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Maternal Grief

Creating an Environment for Dialogue

This paper is about the elephant in the room that only those who have faced its presence want to talk about. As two bereaved mothers, we write about the silenced, the unspoken or, at best, the seldom spoken. This difficult dialogue is called 'maternal grief'. Our aim is to open space, to create an environment for this dialogue. To do so, we discuss death in the neo-modernity, maternal grief, our own stories of bereavement, and ways in which well meaning others can help assuage maternal grief. This work is based on experiential knowledge of the authors as bereaved mothers, as volunteers working with bereaved parents, and on scholarly research.

We live in a culture where death is a taboo subject and talking about death is a difficult dialogue. Ultimately, death is unavoidable, a natural part of the life cycle. The death of a child of any age however, seems like a perversion of nature and is understood as a death out of order (Leming and Dickenson). Parents expect to predecease their children, not bury them. Although male parents also experience grief at the death of a child, and their grief often goes unrecognized and unvalidated, the focus here is on maternal grief. Maternal grief is a mother's highly variable emotional, physical, psychological, and social response to the death of her child of any age. Maternal grief is thought to be the most persistent and profound grief; mothers themselves are surprised by its depth and intensity (Davidson 2010; Oliver cited in Leming and Dickenson).

> While there are common maternal responses to the death of a child, experiences of maternal grief are diverse, inconsistent, and change over a lifetime. Experienced as a deep wound, mothers say that a vital

> part of themselves has died along with their child. Healing after the death of a child is a lifelong process, grief changes rather than ends. (Davidson 2010)

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There is significant agreement in the literature on death and dying that since the late nineteenth century through the mid-twentieth century, at least in the developed world, death became sanitized, medicalized, and professionalized (Ariès; Armstrong; Auger; Ellor and Harris; Littlewood; Homans; Katz; Mellor; Small and Hockey; Walter, 1994, 2000). Philippe Ariès, perhaps the preeminent Western historian of death, argues that while changes in death practices over the past thousand years have been gradual, infinitesimal and spread over generations, a sharp change in practices occurred just prior to the mid-twentieth century. Prior to that time, death was a significant community event and grief was allowed expression within that community. Ariès' principal thesis is that by the mid-twentieth century death was made invisible as it was removed from the home and community, medicalized by being placed in health care facilities, and administered by the funeral industry.

Similarly, Tony Walter (1994) periodizes death into traditional, modern, and neo-modern frameworks. These three cultural responses to death are "rooted in a particular social context and a particular bodily context, which then enable a particular structure of authority" (Walter 1994: 47). Walter analyzes the bodily context in terms of causes, frequency, and type or length of death within each period. The social context of each period describes the place dying is located, such as in the home or the hospital. As well, the social context describes who presides over the dead and the rituals related to death. The authority context describes who holds authority over death in the each period. Walter's notion of the "revival of death" describes death in the neo-modern period where modern medicine and more traditional elements of death are combined for a "more personal way of death, disposal and/or grief" (Walter 1994: 204).

In the traditional period death was quick, frequent and expected; generally, occurring in the home and presided over by family and community; religious authority predominated. Death in the modern period was characterized primarily by its medicalization. It was hidden in the hospital, and presided over by professionals. In the neo-modern period death, still medicalized, has become prolonged by technology, and has come to be managed within public-private space of a more open hospital, hospice, or in medically supervised home care. While neo-modern death is still dependent on technology ideally, the individual is understood to have the ultimate authority over her or his own death, and is offered choice in that matter.

While the dying individual is offered an increasingly authoritative role in her or his death, what of the bereaved—those who experience, and must live with, the death of a loved one? Bereavement "identifies the objective situation of individuals who have experienced loss…. In short a bereaved person is one who has been deprived, robbed, plundered or stripped of something" (Corr, Nabe and Coor cited in Katz 5). When it comes to the death of a child, at least in the developed world, where children are not supposed to predecease their parents, where parents are not supposed to bury their children, what mothers want is some authority over their experience (Davidson 2008a, 2008b). They want others to walk with them in their grief, to keep to their pace, to recognize and validate their loved one and their loss.

