

# Cultural Competency in Paediatric Palliative Care: A Literature Review

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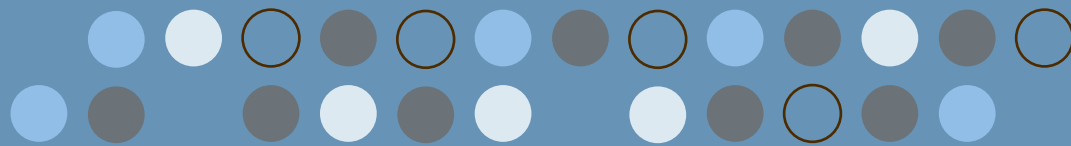
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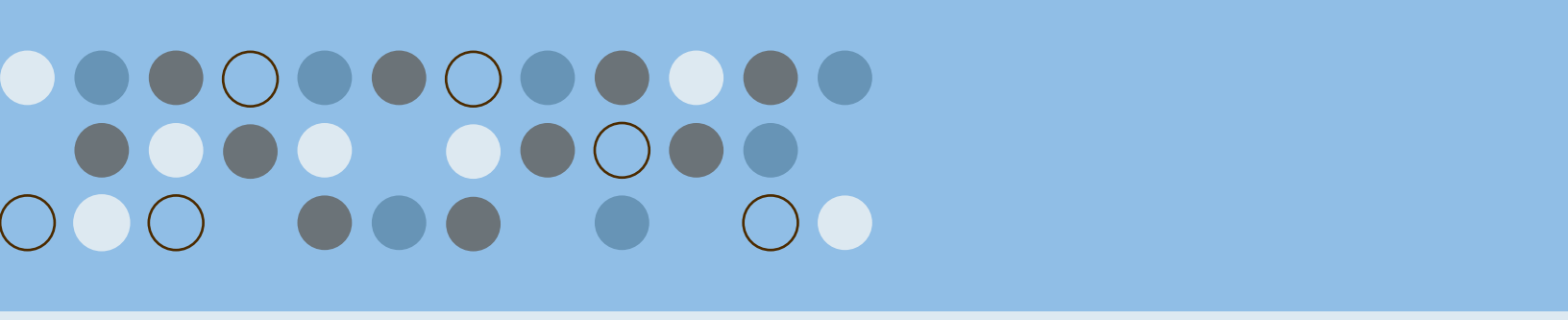
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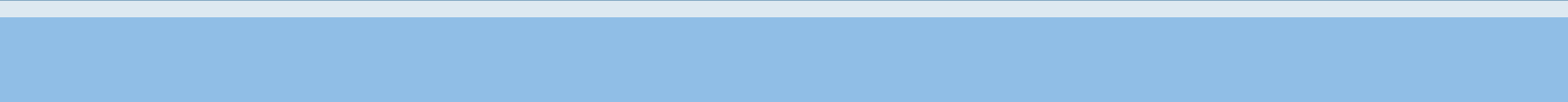
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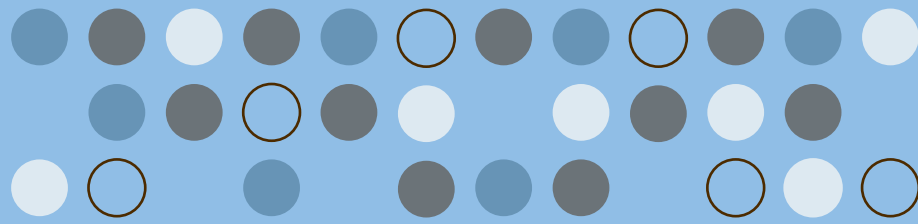
*Prepared by Dr. Deb Bennett and Linda Kongnetiman MSW, RSW*





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## Introduction

Calgary, like other Canadian cities, is culturally diverse with an increasing visible minority population. Statistics show that between 1981 and 1996, 2.1 million immigrants settled in Canada from non-traditional source countries (Statistics Canada, 2001). These newcomers arrived from regions such as Asia and Africa. The 2006 Census from Statistics Canada showed that between 2001 and 2006, Canada's foreign-born population increased by 13.6 percent. This number is four times higher than the growth rate of 3.3 percent for the Canadian-born population during the same period (Statistics Canada, 2007). By 2012, immigration is expected to account for all net labour force growth in Canada. According to a Canadian Council on Social Development (2000) research report, one-third of immigrants arriving in Canada are children and youth under the age of 25.

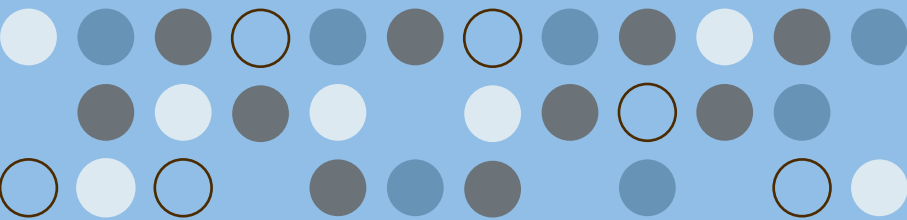
With the increasing visible minority population in Calgary, health care professionals, often without any formal training in cultural sensitivity, are faced with the task of providing care to newcomers. If the patient and family carry a cultural perspective that differs from that of the professional care providers, the process of assessment and intervention can be very complex (Hall, Stone, & Fiset, 1998). This challenge is intensified when providing palliative care and grief support to newcomers. Hall et al. (1998) suggested that the needs of ill members of cultural minorities generally are not being adequately addressed. Ethnic minorities are underrepresented in palliative care programs, a situation which has been identified at Alberta Children's Hospital.

The migration of people from Asian, Middle Eastern, Caribbean, and African countries, who

have different cultural and religious values, beliefs and traditions compared to those of North Americans, is pressuring health care professionals and services to become more culturally competent when providing paediatric palliative care. In a multicultural and trans-cultural environment, it is imperative that nurses and other health care professionals understand the care practices of people of different cultures (Liang & Zoucha, 2002). Cultural competence as described by Feser and Bernard (2003) encompasses a set of values, behaviors, attitudes, knowledge, and skills that allow health care providers to offer patient care that is respectful and inclusive of diverse cultural backgrounds.

The experiences of families who are caring for a child who is dying and their subsequent bereavement process are largely influenced by cultural and religious beliefs. An individual's social, cultural, ethnic, religious, and philosophical values and beliefs can have a large impact on their response to death and grief (Rando, 1984). Misunderstandings and lack of knowledge regarding the significance of these contributing factors can compromise the sensitive and competent care needed for all family members when a child is dying. The grief experience can also impact the community, a factor which is often overlooked or neglected. Since Canada is a multicultural and multi-ethnic society, health care institutions must adapt to meet the needs of newcomers. The need for culturally sensitive end-of-life care services is growing. Gatrad and Sheikh (2002) identified that respect for all faiths and cultures are crucial considerations if health care professionals are to deliver care that is truly patient-centered.

The purpose of this literature review is to explore the information addressing cultural competence



in paediatric palliative care. Field and Berhman (2003) identified that families are vulnerable to misunderstandings related to differences in cultural experiences and values about illnesses. The authors indicated that the quality of research needs to be improved to address these misunderstandings. It has also been suggested that further studies are needed to address the current gap in knowledge related to clinical, cultural, and organizational practices that could improve end-of-life and bereavement care for children and their families (Field & Berhman, 2003; Gatrads & Sheikh, 2002; Koenig & Davies, 2002). To truly adhere to the philosophy of paediatric palliative care, a focus on cultural competence is a crucial consideration. All families who have children with life-limiting illnesses deserve to receive unprejudiced and effective treatment in a culturally and linguistically appropriate manner (Munet-Vilaro, 2004).

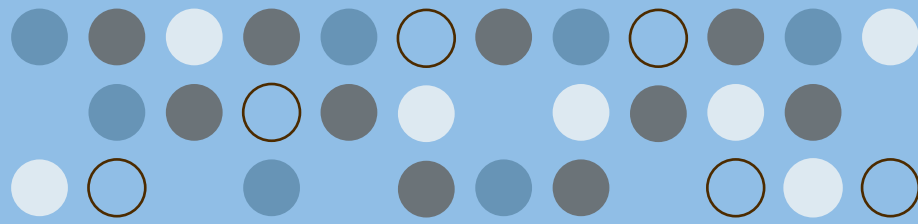
## Palliative Care

There has been a substantial increase in research in the field of adult palliative care. Auger (2000) maintains that Canada has an abundance of articles on adult palliative care due to the *Journal of Palliative Care* being published out of the Centre for Bioethics at the Clinical Research Institute of Montreal. Within Canada, a range of palliative care programs have been developed in hospitals, hospices, home care services, and long-term care facilities to help fill the gap between traditional hospital care and community-based home care. Until recently, the benefits of palliative care have been neglected; however, there has been a dramatic increase in awareness with advances in this area of medicine (Auger, 2000).

Palliative care is a philosophy of care (Corr, Nabe & Corr, 2006). Palliative care is patient-centered

and family focused with patients participating in informed decision-making (Cairns, Thompson, & Wainwright, 2003). The Victoria Hospice Society (2003) described the core values of palliative care as relieving suffering and improving the quality of living and dying (Cairns et al., 2003). Cairns et al. (2003) described this care as focusing on physical, emotional, psychological, social, spiritual, and practical concerns. The World Health Organization (Bernat, 2008) stated that in end-of-life care, “the control of pain, of other symptoms, and of psychological, social, and spiritual problems” is paramount (p.155). As palliative care has a psychosocial focus, it also aims to help prepare individuals and families for the dying process and self-determined life closure, as well as supporting those involved in their loss, grief, and bereavement processes (Cairns et al., 2003). As Auger (2000) points out, “In this sense, the unit of care is all individuals connected to the dying person who may be impacted by the death” (p.89)

Most palliative care programs serve adults (Himmelstein, Hilden, Boldt, & Weissman, 2004). Wolfe, Klar, and Grier (2000) suggested that more work is needed in paediatric palliative care. Frager (1996) argued that palliative care must be accessible to those who provide care for a dying child, irrespective of whether the child is in the critical care unit of a tertiary care hospital or at home. Currently, new efforts are underway to expand paediatric palliative care services (Palliative Care Leadership Centres and Centre to Advance Palliative Care, 2004). Children’s Hospice International focuses on educating health care professionals about the crucial importance of providing palliative care for children through advocacy and education programs (Kastenbaum, 2004).



