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# FROM DEATH NOTIFICATION THROUGH THE FUNERAL: BEREAVED PARENTS' EXPERIENCES AND THEIR ADVICE TO PROFESSIONALS*

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**ABSTRACT**

Parents who experience the sudden death of a child will interact with many professionals in the period immediately following the death notification through to the funeral. The way these professionals respond to the parents during this critical period may be perceived as helpful, and thus support them in beginning the process of managing the trauma and starting a healthy grieving process. It may also be perceived as unhelpful, though, and contribute to more prolonged and complicated grieving. This article identifies the interventions that a sample of 20 parents who had experienced the sudden death of a child found helpful with different aspects of grieving. Specific advice is given to police, nurses, doctors, coroners, social workers, crisis counselors, funeral directors, and chaplains or clergy.

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## INTRODUCTION

The sudden death of a child is, for parents, the single most catastrophic event imaginable. The loss of a child is commonly held in the literature to be the most devastating, intense, traumatizing, and difficult to process loss of all (Brabant, Forsyth, & McFarlain, 1994; Klass, 1993; Parkes, 1998; Rando, 1986, 1993, 1998; Rosof, 1994; Smart, 1994), and bereaved parents are thought to be at increased risk of developing post–traumatic stress disorder (PTSD) (Murphy et al., 1999; Thompson, Norris, & Ruback, 1998). Although the current trend of joining traumatology and thanatology to understand the loss of a child will surely deepen our understanding of this process, there is not a great deal of literature from the perspective of the parents available to guide professionals on how to help parents at the time of a child's sudden death.

The crisis precipitated by the death of a child threatens the most elemental assumptions of a parent's beliefs about the world (Wheeler, 1994; Wickie & Marwit, 2001). Unresolved or pathological grief processes explain a great deal of the psychiatric illness experienced in North America (Kempson, 2001). Raphael (1983) and Rando (1993) have noted the high rate of complicated mourning processes after a traumatic bereavement. Rees and Lutkins (1967) found a higher mortality rate among parents whose children have died sudden, violent, or destructive deaths.

The way in which this crisis is dealt with has significant implications for the grief process (Wheeler, 1994). Videka-Sherman (1987) found that constructive intervention after a child's death predicts improved adaptation over time, and Spooren, Hendrick, and Jannes (2001) identified the need for close immediate assistance to parents of deceased accident victims. The personal and social costs that can flow from inept or inadequate professional interventions, or the lack of any intervention at all, can be quite high. These findings suggest that the importance of educated professional interventions when a child dies suddenly cannot be underestimated either in terms of the costs to the mourners, or the cost to society resulting from medical and mental health issues.

Professionals involved with parents at the time of the sudden death of a child experience this work as extremely emotionally draining and stressful. They are often deeply affected by the work (Kalkofin, 1989; Neidig & Dalgas-Pelish, 1991; Sugimoto, 2001), and need to be supported in it. The difficulty of this work may result in role conflicts and a lack of trust between parents and professionals (Weaver, Koenig, & Ochberg, 1996), which may mean that parents are not adequately supported at this traumatic moment (Bradfield & Myers, 1980). The importance of professional intervention in facilitating a healthier grieving process has been debated with respect to several professional groups, including clergy (Frantz, Trolley, & Johll, 1996; Weaver et al., 1996), healthcare professionals (Gyulay, 1989), funeral directors (Kalkofin, 1989), and police (Clark, 1981). The need for both a deeper understanding of the issues bereaved parents

face at the time of their child's death and training for professionals in how best to help parents has been identified in the literature (Gyulay, 1989; Kalkofin, 1989; Neidig & Delgas-Pelish, 1991; Parry, 1994; Weaver, 1993; Weaver et al., 1996). In this article we report the advice given by parents who have experienced the sudden death of a child to the professionals involved with them in the period between their notification of the death and the funeral.

A number of the needs and issues faced by parents at the time of the sudden death of a child have been documented in the literature. First among these is information regarding the death and ensuing processes. Parry (1994) and Kalkofin (1989) have identified the need to talk about and process information after the death. For example, parents need to discuss the details of the death and review the circumstances leading up to the death. Gyulay (1989) has outlined the differences in need for information among parents, the significance of the timing of the information, and the differing abilities of parents to comprehend and retain the information. Winje (1998) described the "need to know" often seen in parents as a normal part of the grief process. Further, he found that feeling adequately informed was correlated with a better adjustment after the loss. Information is also central to the ability of parents to make sense of what has occurred (Bowman, 1999; Rando, 1993; Winje, 1998), and is an essential precursor in working through their grief.

