

PREPARING FOR DYING: MEANINGFUL PRACTICES IN PALLIATIVE CARE

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ABSTRACT

This article describes three exemplars that depict the meaningful practices associated with caring for the dying. The exemplars are illustrative of the way culture shapes our attitudes toward dying and the practices adopted by groups that assist them to make sense of their world. Acknowledging these practices enables health professionals to provide interventions that support the dying and their family within their own cultural network. Acceptance of the cultural practices displayed by the family unit allows for the expression of grieving behaviors and has the potential to contribute to the peaceful death of the individual. The provision of quality palliative care is enhanced when health professionals acknowledge the significance that culture plays in the meaningful practices associated with the dying process.

INTRODUCTION

Storytelling (Aranda & Street, 2001) is a way of passing on experiences and knowledge to others, offering the opportunity to make sense of events through the means of reflection. In this article, storytelling was used as the reflection tool to recount one of the author's experiences (Bourgeois, 2000) following the caring episode of her mother who was dying. The storytelling process became a way of communicating thoughts and feelings to the rest of the family and provided a means for the management of her loss. Drawing together the personal elements associated with this protracted period of time has since created a snapshot of

memories and life experiences that have been shared with all family members. These experiences are drawn upon as illustrations of meaningful practices (Johnson & Bourgeois, 2003) that arise from the storytelling and are analyzed (Van Der Molen, 2000) and discussed as issues significant to health professionals in regards to palliative care.

Caring for a person who is dying is unique in that their environment involves significant personal events within which people may use cultural patterns, beliefs, and rituals (Smith, Flowers, & Osborne, 1997) that serve to act as a stabilizing influence and have an effect on all aspects of our lives (Loseth, 2002). A person's experience with dying is culturally determined (Prior, 2001; Vardanega & Johnson, 2002) and cultural patterns, rituals, or practices, as adopted by a group of people, assist them to make sense of their world (Kellehear, 2000). Culture is conceptualized as a system of meaning and determines beliefs, values, and behaviors (Campbell, Moore, & Small, 2000; Leininger, 1991) that can be defined as a set of practices used or adopted by a group to make sense of their world (Campbell et al., 2000).

Meaningful practices have the potential to support the person dying by allowing them to feel less isolated, more intimate in their relationships with others, and may assist with a sense of closure (Bowman, Martin, & Singer, 2000) affording those involved to seek understanding and meaning. They are also an expression of the grieving reactions shown at this time (Lewis, 1998) and, therefore, beliefs and practices associated with dying play an important role in our significant life events. They provide personal meaning and can assist in defining the care for others in a respectful manner (Prior, 1999).

The first exemplar illustrates a meaningful practice that is inherent in normal life events. A party is viewed by society as a happy and joyous occasion and it was through this happy event that saying goodbye was adopted as a means of farewell for this family, but it also allowed for the sharing of the experiences of dying, which were made visible during the event. The party created an opportunity to bring others together within the framework of the dying person's experience, and also provided them with a valuable role where it facilitated the display of grieving behaviors.

Exemplar 1—The Party to Say Goodbye

On the Wednesday Mum had said to me she wanted a party. At first I didn't take too much notice of it. Our Mum loved her parties and I did not think she was really well enough to cope with a party. . . .

. . . We had decided that the party would be 3pm in the afternoon. I spoke to Mum telling her that we could organise her medication ("happy pills") so that she wasn't too sleepy at 3pm and that her morphine tablets would be well and truly on board and she would be more awake than if she had just taken them. . . .

. . . A party to her involved the guitar and some friends, all singing with her. . . . Mum knew all the words and at the parties it was Mum that kept the

songs going. At this her final party, it was mainly her friends who entertained her. As breathless as she was, she still managed to sing along with some of the songs. At other times her friends would sit with her and hold her arms so they waved in time with the music . . . (Bourgeois, 2000).

Loss and grief are a part of all societies and the manner in which they are displayed will vary from group to group (Raphael, 2000). They formulate a natural reaction that continues to change over time (Roberts & Berry, 2002), with culture contributing to the shaping of attitudes about dying. Associated cultural practices and rituals have the potential to help people to cope with their fears, stress, and associated grief (Krakauer, Crenner, & Fox, 2002). The implicit nature of cultural practices defines the dying person as a unique individual in the context of palliative care. This individuality is identifiable in the exemplar. The party signifies this uniqueness and as a meaningful practice it supported the person dying, the family, and significant others through their participation, in what is deemed a normal happy life event. The party also provided an opportunity to grieve with others in an open and supportive environment yet it incorporated a different social response and cultural prescription (Raphael, 2000). Thus, the sadness and grief arising from the bereavement process was able to be displayed within the confines of a “normal” life event.

Dying should be on our own terms (Cobbs, 2001) and the ability to die at home in the presence of family and friends allows for these significant meaningful practices to be undertaken. The party is somewhat profound and not a practice that all persons could accommodate during the dying process. However, for this family it is one practice that embraced a holistic perspective in regard to the process and meaning of dying (O’Gorman, 1998). The ability to say goodbye as demonstrated by this family signifies an important part of this process, illustrating the practices and rituals of this group. Using the party as a means of saying goodbye can help those present to achieve a sense of closure. As an illustration of a meaningful practice, the party can provide a time for those present to enjoy each other, to be a part of the group, and to share the experiences associated with dying.

