

# Cultural Competency in Paediatric Palliative Care Research Report

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*In loving memory of*  
*Tehilla and Sefanja*


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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; Gatrad & 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 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.

## Background

Calgary, like other Canadian cities, is culturally diverse with an increasing visible minority population. Statistics show that nearly 6.2 million people in Canada were foreign-born (Statistics Canada, 2006). These newcomers arrived from countries in Asia and Africa, among others. 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 Canada Council of Social Development (2000) research report, one-third of immigrants arriving in Canada are children and youth under the age of 25.

The immigration of people from Asian, Middle Eastern, Caribbean, and African countries with different cultural and religious values, beliefs, and traditions has resulted in an increased and growing need for culturally sensitive end-of-life care services. Within a multicultural environment, it is imperative that nurses and other health care professionals understand the care practices of a variety of cultures (Liang & Zoucha, 2002). The Alberta Children's Hospital Paediatric Palliative Care & Grief Support Program has identified a growing population of children and families from diverse backgrounds within their clinical service. These children and families, when needed, receive palliative services; however, many of these families do not go on to access the bereavement services offered when their child passes away.

The objectives of this study were to


- Gain knowledge and increase understanding of the values and beliefs of various ethno-cultural

communities as a child is dying and after a child has died.

- Examine the level and quality of palliative care received when a child is dying as perceived by bereaved parents from various ethno-cultural communities.
- Gain an understanding of the roles and functions of specific ethno-cultural community organizations and the social support provided to families.
- Explore the level of health care professionals' understanding of diverse cultures when providing paediatric palliative care to families.
- Determine the learning needs of health care professionals in order to provide culturally competent (Appendix A) paediatric palliative care.

This study represented the shared interests and efforts of the Palliative Care and Grief Support Services and the Child and Women's Health Diversity Program at the Alberta Children's Hospital. These combined programs desire to address the needs and challenges that families from various ethno-cultural communities and healthcare professionals face when caring for children who are dying, or have died.

Grounded theory was selected to explore and understand cultural competency in paediatric palliative care as well as to develop theoretical formulations that will contribute to a substantive theory about the phenomenon under study. This approach is useful in the identification of relevant concepts and their relationships in describing a phenomenon about which little is known or in expanding on existing knowledge about a phenomenon. Since there is a lack of empirically



tested theoretical models exploring cultural competence in paediatric palliative care, it would have been premature for the research team to investigate this research topic using a quantitative methodology. Therefore, it was the intention of the research team to focus on theory building and creating an in-depth understanding of cultural competence in paediatric palliative care through the use of a qualitative method that included two components, interviews and focus groups.



## Literature Review

### Cultural Competence

Since Canada is a multi-cultural and multi-ethnic society, health care institutions must adapt to meet the needs of newcomers. Cultural competence as described by Feser and Bernard (2003) encompasses a set of values, behaviours, attitudes, knowledge, and skills which allow care providers to offer patient care that is respectful and inclusive of diverse cultural backgrounds. If the patient and family carry a cultural perspective that differs from that of professional care providers, the process of assessment and intervention can become complex (Hall, Stone, & Fiset, 1998). 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.

Social, cultural, ethnic, religious, and philosophical values and beliefs can have a large impact on one's response to death and grief (Rando, 1984). Rituals surrounding death and bereavement help to define the meaning of life and death, and are influenced by the role of the deceased and cause of death (Rosenblatt, 1997). Rituals also define the role of the bereaved and their interaction with others in the community. It is important to note that even those who do not usually adhere to traditional practices may do so in times of crisis, such as death and bereavement. Those from western cultures may find some practices 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 & Davies, 2002).

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). Crawley, Marshall, and Koenig (2001) described great diversity within ethnic and cultural groups, with individuals not always sharing the same cultural traits, values, beliefs, and practices. It is crucial that individual or sect variation within each cultural group is taken into account to avert the danger of stereotyping (Waddell & McNamara, 1997). Waddell and McNamara (1997) caution that stereotyping may prove harmful and that culture must be interpreted in the context of a patient's history, family constellation, and socio-economic status. In order to ensure culturally competent paediatric palliative care, health care professionals should also be aware of how the life experiences of culturally diverse groups have been shaped by a wide variety of historical, political, and socio-economic circumstances (Munet-Vilaro, 2004).

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; Gatrad & Sheikh, 2002; Koenig & Davies, 2002). To truly adhere to the

philosophy of palliative care, a focus on cultural competence is crucial.

## **Palliative Care**

Until recently, the benefits of palliative care have been generally neglected; however, there has been a dramatic increase in awareness with advances in this area of medicine (Auger, 2000). 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. Palliative care is a philosophy of care that is patient centered and family focused (Cairns, Thompson, & Wainwright, 2003; Corr, Nabe & Corr, 2006). Cairns et al. (2003) described palliative care as focusing on physical, emotional, social, spiritual, and practical concerns with patients participating in informed decision-making. Palliative care and its psychosocial focus also aims to prepare individuals and families for the dying process, as well as supporting those involved in their loss, grief, and bereavement processes (Auger, 2000; Cairns et al., 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).

Most palliative care programs serve adults (Himmelstein, Hilden, Boldt, & Weissman, 2004). Paediatric palliative care is a new field that only recently has received the attention of researchers and academics (Koenig & Davies, 2002). Wolfe, Klar, and Grier (2000) suggested that more work is needed to address the gap 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 hospital, hospice, or home setting. Currently, efforts are underway to expand paediatric palliative care services and educate health care

professionals on the crucial importance of providing palliative care for children (Kastenbaum, 2004; Palliative Care Leadership Centers and Centre to Advance Palliative Care, 2004).

## **Paediatric Palliative Care**

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). A child's death disrupts the natural order of the life cycle in most industrial societies. It is the fact that a child has died that makes it profoundly different from other deaths (Arnold & Gemma, 1994).

Similar to adult palliative care, paediatric palliative care is a philosophy of care focused on the enhancement of the quality of life for a child and family. 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" (Pediatric Palliative Care Special Interest Group, 2001).

The death of a child is managed differently in paediatrics than in adult medicine. As a result, there are a number of differences between adult palliative care and paediatric palliative care. The causes of death in children are varied, and the pathways to death are more complex and unpredictable. There is tremendous diversity encountered with respect to age, developmental level, and disease process, which makes the task of prognostication difficult. In addition, deficiencies in knowledge of the fatal diseases of childhood and the complexity of children's illnesses create

difficult dynamics for the care providers. Wolfe, Klar, and Grier (2000) noted that the lack of developmentally appropriate methods for assessment and management of symptoms can create further challenges in paediatric palliative care.

Traditionally, palliative care requires giving up curative interventions, a step for which the family may not be ready. Parents and care providers are forced to make the impossible choice between interventions directed to cure or those directed to comfort the child (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 are 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.

A crucial component in the delivery of effective 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 care. However, the philosophy of palliative care can be jeopardized when families feel that their customs, needs, and wishes were not attended to, understood, or incorporated into their child's care. Such experiences have the potential to become a large part of their lifelong grief journey (Field & Behrman, 2003).

## **Culturally Competent Paediatric Palliative Care**

Many researchers (Doorwnbos & Schim, 2004; Feser & Bernard, 2003; Koenig & Davies, 2002; Turner, 2002) have recognized the need to increase cultural competence within palliative care. Progress has been made towards understanding the relevance and importance of cultural competence in end-of-life care for adults; however, there still remains a gap in the literature when addressing paediatric palliative care (Kagawa-Singer & Blackhall, 2001; Koenig & Davies, 2002). 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 is evident. As identified by Braun and Nichols (1997) only a small amount of information is available for health care professionals relating to diverse cultural rituals and beliefs involving death and dying practices. This paucity of information is of critical concern when dealing with dying children and their families as gaps in knowledge and sensitivity compromise paediatric palliative care and bereavement support.

An individual's ethno-cultural background influences all aspects of health care, particularly end-of-life care (Saiki-Craighill, 2001). Culture influences aspects such as the meaning ascribed to illness and the death of a child, the language used to discuss illness and death, the symbolic value placed on a child's life and death, the lived experience and expression of pain and suffering, the appropriate role of health care providers to assume care of the body after death, and expression of grief (Koenig & Davies, 2002; Saiki-Craighill, 2001). Cultural and religious differences also play a crucial role in understanding family obligations, community responses, the proper conduct of physicians and other health care workers during the illness, the extent to which the

dying process should be anticipated and planned, and if dying should be a matter of fate (Turner, 2002). Saiki-Craighill (2001) identified a need for research to determine how mothers and fathers in different cultural and religious groups cope with dying and the death of children.

In the efficient delivery of palliative care, communication, understanding, and respect for culture and religion have been identified as vitally important. Hebert (1998) emphasized the need for a culturally sensitive approach, rather than a mainstream model when providing care to dying children. Kagawa-Singer and Blackhall (2001) and Lewis, Brecher, Reaman, and Sahler (2002) have suggested that a number of issues be considered when providing culturally competent end-of-life care. These include communication and language barriers, religion and spirituality, patient and family involvement in decision-making, the appropriate display of emotion, gender roles, generational family roles, the concept of the afterlife and how it is prepared for, funeral and burial customs, and the duration of mourning.

The needs of patients and families vary depending on their culture, level of acculturation, education, social status, immigration status, and the generations of the family that are involved. Considerable research shows that while providing paediatric palliative care, health care providers need to develop an ongoing and trusting relationship with the families of terminally ill children to ensure an understanding of the family dynamics as well as how various cultures differ in their grieving process. Knowledge of the cultural background of the family is crucially important in planning for and providing bereavement care following the death of a patient (Srivastava, 2007). Though much is known about culture and bereavement generally, research specific to children in a multicultural setting is lacking (Davies et al., 1998). Hebert (1998) described

that current paediatric palliative care practices are based on Euro-American theories of grief and loss aimed at facilitating familial adaptation through the creation of memories of the deceased child. The influence of cultural components on bereavement patterns are often ignored, and little attention has been paid to the suitability or appropriateness of these practices for the ethnic population. There is a need for a thorough understanding of the cultural factors that influence each family's bereavement experience. 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.

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

There are numerous barriers to the provision of culturally competent paediatric palliative care. These include attitudinal, clinical, ethical, educational, financial, institutional, regulator, and linguistic factors (Rushton, 2001). A major barrier in the provision of paediatric palliative care is a lack of understanding surrounding hospice philosophy in ethno-cultural groups (Hills & Penso, 1995; Koenig & Davies, 2002). Firth (2001) suggested that the ethnic minority population's use of palliative care services was disproportionately low because the provision of care is based on western models. Turner (2002) noted that palliative care practices in western cultures focus on autonomy while the practices of other cultures do not share this view. Lack of information and education on bereavement models related to various ethno-cultural communities after the death of a child are additional barriers.

It is evident within the literature that 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 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) 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 health care providers cannot communicate with patients and families because of a language barrier, palliative care may not be provided effectively, no matter how culturally competent health care professionals become. 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 the needs of ethno-cultural communities.

Knowledge of customs and traditions as well as of individual expressions of grief within groups from a variety of ethno-cultural backgrounds will help to provide more inclusive palliative and bereavement care for children and their families. The need for culturally sensitive end-of-life care

services is growing. Gatrad and Sheikh (2002) identified that respect for all faiths and cultures is crucial if health care professionals are to deliver care that is truly patient-centered. A fundamental concept of competent care is the understanding and integration of the child and family's strengths. To ensure this process, their cultural, ethnic, and religious values must be honoured and incorporated within all care.





## Methodology

This study used a grounded theory approach to explore and understand cultural competency in paediatric palliative care. This research methodology was chosen because of its usefulness in theory building and the possibility of creating an in-depth understanding of cultural competence in paediatric palliative care.

### Individual Interviews

The first research component consisted of individual face-to-face, semi-structured interviews which were conducted with bereaved parents from the Chinese, South-Asian, Filipino, Middle-Eastern, Hutterite, and Sudanese communities (19 participants), health care professionals (13), key informants from various ethno-cultural communities (6), and religious leaders (8). The parents and health care professional participants were identified through the Grief and Palliative Care Program at Alberta Children's Hospital. Religious leaders and key informants were recruited by the Child and Women's Health Diversity Program Coordinator.

Participants were interviewed by trained interviewers, who utilized a semi-structured interview guide (see Appendix B). Due to the sensitive nature of the topic and the interview questions that were explored, the interview guide was developed utilizing experts in the areas of cultural competency, death and dying, and qualitative research. A review of the literature and previous research interview guide development also informed the process. Interviews took about two hours to complete.

All interviews were taped after informed consent was obtained (see Appendix C). The tapes were then translated if necessary and transcribed.

The interview transcripts were imported into a qualitative data management program (ATLASit 5.0).

### Focus Groups

In the second research component, focus groups were conducted to gather information regarding the perception of grief and loss in various ethno-cultural communities, particularly regarding paediatric palliative care and paediatric death. Seven focus groups in total were held over a 6-month period, with specific groups representing the Middle Eastern, Sudanese, Filipino, Hutterite, South Asian, and Chinese communities. The focus group participants were recruited through key informants in the specific ethno-cultural communities and the Child and Women's Health Diversity Coordinator. For the Hutterite community, the focus group was held on a colony and participants were recruited through a bereaved parent. An interpreter was present for the Chinese, Sudanese, and Middle Eastern focus groups. All participants involved in the interviews or focus groups were given a list of community resources for psycho-social support if desired at any point during the research process (see Appendix D) and were also informed of the right to discontinue their involvement in the research at any time.

The Child and Women's Health Diversity Program Coordinator and two research assistants conducted the focus groups. Groups were tape recorded and transcribed verbatim. The transcripts of the focus groups were then imported into a qualitative data management program (ATLASit 5.0).





## Participant Demographics

Demographic data have been broken down according to the type of participants (bereaved parents, ethno-cultural focus groups, key cultural informants, religious leaders, and health care professionals). Table 1 presents a summary of participant demographics; for a more detailed description of participants, see Appendix E.

Of the 19 bereaved parents interviewed, at least 7 were male and 8 were female (4 participants did not provide their gender). All were married, with the exception of one who was single and one who was widowed. Their age ranged from 18 to 50.5, with an average of 37. The ethno-cultural background of the participants was varied including Hutterite, Afghan, Chinese, Cambodian, Filipino, Burmese, Pakistani, and Ismaili Muslim. Participants spoke a similarly wide range of languages (Persian, Chinese, Cambodian, Filipino, Burmese, English, Urdu, Punjabi, German, Gujarati, and Ibanag) and identified their religion as one of the following: Islam, Buddhist, Christian, Roman Catholic, or Protestant. They had been in Canada for an average of 13 years.

Forty six participants made up the ethno-cultural focus groups. Of the 41 who identified their gender, 19 were male and 22 were female. The average number of languages spoken for all focus group participants was just over two, and they had been in Canada for an average of 21.5 years. The Chinese focus group was made up of 6 females, 2 from Hong Kong and 4 from China. Cantonese was the only language mentioned that was spoken and no religious beliefs were identified. The average number of years they had been in Canada was 14. The Hutterite focus group was composed of 1 male and 4 females, who spoke an average of two languages and had been in Canada for an average of 44 years. Hutterite

was cited as both their ethno-cultural background and religion. There were 13 participants in the South Asian focus group, all of whom were males. Participants in this group spoke Punjabi, English, Hindi, or Urdu and were either of Hindu or Sikh faiths. Their ethno-cultural background was Indian and they had been in Canada for an average of 19 years. The Sudanese focus group included 9 females. On average, these participants spoke three languages and had been in Canada for 4.5 years. They identified their faith as either Christian or Catholic faith. The Filipino focus group had 4 male and 2 female participants. They spoke an average of three languages, including English and various Filipino dialects. The average number of years they had been in Canada was 30, and all were Catholic. Two separate Middle Eastern focus groups were conducted, with a total of 7 participants. At least 1 male and 1 female participated. Only one language was spoken on average, and they were Muslims. The average number of years they had been in Canada was 18.

