# Health care professionals' grief after the death of a child

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**OBJECTIVES:** To evaluate the intensity of grief experienced by health care professionals (HPs) after the death of a child, to explore factors associated with a memorable death (defined as an unforgettable child's death that has touched them in their career) and to identify the needs of HPs.

**METHODS:** A cross-sectional study was performed to assess emotional reactions, coping strategies and perceived needs of paediatric HPs in a general hospital.

RESULTS: One hundred one HPs (46 nurses, 22 paediatric physicians, 11 paediatric residents, 13 respiratory therapists and nine 'others') completed the questionnaire. The level of grief experienced by HPs after a memorable death was intense. Respiratory therapists showed the highest mean (± SD) intensity of grief after a memorable death versus other HPs, as measured by the Texas Revised Inventory of Grief (TRIG) (29±15 versus 16±14; P=0.002). Younger HPs (20 to 25 years of age) reported higher early grief intensity than older ones (older than 50 years of age) (22±16 versus 10±8; P=0.01). There was no significant association between the TRIG score and an HP being a parent, having received palliative care training or the length of his/her relationship with the child and family. Seventy per cent of HPs spoke with their colleagues after the death of a child and 48% with family and friends. Many participants (37%) believed that this social support helped them the most.

**CONCLUSION:** Grief after a child's death is intense for HPs. This emotional intensity and difference between professions raises issues about the emotional support received following the death of a patient.

Key Words: Child; Death; Grief; Health care professional

# Caring for children is a rewarding experience. Despite major advances in medical care, children still die. Paediatric health care professionals (HPs) are frequently affected by children's deaths and experience bereavement (1-3). In the province of Quebec, approximately 840 children die each year, mainly from injuries and complex chronic conditions (4). Paediatric HPs must provide emotional support to their dying patients and their bereaved families. This task is challenging, and is a recognized cause of burnout and other forms of emotional distress (1,2,5-7).

Little is known about the impact of a dying child on HPs. Evidence suggests that doctors and nurses mainly experience guilt, sadness and stress when faced with the death of their patient (1,2,5,8,9). According to Papadatou et al (10), the death of a young patient causes pain and distress in nurses and physicians. Several similarities were noted between these two groups. They experienced, among other feelings, a great deal of stress, sadness

## Le deuil des professionnels de la santé après le décès d'un enfant

OBJECTIFS: Évaluer l'intensité du deuil que vivent les professionnels de la santé (PS) après le décès d'un enfant, explorer les facteurs associés à un décès mémorable (défini comme le décès inoubliable d'un enfant qui les a touchés pendant leur carrière) et déterminer les besoins des PS.

**MÉTHODOLOGIE :** Les auteurs ont mené une étude transversale pour évaluer les réactions affectives, les stratégies d'adaptation et les besoins perçus des PS en pédiatrie dans un hôpital général.

RÉSULTATS: Cent un PS (46 infirmières, 22 pédiatres, 11 résidents en pédiatrie, 13 inhalothérapeutes et neuf « autres ») ont rempli le questionnaire. Le taux de deuil ressenti par les PS après un décès mémorable était intense. Les inhalothérapeutes présentaient l'intensité moyenne de deuil (± ÉT) la plus importante de tous les PS, telle qu'elle était mesurée par l'inventaire révisé du deuil du Texas (TRIG) (29±15 par rapport à 16±14; P=0,002). Les PS plus jeunes (de 20 à 25 ans) déclaraient une intensité de deuil immédiate plus élevée que les plus âgés (plus de 50 ans) (22±16 par rapport à 10±8; P=0,01). On ne remarquait aucune association significative entre l'indice de TRIG et le fait que le PS était un parent, le fait qu'il avait reçu une formation en soins palliatifs ou la durée de sa relation avec l'enfant et sa famille. Soixante-dix pour cent des PS parlaient avec leur collègue après le décès d'un enfant, et 48 % avec leur famille et des amis. De nombreux participants (37 %) étaient d'avis que c'était ce soutien social qui les aidait le plus.

CONCLUSION: Les PS ressentent un deuil intense après le décès d'un enfant. Cette intensité affective et la différence entre les professions soulèvent des questions quant au soutien affectif reçu après le décès d'un patient.

and recurring thoughts of the dying child. However, doctors seemed to express their grief differently from nurses. Doctors in the study rarely sought emotional support from colleagues, whereas nurses usually did.

