Understanding how Bereaved Parents Cope With Their Grief in Order to Inform the Services Provided to Them

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Abstract

Our objective was to develop a rich description of how parents experience their grief in the first year after the death of their child, and how various bereavement follow-up and support services helped them during this time, with the aim of informing follow-up and support services offered to bereaved parents. Our findings situated parents' individual experiences of coping within the social and institutional contexts in which they grieved. In the first year after the death of their child, parents regulated their intense feelings of grief through loss-oriented, restoration-oriented, and/or meaning reconstruction strategies. Often parents' relationships with others and many of the bereavement follow-up and support services helped them in this regard. This article also explores how the results may aid service providers in accompanying parents in a way that optimizes outcomes for these parents.

Keywords: bereavement/grief; end-of-life issues; cancer, coping, psychology/psychosocial issues; children; families, caregiving; knowledge transfer; interpretive description; infants; adolescents / youth; program evaluation; palliative care; psychosocial issues; relationships, parent-child

The death of a child is recognized as leading to one of the most devastating and intense forms of grief (Davies, 2004; Rando, 1986), and many studies have demonstrated that the death of a child has a greater negative impact on the mortality and psychosocial outcomes of the bereaved than other types of loss (Li, Laursen, Precht, Olsen & Mortensen, 2005; Li, Precht, Mortensen & Olsen, 2003; Pudrovska, 2009; Rosenberg, Baker, Syrjala & Wolfe, 2012). Research examining the needs of bereaved parents of minor-aged children highlights a need for support from staff in pediatric hospitals where the child was cared for, particularly in the first year after the death (Contro, Larson, Scofield, Sourkes & Cohen, 2002; D'Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Decinque et al., 2006). Such hospital-based support is also emphasized in publications from the Canadian Hospice Palliative Care Association, the Canadian Pediatric Society , the American Pediatric Association, and the Institute of Medicine (Aerde, 2001; Canadian Hospice Palliative Care Association, 2006; Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003). To address the needs of bereaved parents, pediatric hospitals in North America are increasingly offering bereavement follow-up services to parents throughout the first year after the child's death, such as sending sympathy cards, conducting follow-up meetings and calls with parents, and holding commemorative services at the hospital (D'Agostino et al., 2008; deJong-Berg & Kane, 2006; Macdonald et al., 2005; Wintermeyer-Pingel, Murphy & Hammelef, 2013).

Several authors have argued that, in order to effectively support parents through this difficult and emotionally fraught period, bereavement services should (a) be based on an empirically-validated understanding of parents' actual experiences, and (b) integrate current psychological theories of grief (Decinque et al., 2006; Murphy, Johnson & Lohan, 2003). These authors, however, further suggest that this might not be the general state of clinical practice (Decinque et al., 2006; Murphy et al., 2003), an argument also made by Wortman and Boerner in their analysis of general bereavement research and practice (Wortman & Boerner, 2007). Therefore, there is still an important gap between evidence-based

research conducted with bereaved parents and actual hospital and community-based psychosocial services offered to these parents (Murphy et al., 2003; Sandler, Kondo & Ayers, 2011).

To date, there is little research examining bereaved parents' experiences with grief in the first year following their loss. Some initial steps have, however, been made in this direction. On the one hand, a few studies have examined specific follow-up services offered to parents, such as commemorative practices for parents whose children died in the pediatric intensive care unit (Macdonald et al., 2005), and follow-up phone calls to parents whose children died of cancer (Darbyshire et al., 2013). These studies, however, did not expressly examine the psychological processes involved in supporting parents through their grief. On the other hand, a few authors have examined parents' coping in the first year, examining parents' experiences at 6 and 18 months post-death (Alam, Barrera, D'Agostino, Nicholas & Schneiderman 2012; Barrera et al. 2007, and Barrera et al., 2009). These authors, however, did not link their research to existing bereavement follow-up or support services. In recent parental bereavement research, then, the intersection of psychological research and service provision remains largely unexplored.

The purpose of the present study was to gain an understanding of how bereaved parents cope with their grief in the first year after the death of their child, as well as to obtain their perspectives on the impact of bereavement follow-up and support services. In the present study, we are using the term 'coping' in it's broadest sense; that is, the means with which individuals address a challenge with which they are faced (see Stevenson 2015 for a discussion on recent research on coping in bereaved parents). The overarching objective was to provide information helpful for bereavement follow-up programs in pediatric hospitals, community services and to individual clinicians and to further inform models and theories of grief potentially applicable to bereaved parents.

Method

Design

Interpretive description methodology was chosen as the methodology to pursue the research goals. This qualitative approach draws on aspects of grounded theory and naturalistic inquiry, and expressly directs the researcher to describe subjective and experiential phenomena in such a way that findings can then be used to inform clinical understanding and practice (Thorne, 1997, 2008). It involves careful attention to matching data collection methods with the clinical phenomenon of interest, and consideration of what each data piece means in its own right and also in relation to other data, earlier research in the field, and particularly, for the clinical setting to which it may be applied.

Participants

After obtaining ethics approval from the research ethics boards at the two participating hospitals, parents whose child died at most one year (Group 1), or from one to five years (Group 2), before the interview were recruited from two tertiary care hospitals in a large urban center in Canada.[1] To recruit bereaved parents, we first identified staff contact people conducting follow-up with bereaved parents at the two participating hospitals, and these staff contact people asked parents if they would like to participate in the study during one of their previously scheduled follow-up phone calls. To further encourage recruitment, a letter of invitation to participate was also sent out to parents. The characteristics of participating parents are provided in Table 1. Parents ranged in age from 29 to 60 years, and included 15 mothers and 6 fathers of children who ranged in age from several days to 19 years at death. The children died from a variety of illnesses, including neurodegenerative and congenital disorders, and pediatric cancers. In addition, 7 health care professionals (HCPs; 4 nurses, 2 psychologists and 1 social worker) who conducted bereavement follow-up practices at the two hospitals were interviewed. Twenty-one bereaved parents were interviewed (10 as mother-father dyads) as to how they experienced their grief in the first year, what was helpful or not helpful during this time,

and their perspectives on various bereavement follow-up and support services (offered either in the hospital or the community). There were 10 parents of 8 children who died in Group 1 and 11 parents of 9 children who died in Group 2. Parents in Group 1 were asked to speak to their current experiences and parents in Group 2 were asked to think back to their experiences in the first year after the death. These two groups were formed to obtain the prospective view of the parents living the experience and the retrospective view of parents who had had the time to reflect on their experiences.

INSERT TABLE 1 ABOUT HERE

Data collection

The interviews were guided by a set of broad questions pertaining to their experiences in the first-year post-loss and what was helpful (or not helpful) during that period, followed by questions specific to various bereavement follow-up services and practices that were in place at the treating hospitals. Following recommendations on enhancing qualitative research credibility, we also interviewed hospital HCPs who conduct bereavement follow-up activities, with questions pertaining to how they go about following-up with parents and what issues (if any) hinder their ability to do that follow-up, as a means of triangulation of data sources and to add to the clinical understanding of the phenomenon (Patton, 2002). In total, 16 interviews with parents and 7 interviews with HCPs were conducted. Observations by Moire Stevenson of the commemorative services offered at the hospitals as part of the bereavement follow-up and support services served as yet another means of data source triangulation. These observations provided a richer understanding of parents' descriptions of the services. All interviews were audio-digitally recorded and transcribed verbatim.