Having a sense of control is another issue/need identified by researchers and practitioners. Gyulay (1989) has clearly identified the need of parents to feel an element of control in relation to decisions such as the access to and timing of information being released about the death; decisions regarding access to the body; funeral procedures; and autopsies. Other research shows that asking parents their opinions and actually listening to them is important to the parents (Kavanaugh & Robertson, 1999). Gyulay (1989) suggests that over-protectiveness in professionals, exemplified by attempting to shield parents from some of the harsher aspects of their child's death, actually disempowers them. It is essential for the parents to be offered choices and to have those choices respected.

Access to the child's body is a third key need identified in the literature (Gyulay, 1989; Kalkofin, 1989). Access to the body provides an opportunity to say goodbye to the child: an important beginning to the grief process (Rando, 1986; 1993). Permitting parents to hold the deceased child, position the body, and dress the body, should they desire to do so, have also been suggested (Gyulay, 1989; Kalkofin, 1989).

Another area developed in the literature relates to the later processes of grief: finding meaning and joy in life without the child. As parents grieve and begin to move forward in their lives without the child, linking objects have been mentioned as one way to assist in this process (Wheeler, 1999). Linking objects can be identified very early in the grief process to assist in forming a bridge between the live child and the parent after the child's death, and can assist the parents in their adjustment by helping them stay connected to the child as they move forward with

their lives (Klass, 1993). They are also an important aspect of the reinvestigating part of the grief process (Rando, 1993). Another way in which parents reinvest and move forward is through the inner representation of the dead child (Klass, 1993). Parents may do this through linking objects, though attempting to experience the spiritual presence of their child, and through finding solace in memory.

Most of the current literature regarding professionals involved with bereaved parents at the time of the death focuses on a particular professional group rather all of the professionals who have contact with a family in the period immediately following the death of a child. Further, the experiences of bereaved parents are not central to most of these studies. Those who do focus on the needs of bereaved parents, such as Murphy et al. (1999), Winje (1998), and Gyulay (1989), have not examined the roles played by specific professionals at the time of the sudden death of a child. Winje (1998) did connect access to information with the grieving process, but did not examine the role of professional interventions in that process. In addition, Winje's use of a sample of parents who had all lost a child in the same school bus accident may have affected the outcome. The work of Gyulay (1989), while informative and reflective of the experience of bereaved parents, is based on her life-long professional experience; she did no formal research in this area.

The purpose of this research was to establish insights to begin building a model of intervention based upon the experiences of parents who have lost a child to sudden death. The general research question guiding this study is: *What can involved professionals do to assist parents through the initial period of the sudden death of a child in order to help facilitate the most healthy grieving process possible*? Our intention was to focus on what parents found helpful among the actions of the various professionals involved at the time of the sudden death of a child; that is, from the death notification through the funeral. This model requires a thorough understanding of the immediate impact of the traumatic death of a child on parents—currently not well formulated in the thanatological literature—as well as in-depth insight into the parents' own experiences and self-identified needs at such a time. In this study, we examined the unique experiences of parents with a broad range of professionals, looked at the impact of those experiences on the parents' perceptions of their grieving processes, and sought parents' advice to professionals about how best to support other parents who experience a sudden death, especially during the period between death notification and the funeral.

For the purpose of this study, we have utilized Straub's (2001) definition of sudden death: that is, a death that occurs suddenly or unexpectedly. The children of families in this study experienced either instantaneous death or succumbed to the precipitating insult within three days of the event that caused their death. The age at which the child died was not limited in selecting participants, though the parents were required to have had an active role in the child's life. The literature suggests that the age of the child is irrelevant to the grief process, but rather that treatment issues may vary according to age (Rando, 1993). The deceased children in this

study ranged in age from birth to young adulthood (24 years of age), except for one adult child who was 38 at the time of death.