Redinbaugh et al (2) also explored physicians' emotional reactions to the recent death of a patient. Their study showed that physicians were "moved by the deaths of the strangers for whom they care", and female doctors seemed to report more psychological distress than male doctors. Moores et al (3) studied reactions of hospital doctors to a memorable patient's death and, in contrast to the study by Redinbaugh et al, men and women showed no significant difference in their emotional response.

Because paediatric HPs are increasingly recognizing the value of working in multidisciplinary teams, we wanted to extend previous research to describe the emotional impact of the memorable death of a child on all HPs. We also wanted to explore what makes a child's death memorable.

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TABLE 1
General characteristics of participants (n=101)

Characteristic	n
Age, years	
20–25	19
26–30	12
31–40	34
41–50	19
>50	17
Sex	
Male	12
Female	78
Data missing	11
Parents	63
Previously lost their own child (including abortion and stillbirth)	20
Profession	
Nurse	46
Physician	22
Resident	11
Respiratory therapist	13
Other	9
Years of professional experience	
0–5	34
6–10	18
11–20	19
>20	29
Number of deaths encountered during their career	
0–10	51
11–20	22
>20	27
Palliative care training	30

#### **METHODS**

After approval from the institutional review board, a Frenchlanguage questionnaire was used. The questionnaire included demographic data, two validated instruments, and a final section exploring the participants' opinions about their needs and coping strategies following the death of a patient. The participants were asked to complete the questionnaire while thinking about a memorable child death, defined as an unforgettable death of a child that affected them in their career. All HPs working with hospitalized children and neonates at the Centre Hospitalier Universitaire de Sherbrooke (Sherbrooke, Quebec) were included.

#### Questionnaire design

The first section of the questionnaire collected demographic information and the respondent's personal beliefs about and attitudes toward death. For the second part, the Texas Revised Inventory of Grief (TRIG) (11) and the Brief COPE (12) were used. The TRIG is designed to evaluate the intensity of reaction to the loss of a loved one. It has been translated into French and validated among young adults. It assesses reaction at the time of loss (TRIG1), the present feeling about the deceased (TRIG2) and aptitudes of coping. Each item is scored from 'completely true' to 'completely false'. The Brief COPE (12) is a multidimensional measure of coping strategies, and is translated and validated in French. The questionnaire was designed with open questions based on the survey by Redinbaugh et al (2), and a visual analogue scale assessing feelings and reactions following the death. In the final section, participants were asked to give their opinion regarding their needs when faced with the death of a patient.

TABLE 2
Respondents' attitudes toward death

Question	Answer, %
For you, what represents an ideal death?	
A. To die rapidly from a heart attack	5
B. To die instantaneously in a car accident	3
C. To die from a cancer after receiving good palliative care	1
D. To die while sleeping	86
E. It doesn't matter	5
What is your level of comfort toward your own death?	
Comfortable	41
Not comfortable	59
What is your level of comfort in caring for a dying patient?	
Comfortable	54
Not comfortable	42
Not applicable	4
What is your level of comfort in providing emotional support to	the family?
Comfortable	39
Not comfortable	59
Not applicable	2

The questionnaire was tested by five HPs to ensure that the content was appropriate and easily understood. Their comments enabled further corrections.

The questionnaires were distributed to 130 HPs between October and December 2008. The anonymous questionnaires were distributed in the care units (paediatric and neonatal intensive care, maternity ward, general paediatric ward and outpatient clinics) to all HPs working with children.

#### Data analysis

Statistics are presented as means  $\pm$  SDs for continuous variables and percentages for categorical variables. The  $\chi^2$  test was used for nominal variables. The Mann-Whitney U test was used to examine relationships between TRIG and other dimensions of HPs' responses. P<0.05 was considered to be statistically significant.

#### RESULTS

One hundred one HPs completed the questionnaire (78% response rate) (Table 1). The 'others' category represents nutritionists, social workers, psychologists, physiotherapists and occupational therapists.

Respondents' attitudes toward death are presented in Table 2. Whereas most respondents felt comfortable taking care of a dying child (54%), 59% were not comfortable with providing emotional support to the family of a dying child. Fifty-two participants (55%) who identified a memorable death knew the child for longer than one month, compared with 14 (15%) who knew the child for less than one day.