Data analysis

The data collection and analysis were done concurrently using an iterative process. Guided by interpretive description methodology, Moire Stevenson analyzed the transcripts for emergent themes and categories, through multiple immersions into the data and using constant comparative methods

(Thorne 2008). For additional analyst triangulation (Patton, 2002 pg. 560-563), results were further analyzed and discussed with project collaborators and service-providers (i.e., experts in parental bereavement and clinicians that conduct follow-up or offer bereavement services). The clinical applicability of the results was then verified through multiple meetings with project collaborators and service/program providers at both pediatric hospitals. Dr. Stevenson then examined how the emergent themes related to preexisting theories, models and research in the field of parental bereavement and coping during bereavement (Stevenson, 2015).[2] On the basis of this analysis, an interpretive description was generated that described how parents coped with their grief in the first year after their child died, and how various bereavement follow-up and support services helped (or did not help) them cope.

Results

To help organize and present our findings, we developed a model that posits four broad thematic categories, each of which encompasses various themes relating to how parents coped in the first year after the death of their child (Figure 1). These four categories are represented graphically in Figure 1 as a series of concentric circles. This framework was developed from comparison of our findings to similar models in the field such as Stroebe and Schut (1999,2010), and Meaning-making models and concepts (Gillies and Neimeyer, 2006; Neimeyer, Baldwin & Gillies, 2006; Park 2010). We also took inspiration from Bronfenbrenner's Ecological Systems Theory of Human Development (Bronfenbrenner, 2005). The first section of the results corresponds to the inner circle of the figure, and describes how parents coped with both the emotional reactions to their loss and the demands of daily living at an individual level. Moving outwards, we go on to depict the social context of the parents' grief, describing how other individuals in the parents' lives impacted the individual coping processes. We follow this with findings on how parents used various services to cope; these services are themselves fundamentally intrapersonal in nature, but are contained within larger institutional structures, therefore, we represent this sphere as being situated on the third concentric circle of the figure, encompassing and growing out of the individual and social spheres. Finally, we move out to the

outermost circle, in which we discuss the issues of time and timing: that is, the effect that the passing of time has on grief, and how this impacts on when services should be offered to bereaved parents.

INSERT FIGURE 1 ABOUT HERE

I. Individual Experiences of Coping With Grief

Through the analysis of the parents' recollections of their individual experiences, the following themes were developed: first, an oscillatory aspect to the coping process; second, coping as a process of reconstruction of meaning in one's life; and third, a reorganization of the relationship to the deceased child.

Oscillations in grief and in coping. As would be expected, the death of a child triggered many negative emotions, such as guilt, frustration and intense sadness. Parents in Group 2 described their grief as most intense during the first year post-loss. After this point, moments of intense grief were often triggered by reminders such as anniversaries or missed milestones (such as the moment when the child would have graduated from high school). The parents interviewed described the intensity of these negative emotions as having ups and downs, with moments of more intense grief followed by moments of less intense grief and vice versa. That is, parents' feelings of grief and loss came in waves of varying intensity.

Similarly to how the intensity of their feelings oscillated, so too did the parents' ways of coping with their feelings. Parents said that at times they wanted to actively process the events and experience the emotions related to the loss, while at other times they preferred to keep a distance and focus on getting back to "normal life". One of the ways parents mentioned actively processing their experiences and feelings of loss was through talking about their child, and their grief, with others. The HCPs interviewed also mentioned that parents seemed to need to recount the circumstances of the death and their feelings related to the loss.

Parents noted that talking about the loss was helpful because it allowed them a means for maintaining a connection to their child, and to reflect on and process their grief at the child's death. However, parents were quite particular as to when, where, and with whom they shared their experiences and feelings, and emphasized the importance of having a "safe space" to speak which they described as an interactional space where they felt understood and not judged. If the parent could not find a safe space, they would not share their feelings or talk about the loss. Another reason parents gave for not 'opening up' to others was that they did not feel capable of sharing due to the intensity of their feelings of grief. One mother described the experience this way: "You know, when you are crying and things are going 2000 miles an hour in your head? You are not capable of getting the words out; you are not capable of expressing yourself." Indeed, many parents reported that, in the very early stages or acute phase of their grief, just being functional while living with these intense emotions was challenging, without the additional burden of delving into their feelings with others. Moreover, parents sometimes made an intentional choice to process the loss by themselves. As one mother recounted:

I decide when I'm going to go into it. When I let myself go . . . when the kids are not around . . . I stay home and have a sort of breakdown . . . I cry and get it out all in one shot. It tires me out. I sleep. Then the next day I'm okay. But, I would never do that in front of anyone else.

Just as parents sometimes chose not to share their experiences with others, parents also at times avoided or kept a distance from situations and objects associated with their child. One father explained it as: "To protect ourselves, we find a refuge." Going through the child's possessions and deciding what to keep, give to others, or throw away was mentioned as particularly difficult for parents in the first year post-loss. Parents recounted not being capable of looking at their child's possessions or only being able to do so for short periods of time. One mother reflecting back on this time said: "I went step by step . . . I didn't do it right away. I think it took me three years to give anything away." This task challenged parents to balance their intense emotions of grief with their strong desire to keep the

memory of their child alive. Mothers and fathers also reported occupying themselves with various tasks to distract themselves from their grief. Interestingly, only a few mothers alluded to distraction as a means to cope with their grief. "When you have an occupied mind, you do not go back . . . I have to keep my mind occupied," said one mother, while another said, "All I was able to do is craft for a long time . . . because then I'd forget a bit." On the other hand, all but one of the fathers interviewed mentioned that keeping busy by going back to work was helpful to them, because it served as a distraction from their grief, it occupied their time, and allowed these fathers an opportunity to receive support from coworkers.

In sum, parents either actively regulated their emotions through attempts at processing the events and affects related to their loss (either on their own or through sharing with others), or avoided possible triggers, or distracted themselves from their thoughts and feelings.

Meaning reconstruction. It was clear that the death of their child changed the parents' lives in fundamental ways, to the degree that the parents narrated their lives as occurring before and after the turning point of their child's death. The parents went on to mention the various ways they adapted to, and found meaning in, this fundamental change in their world. Parents reported finding meaning through making sense of the loss, finding benefits or positive aspects from the experience, and reorganizing their self-identity.

