



**Death and Dying Beliefs and Practices
Among Low German-speaking
Mennonites: Application to Practice**

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Executive Summary

Low German-speaking (LGS) Mennonites are one group whose religious beliefs are fully integrated into their cultural perceptions and practices. Our study findings on death and dying among this group have led us to conclude that application of the cultural safety framework to the palliative or end-of-life care of LGS Mennonites is warranted but has not been completed on a formal basis. The creation of our accompanying Best Practice Document (Kulig & Fan, 2013) will hopefully be a first step toward seeing consistent application of such a framework in practice situations with the LGS Mennonites.

Approach

The purpose of this mixed-method study was to gain an understanding of beliefs and practices related to death and dying among the LGS Mennonites, in order to develop evidence-based palliative-care guidelines that will allow healthcare and social service providers who assist individuals from this religious group to provide effective care. The research was conducted in the rural area of Southern Alberta and Southern Manitoba, where there are 37,000 to 40,000 LGS Mennonites.

Including Mennonites who work with this population and meeting with LGS Mennonite ministers in the participating provinces were essential steps in helping to ensure the success of the research. The data analysis was conducted simultaneously with the data collection, which allowed for alterations in the questions and probes that were used.

For this study, our research questions were:

1. What are the beliefs and practices about death and dying among LGS Mennonites in Southern Alberta and Southern Manitoba?
2. What are the current policies regarding provision of palliative care for this unique population?
3. What are best practice guidelines for palliative care of LGS Mennonites in the two participating geographic areas?

Data Collection

We completed a documentary analysis of policy statements and standards regarding end-of-life and palliative care in four countries (Canada, Australia, New Zealand and the United States). We located these documents through web searches for specific terms (palliative, end-of-life), and by government agency (health).

Qualitative interviews were conducted with both healthcare personnel and members of the LGS Mennonite community. In total, we conducted interviews with 58 LGS Mennonite individuals (Manitoba: 34; southern Alberta: 24) and completed 36 interviews with healthcare personnel (Manitoba: 27; southern Alberta: 9). The use of Mennonite research assistants helped to increase the participation of the LGS Mennonite individuals, who have traditionally been taught to isolate themselves from the mainstream. The advisory team consisted of Mennonite representatives and key clinical personnel in each of the three participating health regions. Community visits were arranged every year to train research assistants, and to meet with local key individuals, ministers, and healthcare providers.

Results

The documentary analysis we conducted revealed that there were few documents that specifically addressed cultural or religious diversity in their policies, guidelines or initiatives and no documents that specifically addressed the palliative or end-of-life care needs of the LGS Mennonites.

From our interviews, we learned that the LGS Mennonites are comfortable with non-Mennonites caring for them in the hospital or at home, but that they do prefer to know that these caregivers respect Christian beliefs. LGS Mennonites believe strongly that a person dies based in keeping with God's will; being asked to consider removing life support from a family member therefore requires spiritual reflection and guidance. In addition, the LGS Mennonites do not always consider "palliative" care in a positive light. For some that we interviewed, admitting that care is palliative is a signal of "lacking hope," which does not mesh with their Christian belief in the need to feel "ever hopeful."

Among the LGS Mennonites we spoke with, care for the ill and dying was provided in a family context. The daughters of elderly parents were the ones to provide the physical care; in some families, decision-making was the son's role. Large family groups in this community are common; when someone is ill, it is typical for family members to sing, pray and sit with that person. The minister's role is important, too: they provide spiritual guidance to the family in circumstances of illness and impending death. The participants discussed burial practices from the perspective of having lived in other countries, including Mexico, Bolivia and Belize. There were variations from one congregation to another but all adhered to the basic principle of publicly respecting the individual who has died.

When we asked healthcare and social-service professionals about their perceptions of LGS Mennonites, they related that this group was not comfortable expressing their emotions and needs, and did not actively ask for help from service providers. Language barriers can lead to miscommunication between the service providers and the LGS Mennonites. Some LGS Mennonites have misunderstood or misinterpreted the term “palliative care,” viewing it as a covert form of euthanasia. Consequently, they refuse to accept this service, or stop seeing their physicians when the service is suggested.

In conclusion, the LGS Mennonites accept death as part of their physical life, and as an opportunity for people to reflect on their lives, so that they can rebuild their spiritual relationships with God. It is important to educate healthcare and service providers to honour their clients’ cultural beliefs and practices, and to be culturally sensitive. It is also important not to make generalizations relating to all LGS Mennonites, since they come from several different backgrounds.