#### Emotional reactions to the memorable death of a child

TRIG values are shown in Table 3. All HPs expressed a moderate to high intensity of grief. Respiratory therapists perceived the highest intensity of grief followed by physicians and residents. Nurses and other HPs had a lower intensity of grief.

There was a major trend toward men having higher early grief scores (TRIG1) than women (26±19 versus 17±14; P=0.06). Younger HPs (20 to 25 years of age) reported higher early grief scores than older ones (older than 50 years of age) (P=0.01). Being comfortable caring for a dying patient was associated with a lower intensity of grief (P=0.02). Being a parent, having lost a child, having received previous palliative care training, and the

TABLE 3
Results of the Texas Revised Inventory of Grief (TRIG)
(French translation)

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	TRIG score	
	Early grief (TRIG1)	Long-term grief (TRIG2)
Total	17.9±1.5	16.1±1.4
Physicians	23.1±3.8*	17.9±3.2
Nurses	13.1±1.8* <sup>†</sup>	12.1±1.7
Respiratory therapists	29.4±4.1 <sup>†‡</sup>	23.1±4.0
Residents	17.1±4.6	17.5±4.3
Others	9.5±0.8 <sup>‡</sup>	17.3±5.9

Data presented as mean ± SD. \*P=0.01 for physicians versus nurses; †P=0.002 for respiratory therapists and nurses versus others; ‡P=0.005 for respiratory therapists versus others

length of the HP's relationship with the child and his/her family were not associated with a difference in the intensity of grief (data not shown).

Following the memorable death of a child, HPs frequently expressed sadness, anger, relief and anxiety. Less frequent reactions were feelings of guilt, the need to be alone, changes in appetite, trouble sleeping or more frequent mistakes at work. On a positive note, 60% of respondents believed that a memorable death made them more compassionate toward others.

### Coping strategies (Brief COPE) and reactions after the patient's death

Ninety-eight per cent of participants believed that they came to emotional acceptance following the death of a patient. A majority turned to others to talk about the child and their emotions (85%), used positive reframing (80%), and sought emotional support (75%) or self-distraction (57%). Seeking religious guidance was another coping strategy evoked by 55% of HPs. Less frequently mentioned – and possibly negative – coping strategies were self-blame (40%), denial (6%), substance use (2%) and behavioural disengagement (1%). Humour (13%) was also used as a coping strategy.

Seventy per cent spoke with their colleagues about the death, and 48% spoke with family and friends. More than one-half (53%) who used this strategy believed that social support helped them the most to overcome this hardship. The second most useful strategy was spending time alone (19%). Thirty-one per cent wished they had more emotional support from their colleagues. While 8% received organized support from their workplace, 40% would have appreciated more 'official' support. Some HPs had contact with bereaved families after the death of a child (Table 4).

#### What makes a child's death memorable?

Unexpected death was frequently identified as a factor associated with a memorable death (25%). The length of an HP's relationship with the child and his/her family, and affective bonding were also mentioned (12% for both). Ten per cent claimed that the memorable death occurred after palliative care. Other factors associated with memorable deaths were a special event connected to the death (Christmas day or the death of the mother) (6%), being personally involved in the withdrawal of treatment (7%), the feeling of guilt linked to the death (6%) or if twins were involved (6%).

#### The needs of HPs when faced with the death of a patient

Sixty-seven per cent of HPs wished to have multidisciplinary meetings after all child deaths, whereas 15% preferred no meetings and 14% only wanted them under certain circumstances.

TABLE 4
Contact with the family after the death of a child (n=101)

Behaviour	Responses, %
Attended the child's funeral	19
Contacted parents by letter	12
Contacted parents by telephone call	15
Met with parents	43

Psychological counselling was frequently mentioned as being an appreciated resource (32%) that could be made more available after the death of a child. While 30% of the respondents already received training in palliative care, three-quarters of all the HPs who answered the questionnaire wanted more training.

After the death of a child, 53% of HPs reported that they would need a break from work (15 min to 30 min was frequently mentioned). Nineteen per cent said they would want to take a couple of days off work, and 15% wished to finish the rest of their work day with the bereaved family. Seven per cent mentioned that their work day had to continue.