Making sense. Sense-making themes were apparent in the discourses of several of the parents. As one mother said, "Everybody had a reason why it happened, . . . but I was the only one that didn't have an answer. And that was very frustrating." One way parents tried to make sense of the loss was through seeking information to better understand their child's illness or cause of death, either online or through staff such as genetic counselors. Parents also relied on their own spiritual or existential beliefs to help them understand their child's death, sometimes reporting their child's life and death as serving some greater purpose, such as bringing happiness and courage to others. To make sense of their relationship to their deceased child, some parents also sought the support of spiritual counselors, and

two parents consulted mediums. We should note here that although sense-making themes were mentioned by one third of the parents we interviewed, the other parents did not mention any attempts to try to make sense of the loss. This does not necessarily mean that they did not try to make sense, only that the parents did not mention it, nor did we ask guiding questions about this specifically. One parent, moreover, mentioned never "accepting" the death of her child, and thus not feeling the need to make any further sense of it.

Benefit-finding. Though the death of their child had been an overwhelmingly painful experience parents were nonetheless often able to perceive benefits that had resulted from the loss. For example, parents mentioned feeling less anxious and more confident in life, knowing that nothing worse could happen as they had already "been through the worst." Parents also mentioned changes in their perspectives on how they live their lives, such as making a conscious decision to slow down and do less, to focus more on oneself, or to not fear death. Parents whose child died after an extended illness were sometimes able to find benefits related to the illness itself, such as providing them a chance to get to know their child better. One interesting finding was that parents often reported helping others as a way of coping. Thus, as well as discovering benefits or positive aspects of their experiences, some parents tried to create benefits through actions such as fundraising or supporting/helping other bereaved parents. Parents mentioned specifically that giving back would give their child's life a greater purpose, which was also related to making sense of the loss.

Reorganizing identity and sense of self. After the death of their child, parents reported trying to reconstruct not only a sense of meaning of the world around them, but also their sense of self. For example, some parents were faced with changed family roles. One father spoke of how he had to reorganize his identity from being a parent to a living child to being a father of a deceased child. In parents whose child had had a long-term illness or disability, and where the care of this child took a central role in the parent's life, parents had to adapt, after the death, to the loss of this role. One couple, whose daughter was disabled and cared for in the home for many years, showed the interviewer all the

many adaptations they had made in their home to care for their child, and spoke about not knowing what to do with these things now that their child was gone. In addition, several parents mentioned positive changes to their sense of self. One mother said she learned to be more assertive through the illness and subsequent death of her son, and one father said he no longer feared death. Along with changes in the sense of self and identity came an acknowledgement of one's own internal resources. In fact, a couple of the parents mentioned that what was most helpful during the first year of bereavement was their own internal strength.

Relationship with the deceased. Another aspect of the parents' individual experience of grief related to maintaining a bond with their child who was no longer physically present in the world. They often spoke about their continuing connection to their deceased child and their attempt to maintain the memory of their child. Parents found many ways of maintaining this connection, including talking about their child with others, creating a trust fund in the child's name, or participating in rituals such as visiting the memorial/burial site. Some parents spoke of simply feeling their child's "presence" or "energy," or receiving symbolic messages from their child in the form of a butterfly or a flower. Parents also mentioned how it was important to continue the memory of their child, that their child not be forgotten. In fact, all the parents interviewed spoke in some way about how they maintain the memory of their child, either through sharing with others and talking about their child, and/or by keeping souvenirs and memorabilia of their child's life.

> We made a special booklet for the people close to us . . . that really helped me a lot to live with the grief . . . that I had that . . . it was an extraordinary therapy.

In addition, parents took pleasure in remembering positive aspects of their child's personality. Indeed, some parents even felt that their child's personality actually helped them cope. For example, one couple mentioned that seeing their infant be so brave through all the treatments encouraged them to be

brave after his death. Another couple spoke about their teenage daughter's positive attitude and how, like her, they tried to keep a positive attitude.

II. Coping Within a Social Context

In the first year after the death, parents were faced with reorganizing their identity and sense of self, revising their comprehension of the world, and finding ways to maintain a new relationship to their deceased child. These themes all related to processes that were deeply individual, but which were also embedded within a social context. That is to say that when the parents grieved, they did not do so in a vacuum, but coped with their grief partly through their interactions with others. In this section, we describe the role of these interactions on the coping process. First, we examine how different social relationships impacted the parents' coping, before discussing some general themes that emerged relating to grieving in a social context.

Relationships with Immediate Family.

Coping as a couple. The first intrapersonal relationship we explore is that between the two parents, who in many cases grieved both as a dyad and as two individuals.[3] Ten of the interviews were conducted with both the mother and the father at the same time, which allowed parents to elaborate on how they coped, both as a couple, and as two individuals coping with the loss together. Several parents spoke of their spouse as a source of support, or of having to fulfill this supportive role for their spouse. As one father put it: "I wanted [my wife] to live it at her rhythm, so that she could grieve; I had to be by her side." Two of the couples interviewed, moreover, mentioned that the loss brought them closer together and strengthened their relationship.

However, both mothers and fathers noted important differences between how they and the other parent coped with their grief. One important difference involved communication. Several mothers reported that while they wanted to talk about the loss (either with their spouse or with others), they felt that their partners (who in this study were all men) generally did not. Two of the fathers interviewed

also mentioned that they did not feel the need to talk about the loss with others. Indeed, mothers used support groups more often, and reported these as being more helpful, than did their spouses. Interestingly, several of the HCPs interviewed noted that fathers would talk to them about their experiences (sometimes at great length) during follow-up calls. Another difference that emerged was that, as previously discussed, all but one of the fathers mentioned that going back to work was helpful in addressing their grief; none of the mothers, however, found this similarly helpful for themselves. As one mother put it: "I work to live, I don't live to work . . . For my husband, work is a real investment, like it is for many men . . . For me it is not that at all." Also in contrast to the fathers, a couple of the mothers mentioned that returning to work was difficult, either due to insensitive comments from coworkers or an inability to focus on work-related tasks because of their grief.

For some parents, these differences in how they and their spouse coped with the death were not particularly problematic, and three parents explicitly noted the importance of respecting how their partner grieved. As one mother said: "There was a psychologist who told me that eventually we'll have to live [the loss] more together . . . but we're living different things," to which her husband added, "We're living it together, too, but I respect that [that we're living it differently]." On the other hand, some parents found such differences particularly challenging:

It was difficult to not have the same tools or the same things that help you.

It was too heavy [for him] . . . He did not want to see me sad. He didn't even want me to talk about it.

HCPs also mentioned the importance of informing parents that their spouse might react differently to the loss:

There are often different reactions between the two parents . . . And they won't necessarily talk about it . . . often they are mutually protecting each other, and it's one of the things that you

have to normalize: that not only do men and women generally live with grief differently, but that any two people will live it differently.

For two of the participants, there were pre-existing issues with the relationship with the other parent that were particularly problematic during the first year after the death. Both these parents mentioned seeking extra support services (such as the services of a psychologist or social worker) to address these issues and better cope with the loss.