Fourteen members of the various ethno-cultural communities were interviewed, 6 were key informants and 8 were religious leaders. The key informants were from Hutterite, Iraqi, Pakistani, Chinese, and Sudanese backgrounds and identified their religions as Hutterite, Islamic, and Christian. They spoke 3.5 languages, on average, including German, English, Urdu, Punjabi, Sardiki, and Hindi, and they had been in Canada for an average of just over 18 years. Of those who identified their gender, 3 key informants were male and 2 were female and 4 religious leaders were male. The religious leaders were of Indian, Hutterite, Cambodian, Filipino, and Pakistani backgrounds, and they identified their religion as Hindu, Christian, Buddhist, Roman Catholic, Islam, or Sikhism.

The final group of participants were health care professionals. Of the 13 professionals interviewed, all but one was female. On average they had been involved in palliative care work for 14.5 years, worked in a hospital setting for just under 8 years, and worked for the Alberta Health Services for just over 10 years. Most were Canadian born, and most spoke only English, although a few also spoke Gaelic, French, or Arabic.

Table 1: Summary of participant demographics

	<b>Bereaved Parents</b>	<b>Ethno-Cultural Focus Groups</b>	<b>Key Ethno-Cultural Informants</b>	<b>Religious Leaders</b>	<b>Health Care Professionals</b>
<b>No. of participants</b>	19	46	6	8	13
<b>No. of males</b>	7	19	3	4	1
<b>No. of females</b>	8	22	5	0	12
<b>Ethno-cultural background</b>	Hutterite Chinese Filipino Pakistani Cambodian Afghan Burmese Ismaili Muslim	Hutterite Chinese Filipino Sudanese Indian Iraqi Hong Kong	Hutterite Chinese Pakistani Sudanese Iraqi	Hutterite Pakistan Filipino Cambodian Indian	Canadian French-Canadian German Ukrainian Irish British Czech Italian Scottish Dutch
<b>Average no. of languages spoken</b>		2.3	3.5		
<b>Languages spoken</b>	English Punjabi Urdu Filipino Persian Chinese Cambodia, Burmese Gujarati Ibanag	English Punjabi Urdu Filipino Cantonese Hindu	English Punjabi Urdu German Hindu	English French Arabic Gaelic	
<b>Religion</b>	Muslim Christian Protestant Catholic Buddhist	Muslim Christian Hutterite Catholic Hindu Sikh None	Muslim Christian Hutterite	Muslim Christian Hindu Catholic Buddhist Sikh	
<b>Avg. no. of years in Canada</b>	13.4	21.6	18.3		

## Results

A key objective of this research was to explore the different beliefs, values and practices surrounding death, especially paediatric death, among various ethno-cultural groups. Three major sets of themes related to this objective, namely afterlife belief, attitude toward the death of a child, and dealing with grief, emerged from the interviews with bereaved parents, key informants, and religious leaders as well as from the focus groups.

### Ethno-Cultural Comparisons Regarding Death and Dying

#### Afterlife Belief

When asked about the whereabouts of a deceased child, a common afterlife belief that seemed to be held throughout all the various ethno-cultural and religious groups was that the child will go to heaven or paradise:

Chinese FG<sup>1</sup>: *The child will go to heaven.*

Hutterite RL: *We know the kids are direct in Jesus' arms.*

South Asian parent: *Well she's up there in heaven.*

Sudanese FG: *They are angels.*

Middle Eastern parents: *She is in paradise.*

As demonstrated by the following excerpts, children were believed to automatically enter heaven regardless of religion because, unlike adults, they are innocent and without sin:

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<sup>1</sup> Participants are identified by their ethno-cultural group followed by either FG (focus group), parents (bereaved parents), KI (ethno-cultural key informant), RL (religious leader), or HCP (health care professional).

Filipino FG: *For some, there's a belief of purgatory as well. In the Catholic belief, there is. But that's only for adults. Children always go to heaven, they're angels.*

Middle Eastern KI: *They would not see the hell ever, they are all to be with paradise because they do no fault, they did not mistake.*

Middle Eastern KI: *For children it is that, as they are innocent they will definitely go to heaven.*

Hutterite FG: *Any child in the outside would still go to heaven, whether it's in colony or not, because this child is without sin.*

Middle Eastern FG: *We believe every child, according to our religion doesn't matter if he's Muslim or not Muslim,...all of them go to the heaven.*

While the belief that deceased children go to heaven seemed to be the most common belief, some other beliefs were expressed. These included the idea that children go on to another life:

Chinese FG: *The child will get another life here on earth.*

Chinese parents: *We thought he would be reincarnated for a while.*

South Asian FG: *Very soon after the death the child would take re-birth, go to a better place.*

Sudanese parents: *She's in a better place and [is] no more.*

Several Chinese participants as well as one Buddhist from South Asia were unsure of where children go after they die. A Chinese focus group participant responded, "I don't know," a Chinese

parent said, “I have a hard time knowing what afterlife is,” another Chinese parent responded, “can’t answer that,” and a South Asian parent said, “I have no idea [where the child is now].” Finally, a participant in a Chinese focus group expressed the idea that “Dead is dead – no more.”

Another afterlife belief that emerged was that of an on-going relationship with the deceased child. This idea was presented in several variations, none of which was unique to any one ethno-cultural group. The two most common versions of this belief were to have the child in the heart/mind or to feel that the child is still around:

Middle Eastern parents: *She can’t go from our hearts, never ever.*

Chinese FG: *They can never forget that child... it is in their heart, in their mind.*

Sudanese parents: *She’s a part of our life, she’s always gonna be a part of our life and to pretend she didn’t exist, I won’t.*

Chinese parents: *A lot of times...we feel his presence.*

Middle Eastern parent: *She is with me all the time, even I can see her, she is always with me.*

Filipino Catholic RL: *Dying is not separation; dying is so much more of temporary separation but the child is still there, still alive.*

As well, a few participants felt that the child is helping:

Sudanese FG: *She can still keep an eye on us and take care of us.*

Sudanese parents: *We got this little guy now and we know that he’s got a big sister out there looking after him in everything that he does.*

Finally, there was also the belief that the parents will meet the child again one day, as stated by two participants as follows:

Middle Eastern KI: *It is said that when the children will go to heaven they will ask for their parents; therefore the parents will also go to heaven.*

Sudanese FG: *You who is alive pray that one day you are going to meet your child.*

### **Attitude Toward the Death of a Child**

The second set of themes that emerged in the research relates to attitudes toward the death of a child. When questioned as to why a child might die or what is the meaning of a child’s death, many participants from a variety of backgrounds (Chinese, Hutterite, Middle Eastern, Buddhist, Christian, Muslim, and Hindu) answered in ways that demonstrated a belief that life and death are out of their hands and under the control of a higher power. This attitude is exemplified by the following excerpts:

Chinese parents: *For me, I come from a Christian home, I believe that maybe it’s God’s will that she has to go...there’s nothing that we can do to prevent it.*

Hutterite parents: *If it shall happen that somebody shall pass or that a child shall pass, then it will happen and we can’t get around that....accepting the fact there is life and then there is death and it is not in our hands. The Lord gives life and he takes life.*

Hutterite parent: *I guess God wanted him more than we did.*

Middle Eastern FG: *The first thing according to our religion, is the same for... every Muslim belief, what Allah give to us he is able to take it back, doesn’t matter what age it is.*

Participants from all ethno-cultural groups, with the exception of Hutterites, commonly expressed the feeling that there is a reason or purpose for a child's death. For some, there was a belief that a child's death may be caused by the actions of a relative, such as "*quarrel[ling] between the husband and wife or maybe the parents or the uncles...the grandparent or the grandma curs[ing] the child*" (Sudanese KI). Similarly, another participant stated that "*some believe you must did something bad either in your past life or present life to have those awful things happen to you*" (Chinese parents). Somewhat more common was the thought that "*everything happens for a reason*" (Middle Eastern parents) and that there may be some positive aspects to the death. This idea is well represented by the following comment:

*Middle Eastern parent: When a child passes away, it has lots of meanings. You cannot explain it, but there are lots of reasons for it happening. It might change over your lifetime, it might change in the future, but it all has meaning. It is hard to accept that, but the reasons are always there. I have strong belief in that. If she is not with me, she still makes me a better person than I was not before that. More caring, more feeling for other people, more humble. When these things happen, it changes you and makes you a better person. It makes you think and not think about only yourself. It is hard, but it gives you lots of lessons too.*

Additionally, several participants from varying backgrounds indicated that they did not have an answer as to why their child died. One participant of Buddhist faith mentioned struggling because "*Buddha said if you do good you can get good;[so] why I did many good things and that happened to me.*"

One attitude that was evident only among participants from a Chinese background was that

one should try to forget about the child who died. One reason for this may be due to the previously mentioned belief that doing "*something bad either in your past life or present life [causes] those awful things to happen to you,*" which makes the parents of the child "*feel shame, they don't want to share, they don't want anybody else to know about it*" (Chinese parents). As a result, people generally pretend the child never existed. For example, friends do not attend the funeral, the child is not talked about nor are pictures taken of it, and another child of the couple may be referred to as the first child even if the one that had passed away was the first. Forgetting about the child is also seen as a way to "*forget about their unhappiness*" (Chinese FG). Another reason mentioned for not acknowledging a child's death is because it is perceived as bad luck that could be transferred to others (Chinese parents).

#### Rituals

The customs and rituals mentioned that occur when a child is dying and after he or she has died varied substantially among participants of different ethno-cultural backgrounds. According to the Chinese participants, "*if a child dies we are not doing a big ritual, a big ceremony*" (Chinese FG) and the parents do not attend the burial (Chinese parents). This seems to be in accordance with the previously mentioned tendency to avoid or forget instances when a child dies. The belief that "*it's better to pass away at home in your house, not outside*" (Chinese FG) was also referred to.

The traditions surrounding death described by those of the Hindu faith were somewhat more elaborate; however, no distinctions for children were mentioned. Shortly before a person dies, the person is transferred from the bed and placed on the floor so that the body can mix with the earth and the soul can go up. If this does not happen, it is believed that *mukti* (freedom) will not be



attained and the soul will wander, causing the cycle of re-birth to be interrupted (South Asian FG). It was also stated that “*God’s name should be said in every way, as there are many Gods according to our faith*” and that “*Srimad Bhagvat Gita should be read*”<sup>2</sup> (Hindu RL). After the person has passed away, *pitra-gayatri*<sup>3</sup> is done and prayers are said, sometimes all day and all night, so that the good deeds done by that person get transferred to him and his soul can find peace. Some people may also pray to give their good deeds to the deceased. Different rituals take place for those who have not had the thread ceremony<sup>4</sup>; for example they cannot be cremated and must either be buried or floated away on water (Hindu RL).

Within Sikhism, what is done with the body after death is different depending on whether a child or an adult has died. If it is a small child, it is buried, but older children (5 to 7 years old) are cremated the same as adults (Sikh RL).

According to a Muslim religious leader, when a person of this faith passes away, it is desirable to turn his or her face towards the Qiblah (the direction Muslims face during prayer) as well as to close his or her eyes and mouth because the

person is considered to be sleeping and unable to move his or her body. However, it is believed that once buried, the person will awaken and the body and spirit will be together again (Islamic RL). Another participant mentioned that “*the person has to be washed and buried as quickly as possible, because that is the best way*” (Middle Eastern parents). When a child who is less than 4 months old dies, the infant is taken by religious leaders to their centre where he or she is covered with a white cloth and put in a small box before being taken to the cemetery. At the cemetery, prayers are said, the body is buried, and then more prayers are said to ask for the forgiveness for the deceased and his or her family (Islamic RL). Afterwards, the leaders visit the family for a few days to inform them of what “*what the god said*” (Middle Eastern FG).

One Sudanese participant mentioned that many prayers are said after a person dies. He related one case of a Christian family in which a priest came to the hospital after the death to pray, the body was then taken to the cemetery and buried, prayers were said again, and more prayers were said once the family returned home (Sudanese FG). A key informant also stated that after a child has died, the parents no longer hold it, so an elder places it in the grave. As a final farewell, the parents throw some earth on the grave, three times if it was a boy that died and four times if it was a girl. It was also pointed out that the deceased are buried in the evening rather than in the morning (Sudanese KI).

## Dealing with Grief

Two main categories that emerged within the theme of “dealing with grief” were the expression of grief and bereavement support.

### Expression of Grief

Some participants mentioned talking and sharing feelings with others as a strategy to deal with grief;

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2 Srimad Bhagvat Gita is part of the Mahabharata. It is the teachings of Sri Krishna to Arjuna on the battlefield before the start of the Kurukshetra war. It is in Sanskrit and is commonly referred to as The Gita.

3 Pitra-gayatri is one of the Gayatri Mantras from the Rig Veda. It is a highly revered mantra in Hinduism.

4 The Thread ceremony or *jenayu do pooja* (sacred thread) ceremony is essential to the members of the three higher classes and marks a boy’s official acceptance into his varna. At this point he becomes “twice-born.” First, is the biological birth, which everyone goes experiences. Second is when a young boy or man seeks his spiritual identity by accepting spiritual teacher as father and the Vedas as mother. At the ceremony, he receives the *jenoi* (sacred-thread), generally worn for his entire lifetime. The thread is replaced at intervals, but never removed until a new one is put on.

however, the idea that these emotions should be limited or not openly expressed at all seemed more common. Those who supported the expression of grief included a Chinese family, a Filipino Roman Catholic religious leader, and a Sikh religious leader:

Chinese parents: *I totally believe in sharing... [it's] very helpful to talk about it... I would be in worse condition if I kept it in the whole time.*

Filipino Catholic RL: *Parents love to talk about their child... Depending on who's asking, if you are someone whom they do not know, they might try and be quite cautious, keep on guard, but if you are someone whom they trust, they will start laughing...they will even have fun because her or his life is good.*

Sikh RL: *Anyone can come and console them... can come to their home and talk to them for 3-4 hours, sorrow is lessened by talking with others.*

Comments indicating that expressions of grief were discouraged and that it is best not to talk about the death of a child were made by participants from five of the six ethno-cultural backgrounds with the exception of Hutterite and included those who identified themselves as of Christian, Roman Catholic, Protestant, and Islamic faiths. For some, it was seen as unacceptable to grieve openly:

Islamic RL: *Mourning is not allowed in Islam.*

Chinese parents: *Our culture is so much, everybody is introvert, they keep emotions inside, we don't talk about it.*

Filipino parents: *I think with our culture [Filipino Protestant] we don't want to see a parent cry.*

Others mentioned that grieving is allowed but only for a limited period:

Islamic RL: *We do cry, crying is ok, but there is a limit for it.*

Sudanese FG: *There's crying but not that much.*

South Asian FG: *In case of child's death, the grieving period is not too long, the mourning period is cut short as much as possible.*

For Muslims, the grieving period is restricted to three days “according to the practice of the Holy Prophet of Islam” during which time “friends and other family members visit them, console the family and share the time of sorrow with them and after three days come) back to normal daily routine” (Islamic RL).

There seemed to be two main reasons given for not talking about a person who has passed away or sharing one's feelings. The first is that doing so may be upsetting. According to one participant, “the friends and relatives will not mention it over and over again because it hurts to hear it” (Chinese parents). Similarly, a Filipino parent commented, “we are hiding our feelings like that. I'm not showing him [my husband] sometimes because I don't like him to be sad, same with him... he's hiding it.” It was also mentioned that during emotional times people “don't want to [talk] to anybody, they don't even want to talk to their own families, they just want to be left alone, peace of mind” (Middle Eastern parents). Another reason for not sharing one's grief is that a death is part of God's plan and part of life and as such it should be accepted without grieving. This attitude is evident in the following excerpts:

Chinese parents: *If your child dies you carry on and just carry on life, have another one, focus on another one, and just forget about it.*

Middle Eastern parents: *They [the community] don't expect you to grieve. They just expect you to forget about it and move on with life.... Just another child dying is part of life – get it over with.*

Islamic RL: *In Islam, it is recommended and preferable that the person should show... patience. This [the child] was God's gift and He has taken it back*

Sudanese FG: *They said the baby is the angel, you don't cry a lot. Like the God bring him and the God take him, you know nothing you can do.... Yeah that's why they say if it's a child you will not cry loudly, it's just like an angel.*

Similarly, another participant believed that “if you take [things] a little bit easier, it's easier for her to rise” (Filipino parent).

