The grieving healthcare provider

Variables affecting the professional response to a child's death

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It is well understood that working with the dying and their families is extremely stressful. However, there is very little detailed research focusing on the grief of health professionals and traditional theoretical models do not necessarily apply here. We have conducted a number of qualitative studies looking at the subjective experiences of care providers exposed to multiple deaths of children and propose a model based on our findings.

During the last two decades the hospice movement has contributed greatly to the development of a comprehensive approach that addresses the complex physical, psychosocial and spiritual needs and concerns of dying patients and their families. Principles have been developed to guide professionals in the provision of personalised services in the face of death[1]. These highlight the importance of remaining emotionally involved with the dying patient and the family. Yet at the same time, they recognise that healthcare workers are likely to experience high levels of stress, emotional exhaustion and burnout which need to be prevented or managed by appropriate support from team members.

EDITOR'S NOTE

In this important paper Professor Papadatou summarises the results of her research into the grief experienced by health providers when faced with the death of a child. The lessons to be learned from her studies are important for all who care for patients and/or their families before or after bereavement, whatever the age of the person who dies. She brings home the oft-ignored difference between 'grief' and 'burnout'. Caregivers who are afraid to acknowledge or express their own grief are at greater risk of becoming ineffective or harmful towards their clients than those who recognise and share it. They may also become disillusioned and depressed. Indeed, many of the 'losses' of trained professionals and volunteers who leave the challenging fields of health and bereavement are attributable to this cause.
The remedies, as Papadatou shows, are clear.

Studies conducted in the 80's and 90's were inconclusive on whether levels of stress and burnout were higher in professionals who cared for dying patients than in those who did not. Nevertheless, researchers were in agreement that caring for the terminally ill is both a highly stressful and a potentially rewarding experience[2,3]. According to Barnard[4], encounters in the face of impending death are often characterised by a form of intimacy that holds risks and opportunities. Risks are related to the 'undoing' of a professional, that is the fear of being overwhelmed by the patient's suffering, agony and chaos, while opportunities refer to personal growth and enrichment through meaningful intimate encounters. By accepting their vulnerability healthcare staff are more likely to acknowledge their losses and engage with their grief.

The responses of hospital or hospice staff to the death of patients in their care have long been described in the literature[5-9] but very few systematic studies have been conducted to look closely at their grief[10-12]. Traditional models describe an individual's mourning process in terms of stages, phases or tasks. However these may not be appropriate for to those who work in a field where loss, death, and patient suffering are daily experiences and part of the work.

OUR RESEARCH

For our studies[13-16], a semi-structured interview was developed and in-depth individual interviews were undertaken with nurses and physicians. A grounded theory approach was used as method of analysis which helped us to formulate a descriptive model of caregivers' responses to death, shaped from the analysis of the collected data[13-16]. In the initial study we compared the experiences of 63 nurses who worked in paediatric oncology with those who worked in critical care in two diverse cultures, Greece and Hong Kong[13]. We further compared similarities and differences between 16 physicians and 14 nurses who worked with paediatric oncology patients[14], and are currently analysing data obtained from physicians who are exposed to childhood death in different pediatric settings within the same culture.

Analysis of our findings revealed that whenever confronted with dying and death, healthcare professionals recognise that they grieve. Their reactions fluctuate between **experiencing** and **avoiding** feelings of grief (see fig 1). This fluctuation is healthy and adaptive and allows them to gradually give meaning to the dying and death of each patient, and integrate these losses into their life and daily work[16].

When healthcare providers are in touch with their distress, they respond to the experience of grief at different levels:

- emotional- eg sadness, anger, despair
- cognitive – eg recurring thoughts or dreams of the dying conditions or death, guilt, praying
- behavioural – eg crying, irritability, withdrawal from people and daily activities, reaching to others for support, funeral attendance
- physical – eg pains, health vulnerabilities, changes in eating and sleeping habits[13,16].