Relationships with surviving children. The parents' immediate family also often included other children. Several parents described these children as a source of support and noted that their shared loss brought them closer together. However, all parents who had other children had concerns about how these children were grieving, and several parents mentioned not knowing how to talk about the loss with their other children. As one mother put it: "I sort of understood how she was feeling but I did not know how to bring it up . . . I have no idea how a young person sees something like that, a loss like that." Indeed, some parents felt that they needed extra help to support their children through their grief and actively sought (and found) external resources in this regard. Two of the parents, however, still thought they lacked resources on how to help their other children. Additionally, one mother was unsatisfied with the amount of follow-up support offered to her children. Another theme that emerged was the necessity of balancing the parents' concern for their children with their own grief-related needs. As one mother put it: "I knew that I could help them, but I also had to help myself." This concern was echoed by the HCPs, who specifically mentioned helping parents assist their surviving children as a focus of their interventions and follow-up support. In addition, some families decided to get a new pet animal as a way to help themselves and their children.

Relationships with extended family, friends, and coworkers. Beyond their immediate family, parents discussed how their relationships with extended family, friends, and co-workers also impacted how they coped with their grief. As previously discussed, parents all seemed to require safe spaces in

which to grieve, and when their pre-existing social and family ties were able to supply this safe space, parents found this helpful. The qualities parents most valued in their relationships were the ability to be present, to listen, and to have a non-judgmental attitude. As one mother put it: "[it helped] just knowing they were there, even if they didn't say anything."

Although many parents felt their extended families were supportive and helpful during the first year after the loss, for several parents, relationships with extended family were problematic. For example, some parents felt that extended family, such as the child's grandparents, aunts and uncles, did not understand what they were going through while their child was ill, or the deep bond they felt to their child after their child's death. In effect, the parents often reported that the nature of their relationships with friends and family changed after the death of their child. For example, one mother said she used to give all of herself to her friends and family, but after her son died she had to set limits on how much energy she put into those relationships. Yet another area where parents felt conflict in their social circle was that they sometimes felt they were not permitted to feel happy or express positive emotions because their child had recently died. As one mother recounted: "When I went back to work, [someone] came to me and said, 'Why are you laughing?' you know like, 'Why are you having fun, why are you smiling?' "

We also noticed differences between mothers and fathers in terms of who they went to for support. For a majority of the mothers, the support of a close friend was mentioned as particularly helpful in coping with their grief. As one mother put it: "A friend is someone who you can talk to without barriers, without judgment; this is rare, but I have friends like that." In comparison to their female counterparts, the fathers more often mentioned receiving support from coworkers.

New relationships developed during the child's hospitalization: other bereaved parents and healthcare providers. The parents who had spent a great deal of time at the hospital with their child spoke about how they developed close, and often supportive, relationships with other parents whose children were also hospitalized. They also often mentioned developing bonds with the staff that cared

for their child at the hospitals. Relationships with other parents in similar situations were considered helpful because they allowed the parents to see they were not alone, and that others understood what it was like to have a sick child, or to have a child who died. In addition, seeing other parents going through comparable experiences served to validate and normalize the intense emotions and reactions they were experiencing. Parents also noted that these other parents were unlikely to say insensitive and hurtful things, such as "at least you can have other children." As for relationships with HCPs, parents often reported that, after the child died, they experienced a double-loss: that of their child, and of their supportive relationships with staff.

> It wasn't just the loss of [name of child] . . . We got to know people at the hospital for many years . . . a third of our working life was spent there. You see the same people, get to know the same people, then from one day to the next it finishes there.

Broad view of coping in a social context. As previously mentioned, the idea of a safe space to speak came up on numerous occasions with both parents and HCPs. Some parents highlighted the lack of understanding that they experience from other people in their day-to-day lives. Indeed, as Wortman and Boerner (2007) point out, bereaved individuals often lack places where they can speak comfortably about their experiences because for many North Americans, speaking about death is a taboo or uncomfortable subject (Wortman & Boerner, 2007). As one mother put it: "I found understanding what I went through, understanding my loss, acknowledging it, was . . . practically non-existent in the outside world." This state of affairs perhaps makes those *safe* relationships all the more precious to grieving parents. The parents appeared to use these relationships to help them continue their bond with their deceased child, as well as to maintain the memory of their child in the minds of others.

III. Coping and the Help of Support Services

In this section, we explore parents' perspectives on if and how various institutional support[4] services (i.e., bereavement follow-up from the hospital and specific bereavement support services) helped them deal with the loss.

Support needs. When asked about bereavement support and follow-up services offered by the hospital or the community, parents expressed varying levels of need for such services. On the one hand, many parents felt they had sufficient social networks and were well supported, and therefore did not feel a need to use support services. As one mother said, "There were people who helped me in all the spheres of my life, so I did not feel the need for additional help on that . . . I already had a lot." In addition, parents mentioned being naturally inclined to depend on themselves and use their own internal resources. Some parents, on the other hand, did not feel adequately supported: either pre-existing relational problems were present, the family was in another country, or the individuals they would normally go to for support were unavailable due to their own grief for the child. As explained by one mother: " . . . the grandparents, the aunts as well, they are also affected and are not really able to provide help."

Most of the parents who felt the need for extra support actively sought it out through various bereavement services (such as support groups, social workers, psychologists, or nurses). Some families who were already receiving support from either a social worker or psychologist before their child died continued to be followed by these HCPs after the death. Several parents, however, found it difficult to get information and resources that met their bereavement support needs. For example, one mother mentioned that the bereavement support group she was referred to, and wanted to attend, was too difficult for her to access using public transit. In addition, parents emphasized wanting information on services even if they were not sure whether they would use those services. As one parent related: "I allowed myself to try [different resources] . . . I permitted myself to say when something wasn't working for me . . . and I moved on to try other things." Interestingly, we also noticed a difference

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between mothers and fathers in terms of bereavement support services used. In general, mothers consulted available services (such as support groups) more often. Some fathers, however, did access psychosocial services; these fathers tended to consult individual services, such as that of a psychologist or social worker, more often than support groups. [5]

Support services with other bereaved parents. As mentioned previously, parents often created relationships with other parents of sick children during the time of their child's illness. In a similar vein, they also reported receiving support from other bereaved parents they met after their child died. Participants most often cited being connected through support groups. Parents described the type of support they received at these groups in both similar and different terms than that received from other relationships. On the one hand, and in a similar way to their more supportive relationships with friends, family, and HCPs, support groups provided a safe space to speak where parents did not feel judged. On the other hand, support groups had the added benefit of giving parents a space to feel understood by others who knew what it was like to have a child who died. They also mentioned that interacting with other bereaved parents allowed them to see that they were not alone, and helped them gain some perspective on their intense emotions and reactions: "You see that you actually went forward in your grief . . . When you see the point [other parents] are at in that moment, and where you're at now."

Support groups often helped parents cope, but parents also mentioned that participating was emotionally difficult; in one mother's words: "when I left there, I was destroyed." Two mothers whose infants died said that at first they were concerned about participating in groups with parents of older deceased children (one, however, eventually did participate, and said it was especially helpful for her). Other parents we interviewed did not attend these types of activities in the first year. Some among them wanted to attend, but logistical issues made it impossible to do so; one mother, for example, could not find childcare. Some, however, simply did not want to share their experiences or feelings ("I didn't want to talk about it"), while others felt sufficiently supported and did not feel the need. Some parents

in Group 2 also mentioned that in the first year after the loss they did not feel ready or emotionally capable of participating in a support group.