For several participants, another aspect that influenced grieving customs was gender. Mothers and fathers were both described to grieve after their child has died, but generally fathers are expected to avoid expressing their feelings. This was mentioned by participants from a variety of backgrounds, including Chinese Christian, Hutterite, Middle Eastern Muslim, and Filipino Roman Catholic, as demonstrated below:

Chinese KI: *But most of the mothers who care so much, the father not so seriously always. That's the situation in Hong Kong, in Chinese community.*

Hutterite parent: *Fathers are like the outside world – they are not as loud with their emotions as mothers are. They are more quiet and grieve inside more.*

Middle Eastern parents: *Fathers grieve very differently – they do it quietly and when you see them you wonder what they are thinking and wonder if they are a robot or something, because they don't show emotion that much. When they are praying, they can cry and they can show emotion, but outside they don't want anyone to see them.*

Middle Eastern KI: *The only difference is that mother shows more and father does not.*

Filipino FG: *We're hurting too of course, fathers are hurting, but we cannot just show it off. It's hard, it's hard.*

Filipino FG: *Maybe the problem is the intensity is similar, they both miss the child but the difference in expression is noticeable. The mothers more noticeable but fathers tend to keep it. They have to keep it.*

There was also some evidence from those of similar backgrounds that there is no “*difference between a father and a mother if a child dies, you can see the same thing, same feeling*” (Middle Eastern FG).

In addition, there were a few instances in which the gender of the child who passed away was described to affect the grieving process. One South Asian participant said that “*back home it is that the grief is not that intense for the girl child and it is more for the son*” (South Asian FG), and a Filipino Roman Catholic religious leader said, “*if it is a girl, maybe the mother will be stronger and if it's a boy the father might be very weak so it depends.*”

### Bereavement Support

The second category within the theme of dealing with grief is bereavement support. Four types of support were described: religious support, support from friends and family, support from the community, and support from health care providers.

Among participants from all backgrounds, religion seemed to play a major role in supporting those who are grieving. Some Hutterite parents described the Lord as their “*greatest help through these tough times*” to the extent that without belief in the Lord, “*there is no way you could bury two*



children and survive.” Expressions of this belief through spiritual readings and singing were also mentioned as “*the only things that can help us*” (Hutterite parent). Similarly, those from Muslim and Protestant backgrounds stated that religion, going to church, and faith in God have “*helped a lot with coping*” (Filipino parents). Some specific rituals that may help in the bereavement process, according to a Sikh religious leader, are to have the Guru Granth Sahib (holy book) recited in one’s home or to “*gather all your near and dear ones and take God’s name*” (Sikh RL). The comments made by the Chinese participants were a little more ambiguous, however. One Chinese parent felt that “*our lack of religion has made it tough*” because they didn’t have the comfort of “*knowing for sure he’s in a place of God,*” and another stated that “*Christians are very helpful, other religions like Tao or Buddhism did not offer much support*” (Chinese FG).

Religious leaders were also mentioned as an important source of support among those from most ethno-cultural backgrounds, with the exception of Chinese. From the interviews, it appears that the main role of a religious leader during times of bereavement is to comfort and console the family, pray for the deceased, and lead the funeral service. Religious leaders may provide support to families just by “*be[ing] with them in their saddest moments*” (Filipino Catholic RL), including being there to eat, talk and laugh with them, helping them overcome their burden and carry the weight of it, financial support, and acting “*sometimes as a resource, sometimes as a shoulder*” (Sudanese parents). Comfort may also be found in spiritual support. Hutterite participants as well as those who identified themselves as of Christian, Roman Catholic, Buddhist, and Islamic faiths indicated that religious leaders read from the bible, preach and “*try to keep the family close to the religion*” (Middle Eastern FG) in order to

console the family and help them understand their situation.

Religious leaders are often responsible for prayer prior to a death as well as after it occurs. Hutterite, Muslim, Christian, and Roman Catholic participants mentioned that religious leaders may come to the hospital if a child is going to die and say a final prayer or even anoint the child with holy water and holy oil because it is believed that this will provide “*God’s blessing to go to heaven if possible*” (Middle Eastern KI). After death, a Hindu religious leader in India may visit families to “*recite 10000 gaitari mantras, then to stay there the whole day, wash all our clothes, change Janayu, do pooja*” (Hindu RL), and a Sikh religious leader may do path in a family’s home (Sikh RL). Related to prayer is the religious leader’s role in leading the funeral service as cited by Hutterite, Christian, Roman Catholic, Buddhist, and Muslim participants. However, for Sunni Muslims, “*if the religious leader is not there, it does not matter as anyone can lead a prayer*” (Middle Eastern KI).

Some bereaved parents described the type of religious support they received in hospital. For a Hutterite, a Chinese Buddhist/Christian, and a South Asian Buddhist Christian family, this mostly involved the hospital chaplain looking in on their child, saying prayers, reading poems, and singing. For one Muslim family, the head of the congregation came to the hospital after their child passed and performed a small ceremony.

Another major support, emotionally and in terms of everyday needs, was that of family and friends. This was evident throughout all the various ethno-cultural groups and is demonstrated by the following excerpts:

Chinese FG: *Other family members will support by offering babysitting, shopping, money, and support for the family emotionally.*

Middle Eastern parents: *They grieve, they cry. The huge family comes there.... being there for me and helping me out with my kids. I can go out and do something else and they will babysit for me. When I am grieving, they are there for me to listen and they are a shoulder to cry on.*

Middle Eastern parents: *Friends and relatives are supporting us. They come here and spend time with us.*

One participant mentioned that in Sudan relatives will come and stay with the family for as long as they can, up to four months, and in Canada they may visit for at least one month.

The community helps families deal with grief in much the same way as extended family and friends, through “*emotional support...and sometimes financial support*” (South Asian FG). For example, within the Muslim community during the first three days after a death, the community provides the family with food and “*come[s] to the house and say okay God bless you...and they read some of the Koran*” (Middle Eastern parent), within the Filipino Roman Catholic community, food is also brought and “*the community does get together for prayers and they express themselves through music*” (Filipino FG), and for the Sudanese, the “*community will usually be around to console the parent, but sometimes they provide...service, they clean the house, they make food, they wash clothes...this is the work of the community providing to those who lost dear ones, especially in the case of children*” (Sudanese KI). One parent from an African Islamic background described a routine within some hospitals that patients could voluntarily sign up for in which community leaders visit patients weekly “*just to let them know we’re here, is there anything we can do for you, to say some prayers with them, just to give them that community support.*”

Support from health care providers was also mentioned as something that helped families deal with grief. One participant recounted, “*after my daughter passed away, I got so many cards [from people from the hospital] and I went to the Memorial in the chapel and that helped me a lot*” (Middle Eastern parent).

Some other ways of dealing with grief that came up during the interviews were to do something to make the deceased child’s life meaningful, such as “*make a donation and put his name on the donor wall*” (Chinese parents) and “*donate some money to maybe the needy children or like Buddhist temple*” (South Asian parents) or visit the gravesite (Filipino Catholic RL).

In regard to professional bereavement support following a child’s death, there were diverse opinions, with most strongly for or against, and others neutral. For example, an African parent said, “*I think it’s an individual thing, I think some people need it and others don’t.*” Several participants felt that it would be helpful to talk to a professional about a child’s death. Hutterite parents, for example, commented, “*we can solve things by going and seeing someone*”; however, there were differing views regarding who the professional should be. One Chinese focus group participant stated that because “*Chinese have a hard time expressing their feelings and friends and family have a hard time talking to the family, so social workers, counsellors would be helpful.*” On the other hand, a Sudanese participant advocated that the counsellor be “*within the community because some of the thing that touches... is about the culture...If you knew the background of the person, you will be able to give a better counsel by referring to other thing at home and by referring to other thing that are here*” (Sudanese KI). Similarly, a Filipino participant stated that “*a counsellor, a nurse or a psychiatrist, they will all help, but if you*

*are asking me whom among all these people [is] better, the language, the culture is very important” (Filipino Catholic RL).*

Although there seemed to be some support for professional counselling, most participants stated that they would rather not attend. One reason given for this response was that it was not necessary to talk to professionals because there are other supports in place, especially within the community. Those that held this view included Middle Eastern Muslim, Chinese Christian, and South Asian participants. Their thoughts are presented below:

*Chinese KI: They don't really ask a counsellor to ask for any counselling help or anything...I think it's a cultural thing, yeah. Only close friends or relative help them.*

*Middle Eastern FG: Counselling – no problem. We be open heart to talk. Muslims are very connected. I don't believe social workers add to it. Maybe it's good for some culture, but our culture, everyone is here.*

*Middle Eastern parents: In our country or in our religion, friends and relatives do this. We don't talk to someone who is a grief counsellor. Older people who are friends or relatives talk to us.*

*South Asian FG: No, they will not like it that the grief counsellors should visit them, and they share their grief. But if it is an isolated family, then they will have to share it.*

Many of the Hutterite focus group participants felt that “Christians don't need counselling because [they] depend on the Lord” through spiritual readings, singing, and talking with their ministers. The final substitute for professional support that was mentioned was personal strength. For example, a Chinese parent explained, “we are more

*independent in a sense, we take it and we deal with it. I mean that's how I was brought up, I deal with things my way you know and then this is something I deal with by myself and take it a day at a time and go from there.”* Similarly, South Asian parents commented on their experience: “we are 3 years already [since our loss]; we can handle ourselves.”

Also evident among South Asian Buddhist and Middle Eastern Islamic participants was the belief that the counsellor couldn't help because the family doesn't “feel connected to this stranger because this bereavement and grief is a very personal issue” (Middle Eastern KI). One participant stated that they “haven't ...seen her... and she hasn't really taken care of her [their daughter] so it's pretty hard to explain like how it was” (South Asian parent). Another said, “they think that they are not sharing the sadness, they are just doing their job” (Middle Eastern KI). Other reasons for avoiding professional counsellors included the fact that it would be upsetting. As a Chinese focus group participant put it, “I don't think everyone from the Chinese family would come, because the invitation will provoke the hurt again.” Fear of negative consequences was also cited as a reason to avoid professional counselling. As a Middle Eastern parent explained, “I think talking to professionals, people think everyone is suicidal. So many think that when I talk to them then they will take my child away.”

Many participants had declined offers of professional support; however, several did receive counselling (including Chinese, South Asian, Middle Eastern, Muslim, Christian, Protestant, and Buddhist participants) and seemed to find it helpful. For one participant, having a woman to talk to was very important because in her religion, they “don't talk to husband or wife or brother or father or uncle, we don't talk to other men that much” (Middle Eastern parents). Another family

really appreciated that their social worker “was interested all the time and wanted to learn everything and asked lots of things. She wanted to know how [we] did things in [our] country. She was hearing [our] sadness and sometimes you can forget your pain and forget your sadness” (Middle Eastern parents). And finally, a bereavement group was a very powerful tool for another family, as demonstrated by the following statement:

Chinese parents: *We have a lot of moments that we share our pain. It seems that only to this group we talk about things that we are dealing with and other people who've gone through it will share their experience. You know so we cry and then they talk about their experience and they cry. So it's a very close knit group... Sharing your weakness, sharing your pain is... very bold, it empowers... not just one particular family but the entire 6 families that were there to be closer.*

## **Culturally Competent Paediatric Palliative Care – System and Services**

### **What is Culturally Competent Paediatric Palliative Care?**

The other major themes that emerged from the interviews centre on cultural competency in paediatric palliative care at a systematic and service level, in particular, what exactly is culturally competent paediatric palliative, how is it defined, what does it mean to people, and what types of practice or behaviours are necessary.

#### Perspectives of Health Care Professionals

When asked how they would define culturally competent paediatric palliative care, health care professionals drew upon concepts such as awareness, sensitivity, respect, and understanding. Awareness was described to include a general awareness of “the cultural diversity within the

community” (HCP) as well as more specifically “being aware that there is diversity amongst the families that we care for – that not every family holds the same values as important and that even within cultural groups there is variation” (HCP). Understanding seems to go one step further than awareness; instead of just recognizing diversity, participants felt that it was also important to make an effort to “understand what [people’s] cultural beliefs are about death and dying” (HCP) and “what values families are likely to hold” (HCP) as well as to be sensitive to and respect “cultural differences, practices, rituals that are important to the family” (HCP).

The following behaviours were mentioned by health care professionals as demonstrating culturally competent paediatric palliative care:

Understanding – The basis of understanding patients and their families was described by health care professionals as having an open mind and thus an “awareness of their client’s culture, meaning, their beliefs, not trying to put your own personal beliefs on clients” (HCP). Many participants also felt that it is important to learn about the culture of their patients either through asking the family questions or by consulting various resources. For example, one health care professional noted, “I think it should be just automatically a question initially; what are the family’s religious beliefs, what are their social beliefs, where are they from, are they Canadian citizens, what is their support like.” Another suggested, “Asking people if they have any individual preferences... is there anything that you would like done differently.”

Listening – For one participant, “listening is the most important thing” (HCP) and related to this was the value placed on “the communication we have with the families” (HCP).

Patience – Patience was described as critical to



establishing a relationship with a family and to ensuring they understand what is taking place. One health care professional commented, *“Patience...is really important, the ability to ensure that you spend a lot of time establishing a relationship and recognizing that many times, due to language barriers, it takes a long time to process the information we are telling them.”*

Sensitivity – This includes being sensitive to the patient and family’s needs as well as their emotions. One health care professional felt that it was important *“to be very sensitive to the person’s needs and the family’s needs and wishes and the things that they are used to”*; another said that they should *“go out of our way to do what family wants us to do in palliative care setting—we really follow their lead.”* A Chinese KI explained, *“the parents and family should not be made to feel like they’re... ignored or all their emotions are not being handled in a sensitive manner.”*

Respect and love – It was mentioned that using respect and love when dealing with patients will encourage the patient’s parents to respond to professionals in a similar manner. One health care professional put it this way: *“if you respond to their children in a loving and respectful manner, the parents will respond to you as a caregiver.”*

Additionally, having a home-like setting was seen as one way the facility could be modified to provide culturally competent paediatric palliative care: *“it should be as close to a home setting as it possibly can be. It shouldn’t look like a hospital, like a hospital room. It should look like a room where the parents and the child can relax”* (HCP).

Health care professionals also commented on behaviours that demonstrate a lack of culturally competent care. The major problematic behaviour that came up was making generalizations and assumptions about families from different cultures. This included stereotyping people based on their

culture, *“that we stereotype people and [think] that they all believe the same thing”* (HCP). It also included judging people when they didn’t conform to expectations. One health care professional commented, *“People cannot be here as much as health care workers think they ought to be and then there is often a lot of judgment placed on families.”* Another cited *“negative comments, complaints, family not reacting the way they should or compared to other families.”* Another problematic behaviour involved doing things without asking permission. For example, one health care professional gave the following example: *“taking pictures when they don’t want it, I mean normally we ask but you know sometimes some wouldn’t know and say ‘oh! I will take the picture, you holding the baby’ and thinking that mom will, of course, will want that, right.”* Another culturally incompetent behaviour mentioned was impatience, for example, *“trying to get stuff over with and not really understanding why they are asking for certain things”* (HCP) and *“being rushed and not paying attention to ensuring that you set it up with good communication with the family and establish a relationship”* (HCP).

### Ethno-Cultural Perspectives

The participants of various ethno-cultural backgrounds were also asked about their expectations for culturally competent paediatric palliative care. A variety of responses were given, several of which aligned with the views of the health care professionals.