Death and Dying Beliefs and Practices Among Low German-speaking Mennonites: Application to Practice

Context

Peoples’ perceptions of and reactions to death and dying, suffering and illness are shaped to a great extent by their cultures and religions. In other words, how end-of-life decisions are made, and how care for the end-of-life stage is provided in a family or in a community, must take cultural and religious values and practices into consideration. Whether a death occurs suddenly or is expected, it is a difficult experience for people who are dying and for those who look after them. It is even harder when healthcare providers do not speak the same language as those who need care, or when they do not consider or understand patients’ cultural and spiritual concerns. Culture and religion are often thought of as two separate terms, but in this study, there is no clear boundary between these two concepts. In our increasingly multicultural society, there are heightened demands for healthcare services and programs that address the individual needs of specific populations. One such group is the Low German-speaking (LGS) Mennonites. In Canada, the majority of the LGS Mennonite population resides in Alberta, Manitoba and Ontario. The research findings reported here focus on the beliefs and practices relating to death and dying among this particular group; we also discuss ways in which care

can be provided in palliative and end-of-life settings in order to uphold the principles of cultural safety. This study was conducted in both Alberta and Manitoba; it provides a contextual understanding of the differences and similarities between these two provinces. In this report, we use the terms “palliative” and “end-of-life” interchangeably.

Background to the Low German-speaking Mennonites

Low German-speaking (LGS) Mennonites are a group of Anabaptists whose heritage can be traced to the Reform Movement in Europe in the 1500s. To escape from religious persecution, during the Reformation many LGS Mennonites moved from the lowlands countries, such as Netherlands, Friesland, and western Germany, to Prussia. There, they developed Mennonite Low German or Mennonite “Plautdietsch” (Epp, 1993; Cox, 2008) which is primarily a spoken language.

The LGS Mennonites were known as hard-working farmers, and at the beginning of the 1800s, Catherine II, the czarina of Russia, invited them to come to Russia. Catherine II not only granted the Mennonites complete religious and educational freedom, but also freed them from military services for a hundred years. When the Russian government later abandoned the “100-year Privilegium,” the LGS Mennonites searched for a new homeland that would allow them to maintain their religious and educational autonomy while also allowing them to live close together and maintain their farming lifestyle.

Migration is a common theme among the LGS Mennonites. They were originally referred to as “Kanadiers” (Loewen, 1993) signifying the Canadian migration that commenced in the 1870s when approximately 18,000 of them migrated to North America (Loewen, 2001). In the 1920s, the Canadian government’s enforcement of public education, and the growing sentiment against LGS Mennonites due to their refusal to serve in World War I, led to their resettlement in Latin American countries. During this time, nearly 8,000 LGS Mennonites left Canada (Dyck, 1967; Janzen, 2004, 2007; Peters, 1988) and resettled in other countries, including Mexico, Paraguay, Belize, and Bolivia (Bowen, 2006). The LGS Mennonites in Mexico encountered similar issues to those they had experienced in Russia and Canada, such as difficulties maintaining their private schools. In the 1950s, more than 5,000 LGS Mennonites moved to Belize (then known as British Honduras) (Dyck, 1967; Pauls, 2004). In the 1960s, more than 100 Old Colony Mennonites from La Crete, a rural area in Alberta in Canada, resettled in San Ignacio in Bolivia (Bowen, 2004).

During the last forty years, social issues and economic struggles in some Latin American countries have led many LGS Mennonites to return to Canada or to migrate to the United States (Janzen, 2010). An estimated 40,000 to 50,000 LGS Mennonites now live in Ontario, 20,000 in Alberta (Banman & Epp, 2010, MCC Networking Minutes Mexico) and 15,000 in Manitoba. Approximately 80,000 LGS Mennonites live in Mexico (Janzen, 2010) and approximately 25,000 reside in the United States.

The LGS Mennonites practice adult baptisms. They believe in pacifism, the separation of church and state, and simplicity (DeLuca & Krahn, 1998; Redekop, 1969; Sawatzky, 1971). Scriptures, as God's word, are considered the only truth, and this has significant influence on this community's daily life. Some LGS Mennonites cannot read, and are therefore not even encouraged to study the Bible. They rely on their ministers' interpretations to understand God and his words.

It is not possible or appropriate to make statements that generalize practices among all LGS Mennonites, given the variations in their church doctrines which range from relatively conservative to somewhat liberal. Examples of specific churches are: the Old Colony Mennonite Church, the Rheinlander Church, the Sommerfelder Church, the Kleine Gemeinde, the Evangelical Mennonite Churches and the Evangelical Mennonite Missionary Church (EMMC) in different geographic jurisdictions. Each of these churches advocates different sets of behaviors and rules, some allowing modern technology and devices such as computers, for example, while others do not. To add complexity, some LGS Mennonites do not agree with, believe in, or behave exactly according to regulations made and reinforced by their church leaders (Kulig & Fan, 2011). Some LGS Mennonites from the Old Colony Mennonite churches attend public schools in Canada and they use the Internet for work or study, while others do not. Some LGS Mennonite churches ban motorized vehicles and public education, believing that such vehicles and institutions bring the community members closer to the material world. To the more conservative practitioners, modern technologies and knowledge are believed to promote a sense of pride or personal uniqueness (Canas Bottos, 2008), which violates their belief of equality and maintaining a simple lifestyle. Among these groups, competition and personal distinctiveness are generally not allowed. In addition, some churches in Canada and Mexico have banned or excommunicated members who disobey the regulations regarding the use of radios, or practice a lifestyle outside the boundaries of expected behavior (e.g., substance abuse), while others do not excommunicate members for these reasons. Clearly, generalizations are not possible.