In addition, several mothers found support from other parents online through forums and blogs. As one mother said: "I found a world of support out there with women who had lost kids due to the same issues . . . I spent a lot of time chatting with women all around the world." However, at least for one of the mothers, searching online for blogs in the first year after the loss was difficult because it was overwhelming and "brought up many intense emotions."

Support and follow-up from the treating hospital. At the two hospitals participating in the study, various follow-up services are offered. Figure 2 provides an overview of the general guidelines that were in place at the hospitals at the time of the study. We asked the parents for their perspectives on these services, as well as the role they played in helping them cope.

Every three to six months both hospitals conduct commemorative services for families and staff. Overall, parents reported that these services were helpful because they allowed them a chance to feel a connection to their deceased child (this was especially noted for the candle-lighting ceremony at one of the hospitals). Parents felt that although the service was emotionally difficult and that it was tough to see that so many children had died, it was also reassuring to realize that they were not alone. Moreover, the service provided a continued contact between the hospital staff and the bereaved families. The parents appreciated seeing the staff and other parents they had come to know while their child was ill. It should be mentioned, however, that not all parents attended these services, either because a parent did not have a desire to attend (i.e. it did not suit their personal needs and/or desires), or because the service occurred at a time when they were not yet emotionally ready for it. The choice of when to attend the service was important to parents, along with knowing they would be invited to another service later in the year if they did not choose to attend at that time.

Some hospital departments gave memory boxes to the parents, containing such items as locks of hair, hospital bracelets and other souvenirs. Parents kept the memory boxes they received, and several

parents mentioned going back to them, to look through their contents and/or to add mementos. Within approximately 1 month of the child's death, staff who had been involved in the child's care often sent a signed sympathy card to the family, and these too were often kept as cherished souvenirs. Parents noted that the memory box helped them to maintain the memory of, and a connection with, their child, whereas the sympathy cards were appreciated by the parents because receiving them indicated that the staff had not forgotten about them and their child. As one mother put it, "When I read it I said, 'Oh, they have not forgotten about us . . . we have not gone by unnoticed in the world.'"

Hospitals also followed-up with phone calls to parents (made by various HCPs, i.e. doctors, nurses, social workers, psychologists, and spiritual care workers). According to the HCPs interviewed, these follow-up calls had three general objectives: 1) to provide a form of continued contact with the hospital; 2) to assess for risks of maladaptive grieving (i.e. non-supportive/negative relationships, financial stresses, and difficulties in day-to-day living); and 3) to refer to services or continued support for family, when appropriate. Staff also specifically mentioned normalizing grief reactions and providing support to siblings (either directly or through informational support given to parents). For the HCPs interviewed, the follow-up phone calls were crucial and they often mentioned wishing they had more time to spend on these calls. On the other hand, most of the parents did not discuss the follow-up calls in detail. Parents who did elaborate on these calls, however, mentioned that they were helpful because they provided them with emotional and information support (when social support was lacking), a place to speak about their loss with someone who was there when their child was sick (or associated with that setting), and a means for continuing a connection with or sharing the memory of their deceased child.

In summary, parents generally had positive opinions concerning the bereavement follow-up they received. They specifically appreciated the HCPs' open-door attitude ("call us when you need us") and their being "present" (i.e., available and attentive). Parents were also very grateful for the help they received while their child was sick, and after their child died many parents felt a need to thank the staff

that had helped them. In fact, several parents noted the importance of being able to thank individual staff for their help, and that such expressions of gratitude were helpful in addressing their grief.

Other bereavement support services. In addition to those services mentioned above, parents and HCPs mentioned other bereavement services offered through the public healthcare system, at either the hospital where the deceased child was treated or in the community (e.g., community health clinics), or privately (e.g., from grief counselors or private practice psychologists). Parents sought the assistance of social workers and psychologists to address various issues related to their bereavement, such as: dealing with contradictory emotions (such as wanting the child to live but not wanting the child to suffer); relational issues with the other parent; support for siblings; normalization of their physical and cognitive reactions; and reassurance. According to the parents, these services were helpful because they provided a place to be open to speak about their loss and their child with someone neutral (who was not directive or prescriptive), and who listened to and accepted them. However, some community services were critiqued for not offering enough sessions or a long enough follow-up, and for lacking expertise on supporting bereaved parents.

It is important to note that some parents received follow-up services from non-governmental organizations (NGOs) while their child was sick, and two of these organizations also provided bereavement support. Parents with children who died of cancer more often mentioned receiving bereavement follow-up services from NGOs than parents whose children died due to other causes. Partially in response to this discrepancy in service provision, HCPs underlined the importance of assessing what other services (from the hospital or NGOs) were in place and if these services were meeting the parents' needs, so that they could adapt their follow-up accordingly.

IV. Time and Timing

Another set of themes that emerged pertained to the effects of the passage of time in the grieving process, as well as the timing of certain bereavement follow-up or support services and interventions on how parents coped with the death of their child.

Changes over time. We focused on how parents coped with grief in the first year following the death of their child, because this is often when hospitals are looking to provide services to parents. As mentioned previously, parents described their grief during the first year after the death of their child as extremely intense, to the point that some altogether avoided certain people, events, or other reminders. Many parents also noticed that the intensity of their negative emotions of grief decreased over time, while their functionality in daily life increased. They also often emphasized the importance of letting time pass, and the comfort of knowing, through their relationships with other bereaved parents, that the intense emotions and physical sensations would decrease over time. For example, one mother used the metaphor of a light at the end of a long tunnel to describe how she would eventually feel better with time. Another participant said her main advice to parents would be to encourage them to just get through that first year, because in the second year they will begin to see things more clearly. This sentiment was echoed by the HCPs, several of whom spoke about "accompanying the family" throughout their bereavement. Importantly, HCPs related that this accompaniment might last longer than the one-year period that is currently the norm for bereavement follow-up, and several of the staff referred to "an open-door policy" in which parents could call whenever they felt they needed help or support even after the first year post-loss.

Timing of services. This last point brings up the importance of timing for services. At the hospitals, bereavement follow-up was supposed to continue throughout the first year post-death, after which point the parent was to be referred to other psychosocial services if necessary. Both parents and staff mentioned issues with the timing of these various bereavement follow-up and support services. First, HCPs and parents both drew attention to the fact that many parents do not feel ready to participate in certain bereavement support activities (such as support groups or the commemorative service) in the first year after the death of their child. As one mother pointed out, a continual presence (follow-up calls, sympathy cards) and contact from the hospital was helpful in the first year, but services requiring a more active participation on the part of the parent were only helpful after she had time to become

more functional and gain perspective. Parents also noted that during the phase of acute grief, they had difficulty reading long texts or actively seeking resources and tools to address their grief. Furthermore, several HCPs stressed the importance of assessing the needs of the family and continuing to do so for more than a year at times as, similarly to the parents, they had noticed that parents' grief tends to come in waves, with emotions, memories and physical sensations that wax and wane in intensity over time.