This overlap included understanding, patience, sensitivity, and a hospital setting that can meet their needs. These participants also believed that staff should ask families questions in order to understand them and their needs better. As Middle Eastern parents put it, staff should ask questions *“just to understand better, get to know the person better and the religion and the culture. Ask them ...they will be happy to tell you what is*

going on, what their experience is, what they need from you.” Several participants mentioned that it was important to them to be treated in a sensitive and patient manner. For example, Middle Eastern parents said that “*the doctors could be more patient*,” while a South Asian focus group participant commented that “*the main expectations are the staff be more sympathetic*.” Sudanese parents offered this suggestion:

*Put yourself in the parent’s shoes for one moment...sometimes you just need that little extra... (Wife): reassurance, comfort, you know, a little bit of tact when you tell us stuff, listen to us, not just this is the way it is, this is what’s gonna happen, deal with it... Explain to us why you do things differently.*

There were several factors that contributed to the ability of the hospital setting to meet the needs of families. The first is to have a place available for parents to get some rest:

Chinese parents: *We really needed to lie down and get some quiet... They didn’t have any rooms some places.*

Sudanese parents: *Having a bed in the room so you could spend the night without having it on a chair because...the reality is if we had stayed on a chair 24 hours a day, we probably wouldn’t have made it, we would have probably ended up in the hospital.*

This point is similar to what was described by one of the health care professionals. Secondly, it seemed important to be able to accommodate large groups of visitors at flexible hours. A South Asian focus group participant noted, “*They should, the relatives, come even at the odd hours*,” while Filipino parents commented, “*Our culture [is] so very close-knit culture that people you know want to be there for you especially at that time. And I think there’s not much space in the Children’s Hospital.*”

And finally, it was mentioned by a Hutterite participant that “*just [having] some refreshments available would be helpful*,” especially because they come from a culture where things such as food are provided collectively by the community.

In addition, there were some expectations that were not shared with the health care professionals. For several participants, interacting with and receiving support from doctors in particular was very important. A Chinese parent commented, “*I would just like to get some better reassurance from the doctors, not just the nurse*,” while a Middle Eastern key informant noted, “*with our culture they rely very much on doctors, they respect them very much... The doctor again he need to be involved in this one, in one way or another*.” Some also expressed the desire that their spiritual needs be acknowledged and provided for. One approach to this that was described involved having a “*spiritual kind of a committee in each hospital...consist[ing] of all different religions...to show that they can have their say and give information to people*” (Middle Eastern KI) and another was to have staff ask “*do you have any priest friend, religious elder that maybe he or she could come and pray for you*” (Filipino Catholic RL).

Another way that was mentioned to promote culturally competent care is to have personnel from ethno-cultural groups available. As Filipino parents put it, “*if there is...you know, a special worker who is also a minority...you get the feeling that you can relate to the same person because she know that you came from the same culture, the same background.*” The provision of respite care was also suggested: “*respite care because I noticed in the community even extended families have been exhausted. ...and that’s the point where they’ve exhausted all avenues, they need maybe community support, maybe someone to look after the kids for just a week*” (Filipino FG).

Finally, some participants mentioned ways in which staff could interact more effectively with families.

For example, some felt that staff could be more open to cultural differences. Chinese parents commented, “*they don’t have to know about our religion or culture but just be open.*” Hutterite parents emphasized openness and honesty as important: “*right from the start they could tell you what you could be facing and tell you what they provide in those circumstances.*” And a South Asian parent commented, “*I just want the professional to keep to their words for any colors, any religions, any knowledge, different kinds.*”

### **Is Culturally Competent Paediatric Palliative Care Provided?**

Another objective of this research was to determine if culturally competent paediatric palliative care is being provided from the viewpoint of health care professionals as well as the ethno-culturally diverse participants.

#### Views of Health Care Professionals

During their interviews, health care providers were asked to use a scale of one to ten to rate themselves, as well as their work place, on the provision of culturally competent care, where 10...(indicate which end of the scale reflected best practice). For the 13 participants who rated themselves, the average score was 6.6 with a range of 3.5 to 9.5. The cultural competency of the workplace was rated by 11 participants and the average was 6.5, almost identical to the individual score. This suggests that health care professionals believe themselves and their workplace to be somewhat culturally competent and that there is also much room for improvement in this area.

One of the main ways in which the health care professionals felt they demonstrated cultural competency was through being sensitive to cultural diversity and to families’ needs as well as by “*mak[ing] an attempt to learn*” (HCP). Several participants mentioned “*follow[ing] the*

*families’ lead*” (HCP) and “*go[ing] out of our way to provide whatever they need*” (HCP). Some specific examples that were given include being open to discharging terminal patients so they can return home, permitting extra family to visit, attending funerals for former patients, accommodating requests to release the body to the appropriate people by certain times (i.e. sunset or sunrise) and allowing rituals such as sweet grass ceremonies and baptisms to take place.

There was some ambiguity in the statements of several health care professionals. There seems to be the belief that staff are providing culturally competent care to the best of their abilities but that their capacity is limited by lack of knowledge and resources. This is shown by the following excerpts:

*HCP: Yes, I think it is being provided, but I don’t know if it is being provided well. I believe we do our best to try to attend to it.*

*HCP: I think we are doing a pretty good job whether we understand or not, but I think just again the knowledge of what these cultures and what their beliefs are and gaining that information so that we can carry out their wishes.*

*HCP: Yes, I think it is being provided as well as it is known how. I don’t think people are being incompetent, but I think that with training and resources that we have we are being as competent as possible. It may be just more training required.*

It was also mentioned that the level of cultural competency is dependent upon the cultural groups being served and who is serving them. For example, there is greater familiarity with some cultures since they are more commonly encountered by health care professionals. One health care professional commented, “*we have more exposure to particular cultures compared*

to other cultures,” while another pointed out, “my colleagues work in their specific areas and are culturally sensitive to the communities they work in, because of the experiences they’ve had with the various families”.

There was also substantial evidence that health care professionals felt that culturally competent care is not provided and that it is necessary to remind staff that this should be a priority. One health care professional commented, “I still feel that I have to remind people, remind staff in many cases that ‘hey, their beliefs can be very different from your own’ and you cannot just generalize because of their age and or there is lot of generalization being made.” Some of the major reasons cited for this shortcoming are lack of knowledge, lack of resources, and limitations of the hospital setting. According to one health care professional, “the gaps are related to not having accurate and detailed information about what beliefs and practices are in cultural backgrounds.” Another specifically mentioned lack of knowledge regarding new immigrants who are not Christians: “I will say that we probably do not have much knowledge ... a very good idea what their beliefs are culturally.”

Similarly, health care professionals did not feel like there are enough resources to support them in the area of cultural competency. One health care professional put it this way: “I just don’t know of the resources that are there, but I don’t get the feeling that there are resources available to me to explain to me where the family is coming from if I am trying to discuss discontinuing treatment or palliative care, there is a gap there that could definitely be improved.” One story that was shared involved a participant who was unfamiliar with Vietnamese culture but was caring for a Vietnamese family whose child was palliative. The participant was not able to find anybody familiar with the culture to provide information and found it “embarrassing being so ignorant of what they [the family] wished” (HCP).

The availability of trained interpreters and the use of different interpreters with a single family was also mentioned as problematic. One health care professional commented, “We currently have the use of interpreters which are useful, but sometimes they aren’t the same interpreter with the family or sometimes they are not trained interpreters, so sometimes it works and sometimes it doesn’t.”

Additionally the inadequacy of the hospital setting to accommodate large groups of visitors from the family and community was cited as problematic. Filipino parents explained, “[they] all want to come in and all want to be there and our rooms are not big enough and there are other sick kids in the unit, you know, things, it is not good. So like I said we need bigger space.” A final gap identified was in regard to follow-up work. It was felt that health care professionals “don’t do enough follow-up work with respect to if the family understood what was going on... especially with cultural groups that we don’t have a lot of commonalities with” (HCP).

Health care professionals were also asked if they felt personally prepared to support families from different cultures. Many participants stated that they do not feel prepared to provide such support due to the absence of a formal process that provides instruction in the details of specific cultures. One health care professional noted, “There is no formal process for preparing us and training during medical training,” and another mentioned the lack of information about “detail of cultures.” As pointed out by one participant, “it is not through us not wanting to but the knowledge is not out there” (HCP). For those that believed they were prepared to provide care in a culturally competent manner, their ability was based on personal and professional experience rather than formal training: “I think I have prepared myself. I don’t think it was ever preparation through our education” (HCP) As another put it, “I think it is mostly from my own experience, it isn’t because of anything I’ve been



*taught or any in-services I've been given at all."* Although one participant mentioned attending a workshop, the majority of the health care professionals' knowledge seemed to be based on such things as "*personal research on belief systems*" (HCP) or through "*working with families*" (HCP).

#### Views of Participants from Ethno-Cultural Groups

The views of the participants who were not health care providers were also sought on the topic of whether culturally competent care is currently provided; mixed responses were received. Some participants felt that health care professionals acknowledge diversity and "*respect the religious traditions and beliefs*" (Middle Eastern KI) while others felt that health care professionals are not culturally sensitive. Understanding, accommodating the needs of families and asking questions were mentioned as ways that health care professionals demonstrated cultural sensitivity. Staff understanding seemed to be based on the communication of beliefs by the families:

Islamic RL: *Only sometimes they or the staff doesn't know anything and if you inform them, they will regard it.*

Middle Eastern parents: *They understood and they were doing what we told them. Nothing particular, but they did what we asked them to.*

The families also seemed to appreciate when staff asked questions. For example, Hutterite parents noted, "*we were asked different questions about what we believe and how we believe.... I think the staff respected our beliefs.*" Others agreed, noting, "*when they asked, we explained to them what we believed in.*"

Participants recounted other ways in which the needs of families were accommodated, including giving families the space and time they needed with their child at the end of his or her life:

Sudanese parents: *We had a private area that we could do the ceremony.*

Sudanese parents: *[Giving] us the time to spend with her after she passed away, [letting] our family be together and [letting] us have our prayers that we needed.*

Filipino parent: *They asked me to just go out, step out and I said I want to say and they let me stay.*

In opposition to these positive responses, several participants from various ethno-cultural backgrounds commented that although professionals may be trying their best to recognize cultural diversity, their efforts are not adequate. This opinion is evident in the following excerpts:

Sudanese FG: *I think it's work in progress, yeah.... I think they do... understand our culture... They are doing it to the best of their abilities.*

Islamic RL: *I think they are doing their duty sincerely and if there is any [lack] caused due to ignorance it should be corrected.*

Filipino Catholic RL: *I think they are trying to recognize that there are differences but of course it's not enough.*

In addition, some felt that there was little to no acknowledgement of diversity. A Chinese parent commented, "*I don't think they really touched on culture,*" while a Sudanese key informant echoed the view that diversity was acknowledged "*actually not very much, not very much with the hospital.*"

There were also conflicting views on whether bad news was conveyed appropriately. Participants who believed that it was conveyed in a suitable manner appreciated being told the truth about what was happening with their child:

Chinese parents: *He is a good doctor because he [is] telling you exactly what he thinks is going to happen.*

Middle Eastern parents: *The doctor here told us she had limited time, that was very hard for us, because in our country the doctors would never tell us that...It was good that the doctor told us that, because we carried her more than before they told us.*

There were also participants who did not feel that directness was the best way to relay unfortunate news. According to some Muslim participants, it is better for doctors to hide some things from the families, especially mothers, because they cannot accept it:

Middle Eastern KI: *In our culture, no, the doctor could hide a lot of things you see. But here they are very straight, they are very clear with the parents and they say look here your baby's going to die, you see. Just clear like this. We cannot accept it you see. It's better in our culture.*

Middle Eastern FG: *According to our custom, we don't let the woman or the mother know right away. In...this country right away they inform the lady or the mother that the child is dying. And this way sometimes the mother collapse and faint or something. Our custom no, we come to the father and we talk to the father then the father or [religious leader?] come to the mother and he talks to her our own way...I wish the doctor not to tell the mother right away "oh your child gone." He should come to her with different way.*

Similarly, a Filipino participant mentioned that doctors should always allow parents to have some hope that their child might survive because "they'll not accept that their kid is dying, they will deny it to the last moment" (Filipino Catholic RL). However,

also evident was the belief that doctors should not "address it in a different way just to please the parent [because] they are sending the wrong message" (Chinese parents) or encourage false hope. South Asian parents commented, "[in] this situation you have a big hope and then crush."

Some aspects of cultural competency that seemed to garner overwhelming praise were the help and support received from health care professionals as well as their openness to talk with families. Staff were described as "always willing to help" (Sudanese parents), "go[ing] way up to help us" (Chinese parents) and being "very nice, yeah they are really supportive" (South Asian parents). The support of health care professionals seemed to be divided into two categories. Firstly, they were seen to provide emotional support to families through being "very caring" (Hutterite parents), "uplifting when you are feeling weary...and [saying] a comforting word [that] can really make your day and get you out of your depression". And secondly, practical support was mentioned in terms of having "information we requested sent to us" (Hutterite parents), "helping with filling out forms" (Middle Eastern parents), setting up private room for family and friends to gather in.

The appreciation expressed by families for the fact that "the hospital environment, the nurses, doctors were open to talk" (Chinese parents) included staff's willingness to answer questions and help the family understand their situation. This is demonstrated by the following comments:

Chinese parents: *If you have any question, you walk up to the doctor, he will tell you, they explain to you.*

Chinese parents: *I had some questions as to how the process of handling [my child] was done and the social worker arranged for the doctors to be there to answer the question. I was pretty upset that time and I ask questions like*

*did anybody care and the doctors were sitting in front of me and they answered face to face, from the heart. Those things I really appreciate because at that time... we were just at a loss and looking for answers.*

Sudanese parents: *She was amazing. They'd let us know what to expect and they'd ask us how we felt about it.*

Also mentioned was that staff went out of their way to make sure they were available to talk with the family when needed. For example, a South Asian parent recounted, “[the doctor] called me like everyday and said that every time like when [my child] needs help just give her a call on her cell phone.” Other South Asian parents commented, “they came all the time to talk to us...and she did call a couple time to see how we are doing” and one said, “many nurse discuss with me...and then we chat a lot in the night time.”

An example of a lack of cultural competency related to the inadequacy of the hospital setting. Participants mentioned that their needs weren't met in terms of privacy: “The family needs privacy, hopefully in the new hospital, the privacy will be a little better” (Middle Eastern parents). A South Asian focus group participant felt that a “little bit that they have to change is food, sometimes it is not appropriate according to the culture.” And religious needs were not always met, as indicated by the following comments:

Chinese parents: *They should have a Chinese monk or priest or whatever so then you don't have to go to one kind of religion there.*

Middle Eastern KI: *One very important aspect is...prayers of worship for example, places of worship....Muslims for example, they are expected to pray 5 times and they need to have a specified place...The day of the death they need to clean themselves and wash their face*

*and body...not many hospitals provide that type of vicinity so people really struggle with that.*

It was also felt that the health care system does not do enough networking with local communities. A Middle Eastern key informant commented, “To develop local networks in the local communities and the people can be there and go there and have connections... with the folks in the neighbourhood, I think that's a very important element of this work that hasn't happened to my satisfaction.”

Families were also asked to describe negative experiences they may have had within the health care system. Several examples given indicated inefficiencies such as doctors not responding quickly or families having to wait a long time to be given an answer:

Chinese parents: *You need some pain killer and it take a long time to come...They have to wait for the doctor to authorize and the doctor was nowhere to be had.*

Chinese parents: *We call the cardiologist and nobody answered.*

South Asian parent: *Two years I wait for this answer [on an autopsy] nobody give us. So sometime I feel oh maybe they look down on us.*

As well, many families raised some concerns in regard to the abilities of the health care professionals. These included questioning their skills, judgment, and knowledge, as demonstrated in the following excerpts:

Filipino parent: *When they put the IV, they cannot find it.*

Chinese parents: *Some of them we got upset at because they were doing things that even we knew were wrong – different dosage of*

*medication, not asking us...if he had been fed, waiting for other doctors to make decisions.*

*Chinese parent: I would raise a question and he just say they don't know... They say we're not that smart or we don't have all the answer. I know that's true but it's not very comforting to hear that... some of the [residents]I don't even know how they can get there...like they don't really know that much. And they have to make a decision and it's kind of scary.*

Finally, lack of communication was also identified as problematic. As Middle Eastern parents commented, “When you don't understand or there are communication problems it is really hard, but you learn to deal with it...So many times the nurses are frustrated and they don't listen to me or I don't listen to them. It is a bad experience.”