Cultural Safety as a Framework

Cultural safety as it applies to the healthcare environment is a concept that has developed as a response to the colonizing processes that severely affected Indigenous peoples. The notion of cultural safety was first applied in New Zealand and Australia (Polaschek, 1998; Williams, 1999) but has also been used in the Canadian context (Smye & Brown, 2002). "Cultural safety" moves beyond "cultural sensitivity" by addressing the need for health professionals to understand the historical and social causes of the power differentials among groups, and to change their behavior to address these differentials (Polaschek, 1998). Cultural safety creates a safe environment for people; it allows for shared respect and enables groups to learn together (Williams, 1999). However, cultural safety cannot occur without cultural awareness, sensitivity and competence. It has become one of the nursing standards expected of registered nurses (RNs) in other parts of the world, and it is becoming more widespread in Canada, where it has been used in curriculum development to prepare the next generation of RNs (Arnold, Appleby & Heaton, 2008). Cultural safety complements nursing standards, including the code of ethics for RNs, which emphasizes preserving dignity and providing safe, compassionate and ethical care (CNA, 2008). It encourages questions such as, "What is the reason the service exists?"; "How do we ensure the clients receive an appropriate and meaningful service delivery?" and "How do we prevent assimilationist practices?" (Williams, 1999).

In Canada, cultural safety in nursing is often focused on the Aboriginal healthcare context, but a similar approach could be used by healthcare professionals in the care of other groups as well, such as the LGS Mennonites. Fostering cultural safety is a reflective process that draws attention to the social and political context of healthcare delivery, and encourages health professionals to consider that the care they provide may place the client at risk or make them feel disempowered or demeaned (Smye & Browne, 2002). We chose this framework for the current study for two reasons: (1) a long history of discrimination and prejudice has already led to repeated relocation of the LGS Mennonites from one country to another, and they continue to be at risk for discrimination by those who assume that their low literacy levels and religious beliefs curtail their ability to become involved in developing appropriate healthcare for themselves or their families; and (2) this study provided the first opportunity to evaluate the usefulness of the concept of "cultural safety" with a non-Aboriginal group and the health personnel who work with other groups. In our study, the issue of cultural safety was highlighted by asking reflective questions about what types of palliative-care policies, guidelines and care would be most beneficial for LGS Mennonites.

Approach

The purpose of this mixed-methods study was to gain an understanding of the beliefs and practices of LGS Mennonites about death and dying, with a view to applying the findings to improve the approaches to healthcare that are provided to this community. Specifically, the research questions were:

1. What are the beliefs and practices about death and dying among LGS Mennonites in Southern Alberta and Southern Manitoba?
2. What are the current policies regarding provision of palliative care for this unique population?
3. What are best-practice guidelines for palliative care of LGS Mennonites in the two participating geographic areas?

The research group conducted qualitative interviews with healthcare providers (e.g., nurses and physicians) and other relevant stakeholders (e.g., social workers, funeral directors), and also undertook analysis of existing documents and policies in relation to palliative care among diverse populations.

The research reported here is one in a series of studies conducted by the lead author. The studies have been carried out in collaboration with an advisory board that has included individuals affiliated with Mennonite organizations that provide services to the LGS Mennonite population, and clinicians and program managers who are responsible for the provision of services and care to this unique group. Through all of this research, it has been crucial to build and maintain trust with the LGS Mennonites to ease their discomfort in working with individuals whose beliefs differ from theirs. Therefore, the inclusion of Mennonites who work with this population has been an essential step in helping to ensure that the research processes – including data collection and analysis – are conducted in a way that is respectful of the LGS Mennonites' lifestyle. The insights and advice of all of these individuals helped to guarantee that the perspectives of the LGS Mennonites were heard and understood (Hall & Kulig, 2004). It also helped to ensure that appropriate plans would be developed to disseminate the findings of the study, and that materials would be produced that are suitable for use by healthcare and social-service providers in caring for the LGS Mennonites.

The research discussed here was conducted in Southern Alberta and Southern Manitoba in 2009 to 2011, and additional field work was conducted by the lead author in Durango Colony, Mexico, in 2012.

Meetings with the LGS ministers in the participating Southern Manitoba communities were conducted before the interviews

began. These meetings included both authors (i.e., the principal investigator [PI] and project coordinator [PC]), who viewed them as an opportunity to gather information that further illuminated our understanding of the topic under study. Meetings with the ministers in the participating Southern Alberta communities proved more difficult; ministers in this geographic location had greater concerns about their membership participating in research studies. We therefore discussed the research with a limited number of ministers in telephone conversations.

Discussions about the study were also broadcast during the research period through a Low German radio program that was based in southern Manitoba; the program was heard by Low German-speaking Mennonites who live in Canada and the United States, as well as those who live in Mexico and a few South American countries. When the data collection was complete, meetings were held with providers and decision makers involved with the LGS Mennonites in both provinces, and the findings and implications for care were discussed. In addition, presentations were made to healthcare and social-service providers as well as to members of the ministry and to community members in general not only in the provinces where the study was conducted but also in southern Ontario where there is a large population of LGS Mennonites.

