

# When a Child Dies:

Cultural Competency in Paediatric Palliative Care

An Educational Resource



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Executive Summary

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## Executive Summary

The immigration of people from non-traditional source countries (Asian, Middle Eastern, Caribbean, and African countries) with different cultural and religious values, beliefs, and traditions has resulted in an increased and growing demand for culturally sensitive end-of-life care services in Canada. Health care professionals and services are challenged by the tasks of providing palliative care and grief support to newcomers, often without formal training in cultural sensitivity. When there are cultural gaps between families and health care providers and these gaps are accentuated by barriers of language, faith, and cultural values and beliefs, it becomes all the more difficult to negotiate transitions on the path of a child's death. 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 unique rituals, values, and beliefs that apply. It has been recommended 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 & Behrman, 2003; Gatrads & Sheikh, 2002; Koenig & Davies, 2002).

The purpose of this research was to explore the challenges and needs experienced by families and health care professionals when receiving or providing paediatric palliative care and grief support. This report

is expected to provide the following: (a) increased knowledge and understanding of the values and beliefs of various ethno-cultural communities as a child is dying and after a child has died; (b) an examination of the level and quality of palliative care received when a child is dying as perceived by bereaved parents from the ethno-cultural community; (c) an understanding of the roles and functions of ethno-cultural community organizations and the social support provided to families; (d) an exploration of the level of health care professionals' understanding of diverse backgrounds and cultures when providing paediatric palliative care to families; and (e) a determination of the learning needs of health care professionals in order to provide culturally competent paediatric palliative care.

*This study used a grounded theory approach. Interviews and focus groups were used to gather data. The participants were divided into the following categories: bereaved parents (n=19), ethno-cultural focus groups (n=7), key cultural informants (n=6), religious leaders (n=8) and health care professionals (n=13). The cultural groups included in this research were as follows: Sudanese, Hutterite, South -Asian, Chinese and Filipino.*

Focus group participants from various ethno-cultural groups described a wide variety of rituals and customs that take place prior to and after a person passes away, many of which are believed to benefit the deceased. Comments from participants were consistent with Turner's (2002) idea that ethno-cultural background impacts community responses and the appropriateness of health professionals' conduct. Some participants mentioned that in a close-knit culture, the community response is quite large when someone is sick and many people come to the hospital to visit and show their support for the family. An example that relates to the proper conduct of staff is the manner in which bad news is conveyed

to families. Muslim participants, in particular, appeared to prefer that a terminal prognosis not be shared with the families, especially with mothers. According to health care professionals, staff often assume that all members of an ethno-cultural group have the same beliefs and family members similarly described a tendency among staff to generalize by community rather than recognizing a person as a unique individual. Prejudices, which are intimately linked to stereotypes, were additionally identified as being held by some professionals. This study suggests that it is essential that health care professionals not only educate themselves about the values, beliefs, and cultural practices around paediatric death and dying but that they acquire skills to care for families from diverse cultural backgrounds.

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# When a Child Dies:

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Cultural Competency

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# Cultural Competency



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## Cultural Competency

In order to provide culturally competent care, organizations and caregivers must respond effectively and respectfully to the unique needs of culturally and linguistically diverse clients.<sup>1</sup> The areas of death and dying intensify the challenge of providing culturally competent care in health care settings. Health care professionals may ask themselves, “how do I practice cultural competence when a child from a different cultural background dies?”

This booklet incorporates specific information regarding cultural competency in paediatric palliative care. It is accompanied by five booklets providing information on specific cultural groups to inform culturally competent practice in end-of-life care.

An additional general booklet on providing sensitive and cultural grief support is also included. While it is impossible to offer information on the values and beliefs surrounding end-of-life for a child, the information provided for the 5 cultural groups pose as a reminder to consider the families cultural background at all times.

### **Foreword**

*This resource is intended as a guide for professionals providing care to families from diverse cultural groups whose child is dying or has died. It is not intended to be used in place of communicating with the family but more of a cultural tool to enrich your practice.*

## Elements in culturally competent practice

In their exploration of end-of-life care, Pottinger, Perivolaris and Howes outline a three-element approach to culturally competent practice.<sup>2</sup> One of these elements is being aware and knowledgeable, and this refers to knowing how cultural differences shape your client's beliefs and perceptions. Cultural and religious beliefs and practices vary significantly across cultures, often differ from Western ideals, and touch on a wide range of aspects of pediatric palliative care.

To practice culturally competent care, you may want to know how your clients and their caregivers feel about the following:

- Perceptions of suffering
  - Actions and therapies to reduce suffering or manage pain
  - Spiritual care regarding forgiveness or acceptance
  - The meaning of suffering (Is suffering seen as a natural part of life? As punishment for sin? As purification?)
- General decision-making in end-of-life care
  - Individual versus family-based decision-making
  - Reliance on physicians to make decisions
  - Collaboration between physicians and families in making decisions
- Organ donation
  - Life-sustaining treatment
  - The actual moment of death (When the brain stops? When the heart stops?)
  - The relationship between the child's essence or spirit and his or her organs.