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

Participants were asked to identify specific barriers and challenges to culturally competent paediatric palliative care and the reasons behind these barriers.

#### Examples of Barriers

Language, poor communication and the hospital setting were challenges that were identified by both participants from ethno-cultural groups and health care professionals.

Language was described as the most “*challenging*” (Chinese FG) or “*biggest*” (HCP) issue by both groups of participants. For health care professionals, this includes difficulties in communication with those who are unable to speak any English as well as with those who speak it as a second or additional language. One health care professional noted, “*language is becoming more a problem, because the recent immigrants a lot of them don't speak English at all or for this*

*type of conversation they don't speak fluent enough English.”* Interpretation services have been somewhat helpful in mitigating language barriers. As Middle Eastern parents noted, “*they also had an interpreter and that was helpful. If we had a meeting with the doctors and we didn't understand everything then we had an interpreter there.*” However, several problems with this service were identified. These included a “*lack of translators*” (HCP), especially ones who are able to meet with families in person. One health care professional commented, “*I'm sure that it has to do with resources, but face to face interpreters are important especially for difficult issues. Resources need to be put in place for this.*” Interpreters' accent was also mentioned as a barrier:

*If they say Arabic, please ask what religion so that one will help. Like I mentioned, different Arabic religions is really hard for most of the people, even for myself, sometimes it's really hard to deal with the Kurdish because they have a very strong accent. Some words sounds like French so it's really hard.* (Sudanese FG)

Technical and logistical difficulties were also cited as barriers when using translators:

*HCP: But we had to do this on the phone and our phone didn't work well, so it was really difficult.*

*HCP: Accessing diversity services is a bit of a challenge – you may even have the interpreter with you at the meeting and you are trying to rebook for the next one and you can't even tell the family when you will rebook it for, because you have to go through a scheduler. You have a code, but lots of times you can't remember the code, so then you have to go through all of the demographics again and then it feels a bit exasperating.*



Although language seemed to be an important barrier to cultural competency, there were many participants from ethno-cultural groups for whom it was not an issue because they felt comfortable with the English language. Here are some of their comments:

Sudanese parents: *Both being educated here it definitely makes a difference. I would imagine yeah, if you didn't speak the language, then you would have had issues.*

Filipino FG: *[Language is not a problem...] for the Filipino community because everybody can speak English. Maybe not to full length but they can express the necessity that they need to be addressed like in terms of services for our families and stuff like that.*

Hutterite parents: *[We were]able to communicate and understand what the doctor was telling us.*

Chinese parents commented that, for them, “the only language barrier was some of the medical terms that we had to look up.”

Related to the language barrier, poor communication was another challenge to cultural competency that was shared by health care professionals and participants from ethno-cultural groups. One doctor stated that “we felt that we were not getting the message across...we felt that parents never really quite understood.” This is similar to the experience described by one Middle Eastern family member: “there wasn't good communication between the doctors, the staff and me. I didn't know what was going on...it took awhile until I understood what I could or could not do.” There also seemed to be a tendency for families to avoid asking questions, as demonstrated by the following comments:

HCP: *You get a sense that the family isn't asking for support or direction or questions. I*

*suspect there are a number of families who just don't let us know if we are not meeting their needs or if their cultural beliefs aren't being honoured. I'm not sure that they do let us know that.*

Middle Eastern parents: *I was really frustrated because I didn't know I could ask them questions.*

Also suggested as potentially helpful was greater communication on specific issues, such as “printed information on what kind of financial support is available to cover funeral costs” (Chinese FG).

The personal attitudes of health care professionals were also mentioned by both groups as an impediment to the practice of culturally competent care. The word “prejudice” was used by several health care providers, and this was echoed in the following statements by participants from some ethno-cultural groups:

Hutterite parent: *There are some staff that act like you are different than they are...Some staff don't understand [...your beliefs] and they react to you because you think that way and they think they know differently.*

Middle Eastern parent: *There were times that I did feel like because I was wearing a scarf, because I was a woman and I was Muslim I got treated differently.*

The description given by a registered nurse was that “the only barrier is only ourselves.” This idea was elaborated on by other professionals who mentioned prejudice, fear, narrow-mindedness, and being judgmental as impediments to culturally competent practice:

HCP: *I think people are prejudiced.*

HCP: *We do occasionally come up against certain people that show racial prejudice.*

HCP: *I think people are afraid of different cultures and beliefs.*

HCP: *Narrow minded in your thinking... judgemental of the way people responded to different things.*

It was also recognized that personal experiences may encourage one to form certain beliefs about certain groups of people but that “*we all need to be smart enough to know that not everybody is the same*” (HCP).

The final challenge that was common to both groups of participants related to inadequacies of the hospital setting. As mentioned previously, the physical structure of the hospital and the rooms within the hospital are often not able to meet the various needs of families, including places for worship and religious rituals as well as space for visitors. According to one doctor, one challenge was

*the specific layout of the space, depending on what the family needs for their cultural beliefs around the end of life. Hospital rooms are probably not factored into that, so I think there are geographical barriers, physical barriers that we can't necessarily overcome.*

There were no barriers that were unique to the participants from ethno-cultural communities; however, there were several that were mentioned only by health care professionals. The first was insufficient knowledge and a lack of resources from which to gain needed information. Knowledge was described as lacking in terms of not knowing enough about different cultures:

HCP: *I don't think you ever know anything about everything... but I think the more we work with different people from different cultures, the more we know that we don't know.*

HCP: *Personally I don't have that knowledge tucked away.*

Other aspects of lack of knowledge included not knowing “*what to say or do*” (HCP) as well as being unaware of people’s ethno-cultural backgrounds: “*you don't always know where these people come from*” (HCP), and “*we just don't realize what other people's belief systems are*” (HCP).

Although health care professionals seemed to be relatively aware of their lack of knowledge, there did not seem to be many resources available to compensate for this deficit. It was observed that “*there have not been adequate opportunities for learning and support, particularly as a physician and in training*” (HCP). One health care provider commented, “*we don't have the resources, sometimes there is not enough information,*” and another noted that, in the case where there are useful resources available, oftentimes people “*may not know where to access the information.*”

Health care professionals also felt that there is a “*lack of appreciation for all of the circumstances in people's lives.*” Because the needs of the patient are the priority for staff, they may tend to not take into account the “*complexities and difficult situations that a lot of these families have*” (HCP) including “*being unable to afford appropriate housing or... transportation*” or having “*two jobs and basically no time to come in*” (HCP). It was felt that this lack of awareness may lead to impatience and frustration among staff, for example “*impatience with trying to get stuff over with and not really understanding why they [the family] are asking for certain things*” (HCP).

Finally, it was apparent that health care professionals felt that cultural competency is not regarded as a priority by management, as demonstrated by the comments below:

HCP: *I personally think it is lack of support from higher up. ... They assume that we are doing a good job and we don't need something.*

HCP: *I think there is a systems issue. I think our system doesn't support us in the way that we can provide the best time and care to families.*

HCP: *People just don't see the need for the resources that we need to have.*

It was mentioned that support in the form of organizing such things as a “regular routine for follow-up” (HCP) and encouraging formal discussion surrounding cultural issues would be helpful. As one health care professional put it, “*The people that I work with work closely with the palliative care team and are very sensitive to different cultural families and I think they use their own time to learn, but we have never taken time to sit down and discuss (these issues).*”

#### Reasons for Barriers

The reasons given for these barriers to cultural competency ranged from lack of funding to personal reasons to the wide variety of ethno-cultural backgrounds encountered. Two aspects of lack of funding were mentioned. Firstly, little money was believed to be allocated specifically towards services to enhance cultural competency. This includes hiring staff such as diversity instructors and face-to-face interpreters:

HCP: *To hire diversity instructors is not a priority.*

HCP: *Face to face interpreters are important especially for difficult issues; resources need to be put in place for this.*

As well, the health region, as a whole, was thought to be underfunded. One health care professional noted, “*well, the health region is underfunded,*” and

it was felt that underfunding leads to staffing issues that may impact professionals’ ability to offer ideal care. Two participants from ethno-cultural groups commented on the shortage of staff:

Chinese parents: *Sometimes we get upset because he didn't get attention but there's only so much staff.*

Filipino FG: *I think that one of the problems too is the quality of attention because of their budget cuts, you know they cut down the number of hours or helpers the nurses have.*

Health care professionals cited finding it difficult to prioritise cultural competency due to lack of time. One noted that “*people don't have time [for in-services]*” while another commented that “*not having the time to step away to do a bit of research in your day... saying I am going to take 30 minutes to read up a little bit and maybe remind myself of appropriate questions.*”

Possible personal reasons mentioned that may discourage cultural competence included staff not feeling comfortable or confident in dealing with patients and families from diverse cultural backgrounds, perhaps because of inexperience:

HCP: *People are really uncomfortable in working with this area and perhaps they don't have the skills, but they don't feel very competent and feel the need to rush through it.*

HCP: *Discomfort how they react when put on the spot or asked questions.*

HCP: *Maybe lack of experience.*

HCP: *I think most of them are inexperienced.... Nurses get nervous and you know the situation has sort of gone out of hand with something they have never experienced.*

Fatigue was also mentioned as a potential personal barrier to culturally competent practice. One health care professional suggested, “*maybe people are tired of their work*” while another commented, “*sometimes you know when they are tired...you just hit this wall and ... it is like I don’t even think about it.*”

The final reason proposed was that because there are so many different cultures it is difficult to be prepared to work with them. As one health care professional noted, “*there is so much diversity within different cultures that I am afraid to predict exactly what a different culture believes in, there is so much out there that it is hard to know.*” Another stated,

*Unless you actually encounter that particular culture on a more consistent basis, and not necessarily at times of death but in general – even in times of life and celebrations within their culture – unless you get that exposure, you really can’t be prepared.*

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

This research also had the objective of exploring how cultural competency in paediatric palliative care could be improved.

#### Knowledge and Communication

Two strategies that were mentioned as important from the perspective of both health care professionals and participants from ethno-cultural communities were increasing knowledge around different cultures as well as encouraging communication and understanding between people of diverse backgrounds.

For the participants from ethno-cultural groups, “*enhancing the cultural awareness of all those cultures within the serving people like the nurses, physicians, social workers*” (Middle Eastern KI) is necessary to improve cultural

competency. Various ways were mentioned through which knowledge of different cultures could be disseminated to health care professionals, including written material. A Middle Eastern key informant suggested, “*have a general guideline of how come this can be different, what are the norm cultural variations depending on where you from,*” while a Filipino focus group participant suggested “*they have to have some kind of diversity training.*” Connecting with experts on various religions and cultures was suggested by a Middle Eastern key informant: “*I’m sure there are people in the religious studies areas [at the University of Calgary] who have done research in these areas and may be valuable informants*” and by an Islamic religious leader, who suggested “*they can approach learned scholars.*” Ensuring that relevant research (such as the current study) is distributed to staff was also mentioned: “*health care professionals need to be familiar of the information we are giving now [in this interview], doctors can read it and train them and go from here*” (Middle Eastern FG). Interestingly, some participants were of the opinion that some of the responsibility for creating cultural awareness falls to members of particular cultures through initiatives such as accepting requests to speak or inviting professionals to attend cultural or community events. As a Sudanese focus group participant put it,

*we are the one that have to do some awareness to them in order for them to understand our culture and the way that we need to be treated.... They have to either invite someone from Sudan community...or we can invite them to attend ours.*

Similarly, health care professionals believed that cultural competency could be improved through increasing awareness and knowledge of cultures. One health care professional noted, “*I think it will be much more helpful if we understood more of their beliefs in depth.*” This suggestion was echoed by another health care professional, who mentioned



the importance of “awareness, to know more about the different cultures and beliefs”. The need for accessible, written information in the form of a reference book was heavily emphasized by many, as demonstrated by the following excerpts:

HCP: *Having a resource guide to look up questions to ask different cultures or just to be aware that this is maybe what they are thinking or perceiving this if you say this, or do this, or offer this. Kind of a cheat sheet for each culture would be helpful to say what would be an appropriate intervention or what they may want.*

HCP: *The written information that would be most helpful would be information around practices around death and after death, so things like disposition of the body, if cremation or burial is preferred, how quickly that needs to take place, preparation of the body. Those types of things would be helpful [and] any other rituals that are important to people of that faith. I think those are the sorts of things that would be really helpful and they aren't usually the kinds of things you tend to ask about and they happen quickly and it is a high stress time. It is hard to have those conversations; it is most difficult to have them. I would say written information is most helpful, because it is there when you need it and when you don't need it, it can sit on your shelf.*

HCP: *I think that resource needs to be available at our fingertips. Even a resource binder that goes through each of the cultures that we could potentially encounter and that would be helpful.*

HCP: *I would like to see more books on different cultures at work. Everything is very medically focused, diagnosis, etc. We have a binder through diversity services that does try to look at the different cultures and stuff like that, but it is one binder. There is also the library.*

HCP: *Written information that you can always read as in the middle of the night or 2:00 in the morning you are not going to phone anybody so just having a binder you know with Sudanese like this, Vietnamese like this, Japanese like this, you know whatever culture, what they believe and what they like to happen during the process.*

One participant also commented that having the resources available is not sufficient but that it is also necessary for professionals to have “time to be able to look into those resources” (HCP).

Another major source of cultural information mentioned by professionals involved educational opportunities. In-services were mentioned most often, as well as inclusion in new staff orientation:

HCP: *In-services coming to the units, not where you have to go somewhere but just quick, brief 15 minutes in-services.*

HCP: *Again in-servicing staff even if it is general reminders, ‘Hey! Beware’ that maybe we are not providing the best culturally competent care.*

HCP: *I would like in-services but not the ones where they like cover all the nationalities in like hours.*

HCP: *In-services are always good.*

HCP: *We should just have it to be part of our orientation.*

HCP: *Maybe partly during the staff orientation, you could cover some of the basics and some of the more common beliefs and requests from certain cultures.*

A health care professional also suggested speakers: “I think they should have speakers come and talk about different cultures.” And certification was also

raised as a possibility: *“I will love to see some kind of certification.... We should have guidelines as to what is acceptable and what really isn’t”* (HCP).