Mennonite individuals who speak Low German (Plautdietsch) were hired to work as research assistants (RAs) and conduct the interviews, and their participation increased our credibility with the LGS Mennonite community. The RAs were selected on the basis of their knowledge of the community's complex social rules, and their personal lack of conflict with the specific group participating in the study. They also had the necessary social skills needed to be sensitive and caring toward the LGS participants during interviews involving potentially uncomfortable topics.

The interviews were normally held in the participants' homes, the office of the ministers, or in a private room in a healthcare facility. In order to reduce concerns among the LGS Mennonites who were uncomfortable with technology such as tape recorders, the RAs took only short notes during the interviews. Immediately after the interview, after they had left the presence of the participants, they tape-recorded a summary of the interview, including actual quotes. Other studies with this group (Kulig & Hall, 2004; Kulig, et al, 2008; Sawatzky, 1971), have been conducted successfully in this manner. A final way in which trust was established was to reduce media coverage of the proposed study out of respect for the privacy of the communities involved, whose members often do not desire such attention and who do not find it complimentary to their religious beliefs.

The research team included decision makers from three health regions (two in Southern Alberta which has since amalgamated into one region, and one in Southern Manitoba which has since expanded its boundaries and become a larger health region). It included individuals who are responsible for policy and program development, health promotion and palliative care in their health regions, and individuals who provide direct care to the LGS Mennonites. Other members of the team worked for non-profit organizations that are responsible for services or provide assistance to the LGS Mennonites in Alberta and Manitoba.

The data analysis was conducted simultaneously with the data collection, which allowed for alterations where indicated in the questions and probes that were used. Thematic analysis was conducted with the application of axial, open and selective coding to derive themes from all of the data that was collected (Liamputtong, 2013). Questions that arose through the data analysis process were clarified with the RAs during our routine teleconference meetings. Further discussion was also held with the members of the advisory board who were of Mennonite background, some of whom had worked with the LGS Mennonites in Mexico. In addition, our attendance at the 2010 Biannual LGS Mennonite Networking meeting in Cuauhtémoc, Mexico – to which we had been invited by the Mennonite Central Committee (MCC) – provided us with an opportunity to present the preliminary findings of the study, discuss any discrepancies, and clarify meaning of Plautdietsch terms that were used by the participants. (Note: Such clarifications are necessary because, for example, in the context of death and dying, the Plautdietsch word that is equal to the English word for “hope” has a particular meaning, and care needs to be taken to be sure it is interpreted correctly.) We also had coffee meetings with a number of individuals of a Mennonite background who were able to answer questions and queries that helped to ensure that our analysis accurately reflected the social and local LGS Mennonites contexts.

We took several steps to ensure the trustworthiness of the findings during our study, specifically the criteria of credibility (the data “fits” the participants’ viewpoints), transferability (the data can be generalized to other LGS Mennonites), dependability (the results “fit” the data that were generated) and confirmability (the interpretation matches the participants’ viewpoints) (Lincoln & Guba, 1986). Our hiring of Mennonite individuals as RAs and inclusion of Mennonite individuals from non-profit organizations to be members of the advisory team also helped us to establish credibility. Furthermore, we conducted the data analysis to include discussions with the RAs and the Mennonite research team members, thereby clarifying the ideas, codes and themes that emerged. We worked to attain transferability through

discussions with the clinical team members, who provided feedback to us about the usefulness of the findings to their practice settings. All of the details provided about the data collection and analysis processes established dependability. Finally, we addressed the issue of confirmability by obtaining agreement among the team members about the themes that were generated through the data analysis process.

The research team employed integrated Knowledge Translation (iKT) to ensure that information about the study, including its purpose, findings and outcomes, were shared with relevant individuals from the beginning of the research until its completion. This was accomplished in part through the meetings that were held with the ministerial members of the relevant churches. In addition, the team made presentations to clinical and other staff members (e.g., funeral directors) as well as to interested Mennonite community members, on an ongoing basis – before the study commenced, when we had preliminary findings, and after our findings were fully available. The researchers also delivered scientific presentations at conferences. The first author conducted a webinar with the Kansas Statewide Farmworker Association to discuss the LGS Mennonite research program in general, including the current study on death and dying. We also developed written materials, including this final report and the Best Practice Guideline (Kulig & Fan, 2013a); which will be distributed widely to relevant groups and posted on our website. Peer-reviewed articles were also developed and published (Kulig & Fan, 2011; 2013b) and are ongoing in development.

Documentary Analysis

To ensure that all relevant documents were located, we conducted web searches for specific relevant agencies (e.g., palliative interest groups), conferences or government agencies (e.g., health agencies). When we located documents, we placed the name of the documents into Google Scholar to determine where it had been cited and followed up on any other leads if citations were located. Finally, we specifically looked at government and care agency sites for Canada, Australia, New Zealand, and the United States to ensure a full search for all relevant documents.