- Advance directives
  - Comfort with these documents, which are based on Western values of autonomy and individualism
- Disclosure of diagnosis and prognosis
  - Full disclosure versus non or minimal disclosure
  - To whom does the health care professional disclose?
- Expectations
  - Of health care professionals
  - Of visitors
  - Preferred location of palliative care
  - Palliative care services
- End-of-life practices and rituals
  - Death itself
  - Preparation of the body
  - Funeral arrangements
  - Religious practices
  - Acceptable treatment and comfort for the caregivers or family
  - Grieving

Another element in culturally competent practice is **bearing witness**, which means being present with your clients and their caregivers and listening non-judgmentally as they share their cultural beliefs and values and as they express their feelings and opinions. Bearing witness is required in order to be truly aware and knowledgeable about your client's cultural or religious beliefs and values, but is also a skill involving the creation of opportunities to “practice authentic therapeutic relating.”<sup>2</sup>(p229)

**Providing comfort** for both clients and their caregivers is another element of culturally competent practice that is the responsibility of

a health care professional. Providing comfort may take many forms. It can involve acquiring knowledge of cultural practices, discussing the hospital experience, and bearing witness. It may also require that health care professionals be open to observing therapies rooted in other cultures. Providing comfort may also involve seeking out resources for clients or caregivers. It is important to ask clients and caregivers about their comfort needs as in many cultures it can be inappropriate to ask for help. Most importantly, providing comfort requires a level of genuineness from the health care professional.

**Cultural competence** refers to a combination of attitudes, values, behaviours, knowledge, skills and policies that enable effective intercultural healthcare. Cultural competence comprises a dynamic or continuously evolving process. It involves respect of differences, a willingness to learn, and acceptance that there are many ways of understanding the world. Culturally competent care involves continual self-awareness, self-examination, and respectful curiosity and inquiry on the part of the health care professional.

### **What can hinder cultural competence?**

There are many potential barriers to culturally competent practice in health care. These may include lack of awareness, lack of knowledge, communication barriers, adverse attitudes and stereotypes, and lack of skill or experience.

## 1. Lack of awareness

Cultural competence in health care relies on the heightened awareness of health care professionals.

- Awareness includes personal or self-awareness, involving identification and understanding of one's own values, beliefs, norms and where these ideals come from, including personal history.
- Awareness also includes system-awareness, involving identification and understanding of the cultural values, beliefs, and norms embedded in the Western medical (or biomedical) model and where these ideals have come from, or their history.
- Increasing awareness is a process involving self-reflection, discussion and research.

## 2. Lack of knowledge

Knowledge of a variety of cultural and religious practices around the world, including knowledge of beliefs, values, norms and health care or family systems, is essential to increasing cultural competence in the health care setting.

- Personal knowledge of other cultures will never be complete; rather, it is a continuous process of learning and willingness to learn from your patients and their caregivers.
- One must avoid stereotyping. This requires acknowledgement that individuals can and do vary significantly within a culture.
- Increasing knowledge is a process that involves research and consultation with clients, colleagues and experts, which can include religious leaders or informal leaders in the community.

### 3. Communication barriers

Effective communication with patients and their caregivers is necessary for culturally competent practice in health care.

- Effective intercultural communication includes knowledge about verbal and non-verbal communication patterns in diverse cultures.
- Effective communication requires adequate resources, including interpretation or translation services, to communicate with clients who have a low level of English.
- Communication requires awareness of one's own communication patterns and stereotypes, and how they may hinder effective communication interculturally.
- Increasing effective intercultural communication involves research, awareness and consultation and dialogue with colleagues or experts about specific situations in the health care setting. It also requires utilizing appropriate resources.

### 4. Adverse attitudes and stereotypes

Adverse attitudes or stereotypes regarding other cultural beliefs or values are facts of being human: we all have them. These attitudes and beliefs are often implicit or hidden and may be uncomfortable to confront. However, adverse attitudes and stereotypes have a strong impact on our work as health care professionals working interculturally.

- Cultural competence requires first a desire to be culturally competent and acknowledgement that one's own perspectives are merely perspectives and are not always the only way of thinking.
- Adverse attitudes and stereotypes can be countered by greater awareness, knowledge, exposure to other cultures, and communication with clients, colleagues and friends.

## 5. Lack of skills or experience

Skill in dealing with patients from diverse cultures or backgrounds may require training and practice.

- Ultimately, increased skills and training in cultural competence should make your own behaviours, beliefs and practices explicit and therefore easier for you to confront and work with.
- Increased skills and training in cultural competence should make your perspectives explicit, and easier for your culturally diverse patients and their families to understand, rather than implicit and more difficult to understand.
- Your health care setting should have policies pertaining to culturally competent practice in your setting. It should also provide workshops on increasing cultural competence and resources (such as interpretation services or diversity consultants) to support staff in providing culturally competent services.

## Tips for improving cultural competence in pediatric palliative care

1. Educate yourself about the birthplace and culture of your client and his or her caregivers and try to understand the family's beliefs around death and dying.
2. Educate yourself about the religion of your client and his or her caregivers and try to understand the implications of that religion on the family's beliefs around death and dying. Also, know your client's level of faith and spirituality as it may influence these beliefs as well.
3. Educate yourself as to what language your client and his or her caregivers speak at home. If the client or caregivers use English as an additional language, you may want to ascertain their level of English comprehension early in the encounter. Clients or caregivers may feel more comfortable speaking to you in a different language via an interpreter. Allowing a family member to act as an interpreter for families and patients in discussing diagnosis, treatment and advanced directives is not an approved practice, as some family members might not do the direct interpretation of the clinical consult.
4. Ask your client or his or her caregivers about practices surrounding death and dying that may be important to them, and what services or practitioners they would find helpful. For example, you might ask, "I am aware that some people of your faith (culture) value \_\_\_\_\_; is that something that is important to you?"
5. Ask the client or caregivers about any specific practices (including faith-based practices) that take place at the time of death or while a child is seriously ill, and how you might fulfill any needs in that area.