Both groups of participants also identified people as an important resource for improving cultural competency. Interpreters and translators were mentioned by professionals and participants from ethno-cultural groups:

Filipino FG: *More multicultural service providers in terms of any interpreters.*

HCP: *There should be more...interpreters in the hospital for families to get more information.*

HCP: *Translators of some sort who will be around to help, that would be a great support.*

For example, a doctor advocated for *“trained health care interpreters more on site so that we can develop a relationship with them and they can... be continuously available to families as there are needs.”* Several participants from ethno-cultural groups similarly commented on the need for written material to be translated:

Chinese FG: *The hospital should have a brochure to list step by step what parents should do...and translate that in different languages.*

Middle Eastern KI: *Information sharing with people in their own language, handouts and pamphlets would be useful.*

The benefit of employing minority personnel in health care was also recognized by both groups as a helpful strategy, as can be seen from the following excerpts:

Filipino parents: *There should be a...culturally minority personnel, that’s very important, cause then you show people that it’s alright if they’re not white.*

Filipino FG: *They should have more available multicultural service providers in the Health Region...because we are so outnumbered*

Islamic RL: *Have at least one person from the society in the hospital.*

HCP: *I think actually having health care workers, or someone within the health care system, who has that cultural background and language would be absolutely ideal...that health care liaison worker who has the same cultural background and can come in and act as a facilitator.*

HCP: *Probably I think person from diverse background so that if we have a patient... of that grouping that we can go to and just to ask questions...sort of like a translator situation but just not the language.*

HCP: *I think we need a facilitator that has the cultural background as the family. That would be our best way of ensuring that (a) family’s needs are met and the health care team has an understanding of what the family’s needs are, and also so that the facilitator can help the family understand the health care team’s situation.*

Unique to participants from ethno-cultural groups was the suggestion of volunteers as a type of resource personnel who could support the families. A Chinese focus group participant commented, *“emotional support by volunteers might be helpful to find out what type of support the family needs,”* and this idea was echoed by Chinese parents, who suggested having *“a volunteer or something that they can get in touch that helps to drive them.”* For health care professionals, individuals hired as “professionals” in cultural diversity were often mentioned as an important resource. These people were described

as “somebody who specialises in that area and maybe has a better idea as to what different cultures physically need or typically wish” (HCP). Such a professional could be available to answer questions and provide consultation “with individual cases, someone to bounce ideas off” (HCP) and might have access to “community members” (HCP). Other important resource people mentioned by professionals were social workers and chaplains. One health care provider commented, “palliative care social work and palliative care services and chaplains are good resources if you access them for guidance of help.” One participant mentioned that it would also be beneficial for

*ACH pastoral services, when they refer a client to us, (to) provide us with some information about the family – I’m sure they’ve been involved and they have that religious focus in the hospital. They could let us know the cultural background and have lots of information.* (HCP)

Communication is another key to improving cultural competency for both groups. It was recognized that health care professionals “have to improve the way they have communication with the ethnic community” (Filipino FG), and asking questions by both staff and families seemed to be regarded as the main way to achieve improved communication:

*Chinese FG: You should ask first.*

*HCP: I would encourage people in other cultures to approach our unit and ask to speak to you know the staff regarding their different issues.*

Some important areas to inquire about included ethnic and religious background as well as specific needs, preferences for treatment, and general comfort level:

*HCP: I think it should just automatically be a question initially what are the family’s religious beliefs, what are their social beliefs, where are they from, are they Canadian citizens, what is their support like.*

*Islamic RL: Ask the person where you are from.*

*Sikh RL: They will ask regarding your diet.*

*HCP: Asking the question-- is there anything that you would like done differently.*

*Middle Eastern parents: I did feel like they could ask me how they could help me better, what I needed.*

*Hutterite parents: Maybe just asking us how we were doing, if we were cold.*

Despite the importance of communicating, it was also acknowledged that both families and health care professionals may be reluctant to approach one another with questions. Hutterite parents noted, “there were times when they could have asked us questions when we didn’t always feel like we were able to ask.” And a health care professional pointed to the importance of “just building confidence in the staff and giving them tools to ask questions that they have in mind and not be afraid to do that.” Listening was additionally mentioned as a significant component of communication: “I think listening is the most important thing – that you listen to families” (HCP).

For participants from ethno-cultural groups, the concept of communication was also linked to understanding. They expressed the desire for health care professionals to understand the wants and needs of families, as well as to understand the families on a more personal level:

*Hindu RL: Try to understand what people want and work according to that.*

Filipino Catholic RL: *Very important for the families is the support of the doctors and understanding that these families needs full amount of support, spiritually, emotionally, even physically, intellectually.*

Middle Eastern parents: *Better understanding, getting to know me better personally...if they get to know you better, they can help you better.*

Sudanese FG: *They need to understand us as unique people not speaking to one person and generalize the whole community.*

In addition, communication in the form of outreach and sharing information about the Health Region's programs and services with communities was identified as crucial: *"they cannot just wait for us to come over, they have to be down the street too and talking to the ethnic minorities or whatever. Outreach is number one"* (Filipino FG).

#### Other Strategies for Improvement

The final way to improve cultural competency in paediatric palliative care that was mentioned by both groups of participants was in regard to hospital setting. Similar to what has been described in previous sections of this report, it was felt that *"physical resources in order for these families to be able to cope"* (HCP) are necessary. These physical resources include space for privacy, as mentioned by Hutterite parents: *"the family needs privacy...you want peace and quiet or you want your own corner."* Other requirements include a *"place for prayers"* (Middle Eastern KI) or a *"special room for the native smoke ceremony"* (HCP).

Health care professionals mentioned several other areas that could influence positive change in cultural competency. The first involved the attitudes of staff and the promotion of awareness, respectfulness, acceptance, and open-mindedness. These ideas were demonstrated by the following comments:

HCP: *I think maybe we need to just step back and consider those who are in the situation. It is okay to feel upset, but to have awareness is important.*

HCP: *Awareness, to know more about the different cultures and beliefs.... I think it is essential for all staff to realize how important it is for every family to be able to deal with stuff in the way that they know how and the way that they need to.*

HCP: *Posters around about acceptance and diversity and that it is all good and [that]we should embrace our differences. I think that sort through general media through Canada would be wonderful.*

HCP: *Part of it is that we do need to educate ourselves about various cultures and faiths and practices, but part of it is that we just need to be respectful and listen to the families that we are looking after, whether they are similar to us or not.*

HCP: *I have learned that we stereotype people and that they all believe the same thing and that I have to really be sensitive and open-minded and don't assume that you know.*

Secondly, professionals seemed to highly value learning through life experience as a way to build cultural competency, as evident by the excerpts below:

HCP: *A lot of it is learned as you are in the actual moment... so I think it is a lot of learning as you go and be sensitive...trial and error.*

HCP: *Most of our learning comes from working and interacting with families and that is where we get the experience of how to handle difficult situations...[It depends on] one's life experience, if you are not exposed to that setting, then you don't grow that way.*



HCP: *I have developed my abilities through working with the families and my preparation has come from my experiences with families.*

HCP: *I guess like I said through training and experience, through watching and learning and watching and maybe having culturally diverse friends on a personal level.*

Finally, improvements in cultural competency are seen as dependent upon management and organizational level support. One participant described this idea in the following way: *“it has to be made a priority regionally...it needs to become prominent...and making sure it is incorporated in every new policy and every new guideline”* (HCP). Support from management was mentioned as necessary to allocate resources. According to one health care professional, *“it is important for management to realize this and make sure that the resources are available in order to support culturally competent paediatric palliative care.”* Another health care professional pointed to the need for *“respite care...you know there needs to be facilities in the region that will look after these children in that capacity to give.”* Others suggested providing organization in terms of committees and meetings: *“maybe even after the fact would be helpful for staff if you are stumbling through it, we’re not all going to be involved in that case anyways, so have a briefing afterwards and explain why they wanted this and why this is important.”*

Health care professionals were also asked about strategies that would improve their own personal ability to provide culturally competent care. The most common responses given for these inquiries were having access to resources and gaining knowledge:

HCP: *A greater understanding of the beliefs of the different cultures and their practices.*

HCP: *To have more knowledge about the difference in cultural backgrounds.*

HCP: *Definitely just more knowledge about the cultures for sure.*

Various ways of obtaining this knowledge were mentioned, including *“reading and just looking at different people and talking with them and having them share with me what their values are”* (HCP), *“really learning from the families when I do have the opportunities”* (HCP) and attending educational events such as seminars and in-services (HCP). The resource that was cited most often, as demonstrated by the following comments, was written information in the form of a handbook:

HCP: *Having a resource guide to look up questions to ask different cultures.*

HCP: *If I could have quick, easy access to written information that describes the beliefs and practices...that I could go to as the need arises, that would be very helpful.*

HCP: *Just kind of the rules, I guess the mannerisms, how to be, what to say between different cultures, handbook if there is such a thing, I think that would be helpful.*

Additionally identified as potentially helpful were *“health care professionals who understand different ethnic, religious groups to explain to us some of the difficulties”* (HCP).

Colleagues and families also emerged as important sources from which health care professionals learn cultural competency. Through colleagues, professionals have learnt compassion and sensitivity, as well as information about different cultures:

HCP: *what I’ve learned from those that took an interest in looking after these kids was watching their compassion.*

HCP: *Be[ing] sensitive to the families’ wishes.*

HCP: *I have learned some specific things about cultural practices from various colleagues.*



HCP: *To appreciate that your colleagues also have different cultural backgrounds and they can offer more insight.*

Colleagues were also cited as an important source of support. One health care professional commented, *“bad things happen around here, you know we talk about it and I guess that is our support system,”* and another noted, *“my colleagues are incredible, there is such a support system.”* Even when colleagues did not practice in a culturally competent manner, health care professionals felt that they could use that as a learning opportunity:

HCP: *I think in general there is a lack of awareness from people.*

HCP: *People are opinionated and it just shows that we just need more reminders that we are multicultural.*

HCP: *Sometimes I have learned how not to do thing, I find that there are many times that information is shared in ways that is not suitable to a family and I have learned how to do it for them.*

Health care professionals also say that have learned a variety of things from families and children. First, they have gained information about specific cultural practices and beliefs:

HCP: *Different families have different roles based on their culture and different expectations.*

HCP: *I have learned that Muslims will want to bury that day usually and they have their own cemetery and there is a Muslim Society that if they are not connected in Calgary they can call this guy and he can arrange that all. We just have to do the white cloth...In Buddhist culture, it is really important to say goodbye to the soul and rituals they have.*

HCP: *Be careful to include the appropriate people...important to us to not always assume*

*that everyone in the room should be part of the conversation and to understand who you should be addressing first and in fact should be our point of contact with the family.*

It was also mentioned that families have taught them the importance of accepting other cultures. One health care professional commented, *“I’ve learned that you may never convince them of your ways and you must learn to accept that.”* Another stated, *“I have learned from the family, we should be accept[ing] of their culture.”* Related to accepting other cultures is being open-minded and avoiding assumptions:

HCP: *Don’t make assumptions.*

HCP: *I have learned that we stereotype people and that they all believe the same thing and that I have to really be sensitive and open-minded and don’t assume...*

HCP: *Every child is different and even regardless of religion, race, background, whatever, we are all different, and...we need to be treated respectfully.*

Lastly, professionals have learnt strength from the families that they work with. This is demonstrated by the comments below:

HCP: *Children and families have most taught me how strong they are; that they have incredible strengths, regardless of cultural background.*

HCP: *Seeing the strength that they gain from their beliefs and their belief system.*

HCP: *Sometimes they surprise me and have such incredible strength right at the end and all pull together.*

HCP: *They are very strong and need to be part of the whole process and respect it. I can’t say it enough time.*

## Health Care Professionals' Views Regarding Learning Opportunity, Resources, and Support for Providing Culturally Competent Care

### Availability of Supports

The perspectives of health care professionals were also sought regarding learning opportunities and resources available to assist staff in improving their cultural competence. When asked if the current availability of learning opportunities and support were adequate, some professionals felt that they were sufficient. One health care professional observed, "*There could always be more but I think it is adequate,*" while another commented, "*I don't think there is a need for anything that isn't already in.*" However, the predominant opinion seemed to be that there was inadequate support, as demonstrated by the following comments:

HCP: *No, not here for sure.*

HCP: *No. Just a few months ago I had a family whose child was palliative and we were taking care of her in her last days of life and they were from the Vietnamese culture and this was very different than I was used to and there really wasn't anybody to help me or help explain it to me; it was a lot of trial and error and it's embarrassing being so ignorant of what they wished would happen. In the end it turned out okay, but I really didn't know where to turn. It was painful.*

HCP: *There have not been adequate opportunities for learning and support, particularly as a physician and in training. This training needs to happen much sooner.*

HCP: *No... I have done some course on palliative care but none of them have touched on cultural differences that I can remember right now. So I would say no.*

Two participants mentioned that opportunities for learning, such as in-services, are offered but are not regarded as a priority:

HCP: *I know that there are in-services but they are not made a priority.*

HCP: *I think [that opportunities are offered] but they are all self-directed. I don't think there is a lot offered unit-wise. I don't think it is a priority higher up.*

HCP: *They might be available...but nothing that I have [taken] or was strongly encouraged.*

A lack of advertising on learning opportunities was also mentioned by participants. One health care professional noted, "*I have not seen a lot posted in this particular area,*" and another echoed that view: "*if they are available, then they are not advertised in a manner that we know about them.*" Additionally, there was some evidence that even if supports were available, they may not be taken advantage of by professionals: "*the reality is that there already are those opportunities and I can't say that I have taken advantage of them*" (HCP).

### Learning and Resource Needs

Learning and resource needs were also identified by health care professionals. Education in general was mentioned by many participants:

HCP: *More education for staff or opportunities for education.*

HCP: *I will just say better education.*

HCP: *I am a huge, huge supporter of better education.*

Education specific to various cultures and various health care settings was also cited as important:

HCP: *It would be interesting to know how other cultures deal with their death and dying.*

HCP: *Learning should be offered in very specific areas – clinic to clinic, ICU, genetics, various clinics.*

HCP: *Short day conferences where we are exposed to people from different communities but also to health care providers who understand both sides.*

HCP: *Make sure that education happens on many different levels, working with groups specific to certain populations or certain diagnoses.*

A range of education formats were mentioned, including short stand-alone opportunities such as half- or full-day conferences or seminars, in-services, speakers and resource fairs, as well as ongoing education in the form of lecture or speaker series:

HCP: *A half-day conference or full day conference.*

HCP: *A day seminar and different speakers.*

HCP: *I would like in-services.*

HCP: *There should be resources available as part of nursing education day, resident education day, etc.*

HCP: *There should be ongoing education for staff so that they can grab the opportunities of either attending workshops or a lecture series.*

HCP: *They should have speakers come...maybe if they did a three-part series instead of just one.*

Other suggestions were to improve the accessibility of these opportunities to staff. One health care professional commented that such opportunities “needs to become more flexible in when it is offered so that we can have more chance to attend,” while another suggested that “there should be mandatory education for people regarding different cultural practices, different belief systems.”

In terms of resource needs in a hospital setting, material resources, resource personnel, and feedback were mentioned. Reference guides containing “culturally-specific information regarding how different cultures view death” (HCP) and information on “cultural beliefs of the family unit – what is unique to that culture, what is important to know about that culture” (HCP) were a commonly identified material resource, as demonstrated by the excerpts below:

HCP: *There is so much out there, it would be helpful to have a reference guide.*

HCP: *Even a resource binder that goes through each of the cultures that we could potentially encounter and that would be helpful.*

HCP: *I think we should have some information of what... certain cultures are, you know. We should have some background where we can reference and we can go to and might not have all knowledge but have something to say ok they like this, this, and this, then we can help them properly through it.*

Information on African culture was cited as particularly important to include in such written material. One health care professional commented, “I think the African culture needs to be beefed up a little as far as resources.” Some additional material resources mentioned were “literature, videos” (HCP) and “some material on who to call when you have questions” (HCP).

Diversity experts were the most commonly mentioned resource personnel believed to be needed within the hospital setting. Examples of some comments include:

HCP: *I think people are the biggest thing to me. I think we can learn a lot from the books but if you have somebody who lives the life and lives the culture and is telling you what is worth, then it makes a stronger impression.*

HCP: *To have someone to call to debrief a situation and, specifically, what would be helpful in a situation – someone that is trained or an expert in diversity.*

HCP: *A professional, somebody who specializes in that area and maybe has a better idea as to what different cultures physically need or typically wish.*

This type of resource personnel was envisioned by participants to provide information to families as well as to staff. One health care professional expressed the view that it would be beneficial “*if we had access to people who had not just explained their background to us, but explained our facilities and abilities and willingness to offer certain things to families.*” Another described it as “*sort of like a translator situation but just not the language.*” It was also hoped that this personnel could “*help facilitate the relationship between the family and the health care team*” (HCP).