The review located few documents that were of value for the documentary analysis component of this study. In total, 13 documents were located. Our documentary analysis revealed that few existing guides to healthcare practice specifically addressed cultural or religious diversity in their policies, guidelines or initiatives. Of the few documents that did exist, we examined three: *A Cultural Competence Guide for Primary Health Care Professionals in Nova Scotia* (Nova Scotia Department of Health, 2005), *Cross-Cultural Considerations in Promoting Advance Care Planning in Canada* (BC Cancer

Agency, 2008), and *Multi-Faith Guide for Health Care Professionals at Hamilton Sciences* (Hamilton Health Sciences, 2010). These had been developed to support healthcare providers to become aware of the cultural or religious issues in providing care to ethnic minorities in a specific region. Of these, no documents specifically addressed the palliative or end-of-life needs of LGS Mennonites, and very few addressed specific palliative care needs of culturally diverse groups in general.

All of the documents were reviewed using the same process. The document was read in depth to determine if key words (culture, religion, and/or minority) were referred to in the discussion of clients, policies or programs that were noted. If there was such a reference, then the document was further analyzed, and a form that had been developed to ensure a standardized format of review and assessment was completed.

Questions on the form included:

- “What are the definitions of palliative care?”
- “Who generated this definition?”
- “What are the standards for palliative care of culturally diverse groups?”
- “For the LGS Mennonites?”
- “What took place previously in response to palliative care for culturally diverse groups?” and
- “What programs and/or courses were developed and implemented to prepare health professionals for palliative care among culturally diverse groups?”

This form was helpful in earmarking the strengths and deficiencies of the documents we located for review. We were also able to identify general and specific statements noted in the document about caring for culturally diverse groups in palliative care situations. In this case, a “general” statement would be, for example, one like this: “People of cultural diversity require care that addresses their specific care needs.” A “specific” statement would name a particular group and provide an example of the type of care that would be given to them.

The British Columbia Provincial End-of-Life Care Framework (Ministry of Health, 2006), for example, had only one reference to cultural groups, noting within its ethical principles that care providers “should respect the autonomy of the individual, their right to confidentiality and privacy and the ethical principles common to their culture” (p. 4).

A Cultural Competence Guide for Primary Healthcare Professionals in Nova Scotia (2005), on the other hand, is intended to assist primary healthcare professionals to provide culturally competent healthcare to all groups. Key concepts

such as “culture,” “cultural competence” and “equitable access to all groups” are defined and expanded upon in this guide, and this document came closest to using a cultural safety framework of all the documents that we reviewed. The Nova Scotia guide included a discussion about oppression and racism, and these concepts were linked to the need for healthcare professionals to examine their values and beliefs when caring for others. Cultural and religious diversity in Nova Scotia were discussed and the document included specific examples from several groups (e.g., First Nations, immigrant groups) to illustrate their presence in the province and the issues identified by these groups in terms of accessing care. The document also included practical tools that could be used by healthcare professionals in the provision of care (including general cultural competence tools such as LIAASSE). Finally, the guide included a self-assessment tool for primary health providers which also addressed end-of-life issues among diverse groups. The thoroughness of the document and its usefulness for healthcare providers make it an excellent example of a guide to the provision of care to culturally and religiously diverse groups, even though it does not specifically address palliative or end-of-life care.

Perspectives of the Low German-speaking Mennonites

Demographic Information

In total, 58 LGS Mennonite individuals (n=58), including 33 females and 25 males, with a range of age from 21 to 84 years, were interviewed in the two participating provinces: Alberta and Manitoba. In southern Alberta, 24 LGS Mennonite participants were interviewed, of which eight were men and 16 women. The range of age in this group was 21 to 64 years. In southern Manitoba, we interviewed 34 LGS Mennonite participants, including 17 males and 17 females, who ranged in age from 25 to 84 years. The participants had a full range of experiences with death including losing immediate family members (parents, spouses, children), extended family members (uncles, aunts, nieces and nephews) and friends.

The majority of the LGS Mennonites in this study had been born in Mexico and belonged to the Old Colony Mennonite churches. After resettlement in Canada, many of them changed to less conservative Mennonite churches. The Mennonite private schools in Mexico have their own educational system, and a different curriculum from the public schools in Canada and the United States. Therefore, the grade levels used in the Mennonite private schools may not be equal to the ones used in Canada. However, according to the demographic information provided by the participants, most of the LGS Mennonite men (many LGS Mennonite men)

had a higher education level than the LGS Mennonite women in this study.

The ministers we spoke with had provided spiritual support for families as well as being responsible for conducting numerous funerals within their churches. In addition, they had developed a close working relationship with specific local funeral directors who had earned reputations for providing respectful services for the LGS Mennonites.

The following discussion reflects the participants' experiences in their countries of origin (Mexico, Belize, Bolivia); the practices that they note may not be routinely held by LGS Mennonites that reside and grow up in Canada. Despite this, their perspectives provide a context for their expectation of what will happen when they experience the death of a loved one in the Canadian healthcare system. For example, some LGS Mennonites have experienced a lack of support by ministers and church congregations in Latin American countries which may mean that they do not expect support from the congregation or minister in Canada.