## Paediatric Palliative Care

The death of a child is the most significant loss and crisis for a family. Parental loss of a child is a unique experience that should not be compared to any other loss, regardless of the age of the child, the circumstances, or cause of death. It is a life-altering and traumatic experience that severely impacts parents, siblings, and extended family members, as well as a multitude of others within a community (Field & Behrman, 2003). It is the fact that a child has died that makes it profoundly different from other deaths (Arnold & Gemma 1994).

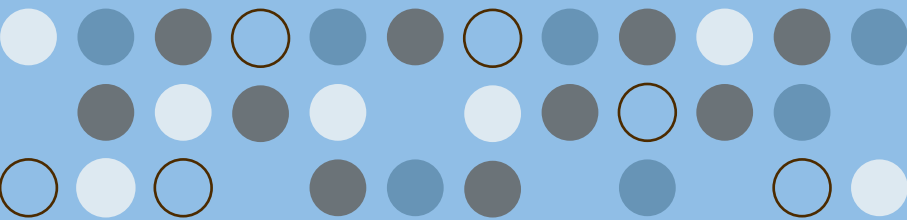
A child's death disrupts the natural order of the life cycle in most industrial societies and is managed differently in paediatrics as compared to adult medicine or geriatrics. As a result, there are a number of differences between adult palliative care and paediatric palliative care. However, similar to adult palliative care, paediatric palliative care is a philosophy of care focused on the enhancement of the quality of life for those involved as well as their family members. This is achieved through the combination of active and compassionate therapies intended to comfort and support children and families who are living with a life-threatening illness and when a child dies. Palliative care "strives to support children and families by assisting them in fulfilling their physical, psychological, social, and spiritual goals while remaining sensitive to their personal, cultural, spiritual, and religious values, beliefs, and practices" (Paediatric Palliative Care Special Interest Group, 2001).

Koenig and Davis (2002) reported that a home death is often considered an ideal within the hospice philosophy. They note that a "good death" is often characterized as one that takes place at home surrounded by family and friends, with pain symptoms under control, spiritual needs met,

followed by appropriate good-byes. Traditionally, this requires giving up curative interventions, a step for which the family may not be ready, and it may become a challenge of palliative care for the dying child. Parents and care providers are forced to make the impossible choice between interventions directed to cure and those directed to comfort the child and family (Frager, 1996). Further, in making difficult choices relating to end-of-life care for an adult patient, decisions are left to the individual rather than the family. In the case of children where the parents become the decision-makers, the situation becomes more complex. The complex ethical, legal, and health policy issues related to child health can complicate the timely provision of palliative care. Wolfe, Klar, and Grier (2000) described how the lack of developmentally appropriate methods for assessment and management of symptoms can create further challenges in paediatric palliative care.

The causes of death in children are varied, and the pathways to death are complex and not easily predictable. There is tremendous diversity encountered with respect to age, developmental level, and disease process in children, and there are fewer commonalities in the cause of death than among adults. These factors make the task of prognostication difficult. In addition, caregivers' lack of knowledge about the fatal diseases of childhood and the complexity in children's illnesses may contribute to delays in implementing palliative care for the terminally ill child.

A crucial component in the effective delivery of paediatric palliative care is open and clear communication between health care providers and the family. During these tragic circumstances, a family can be comforted and supported by skilled and compassionate professional caregivers. Health care professionals face an additional set



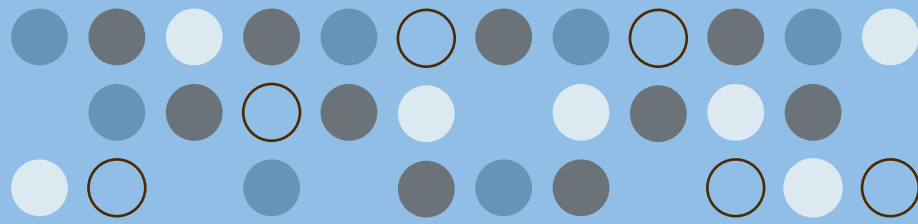
of challenges when dealing with immigrants, who may adhere to traditional health beliefs and practices while at the same time embracing the ways of life and beliefs of their host country. Professional care and the philosophy of palliative care can be jeopardized when families feel that their customs, needs and wishes are not attended to, understood or incorporated in their child's care. These experiences have the potential to become a large part of their lifelong grief journey (Field & Behrman, 2003). A fundamental concept of culturally competent care is accommodation of family strengths. When families' cultural, ethnic, and religious values are respected in paediatric palliative care, they are better able to cope (Field & Behrman, 2003).

### **Culturally Competent Paediatric Palliative Care**

Health care providers are facing the challenge of working with and providing care to increasingly diverse populations. An individual's ethno-cultural background influences all aspects of health care, particularly end-of-life care (Saiki-Craighill, 2001). Every aspect of end-of-life care is shaped by culture. For instance, culture influences the meaning ascribed to illness, the language used to discuss illness and death, the symbolic value placed on a child's life and death, the lived experience and appropriate expression of pain and suffering, the appropriate role of health care providers to assume the care of the body after death, and appropriate expression of grief (Saiki-Craighill, 2001). Cultural and religious differences also play a crucial role in understanding family obligations, the proper conduct of physicians and other health care workers, the extent to which the dying process should be anticipated and planned, and if dying should be a matter of fate (Turner, 2002).

The differences in the value and belief systems of different cultures are creating the demand for culturally competent paediatric palliative care. Many researchers (e.g., Doorwnbos & Schim, 2004; Feser & Bernard, 2003; Koenig & Davies, 2002; Turner, 2002) have recognized the need to increase cultural competence within palliative care. When there are cultural gaps between families and health care providers and these gaps are accentuated by barriers of language, social class, faith, and cultural values and beliefs, it becomes all the more difficult to negotiate transitions on the path of a child's death. Terminally ill patients and families come in contact with health care professionals in outpatient and inpatient settings as well as in the home and community. If the patient and family carry a cultural perspective that differs from the professional care providers, the process of assessment and intervention can be very complex (Hall et al., 1998).

Review of the literature reveals that a substantial amount of progress has been made to understand the relevance and importance of cultural competence in end-of-life care for adult patients (Kagawa-Singer & Blackhall, 2001; Koenig & Davis, 2002); however there is limited information addressing cultural competence in paediatric palliative care. According to Koenig and Davies (2002), there seem to be two reasons for the paucity of this type of research. First, paediatric palliative care itself is a new field and only recently have researchers and academics started focusing their attention on this topic. Secondly, in today's rapidly changing world, the phenomenon of migration of people belonging to different cultures, religions, and ethnic groups, is happening so rapidly that educational institutions lag in the development of curricula to provide cultural competency training in the field of paediatric palliative care.

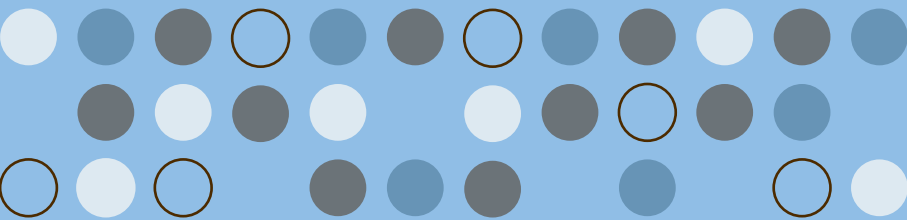


Knowledge of the cultural background of the family is crucially important in planning for and providing bereavement care following a child's death. Though much is known about culture and bereavement generally, research specific to children in a multicultural setting is lacking (Davies et al., 1998). In 1993, the Institute of Medicine published its first report describing the importance of increasing cultural competency in the provision of palliative care services. It emphasized the importance of promoting an understanding of the nature of cultural differences in order to avoid the harmful effects of stereotyping (Koenig, 1997). Koenig and Davis (2002) found approximately 20 articles published over the previous 10 years that reported empirical findings related to cultural issues in families where a child is terminally ill, is dying or has already died.

The most comprehensive review on paediatric palliative care was conducted by Koenig and Davis (2002). These investigators attempted to address frequently raised questions on cultural competence in paediatric palliative care. These included 1) what is the meaning and significance of the loss of an infant or child in various ethnic, cultural, and religious groups, 2) is it critical to fight death or should it be accepted as part of life, beyond the control of medicine, 3) how do parents, the family, and the broader community react to the crisis of life-threatening illness and experience a child's loss, 4) how should the health care system incorporate attention to cultural differences in efforts to reform and improve care for children and their families living with life-threatening or life-limiting illness. Saiki-Craighill (2001) further identified that research should be conducted to determine how mothers and fathers in different cultural and religious groups cope with dying and the death of children.