Common to all maternal grief, is its lack of sustained social acknowledgement, validation, and support. In *When Elephants Weep: The Emotional Lives of Animals,* Jeffrey Moussaieff Masson and Susan McCarthy offer lessons from the animal kingdom:

> Social animals who live in groups often behave in a friendly way toward other members of the group, even when they are not relatives….
>
> Elephants appear to make allowances for other members of their herd…. A park warden reported coming across a herd with a female carrying a small calf several days dead, which she placed on the ground whenever she ate or drank: she traveled very slowly and the rest of the elephants waited for her. This suggests that animals, like people, act on feelings as such, rather than solely for purposes of survival…. There appears to be so little survival value in the behavior of this herd that perhaps one has to believe that they behaved this way just because they *loved* their grieving friend who loved her dead baby, and wanted to support her. (78)

What grieving mothers want from others is what this grieving elephant got from her herd—for others to walk with her in her grief, and to let her set the pace.

Grief is an individual, multidimensional response to a loss and a *normal* process, involving somatic, behavioural, and emotional components that help the griever adjust to loss. Maternal grief is understood to be lifelong, changes over a lifecourse, and is thought to be the most persistent and profound grief, such that even mothers are surprised by its depth and intensity, regardless of the age of the deceased child. Even well-meaning others seldom know how to assuage a mother's grief. Thinking what will hurt is best unseen and unsaid, mothers rarely get the support they need and the validation they so deeply desire. (Davidson 2010)

Mothers often report their child's death was a life-changing event, and that they were not the same person they were prior to the loss. Time becomes measured by "before" and "after." And a new sense of "normalcy" is being established. Family and friends of bereaved mothers, however, expect them to return to their 'old' selves after a brief period of mourning, culturally determined by those who have not experienced child loss. Grieving mothers are put under a "time gun," which does not help to assuage their grief (Davidson 2010).

While the lifespan of an infant or child is often used as consideration for how much one is *expected* by others to grieve, when children die as adults, their mother's grief is often not sufficiently validated because, as adults, they are thought of as having become less a part of their mother's lives. Mothers, however, remain mothers, *not until the day their children die*, but in experiential terms, *until they themselves die,* and in terms of family histories, even after their own deaths (Davidson 2010).

Mothers of children who die suddenly by violence, through suicide, homicide, in natural disasters, in war, terrorist attacks, or accidents experience grief that is especially traumatic. In the case of prolonged, fatal illness, grieving often begins before death, and mothers have to deal with knowledge of their child's suffering and impending death. Short illnesses that end in death come as an acute shock. (Davidson 2010).

It is important to note, however, that losses should not be weighed, nor should grief. Each loss is unique as is each experience of grief. It is important to know that maternal grief is profound, and judgment is unwelcome and unhelpful. Making judgments and saying things like the mother of a baby that died did not have as many memories as the mother of an older child; that the mother of an adult child at least got to see her child grow up, graduate, marry, have children; or that the mother of a child who died while sleeping at least did not suffer, exacerbate rather than assuage grief. (Davidson 2010)

And it is important *not to assume* that bereaved mothers who seem to be doing well are well. They may be only as well as they can be, in public, and under the circumstances. Their internal distress may be far greater than they show in public. And if they are obviously distressed in public, this does not mean that their grief is pathological (Davidson 2010).

While bereaved mothers are, more often than not, silenced by others, especially after some arbitrary time limit, there is a need for mothers to talk about their deceased children, and about their loss (Davidson 2008a, 2008b, 2010; Layne; Simonds and Katz-Rothman). Our stories also help us open dialogue about dying, death, and bereavement. And our stories help hold our children to us. Helena's story is told here in the form of a letter to her daughter, Donna.