6. Educate yourself about the support systems in the client's or caregivers' lives. For example, ask, "Who would you like to be a part of this process?"
7. Understand and appreciate the importance of individualizing each situation based on the multitude of cultural issues that can arise.
8. Assess the emotional state of the client or caregivers and try to determine the cultural dimensions that support it.
9. Allow the client and his or her caregivers to assist you in learning the words that describe the client's illness, sorrow, grief, or other feelings around death and dying.
10. Try to engage the client and caregivers in a trusting, respectful relationship and in an open, non-judgmental manner.

**And:**

- Speak clearly
- Ensure the client or caregivers understand what you are communicating
- Avoid jargon, idiomatic expressions, and complicated medical terminology
- Understand that the meaning of facial expressions, eye contact and silence vary cross-culturally
- Respect and appreciate the cultural differences that surround death, dying and grief.

**Special thanks** to Srivastava, R. H. (editor). The Healthcare Professional's Guide to Clinical Cultural Competence (pp.227-246). Copyright © 2007 Elsevier Canada, a division of Reed Elsevier Canada, Ltd. All rights reserved. Used by permission of Elsevier Canada, 2008.

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# When a Child Dies:

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Grief Support

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# Grief Support



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## Grief Support

Caring for a child who is dying and dealing with a child's death can be the most significant and devastating stress that a family may ever have to face, and it can put an enormous strain on family relationships. Supporting families through the death of their child makes a difference in the grief recovery process. Families remember the support, caring, and guidance provided at the time of their loss. Gentle and sensitive care is very comforting to families, and interventions that offer comfortable environments, compassion, support, and lasting memories of their child, are therapeutic for the family's grief process.

As time goes on, it is natural for parents to repeatedly review all circumstances surrounding the death event of their child and the people involved with providing care. This affirms the critical role caregivers have in supporting and responding to the needs of the family. The death of a child is a time no parent ever forgets. Research has shown that what happens in the hospital while a child is dying often has lifelong repercussions and can impact the severity and healing of parental grieving.<sup>1,2</sup> Interventions that acknowledge the loss of the child and provide support and compassion help to facilitate the grief process.

Whether a child's death is anticipated or unexpected, families are in a natural state of shock, confusion, disbelief, and despair.

Reactions of parents to the loss of a child vary and are dependent upon a number of factors, such as personality, support systems, previous life crisis and trauma, personal coping styles, relationship to the child, and ethnic spiritual and cultural beliefs. Grieving, although a collective and universal response to loss, is very individualistic. Responses may involve a range of emotional reactions, including withdrawal, panic, shock and numbness, or a void of emotional expression.

It is important to realize that there is no correct way to grieve. Customs, behaviors, and emotions that may be considered normal in one culture may be considered as inappropriate ways of grieving in another culture. It can be difficult to know how to be sensitive to the grief expressions and needs for a support of a family from a different cultural background. As Doka and Davidson remind us,

*The danger is in assuming that one's worldview is the sole one of value, judging others' perspectives, forgetting that a basic goal of caregiving is to assist clients in understanding the ways their own worldview can provide strength, comfort, and meaning rather than attempting to impose another worldview on them.<sup>3</sup> (p4)*

In providing grief support, professionals need to examine their knowledge base about death dying and grief and how this knowledge base shapes their practice. Professionals who work in the area of grief and loss need to access professional development to increase knowledge and skills in order to provide sensitive and appropriate interventions. Professionals need to be aware of how their own reactions to death, positive and negative, impact the professional relationship with families and the ability to support all families in a non-judgmental fashion, regardless of social, cultural, or spiritual beliefs.

The ability to move outside of their own beliefs allows professionals to be open to learn from the grief experience of others.

Professionals providing support to families in end of life care need to develop skills that support and allow for the unique grief expressions of the child and family. Professionals need to encourage a safe and non-judgmental atmosphere so that these expressions can occur and be respected. Professionals need to learn about bereavement and how it affects individual families.

It is difficult to talk about the possibility of death with children and families. Addressing the needs of a dying child and his or her family often evokes fears and uncertainties and, ultimately, the needs of the child and the family may not be well identified or supported. Families who struggle with the complexity of issues that these difficult circumstances bring are often left feeling overwhelmed and require a great deal of specialized support and interventions. Providing care to a dying child, and supporting his or her family, is a difficult and emotional experience for all caregivers involved. These times call upon the need to respond to families in caring, culturally sensitive, and supportive ways in the midst of complex issues.

### **What Can You Do For a Family?**

- Be a presence: Sit and listen.
- Allow parents to set the pace.
- Understand the ways families want information shared and with whom.
- Use the child's name and invite families to share stories about their child.
- Provide opportunities for privacy as desired by the family.
- Access interdisciplinary support as needed for the family.
- Explain the physical changes that are happening to the child.
- Pay attention to what you say and how you say it. During

this difficult time, families have an increased awareness and sensitivity.