Kagawa-Singer and Blackhall (2001) have suggested that culture shapes how individuals make meaning out of illness, suffering and dying. They identified six specific issues to be considered when providing end of life care: 1) responses to inequities in care, 2) communication and language barriers, 3) religion and spirituality, 4) truth telling, 5) family involvement in decision-making, and 6) hospice care. They concluded that there are visible differences between these cultures and the dominant culture in respect to these issues. Lewis, Brecher, Reaman, and Sahler (2002) identified factors which may be a reflection of cultural perspectives and should be taken into consideration. These factors include the following: 1) how much information should be revealed to a patient about diagnosis and prognosis, 2) how much do individuals wish to participate in medical decision making, 3) the amount of emotional display that is appropriate, 4) the role of women, 5) the role of various generations of the family, 6) the concept of afterlife and how it is prepared for, 7) whether the death takes place with the family or extended group, 8) funeral and burial customs, and 9) length of mourning.

In the efficient delivery of palliative care, communication, understanding and respect for culture and religion have been identified as important factors. For health care providers, it is difficult to use the mainstream model without adaptation for providing care to dying children in minority communities. A needs assessment is needed to ensure effective services for terminally ill and dying children in minority communities in North America. Hebert (1998) emphasized the need for a culturally sensitive approach. She mentioned that the current practices are based on Euro-American theories of grief and loss aimed at facilitating familial adaptation through the creation



of memories of the dead child. The influence of cultural components on bereavement patterns are often ignored and little attention has been paid to the appropriateness of these practices for the ethnic population; thus, there is a need for thoroughly understanding the cultural factors that influence each bereavement case.

When it comes to palliative care, western cultures are focused on patient autonomy. The studies on adult palliative care show that it would be better if health care providers acquired knowledge about the family system and the cultural values of other societies immigrating to this country, in order to develop cultural competence (Pottinger, Perivolaris and Howes, 2007). The needs of the patients and families from these cultures may also vary depending on their level of acculturation, education, social status, immigration status, and the generations of these cultures that health care providers are dealing with. In the efficient delivery of palliative care, communication and respect for culture and religion have also been found to be of vital importance (Walsh & McGoldrick, 1991).

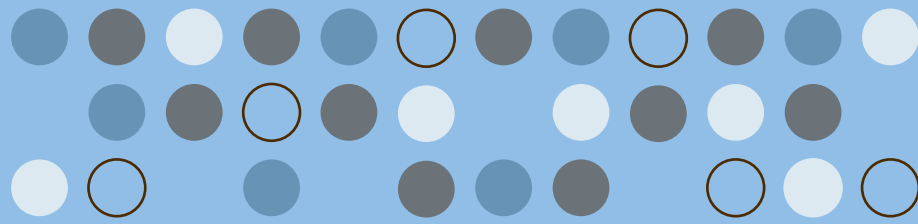
Obviously there is a great need for further research on cultural diversity and the impact on end-of-life care for children and families. It is essential that researchers and health care providers increase their awareness about ethno-cultural issues and become skilled in identifying and responding to the needs of terminally ill children and their families from culturally diverse backgrounds. A review of the literature shows that while providing paediatric palliative care services, health care providers need to develop an meaningful therapeutic relationship with the families of terminally ill children (Baker, Hinds, Spunt, Barfield, Allen, Powel, Anderson & Kane, 2008). This alliance helps in understanding the dynamics of the family in different cultures and religions and how each differs in its grieving process.

## **Barriers to Culturally Competent Paediatric Palliative Care**

Barriers to the provision of culturally competent paediatric palliative care are many and diverse. They include attitudinal, clinical, ethical, educational, financial, institutional, regulatory, and linguistic barriers (Rushton, 2001). A major barrier in paediatric palliative care is the frequent lack of understanding of hospice philosophy among people from various ethno-cultural groups. Hills and Penso (1995) and Koeing and Davies (2002) suggested that minorities in general were not using hospice and palliative care services in proportion to their numbers. Firth (2001) also suggested that the use of palliative care services was not equivalent with the ethnic minority population partly because the provision of care was based on western models. Lack of information and education on bereavement models related to families from other cultures after the death of a child are additional barriers to providing effective paediatric palliative care. Finally, the cultural denial of the fact that children do die constitutes a huge barrier (Rushton, 2001).

It is evident from a review of the literature that lack communication is a prominent challenge in facilitating cultural competence in paediatric palliative care. Language barriers can be seen as critical as they permeate every aspect of the patient's and family's experiences. Researchers in the field of thanatology have long recognized the role of language and culture as it relates to an individual's response to the death of a loved one (Chan & Woodruff, 1999; Garro, 1990; Hall et al., 1998; Noogle, 1995). Families from other cultures who cannot speak or understand English experience a heightened sense of despair resulting from their inability to communicate with health care providers. Cantro, Larson, Scofield, Sourkes, and Cohen (2002) also emphasized that the lack





of a common language compromised parents' ability to fully understand and acquire complete information about their child's medical condition, treatment, and prognosis.

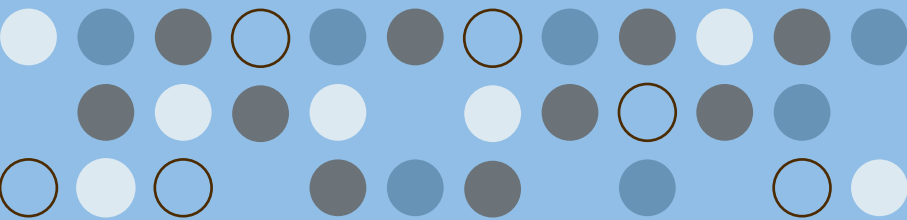
If the health care providers cannot communicate with the patient and family members because of a language barrier, palliative care may not be provided effectively, no matter how culturally competent they become. Therefore, in such situations, it is important to have trained interpreters in palliative care settings who can mediate communication between family and health care providers (Field & Behrman, 2003). It is important to be aware of research indicating that using children and family members as interpreters may not be effective when providing palliative care (Koenig & Davies, 2002; Randhawa et al., 2003). A study by McNamara, Martin, Waddell, and Yuen (1997) found that language was also an issue for health care professionals. They identified a need for more skilled professionals and volunteers as well as educational resources, language aids, and guidelines for their use. Health care professionals also described their concerns, including the concern that inability to communicate restricts the services that can be offered to patients and their families.

Researchers have identified that although there are a variety of methods used for communication and interpretation, it is evident that problems associated with communication are resulting in palliative care needs not being met. Services cannot be considered culturally competent under these circumstances. As a result, there is a need for greater communication among care providers and a more coordinated promotion of services to communities by individuals who understand both community needs and professional priorities. The Alberta Health Services has been working on this

communication barrier problem in palliative care by hiring the services of interpreters in different languages. It is a good start for general health care and particularly paediatric palliative care. However, it will be better if such services are preceded by a study focusing on the assessment of needs of ethno-cultural communities.

O'Neill (1994) has suggested that the appointment of palliative care staff from minority ethnic backgrounds could be "the single most effective way of helping ethnic minority patients and their families cope" (p.219) In their study, Randhawa et al. (2003) found that many respondents felt that not enough people were hired from their community who spoke their languages and understood their cultural and religious beliefs. Although the patients and their families were satisfied with the health care they received, some of them found difficulty in communicating with the health care providers because of the language barrier. Chan and Woodruff (1999) found that individuals who do not speak English in an English-speaking environment are likely to receive less than optimal palliative care. They also found that control of non-pain symptoms was less effective for non-English-speaking patients.

Field and Behrman (2003) also described the lack of communication between families and health care providers as a barrier in paediatric palliative care. One of the critical goals inherent in the delivery of paediatric palliative care is the communication and decision making required during the illness trajectory and at the time of death. A fundamental concept of competent care is to understand and accommodate the strengths of the child and family; caregivers should incorporate families' abilities to cope along with their cultural, ethnic, and religious values into palliative care. Huddleston and Alexander (1999) suggested that communication is



the key element in paediatric palliative care because parents and other family members are as involved as the child is. These authors emphasized that the end-of-life settings make the need for quality communication even more important.

Turner (2002) suggested that although linguistic barriers can make communication difficult, cultural and religious differences also play an important role in distinctive understanding of family obligations and the appropriate role of health care providers. For example, in some South Asian cultures family members shield the seriously ill relatives from bad news, and health care providers then face the dilemma of truth telling. Turner (2002) also noted that practices of other cultures often do not share the western cultural perspective of the importance of autonomy, access to information, and planning for end-of-life care by individuals. Therefore, the western principle of autonomy cannot be the sole value guiding medical care in a multicultural society. In order to ensure the efficient delivery of the palliative care, communication and respect for culture and religion are crucial factors for consideration.

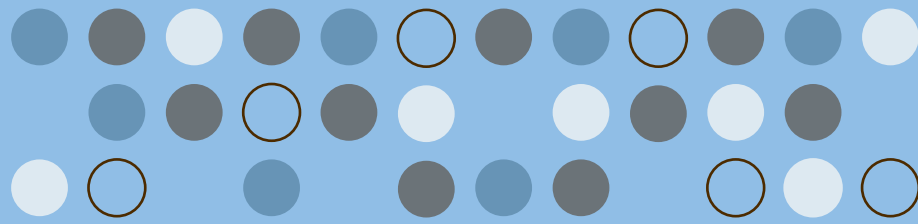
## **Death and Dying: Customs, Traditions, and Practices Across Cultures**

The challenges for health professionals who help families face the crisis of a child's dying process and death are multiplied when dealing with different belief systems (Parkes, Laungani & Young, 1997). Review of the literature suggests that different cultural groups view dying and the meaning of death in different ways. Both ethno-cultural and religious groups have unique beliefs, values, and rituals regarding death and bereavement. It is crucial that the individual or sect variation within each cultural group is also taken into account

to avert the danger of stereotyping (Waddell & McNamara, 1997). Crawley, Marshal, Lo, and Koenig (2001) described great diversity within ethnic and cultural groups, with individuals not always sharing the same cultural traits, values, beliefs and practices. They cautioned that stereotyping may prove harmful and that culture is only meaningful when interpreted in the context of a patient's unique history, family constellation and socio-economic status. Health care providers who have the opportunity to increase their knowledge of cultural influences and their implications for the care of the dying child and their family can help ensure that the unique needs of each are met.

