DEVELOPMENT OF A RESOURCE MANUAL FOR CRITICAL CARE NURSES CARING FOR CULTURALLY DIVERSE FAMILIES INVOLVED IN THE ORGAN AND TISSUE DONATION PROCESS

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Abstract

Approaching ethnocultural families grieving the death of a family member to discuss the option of organ and tissue donation (OTD) can be challenging for nurses. At a large urban multi-site hospital organization in Montreal more than a third of referred and eligible deceased patients are members of an ethnocultural community. Despite the large number of ethnocultural families there is a dearth of knowledge amongst nurses on how to provide culturally congruent care to this population. This resource manual provides nurses with the skills to complete a cultural assessment in order to offer culture congruent care throughout the OTD experience. Leininger's Theory of Culture Care Diversity and Universality (1988), and Morrison, Ross, Kalman, and Kemp's Model of Instructional Design (2011) were used to design and plan the contents of a resource manual. The evidence-based manual evaluates nurses' cultural self-competence, provides an overview of some of Québec's ethnocultural community OTD process concerns, provides guidance on how to gather pertinent ethnocultural information from families, and how to use the information to offer culture congruent care (Leininger, 1995). This practicum report describes the development of this nursing resource manual and how advanced practice nursing competencies informed the chosen course of action. Included are the methods to evaluate the resource manual and the identification of limitations and recommendations.

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Canada has over 4100 people actively waiting for an organ transplant; approximately 23% of this population live in the province of Québec (Canadian Institute for Health Information, 2014; Transplant Québec, 2014). In Québec, as in the rest of Canada, the demand for organs exceeds the supply. Although in 2013, 165 Québec donors donated 601 organs, 37% of families declined organ and tissue donation (OTD) (Transplant Québec, 2014). At the McGill University Health Centre **(**MUHC) between 2011 and 2012, 35% to 40% of eligible donor patients were from ethnic minorities (Fernandez, 2013). In another Montreal hospital, ethnocultural community members represented 26% to 36% of eligible donors in 2011 to 2012 (M.-C. Prud'homme-Lemaire, personal communication, September 27, 2013). Given the large number of ethnocultural families who are faced with the OTD decision, nurses need to be equipped with the knowledge and skills to provide culturally congruent care to this population. Attention to families cultural needs may help them move through the OTD process in a positive manner, may increase uptake of potential OTD, and may improve patient care outcomes.

In my role as nurse clinician for OTD at the MUHC, I am responsible for ensuring nursing staff are educated on how to care for families involved in the OTD process. This is partially accomplished by translating research findings into clinical practice. For example, research has shown cultural values impacts the OTD process (Irving et al., 2011). Differing cultural values and beliefs generates a need to adapt nursing care in critical care settings to create meaningful experiences for ethnocultural families (Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011). Based on discussions with my nursing colleagues, my expertise working with OTD families, management (Patricia Rose, MUHC Associate Director of Adult Surgical Nursing Services), researchers (Dr. Andréa Laizner, MUHC Nursing

Practice Consultant-Research), and statistical trends that points to an increasing number of potential ethnic donors, it was felt that a resource manual that guides nurses to provide culturally sensitive nursing care to families throughout the OTD process was needed. Furthermore, given the culturally diverse population at the MUHC, the complexity of the OTD process, and that a resource manual which addresses cultural diversity in OTD does not exist, this practicum project fills a gap in existing knowledge. The proposed resource manual (see Appendix A) would also be used as partial fulfilment of the requirements for the practicum component of the Master of Nursing program.

This practicum report provides a synopsis of the background and rationale for the practicum. This includes an overview of the literature on OTD and a discussion of how Leininger's (1988) Theory of Culture Care Diversity and Universality, and Morrison, Ross, Kalman, and Kemp's (2011) Model of Instructional Design guided the development of the resource manual. The advanced nursing practice competencies (Hamric, 2009; Hamric, Hanson, Tracy, & O'Grady, 2014) of direct clinical practice, guidance and coaching, consultation and collaboration, evidence-based practice, leadership, and ethical decision-making are threaded throughout the practicum report. Limitations and recommendations for practice are addressed, along with suggestions for evaluation.