- Inquire about and involve siblings.
- Invite the family to participate in the physical care of their child if they wish to be involved. If parents want to be at the bedside during procedures, explain what is being done as their child is treated.
- Reassure families that everything possible is being done. They don't automatically know or assume this. Continue to reassure them that no measure will be left untried in the attempt to save their child's life.
- Make every effort to arrange for parents to be with their child at the moment of death, if they wish to be.
- Ask the family if they would like you to stay with them, or if they want time alone.
- Give parents permission to talk about their feelings if they wish. Some parents may not be able to accept bad news and may cope by denying it. Do be patient with parents in denial as this is a form of emotional protection that will disappear when an individual is ready. Everyone has a different timetable of acceptance.
- Encourage the use of rituals. In the book *Lessons of Loss: A Guide to Coping*,<sup>4</sup> Niemeyer observes that rituals provide a structure for emotional energy, symbols for transitions in life, and opportunities for socially shared meanings of events. Rituals can affirm communal bonds and provide a container for frenetic energy and intense grief. It is helpful for health care professionals to suggest possible rituals that a family may want to engage in based on their ethno-cultural and religious background and their family and social circumstances. Gathering mementoes when a child is dying or has died is one way of engaging in ritual. It is helpful to support the family's

ability to continue to care for their child in ways that are meaningful for their cultural and spiritual beliefs.

### **Helpful Questions When Caring For Families**

- How can we be most helpful to you and your family right now?
- What are you hoping for?
- What is the greatest challenge facing you right now?
- Are there any questions you would like to have answered right now?

### **Helpful Things To Say**

- I'm sorry.
- I can't imagine how hard this must be.
- I wish there was something I could say that would help.
- Tell me about your child.

Talk about what has been helpful to other families without implying they ought to follow a certain pattern of behavior.

### **Words That Are Hurtful**

- You will get over it . . . Time heals all wounds.
- You can have another child.
- It was God's will.
- At least you can have other children.

### **How You Can Help Bereaved Families**

- Learn about bereavement and how it affects family members.  
Symptoms of grief may take many forms:
  - Feelings of sadness and body distress (lump in throat, sleeplessness, loss of appetite, exhaustion)
  - Anger or hostility

- o Changes in social patterns (isolation, inability to perform daily living tasks, vulnerability to physical illness)
- o Guilt or search for causality (asking how I could have prevented this from happening?)
- Listen for the beliefs parents may have as to how the illness or death may have occurred.
- Understand that parents do not wish to hear rationalizations about their child's death. Never tell a parent such things as "Your child would just have been a burden to you" or "She just would have suffered if she had lived."
- Remember that talking – expressing shock, pain, and grief – helps parents adjust to the death of their child. Be available to listen, knowing that it will take years to adjust to what many people consider the worst loss of all.
- Understand that anger with the hospital or doctors and nurses is not always misplaced. Be open to examining, and discussing with the parents, decisions made and procedures performed in regard to treatment of their child.
- Understand that the family is doing their best to cope with this tragedy given their strengths, abilities, social and cultural circumstance, and systems of support.

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# When a Child Dies:

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Chinese

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# Chinese Perspectives



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## Chinese Perspectives

### **The Chinese community in Canada**

Chinese immigrants first came to Canada in the 1850s with the discovery of gold in the Fraser Valley in British Columbia. According to the 2006 census, there were about 1.2 million Chinese in Canada, accounting for 24% of the visible minority population and 3.9% of the total Canadian population.<sup>1</sup> Major waves of Chinese immigrants to Canada consisted of immigrants from Hong Kong and most recently from Mainland China. Other Chinese immigrated to Canada from Taiwan, Singapore, Malaysia, Vietnam, Indonesia and other Southeast Asian regions, bringing different layers of diversity to the Chinese population in Canada. Currently in Canada, 28% of the Chinese population are Canadian born and 72% are immigrants.<sup>2</sup>

### **Meaning of death**

A Chinese saying states that black hair should not precede white hair, meaning that a child should not die before the parents.<sup>3</sup> Death is often considered a forbidden word, and many Chinese still avoid talking about the subject.<sup>4</sup> Death can be seen as natural and inevitable, but only in old age. If the death is seen as untimely, unfair and hard to accept, some Chinese believe it may be caused by evil spirits.<sup>5</sup>

Among Chinese, the belief in ghosts is common. Ghosts of family members are not feared, but hungry ghosts who cause illness are seen as a threat.<sup>6</sup>

## Values and beliefs related to dying

In Chinese culture, talking about a child's death is usually discouraged as it is considered bad luck.<sup>6</sup> Early death is considered a punishment, caused by an evil spirit.<sup>5,6</sup> The death of a child is often perceived as a punishment for a misdeed either in the child's past life or for actions of the child's parents in the child's current or past life.<sup>6</sup>

Family support and solidarity is a crucial part of patient care.<sup>5</sup> Families prefer that health professionals not reveal a prognosis to dying patients because their last days should be worry-free and painless,<sup>7</sup> and knowing their prognosis may be harmful to patients and hasten their death.<sup>5,8</sup> It is believed that delivering news in a sensitive way preferably by other family members helps to protect the loved one from emotional turmoil.<sup>5</sup> It is usually the family's wish and responsibility to share the prognosis.<sup>6</sup> This indirect approach should be used when discussing the patient's illness and prognosis with family members.<sup>5</sup>