Discussion

Through in-depth interviews conducted with both parents and HCPs, and multiple discussions with project collaborators and service-providers, we present a rich description of how parents experience their grief in the first year after the death of their child, and how various bereavement follow-up and support services helped them during this time. This interface between the psychological aspects of the parents' grief and the services provided to help these parents is a particularly salient and novel dimension of the present study. Indeed, one overriding contribution we have sought to make to the field of parental bereavement is to conceptualize and present our findings from an eco-systemic viewpoint (Bronfenbrenner, 2005), situating parents' individual experiences within the greater social and institutional contexts in which they grieve. To this end, we propose a model, depicted in Figure 1, that can be employed as a tool by clinicians in assessing risk for maladapted coping and in identifying areas where additional support for coping could be provided. In this discussion, we elaborate on these findings in terms of the relevant theories and empirical research in the area, while highlighting the clinical implications of these results and the theoretical models to which they relate.

Our finding that parents seem to go back and forth between actively processing their grief and focusing on other aspects of their lives agrees with aspects of the Dual Process Model of Coping in Bereavement (DPM; Stroebe & Schut, 1999; Stroebe & Schut, 2010). According to the DPM, grieving individuals oscillate between loss-oriented coping and restoration-oriented coping. The former refers to coping processes that focus directly on the stress of the loss itself (such as grief work, intrusion of grief,

letting-go-continuing-relocating bonds/ties, and denial/avoidance of restoration changes); the latter refers to coping processes that focus on adjusting to life after the loss (such as attending to life changes, doing new things, distraction from grief, denial/avoidance of grief, and new roles/identities/relationships). Both loss-oriented and restoration-oriented coping are considered important ways of coping with the loss of a loved one. Neither is inherently better or more adaptive than the other; rather, the DPM maintains that adaptive grieving is often characterized by the alternation between these two coping processes. If, as our results imply, the ways in which parents cope with their grief does indeed alternate between these two types of coping processes over time, this emphasizes the importance of parents being able to access services when they need them, and not at some pre-established time-point. An important finding of the current study is that parents appreciated an "open-door" policy, where the parents could consult services when they so needed (and not necessarily at a specific time or within a fixed number of sessions).

The DPM has been critiqued for not adequately addressing "whether individuals are actively and purposively choosing to loss-orient or restoration-orient, or whether they are passively defaulting to strategies due to lack of options" (Carr 2010). The parents we interviewed described purposely choosing to loss-orient or restoration-orient. These choices, however, were highly sensitive to various triggers: coming across an object that reminds the parent of the child, for example, or finding oneself (or not) in a 'safe space' to speak about the loss. This finding underscores that the importance, as posited in situated action theory (Schuman, 1987), of recognizing the "emergent, contingent nature of human activity, the way activity grows directly out of the particularities of a given situation" (Nardi, 1996).

Another concept from the general bereavement literature that previous studies have investigated in samples of bereaved parents is meaning-making. The term *meaning-making* describes several specific processes that contribute to adaptation to bereavement and other stressful life experiences (Park, 2010). Though many conceptualizations of meaning-making have been proposed (see Park 2010

for a review), the model that best fits our results of how parents cognitively process the death of their child is the meaning reconstruction model proposed by Gillies and Neimeyer (2006). In this model, the authors describe meaning reconstruction as involving making-sense, benefit-finding, and changes to self-identity (Figure 1). Making-sense refers to constructing an explanation of a loss based on one's beliefs/worldviews; benefit-finding refers to ascribing positive value to aspects related to or following from the loss, e.g., increased appreciation of life and improved relationships; identity-change posits that by reconstructing meaning in our lives in response to a loss, we necessarily reconstruct our self-identity. In our study, aspects related to meaning emerged in parents' descriptions of how they coped. In this way, our findings are similar to those of other studies on the experiences of bereaved parents (Wheeler, 2001), and of parents in the first year of grief in particular (Alam et al., 2012; Barrera et al., 2009). Interventions oriented towards supporting the bereaved in their reconstruction of meaning, such as Meaning-Centered Grief Therapy (MCGT), aim to address the existential challenges that often accompany the loss of a child, by facilitating the kinds of meaning making processes described above (Neimeyer & Lichtenthal, in press; Park 2010). Such interventions are in the early stages of development and evaluation. Furthermore, we did not find any published clinical trials examining the usefulness of meaning reconstruction interventions in bereaved parents specifically, although a pilot study of MCGT for parents bereaved by cancer is currently underway (Neimeyer & Lichtenthal, in press). We suggest that further research in this area is warranted in order to ascertain whether interventions aimed at helping parents find meaning are indeed considered helpful by bereaved parents during their bereavement, what impact such interventions may have on psychosocial outcomes.

Yet another area of bereavement research and theory that proved to be germane in our analysis concerned the idea of maintaining a connection to the deceased child. There was, for many years, a debate in the grief literature as to whether the grieving person should strive to 'let go' of bonds to the deceased. After the seminal work of Klass, and Riches and Dawson (Klass, 1993; Klass, 1997; Klass, 2006; Riches & Dawson, 1996a; Riches & Dawson, 1996b), however, it is now recognized that

continuing bonds to their deceased child is an important element of coping with their grief. Similarly, Neimeyer, Baldwin and Gillies discuss the importance of reorganizing bonds to the deceased in their 2006 article on meaning reconstruction in adults (Neimeyer, Baldwin & Gillies, 2006). Recent research by Barerra (2009) and Darbyshire (2013), moreover, suggests that one of main stressors in coping for bereaved parents is the potential for a loss of connection to their child. In the present study, the parents we interviewed all mentioned, in some way, the importance of continuing a bond to their deceased child, which is consistent with the results reported in a 2011 article by Foster et al. Moreover, many forms of support these parents perceived as helpful in their coping were felt to be so precisely because they afforded a means of maintaining this connection. One example of this is the follow-up phone calls from HCPs; while the rationale for these calls is to allow the HCPs to evaluate the parents' needs, these calls were often perceived by the parents as a chance to maintain a connection to their child by talking with someone who had known him or her. This finding, which has analogues in research by Darbyshire et al. (2013) specifically examining follow-up calls, provides insight into why certain bereavement follow-up practices are important in helping parents cope.

As we mention above, the parents' experiences of coping was highly personal in nature and affected by various situational factors. One particularly important aspect that emerged from the current study was the impact of the parents' social world on how they coped with their grief (Figure 1). This should not be surprising; humans, after all, are social beings, who create narratives in their lives through interactions with others (Neimeyer & Stewart, 1998; Walter, 1996). This social aspect, however, is often neglected in psychological models of bereavement (Wortman & Boerner, 2007; Stroebe & Schut, 2010; Rubin 1999). As Neimeyer and Stewart (1998), Barrera et al. (2009), and Hooghe et al. (2012) highlight, grieving happens within a social field, and it is therefore imperative to understand the interpersonal factors involved in the grieving process (Barrera et al., 2009; Hooghe et al., 2012; Neimeyer & Stewart, 1998). In relating how parents' experiences of grief were shaped by their relationships, our findings shed light on social and interactional processes that impacted how

parents coped with grief in the first year post-loss. Indeed, many of the emergent themes were inherently interpersonal in nature. In particular, parents noted how relationships were helpful for maintaining a collective memory of their child, a continued connection to their child, and a safe space to reconstruct meaning and process the loss and cope with loss-oriented stressors. In other words, supportive relationships provided a forum for parents to engage in the types of individual coping processes described in the meaning reconstruction and DPM paradigms. Conversely, where such support was lacking, parents voiced a need for external support from services such as psychology and social work. Moreover, our finding that some parents turned to the Internet for support hints at a technology-driven evolution of the social aspect of grief (as has been studied in Mitchell, Stephenson, Cadell & Macdonald, 2012).