## METHODOLOGY

The approach used in this research was qualitative, drawing upon heuristic inquiry, in that the first author had experienced the sudden death of her own son. Heuristic inquiry asks the question, "What is my experience of this phenomenon, and the essential experience of others who also experience this phenomenon intensely?" (Patton, 2002, p. 133; see also Moustakas, 1990). Heuristic inquiry is understood to have a phenomenological focus, in that it intends to capture people's understanding of a life experience. Qualitative inquiry lends itself well to a heuristic approach "in which human experiences are examined through the detailed descriptions of the people being studied" (Cresswell, 1994, p. 12).

In keeping with the heuristic approach, a purposeful sampling approach was utilized. Information-rich cases were sought for in-depth inquiry into the issues thought to be of central importance in such a study (Patton, 2002). This purposeful sample consisted of 20 individuals who had experienced the death of a son or daughter 11 months to seven years prior to the interview. The 20 parents were identified through three Bereaved Families of Ontario (Canada) affiliates. Bereaved Families of Ontario is an organization formed in 1978 to provide support to parents who have experienced the death of a son or daughter, and to children who have experienced the death of a sibling or parent.

The sample was comprised of four couples, 11 mothers, and one single father. The couples, except for one, were interviewed individually. Participants were all white, European-Canadian, Christian, and middle class, and ranged in age from early thirties to early sixties. Some of the parents had experienced other losses since the death of their child (e.g., the loss of a parent or sibling), and were able to draw comparisons between the experiences. At the time the interviews were conducted, some of the parents were involved in continuing litigation stemming from the death of the child. All were eager participants willing to share their stories in the hope that doing so would help future bereaved parents. This is a philosophy central to the Bereaved Families mission.

The primary limitation of this research is in the sampling process. Though many attempts were made to find a sample of people from outside of Bereaved Families of Ontario, all of the participants were currently or had at some time been involved with the organization. The fact that the sample was entirely from Bereaved Families leaves open the possibility that the philosophy of the organization influenced the thinking of its members in a systematic way that may not be manifest among non-group members. Study participants were from several Bereaved Families affiliates and included both former members as well as present members, but this does not mitigate the potential effects of organizational

membership. In addition, the participants were all white, Christian, and middle-class. The experiences of bereaved parents of other ethnicities, religious backgrounds, and socioeconomic classes, as well as those parents who choose to grieve without seeking group support, may be entirely different.

For the purpose of this research, participants whose children had died at least one year prior were sought. The staff of Bereaved Families of Ontario, who assisted in identifying potential participants, was given this time frame as a guideline and was asked to approach parents who they felt had reached a stage in their grief where they could be reflective with respect to their experiences. The study utilized in-depth individual face-to-face interviews between the first author and the participants, who had been invited to participate in a study that would assist professionals in understanding the needs of parents at the time of a child's death by discussing how they were personally affected by professional interventions. The consent form signed by all parents who participated explicitly stated this purpose. During the interviews, parents frequently highlighted information that they particularly wanted professionals to know, and their suggestions were incorporated into the findings of the study. All interviews were held in the homes of the participants. The interviews were unstructured and open-ended, with an emphasis on the individual's experience of the phenomenon (Berg, 1995; Lincoln & Guba, 1985; Patton, 2002).

Data analysis consisted of transcription of the tapes, identification of categories through first–level coding, and identification of themes uniting the categories through second–level coding (Tutty, Rothery, & Grinnell, 1996). First–level coding using Bogden and Bicklin's (1982) "folder approach" yielded a descriptive list of interventions by each of the professional groups (i.e., police, emergency room staff, coroners, chaplains, clergy, funeral directors, social workers, and crisis counselors) that parents found helpful. Drawing on theory about the grieving process and trauma, a conceptualization of aspects of grieving associated with losing a child to sudden death was also produced. Second–level coding produced a conceptualization of the three types of interventions that are helpful with each of the five aspects of the grieving process for parents who have lost a child to sudden death. These are reported in detail below. A "member check" (Lincoln & Guba, 1985) was conducted with participants to verify that the various conceptualizations made sense in light of their personal experiences as an indicator of the trustworthiness of the analysis. Data were also drawn from field notes in constructing this analysis.