Family members should be asked if they would like a minister or other spiritual leader to attend to them.<sup>6</sup>

The physical condition of the deceased is seen as one of the determinants of a good death. For instance, the deceased's facial expression is an indicator of a good or bad death.<sup>9</sup>

## **Rituals at the time of the death**

There is no monolithic Chinese culture.<sup>8</sup> Mourning and funeral rituals depend on the family's religion, which could be Buddhism, Confucianism, Taoism, or Christianity. These philosophies' emphasis on endurance and acceptance of suffering as well as the importance of forgiveness are highly valued.<sup>9</sup>

Burial is preferred to cremation as it ensures the body remains intact.<sup>6</sup> Organ donation is not preferred as the body should remain intact and one's body is considered a gift from one's parents.<sup>6</sup> Ritual is important and there are strict rules for funeral practices.<sup>6</sup> For Buddhists, the deceased should not be moved for eight hours after death because they believe the soul has not left the body and is in the process of trying to be reincarnated.<sup>6</sup>

The burning of symbolic paper money, cars, and servants helps the deceased on their journey, ensuring they are financially secure and safe.<sup>6</sup> Symbolic money is also burned to ward off hungry ghosts in an effort to encourage them to leave the living alone.<sup>9</sup> Rice is offered to the spirits and incense is burned for ghosts.<sup>6</sup> Many Chinese believe that if proper rituals are not adhered to, ghosts will return to plague the living.<sup>6</sup>

## **At the funeral ceremony**

White or black is worn at funerals and female family members may also wear a woollen flower in their hair.<sup>5</sup> Male family members may wear black arm bands.<sup>3</sup>

Everyone attending the funeral will receive a white envelope that usually includes a coin and candy. Years ago the white envelope used to include a handkerchief as well. The meaning of the coin and the candy is a symbol representing closure. The handkerchief signifies the tears that were shed.

The body is viewed at the funeral with priests calling forth the Gods and scaring the ghosts.<sup>9</sup> Some funeral rituals are performed only by male family members. Pregnant women are discouraged from attending as it is feared that the sadness may harm their health.<sup>3</sup>

In Taoist traditions, chanting is an important part of the ceremony as it aims at appeasing the deceased spirit.<sup>9</sup>

### **After the funeral**

Memorial rituals are performed every seven days for 49 days, and during that time, prayers are chanted.<sup>6</sup>

It is believed that the deceased spirit will return on the seventh day for a visit after death to say goodbye. The deceased's favourite food and books or magazines are set out in anticipation of the visit. After that time, the clothes and personal belongings of the deceased are given away.<sup>6</sup>

Relatives may not visit the deceased's family for a period of time, for fear that they will bring bad luck.<sup>3,10,11</sup>

A three-year mourning time is common after the death of a child or parent, one- three years for a spouse. For certain period after the death, involvement in entertainment such as parties and celebration is avoided among immediate family members, depending on the relationship with the deceased.<sup>6</sup>

The Qing Ming festival is a memorial day (annual) ritual after someone has passed away. During this festival, family members go to the graveside to clean and sweep the graveside. Offerings such as a roast pig and incense for burning are taken to the graveside.<sup>6</sup>

## **Bereavement and mourning**

Grief is kept within the family and strong emotions are not expressed.<sup>6</sup> Most Chinese prefer to keep emotional distress to themselves.<sup>5</sup> Many families are not open to asking for help, especially from professional counsellors.<sup>5,6</sup>

Bringing food to the family is considered a better gift than cut flowers as flowers are associated with death.<sup>6</sup>

Some Chinese do bring flowers to the family in mourning. As the culture evolves with time and social locations, traditional practices may be modified. It is therefore recommended to ask the family of what is appropriate.

## **Afterlife beliefs**

Among the Chinese, there is a strong belief in reincarnation and afterlife.<sup>9</sup>

## **Acculturation**

For culturally competent practice, it is crucial to not be guided by stereotypes, expecting all members of a cultural group to share similar views about death and dying.<sup>5</sup> Many Chinese have adopted western beliefs, and as culture evolves, traditional rituals may be modified or simplified and co-exist with Westernized beliefs and practices.<sup>6</sup>

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Linda Kongnetiman MSW, RSW



# When a Child Dies:

Cultural Competency in Paediatric Palliative Care

Hutterite

## An Educational Resource

# Hutterite Perspectives



Alberta Health  
Services

## Hutterite Perspectives

### **The Hutterite community in Canada**

The Hutterites are a Christian group who strictly follow the Ten Commandments and the teachings of Jesus Christ.<sup>1</sup> According to the 2006 census, about 30,000 Hutterites live in Canada, with about half living in colonies in Alberta and the remainder in colonies across western Canada.<sup>2</sup>

Hutterites are the followers of Jacob Hutter and are named after him. The religion and lifestyle started in Switzerland in the 16th century, and Hutterites immigrated to North America in the early 1900s. Hutterites live in communities known as colonies. They do not have privately owned property; all the property is owned by the colony.

Hutterites believe that only adults can choose their faith; hence, Hutterites are not baptized until they are 20 to 25 years of age. They go to church services on Sunday and also attend half-hour services everyday. They keep separated from the outside world by not watching TV or listening to the radio.<sup>1</sup> The Hutterite groups in Alberta and Saskatchewan do not believe in having their photos taken, based on the second of the Ten Commandments: “You shall not make for yourself a carved image, or any likeness of anything that is in heaven above, or that is in the earth.

