need to remember and “re-member” (White, 1989); it is about tending to the woundedness and rawness that lies in loss (Moules et al., 2007).

In the face of many beliefs that may either constrain or create more suffering for families in grief or that may facilitate healing, it is often in discussions of spiritual beliefs where conversations of therapeutic healing are located (Moules et al., 2007). The work of grief is often about making sense of it, searching for meaning and understanding. “The core of work with the bereaved is spiritual in nature because the core of grief is a spiritual experience. It is an

experience of making meaning, doubting meaning, or questioning the purpose of lives lived, living, and lost” (Moules et al., 2007, p. 127).

Another belief that seems to find its way often into therapeutic conversation is the notion of the purpose of “grief work” as being that of simply letting go or saying goodbye. In the uncovering of this belief, the clinician might recognize the opportunity to gently offer challenge and an invitation to consider grief as a process of connection rather than just separation.

The challenging of beliefs that contribute to suffering in grief happens in many ways (Wright et al., 1996). The challenge is embedded in commendations (Houger Limacher & Wright, 2003; Wright & Leahey, 2005; Wright et al., 1996) that recognize families’ strengths in the face of immense pain, resilience at times of most wanting to abandon faith and belief, and in the offering of hope in a family’s ability to navigate the pain of grief and re-negotiate a life that continues in the absence of a loved one’s physical presence. The challenge to these beliefs can be embedded in thoughtful comments, observations, new ideas, and suggestions offered by clinicians or in reflecting teams (Andersen, 1987; 1991). They can be incorporated into therapeutic letters (Epston, 1994; Moules, 2002, 2003) in efforts to extend and expand the clinical conversation. The



challenge lies in skilfully considered and crafted questions (Tomm, 1987; 1988) that invite reflection and ultimately offer the possibility of new beliefs that might better serve the family.

Of all the beliefs that most show up in the loss of a child the most powerful might be the socially sanctioned, erroneous idea that grief work only involves the process of saying goodbye. The offering of a “professional” belief that staying connected is also the work of grief seems to have the potential for initial relief and, then, the development of a sustaining sense of peace in the recognition that to feel connected is not only “normal” and “okay” but healthy. For example, in one therapeutic conversation, the clinician offered her belief that grief work is not just about saying goodbye but finding ways to stay connected to the deceased in such a way that there is comfort and relationship; there is re-remembering. After this offering of the clinician’s belief, a family member offered her insight that, prior to this, she may not have been open to admitting that she did still feel connected. Instead, she might have been conscripted into a conspiracy of silence and hiding, only admitting to herself that she felt connected and had found private ways to allow the connection. With the offering of our belief, she felt the courage and confidence to express her own belief which was seen by

the team as facilitating. She insightfully offered this comment:

When you lose somebody, it’s almost like you’re building a house and when somebody dies, all the top gets taken off but the foundation is still there ... So we still have this foundation but we have to build it up again and in that foundation are my dad and brother — still there. They’re still there. And they’re so much engrained in who we are but all of the physical manifestations of them are gone (Moules et al., 2004, p. 102).

Once a parent, one is always a parent, whether the child is physically present or not.

The Death of a Child: Unspeakable Things

There are no gradients of grief and one experience of grief cannot be held up against another. There are, however, aspects of particular bereavements that are distinctive. We expect to bury our parents, not our children. The unspeakable nature of children dying (Rallison & Moules, 2004) shrouds the experience of childhood death.

We do not speak of a child’s death. This silencing of the nightmare adds further insult to it and renders it silenced and located in a private and clandestine relationship between parents and their children (Moules, 1998; Moules & Amundson, 1997; Rallison &

Moules, 2004). Caputo (1993) posited that ethics are obligations with proper names. We are ethically obliged to engage with bereaved parents in conversations about their children and, further, in taking the lead of inviting families to speak the unspeakable around many aspects of their loss experience. It is here where the clinician moves into conversations of guilt, remorse, responsibility, fears, normalcy, and sometimes contradictory responses such as the mixture of loss and relief after periods of long suffering in illness. These poignant, fragile yet robust conversations involve courage on the part of the family and the clinician; tenacity, timing, and discernment on the part of the clinician; and ultimately faith that talking is healing. It is often in these conversations that the family is able to shift from beliefs of self-blame to beliefs and actions of forgiveness (of self and others) and of atonement.

In this giving voice to the unspeakable, there may come realizations: The realization of family members that they are doing “okay,” that their experiences of the continuing presence of grief is normal; that the continuing sense of connection to their deceased loved one is exactly what is supposed to happen; that guilt is something that needs to sometimes be considered but cannot be allowed to consume; that grief is evidence of having loved well; that suffering,

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sadness, joy, memory, and celebration can live simultaneously; that there is hope for the future; that they are not alone; and that they are entitled to all their feelings, behaviours, and thoughts. In the words of one mother who had lost her 18 year old son and her husband within one year, change for her was “I feel more at peace.” She attributed this change to having had the opportunity to be heard, to have witness to her pain, to be challenged around her sense of responsibility, and to “not be alone here having to hold it all together,” but rather having had the clinician move into this role, allowing her the luxury and pain of her grief and the expression of her guilt. She also reported that what was offered her was hope — hope from the clinical team, the clinician, from her family members, and from her heart that there will be joy, there will be laughter, and there will be “good times to come.” There *is* hope in grief — hope in the belief in our human capacity to suffer, sorrow, heal, celebrate, and love.

Summary

“Children are not supposed to die, but they do” (Rallison & Moules, 2004, p. 288). The work of healing in grief with families of children who have died or are dying is work of courage and love. It embodies a “character of connection to the living and the dead, a life-long work that is borne by the bereaved who carry the

inherent capacity to heal through love, and clinicians willing and skilled to join in behind” (Moules et al., 2007, p. 139). The work of healing in these experiences seems to be tethered to the capacity and courage to engage in therapeutic conversations which are, at their heart, privileged conversations that the portal of grief open to us. Rallison and Moules (2004) reminded us that:

The unspeakability of children dying should not be relegated to the shoulders of family members, for it is something we all must bear and, as nurses, we are obligated to bear. Children die and families suffer, and nurses need to be there alongside to mediate the unspeakableness of it, to ameliorate the suffering that accompanies it, and to embrace the privilege and obligation of such profound events in the life of a family (p. 300).

It is not just nurses, but all of us who bear the privilege and obligation of working alongside families. Parents will always be parents even in the physical absence of the child. Being present with children who are dying and with parents of these children bears us as witnesses to the almost inhuman strength that in which parents are cloaked in doing the hardest thing possible in watching their children die. For us, it requires a courage that does not come without a cost

or a gift. As witnesses to suffering, we are always, already in the position of listening to, and offering presence, experience, and language that may invite healing, diminishing, even amelioration of suffering. We are in positions of giving and receiving unforgettable and sometimes even unspeakable gifts.

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