The Low German-speaking Mennonite Interviews

Perceptions of Illness

We discussed the sources of illness and types of diseases with all LGS Mennonite participants. They were able to provide a long list of illnesses and diseases that they attributed to lifestyle choices. In this regard, they noted for example that if pregnant women engage in activities such as smoking and drinking alcohol, they may compromise fetal development, leading to fetal injury and premature birth. One of the women we interviewed noted that poor nutrition may cause malnutrition, while high levels of stress may damage the immune system, meaning "the body no longer has the strength to fight illnesses." They discussed the relationship between lifestyle choices and diseases even when they did not always understand the actual links between these two concepts. Those we interviewed also noted that illnesses may be inherited (e.g., diabetes), but again they were not aware of the scientific reasons for this. Finally, some individuals with whom we spoke, particularly those from the more conservative churches, also related that some diseases, and the pain that accompanies them were caused by God or Satan.

Suffering was an important recurring element in the discussions we had with the LGS Mennonites. They felt that suffering can originate in sinfulness, or derive from the illness or disease, or from broken or difficult relationships. Some of the LGS Mennonites noted that God provided opportunities for suffering in order to help the individual realize that they had strayed from God and needed to alter their behaviors.

Examples included individuals who had made lifestyle choices of engaging in substance abuse or behaving inappropriately in their relationships with others (e.g., initiating domestic violence). They felt that through suffering and attending to their inappropriate behaviors, the individual would become closer to God and experience a life that is more personally fulfilling but also one that includes more positive relationships with family members and friends (Kulig & Fan, 2011).

Caring for Someone who is Dying

Family members are intimately involved in the care of Mennonites who are dying. Family members engage in activities such as sitting by the bedside, singing to the dying person or providing physical comfort. The provision of physical care is usually provided by the mothers and daughters. In some families, discussion of the person's condition is restricted to the physicians and the sons or husbands.

The LGS Mennonites are comfortable with non-Mennonites caring for them in the hospital or at home, but they do prefer to be cared for by people who adhere to Christian beliefs. Healthcare providers should not be surprised if family members ask about their belief systems, and they need to be prepared to be asked if they are Christians or read the Bible. The LGS Mennonites do not always consider "palliative" care in a positive light. Palliative care sometimes is perceived as a form of assisted death and palliative care providers are seen as supporters of euthanasia. It is also believed that people who receive palliative care services are encouraged to end their lives. Some individuals that we interviewed believed that accepting palliative care is a signal of "lacking hope," which does not fit with their Christian belief that they need to feel ever-hopeful. Hope, for the LGS Mennonites, describes the sense of spiritual future, which can only be given by God. Hope and God's mercy still exist even when there are no curative treatments available for the patients and they can no longer expect to return to a fully functioning role.

End-of-Life and Palliative Care

The LGS Mennonites we interviewed said that they routinely sought and listened to the advice provided by physicians when family members were diagnosed with terminal conditions, such as a terminal cancer. They said that their minister also played a large role in helping the family members to determine if procedures such as surgery that had been suggested by the healthcare team should be conducted. Participants indicated that it was more common for the husband and/or the oldest son to be involved in discussions with the physician and ministers about their loved one's illness and outcomes than for such discussions to involve other members of the family.

Some topics were difficult for the LGS Mennonites to fully comprehend and in many cases they were not able to accommodate certain measures within their religious principles. For example, most of the LGS Mennonites we interviewed said they would not be comfortable with developing an end-of-life directive. Considerable discussion was held about the meaning of this document, and this in turn led to discussions about God's will in reference to the person's chances of surviving. After a lengthy discussion, participants often indicated that they preferred to give oral instructions to their children than to prepare an end-of-life directive. They did not understand that, unlike a written document, oral directions would not be upheld in a court of law.

We also spoke with the participants about the removal of life support. Their answers conveyed their concern about the meaning of life and death. Many felt that in order to consider the removal of life support, it would be necessary to know for certain that the patient had no hope for survival. A number of interviewees noted that they would request guidance from their minister to deal with a specific situation like this. The ministers we spoke with also indicated that the issue of removal of life support is a very important one for their congregations. They also questioned the validity of diagnoses that dying individuals were in such grave health that survival could not be expected: they provided examples of instances where individuals had recovered and gone on to good health despite diagnoses by physicians that they would not survive. The ministers emphasized that they did not want to take a chance and have an individual removed from life support if there was any hope of recovery. They also emphasized that ultimately it was God's will to determine if the person would survive or not, and thus a decision about removal of life support would not be one that some of them would be comfortable in making. Finally, the ministers wanted to ensure that removing of life support did not constitute euthanasia.

Funerals and Burial Practices

In the matter of funeral and burial practices, there were variations from one congregation to another among the LGS Mennonite churches in southern Manitoba and southern Alberta, but all participants we interviewed supported the basic principle of publicly honouring individuals who have died. Many interviewees had acquired their perspectives on funeral and burial practices while living outside of Canada – in Mexico, Bolivia or Belize. These practices had changed in some cases when the LGS Mennonites moved to Canada. For example, at one time “singing off” occurred routinely in Manitoba LGS Mennonite communities, but it is no longer common. “Singing off” is a practice done the evening the person has died when family and friends gather at the home of the deceased. Singing off provides comfort to the family

of the deceased and is believed by some to represent the “singing off of the soul” to its final resting place.