My dear Donna,

I gave birth to you on December 26th, 1964 when I was just 17 years old, and, as with all parents, your dad and I had dreams that our little girl would grow up to have "the perfect life" and maybe have children of her own. Well that dream almost came true. We lived a fairytale life until you were 18 years old and skating overseas in France with "Holiday on Ice." For reasons that we did not understand you became clinically depressed and I flew over to bring you home.

You were admitted to the psychiatric ward, and diagnosed with bi-polar disorder; and from that day forward our world, as we knew it, would never be the same again. You spent many months in and out of hospital. Shortly thereafter, you met your future husband, and for a few years all seemed to be going well.

But that was not to be; just before your wedding date, you were diagnosed with Crohn's disease. Little did we know what lay ahead for our family. Yes, you had a fairytale wedding, and flew to Hawaii for your honeymoon. Well, that dream came to a quick halt when you attempted suicide.

Your dad and I anxiously awaited your return home, and once again you were admitted to the hospital. A few years later you gave birth to our first grandchild, and 19 months later to our second grandchild. Our family shared many, many happy days with you and your girls.

For many years you were able to fight off the demons of having to live with these two insidious diseases that fed off each other. You did attempt suicide a few times, but always seemed to recover enough to come back home. But in November 1999, while in the psychiatry ward, you went through shock treatments. You and I had many discussions around how this might affect your mind.

On December 15th, you completed suicide, nine days before Christmas, ten days before your birthday, seventeen days before the new millennium and three weeks before your oldest daughter's birthday. I know in my heart, that you suffered for many years with the constant pain of Crohn's disease and that you could not lift yourself out of that horrible depression. But you always thought of the other person before yourself, and in your note wrote about being a burden and hoping that life without you would be that much better for all of us.

How terribly wrong you were. When you passed away, I fell into a huge hole and was not sure how I could go on. You also left behind your brother, who has gone from being the youngest, to an only child, and now he is older than you were when you died.

One of the hardest tasks I was asked to do after you died was to go through your clothes and pick out your burial outfit. I remember saying to myself when I was getting dressed for your funeral, if I do not go, then you have not died. I do not remember much about that now, other than I felt like the whole scene was surreal.

A few months later when your husband was ready to move from your home, your dad and I were asked to go through your personal items that were still around and take what we wanted. Well, we faced two green garbage bags that held all of your possessions. I remember your dad just sobbing at what we had to face. I took a couple of items, put some away for your girls, and gave most to friends. I had dreams that you would be here to share the milestone events that we all take for granted. I still cannot take part in family pictures, because you are not there. The pictures that I have are the only ones that I will ever have.

When I see your friends, I try to imagine what you would look like now. I cannot attend family reunions; when I see other moms with their daughters beside them, my heart aches. One of the worst parts for me was when your oldest daughter recently graduated from high school; I was not invited to the ceremony. I once again cried like a baby, knowing that you should be there to share in that moment, and how proud you would have been when she left for university. I cried for days, thinking that you should be the one driving her to school. To this day when I attend a wedding, I cannot watch the bride dance with her dad; it is too emotional to watch.

Donna, you were my best friend, we talked almost every day, and on the weekends went out shopping. I still find the weekends hard to deal with. I have a huge void and sometimes just run around like a mad woman trying to fill in my time. I have not put up a Christmas tree since you passed, since that was the holiday that you always enjoyed the most and one that your dad and I were always invited to watch your girls open their presents.

That has changed. When their dad remarried shortly after you passed away, we were no longer considered part of his family, and have not been part of family celebrations. Yes, we do get to see your girls once in awhile, but when you died, our direct link to the girls was broken, knowing that you will not be there to see them graduate, meet their first boyfriends, get married and have children of their own some day. I think of you every day, and just want you to know, that I am proud that I am your mom, and do cherish the time that we did have together. I will carry you in my heart forever and always.

Mom

Deborah's story is described here within her life course, as a significant part of who she has become, of how her experience and the short but meaningful lives of her children have shaped her life.