Rituals surrounding death and bereavement help to define the meaning of life and death (Rosenblatt, 1997). Rituals also define the role of the bereaved and their interaction with others in their community and environment. Customs and traditions may also be influenced by the role of the deceased or the cause of death (Rosenblatt, 1997). Research indicates that "culture shapes values, beliefs, and practices, and its impact on these areas is intensified during death and dying" (Pottinger, et.al, 2007. p.227). The life experiences of people from culturally diverse groups have been shaped by a wide variety of historical, political, and socio-economic circumstances (Munet-Vilaro, 2004). Palliative care of children should be delivered in a way that acknowledges these factors (Gatrad & Sheikh, 2002).

In many societies, death rituals are extended over considerably more time than those in western societies. Those from western cultures may find some practices, such as tearing at one's clothing or hair, unconventional and may fail to appreciate their social, cultural, religious, or personal significance (Parkes, Laungani, & Young, 1997). When this occurs, immigrant families who now



live in western societies may feel unsupported within health care institutions and during their bereavement (Koenig & Davis, 2002). Knowledge of customs and traditions as well as individual expressions of grief within groups from a variety of ethno-cultural backgrounds will help to provide more inclusive palliative and bereavement care for families.

When reviewing the literature on cultural groups and their traditions, customs, and practices related to death and dying, it is evident that there is an extremely small amount of information that speaks specifically to the death of a child and the rituals that apply. This gap has significant implications as this lack of knowledge has the potential to compromise the quality of palliative and bereavement care given to dying children and their families. Mak (2001) identified “work in eastern cultures such as Chinese remains scarce” (p.259). In this literature review, cultural perspectives on death and dying within the Chinese, Japanese, Vietnamese, Korean, Hindu, Muslim, and Hutterite cultures will be presented, with a focus on the beliefs and practices related to children.

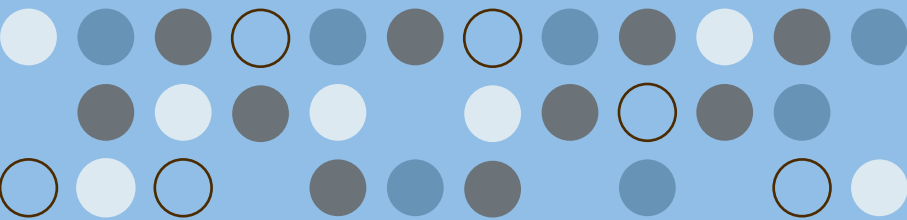
## Chinese Culture

A Chinese saying states that black hair should not precede white hair, meaning a child should not die before the parents (Irish, Lundquist, & Nelsen, 1993). Chan, Chow, Ho, Tsui, Tin, Koo, & Koo, (2005) described that “the white headed witnesses the death of the black headed” with great pain p.934 Talking about a child’s death is usually discouraged in Chinese families as it is considered bad luck (Braun & Nichols, 1997). An early death is also considered bad luck, as it is believed to be caused by evil spirits or is considered a punishment (Braun & Nichols, 1997; Woo, 1999). The death

of a child may be perceived as punishment for a misdeed in the child’s past life or for actions of his or her parents in their past or current life, as punishments can be passed onto siblings, children, or grandchildren (Braun & Nichols, 1997). If a death is untimely, unfair and hard to accept, Chinese may believe that it may be caused by evil spirits (Woo, 1999).

Mak (2001) identified that “death is often considered a forbidden word in Chinese culture” and many still avoid talking about the subject (p.275). Many new Canadians still feel it is bad luck to talk about death and health related topics (Braun & Nichols, 1997; Waddell & McNamara, 1997). Death may be considered the result of bad karma (fate), bad energy that passes through those who are unlucky, illnesses caused by evil spirits, sick qi or punishment for bad deeds (Chan et.al, 2005; Mak, 2001). The belief in ghosts is common among the Chinese. Ghosts of family are not feared; rather, hungry ghosts who may cause mischief or illness are seen as a threat (Braun & Nichols, 1997). Death can be seen as natural and inevitable, but only in old age (Woo, 1999).

Chinese families prefer that health professionals not reveal a prognosis to dying patients as their last days should be worry free and painless (Turner, 2002). It is also believed that sharing a prognosis of terminal illness can be harmful to patients and it may even “hasten their death” (Payne, Chapman, Holloway, Seymour, & Chau, 2005; Woo, 1999). Woo (1999) described that it is the family’s wish and responsibility to share prognosis news in a sensitive way that helps to protect their loved one from emotional turmoil. Braun and Nichols (1997) identified the importance of taking an indirect approach when discussing the patient’s illness and prognosis with family members.

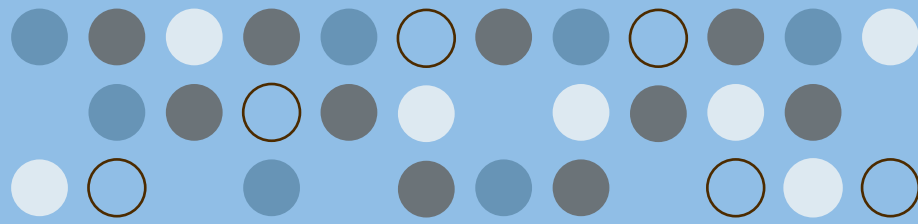


When a family member is admitted to hospital, it is important that all family members, including children, are able to visit. Family support and solidarity is a crucial part of patient care (Woo, 1999). Allowing them to bring food is also important as it is considered a better gift than cut flowers as they are associated with death (Braun & Nichols, 1997). The family should also be allowed to provide bedside care such as providing liquids and cleaning (Chan et. al, 2005; Woo, 1999). This is especially important at the time of death as the physical condition of the deceased is seen as one of the determinants of a good death (Chan et. al, 2005). If death is close, it is crucial that the family is contacted so they can say their goodbyes (Braun & Nichols, 1997). This also allows the family to “tidy up” the body at the time of death as the deceased’s facial expression is an indicator of a good or bad death (Chan et. al, 2005). The relaxing of the muscles of the eyelids and mouth should occur at the time of death as well. These actions are crucial considerations as Chan et. al (2005) identified that the bereaved family will be overwhelmed with guilt if they have been unable to facilitate a good death for their loved ones because there is the belief that a bad death is a curse. Braun and Nichols (1997) also suggested that family members should be asked if they would like a minister or other spiritual leader present during this time.

Most Chinese prefer burial to cremation as it ensures the body remains intact (Braun & Nichols, 1997). There is also a resistance to organ donation for this reason. Some Chinese hold traditional beliefs in regard to organ donation and believe that a body should remain intact as it is a gift from one’s parents (Braun & Nichols, 1997). Braun and Nichols (1997) identified an additional belief that the deceased should be buried in one piece as the family does not want the person to be born in the next life with the donated part missing.

Ritual is important in Chinese culture and there are strict rules for funeral practices (Watson & Rawski, 1988, cited in Braun & Nichols, 1997). However, it is important to acknowledge there is no “monolithic Chinese culture” (Payne et al., 2005 (p.112). Waddell and McNamara (1997) described that culture is not static and it is imperative not to assume that all Chinese will think and react in the same way. Payne et al. (2005) stated the “extent of acculturation can not be assumed from either length of residence or place of birth” (p. 111). They described the existence of a mix and match of Chinese and western practices related to treatment, death, and dying. Braun and Nichols (1997) stated that many Chinese have adopted western beliefs that now co-exist with their traditional beliefs and practices. Chan et. al. (2005) suggested that many Chinese do not know the meaning behind rituals; they adhere to them based on traditions. It is crucial that health care is not guided by stereotype, expecting similar views about death and dying for all Chinese as there are diverse views and experiences (Woo, 1999).

Mourning and funeral rituals depend on the family’s religion. Eerdmans (1994, cited in Braun & Nichols, 1997) described that Chinese philosophy has three religions which have an influence on rituals and practices: Buddhism, Confucianism, and Taoism. Within these philosophies, endurance and acceptance of suffering as well as the importance of forgiveness are highly valued (Chan et. al., 2005). Strict adherence to social hierarchy, family solidarity, filial piety, and respect for elders as well as a submissive and collectivist approach are also highly valued (McNamara et al., 1997). Woo (1999) described that the Chinese desire to conform stems from philosophical teachings in which the achievement of harmony and peace is desired above all. Payne et al. (2005) further identified values that have implications for



palliative care: loyalty, self-restraint, self-blame, and self-respect. Chan et. al. (2005) noted that there is a strong belief in reincarnation and afterlife within Chinese culture.