## THEMES RELATED TO PROCESSING THE DEATH

Five themes that related to the parents' understanding of how they processed experiencing the death of their child emerged from the analysis of the data. These themes will be reported first, followed by an analysis of the kinds of interventions most helpful around each of these aspects of grieving. The first theme identified

was the need to reconstruct the death scene of the child. Parents who were present for the death already knew the information necessary to remember and process the death scene. For those who were not present when the death occurred, the need for information to piece together the last moments of their child's life and develop a death scene script was often intense. Many of these parents described going to great lengths to obtain detailed, specific information regarding the last moments of their child's life and exactly how he or she died. One parent said:

> I was desperate for the details. Desperate. I read those papers over and over and over again. I had to reconstruct that accident. I needed to know what went on in the final ten or fifteen minutes before he died, and what happened. Very important. Very important for parents to do. I don't think authorities know how important that it is. That's why an accident is so important for parents to reconstruct. You need that final fifteen minutes.

The information sought by parents after a child's death has two purposes related to the grieving process: to assist with processing the trauma that stems from the violation of the assumptive world (Rando, 1998), and to accomplish the first phase of grieving—intellectually and emotionally understanding the loss (Rando, 1993). Parents' need for adequate information is significant (Winje, 1998), and has been found to be both a normal reaction to trauma and related to psychological outcome. Intrusive remembering allows parents to assimilate the experience of the loss (Lindemann, 1944), and to modify the level of affect associated with the trauma created by the death of the child (van der Kolk & McFarlane, 1996). Intrusive thoughts are part of a normal response to this type of trauma. Information assists in the construction of a narrative regarding the trauma, and the failure to construct such a narrative may lead to the development of PTSD (van der Kolk & Fisler, 1995).

The second theme noted in the interviews was feeling a loss of control, and the shattering of the world the parents knew prior to their child's death. This stems from the shattering of the assumptive world (Epstein, 1980; Figley, 1984; Janoff-Bulman, 1985; Parkes, 1971). The data with respect to this theme demonstrates the parents' appreciation for those who assisted them in regaining some sense of control, as well as the intense anger many parents felt toward professionals who were perceived to have interfered with their efforts in that regard:

> . . . with the funeral home I had made one request. I said I needed to see my daughter's coffin lowered to the ground level. I don't need it all the way down into the ground. I don't know why. I can't tell you why. I know I needed to see that coffin lowered to the ground level because that was the last time, the last time I would ever . . . . At any time during visitation after hours I could say "Open the coffin" and I could see her. But to me once it sat down at ground level, I'll never get the chance to say to go back and open up her coffin or anything. And when I requested they denied me. . . . I'm not asking them to put it all the way down into the vault or anything. It did nobody harm. Why were they giving me such a hard time about it?

Supporting parents in regaining control is vital to helping them process the trauma of death. Feelings of control help reduce feelings of helplessness and powerlessness, and lower rates of PTSD in trauma survivors (Regehr, Cadell, & Jansen, 1999; Silver, Wortman, & Kloss, 1982). Regaining control is also important in rebuilding the assumptive world: a significant task of the grieving process (Rando, 1993).

The third theme evident in the parental interviews was the need to say goodbye. This incorporates the need to have access to the child's body with the need to have professionals demonstrate an understanding of the extent of the loss, through treating the child with respect and dignity and through demonstrating compassion to the parents, and is part of the process of reconstructing the death scene. Saying goodbye is a vital part of the first phase of grieving, and can also assist in the processing of the trauma. Again, where professionals facilitated this process, the parents felt supported as this parent did: "Her long hair was all laid out properly. . . . Somebody went to a great extent with her hair to lay it out nicely. I'll always remember that." When professionals were perceived to have interfered, for whatever reason, parents felt additionally traumatized and had increased difficulty with the first phase of grieving:

> They had him laying on one of those metal tables. Not tables, you know, those tables they push with. It was disgusting. Why couldn't they have put a nice blanket—why couldn't they—they must have blankets upstairs in the maternity ward, with a, with a pillow. It was, it was bad enough . . . I still have nightmares about that.

The fourth theme, the attempt to make sense out of the death and find meaning in it, is affected by access to information and related to the reconstruction of the death scene. Intellectually and emotionally understanding the loss assists in the first phase of grieving (Rando, 1993). Furthermore, it is significant to the process of rebuilding the assumptive world and gaining some semblance of control in a chaotic experience (Figley, 1984; Janoff-Bulman, 1985; Rando, 1998). The ability to understand and make sense of the death is a factor in the future psychological adjustment of the survivor (Bowman, 1999; Winje, 1998). In their interviews, many parents shared the struggle they engaged in to make sense out of the death, and to find meaning in it. One parent said:

> A lot of people ask me, "Well, what is that? How could the doctor let him go at that high fever?" I have to know these answers. I'm just that way. I can't be left wondering. If I find the answers I'm more at peace with myself and I can help other parents. You know, when their child is sick in an emergency department setting.