#### **DISCUSSION**

The present study corroborates many concepts put forward in other descriptive studies about HPs' grief (2,10,13,14). The intensity of early grief expressed by HPs after the death of a child is significant – lower but close to the intensity expressed by parents who have lost a child (15). The difference between HPs and parents increases with long-term grief, with parents expressing obviously more grief. This indicates that paediatric HPs experience strong emotions at the time of death, but their sorrow diminishes more rapidly with time.

Members of different professions express different intensities of grief. These differences raise questions about their training and the emotional support received following the death of a patient. In our study, respiratory therapists experienced a higher intensity of grief than any other HPs. Respiratory therapists in our centre follow many patients in one day, and are more likely to be involved when the child's condition deteriorates and requires more advanced care. Unfortunately, they often have to leave right after the death to continue with their work, often without a debriefing with the team. Older HPs and those who felt comfortable taking care of a dying patient expressed a lower intensity of grief. This may demonstrate that experience and a reflective attitude of the caregiver toward death help to minimize grief intensity.

Reactions after the death of a young patient include sadness, anger, deliverance and anxiety. All HPs are vulnerable when a child dies. All participants described a form of suffering from the emotional, social and spiritual impact of bereavement. Memorable deaths were often associated with a vulnerability that may bring to the surface professional issues (perfection, control and omnipotence) and/or personal issues (previous losses, personal wounds and sympathy). Vulnerability is often perceived as a sign of weakness. We believe that this vulnerability is a necessary condition to care for dying children. It gives us the ability to remain open and willing to become close and develop a relationship with a child and his/her family. This connection is risky, and can lead to identification with the dying or bereaved person. This is illustrated by the high number of HPs who scored almost the same intensity of grief as the bereaved parents.

The present study also investigated what makes a death memorable. The type of relationship seemed to be important. Long-standing and close relationships between the staff and the child and family seemed to have a more important role than the

circumstances of the death or social support received. This finding was also highlighted in other studies (2,5).

Coping strategies used by caregivers seemed to be healthy. As described in other studies (3,8,14), social support from colleagues, friends and family helped many respondents overcome the loss of a patient, stressing the importance of 'ventilation and validation' for HPs (16). Few respondents used help provided by the institution they work for, but many wished more support was available.

Consistent with the findings of others (14), we believe that HPs need support to continue providing high-quality care after the death of a patient. Many studies showed that repeated exposure to intense emotions in an unsupported environment may lead to burnout or compassion fatigue (5,17). Many respondents in the present survey wished to have a break after the death of their patient and to have the possibility of spending more time with the family. We believe that this would help mitigate the mourning process. The majority of respondents requested multidisciplinary meetings after the death of a patient and that psychologists should be more readily available if needed. A functional working environment enhances in its members a sense of belonging to a group, which can help staff tolerate suffering and foster learning and growth from the experience.

Whereas most respondents felt comfortable caring for a dying child, they seemed to find that providing emotional support to the family was not as easy. Making HPs more comfortable with taking care of the emotional needs of dying patients and their families, through education and reflection, may be beneficial in helping them deal with their emotions and promote a healthy mourning process.

The main limitation of the present study is the retrospective nature of the questionnaire. Participants were asked to think about their feelings and behaviours near the time of death, which may have occurred many years previously, leading to potential recall bias. The present study's population consisted mainly of women, and described the experience of HPs working with hospitalized children in one centre, which may limit generalization of our results. Because the questionnaire was administered anonymously, there was no information regarding the characteristics of the nonrespondents.

Most of the HPs believed that they have more compassion following the memorable death of a patient. Personal growth could be a positive outcome of vulnerability. To develop empathy, HPs need to identify with certain aspects of the patient's experience (sadness, suffering and fear) while maintaining their own perspective on the situation. We believe that recognizing and accepting vulnerability is a natural and healthy response. It invites us to realize our strengths, limitations and personal sufferings. This vulnerability may become a source of maturity and professional growth. If ignored or suppressed, it may become a source of stress and even dysfunction.

The present study highlights the emotional intensity associated with a child's death and suggests that suffering related to the death of a child can lead to professional growth. The majority of respondents believed they needed a short break from work after the death of a child. More than two-thirds wanted a multidisciplinary meeting to follow a death, and one-third wished for more immediate and easy access to a psychologist. Further research should investigate the response of respiratory therapists to the death of a child and the effect of debriefing sessions on HPs after the death of a child.

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