## Meaning of death

In the Hutterite community, the death of a child is considered a blessing, and there is a happy acceptance when a child dies.<sup>3</sup> Hutterites believe that the misdeeds of children are forgiven through Christ's sufferings and that they go to heaven after death.<sup>4</sup>

Hutterites believe that all death results from the will of God, whether the death is natural or due to disease.<sup>4</sup> Hutterites believe that the ability to keep faith even in pain is the hallmark of a true Christian martyr.<sup>4</sup>

## Values and beliefs related to dying

While there is a joyous acceptance of a death that is willed by God, offering heaven as a final reward, not all Hutterites gladly accept the death of their children, due to the emotional sense of loss.<sup>4</sup> This can lead to a particular kind of depression which is termed "anfechtung," meaning temptation by the devil. The parents of the child may also feel depressed because their feelings are not attuned to the values of the Hutterian culture, exacerbating the loss with a sense of unworthiness.<sup>4</sup>

Hutterites view a long, slow death as more desirable than a sudden death. 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 a person is dying, word is sent to all relatives and friends, who then come to visit the dying person.<sup>4</sup>

## Rituals at the time of the death

The dying person is never alone as he or she is always surrounded by family and friends and is the focus of all activity. Often the conversation is religious and visitors and the dying person socialize together, furthering their awareness of mortality and moving

towards grateful acceptance. It is ideal if the dying person slowly passes into eternity because he or she has a moral obligation to self and others to die socially before he or she dies physically.<sup>4</sup>

### **The funeral**

Funeral ceremonies are major social events, and a wake follows the death. Funeral buns are baked and a coffin is made by a life-long friend.<sup>4</sup>

Display of grief occurs only at the graveside. It is highly stylized and the sobs of the bereaved are only made by women and are meant to represent the grief of the living for their own sad plight.<sup>2</sup>

### **Afterlife beliefs**

Hutterites believe that children automatically go to heaven.<sup>4</sup>

Adults who are on their deathbed are supposed to relive their lives in order to forgive others and be forgiven.<sup>4</sup> The baptised adult has already died and been reborn in ritual once before; it is clearly implied that his or her final death is nothing more than a birth to eternal life. Heaven is seen as a final reward.<sup>4</sup>

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Linda Kongnetiman MSW, RSW



# When a Child Dies:

Cultural Competency in Paediatric Palliative Care

Filipino

## An Educational Resource

# Filipino Perspectives



Alberta Health  
Services

## Filipino Perspectives

### **The Filipino community in Canada**

The Filipino community is the fifth largest visible minority group in Canada.<sup>1</sup> In 2001, 70% of Filipinos in Canada were foreign-born.<sup>2</sup> The Filipino community is growing faster than the overall population in Canada. Between 1996 and 2001, their population increased by 35% compared to 4% of population growth overall.<sup>2</sup> The majority of Canadians of Filipino origin belong to a Christian faith, with 81% identifying themselves as Catholic, 15% as Protestant or another Christian denomination, and 3% as having no religious affiliation.<sup>2</sup>

### **Afterlife beliefs**

Filipinos believe that children go to heaven when they die because they are innocent and without sin.<sup>3</sup> 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.<sup>4,5,6</sup>

Filipinos perceive heaven as a physical place.<sup>6</sup> Personal items are buried with the deceased for their comfort as they make their journey to heaven. Items such as razors, eyeglasses, needles and thread, coins in a wallet, and paper or pencils for messages are buried along with the deceased.<sup>6</sup>



## **Spiritual beliefs**

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.<sup>6</sup> Many Filipinos also believe that individuals can have two souls, one that goes to heaven or purgatory and one that remains on earth to watch over loved ones.<sup>6</sup>

It is important to note that Filipinos may be reluctant to identify traditional beliefs to westerners. These may include beliefs in animism, a faith in the existence of spirits and their power to influence the world of the living.<sup>6</sup>

## **At the time of death**

When someone from the Filipino culture dies in a hospital, it is important that family members be allowed to visit when they wish in order to ensure that their loved one will not die alone.<sup>5</sup>

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.<sup>5</sup>

## **Funeral**

White is worn to the funerals of children because it is believed that children are angels, who do not wear black. A combination of white and black may be worn when a younger person dies.<sup>5</sup>

In some cases, Filipinos may view cremation as an acceptable alternative to a traditional burial.<sup>5</sup>

## **Organ donation**

Traditionally, Filipinos consider organ donation as undesirable because of the importance of having the body remain intact for

burial. However, some Filipinos who adhere to the Catholic faith may view organ donation as helping others.<sup>5</sup>

## **Rituals**

Rituals related to death and dying are simpler and shorter for children than for adults in order to reduce the pain for parents.<sup>3</sup> Many of the rituals and customs related to death and dying are influenced by the Catholic faith and co-exist with traditional Filipino beliefs.