The final theme involved the attempts many parents have made to carry forward a new relationship with their deceased child in their lives. This was often done by memorializing, ritualizing, and carrying on an active involvement in activities or organizations that were relevant to their child's life and/or death. This theme

relates to the third phase of grieving, where the parent moves forward in a new world without the child (Worden, 1991). In this phase, the relationship of self to the deceased is changed, and the parent reinvests in life with an integrated past and present (Rando, 1993).

> So when I got to the point where I could come to terms with her death, I decided that I would try to take on some of her characteristics, and try to be a little less aggressive, and try to be a little less judgmental.

## HELPFUL AND UNHELPFUL INTERVENTIONS

It is apparent from these interviews that professionals have a strong impact on bereaved parents at the time of the sudden death of their child—whether that impact is positive or negative. Negative impacts add to the trauma, while positive ones help mitigate the trauma and assist parents with the beginning of the grieving process. Table 1 summarizes the kinds of interventions that were reported as helpful by each of the professional groups. While some of the interventions identified were related to the responsibilities of a specific professional (e.g., the coroner giving parents access to the body; a nurse helping parents get medical attention for themselves; the police being thorough in their investigation), others applied to all professional groups. Showing compassion and empathy is the primary example of a helpful intervention. Unhelpful interventions will not be outlined in a parallel way, but were generally the opposite of what was seen as helpful—not showing compassion, for instance, or failing to provide information to parents.

Further analysis of the data, as reported in Table 2, shows the types of interventions identified as helpful in relation to the five themes mentioned above as central to the grieving process during this period of crisis. These interventions were categorized as providing instrumental assistance, providing information, and displaying compassion and empathy. Participants reported that these types of interventions assisted them in surviving the trauma, processing it, and beginning to grieve in a healthy way. Specific professionals may be able to provide a particular kind of support that was identified as helpful—like providing pictures or reports about the child's death—or they may be able to advocate for the parent if another professional is reluctant to assist in ways that they have requested.

## DISCUSSION

Ultimately, the goal of grief is the incorporation of the deceased into the bereaved's life in a different way, and reinvestment in the bereaved's new life without the deceased (Rando, 1993). As stated by Fleming & Robinson (1991), grief is the process by which one moves from losing what one had to having what one lost. The parents in this study have each found their own ways to do this.

Table 1. Summary of Interventions that were Helpful by Profession

| Professional group | Interventions |
|---|---|
| Police | • Helping to contact relatives/friends<br>• Transportation to the hospital<br>• Being thorough in the investigation<br>• Respecting parents wishes<br>• Providing information<br>• Demonstrating empathy and sensitivity |
| Nurses | • Preparing parents for seeing the child's body<br>• Providing information re: status of child<br>• Offering food, blankets, a cot, etc.<br>• Helping parents get medical attention for themselves<br>• Explaining procedures and processes<br>• Comforting the dying child<br>• Providing empathy and support to parents and family<br>• Ensuring access to child's body, time, and privacy<br>• Offering a naming ceremony (stillbirths)<br>• Respecting that a real baby was born and lost (stillbirth)<br>• Normalizing and validating feelings |
| Doctors | • Meeting medical needs of parents<br>• Showing compassion<br>• Giving information<br>• Explaining procedures and processes<br>• Providing referrals and follow-up |
| Coroners | • Showing compassion and sensitivity<br>• Providing information<br>• Giving access to the child's body, time, and privacy<br>• Ensuring accuracy on documentation |
| Social worker/ Crisis counselors | • Normalizing and validating feelings and experiences<br>• Providing information about grief<br>• Providing referrals<br>• Obtaining information for parents<br>• Offering assistance in problem-solving issues<br>• Listening<br>• Facilitating the meeting of basic needs of parents<br>• Advocacy |

Table 1. (Cont'd.)