Background and Rationale

Canada's foreign-born population represents 20.6% of the total population and is comprised of more than 200 ethnic origins (Statistics Canada, 2014); the highest proportion among the G8 countries (Ask, 2013). Recent immigrants make up 17.2% of the foreign-born population and 3.5% of the total population in Canada. The majority of immigrants reside in the provinces of Ontario, British Columbia, Québec, and Alberta; with 70% living in three of

Canada's largest metropolitan areas: Toronto, Vancouver, and Montreal. The MUHC, located in Montreal, is an integral member of the Réseau Universitaire Intégré de Santé (RUIS) McGill (RUIS McGill, 2013). Created in 2003, the RUIS McGill is the largest of four territories and covers 63% of the province while providing healthcare to 1.8 million people (RUIS McGill, 2014). A large majority of these people come from a varied ethnocultural background. The MUHC has six facilities that participate in OTD (Lachine General, Montreal Chest, Montreal Children's, Montreal Neurological, Montreal General, and Royal Victoria hospitals). Given the large number of immigrants residing in Montreal, coupled with the increasing number of potential organ and tissue donors from this population (Fernandez, 2013), resources are needed to ensure these families receive culturally congruent care as they are faced with the OTD decision-making process.

There are limited clinical practice resources that specifically address the needs of ethnocultural families within the context of OTD however, recognition of culture as a determinant of health is embedded in social media websites (e.g., Colorado University School of Medicine - Department of Pediatrics, 2014; Queensland Government, 2013; University of Washington Medical Center, n/d). One website in France (Fondation Greffe de Vie, 2013) was found that promotes culturally congruent care for OTD families and provides resources (e.g., videos) for health care professionals to refer to when approaching ethnocultural families for OTD. Two Canadian websites were reviewed for ethnocultural consideration for the OTD process (Transplant Québec, 2013; Trillium Gift of Life, 2013). These three resources were created by healthcare professionals in collaboration with members of ethnocultural communities and offer valuable insights into creating the proposed resource manual.

The significance of culturally congruent care throughout the OTD process is supported by Québec legislation. The Québec Civil Code law that governs OTD (Éditeur officiel du Québec, 2010) requires that a hospital organization have a structure in place to facilitate OTD. At the MUHC, when a potential donor is identified the OTD nurse clinician and the health care team meet with family members to discuss OTD. Patient eligibility is based on the MUHC's OTD referral clinical triggers for potential deceased organ donation (see Appendices B and C) and Héma-Québec's clinical trigger for deceased tissue donation (see Appendix D). There are two types of deceased organ donation. The first type is organ donation after neurological determination of death (NDD). NDD is the irreversible loss of the capacity for consciousness combined with the irreversible loss of all brainstem functions, including the capacity to breathe (Canadian Council for Donation and Transplantation [CCDT], 2003). The second type is organ donation after cardiocirculatory death (DCD). DCD refers to patients who do not fulfill neurological criteria for death and for whom continuing medical care is considered futile. Death is anticipated to occur imminently upon withdrawal of life-sustaining therapy (CCDT, 2005a). Deceased tissue donation refers to the potential procurement of eyes (corneas), cardiac valves, skin, bone, and tendons (Héma-Québec, 2010). Nurses and families need to have an understanding of the above terminology and guidelines to ensure the OTD decision is an informed choice and to address OTD family concerns.

Reasons given by ethnocultural family members at the MUHC and the other Montreal hospital center for declining donation include issues about body integrity, lack of knowledge on deceased donation, failure to accept the diagnosis of neurological death, and a lack of family pre-mortem discussion on OTD (Fernandez, 2013; M.-C. Prud'homme-Lemaire, personal communication, September 27, 2013). Cultural values, traditions, and spiritual beliefs

often regain importance when people are ill or dying (Kemp, 2005; Warren, 2005), may influence the OTD decision. These take on added significance when a death is sudden or traumatic, and the family is approached for OTD.

Nurses need to be cognizant of the influence that culture plays in a family's OTD experience. Nurses play a critical role in supporting families throughout the OTD process and must address the dying process, the withdrawal of life sustaining therapy, and OTD with sensitivity (Lloyd-Williams, Morton, & Peters, 2009). In addition to cultural values and beliefs, a family's coping skills and emotional reactions are dependent upon the individuals involved and the context of the situation (Lazarus, 2000; McCubbin & McCubbin, 1996). Research has shown that families involved in the OTD process appreciate an individualized approach to care as it conveys that the goal of nursing care is not just about procuring body parts, but rather helping the family cope with a difficult situation, and to ensure informed decision making (Jacoby, Radecki-Breitkopf, & Pease, 2005). In order to provide culturally congruent care to families throughout the OTD process, it is important that nurses are aware of their own culture and that of potential OTD families. This resource manual will provide nurses with the knowledge and skills to complete a cultural self assessment, a family cultural assessment, and to develop a plan of care that is unique to each OTD families' needs. This is evident within the objectives of the practicum.