The traditional nine-day Novena is the most common ritual related to death and dying among Filipinos.<sup>5</sup> Prayer services are held each night following the death as a way of helping the soul's journey to heaven.<sup>6</sup> The nine days correspond with the nine basic virtues and the nine choirs of angels.<sup>5</sup> The body is watched over by family members during this time. In the Philippines, it is customary to keep the body at home; however, in Canada, the body is more often held at the funeral home during this time. On the ninth night, it is believed that the deceased returns to say good-bye. A feast is prepared with the favourite foods of the deceased. There is a place set for the deceased loved one so that he or she may also eat. A memorial service is held again 40 days after burial.<sup>5,6</sup>

Grief is expressed in different ways depending on socio-economic status. Filipinos 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.<sup>4</sup>

## **Mourning practices**

Rituals and mourning practices 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 is yet another ritual that some Filipinos adhere to.<sup>6</sup>

Cleansing rituals are performed, whereby one washes if they have come in close contact with the body during the service. Washing one's face from a bowl filled with a mixture of vinegar and water after the service helps to purify oneself.<sup>6</sup>

In the Philippines, family members may wear black clothing, a black arm band or a pin for up to a year after a loved one's death.<sup>6</sup>

### **Grief process**

The graves of the deceased are usually visited by families on holidays and anniversaries. On the first anniversary of the death, family members normally have a ceremony that honours their loved one.<sup>6</sup>

In the Catholic tradition, some families celebrate the deceased through All Saints or Souls Day, when a picnic by the grave takes place. 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. Children are taught that spirits exist for various purposes, and many Filipinos believe that children often have a role as mediums who receive messages from the dead.<sup>6</sup>

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# When a Child Dies:

Cultural Competency in Paediatric Palliative Care

Arab Muslim

## An Educational Resource

### Arab Muslim Perspectives



Alberta Health  
Services

## Arab Muslim Perspectives

### **The Arab community in Canada**

About 265,500 people of Arab origin live in Canada, accounting for less than 1% of the total Canadian population.<sup>1</sup> In Calgary, this community accounts for almost 5% of the visible minority population.<sup>2</sup> In 2006, among foreign-born Arabs, Lebanese (24%) and Egyptians (13%) were the two main groups in Canada.<sup>3</sup> Over half the Arab population living in Canada were born outside the country.<sup>4</sup> It is projected that by 2017 the Arab community will be one of the fastest growing communities in Canada.<sup>5</sup>

It should be noted that not all Arabs are Muslim and not all Muslims are Arabs. In fact, the Arab community in Canada is evenly split, with half reporting belonging to a Christian group and the other half identifying themselves as Muslim.<sup>4</sup>

### **Meaning of death**

Within the Muslim culture, death is viewed as an act of God which is not to be questioned by humans.<sup>6</sup> Death is seen as a return to God where the ugliness of the present world gives over to the beauty of the afterlife.<sup>6</sup> Death is accepted as part of a divine plan, and Muslims are often encouraged to talk about death and reflect upon their own experience.<sup>7</sup>

### **Afterlife beliefs**

Muslims believe that all children are innocent and that after death their souls will ascend directly to paradise. This is also the case for stillbirths and miscarriages, in which case these babies are given names, bathed, and shrouded.<sup>7</sup>

### **Dealing with the news**

Many Muslim families do not wish their dying relatives to be told about their prognosis; rather, they prefer that this information be communicated to an immediate relative, who may or may not disclose it to the patient.

### **Rituals at the time of death**

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.<sup>8</sup>

### **Rituals after death**

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.<sup>9</sup>

Once death occurs, it is undesirable to leave the body alone. If a death occurs in the hospital, Arab Muslims prefer that staff not wash the body. A staff member may turn the head toward the right shoulder, straighten the legs and stretch both arms by the sides. A family member will be responsible for the following after death: turning the body toward Mecca, closing the mouth and eyes,



straightening both legs, placing the arms by the sides, bathing and covering the body, and immediately announcing to relatives and friends that the individual has died.<sup>8</sup>

When someone dies within the Muslim culture, males always bathe males and females always bathe females.<sup>10</sup> 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.<sup>8</sup> In the immediate post-natal period, the mother should not perform the bathing of the deceased baby due to her experience of loss. The ritual is considered an act of worship, and the father or another family member may wish to undertake the bathing.<sup>7</sup>

The body is then wrapped in plain white cotton. During these procedures, family members may wish to read passages of scripture or to make lamentation.<sup>11</sup> 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.<sup>8</sup>

Hospitals' common 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.<sup>12</sup>

### **Grief process**

Grief is shown by way of loud crying, wailing, and lamenting. Health care professionals may need to find private spaces to accommodate families in expressing their grief. The death rituals for Muslims form the final bond between the deceased and the bereaved.<sup>7</sup>

## **Funeral**

In Islam, cremation is not allowed; every part of the human body including the umbilical cord and placenta should be buried.<sup>12</sup> There is a belief that two angels and Satan will be close at hand and that God will send the believers to heaven.<sup>8</sup>

The purpose of the funeral is to prepare souls for the Day of Judgment.<sup>8</sup> 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 person 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.<sup>13</sup>

With miscarriages and stillbirths, there is no formal funeral prayer; however, the family is remembered in individual prayers.<sup>7</sup>

## **After the funeral**

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 this time.<sup>13</sup> Three days after burial, a ceremony is held at the Mosque with friends and relatives praying while a religious leader reads from the Koran. A prayer, a blessing at the house and reading from the Koran will occur at this time.<sup>8</sup> One year after the death, there is another remembrance and prayer ceremony.