Interpreters and translators were additionally mentioned as helpful personnel, especially those that would be immediately accessible. A health care provider commented, “*I would like to see improved the ability to be able to translate for these people in an immediate situation.*” Another said, “*I would like to see us have trained health care interpreters more on site so that...they can be continuously available to families as there are needs.*”

The final resource that professionals mentioned they would like to have within the hospital setting was feedback. This included feedback from the families as well as from peers. One health care professional said it would be helpful to hear “*feedback from the families who have been here and how I have treated them, have I offended anyone, just those kinds of personal reminders... group discussions, maybe de-briefing.*” Another commented, “*I think it will be nice sometimes to*

*hear feedback from the family ourselves because sometimes we hear from the doctor or social worker but a lot of time we don't and...you can't improve on a job that you are doing if you don't get any feedback.*”

Lastly, participants commented that community resources were also important sources of cultural information as well as support for families:

HCP: *Workshops and in general any in-services from multicultural centres or in-group women aids society.*

HCP: *If there is community support for this particular culture for a particular family.*

HCP: *The only thing I can say for the community is sort of that there is a lot of time people from their church or whatever their support system is for the family.*

It was also acknowledged that health care professionals should become more knowledgeable about community resources: “*we should increase our knowledge of community and other community resources*” (HCP).





## Discussion

The findings of this research align with much of the information found in the literature regarding the pervasive influence of one's ethno-cultural background on culturally competent care as well as barriers and supports to providing such care. In addition, some new aspects of culturally competent paediatric care have been brought to light by the results, namely the significance of the hospital setting.

The literature emphasized the importance of adhering to the rituals involved in death and bereavement as the experiences that take place during this time can potentially have a lasting effect on families, an idea which was supported through this research (Koenig & Davies, 2002; Parkes, Laungani, & Young, 1997; Rosenblatt, 1997). Participants from 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. For example, rites are performed by religious leaders to provide "*God's blessing to go to heaven*" (Middle Eastern KI) and traditions such as placing the body on the floor instead of the bed are hoped to allow the soul to find peace (South Asian FG). It can be assumed that failure to respect and accommodate such rituals may bring distress to surviving family members regarding the afterlife of the deceased.

Waddell and McNamara (1997) warn against stereotyping individuals by their cultural groups, a behaviour that was also recognised by health care professionals as demonstrating a lack of culturally competent care. Despite this, both professionals and families acknowledged the occurrence of stereotyping within the hospital setting. 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 (Sudanese FG). Prejudices, which are intimately linked to stereotypes, were additionally identified as being held by some professionals.

Also identified by the literature as being influenced by ethno-cultural background was the expression of grief and the grieving process (Koenig & Davies, 2002; Saiki-Craighill, 2001). This was verified by the wide range of responses given by the study participants from various ethno-cultural groups in regards to dealing with grief. Depending upon the background of an individual, open expressions of grief were described as either acceptable for limited or extended periods of time or entirely discouraged. As pointed out by Saiki-Craighill (2001) as well as several study participants, the gender of the parent may also determine grieving customs. Further, the role of religion in the grieving process was found to be similarly varied, acting as the main support for some and as a source of frustration and confusion for others. Given this diversity, it seems apparent that without some direction, the provision of culturally competent support by health care professionals would be very difficult.

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, coming from 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. It seemed as though Muslim participants, in particular, preferred that a terminal prognosis not be shared with the families, especially with mothers. Although other obvious cultural preferences for being told the truth or being spared bad news were not apparent, it was clear that many participants had strong opinions on the issue, indicating that it is important for professionals in this situation to try to respect the wishes of the family to the best of their ability.

Relationships, understanding, and respect for diversity were identified as vital aspects of palliative care by both the literature and the study participants. Understanding and respect were integral to the definition and demonstration of cultural competency for both health care professionals and ethno-cultural participants. One way of gaining understanding that was mentioned several times was for staff to ask the families questions when they didn't know something or needed clarification. After reviewing the literature it is clear that establishing trusting relationships between health care providers and families is an imperative step in providing culturally competent paediatric palliative care. This opinion was shared by several of the professionals who were interviewed. They cited patience, interpreters and resource personnel as important components in facilitating this relationship. While the interpretation service seemed to be generally appreciated, some limitations were identified such as lack of translators, technical difficulties, inappropriate accents and the inability to limit the number of different interpreters used per family.

According to both the literature and the participants in this study, poor communication, language barriers, and lack of knowledge are major obstacles to providing culturally competent care. Despite the availability of interpreters, language was described as the biggest challenge by some

professionals and families. There were some participants from ethno-cultural communities who mentioned that language was not a barrier for them since they felt confident with the English language, yet there was evidence that communication may still break down, particularly in regard to medical conditions and treatments. Cantro, Larson, Scofield, Sourkes, and Cohen's (2002) warning that non-native English-speaking parents may not be able to fully understand all the medical details was demonstrated by comments from participants indicating that family members did not know what was going on and professionals who felt that they weren't getting their message across to family members. Efforts to improve this communication, such as staff being willing to ask and answer questions, seemed to be very much appreciated by family members.

As well, there was evidence that responsibility for effective communication falls on both staff and family members. Another area in which communication could be improved, according to previous research, is with the ethno-cultural community, a view which seems to be supported by this study's participants. Participants mentioned a desire for the health care system to do more networking and outreach with local communities and for the system to take advantage of community resources as a source of cultural information as well as support for families.

The literature indicates a lack of information and education on bereavement models specific to ethno-cultural families, without which health care professionals have little support in trying to meet the needs of such families. This deficiency and the frustration of professionals about it were clearly evident in the interviews. Professionals stated that they did not feel prepared to offer culturally competent care because they had insufficient knowledge of the needs and beliefs of those from diverse cultures. In addition, they felt that there

were little to no resources in place through which they could gain this information and, even if there were, they did not feel that they had the support or encouragement from higher level management to do so. Currently, much of their knowledge comes from previous experience or personal research, however professionals were eager to suggest various ways to increase staff knowledge including, formal education/in-services, reference guides and access to diversity experts.

Lastly, one barrier to culturally competent paediatric palliative care that came up frequently during interviews but was not mentioned in the literature was hospital setting. For participants, the physical layout of the hospital and the patient rooms could not accommodate the large groups of families and friends that often came to visit, provided inadequate privacy and made it difficult for families to attend to their spiritual needs and religious customs.

This research was limited by the inability to interview Sudanese parents whose child has died. A booklet for the Sudanese community could not be developed because of inadequate literature and research participation from parents.



## Recommendations

It is recommended that:

- Regular in-services on cultural competency and paediatric palliative care be facilitated for health care professionals.
- A training tool be developed for the paediatric units focusing on in-depth skill development in the area of cultural competency.
- Cultural competency resources be developed for healthcare professionals to have quick easy access prior to meeting with families and throughout the day
- Better access to interpretation and translation services be provided, with easier access to face to face interpreters for families and healthcare professionals.
- Multilingual resources focusing on bereavement, death, and dying be developed to support families.
- The hospital have cultural liaisons who have knowledge in the area of death and dying available as a support to staff.

Areas for Further Studies

- Conduct further research with a focus on all cultural groups, including white Canadians who have experienced the death of a child.
- Conduct research focusing on the experiences of the fathers and siblings.



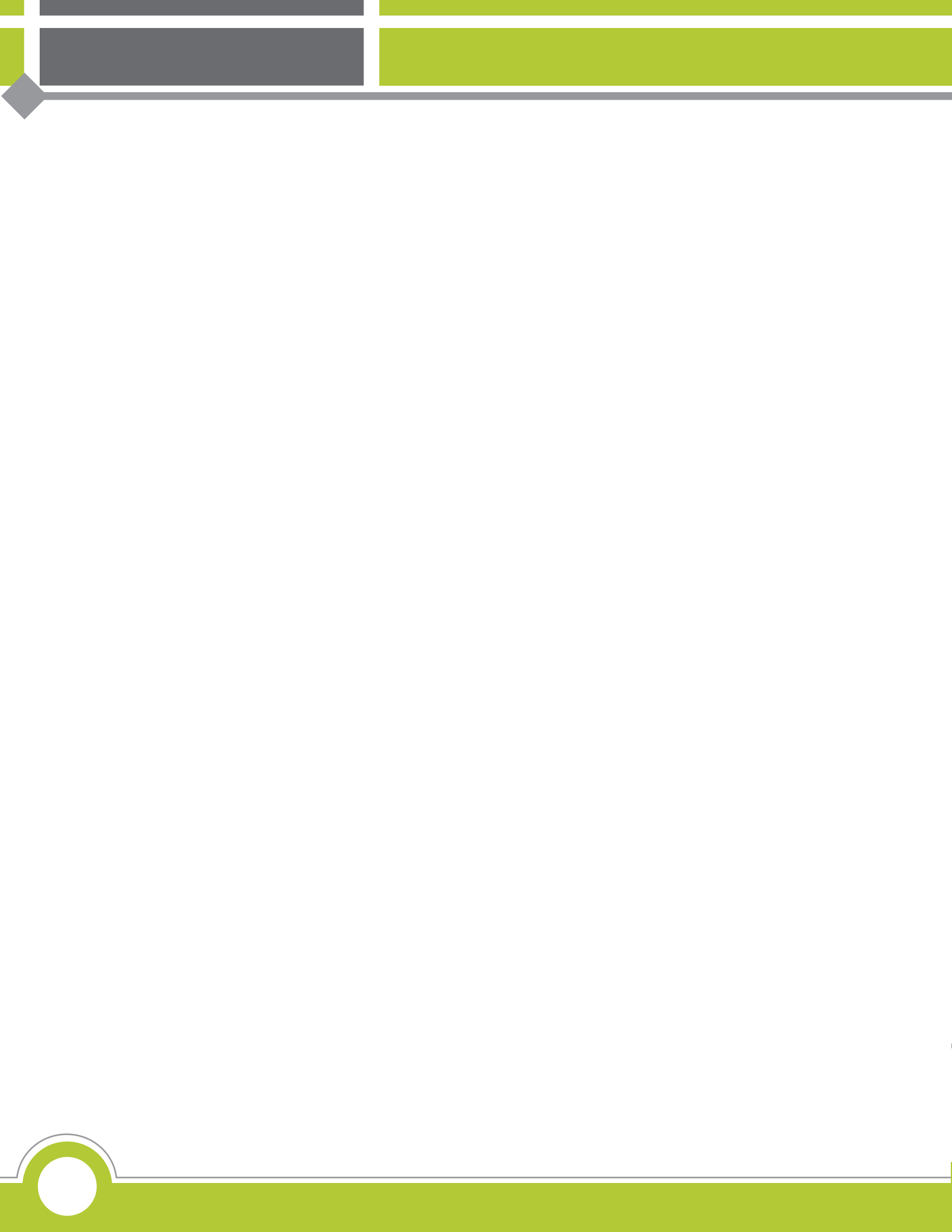


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# APPENDICES







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**APPENDIX A:  
GLOSSARY OF TERMS**





## Glossary of Terms

**Bereavement:** The state of having suffered a loss. (Librach & Abrahams, 2003)

**Cultural Competency:** A continuous process of seeking cultural sensitivity, knowledge, and skills to work effectively with individuals and families from diverse cultural communities and with their culturally diverse providers. (Agger-Gupta, 1995)

**Culture:** Patterns of learned behaviours and values that are shared among members of a group, are transmitted to group members over time, and distinguish the members of one group from another. Culture can include ethnicity, language, religion and spiritual beliefs, race, gender, socioeconomic class, age, sexual orientation, geographic origin, group history, education and upbringing, and life experience. (Agger-Gupta, 1995)

**Diversity:** All the ways we are unique and different from others. This term describes the differences that exist within Canadian society, across all four levels of diversity – individual, team/organizational, professional, and societal. In some contexts, diversity can be discussed narrowly as individual style differences or much more broadly across demographic and systemic historical/socio-political differences. In the latter context, there is a relationship with exclusion and inclusion (out-group/in-group) power dynamics. These qualities are included in the term culture. (Agger-Gupta, 1995)

**Grief:** The process of spiritual, psychological, social, and somatic reactions to the perceptions of loss. (Librach & Abrahams, 2003)

**Immigrant:** A person who has moved themselves (and often their families) to take up permanent residence and often citizenship in the new country. (Agger-Gupta, 1995)

**Mourning:** The cultural response to grief. (Librach & Abrahams, 2003)

**Paediatric:** Related to children who are 18 years and younger.







**APPENDIX B:  
INTERVIEW GUIDES**





## Family (parent) Interview Guide

### Demographic information

Name:	Names and age of children:
Age:	Arrival in Canada:
Marital status:	Country of origin:
Ethno-cultural group:	Arrival in Calgary:
Religion:	Languages spoken:
Number of children:	Extended family residing with you:

### Death surround (experience of illness / condition)

Date of diagnosis:	Number of hospital visits:
Name of illness / condition:	Length of last hospital visit:
Child's date of birth:	Date of child's death:
Age of child when diagnosed:	

**Every culture/person has a different view of death and dying. How would you like to refer to this life cycle ? (e.g. passing away, eternal rest)**

### Customs and traditions

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

- What are the customs and rituals that take place while a child is terminally ill in your cultural home country?
- What are the customs and rituals that take place as a child is passing away in your cultural home community?
- What are the rituals that take place after a child has passed away in your cultural home community?
- Have these changed for you since relocating?
- How have they changed?
- Were there any customs or traditions that you had to change or adjust?
- How was that process for you?
- What are your beliefs and customs regarding bereavement?
- What are the afterlife rituals?
- What are your afterlife beliefs?

- Would these be the same in your country of origin?
- Are there differences in the beliefs and rituals when dealing with the passing away of children and adults?
- How would these be different?

### The hospital experience

*Study Objective 2: To examine the level of care received as perceived by parents from the ethno-cultural community.*

- Tell me about your experiences at the hospital?
- How would this be different in your country of origin?
- Was there an opportunity for you to communicate your beliefs and customs to health care providers?
- Do you feel your beliefs and customs were honoured in the hospital?
- Did you feel that the hospital staff was culturally sensitive?
- Did you feel comfortable with the hospital staff?
- What responses of the staff were helpful to you?
- What responses were not helpful to you?
- Were you involved in counselling support at the hospital?
- Was counselling helpful for you or your family?
- What rituals took place in the hospital?
- What would you like to have happened in the hospital?
- Do you feel there were language barriers that had an impact on your experience?
- What words, phrases or expressions would you have liked to hear?
- What meaning do these have to you?
- Did you feel supported in the hospital?
- What could have happened to provide more support to you?
- What could have been offered to you while in the hospital?
- Are there any questions you would like to have been asked?
- Did you have experiences that were not supportive?
- What would you like to see change?
- What would you like to say to the health care professionals you encountered?
- What would you like them to know about your cultural beliefs, customs and traditions?
- What do you think those working in a hospital need to learn?



### Extended family and support system

*Study Objective 3: To understand the role and functioning of the ethno-cultural specific organizations as social supports for families.*

- Do you have extended family in Calgary?
- When did they arrive in Calgary?
- Do you have extended family in Canada?
- When did they arrive in Canada?
- Who in your family has been a source of support to you?
- What role do extended family members fulfill in providing support?
- Who outside of your family has been supportive to you?
- Are there any groups or organizations that have been a source of support to you?
- In what ways have they been supportive?
- Are there ways in which they could have been more supportive?

### Parent grief and bereavement experiences

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

*Study Objective 3: To understand the role and functioning of the ethno-cultural specific organizations as social support for families.*

- How do fathers/mothers grieve in your cultural home country?
- What is the role of family in supporting the bereaved parents?
- What is the role of community or friends in supporting bereaved parents?
- What are the roles of religious leaders when supporting bereaved parents?
- Is there a difference in the beliefs and customs regarding bereavement with a child's passing away (compared to an adult's passing away) in your cultural home country?
- Do you feel the beliefs and customs regarding a child's passing away and parent bereavement are honoured in your current community?
- Is your current community providing support to you and your family?
- Who has been supportive to you in your grief journey?
- Have you been involved in any bereavement counselling or group support?
- What are your beliefs about accessing and receiving counselling/support with the death of your child, i.e. talking about your child and emotions with professionals?
- What are your beliefs about talking about your child, and your feelings, with others?