Practicum Objectives

The objectives of this practicum were based on advanced practice nursing core competencies identified by Hamric (2009; Hamric et al., 2014): direct clinical practice, guidance and coaching, consultation and collaboration, evidence-based practice, leadership, and ethical decision-making. The main goal for this practicum was to develop a resource manual for nurses

working in critical care to enable them to provide culturally congruent care to families throughout the OTD experience. Specific objectives of this practicum were:

1. To complete a literature review that explores the educational needs of nurses who care for ethnocultural families throughout the OTD experience.
2. To consult and collaborate with key stakeholders (e.g. nurses, members of ethnocultural community) to inform the development of the content of the resource manual
3. To provide a framework for nurses to complete a cultural assessment of families involved in the OTD process.
4. To promote collaboration between the OTD multidisciplinary team and the family to provide culture congruent care.
5. To demonstrate application of the advanced practice nursing core competencies within the context of OTD.

Literature Review

A review of the literature was carried out utilizing the databases of CINAHL, PubMed, social sciences literature, and Google Scholar. Key words were individually searched and then combined to identify research studies and bodies of work to inform the creation of a resource manual on Québec's ethnocultural communities. There are three key bodies of literature that facilitate an understanding of the needs of nurses and ethnocultural families throughout the OTD experience: (1) ethnocultural communities in Canada, (2) nurses' perceptions of OTD, and (3) family needs and OTD. In order to situate the context of this literature review and this practicum it is necessary to briefly define culture.

What is Culture?

This practicum is guided by Leininger's (1995) definition of culture which is "the learned, shared, and transmitted knowledge of values, beliefs, norms, and lifeways of a particular group of people that guides an individual or group in their thinking, decisions, and actions in patterned ways" (p. 60). There are five key terms threaded throughout the literature that address culture in nursing practice: Cultural awareness (Goode, 2006), culture congruent care (Leininger, 1995), cultural humility (Tervalon & Murray-Garcia, 1998), cultural safety (Wood & Schwass, 1993) and cultural sensitivity (Srivastava, 2007) (see Appendix E). Each term highlights aspects of respectful cultural care and is evident in Leininger's theory of transcultural awareness. If nurses gather information on a family's ethnocultural values, beliefs, and needs as defined by Leininger, nursing care will reflect the five terms noted above.

Ethnocultural Communities in Canada

According to Statistics Canada (2014) Canada's foreign-born population represents 20.6% of the total population and that Asia and the Middle-East are Canada's largest sources of immigration. Statistics Canada data reports that 19.1% of the Canadian population identify themselves as a visible minority. Many of the ethnocultural communities have been grouped together, for example Blacks represent a number of distinct cultural groups such as African, Haitian, Jamaican, etc. (Statistics Canada, 2014). In Québec, 11.7% of the populations' mother tongue is not French, English or Aboriginal (Statistics Canada, 2014). The ten most commonly spoken languages in this group are Arabic, Spanish, Italian, Creole, Chinese, Greek, Portuguese, Romanian, Vietnamese, and Russian. This information, in conjunction with previous data gathered on ethnocultural families offered OTD at the MUHC (see Appendix F), was used to inform the selection of represented ethnocultural communities in the proposed resource nursing

manual for OTD. The five ethnocultural communities that were consulted were Arabic, Chinese, Italian, Spanish-American, and Romanian. Given the number of ethnocultural communities, nurses need to be prepared to provide culturally congruent care.

Nurses' Perceptions of Organ and Tissue Donation

The role of nurses throughout the OTD process is complex as they are expected to care for both the patient and the family at a time when families are trying to cope with the circumstances and consequences of a death (Daly, 2006; Monforte-Royo & Roqué, 2012). Adding to this are the diverse needs of families who are members of an ethnocultural community. There are two main factors identified in the literature that impact a nurse's role in caring for ethnocultural families throughout the OTD process: (1) nurses' attitudes and knowledge about OTD, and (2) nursing care experiences with ethnocultural families involved in the donation process.