In Mexico and other southern locales, preparation of the body was routinely done by specific women within the LGS Mennonite community. Many of the LGS Mennonites who live in Canada today will work with funeral directors for the funeral preparations; these directors are chosen carefully to ensure that they are respectful of the LGS Mennonite traditions and beliefs. In some places in Canada, LGS Mennonites still prefer to dig graves and lower caskets into the graves without outside intervention. In some congregations, however, even when the community does the work itself, it is becoming more common for mechanized equipment to be used for digging the graves.

The funeral begins with a service in the church where all are welcome. In Mexico, the entire family would routinely attend, but in Canada this custom has changed slightly: some families do not take their children out of school to attend funerals. In Mexico and other places in the south, buildings such as implement sheds may be used for the service if a large crowd is expected, which it often is. Family members from Canada and the United States drive to the funerals in Mexico as a matter of course. Under normal circumstances, it is important that families of the deceased receive support from those in their church congregation and members of the community.

We learned that in the case of excommunications or banning of church members, which may result from a variety of inappropriate behaviors ranging from using electronic devices or owning a computer to engaging in substance abuse or infidelity, ministers may alter the normal burial practice depending on their interpretation of the bible in regard to the excommunicated person. In Mexico, in the case of the death of an excommunicated individual, he or she may be referred to at the funeral as “a friend,” rather than being fully recognized as a brother or sister, and the body may be on display outside of the church rather than inside it. In addition, individuals who are excommunicated and closely related to the deceased may not be allowed to sit with the family of the deceased in the church. Excommunications also occur in Canada and depending upon the church, decisions may be made to include or exclude such individuals. For example, we did hear about individuals who had been excommunicated who were not allowed to sit with their families during relatives' funerals.

The graveside service is a community event at which there are prayers and singing, followed by the filling in of the grave. In Mexico, it is routine for family members and others who attend the funeral to participate by using the shovels to

place dirt on the coffin. After the graveside service, it is normal practice for the attendees to visit with the deceased's family members while they share *faspa*, or an afternoon meal of coffee, tea and buns.

Two other issues to note: cremation is not commonly supported among the LGS Mennonites given their belief that the body needs to return to dust as noted in the bible; burial of body parts and stillborn babies or miscarried fetuses are commonly practiced among some individuals and families.

Healthcare and Social Service Providers

Demographic Information

In addition to the 58 interviews with the LGS Mennonites, we interviewed 36 care providers who were experienced in end-of-life care for the LGS Mennonites and their families. They came from various disciplines, and included social workers, pastoral care providers, physicians, nurses and healthcare assistants. Nine of the 36 care providers were from southern Alberta and 27 of them were from Manitoba. Many of the participants had a Mennonite background and could speak various levels of Plautdietsch, High German or both languages.

Interview Themes

We asked the healthcare and social-service professionals that we interviewed about their perceptions of the LGS Mennonites. The fact that LGS Mennonites typically do not complain was perceived as a positive approach. Complaining among this group is not only a sign of weakness, but also a sign of religious disbelief. Group members have been taught to accept and appreciate what they have in their lives because everything is in God's hands. The LGS Mennonites also have great respect for healthcare and social-service providers. They routinely take their medications and follow their physicians' medical recommendations.

Some healthcare providers were aware that many LGS Mennonites use home remedies, such as "Wonder Oil" and "Mennonite Juice," for health problems such as stomach aches and headaches. They may show the medicines they used in Mexico or other Latin American countries to their physicians, but they do not openly talk about their home remedies with healthcare providers.

The care providers also found that the LGS Mennonites do not actively ask for help and suggestions when they are receiving care. Instead the LGS Mennonites prefer to ask their friends, church members, and ministers for suggestions before they

use the available formal health services. In addition, this group is not inclined to provide feedback or suggestions to caregivers. The service providers we interviewed also related that the LGS Mennonites are not comfortable expressing their emotions and needs. This lack of communication enhances the difficulty caregivers have in providing care to the LGS Mennonites in a manner that meets the needs of community members.

Healthcare and social service providers told us that the LGS Mennonites to whom they have provided care accept the diagnosis of "brain death," but do not support the use of technology such as ventilators or other life-support systems. Generally, LGS Mennonites do not have advanced life directives (ALDs), living wills, or wills; the uses of such documents all remain unfamiliar concepts for them. Organ donation is also not common among this group of people; conservative LGS Mennonites believe that it is inappropriate to donate or accept an organ because in doing so the perception is that the organ is being removed from a person who is still alive and the natural dying process is being interrupted. Some ministers from both liberal and conservative churches stated that they do not encourage organ donation, but they will not criticize members of their congregations who do decide to donate organs after their deaths.