## Meaning of your child's death

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

- Why do you think your child died?
- Where do you think your child went?
- Where do you think your child is now?
- Do you believe you have an ongoing relationship with your child after his/her passing away?
- Do you think you and your spouse (partner, child's other parent) have made the same meaning of your child's passing away?
- Have there been any changes to your beliefs, faith or spirituality as a result of this experience?
- Have you learned anything from this experience?
- What would you like others to know about this experience?

## Health Care Professionals Interview Guide

*Study Objective 4: To examine the level of understanding of health care professionals working with these families and their learning needs.*

### Demographic information

Place of birth:

Education:

Gender:

How long have you been doing this type of work?

Ethno-cultural background:

How long have you worked in this type of setting?

Languages spoken:

How long have you been with the Alberta Health Services?

### **Definitions: Culturally competent paediatric palliative care**

- How would you describe culturally competent paediatric palliative care?
- In your opinion what does culturally competent paediatric palliative care currently look like in your work setting?
- In your opinion what should it look like?

### Cultural competence: Personal awareness

- On a scale from one to ten, how would you rate how good you are at providing culturally competent care?
- What strategies would be helpful in raising this rating?
- Do you feel that you have been prepared to support parents from a variety of cultures?
- How did this take place?
- Do you feel there are any gaps in your knowledge?
- What do you think is missing and why?
- What have you learned from the children you have worked with?
- What have you learned from families?
- What have you learned from your colleagues?
- What resources for learning should be offered to you in the work environment?
- What resources for learning in the community should be available to you?
- What resources for support should be available to you?
- Do you feel there have been adequate opportunities for learning and support available to you?

### Cultural competence: within the hospital setting

- On a scale from one to ten, how would you rate the overall provision of culturally competent paediatric palliative care in your work setting?
- In your opinion is culturally competent paediatric palliative care being provided?
- What strategies do you think should be put in place to raise awareness?
- What are some of the behaviours that illustrate culturally competent paediatric palliative care in your work setting?
- What are some of the behaviours that illustrate a lack of culturally competent paediatric palliative care in your work setting?
- Why do you think these behaviours occur?
- In your opinion are there any barriers to providing culturally competent paediatric palliative care?
- Why do you think these barriers exist?
- What do you think needs to be accomplished or changed in order to ensure culturally competent paediatric palliative care?
- What resources for learning and support should be available to hospital staff?
- In your opinion have there been adequate opportunities for learning and support for all hospital staff?
- Are there other suggestions you have that would help to ensure culturally competent paediatric palliative care?

## Key Informants Interview Guide

### Demographic information

Name:	What is your occupation?
Gender:	What is your community, organizational or occupational role?
Ethno-cultural background:	What is the setting of the service you deliver?
Number of Languages Spoken:	Who are the individuals you serve?
Religion:	How many years have you spent in your current role?
When did you arrive in Canada?	
When did you arrive in Calgary?	

### Customs and Traditions

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

- What are the customs and traditions that take place while a child is dying in your cultural home country?
- What are the customs and rituals that take place after a child has died in your home community?
- Do you think any of these customs or traditions have been changed or adjusted in this country?
- How have they changed?
- What impact have these changes had?
- What are the beliefs and customs regarding bereavement after the death of a child in your cultural home country?
- Are there differences in rituals and customs depending on the child's gender?
- What are the afterlife beliefs?
- What are the afterlife rituals?
- Would these be different after the death of an adult?
- Is there a diversity of faith beliefs in your community?
- Do you feel this diversity is acknowledged in the Calgary community?



## Hospital Settings

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

- Are you called upon to support families within the hospital setting?
- Are you called upon to provide support after the family's hospital experience?
- Would you like to be called upon to provide this type of support?
- Are the traditional hospital settings meeting the needs of your community?
- What can be put in place to ensure these needs are consistently met?
- How can services and supports to parents and their dying children be improved?
- In your opinion does the Health Region provide culturally competent palliative care?
- Why do you feel this way?
- Do you feel that the diversity within your culture and faith is honoured in the hospital setting?
- What information do you feel is crucial for health care providers to be aware of in order to be culturally competent?
- What other information is important to be aware of?
- Are you aware of learning opportunities that health care professionals could utilize to improve their cultural competence?
- Do you have any messages for health care professionals?

## Community Support

*Study Objective 3: To understand the role and functioning of the ethno-cultural specific organizations as social support for families.*

- What type of informal community support is offered to parents as their child is dying?
- What type of informal community support is offered to parents after the death of a child?
- Do you feel this support is consistently offered to all parents in your community?
- What are your community's strengths in the area of grief and bereavement support?
- Do you feel there may be some gaps in this area?
- Why do you feel this way?
- What are your cultural beliefs about accessing external professional support for grief counselling?

## Focus Groups

*Study Objective 1: To gain knowledge and understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

We are currently developing focus groups in order to gain knowledge and increase understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died. This information will be used to develop teaching tools in order to increase the understanding of health care professionals when working with these families.

- Who do you think we need to talk with in order to learn more about customs and traditions in your community?
- Who would you suggest we contact?
- Do you think they would be interested in being involved in a focus group?
- Would they know of others who would be interested in being involved in a focus group?
- What would be the best way to contact these individuals?

## Religious/Spiritual Leaders Interview Guide

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

### Demographic information

Denomination/Faith:

Gender:

Role:

Cultural and ethnic history:

Number of years in current role:

Individuals served:

Place of birth:

Setting of service:

### Rituals and customs

- In your faith, what rituals are associated with death and dying?
- Are there different customs and rituals utilized when a child is dying?
- Are there changes in values, attitudes or beliefs surrounding a child's death?
- Are there differences in rituals or customs depending on the child's gender?
- Are there rituals associated with the afterlife?
- Are there beliefs associated with the afterlife?
- What rituals and beliefs are associated with bereavement and grief?
- Is there a diversity of faith beliefs in your community?
- Do you feel this diversity is acknowledged in the Calgary community?
- Do you feel this diversity is acknowledged in your own community?

### Roles of religious leaders

- What roles do religious leaders play when a child dies in your community?
- Do they perform religious ceremonies?
- When are they performed?
- Where are they performed?
- How are they performed?
- What are the meanings behind these ceremonies (why are they performed)?
- Do religious leaders provide bereavement support and, if so, for how long?
- How is it provided?
- What are your beliefs about accessing professionals for grief support?

## Hospital settings

- Are you, or others in your community, called upon to support families within the hospital setting?
- If so, who are the others in your community who are called upon to support families within the hospital setting?
- Would you like to be called upon to provide this type of support?
- Are the traditional hospital settings meeting the needs of your faith community?
- What can be put in place to ensure these needs are consistently met?
- How can services and supports to parents and their dying children be improved?
- In your opinion does the Health Region provide culturally competent paediatric palliative care?
- Why do you feel this way?
- Do you feel that the diversity within your culture and faith is honoured in the hospital setting?
- What information do you feel is crucial for health care providers to be aware of in order to be culturally competent?
- What other information is important to be aware of?
- Are you aware of learning opportunities that health care professionals could utilize to improve their cultural competence?
- Do you have any messages for health care professionals?

## Focus Group Question Guide

### Demographic information

Name:	What is your occupation?
Gender:	What is your community, organizational or occupational role?
Ethno-cultural background:	What is the setting of the service you deliver?
Number of Languages Spoken:	Who are the individuals you serve?
Religion:	How many years have you spent in your current role?
When did you arrive in Canada?	
When did you arrive in Calgary?	

### Customs and Traditions

- What are the customs and traditions that take place while a child is dying in your cultural home country?
- What are the customs and rituals that take place after a child has died in your home community?
- Do you think any of these customs or traditions have been changed or adjusted in this country?
- How have they changed?
- What impact have these changes had?
- What are the beliefs and customs regarding bereavement after the death of a child in your cultural home country?
- Are there differences in rituals and customs depending on the child's gender?
- What are the afterlife beliefs?
- What are the afterlife rituals?
- Would these be different after the death of an adult?
- Do you feel the customs and beliefs regarding a child's death are honoured in your current community?
- Is there a diversity of faith beliefs in your community?
- Do you feel this diversity is acknowledged in the Calgary community?

## Roles of Religious Leaders

*Study Objective 1: To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

- What roles do religious leaders play when a child dies?
- Do they perform religious ceremonies?
- When are they performed?
- Where are they performed?
- How are they performed?
- What are the meanings behind these ceremonies (why are they performed)?
- Do religious leaders provide bereavement support?

## Grief and Bereavement Experiences After the Death of a Child

*Study Objective 3: To understand the role and functioning of the ethno-cultural specific organizations as social support for families.*

- How do parents grieve in your cultural home country?
- What is the role of family in supporting bereaved parents?
- What is the role of community or friends in supporting bereaved parents?
- What role do you think religious plays for grieving parents?
- Do you believe that parents have an on-going relationship with their children after a child dies?
- How do you think this relationship is expressed (looks like)?
- Does your belief fit with those of your home country?
- Do you think the meaning of a child's death is different for mothers and fathers?
- How would you describe the differences?
- Do you feel these beliefs fit with those of your home country?
- What do you believe happens to a child after they have died?
- Do you feel your beliefs or values are similar to those of your home country?



## Hospital Settings

*Study Objective 1: To gain knowledge and understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.*

- Are the traditional hospital settings meeting the needs of your community?
- What can be put in place to ensure these needs are consistently met?
- How can services and supports to bereaved parents be improved?
- In your opinion does the Health Region provide culturally competent paediatric palliative care?
- Why do you feel this way?
- Do you feel that the diversity within your culture and faith is honoured in the hospital setting?
- What information do you feel is crucial for health care providers to be aware of in order to provide culturally competent paediatric palliative care?
- What other information is important to be aware of?
- Are you aware of learning opportunities that health care professionals could utilize to improve their cultural competence?
- Do you have any messages for health care professionals?



**APPENDIX C:  
PARTICIPANT CONSENT FORM**







UNIVERSITY OF  
CALGARY

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**Title of Project:**

*CULTURAL COMPETENCY IN PAEDIATRIC PALLIATIVE CARE.*

**Sponsor:**

The project is funded by the Child and Women's Health Diversity Program and the Grief Support and Palliative Care Team budget.

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This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

## Purpose of the Study:

- To gain knowledge and increased understanding of the values and beliefs of the ethno-cultural community when a child is palliative or has died.
- To examine the level of care received as perceived by parents from the ethno-cultural community.
- To understand the role and functioning of the ethno-cultural specific organizations as social support for families.
- To examine the level of understanding of health care professionals working with these families and their learning needs.

## What Will I Be Asked To Do?

The interview will take approximately two hours. We would like to interview you to understand your family outlook and values. You will be asked a few demographic questions and then some questions related to the illness and death of your child. This is a taped interview to ensure that we capture everything you discuss today, however the demographic information will not be taped. We realize that discussing the death of your child (name of child) will stir up emotions in you so your trained interviewer will call you a few days after your interview to ensure that you are doing alright. Your participation in this interview is voluntary and you may choose to end the interview or withdraw from the study at any time. You may also refuse to answer any questions at any time during your interview. There is no penalty for withdrawal from the study and you may still access all services at the Alberta Children's Hospital or have support in accessing alternative services.

## What Will I Be Asked To Do?

“Although your name is collected for publication and training purposes all participants shall remain anonymous.”

“Should you agree to participate, you will be asked to provide your gender, age, illness of your child, immigration history, country of origin, languages spoken, social support and religion.”

”There are several options for you to consider if you decide to take part in this research. You can choose all, some or none of them. Please put a check mark on the corresponding line(s) that grants me your permission to:”

I grant permission to be audio taped: Yes: \_\_\_ No: \_\_\_

I wish to remain anonymous: Yes: \_\_\_ No: \_\_\_

I wish to remain anonymous, but you may refer to me by a pseudonym: Yes: \_\_\_ No: \_\_\_

The pseudonym I choose for myself is: \_\_\_\_\_

You may quote me and use my name: Yes: \_\_\_ No: \_\_\_

## Are there Risks or Benefits if I Participate?

If you feel like you need some emotional support, someone to talk to after this interview please call Linda Kongnetiman 943-7742 or Bev Berg 943-7671 at the Alberta Children's Hospital. There is no additional cost to you to access these services.

For participating you will receive a small honorarium of \$25.00 plus the cost for child care.

## What Happens to the Information I Provide?

*Explain who will have access to the information collected.*

The information provided will be used to educate health care professionals within the Alberta Health Services to become more culturally competent when working with families from diverse backgrounds whose children are palliative or have died.

“Participation is completely voluntary, anonymous and confidential. You are free to discontinue participation at any time during the study. No one except the researcher and her supervisor will be allowed to see or hear any of the answers to the questionnaire or the interview tape. No names will be incorporated on the final report. Only group information will be summarized for any presentation or publication of results. The questionnaires are kept in a locked cabinet only accessible by the researchers and their supervisors. The anonymous data will be stored for seven years on a computer disk, at which time, it will be permanently erased.”

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## Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) \_\_\_\_\_

Participant's Signature \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Name: (please print) \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_



## Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

Ms. Linda Kongnetiman  
Diversity Program Coordinator  
Child and Women's Health  
Alberta Health Services  
403-943-7742

**[Linda.kongnetiman@albertahealthservices.ca](mailto:Linda.kongnetiman@albertahealthservices.ca)**

If you have any concerns about the way you've been treated as a participant, please contact Patricia Evans, Associate Director, Research Services Office, University of Calgary at 403-220-3782; email **[plevans@ucalgary.ca](mailto:plevans@ucalgary.ca)**

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form



**APPENDIX D:  
COMMUNITY RESOURCES  
FOR BEREAVED PARENTS**





**Alberta Children's Hospital - Palliative Care & Grief Support Service ♦ 403-943-7671**

Consultation, support and referral for bereaved parents and children. A six-week bereaved parent support group is offered for parents in conjunction with the Rockyview Grief Support Program

**Alberta Health Services Grief Support Program ♦ 403-943-3533**

- Rockyview Hospital
- Individual and group Grief Support Services.
- Lending library.

**Hospice Calgary ♦ 403-263-4525**

- Individual and group counseling for bereaved children and teenagers.
- Coinciding group for parents on “parenting grieving children”.
- Individual counseling for bereaved parents.
- Lending library.

**The Compassionate Friends ♦ 403-230-6062**

- Self-help group for bereaved parents.
- Monthly support meetings and telephone support.
- Newsletter and lending library.

**Caring Beyond ♦ 403-294-1131**

Self-help group for parents who have lost a child through miscarriage, stillbirth or neonatal death

**S.I.D.S. Support Group ♦ 403-265-7437**

Self-help group for parents who have lost a baby through sudden infant death syndrome.

**Victim Assistance Unit & Victim Assistance and Support Team (VAST) ♦ 403-268-8398**

Calgary Police Service: Volunteer support for families when police have been involved in responding to a death.

**Calgary Family Service Bureau ♦ 403-233-2370**

- Individual, family and marriage counseling.
- Multi-lingual counselors are available.

**Catholic Family Service ♦ 403-233-2360**

Individual, family and marriage counseling.

**Calgary Counseling Centre ♦ 403-265-4980**

- Multi-Lingual counselors are available.
- Individual, family and group counseling around anger management and other issues.

**AADAC ♦ 403-297-1071**

Individual, group and family counseling around substance abuse.

**Distress Centre ♦ 403-266-1605**

24-hour telephone support and counseling

**Suicide Services**

**403-297-1744** (regular office hrs);

**403-266-1605** (Crisis Line)

Prevention, Intervention and Bereavement counseling.

**Alive Alone ♦ 403-276-2296**

**(Contact: Kathy Cloutier)**

A support group is offered for bereaved parents who do not have surviving children. The group meets through McInnis & Holloway Funeral Homes. There is also an international website [www.alivealone.org](http://www.alivealone.org) to support these families.