| Profesional group | Interventions |
|---|---|
| Funeral directors | • Allowing participation in setting up visitation room<br>• Access to body<br>• Offering opportunity to assist in final preparations<br>• Running interference during visitation<br>• Ensuring smooth visitation and funeral process<br>• Providing support and follow-up<br>• Encouraging the personalization of the visitation/ funeral |
| Chaplains and clergy | • Being available<br>• Following through with commitments<br>• Assisting in transportation, contacting friends, and family<br>• Learning about the child to personalize the funeral<br>• Respecting parents' wishes re: funeral<br>• Obtaining and providing information<br>• Attending at hospital and home to be with parents<br>• Suggesting appropriate referrals<br>• Providing tapes of funerals<br>• Follow-up support and counseling if necessary |

Professionals have the unique opportunity to contribute to this process in the early stages of grief by helping parents create rituals and memorials for their children during the processes of saying goodbye and making sense of the death. Most importantly, professionals can contribute to the attainment of the first phase of grieving. This will promote both a healthy grieving process and a positive readjustment to life by helping parents identify their needs, and supporting them in meeting those needs. Crisis Theory (Golan, 1979), with it's emphasis on helping the individual establish coping mechanisms in a crisis, provides a sound basis upon which to inform the role of a professional at such a time. Crisis intervention skills are an excellent fit with helping traumatized parents, as they both support the facilitation of a sense of control for the bereaved parent and assist the bereaved parent in actively making choices and moving toward resolution.

These study results must be considered with some caution because of the small sample size and the fact that the sample was drawn only from participants in one bereavement support organization, was invited to participate by staff, and varied considerably in age. Nonetheless, the themes identified in this study highlight the significance of professional intervention at the time of a child's death, and the enormous impact that such interventions have. Each parent participated in this research because he or she wanted professionals to have a better understanding of

Table 2. Helpful Interventions Professionals Can Provide

| Processes | Instrumental assistance | Provision of information | Compassion and empathy |
|---|---|---|---|
| Reconstruction of death scene | • Offering/providing pictures and reports if desired<br>• Provide access to child's body<br>• Being thorough in responsibilities | • Providing details of death and death surround<br>• Timely information<br>• Written information<br>• Repetition of information | • Give control over timing and detail of information<br>• Provide active listening<br>• Present a calm, warm presence |
| Issues of control | • Listening to needs/wishes of parents<br>• Respecting parents' decisions<br>• Providing access to child's body | • Explain procedures and processes<br>• Offer explanations if parents' wishes cannot be provided | • Be sensitive to parents' vulnerability<br>• Be present, but not intrusive<br>• Offer and provide comfort as requested by parents |
| Saying Goodbye | • Allow time and privacy with child's body<br>• Encourage involvement in planning visitation and funeral<br>• If desired permit parents to assist in dressing child's body | • Explain what to expect as child dies<br>• Explain what parents will see, hear, etc., when seeing child's body<br>• provide information re: processes and procedures | • Show respect for the child's body<br>• Make child's body appear cared for (e.g., cover with blanket, remove apparatus, etc.)<br>• Provide support |
| Making sense of the death | • Inform parents of and provide access to child's medical charts, autopsy report, police reports, pictures if requested | • Provide information re: death, death surround, and outcomes<br>• Help process information<br>• Be prepared to repeat information often if needed | • Be an active listener<br>• Acknowledge the immensity of the loss<br>• Be sensitive to parents' needs<br>• Facilitate process of making sense of the death |
| Carrying the deceased child forward | • Assist parents to identify mementos of their child to keep | • Assist in developing rituals and memorials | • Be supportive of parents' faith beliefs<br>• Support parents in carrying out rituals<br>• Provide follow-up support if desired |

what they can do to help, and what it is like to have your child die. All felt that better-informed professionals will be more helpful to others whose children may die in the future. A clear understanding of the themes identified here will enable professionals to form interventions that support parents' grief in a positive manner.

One participant offered this powerful summary of the need for better understanding and improved skills among those professionals who encounter parents during the trauma of loss:

> Grief was a new experience for me. When my son died, I had not experienced the death of anyone I loved. I had no idea what to expect, either in terms of my own emotional reactions or in terms of other people's reactions. I suppose that I expected that the professionals we encountered would be kind, compassionate and helpful. After all, we are conditioned to respect police officers, doctors, clergy, etc., and the assumption is that they know what to do in a crisis. They are trained to handle these things. In actual fact, some were kind, compassionate and helpful, and some were not. It is amazing what an impact the actions/reactions of others can have during this traumatic and very vulnerable time. I remember very clearly the things that were said and done which were comforting. I remember just as clearly, in fact, perhaps more clearly, the things that were said and done which were hurtful and upsetting.