In the second exemplar, preparing for impending death meant that all family and friends became engaged in the making of a blanket. The significance of this meaningful practice as described by Bourgeois (2000) created a support network for the person dying and allowed others to be involved in contributing to the preparation for dying. The sharing of the caring experiences within the family brought about a sense of harmony. Practically, the blanket had the function of covering the body while lying in an open casket at home, which for this family was a ritual derived from their cultural practices. However, the making of the blanket meant so much more to those participating and became a significant prop within the dying process for those involved.

Exemplar 2—The Blanket “Symbolic in Life and Death”

On diagnosis of her illness and on discharge from hospital, Mum went to the wool shop in town and brought some white wool and gold thread. Our Mum was always doing craft and over the years had crocheted some beautiful items . . . this white wool and gold thread was to be used to make her blanket.

By the time we arrived at home on the Friday . . . , Mum had already done about 8 squares and over the next few days . . . she was busy crocheting her blanket. One [sister] had already started to crochet a few squares, which Mum had shown her how to do and [another sister] had done a few too. Our cousin . . . also picked up the crochet hook and wool and added to the squares, whilst chatting with Mum. Mum showed me how to crochet while I sat on the floor beside her, but my attempts were often interrupted with things I would be doing to make Mum more comfortable and I unpicked more squares than I actually finished—the blanket had to be perfect. Over the first few days we were furiously working on this blanket, then as Mum became more ill, she stopped crocheting and would watch us or help us when we got into trouble with the stitches. [One sister] decided she just couldn’t get this act together of crocheting the squares, so Mum showed her how to use the gold thread and white wool and her job was to join the squares together. [Another sister] who also found the squares were not on her agenda ended up making the tassels for the blanket, after Mum showed her how to do the tassels and where they should go on the blanket. [Another] cousin proved to be the strength for this blanket. Originally Mum had said that 30 squares should be enough, but when we completed this amount we all felt the blanket should be bigger and that it should cover her from her chest down. Unfortunately time had moved along and Mum was quite sick at this time and we found that we were accomplishing less and less on the blanket. One of our fears now was what if something happened to Mum and her blanket wasn’t finished. [This cousin] worked very hard at finishing the blanket, she edged it at the top with gold thread and all of the tassels were applied.

When the blanket was finished, it was brought in for Mum to see. It was truly beautiful, 60 white squares, captured together with white wool and gold thread and an edging in gold, perfect for a Queen. Mum’s words were, “Oh it’s beautiful, me and my 30 squares! But . . . , what about my pillow”? We all laughed and [our cousin] set about making another 8 squares for Mum’s Pillow. She decided not to put the gold thread around the edge of the pillow because it would be too rough for Mum to lie on.

Mum’s blanket was finished a few days before she died. She saw it in the completed form and was very happy with the finished piece. We placed it on the table to keep it flat with a sign stating “No food or drink, Mum’s blanket” and then covered it with a sheet (Bourgeois, 2000).

Items may hold a special significance and feature during the rituals of death and dying (Campbell et al., 2000). The ordinariness of making a blanket as identified in the above exemplar wove together the network of family and friends and therefore created an atmosphere of safety for people to begin to grieve during

the physical task of the blanket making. As the blanket increased in size, the significance that the terminal phase of the dying process was drawing near became evident to all involved, especially when the growth of the blanket seemed to correspond to the illness process of the individual. The completion of the blanket became a recognized death ritual of significance for this family.

Spiritual comfort contributes to the preparation for impending death and enhances the bereavement process for those involved (Loseth, 2002). The symbolism of the blanket as a meaningful practice served to promote spiritual comfort to the person dying and to others involved. Furthermore, it created a sense of psychological well-being in knowing that in death dignity is preserved and that respectful practices are acknowledged and shared by the family.

In our society, alongside respect is the notion that care of the body in death has social and personal meaning for individuals (Kellehear, 2000) in that the body is the physical evidence of a person's distinctiveness and cultural identity (Prior, 2001). Formulating a coverture for the body in the form of a blanket brings together the notion of respect for the person and provides for privacy and dignity in death. The blanket making is a significant cultural practice and allows the person dying to have input into their own death ritual ensuring that their personal wishes are met.

The third and final exemplar highlights the supportive and proactive nature of the family to assist their Mum during her preparation phase for dying. The family has actively brought dying to the foreground and has ensured that all members are informed about her wishes (MacIntyre, 2002). That is, that dying can be interpreted as a journey and preparation for that journey (Lugton & Kindlen, 1999) is extremely significant and important to the persons concerned. Plans were made, items readied, and looking her best was certainly a priority.

Exemplar 3—Self Preparation for Death

Mum requested we call the undertaker to the home, so we arranged a 12 o'clock meeting on the Saturday at home. . . .