Nurses' attitudes and knowledge about organ and tissue donation. Hibbert (1995) carried out an exploratory study with a group of Canadian ICU nurses who had cared for neurologically dead patients and their families. Nurses spoke about the stress they felt trying to maintain donor stability while supporting grieving families. This stress however, was balanced with a sense of acquired satisfaction as they supported the family throughout the OTD experience. Similar findings have been reported in other studies that explored ICU nurses' OTD experiences in Australia (Pearson, Robertson-Malt, Walsh, & Fitzgerald, 2001), Brazil (Guido, Linch, Andolhe, Conegatto, & Tonini, 2009; Lemes & Bastos, 2007; Sadala & Mendes, 2000), Norway (Høye & Severinsson, 2008; Meyer, Bjørk & Eide, 2012), and Sweden (Flodén, Berg, & Forsberg, 2011; Flodén, Persson, Rizell, Sanner, & Forsberg, 2011). In contrast, Lemes and Bastos (2007) found that ICU nurses' attitudes toward OTD were not always positive. In fact,

nurses that cared for both donors and recipients questioned whether donation was doing more harm than good. Nurses found it distressing to care for transplant recipients who struggled to regain their health or who died post-transplant.

Nurses described feelings of being unprepared to deal with a family's needs, grief, and questions throughout the OTD process (Guido et al., 2009; Høye & Severinsson, 2008; Pearson et al., 2001). In two studies this sense of unpreparedness was felt to negatively impact the nurses' relationship with the family (Høye & Severinsson, 2008; Sadala & Mendes, 2000). Educational opportunities that focus not only on how to care for a potential donor but how to deal with the needs of family members throughout the OTD process have been identified as being essential to facilitate nurses' coping (Daly, 2006; Guido et al., 2009; Hibbert, 1995; Lemes & Bastos, 2007; Meyer et al., 2012). In several studies ICU nurses offered suggestions to decrease their emotional stress such as team debriefings, seeking peer support to talk about and acknowledge feelings and emotions (Hibbert, 1995), and physical activity (Guido et al., 2009; Pearson et al., 2001).

Nursing care experiences with ethnocultural families involved in the donation process. Threaded throughout the literature is the significant role that culture and ethnicity plays in end of life care (Mazanec & Tyler, 2004; Pottinger, Perivolaris, & Howes, 2007). There is a consensus in the literature that in order to provide holistic cultural competent care it is critical that nurses understand how their beliefs influence their perceptions, decisions, and coping skills (Maloney & Wolfelt, 2001; Pottinger et al., 2007; Srivastava, 2007). Nurses need good communication skills, and a knowledge of different ethnocultural end of life rituals, values, and beliefs as they support families throughout the OTD process (Carey & Cosgrove, 2006; Kagawa-Singer & Blackhall, 2001; Kemp, 2005; Kongnetiman, n/d; Lobar, Youngblut, & Brooten, 2006).

Nurses who are aware of their own cultural beliefs and those of OTD families can develop a plan of care reflective of their patient and family's unique cultural needs and hopefully influence families' OTD experience in a positive manner. A recent example where nurses bridged end of life care, family needs, and donation was the use of technology that allowed a family living in Iran to be virtually present with their deceased daughter in a United States hospital (White, 2014).

Research examining nurses' experiences of OTD with ethnic groups found that a cohort of Australian ICU nurses cared for everyone connected to the deceased as if they were family members (Pearson et al., 2001). This expanded view of family allowed the nurses to offer tailored therapeutic nursing interventions to everyone present by not judging the merit of support based on biology or type of relationship (Wright & Bell, 2009). This approach fostered an experience that was emotionally and professionally rewarding for the nurses (Pearson et al., 2001). In contrast, a group of Norwegian ICU nurses remarked how work patterns were disrupted as immigrant families to Norway invited immediate, extended family members, and friends to the bedside (Høye & Severinsson, 2008).