The first people we encounter after the death of a child are the professional people listed in this document. These people can have a tremendous impact. The authors hope that the conclusions herein will reach the appropriate professional groups and will be included in training. Hopefully, positive changes will result.

## CONCLUSION

Five themes associated with the grieving process of parents who have lost a child to sudden death have been identified: the reconstruction of the death scene, issues of control and the shattering of the assumptive world, saying goodbye, making sense of the death, and carrying the deceased child forward in the parents' lives. In addition, three types of interventions helpful to parents have been specified and cross-tabulated with the five themes of grieving. Participants in this research have provided important information for professionals regarding the helpfulness of certain interventions. There is no uniform prescription for helping parents through this trauma; however, the guidelines offered by these parents promise to help professionals be better helpers.

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## REFERENCES

Berg, B. L. (1995). *Qualitative research methods for the social sciences* (2nd ed.). Toronto: Allyn & Bacon.

Bogden, R., & Bicklin, S. (1982). *Qualitative research for education: An introduction to theory and methods*. Boston: Allyn & Bacon.

Brabant, S., Forsyth, C., & McFarlain, G. (1994). Defining the family after the death of a child. *Death Studies*, *18*, 197-206.

Bradfield, C., & Myers, I. (1980). An uneasy alliance: Doctors of grief and doctors of divinity. *Association for the Sociology of Religion*, (Association paper).

Bowman, M. L. (1999). Individual differences in posttraumatic distress: Problems with the DSM-IV Model. *Canadian Journal of Psychiatry*, *44*, 21-23.

Clark, D. (1981). A death in the family: Providing consultation to the police on the psychological aspects of suicide and accidental death. *Death Education*, *5*, 143-155.

Cresswell, J. (1994). *Research Design*. Thousand Oaks, CA: Sage Publications.

Davidson, K., & Foster, Z. (1995). Social work with dying and bereaved clients: Helping the workers. *Social Work in Health Care, 21,* 1-16.

Epstein, S. (1980). The self-concept: A review and the proposal of an integrated theory of personality. In E. Straub (Ed.), *Personality: Basic issues and current research* (pp. 404-416). Englewood Cliffs, N.J.: Prentice-Hall.

Figley, C. (1984). *Helping traumatized families*. San Francisco: Jossey-Bass.

Fleming, S., & Robinson, P. (1991). The application of cognitive therapy to the bereaved. in T. Vallis, J. Howes, & P. Miller (Eds.), *The challenge of cognitive therapy: Applications to non-traditional populations* (pp. 135-158). New York: Plenum Press.

Frantz, T., Trolley, B., & Johll, M. (1996). Religious aspects of bereavement. *Pastoral Psychology*, *44*, 151-163.

Golan, N. (1979). Crisis theory. In F. J. Turner (Ed.), *Social work treatment: Interlocking theoretical approaches* (2nd ed.) (Pp. 499-533). New York: Free Press.

Gyulay, J. (1989). Sudden death: No farewells. Special issue: The death of a child. *Issues in Comprehensive Pediatric Nursing*, *12*, 71-101.

Janoff-Bulman, R. (1985). The aftermath of victimization: Rebuilding shattered assumptions. In C. Figley (Ed.), *Trauma and its wake* (pp. 15-36). New York: Brunner-Mazel.

Kalkofin, R. (1989). After a child dies: A funeral director's perspective. *Issues in Comprehensive Pediatric Nursing*, *12*, 285-297.

Kavanaugh, K., & Robertson, P. (1999). Recurrent perinatal loss: A case study. *Omega*, *39*, 133-147.

Kempson, D. A. (2001). Effects of intentional touch on complicated grief of bereaved mothers. *Omega*, *42*, 341-353.

Klass, D. (1993). The inner representation of the dead child and the world views of bereaved parents. *Omega*, *26*, 255-272.

Klass, D. (1996). The deceased child in the psychic and social worlds of bereaved parents during the resolution of grief. In D. Klass, P. R. Silverman, & S. L. Nickman (Eds.), *Continuing bonds* (pp. 199-215). Washington, DC: Taylor & Francis.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, *101*, 141-148.

Moustakas, C. (1990). *Heuristic research: Design, methodology and applications*. Newbury Park, CA: Sage.