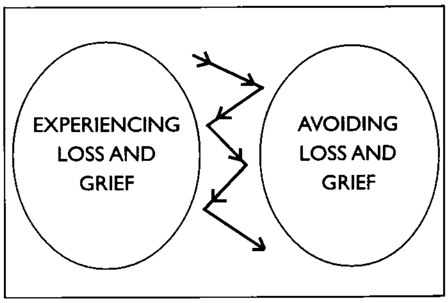

Figure 1 The health professional's grieving process

At other times, professionals tend to avoid the loss experience and repress their grief in a number of ways:

- urging themselves to suppress feelings – 'I must be strong', 'I must withhold my tears, because I wear a uniform', 'I should hide my vulnerability'
- emotional numbness
- avoiding or minimising interactions with patients and family members
- actively engaging in clinical duties which keep professionals busy and distracted from painful feelings
- de-humanising the dying patient
- humanising the dead patient who is perceived as alive and asleep in order to tend to his/her dead body[13,16].

By moving in and out of their grief, healthcare professionals can slowly attribute meaning to the death of a patient, as well as to their contribution to the patient's care. Complications occur when there is a persistent lack of fluctuation between expressing and avoiding grief because professionals are either totally overwhelmed by feelings of bereavement, or remain detached and systematically repress them. In both situations they have a sense of immobilisation that is conducive to burnout. Occasionally, they may display symptoms of a secondary post-traumatic stress disorder that complicates their grieving process.

VARIABLES AFFECTING THE GRIEVING PROCESS

The grief of healthcare providers is affected by a number of interacting variables that could be grouped in three major categories: personal variables situational variables and environmental variables (see fig 2).

PERSONAL VARIABLES

These variables include age, gender, family status, network of support, along with life style and loss history. According to Adler[17], life style is the system of basic beliefs, assumptions and values about self, others and life that each person develops during early childhood and which provides a consistent way of perceiving, thinking, feeling and behaving in everyday living.

All professionals interpret and cope with patient death with reference to their own idiosyncratic life style. Within such a frame, major losses in a person's life, particularly those occurring in early childhood, determine how they are likely to perceive, approach or avoid loss and deal with the resulting grief. Moreover, life style often determines the sources, nature and use of support a person expects or is likely to seek.

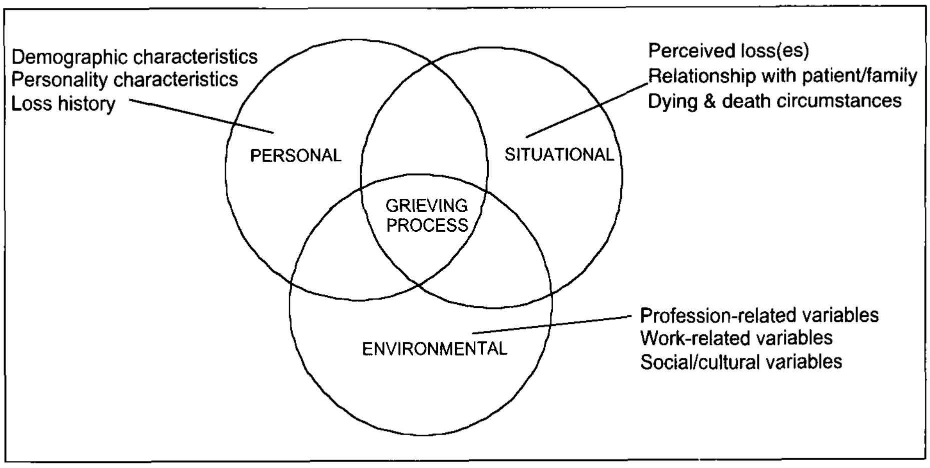

Figure 2 Variables affecting the grieving process of health professionals

Previous unresolved or traumatic losses may sometimes unconsciously motivate providers to work in a field that confronts them with death, in the hope of overcoming these personal issues. However, work may then become a source of increased distress.

SITUATIONAL VARIABLES

Perceived losses related to patient death

Professionals emotionally invest in their relationship with a patient and family in a unique way and, as a result, they are affected differently every time a patient dies. The analysis of our data revealed seven distinct situations that can trigger a grieving reaction in health care providers[13,16].

- The loss of a close relationship with a patient where a special bond had been formed.
- Sympathetic grief for the loss and pain felt by family members with whom the professional identifies, especially if they are the same age or have the same role within the family.
- Being unable to realise professional goals and expectations (eg to cure the disease) leading to secondary losses of power, control, meaning, or recognition.
- The loss, or undermining, of a personal system of beliefs and assumptions about self, others and life (eg childhood death reverses our sense of order and predictability in life).
- The recurrence of a personal unresolved or traumatic loss.
- The threat of an anticipated, future loss (eg of a loved person)
- Realisation of personal mortality.