As mentioned in the introduction, there is a lack of research that links parents' individual psychological coping processes with existing bereavement follow-up or support services. In the current study, we found that the socially embedded nature of grieving was related to why certain bereavement services and follow-up practices offered by the hospitals or broader community were considered helpful by the parents. Indeed, when parents were asked about their perspectives on these services, their responses had much in common with their descriptions of the support they received from their network of family and friends. Commemorative services, sympathy cards, and follow-up calls allowed for sharing the memory of the deceased child with the staff and other families they had come to know throughout their child's illness; follow-up calls and support groups fostered a 'safe space' to speak about the loss (or, to use the DPM's terminology, provide an appropriate situation in which to engage in loss-oriented coping). Relationships with HCPs, moreover, not only provided a context for processing grief; in many cases these relationships were valued by the parents in their own right, having become woven into the fabric of the parents' lives during the days, weeks, months, or years of their child's illness. After the death of their child, some parents faced the added stressor of losing these relationships, echoing similar findings by Darbyshire et al. (2013). Accordingly, these services were

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considered beneficial because they provided a means for continuing these relationships after the death of the child.

One finding of the present study which might have important clinical relevance concerns differences in coping that related to gender. For example, the fathers we interviewed more often mentioned going back to work as helpful in coping with their grief in the months following the death of their child, whereas mothers did not, which is similar to findings from Alam et al. (2012).[6] Also, mothers more often mentioned benefiting from support groups, whereas fathers more often sought individual services, either from a social worker or psychologist. Martin and Doka suggest that gender differences in coping are related to contemporary patterns of male and female socialization (1999; updated in Doka & Martin, 2010). They are careful to note, however, that in a given individual there can be substantial overlap in these patterns, and that though these patterns are *influenced* by gender, they are not *determined* by it (Doka and Martin, 2010, pg.126). In any case, ours and others' findings highlight the fact that any two people might exhibit very different ways of coping, which has important implications for support services and clinicians working with couples (Aho et al., 2011; Doka and Martin, 2010; Martin and Doka, 1999).

Finally, our findings on the effect of the passage of time on parents' grief, and on their perspectives on the timing of services offered to them, have direct implications for clinicians and service providers. As has been previously reported, experiences of grief change over time (Murphy, Johnson and Lohan, 2003; Rubin and Malkinson, 2001). In addition to our previous recommendation that services be provided in a way that is sensitive to how parents' grieving processes might evolve over time, our findings also suggest that, although follow-up services are considered important in the first year (Contro, Larson, Scofield, Sourkes & Cohen, 2002; D'Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Decinque et al., 2006), some parents might not yet be "ready" to make use of such services during this period, particularly those services which require an active participation on their part (e.g., memorial services and support groups).

Losing a child is recognized as one of the most devastating and intense forms of grief. To address the needs of bereaved parents, pediatric hospitals are increasingly offering bereavement follow-up services to parents during the first year after the death of their child. The imperative, however, to base such services on a firm empirical and theoretical basis has so far been hindered by the relative dearth of research examining parents' early bereavement experiences. Findings such as those presented in the current study can help service providers operate from a deeper, more global understanding of parents' lived experiences of grief, and more effectively target services and resources to help parents in need through this difficult and profoundly meaningful period in their lives. That being said, we should highlight certain limitations to the present study. For one, the transferability of the findings is limited by the lack of internal diversity in the sample of bereaved parents; the vast majority of parents had White/European backgrounds, and we do not know to what degree our findings would apply to parents of markedly different cultural heritages. In addition, there was an absence of parents whose children died from violent deaths or accidents; this presents an important limitation of the study, as cause of death has been found in previous research to be associated with how a parent copes with the loss (Murphy et al., 2002; Lichtenthal et al., 2013). Also, we did not obtain the perspectives of parents who were not followed by any of the recruiting hospital departments, or who otherwise chose not to participate in the study. These limitations notwithstanding, the present study has notable strengths. First, it is one of only a handful of studies to research the first year of parents' bereavement, and also one of the very few studies that examines how bereavement follow-up services meet parents' needs. Moreover, by seeking to elucidate the deeply personal patterns and themes relating to parents' grieving process, but also situating these experiences within the societal and institutional contexts in which parents grieve (Fig.1), the present study offers a concise and global model of parental bereavement that, through close collaboration with relevant stakeholders, has been specifically oriented to informing clinical practice. It is our hope that the insights thus gleaned might strengthen our collective capacity to accompany parents in a way that optimizes outcomes for these parents.

Notes

1. Written informed consent was obtained from all the participants. The consent form explained the nature of study and that participants could be referred to additional support if needed.

2. If and when applicable, these pre-existing theories and models were used to help frame and present the results, at times employing pre-extant terminology in lieu of reinventing the wheel, with all sources duly cited in the discussion. It is important to note, however, that the analysis was not conducted deductively or in an attempt to prove or disprove any specific theory; rather, the inductively gleaned findings have been, post hoc, compared and harmonized with previous work, with the goal of furthering our collective understanding in this area.

3. Most (18 out of 21) of the parents interviewed had a spousal partner.

4. Parents mostly discussed the emotional support they received. They also mentioned receiving information and spiritual support from friends, the internet and various professionals. In discussions of their relationships with other bereaved parents it was clear that these individuals served as a source of network support as well. More tangible forms of support were not mentioned, though parents did mention needs related to logistical issues and financial concerns.

5. Either the fathers we interviewed said this, or the mothers mentioned that their spouse (who we did not interview) had accessed these services.

6. None of the parents we interviewed mentioned difficulty in taking bereavement leave from work. That being said, the issue of parental bereavement accommodation in Canadian labor standards has been explored in a 2015 study by McDonald and colleagues.

bereaved families, and lastly, to the undergraduate transcriptionists (Annie-Jade Pépin, Timothy Li, Benjamin Lachance, Louisa Starnino, Catherine Thibault, Audrey Girard, Magalie Carier Roy, Minh Thi Nguyen, Kim Laporte, and Catherine Soucy) who worked with us in close collaboration to diligently transcribe the words of the parents.