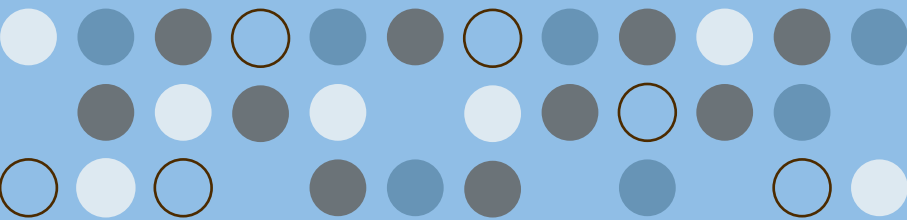
Braun and Nichols (1997) identified that the deceased should not be moved for eight hours after death if the family is Buddhist. This is because Buddhists believe that the soul has not left the body and it is in the process of trying to be reincarnated. Ryan (1986, cited in Braun & Nichols, 1997) described other traditional practices which include the importance of choosing the right day for the burial as well as the right place to be buried. The burning of symbolic paper money, cars and servants helps the deceased on their journey, ensuring they are financially secure and safe (Braun & Nichols, 1997). Chan et. al. (2005) described that symbolic money is also burned to ward off hungry ghosts so that they will leave the living alone. Family may also offer rice to the spirits and burn incense for them. There can be a belief that ghosts will return to “plague the living” if proper rituals are not adhered to (Braun & Nichols, 1997, p.329)

White is worn at funerals. Female family members may also wear a woolen flower in their hair and males may wear black arm bands (Irish et al., 1993). If it is the funeral of an elder, bright colors such as red may be worn because the funeral is viewed as a celebration of a long life. Chan et. al. (2005) described that the body is viewed at the funeral with priests calling forth the Gods and scaring the ghosts. They identified that chanting is an important part of a Taoist funeral as it is “aimed at placating the deceased spirit” (p.936). Some Chinese funeral rituals are performed by male family members, such as the “Soul-flag” ritual whereby the soul is helped to travel in the right direction through a symbolic “purifying wash” (Chan et.al, 2005., p. 936) Pregnant women, even

if they are close family, are often discouraged from attending funerals as it is feared that the sadness may harm their health (Irish et al., 1993).

Memorial services for the deceased are held every seven days for 49 days. During that time, prayers are chanted (Braun & Nichols, 1997). From a traditional perspective, it is believed that the deceased spirit will return for a visit on the third day after the death to say goodbye (Braun & Nichols, 1997). The favorite food and books or magazines of the deceased are set out in anticipation of the visit as the family waits. After that time, the clothes and personal belongings of the deceased are given away as surviving family members will not use them. Furniture in the house is also rearranged, as it is bad luck to leave things as they were (Braun & Nichols, 1997). Relatives of the deceased may not visit each other for a period of time, fearing that they will bring bad luck (Gatrad & Sheikh, 2002; Irish et al., 1993; Martinson, Lee, & Kim, 2000; Naquin, 1998). Mourning depends on the relationship with the deceased (Braun & Nichols, 1997). A three-year mourning time is common after the death of a child or parent, one year for a spouse. Braun & Nichols (1997) also identified the general practice of not being involved in entertainment such as parties and celebrations for 100 days after the death.

Rituals after the death include a Qing Ming festival which occurs in early spring. During this festival, Chinese families go to the graveside to clean and sweep as well as repaint the name of the dead on the memorial if the weather has removed the paint. Braun and Nichols (1997) noted that offerings such as a roast pig and incense for burning are taken to the gravesite. Altars are traditionally set up for ancestors in the home, where blessings are asked for (Chan et. al., 2005).



Braun and Nichols (1997) described that grief is kept within the family. Strong emotions are not expressed and there is a preference to keep emotional distress to one's self (Woo, 1999). Many families are not open to asking for help, especially from professional counselors (Braun & Nichols, 1997; Woo, 1999). Chan et. al. (2005) cited Bond and Hwang (1986) who suggested using a consultation approach with families. This helps in avoiding the "loss of face" that can occur within a client approach as within a consultation approach, the family become a part of the problem-solving process. Chan et. al. (2005) also suggested that when it becomes difficult to discuss the emotions associated with death and illness, using the language of suffering can facilitate the communication of the grieving "in a language that makes cultural sense to them" (p. 77).

## Japanese Culture

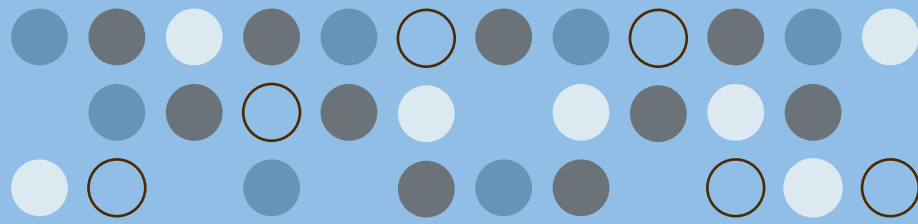
Japan is seen as a death denying society (Sagara & Pickett, 1998). Parents wish to protect terminally ill children from knowing about their illness and prognosis. The family prefers to be informed directly about the extent of the disease, and treatment decisions are made collectively by the family (Saiki, Martinson, & Inano, 1994). Saiki, Martinson, and Inano (1994) noted that in many cases there is not enough communication between physicians and parents about illness and treatment plans. Individuals within the Japanese culture prefer not to talk about sad things, and not sharing bad news has been observed to be common in families and communities (Miyaji, 1994). When dealing with children who have a diagnosis of cancer, it is important to note that families may be reluctant to acknowledge it as the cause of death because of the stigma associated with cancer (Davis, Konishi, & Mitoh, 2002). Saiki et al.

(1994) suggested that health professionals should recognize the family's perception of illness in order to provide comprehensive care.

Within the Japanese culture, it is considered preferable to die at home rather than in a hospital (Irish et al., 1993). In some cases in Japan, doctors may advise the families of terminally ill patients to take their family members home. Although dying at home is considered the ideal, many families feel unable to cope with a dying patient and prefer to keep him or her at the hospital. It is important that the family is able to gather at the deathbed while a minister chants for the dying person and their family (Braun & Nichols, 1997). This is crucial as some Japanese believe that a person's last thoughts have an impact on their rebirth (Braun & Nichols, 1997). When a family member is dying, the family is responsible for contacting relatives and friends who are then expected to pay their last respects (Irish et al., 1993; Parkes et al., 1997).

The family decides on the treatment of the body after death. Cremation is preferred over burial as there is a belief that "you have to go whole" (Braun & Nichols, 1997, p. 340). Organ donation is also resisted because the body is considered a gift from one's ancestors and is sacred (Braun & Nichols, 1997). The prayer of "pillow sutra" should be preformed before moving the body (Braun & Nichols, 1997).

Japanese people are generally Buddhists with beliefs in reincarnation (Irish et al., 1993). Buddhists believe that within the next world there is peace and no attachment to material possessions and as a result there is less pain in the next world as souls are born into a better place (Braun & Nichols, 1997). There are many denominations of Buddhism; however, all view death as natural, inevitable, cyclical, and without finality because of



reincarnation (Braun & Nichols, 1997). Death is talked about and planned for within Buddhism; “if you don’t think about death you don’t live” (Braun & Nichols, 1997, p.348). A belief in karma and its definition also differs among denominations. It is important to note that many Japanese have adopted Christian philosophies and rituals, beliefs, and practices related to death and dying (Braun & Nichols, 1997).

After death, a Buddhist is given a name (ho-myo) by a priest. A wake which includes a watch over the body of the deceased is held. There are memorial services held every seven days for seven weeks and again at 100 days (Sagara & Pickett, 1998). White is usually worn to services. Additional services for the happiness of the dead are held the first, second, sixth and twelfth anniversaries (Sagara & Pickett, 1998). It is believed that the recently deceased may contaminate others, and funeral, memorial services and associated rituals counteract the essential pollution associated with death. For example, salt sprinkled over those returning home from a funeral is an act of purification. Many families maintain an altar in their homes where deceased family members are made offerings at special celebrations.

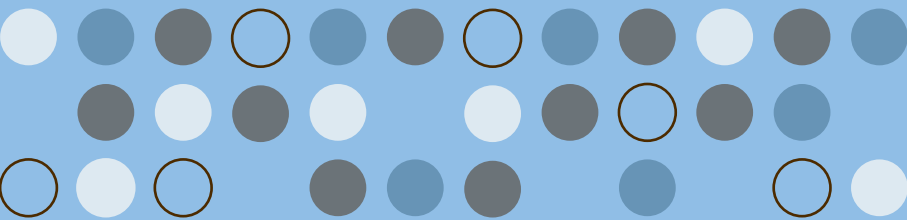
Sagara and Pickett (1998) described Japanese culture as one that maintains social behavior and belief patterns that are consistent with stoicism and fatalism. They also identified a cultural emphasis on interdependence and conformity. Importance is placed on hierarchy, family duty, and harmony. Japanese communication style is based on nonverbal, subtle, and indirect approaches with confrontation avoidance (Sagara & Pickett, 1998).

## Vietnamese Culture

If a child from the Vietnamese culture dies, there is a belief that the death was the result of a misdeed in the child’s past life or a misdeed in one of their relatives’ past lives (Braun & Nichols, 1997). This view originates from the culture’s strong belief in karma, a belief that describes how a person is reborn when the body is destroyed in death. The soul remains and goes through a rebirth depending on one’s actions in life (Braun & Nichols, 1997).

The Vietnamese prefer that the diagnosis of a terminal illness not be discussed with the patient (Braun & Nichols, 1997). Among the Vietnamese, there is a strong feeling that death should occur at home and not in a hospital. At one’s home, family can provide comfort and their loved one can die in peace. When a person is dying, some families will make every effort to bring their loved one home. Some believe a death away from home means that the soul will wander with no place to rest (Braun & Nichols, 1997). It is important to allow a family member to stay with the ill person, whether at home or in the hospital, so that someone is with them at the time of death (Braun & Nichols, 1997). If death occurs in the hospital, it is important to move the body home as soon as possible. Autopsies are only performed if required by law (Irish et al., 1993). Vietnamese are also reluctant to agree to organ donation because of the importance of the body remaining intact (Wheeler, O’Friel, & Cheung, 1994, cited in Braun & Nichols, 1997).