It was found that nurses grieved more often over the loss of a special relationship developed with patients and families, while physicians were more likely to grieve over their inability to achieve goals and realise expectations about the patient's treatment and cure[14].

Dying and death circumstances

Grieving is greatly affected by the way a patient dies. Each death is measured against a number of individual and team-related standards of what constitutes an 'appropriate' death. A death that validates the role and contribution of care providers may be more readily accepted and grieved for than one that triggers anger, guilt, and increased feelings of helplessness and meaninglessness. In our studies, oncology nurses and physicians considered caring for a dying child who suffers pain highly distressing because it made them feel powerless. The unexpected death of a child was also considered highly distressing because it deprived them of the opportunity to offer something meaningful[14]. By contrast, findings which are in the process of analysis reveal that critical care professionals experience higher levels of distress over slow and lingering death of a child with whom they are likely to develop a close and intimate relationship.

ENVIRONMENTAL VARIABLES

Profession-related

In their basic training, health care providers acquire a philosophy of illness, dying and death, as well as a set of prescribed practices and behaviours towards the dying patient. These determine not only their goals and interventions in terminal care, but also their responses to the dying process and death of patients.

The prevailing attitude towards the dying still remains largely affected by a biomedical model of care. The traditional education of medical students is being revised in some academic settings (mostly in the UK and North America) and a few, but significant, efforts are being undertaken to sensitise undergraduate students to the principles of palliative care. However, most medical schools continue to educate future physicians to assume a cure-oriented approach, without adequately preparing them to provide appropriate care and comfort to dying individuals or to grieving families. Moreover, they neglect the importance of understanding and dealing with the doctor's personal responses to death.

Nurses, on the other hand, who have traditionally assumed a more holistic approach, tend to see themselves as having an important role in supporting and accompanying the patient through death, and recognise more readily that they are being affected by their involvement with patients. It is not surprising that most articles addressing issues about work-related stress, burnout, and care providers' grief are published by nurses who tend to emphasise the importance of mutual support.

In our Greek study, both physicians and nurses acknowledged that they grieved over the death of a child. However they differed in the way they expressed their grief as a result of the way they had been socialised and educated to care for the dying. In general, for physicians, grief was experienced as a private and often a lonely process since they rarely relied upon others for support, while for nurses it was openly displayed and shared within the confines of the nursing team[14].

Work-related

The nature of professionals' work affects the types of death-related experiences to which they is likely to be exposed. Comparing workers in intensive care units with those in oncology, we found that these groups experienced different types of patients and deaths, occurring at different frequencies. Each group had its own goals of care and each invested in the patients' care in a unique way[14,15].

Moreover, each environment has its own work-style which includes an explicit and implicit system of beliefs, values and assumptions about the goals of care[16]. Based on this, a number of rules are developed that prescribe the role and behaviour expected of care providers confronted with dying and death. Among other things, they determine whether professionals should grieve, express feelings, and be supported. In many ways, these rules regulate the fluctuation process between experiencing and avoiding grief, and seem to be more or less effective in helping providers to deal with the daily losses at work.

When all members of a Greek oncology team were interviewed, it became apparent that the goal of care for a dying child was palliation through symptom management, family support, and promotion of appropriate dying conditions according to the needs and priorities of both the patient and family. Based on these goals and values, implicit rules about professionals' behaviour in the face of death were developed, for example, health professionals were expected to develop close relationships with dying children and family members and subsequently grieve in anticipation, during or after a patient's death. Sharing personal experiences and mutually supporting each other were encouraged, but at designated times, in formal or informal gatherings. Other rules determined the timing, intensity, and expression of grieving, which was expected to be tempered and controlled to avoid impairing clinical judgment, leading to emotional breakdown, or exceeding the grief experienced by family members.

In a paediatric intensive care unit within the same hospital, different rules were established, discouraging the expression of grieving and encouraging self-control and suppression of feelings. Close relationships with children and parents were not encouraged. Family members were only allowed to spend limited time in the unit and interactions with care providers were brief. There was a rule that implied, 'Do not grieve, at least not openly, because it may be contagious to your colleagues. Be strong and brave in the face of death'. This rule determined the nature of support among team members who helped each other to control their grief responses[15]. The child's illness and dying process were discussed mostly in scientific terms and personal vulnerabilities were minimised or dismissed.