Nurses have also reported difficulties in tailoring interventions to meet specific needs of ethnocultural families (Guido et al., 2009; Høye & Severinsson, 2008; Kierans & Cooper 2013). Nurses in Høye and Severinsson's (2008) study expressed distress as they struggled to develop a therapeutic relationship with family members. They stated that caring for ethnocultural families was challenging as customs, such as ensuring female patients had their heads covered when visitors were present, needed to be integrated into routine nursing care. Communication challenges were also experienced as family members were often asked to act as interpreters, which caused conflict when the message was sensitive or children had to translate. Nurses spoke

of being perturbed by the emotional outbursts of some family members as this was not something they typically dealt with when care involved non-immigrant families. Nurses described being distressed with the attitude of some of the male ethnocultural family members who treated them like physician handmaidens or who would refuse to talk to them because they were female. Guido et al.'s (2009) exploratory study with a group of Brazilian ICU nurses uncovered similar themes to Høye and Severinsson (2008) as to the emotional and work life distress caused by differing family values and beliefs.

While research studies have begun to demonstrate how ethnocultural values and beliefs impact nursing care, the OTD experience recommendations arising from the studies to address this important issue are few. Breitkopf's (2009) survey of a group of predominantly Hispanic women found that although donation attitudes were positive, medical mistrust, a belief of non-equity in donated organs, and that the approach was made during at time of family crisis created barriers to donation. As Hispanic-American groups are heterogeneous, the author recommended an assessment of cultural values, religious concerns, and language preferences be carried out.

Three other studies, did make some general recommendations for nurses working with ethnocultural families throughout the OTD experience (Bellali & Papadatou, 2007; Ghorbani et al., 2011; Schirmer & de Aguiar Roza, 2008). Bellali and Papadatou's (2007) research with Greek parents and Schirmer and de Aguiar Roza's (2008) work with Brazilian family members both found that family members needed to understand the donation process and to be actively involved as they were the primary decision-makers. Suggestions focused on the family and individualized plans of care, a respectful OTD approach, a clear explanation of the concept of neurological death, and family time to reflect on presented information. Recommendations from Ghorbani et al.'s (2011) retrospective review of Iranian family members who declined donation

centered on the need for conveying information on the concept of neurological death and the development of strategies to help families understand neurological death. These recommendations stem from the fact that almost half of family members did not equate or believe the absence of brainstem reflexes meant a person was dead and family members had continued to hope for a miraculous recovery.

Despite the fact that recommendations for the integration of culture congruent care (Leininger, 1995) have been insufficiently addressed in research, several groups have attempted to address the issue. The Commission de l'éthique de la science et de la technologie (2004), published their review of the ethics involved in balancing organ need and family approach for donation for the Québec government. The report was based on the principles of respect, autonomy, and trust toward family members. Cultural values and religious beliefs were not addressed, but based on the emphasis of the aforementioned principles; an inference could be made that the families' values and beliefs should be respected. The Expert Panel on Global Nursing and Health (2010) formed a task force responsible for developing a set of standards for cultural competence in nursing practice. The goal was to define standards that can be universally applied by bedside nurses, as well as those working in administration, education, and research. One of the standards focused on the need for cultural knowledge and the need to create resources for nurses containing specific information on commonly cared for ethnocultural communities; something this practicum aims to create.

Family Needs and Organ and Tissue Donation

Health care professionals need to assess family values, and beliefs, in order to develop culture sensitive care throughout the OTD process (Baldinazzo, 2008; Daly, 2006; Maroudy, 2008). The dying process can create an intense emotional time for family members who may

experience difficulty accepting a diagnosis of neurological death, while at the same time having to make a decision about OTD (Pottinger et al. 2007; Ralph et al., 2014). These concerns, in addition to respecting death rituals and body preparation (Pottinger et al., 2007), requires nurses to practice from a family centered care approach that incorporates recognition of the influence that one's spiritual and cultural needs can have on the OTD experience (Randhawa 2012).

There is a consensus in the literature that an exploration of a family's cultural beliefs and values positively impacts end of life care (Furukawa, 1996; Leduc, Rachédi, Labescat, Montgomery, & Mongeau, 2010; Schenker et al., 2012; Truog et al., 2001; Wright & Bell, 2009). Therefore, an awareness of cultural needs is critical when caring for ethnocultural patients and their families (Truog et al., 2001). Families need time to understand and process information, to participate in decisions regarding care of their family member, to express their emotions, and to have their questions answered in simple terms (Furukawa, 1996; Wright & Bell, 2009). Family members need to able to acknowledge the death, to perceive support from the nurses, to visit the bedside often, and to involve the services of spiritual and allied healthcare professionals (e.g., social worker) (Furukawa, 1996; Wright & Bell, 2009). Despite existing literature that acknowledges the importance of completing an end of life cultural assessment and actively involving family members in the care of the patient, there is a dearth of literature that fully explores the significance of completing a nursing cultural assessment for the OTD process. The following sections examine (1) families' experiences with OTD, (2) ethnocultural families and OTD, (3) factors that influence OTD decision-making, and (4) Montreal area ethnocultural communities involved in the OTD process.