Social service and healthcare providers told us that the lack of education and language barriers of LGS Mennonites make it difficult for them to understand complex health issues. For example, while many understand that diabetic patients should not ingest sweet foods such as sugar and honey, they do not understand the biological causes of the disease or the importance of having a balanced diet to prevent or maintain it. This lack of full understanding means that providers are challenged to determine ways to explain diseases. Both social and health service providers indicated that language barriers also lead to some miscommunication between service providers and the LGS Mennonites. For example, the terms "germ" and "palliative care" cannot be directly translated into Plautdietsch. Without appropriate translation and interpretation, palliative care can be misunderstood or misinterpreted by some LGS Mennonites. Palliative refers to the care of individuals who have chronic or disabling diseases. This term has been misinterpreted by LGS Mennonites as a process to hasten death and was interpreted as a covert form of euthanasia. This would mean that they would refuse to accept palliative care service or would stop seeing physicians who suggested it because they would feel that they had been given an inappropriate suggestion.

Other cultural differences can also create difficulties for those providing health and social service care to LGS Mennonites. For example, in western healthcare facilities, it is common to

put up decorations to celebrate what would be considered “routine holidays” such as Thanksgiving, Halloween, and Christmas. However, some of these decorations are not appropriate in a healthcare setting where LGS Mennonites are receiving care. For example, the celebration of Halloween is considered inappropriate in the LGS Mennonite community as they are seen to celebrate death and demonic power. Entering a health facility and seeing symbols that focus on this particular day may be uncomfortable for this particular group of people.

We also spoke with funeral providers who have provided care to LGS Mennonites, and have been chosen based upon the expectation that they will provide respectful and genuine care during the planning and delivery of the funeral. Their experiences vary depending on location. For example, a mechanized earth digger is used in some conservative graveyards in Winkler in southern Manitoba, but it is not allowed by their sister churches in southern Alberta. Funeral directors also mentioned that conservative church members often request that makeup not be applied to the deceased.

The funeral for the LGS Mennonites is a review of the deceased member’s faithful life in the physical world, and a reaffirmation of the faith of the community. In Alberta where there are fewer LGS Mennonites and funeral directors therefore had a limited history with this group, there was much to learn. For instance, funeral directors who had little nor no experience with a group that still dug their own graves (in one instance by hand) or moved the coffins themselves to the graveside and into the grave had to learn that this was routine and respectfully watch as the funeral service unfolded.

Cultural Safety and the LGS Mennonites

The documents we reviewed that were relevant to palliative and end-of-life care showed no indication that cultural safety was considered or incorporated. In addition, the interviews we conducted with healthcare professionals did not identify any formal consideration or application of cultural safety measures for the LGS Mennonites. Some individual healthcare professionals did recognize the need for this group’s cultural and religious backgrounds to be assessed in the planning and implementation of their care plan, but did not understand their socio-history or religious background sufficiently to understand the links between their beliefs and their actions. For example, some of the individuals we interviewed understood the importance of the family being together as a group with their relative when they were dying, but did not understand the LGS Mennonites’ choice to be “non-complainers.”

Our assessment leads us to conclude that application of a cultural safety framework to the palliative and end-of-life care of LGS Mennonites is warranted, but there is no evidence that one is being applied in clinical practice.

Conclusions

In conclusion, this multi-methods study revealed that the understandings of, and practices related to, death in the LGS Mennonite community is heavily influenced by their cultural and religious beliefs. In general, the LGS Mennonites accept death as part of their physical life, and as an opportunity for people to reflect on their lives, so that they can rebuild their spiritual relationships with God. Their spiritual needs are addressed through some important rituals, which need to be respected by healthcare and social service professionals, such as singing and sitting in silence around the sick person’s bed. It is important to educate healthcare and service providers to honour their clients’ cultural beliefs and practices, and to be culturally sensitive. It is also important not to make generalizations relating to all LGS Mennonites, since they come from several different backgrounds. The cultural safety framework holds promise as a means to work with LGS Mennonites in the provision of care that addresses their cultural and religious needs.

Key Recommendations for Decision Makers

- Communicate with LGS Mennonite patients, their families, and their church leaders as necessary to ensure their culturally and religiously relevant needs and preferences are met.
- Provide inservice education to all healthcare and social service providers to enable the provision of culturally safe and appropriate end-of-life care to LGS Mennonites.
- Use culturally appropriate vocabulary – e.g., avoid use of phrases such as “for God’s sake.”
- Respect individuals’ cultural practices and rituals – e.g., do not interrupt their singing, prayers or sitting in silence.
- Provide interpretation services for those who are not fluent in English.
- Provide ongoing mutual education, training and support between service providers and the LGS Mennonites.
- Provide simple explanations about palliative care services and advanced healthcare directives, even if you are not asked.
- Be aware that some clients simultaneously ingest prescription medications with a variety of over-the-counter medicines (e.g., Wonder oil) as well as home remedies.
- Be aware that the interactions among family members and clients and their behaviors are based in values and beliefs that deserve respect. Avoid behaviors and language that make the patients and their family members feel ashamed and excluded.
- Support efforts by patients and their families to seek culturally safe and competent care.
- Work with LGS Mennonite communities to recruit LGS individuals into the regulated nursing workforce.

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