Murphy, S. A., Braun, T., Tillery, L., Cain, K. C., Johnson, L. C., & Beaton, R. D. (1999). PTSD among bereaved parents following the violent deaths of their 12 to 28 year-old children: A longitudinal prospective analysis. *Journal of Traumatic Stress*, *12*, 273-291.

Neidig, J., & Dalgas-Pelish, P. (1991). Parental grieving and perceptions regarding health care professionals' interventions. *Issues in Comprehensive Pediatric Nursing*, *15*, 179-191.

Parkes, C. (1971). Psychosocial transitions: A field for study. *Social Science and Medicine*, *5*, 101-115.

Parkes, C. (1998). Bereavement in adult life. *British Medical Journal*, *316*, 856-859.

Parry, J. (1994). Death review: An important component of grief resolution. *Social Work in Health Care*, *20*, 95-110.

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage.

Rando, T. (1986). *Parental loss of a child*. Champaign, IL: Research Press.

Rando, T. (1993). *Treatment of complicated mourning*. Champaign, IL: Research Press.

Rando, T. (1998, May). Traumatic loss. Lecture presented at the annual conference of Bereaved Families of Ontario. Toronto, Canada.

Raphael, B. (1983). *The anatomy of bereavement*. New York: Basic Books.

Rees, W., & Lutkins, S. (1967). Mortality of bereavement. *British Medical Journal*, *4*, 363-368.

Regehr, C., Cadell, S., & Jansen, K. (1999). Perceptions of control and long-term recovery from rape. *American Journal of Orthopsychiatry*, *69*, 110-115.

Rosof, B. (1994). *The worst loss*. New York: Henry Holt & Co.

Silver, R., Wortman, C., & Kloss, D. (1982). Cognitions, affect and behaviour following uncontrollable outcomes: A response to current human helplessness research. *Journal of Personality*, *50*, 480-514.

Smart, L. (1994). Parental bereavement in Anglo American history. *Omega*, *28*, 49-61.

Spooren, D. J., Henderick, H., Jannes, C. (2001). Survey description of stress of parents bereaved from a child killed in a traffic accident: A retrospective study of victim support groups. *Omega*, *42*, 171-185.

Straub, S. H. (2001). *Death without notice*. Amityville, NY: Baywood Publishing.

Sugimoto, J. D. (2001). The environment of death and its influence on police officers in the United States. *Omega*, *43*, 145-155.

Thompson, M. P., Norris, F. H., & Ruback, R. B. (1998). Comparative distress levels of inner-city family members of homicide victims. *Journal of Traumatic Stress*, *11*, 223-241.

Tutty, L., Rothery, M., & Grinnell, R. M., Jr. (1996). *Qualitative research for social workers*. Toronto: Allyn & Bacon.

van der Kolk, B. A., & Fisler, R. E. (1995). Dissociation and the fragmentary nature of traumatic memories: Overview and exploratory study. *Journal of Traumatic Stress*, *8*, 505-523.

van der Kolk, B. A., & McFarlane, A. C. (1996). The black hole of trauma. In B. A. van der Kolk, A. C. McFarlane, & L. Weisaeth (Eds.), *Traumatic stress: The effects of overwhelming experience on mind, body, and society* (pp. 47-74). New York: Guilford Press.

Videka-Sherman, L. (1987). Research on the effect of parental bereavement: Implications for social work intervention. *Social Service Review*, *61*, 103-110.

Weaver, A. (1993). Psychological trauma: What clergy need to know. *Pastoral Psychology*, *41*, 385-408.

Weaver, A. J., Koenig, H. G., & Ochberg, F. M. (1996). Posttraumatic stress, mental health professionals, and the clergy: A need for collaboration, training, and research. *Journal of Traumatic Stress*, *9*, 847-855.

Wheeler, I. (1994). The role of meaning and purpose in life in bereaved parents associated with a self-help group: Compassionate friends. *Omega*, *28*, 261-271.

Wheeler, I. (1999). The role of linking objects in parental bereavement. *Omega*, *38*, 289-296.

Wickie, S. K., & Marwit, S. J. (2001). Assumptive world views and the grief reactions of parents of murdered children. *Omega*, *42*, 101-113.

Winje, D. (1998). Cognitive coping: The psychological significance of knowing what happened in the traumatic event. *Journal of Traumatic Stress*, *11*, 627-643.

Worden, J. (1991). *Grief counselling and grief therapy*. New York: Springer Publishing.

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