After a death, the soul leaves the body and the dying person surrenders to the afterlife. This peaceful process should not be prevented by the family crying out or showing emotion at the time of death (Braun & Nichols, 1997). In Vietnamese culture, many have a strong belief in the Buddhist faith, in which death is a fact of life and seen as



natural “as everyone is born and must die” (Braun & Nichols, 1997, p. 342) Some Vietnamese follow the Catholic faith. As a result, traditional and Christian practices co-exist (Braun & Nichols, 1997). For example, it is becoming more acceptable to cremate loved ones so they may be returned to their home country (Braun & Nichols, 1997).

Phan (1993, cited in Braun & Nichols, 1997) described that Vietnamese death rituals are “the most important act of filial piety” (p329). To determine the day of burial, a monk is consulted (Braun & Nichols, 1997). Blessings occur before burial. Bodies are buried in beautiful clothing with a piece of rice or gold in the deceased’s mouth (Braun & Nichols, 1997). Coffee and tea may also be placed in the casket to help preserve the body, and candles may be placed at the four corners of the casket to help keep ghosts away (Braun & Nichols, 1997).

Traditional mourning practices entail family members wearing white clothing for 14 days, followed afterwards by the wearing of black cloth pinned to clothing (Braun & Nichols, 1997). A white headband is worn during services that are held every seven days for seven weeks. On the 49th day after the death, the surviving family members organize a ceremony where food is provided for the family, friends, and neighbors. A smaller ceremonial gathering may occur after 100 days (Braun & Nichols, 1997). After that time, ceremonies are held on the one year, three year, and seven year anniversaries. However, as families become more scattered, the rituals that involve entire families are becoming shortened (Braun & Nichols, 1997).

Braun and Nichols (1997) identified further practices such as the family donating their loved one’s clothing so they can “get to a higher plane

more quickly” (p. 343). Altars for ancestors are also kept in the home, and they are remembered each year during the third and seventh lunar months.

## **Korean Culture**

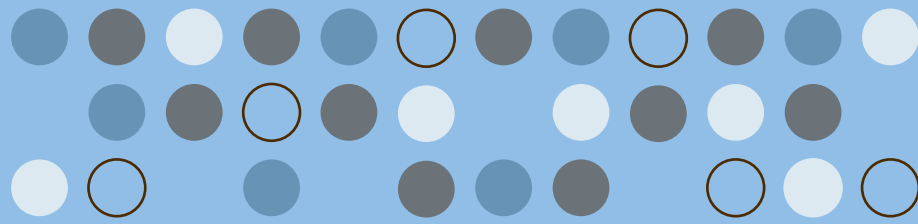
According to a Korean adage, if your parents or spouse die, you bury them underground, but when your child dies you bury them in your heart (Martinson, Lee, & Kim, 2000). The external expression of grief is expected in Korea, but when a child dies this expression is complicated by the parents’ wish not to burden others. They often cry by themselves or smile artificially to protect other children and family members from their sadness (Martinson et al., 2000).

Though guilt tends to be present during the grief process in most societies, Martinson et al. (2000) found that Korean mothers carry a heavier burden of guilt. When a child becomes sick or dies, Korean mothers often find themselves attributing the cause to their inadequate nurturing or heredity. For example, a belief can exist that a child’s cancer originated from an inherited gene. Martinson et al. (2000) suggested that intervention with parents regarding feelings of guilt should start at the child’s diagnosis and continue throughout treatment and palliative care. Education about causes, treatment, and prognosis of conditions such as cancer can have significant benefits.

## **Filipino Culture**

Filipinos believe that children go to heaven when they die because they are innocent and without sin (Parry & Ryan, 2000). When someone from the Filipino culture is dying in a hospital, it is important that family members are allowed to visit when they wish in order to ensure that their loved





one will not die alone (Braun & Nichols, 1997). In Philippine hospitals, the bantay (watcher) system is in place. With a sick child in the hospital, the mother usually is the full time “bantay” of the child (Atuel, Williams, & Camar, 1988). White is worn to the funerals of children because it is believed that children are angels, who do not wear black (Braun & Nichols, 1997). A combination of white and black may be worn when a younger person dies. Parry and Ryan (2000) described that rituals related to death and dying for children are simpler and shorter than those for adults in order to reduce the pain for parents.

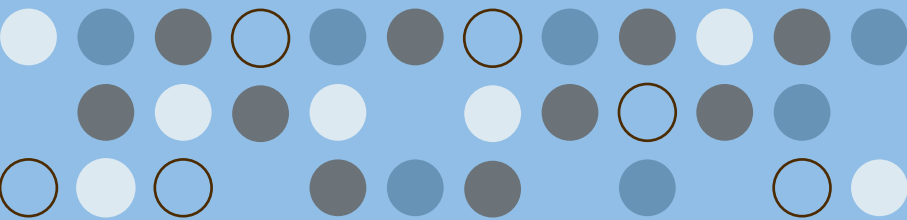
According to Shimabukuro, Daniels, and D’Andrea (1999), little is known about the spiritual beliefs and customs related to death and dying of Filipinos living in the United States. Many Filipinos follow the Catholic faith, which postulates that those who follow the doctrine will find themselves in heaven. Those who do not are considered sinners and are thought to go to hell (Atuel et al., 1988; Braun & Nichols, 1997; Shimabukuro et al., 1999). Many of the rituals and customs for death and dying are influenced by the Catholic faith and can co-exist with traditional Filipino beliefs (Shimabukuro et al., 1999). It is important to note there may be a reluctance to identify traditional beliefs to westerners. These beliefs may include beliefs in animism, a faith in the existence of spirits and their power to influence the world of the living (Shimabukuro et al., 1999).

Traditional Filipino spiritual beliefs include those related to ancestral spirit visitations. Souls may linger on earth for a time after death to watch over loved ones (Shimabukuro et al., 1999). An example of co-existence of beliefs includes the belief that individuals can have two souls, one that goes to heaven or purgatory and one that remains on earth to watch over loved ones. Traditionally, organ

donation is considered undesirable because of the importance of having the body remain intact for burial (Wheeler, O’Friel, & Cheung, 1994, cited in Braun & Nichols, 1997). Braun and Nichols (1997) identified that it is important to note that for some Filipinos who adhere to the Catholic faith, organ donation may be interpreted as helping others. They also noted that in some cases cremation is an acceptable option to a traditional burial.

The traditional nine-day Novena is the most common ritual related to death and dying among Filipinos (Braun & Nichols, 1997). Prayer services are held each night following the death as a way of helping the soul’s journey to heaven (Shimabukuro et al., 1999). The nine nights correspond with the nine basic virtues and nine choirs of angels (Braun & Nichols, 1997). The body is watched over by family members during this time. In the Philippines, it is customary to keep the body at home; however, now in Canada the body is more often held at the funeral home during this time. It is believed that on the ninth night the deceased returns to say good-bye. A feast is prepared with the favorite foods of the deceased. There is a place set for the deceased loved one so that he or she may also eat (Braun & Nichols, 1997; Shimabukuro et al., 1999). A memorial service is held again 40 days after burial. Atuel et al. (1987) noted that the grief of Filipinos is expressed in different ways depending on socio-economic status. Those in lower economic groups will wail their grief at the wake and funeral, while those in higher economic groups tend to engage in more muffled sobbing.

Shimabukuro et al. (1999) identified additional rituals and mourning practices, which include not sweeping the floor until burial to ensure that the spirit is not swept away, talking to the deceased spirit, and expecting visits from other spirits. Cleansing rituals are also performed. Verger (1986,



cited in Shimabukuro et al., 1999) described a cleansing ritual wherein one washes if they have come into close contact with the body during the burial service. Washing one's face from a bowl filled with a mixture of vinegar and water after the service helps to purify one's self.

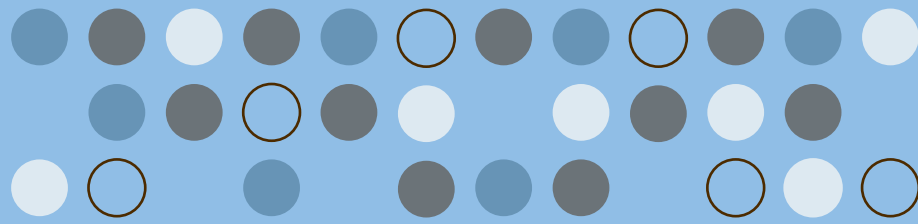
Vergara (1986, cited in Shimabukuro, 1999) noted that Filipinos perceive heaven as a physical place. Personal items are buried with the deceased for their comfort as they make their journey to heaven. Examples of belongings include razors, eyeglasses, needles and thread, coins in a wallet, and paper or pencils for messages. In the Philippines, family members may wear black clothing, a black arm band, or a pin for up to a year after the death (Alega, 1991, cited in Shimabukuro et al., 1999).

The graves of the deceased are usually visited by families on holidays and anniversaries. On the first year anniversary of the death, family members normally have a ceremony that honors their loved one. In the Catholic tradition, some families celebrate the deceased through "All Saints or Souls Day" when a picnic by the grave takes place (Shimabukuro et al., 1999). Connections with loved ones are commonly maintained after death. For example, photos of deceased relatives are brought to family gatherings and stories are told. Visitations through dreams or unexplained physical phenomena are also described (Shimabukuro et al., 1999). Children are taught that spirits exist for various purposes, and there is the belief that children often have the role as mediums who receive messages from the dead (Atuel et al., 1988; Shimabukuro et al., 1999).