Rules may be more or less rigid, and may change over time. The identified or hidden leader(s) of a team may greatly affect the process by which they are established, maintained or revised.

Social and cultural

The social and cultural context determines the social meanings attributed to life-threatening disease, suffering, dying and death. These, in turn, affect the goals of medicine and nursing, the types of services offered to the terminally ill, and the expected attitudes and behaviours assumed by care providers, as well as by the family.

When Greek and Hong Kong paediatric nurses were compared, similarities were found in terms of the increased stress they experienced when confronted with a dying patient, as well as in their grieving while a child was dying and after the death. However there were differences in the ways their grief was expressed[13]. In particular, Greek nurses displayed their emotions more openly, cried more frequently, and sought support among each other, in comparison with Hong Kong nurses who were more private in their grief and who suppressed it more often by retreating into practical duties and work responsibilities.

While both Greek and Hong Kong nurses attributed childhood death to higher, mostly religious forces, the feelings associated with such interpretations were quite distinct. Greeks reported a strong sense of injustice and anger usually directed towards God who, according to their Christian Orthodox beliefs, is perceived as all-powerful, loving, and protective of the innocent. Chinese nurses, on the other hand, accepted death more readily and perceived it as a form of salvation and the result of a child's karma, which explains suffering in terms of a debt to be paid for sins committed in a past or present life. It could also be speculated that the influence of Buddhism, which is strong in Hong Kong – even among atheists and Christians – may affect responses to the dying and death of a child. Buddhists believe that a peaceful death is of great importance to ensure a good reincarnation. Such a death is attained by severing attachment to people and things, thus making it easier for the dying and the bereaved to 'let go' of each other.

Finally, it became apparent that professionals' grief remains largely disenfranchised by both Greek and Chinese society, which expect experts to be 'strong' and 'brave' in the face of death. At best, support for care providers was offered within the confines of their work setting.

CONCLUSION

The grieving process of health care professionals is complex and necessitates further research in order to understand better its nature, particularities and development through time. This proposed model, derived from our qualitative studies and the description of the interacting variables that affect a professional's grieving process, lays the ground for further debate. Some similarities, yet also distinct differences, may exist with Stroebe and Schut's dual model of coping with bereavement[18] and these may warrant further in-depth exploration. We hope the present model may contribute to the development and implementation of appropriate interventions that will effectively support team members.

It is important for care providers to recognise their losses and grief responses to the dying and death of their patients, and to feel assured that they can rely upon a network of colleagues who will provide and offer each other various forms of support[15]. This could be progressively achieved through basic education, professional training and ongoing support to meet the individual and collective needs of members of a specific team, at a given time. In this way, quality services can be ensured and professionals can derive a deep sense of satisfaction by contributing meaningfully and creatively to the living and dying of their fellow humans.

References

1. Statements on Death, Dying, and Bereavement. King's College, Ontario, Canada: International Work Group on Death, Dying, and Bereavement, 1994.
2. Vachon M. Losses and gains: A theoretical model of staff stress in oncology. In: McCorkle R, Hongladarom G (eds). Issues and Topics in Cancer Nursing. Norwalk, CT, USA: Appleton-Century Crofts, 1986.
3. Vachon M. Recent research into staff stress in palliative care. *European Journal of Palliative Care* 1997; **4**: 99-103.
4. Barnard D. The promise of intimacy and the fear of our own undoing. *Journal of Palliative Care* 1995; **11**: 22-26.
5. Benoliel J. Anticipatory grief in physicians and nurses. In: Schoenberg B (ed). Anticipatory Grief. New York: Brunner/Mazel Publishers, 1974.
6. Mount B. Dealing with our losses. *Journal of Clinical Oncology* 1986; **4**: 1127-1134.
7. Shanfield S. The mourning of the health professional: An important element in education about death and loss. *Death Education* 1981; **4**: 385-395.
8. Saunders JM, Valente SM. Nurses' grief. *Cancer Nursing* 1994; **17**: 318-325.
9. Shread T. Dealing with nurses' grief. *Nursing Forum* 1984; **21**: 43-45.
10. Davies B, Clarke D, Connaughty S, Cook K, Mackenzie B, McCormick J, O'Loane M, Stutzer C. Caring for dying children: Nurses' experiences. *Pediatric Nursing* 1996; **22**: 500-507.
11. Rashotte J, Fothergill-Bourbonnais F, Chamberlain M. Pediatric intensive care nurses and their grief experiences: a phenomenological study. *Heart Lung* 1997; **26**: 372-386.
12. Hinds PS, Puckett P, Donohoe M, Milligan M, Payne K, Phipps S, Davis SEF, Martin GA. The impact of a grief workshop for pediatric oncology nurses on their grief and perceived stress. *Journal of Pediatric Nursing* 1994; **9**: 108-116.
13. Papadatou D, Martinson I, Chung B. Caring for dying children: A comparative study of nurses' experience in Greece and Hong Kong. *Cancer Nursing* (accepted for publication).
14. Papadatou D, Bellali T, Papazoglou I, Petraki D. A comparative study of physicians' and nurses' grief as a result of caring for children dying of cancer. *Pediatric Nursing* (submitted for publication).
15. Papadatou D, Papazoglou I, Petraki D, Bellali T. Mutual support among nurses who provide care to dying children. *Illness, Crisis, & Loss* 1999; **7**: 37-48.
16. Papadatou D. A proposed model of health care professionals' grieving process. *Omega* 2000; **41**: 59-77.
17. Adler A. The practice and theory of individual psychology. London: Routledge, 1971.
18. Stroebe M, Schut H. The dual process model of coping with bereavement: Rational and description. *Death Studies* 1999; **23**: 197-224.