In 1975 and again in 1977 my babies were born prematurely and died shortly after birth. According to hospital practice at the time, I did not see, hold, or name my babies. I was told by doctors, friends, family—by everyone—to go home and forget about "it"; just have another "one." As if one child could replace another. But I would not forget about my experience or my children. For many years I grieved alone and in silence, presenting the false face of a woman who has gotten over "it." I had no herd to walk with me, nor was I the authority of my own grief.

My grief was not recognized or acknowledged or validated, and that made it worse. I had no outlet and no support. Years later when I returned to university I began to research the topic of maternal grief in perinatal death. Eventually, my Ph.D. dissertation in sociology came to be about *how and why* hospital protocols, in the event of a perinatal death, changed profoundly over about a 15-year period. In hospitals at least, women are no longer assumed *not* to grieve, or that their grief is short-lived. They are now assisted in their grief. Compassionate caregivers are expected to walk with them in their grief, to share and negotiate in their griefwork (Davidson 2008a, 2008b). But when women leave the hospital, the world they meet is not so compassionate.

One of my earliest research interviews on the topic of perinatal bereavement was with Natalie, a woman whose baby, Tricia, was born prematurely and died shortly after birth. Early on in the interview, Natalie excused herself briefly and came back to the room holding a beautiful wooden box. She held the box out to me and said, "This was my baby and she was *real*." The box contained:

- photographs of Tricia;
- Tricia's blanket, complete with vernix;
- Tricia's booties, cap, and name bracelet;
- Tricia's Baptismal Certificate;
- a Baby Experience Book;
- Natalie's before and after pregnancy journal;
- a newspaper article about a baby that survived after being born at 22 weeks, ("Proof of a—real live baby!" Natalie exclaimed. Tricia was 24 weeks gestation);
- a letter from her Mom, written after Tricia's death;
- a card and note from a friend;
- a Christmas card from Natalie to her recently deceased grandmother;
- a heart plaque previously given to the same beloved grandmother.

This box thus contained material evidence, tangible proof, of Natalie's experience and of Tricia's life. The items positioned Tricia as part of Natalie's cherished family. Natalie continued to speak of her grief, and how it was not understood, or responded to compassionately, even by well meaning others.

How do others come to understand our grief and our need for support? How is dialogue about maternal grief and the death of one's child fostered? Here is what Helena suggests.

One of my missions since Donna has passed is to open dialogue and help take away the stigma of mental illness and suicide. I speak about it every chance I get. After many months of grief counseling and attending a peer support group at Bereaved Families of Ontario, I was able to put my strength into chairing an annual event, "Just gotta Skate," in Donna's memory, with all funds raised donated to the Crohn's & Colitis Foundation of Canada. I have also found some sense of peace by volunteering as a facilitator for Bereaved Families of Ontario—Halton/Peel Chapter, for other parents that have suffered the loss of a child. Maybe along the way I can help them with the burden of losing a child and offer them hope that I did survive and so will they.

A parent's biggest fear when a child is lost is that they will be forgotten, not by the parent but by other people. Normally you live on by your children's memories and so on and so on. Now Donna can only live on by us talking about her, remembering her, mentioning her. We find it very painful when she is not mentioned. She did exist and still does to us and to the people that loved her.

Like Tricia, Donna was real, and so was their mother's grief. Social support is the most frequently mentioned needs of bereaved persons (Corr, Nabe and Coor). We realize, however, that most people are well intended but do not know how to provide that support. Not knowing what to say, they either say nothing or quite possibly something that hurts more than helps. Dialogues about grief can facilitate understanding and validation of the mother's experience and for the life of her child. To "validate" means to entitle, permit, sanction, confirm, authorize, approve, to support. Validation, we believe, is key to social support.

Not only do elephants walk with their grieving friend, elephants remember. Grieving moms want you to walk with them and to remember their beloved children. Tony Walter (1994) has described the current historic period as one of a "revival of death"—where more traditional elements of death, dying, and bereavement are combined with modern elements—where the dying themselves are the authorities of their own death. What bereaved mothers want is to be allowed the authority over their own grief. Begin dialogue by validating that grief.

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