Declaration of Conflicting Interests

Funding

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Figure 1. An Ecosystemic view of coping with grief

Time

Impact of time passing
Timing of services

Services

Follow-up practices
  Phone calls
  Memory box
  Sympathy cards
  Commemorative
  service

Bereavement support
  Support groups
  Social work
  Psychological
  services

Social Context

Spouse
Other children
Friends
Extended family
Other parents
Coworkers
Hospital staff

Individual Coping Processes

Loss-oriented

Thinking about the
loss
Actions related to
the loss

Restoration-oriented

Being functional in
daily life
Distraction from grief

**Reorganize
relationship to
deceased child**

Continue a connection

Maintain the memory

**Meaning
Reconstruction**
Making-sense
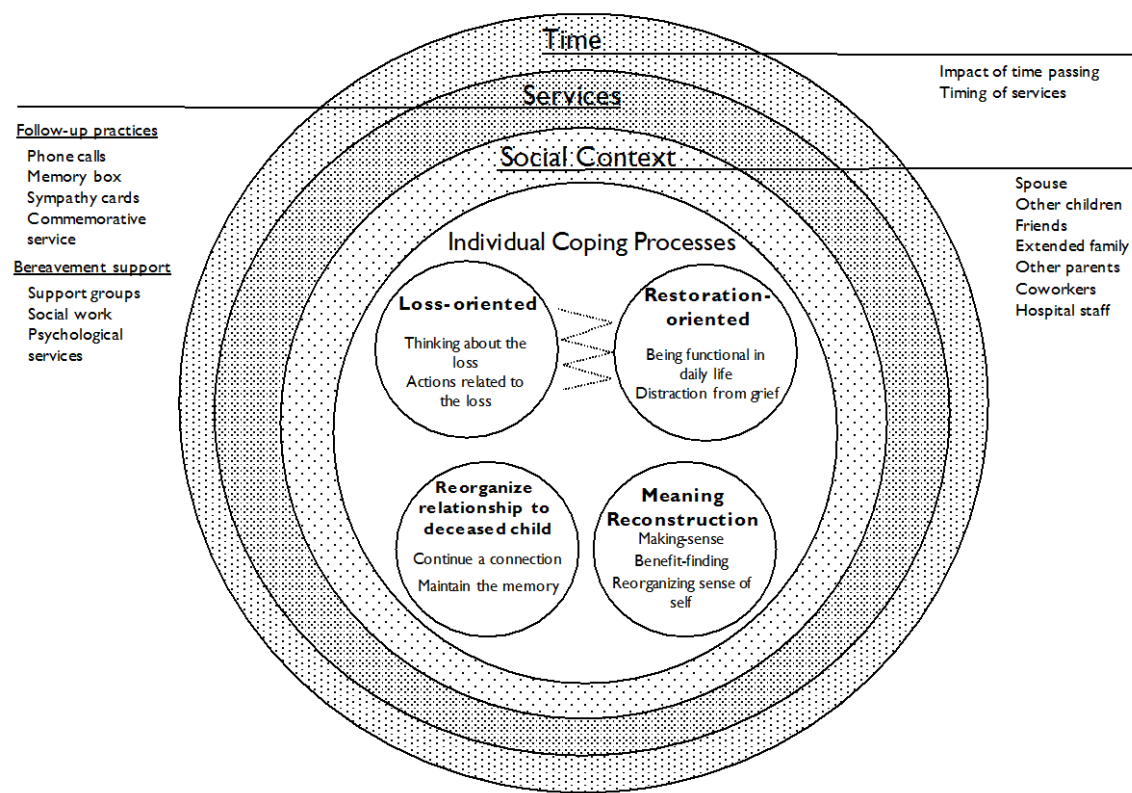Benefit-finding
Reorganizing sense of
self

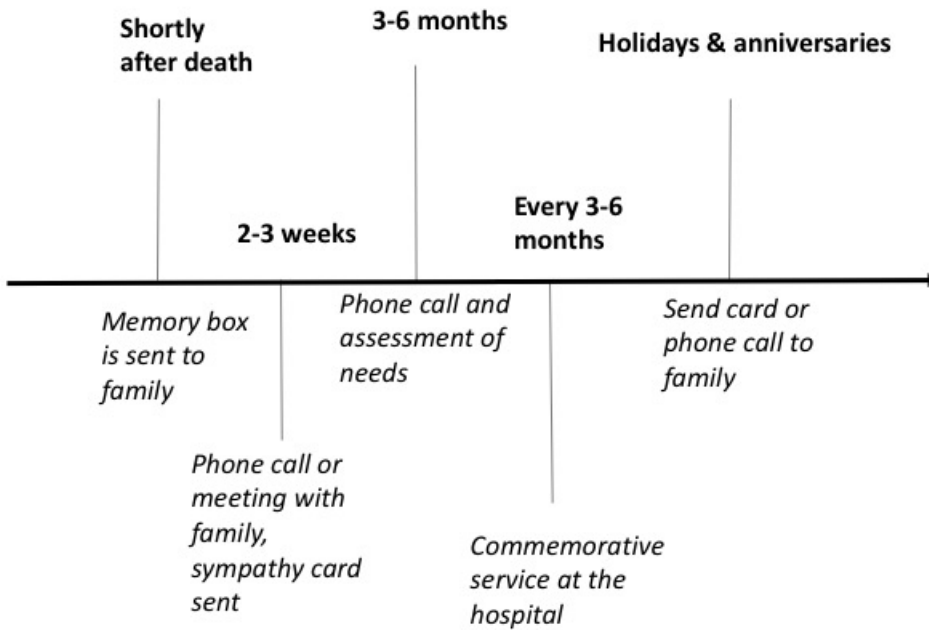**Figure 2.** General guidelines for bereavement follow-up

Table 1. Characteristics of Bereaved Parents who Participated in the Study

Characteristic	Number of participants (%)
Age of parent	
20 to 30 years	2 (9)
31 to 40 years	3 (14)
41 to 50 years	13 (62)
51 to 60 years	3 (14)
Primary speaking language	
French	18 (86)
English	2 (9)
Bilingual	1 (5)
Gender of parent	
Female	15 (71)
Male	6 (29)
Annual household income	
Less than $10 000	3 (14)
$30 001 - 50 000	1 (5)
$50 001 - 70 000	3 (14)
$70 001 - 90 000	4 (19)
More than $90 000	10 (48)
Employment (at time of interview)	
Employed	14 (67)
Retired	2 (9)
Unemployed	4 (19)
Maternity leave	1 (5)
Education (e.g. Primary school or less)	
Primary school or less	1 (5)
High school or technical school graduate	2 (9)
Some college or university	4 (19)
College/university graduate	14 (67)

Relationship to other parent	
Married	11 (52)
Common-law	5 (24)
Separated	3 (14)
Friends/Dating	2 (10)
Other children (y/n)	
Yes	17 (81)
No	4 (19)
Time since death (at recruitment)	
1 year or less	10 (48)
1 to 5 years	11 (52)
Cultural background or Ethnicity	
Caucasian	20 (95)
African-Canadian	1 (5)
Gender of child	
Female	5 (29)
Male	12 (71)
Cause of death	
Neurodegenerative/neurological disorder	4 (24)
Cancer	4 (24)
Congenital disorder	9 (52)
Child's age	
Infant (0 – 1 y)	9 (52)
Child (1 – 13 y)	4 (24)
Adolescent (13 – 19 y)	4 (24)