COUNSELLING BEREAVED CHILDREN

Button sculpting

AGE RANGE
5-6 to adult

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All human relationships are imperfect and, when someone dies, it is the imperfections that are the hardest things to mourn. We all have regrets about what we have or have not done or said during the person's lifetime and these are often the elements of the relationship which trouble us most. It is these aspects that evoke the 'If only …' statements that express the longing for things to have been otherwise. Our inability to make it different, have another chance to make amends, is absolute and the process of mourning is, in part, about recognising these flaws and reviewing the reality of the relationship, warts and all.

The review depends upon having a degree of clarity about the nature of the relationship and personal honesty about its less positive aspects. One of the key factors in this process is the ability to form an objective overview of the context of the relationship and the dynamics at play. Clearly all these elements present immense difficulties to children and young people, not least because of their cognitive immaturity and limited ability to have insight into other people's behaviours.

Button sculpting offers a simple technique which enables a child to begin to explore someone's personal characteristics, analyse the quality and significant features of their relationship with them and look at the effect other relationships had upon them both. From there it is a considerably smaller step to piece together a clearer understanding of the nature of the relationship and the meaning of what has been lost. The technique can also be used with families and in supervision, to explore and explain family dynamics.

All you need for this exercise is a sheet of A4 paper and a box of assorted buttons. It is helpful to have a range of buttons that include some from baby clothes (eg bunnies, decorated etc), some ornate, glittery buttons (eg diamanté, gold etc) and some from a range of outdoor wear (eg toggles, leather, metal etc). If possible include some sequins, keys, twigs, conkers, shells, small pebbles, feathers, in fact anything which is inanimate and of a similar size to the main collection of items.

It is advisable to model to the child what the exercise entails rather than try to explain it verbally. I suggest you think of someone you both know and with whom the child has no emotional relationship, perhaps a character from a television programme, film or book etc. Together you can explore that person's defining personal qualities – general mood, sense of humour, friendliness – and some of the activities associated with them – sport, talents, interests – as a way of building up a picture of who they are and significant things they do. As you are identifying each element, look for a button or object in the collection that could stand for each one and place them close together on the paper. Sometimes the qualities identified might lead to one button overlapping or being placed on top of another. By the end of the activity there will be a cluster of objects that describe the chosen person.

This preparatory activity defines the exercise and enables the child to go ahead and choose someone from the family and analyse and construct them similarly. Once one person is on the page it naturally leads the child on to putting the rest of the family around them. Remember, pets are often important members of a child's family too.

The ways in which children choose buttons, searching carefully for one which is either just right or good enough, is fascinating and demonstrates their involvement with the exercise. The patterning of family members on the paper, particularly the spaces in between, can reveal an insight into the child's perception of his family which words could never describe. The process makes concrete the child's view and facilitates a conversation alongside the activity which is indirectly determined by the child's initiative. The process can enhance the child's appreciation of the different relationships within the family and their own place within it. In addition lines can be drawn between the different people to represent the strength and quality of the relationships within the group.

Anyone else looking at the page would only see a pile of buttons but you both know it has a much greater significance.