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**Alberta Health  
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# When a Child Dies:

Cultural Competency in Paediatric Palliative Care

South Asian

## An Educational Resource

# South Asian Perspectives



Alberta Health  
Services

## South Asian Perspectives

### **The South Asian community in Canada**

Although South Asians have a long history in Canada, their growth has been fuelled by recent immigration. In 2006, South Asians were the largest visible minority group in Canada. With a population of over one million, they represented approximately 25% of all visible minorities, or 4% of the total population in Canada.<sup>1</sup> The vast majority of South Asians in Canada reported being of East Indian (69%) or Pakistani (9%) origin, with smaller numbers reporting Sri Lankan, Punjabi, Tamil or Bangladeshi origins.<sup>2</sup> Other South Asians reported countries of birth including Guyana, Trinidad and Tobago, Fiji, the United Republic of Tanzania, Kenya, and the United Kingdom. In 2006, 29% of South Asians were Canadian born.<sup>1</sup>

The majority of South Asians in Canada are of the Hindu faith. The Hindu faith encompasses a diversity of beliefs and practice. It is difficult to make generalizations about Hindus' beliefs and practices because these are dependent on class, education and religion.<sup>3</sup> In addition, because Hindus may not be able to carry out certain traditional rituals within Western cultures, they may conform to practices which differ greatly from their own fundamental religious beliefs, values, and practices.<sup>3</sup>

## Meaning of death

The death of a child within the Hindu faith is viewed as Gods' will.<sup>4</sup> Hindus believe that things happen because they are predestined and that actions in the present life are the result of sins in a past life.<sup>4</sup>

Most Hindus share the same beliefs regarding death and dying, with the most important rituals surrounding the time of death.<sup>3</sup> Death is viewed as rebirth, the transition to another phase of the life cycle.<sup>3,5</sup> Life begins before birth and continues after death. There will be multiple cycles of death and rebirth (reincarnation) until the soul's final karmic passage into "nirvana." 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.<sup>3</sup> The lower an individual is within the caste system, the more rituals are needed in the death and rebirth process to move toward tranquility.

Within the Hindu culture, death is consciously prepared for throughout life to help ensure a good death. Preparation for a good death through prayer and rituals is of the utmost importance as a bad death is feared.<sup>3</sup> Righteousness, morality, passivity and sacrifice are highly valued and inform family roles and individual conduct. Activities of one's life are guided by religion and structured around rituals. It is important that rituals are followed as prescribed to ensure that an individual is not reborn to the same life or karma without progressing.<sup>3</sup>

A good death is 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.<sup>3</sup> Preparations for a good death include keeping a small container of Ganges water at home to be placed on the lips of the deceased. A good death requires completion of the customary rituals throughout the process. Signs of a good death



include a shining forehead and peaceful expression.<sup>3</sup> 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 soul of the deceased and family cannot be set free.<sup>3</sup>

### **At the time of death**

When working with Hindu families, it is most important to try to facilitate a “good death” for the loved one.<sup>3</sup> This is achieved if the family is actively involved in their loved one’s care and rituals are performed at death. The family’s active involvement in the decision-making process is seen as crucial since death is viewed as a family and communal process.<sup>4</sup>

If someone is dying in hospital in India, the patient is often taken home so that proper rituals may be performed.<sup>3</sup> At the time of death, it is important that the dying person is placed on the ground or as close to the ground as possible as this helps the spirit to be absorbed into the ground.<sup>5</sup> 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.<sup>6,7</sup> 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.<sup>4</sup>

Some families may be reluctant to agree to a post-mortem on the body.

## Rituals

The caste system and status of women within the Hindu culture have a large impact on rituals and beliefs related to death and dying.<sup>8</sup> For example, the illness or death of a female baby is considered as less of a loss than that of a male infant.<sup>5</sup> This is particularly the case in the lower castes.

After a death, readings from the Bhagavad Gita (holy scriptures) are conducted by Brahmin priests or elders from the upper caste community.<sup>5</sup> A relative then bathes and anoints the body, males washing males and females washing females.<sup>4</sup> After a tulasi (basil) 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.<sup>5</sup> These preparations are vital to ensure purity surrounding rebirth and the final transmigration of the soul.<sup>5</sup>

## Funeral ceremonies

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.<sup>5</sup>

After death, funeral arrangements must be made as soon as possible to ensure repose of the departed soul.<sup>4</sup> Funerals are open to the community and are often flexible, spontaneous, and chaotic.<sup>4</sup> After the priest identifies the time for the funeral, mourners gather at the house and bow before the cloth-wrapped body on the floor.<sup>4</sup> Mourners traditionally wear white.

The priest then chants and women gather to take part in the expected crying and wailing.<sup>4</sup> 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.<sup>9</sup>

Cremating the deceased less than 24 hours after death is crucial. It is important to keep in mind that if this does not occur, it can cause great distress for the family.<sup>4</sup> 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.

### **After cremation or funeral**

Hindus believe that after cremation, the soul travels through a variety of temporary heavens or hells in order to release sins. This process is influenced by offerings made by family members.<sup>3</sup> 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 their loved one's ashes in a local river. This process ensures the spiritual salvation of the deceased.<sup>4</sup> Ceremonies are held again after 12 months.

After someone dies, a mourning period of 40 days follows. 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 grief.<sup>4</sup>

The bereaved are expected to 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.<sup>4</sup> As the days progress, there is less intensity in emotional responses. Family support through the male lineage also plays a large role in the grief support and healing process.<sup>4</sup>

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