## Hindu Culture

The death of a child within the Hindu faith is viewed as God's will (Laungani, 1996). Laungani (1996) described the belief that things happen because they are predestined and that actions in the present life are the result of sins in a past life. The caste system and status of women within the Hindu culture have a large impact on rituals and beliefs related to death and dying (Firth, 2001). For example, the illness or death of a female baby is considered a less of a loss than that of a male infant (Altekar, 1959; Bardhan, 1982; Krishnaswamy, 1984 cited in McGoldrick et al., 1991). This is particularly the case in the lower castes. Although cremation is customary for adult Hindus, infants and young children under the age of five are usually buried, as children are expected to return to an earthly life and enjoy a longer experience with it (McGoldrick et al., 1991). Hindus are often reluctant to agree to a postmortem on the body (Irish et al., 1993; Parkes et al., 1997).

Firth (2005) described that the most important thing to keep in mind when working with Hindu families is to help facilitate a good death for their loved one. To do this, the family will need to be actively involved in their loved one's care and rituals performed at death. The family's need to be part of decision-making is also crucially important as death is seen as a family and communal process (Laungani, 1996). In India if someone is dying in the hospital and death is close, the patient is often taken home so that proper rituals may be performed (Firth, 2005). It is important that the dying person be placed on the ground or as close to the ground as possible as this helps the spirit to be absorbed into the ground (McGoldrick et al., 1991). The windows and doors in the home are kept open during this time so the soul can leave



without difficulty. When a Hindu person dies in a Canadian hospital, the family prefers to wash and dress the body before it is removed from the hospital (Irish et al., 1993; Parkes et al., 1997). If a child dies, the body is cremated in less than 24 hours after the death, unless there is a compelling reason not to do so (Laungani, 1997).

Firth (2005) stated that the Hindu faith is “a diverse umbrella or family of beliefs and practices” (p.682). He indicated that it is difficult to make generalizations about beliefs and practices because much is dependent on class, education, and religion. This diversity is compounded by practices carried out in India that may not have the same meaning in western cultures. In addition, some rituals may not be able to be carried out within western cultures, forcing Hindu families to conform to practices which may be different from what they are used to (Firth, 2005).

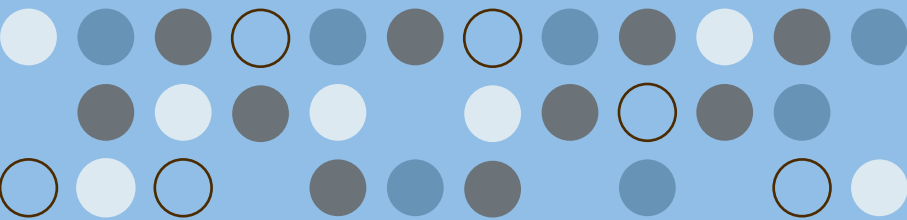
Firth (2005) described that most Hindus have the same beliefs regarding death and dying, with the most important ritual surrounding the time of death. Death is viewed as rebirth, the transition to another phase of the life cycle (Firth, 2005; McGoldrick et al., 1991). Life begins before birth and continues after death. There will be multiple cycles until the soul’s final karmic passage into “nirvana” (Firth, 2005; McGoldrick et al., 1991). Belief in karma includes a belief in fate, which cannot be changed. Good karma leads to a good rebirth, bad karma to a bad rebirth (Firth, 2005). Almeida (1991, cited in Walsh & McGoldrick, 1991) identified that the lower an individual is within the caste system, the more rituals are needed in the death and rebirth process to help to lead to tranquility.

Within the Hindu culture, death is consciously prepared for throughout life to help ensure a good

death. Preparations for a good death through prayer and rituals are of the utmost importance as a bad death is feared. Firth (2005) described a good death as one that occurs in old age, at the correct astrological time, and on the ground at home or on the banks of the sacred Ganges River. Preparations for a good death include keeping a small container of Ganges water at home to be placed on the lips of the deceased as a good death requires completion of the customary rituals throughout the process (Firth, 2005). Signs of a good death include a shining forehead and peaceful expression (Firth, 2005). Bad deaths are seen as those which are violent, premature and at the wrong place and time, without traditional rituals taking place. For example, a bad death would be one where the deceased was not given Ganges water or last rites were not performed. If someone dies without water, the souls of the deceased and family cannot be set free (Firth, 2005).

Readings from the Hindu bible (Bhagavad Gita) are conducted after a death by Brahmin priests or elders from the upper caste community (McGoldrick et al., 1991). A relative then bathes and anoints the body, males washing males and females washing females (Laungani, 1996). After a basil (tulasi) leaf is placed in the mouth, the body is dressed in white cloth and is faced north with the feet facing south in preparation for rebirth (McGoldrick et al., 1991). Radhakrishnan (1977, cited in McGoldrick et al., 1991) described that these preparations are “vital” to ensure “purity” surrounding “rebirth and the final transmigration” of the soul (p. 183).

After a death, funeral arrangements must be made as soon as possible to ensure “repose of the departed soul” (Laungani, 1996, p. 193). Funerals are open to the community and are often flexible, spontaneous, and chaotic (Laungni, 1996). After



the priest identifies the time for the funeral, mourners wearing white gather at the house and bow before the cloth-wrapped body on the floor. The priest then chants and the women gather to take part in expected crying and wailing (Laungani, 1996). The body is then taken for cremation as the priest continues chanting and seeks blessings for the soul. Traditionally, cremation ceremonies are carried out by men, with the eldest son usually lighting the funeral pyre (Waxler-Morrison, Anderson, & Richardson, 1990). Cremating the deceased less than 24 hours after the death is a crucial consideration. It is important to keep in mind that if this does not occur, it can cause great distress for the family (Laungani, 1996). Once the family and friends return home from the funeral, custom dictates that purification rites are performed. These include taking a bath, dressing in a clean set of white clothes, and praying before a family meal is eaten.

Hindus believe that after cremation, souls travel through a variety of temporary heavens or hells in order to release their sins. This process is influenced by offerings made by the family (Firth, 2005). The ashes are usually kept for 12 days and are then collected by the family for a ritual where they are immersed in the sacred Ganges River in India. In some cases, families residing in Canada will scatter them in a local river. This process ensures the spiritual salvation of the deceased (Laungani, 1996). Ceremonies are held again after 12 months.

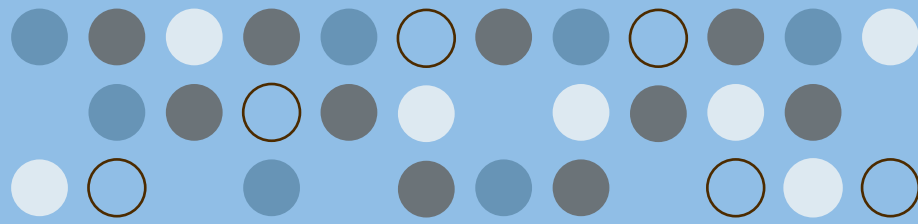
A mourning period of 40 days follows a death. For the first 18 days after the death, friends and relatives visit and care for the deceased person's family to help support them in their initial grief (Laungani, 1996). The bereaved are expected to grieve as well as be seen and heard grieving. For 12 days after the death, there is a fixed time where

a mourner takes the lead and facilitates crying, wailing, and lamenting with the bereaved family (Laungani, 1996). As the days progress, there is less intensity in emotional responses. Laungani (1996) described this as a necessary catharsis for the family. Family support through the male lineage also plays a large role in grief support and the healing process.

Firth (2005) identified that righteousness, morality, passivity, and sacrifice are highly valued in Hindu culture and inform family roles and individual conduct. He further described that religion and ritual structure the activities of individuals' lives. It is important rituals are followed as prescribed to ensure that an individual is not reborn to the same life or karma without progressing.

## Muslim Culture

Muslims believe that all children are innocent and after death their souls will ascend directly to paradise (Gatrad & Sheikh, 2002). This is also the case for still births and miscarriages, in which case these babies are given names, bathed, and shrouded. With miscarriages and stillbirths, there is no formal funeral prayer; however, the family is remembered in individual prayers (Gatrad & Sheikh, 2002). Arshad, Horsfall, and Yasin (2004) documented that in Muslim culture when a baby dies, the family may wish to undertake customary religious rites. These include sitting close to the cot of the baby, reciting verses from the Holy Koran, and praying for the peaceful departure of the soul. The family will wish to close the baby's eyes and turn the body to the right, facing the direction of prayer. The body is washed using running water so that the water flows off the body in accordance with Islamic tradition. In the immediate post-natal period, the mother should not perform the bathing



of the deceased baby due to her loss experience. The ritual is considered an act of worship, and the father or another family member may wish to undertake the bathing (Gatrad & Sheikh, 2000). As cremation is not allowed in Islam, every part of the human body including the umbilical cord and placenta should be buried (Gatrad, 1994). Gatrad and Sheikh (2000) pointed out that the common hospital practice of gathering memories, such as handprints or footprints as well as photographs of the baby, may cause distress to a Muslim family. This may be considered a desecration of the body.

Many Muslim families do not wish their dying relative to be told about the prognosis; rather, this information should be communicated to an immediate relative who may or may not disclose it to the patient. Within the Muslim culture, death is viewed as an act of God, which is not to be questioned by humans (Long & Elghanemi, 1987). Death is seen as a return to God, where the ugliness of the present world gives over to the beauty of the afterlife. Gilanshah (1993) described that Muslims often learn more about death than life itself. Death is accepted as part of a divine plan and Muslims are often encouraged to talk about death and reflect upon their own existence (Gatrad & Sheikh, 2002).