Mum told him that she wanted to go through her funeral details with him, which he agreed he could do with her. We all [of her daughters] sat with Mum and prompted the issues that had come up a few nights earlier. . . . The undertaker was told what Mum would like to wear and her jewellery, how she didn't want her hair to be blow waved but left to dry naturally and that she wanted her money in her hand to get through the "pearly gates" (Mum's joke). Mum also told him that she would be staying at the house in her coffin. We added that we wanted her to come home as soon as possible so that she could rest at home. He agreed to do all this for Mum. She then asked him what colour choices there were for her coffin. He took out the samples and she selected a teak colour saying "this would go nicely with my red pyjamas and my white blanket." Then she asked about an urn to match the coffin . . . (Bourgeois, 2000).

During the dying phase, this mother made her own decisions related to the care of her body following death. She initiated these decisions in a planned way as part of the preparation for her impending journey, and the locus of control (Kellehear, 2000) shown by the mother reveals insight and openness, conveying acceptance of the anticipated death. Within a palliative care framework, locating the locus of control explicitly supports the notion of empowerment through the process of decision making. In this exemplar, the family took the lead in caring and were supported by the health professionals, thus embracing the concept of empowerment (Andershed & Ternstedt, 2001). Facing death with the help and support of loved ones provides a mechanism where all involved can feel less isolated, more supported and where they can discover opportunities for intimacy, reconciliation, and closure (Bowman et al., 2000). Collectively this leads to a situation where the grief experienced is uncomplicated and progresses in a manner comfortable for the persons involved.

DISCUSSION

Knowledge about bereavement and understanding the significant role that culture plays in the dying process enables health professionals to provide interventions that enhance the provision of quality care in supporting the person dying and their family within their own cultural network. These interventions should acknowledge the cultural practices of the family unit, allow for the expression of grieving behaviors, and contribute to the peaceful death of the individual.

Understanding the influence that culture has in death on the person dying, their family, and the health professionals involved is an important consideration in the delivery of care as underpinned by the philosophy of palliative care (Andershed & Ternstedt, 2001; Smith, 2000). Health professionals, in their role as a caregiver, also have a responsibility to be informed about the dying process in order to meet the needs of the individual and the family at the appropriate phases of their illness. Implicit within this process is the role that cultural practices have in shaping the experience of death for individuals and family. The resulting interventions translate to an explicit acknowledgment of these practices being integrated in the delivery of care.

Respecting the cultural practices of people cared for by health professionals must occur in a non-judgmental way and translate into meaningful and appropriate strategies. This display of respect creates a space for the formation of a trusting relationship, the outlet for emotional expression, the promotion of communication, and contributes to informed decision making (Loseth, 2002) between the person dying, their family, and health professionals. Embracing the notion of respect mirrors the tenets of palliative care therefore contributing to the provision of quality care and serving as an anchor during this final life event.

Learning about how different cultural practices may influence the degree of involvement of family and friends is important for health professionals

(Andershed & Ternestedt, 2001) because acknowledging the cultural practices of the person dying contributes to the preparation for death of the individual. These practices help people cope with the fear, stress, and grief associated with dying by providing a context of meaning and a structure of support. This is especially important as it shapes the attitudes and the preferences for palliative care (Krakauer et al., 2002) that are expressed by the individual and family.

While our culture denies and defies death (Roberts & Berry, 2002), engagement in the preparation for death (Copp, 1998) recognizes a level of acknowledgment by the person of their impending death which has significant meaning for the individual. The timeliness of the activities related to preparation for death are largely determined by the phases of the person's illness, their energy levels, and the resulting dysfunctions experienced as part of their disease process (Loseth, 2002). The result should be that preparation for death is primarily shaped by the individual's attitudes and responses to their cultural, environmental, and social contexts and lends support to the individual's and family's bereavement. Support from the health professional in the preparation activities may include assessment and the improvement of social situations through the provision of information, planning, and counseling, which are directed at supporting the person dying and their family in the anticipation of death, bereavement, and grieving (George, 2000; Smith, 2000).

CONCLUSION

Meaningful practices used in this context illustrate the preparation for death undertaken by individuals and families, and the three exemplars arising from the storytelling process demonstrate the crucial role they can play in the bereavement process and in the acceptance of dying. The notion of palliative care and the practices that are meaningful to individuals and families within their cultural environment are clearly evident in the exemplars cited.

Health professionals need to be aware of meaningful practices that are inherent and valued within cultural groups. The benefits of giving individuals the locus of control over their death experience is empowering for all involved. The practices are displayed as normal life activities and shape the attitudes about dying held by members of the cultural group. Understanding these cultural practices has the potential to enable health professionals to provide quality palliative care which meets the unique needs of individuals and families. Being informed about these meaningful practices and the process of dying supports the health professional to provide care in a manner which is both non-judgmental and respectful. Through knowing, understanding, and being respectful about meaningful practices, health professionals have the capacity to support individuals and their family to cope with their fears and stressors associated with impending death. The ideas discussed in this article have the potential to encourage people to become more actively

involved in the bereavement process at a much earlier time than would be considered normal for cultural groups.

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