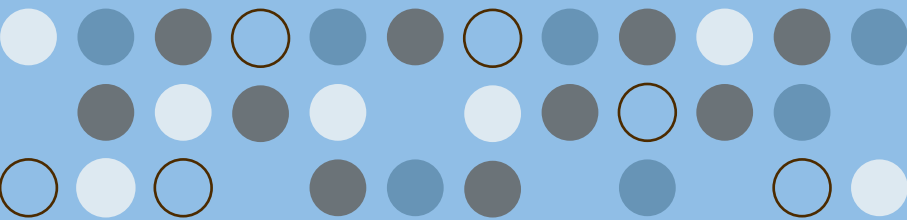
During an individual's last moments before death, a close relative stays with him or her, praying and reading from the Koran. As the dying person may not be able to talk or pray, it is the relative's responsibility to do so. There is a belief that two angels and Satan will be close at hand at the time of death and God will send the believers to heaven (Gilanshah, 1993). Once the death occurs, it is undesirable to leave the body alone (Parkes et al., 1997). If a death occurs in the hospital, it is preferred that staff not wash the body; rather, it is preferable that they turn the head toward the right shoulder, straighten the legs and stretch both arms

by the sides (Gilanshah, 1993).

A family member is responsible for the following after death: turning the body toward the Mecca, closing the mouth and eyes, straightening of both legs and placing the arms and hands by the sides, bathing and covering the body, and announcing the death to relatives and friends right away (Gilanshah, 1993). Within Muslim culture, males always bathe males and females always bathe females (Hedayat & Pirzadeh, 2001). Two relatives wash the body using three kinds of water: water from a plum tree, camphorated water, and pure water. If these are not available, the body is washed three times (Gilanshah, 1993). The body is then wrapped in plain white cotton. During these procedures, family members may wish to read passages of scriptures or to make lamentation (Parkes et al., 1997). There is a belief that the more prayers said at the time of death as well as seven days after death, the more peaceful the departure to the afterworld (Gilanshah, 1993).

The purpose of the funeral is to prepare souls for the Day of Judgment. This is an important concept for those Muslims who are new immigrants (Gilanshah, 1993). Burials should take place the day after death, with the body facing Mecca. At the time of the burial, there is no discussion; rather, prayers from a religious leader are spoken while those attending the funeral cry and release their sorrow. The funeral is meant to be expressive, and emotional release is expected as a way to help obtain peace. Grief is shown by way of loud crying, wailing, and lamenting (Irish et al., 1993). Gatrad and Sheikh (2002) described that death rituals for Muslims form the final bond between the deceased and the bereaved.

After the funeral, the grieving family is visited and guests may stay for the day or night, with close



relatives often staying for a week. There is much emotional expression during that time (Irish et al., 1993). Three days after burial, a ceremony is held at the Mosque with friends and relatives praying while a religious leader reads from the Koran. After 40 days, black is no longer worn. A prayer, a blessing at the house, and reading from the Koran will occur at this time (Gilanshah, 1993). One year after the death, there is another remembrance and prayer ceremony.

Filial piety, which implies unconditional loyalty, respect, love, and honor for the elders in the family, is still very much present in the Muslim culture (Gatrad & Sheikh, 2002). Submission and achievement of peace are values that adhere to God's will (Gilanshah, 1993). Rituals surrounding dying and death focus on prayers, cleanliness, and purity.

## Hutterian Culture

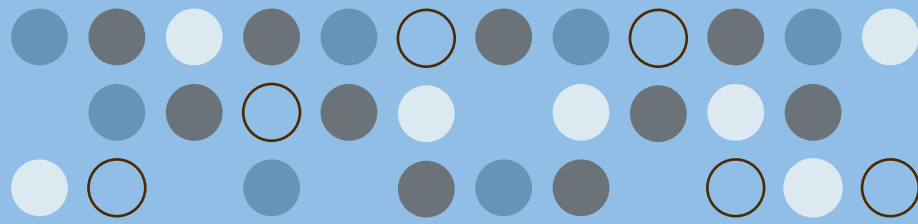
In the Hutterite society, the death of a child is considered a blessing and there is a happy acceptance when a child dies. This is in sharp contrast to most contemporary societies, where a child's death is regarded as a very unfortunate thing (Stephenson, 1983-84). Stephenson (1983-84) quoted a bereaved parent following the death of a seven-year-old child: "She will sure be a beautiful angel, when these little ones die we know they are in heaven, but we never know what will happen to them when they grow up. I sure wish I would have died when I was a kid"(p. 129). Hutterites believe that the misdeeds of children are forgiven through Christ's sufferings and they go to heaven after death.

Stephenson (1983-84) described that although norms dictate acceptance, not all Hutterites gladly accept the death of their children. There

can be a conflict with the ideal value because of the emotional sense of loss. This can lead to a particular kind of depression termed "anfechtung," meaning temptation by the devil. The parents of the child may feel depressed because their feelings are not attuned to the values of the Hutterian culture, exacerbating the loss with a sense of unworthiness.

According to Stephenson (1983-84), for Hutterites there is a joyous acceptance of a death which is willed by God, offering heaven as a final reward. In Hutterian colonies, long, slow death is considered more desirable than a sudden death (Stephenson, 1983-84). They believe that an extended period of time before death allows the dying person to socialize with his or her extended family, friends, and community. When the person is dying, word is sent to all relatives and friends, who then come to visit the dying person. The dying person is never alone as he or she is always surrounded by family and friends as well as being the focus of all activity. Often the conversation is religious and visitors and the dying person socialize with each other, furthering their awareness of mortality and moving toward graceful acceptance of death. The dying person must slowly pass into eternity because he or she has a moral obligation to self and others to die socially before he or she dies physically (Stephenson, 1983-84).

Hutterites have preserved the bedside accounts of their ancestors, whose last words are often put into verse and song. Adults who are on their death bed are supposed to relive their lives in order to forgive others and be forgiven. In this respect, a person's death corresponds to baptism. Eaton (1964, cited in Stephenson, 1983-84) reported that Hutterites show little fear of death and actually embrace it as their final reward for a life filled with suffering and pain. Hutterites regard the ability to keep faith even in pain as the hallmark of a true Christian martyr.

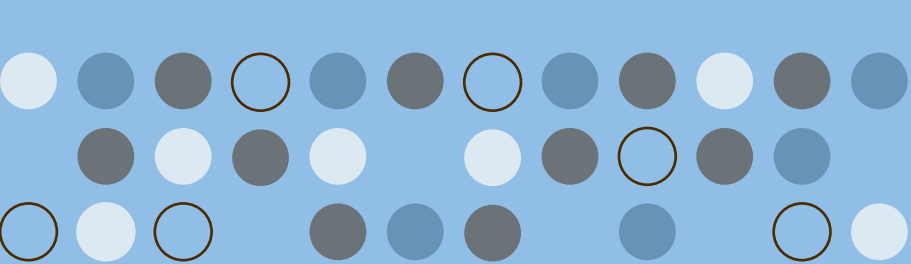


According to their belief system, all deaths are willed by God and there is no distinction between natural causes of death and other diseases.

Funeral ceremonies are major social events, and a coffin is made by a life-long friend. The display of grief occurs only at the graveside; it is highly stylized and the sobs of the bereaved are made only by women (from oldest to youngest in sequence). The sobbing is meant to represent the grief of the living for their own sad plight (Stephenson, 1983-84).

## **Conclusion**

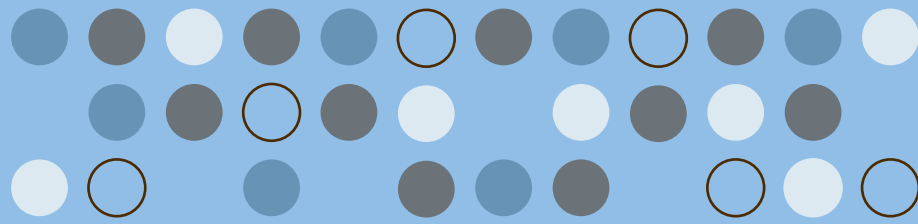
This literature review clearly identifies the need for deeper investigation into the cultural and religious values, beliefs, and rituals surrounding serious childhood diseases, end-of-life care, and bereavement support for new Canadians. Health care professionals require further information to help them better understand the needs of patients and families belonging to a diverse and growing ethno-cultural population. As identified by Braun and Nichols (1997), only a small amount of information is available for health care professionals relating to diverse cultural rituals, beliefs, and practices related to death and dying. This paucity of information is of critical concern when dealing with dying children and their families. Gaps in knowledge and sensitivity compromise paediatric palliative care and bereavement support care for all.



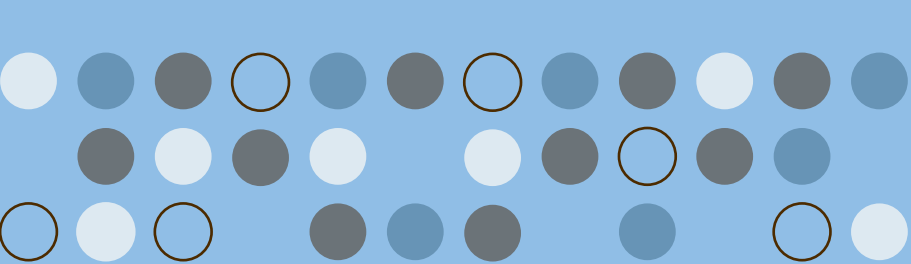
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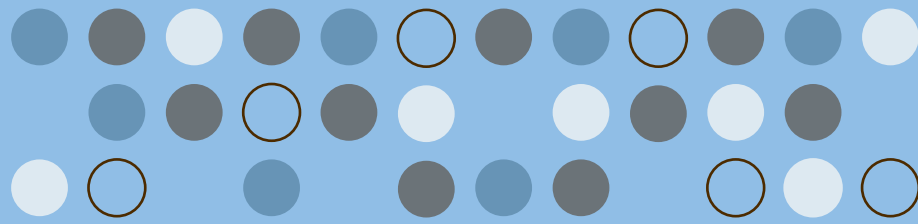




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