Families' experiences with organ and tissue donation. Jacoby et al. (2005) used focus groups to examine the experiences of family members who consented to or declined OTD.

Participants valued the support, concern, and respect expressed toward them and the deceased relative. Needs identified by participants included a clear explanation of neurological death, time to absorb the bad news, an explanation of the donation process, confirmation that their family member would not be treated like a body of parts, a lack of pressure to consent to OTD, and privacy to make their decision. Spiritual and religious practices were important to donor families, with some of them choosing to invite their own spiritual leader to the bedside. Keeping in line with Jacoby et al. (2005), other research (e.g., Randhawa, 2012) found that exploring a family's religious beliefs and giving them the opportunity to carry out end of life cultural practices influences the OTD experience in a positive manner. Considering the lack of unanimous OTD support from Orthodox Catholics (Randhawa, 2012), Muslims (Van den Branden & Broeckaert, 2011) and Jews (Randhawa, 2012; Sharif et al., 2011), seeking out spiritual resources that will enable a family to make a decision that reflects the deceased's wishes, and the family's beliefs and values, should be included in a family needs assessment.

Similar to Jacoby et al. (2005), other researchers found that OTD families had questions about the meaning of neurological death, however they were comforted by the thought that their family member helped save another person's life (Manuel, Solberg, & MacDonald, 2010; Merchant, Yoshida, Lee, Richardson, Karlsbjerg & Cheung, 2007). A lack of understanding of what it meant to be neurologically dead, age of the deceased, and length of time since the death increased the chances a family member would experience depressive symptoms; supporting the need for bereavement follow-up services for all organ donor families (Merchant et al., 2007).

Manuel et al.'s (2010) research captured participants struggle to understand neurological death. Being present throughout the process of declaring their relative neurologically dead gave the family members' time to say goodbye, and in the case of paediatric donors, hope for a

miraculous recovery. The importance of support from family, friends, and healthcare professionals, the need for conversations in simple terms, and the involvement of families in medical decision-making were stressed. Cleiren and Van Zoelen's (2002) telephone survey involving Dutch family members also highlight the need for adequate patient and family support. While no differences were found in the rates of depression between donor, non-donor, and families not approached for donation; depressive symptoms increased when dissatisfaction with hospital care was expressed. Although the studies in this section offer excellent insights into family experiences with OTD, they do not address how family cultural values influence the OTD experience as participants were primarily Caucasian.

Ethnocultural families and organ and tissue donation. Irving et al.'s (2011) systematic review of qualitative studies that examined community views on organ donation found that one's personal values, cultural and spiritual beliefs, lack of knowledge about OTD, concerns about body integrity, interference with end of life rituals, and misconceptions such as not being able to have an open-casket funeral, affected the donation process. These findings solidify the importance of exploring cultural values and religious beliefs with family members, as well as perceptions of the medical system to address concerns and correct misconceptions about OTD.

The integration of cultural practices and retrospective unveiling of ethnocultural concerns is threaded throughout the OTD literature. For example, following the neurological death of a young Chinese woman, the ICU treating team agreed to let the deceased's father administer an herbal medicine (Applbaum, Tilburt, Collins, & Wendler, 2008). The collaboration between the treating team staff members, the parents, and the hospital organization demonstrated how ethnocultural concerns can be woven into North American standards of care.

Molzahn, Starzomski, McDonald, and O'Loughlin's (2004) exploratory study with members of the Coast Salish Nation, the CCDT's (2005b) exploratory study with Aboriginal Elders, and Hodge, Bellanger and Norman's (2011) symposium with American Indian healers revealed the importance of death rituals, body integrity, families' unwillingness to discuss organ donation, and families beliefs in transfer of the spirit conflicted with their desire to donate their relative's organs. Accepting one's fate (Molzahn et al., 2004; CCDT, 2005b), the presence of medical and societal mistrust (CCDT, 2005b), the need to reconnect or stay connected to their culture (Hodge et al., 2011; CCDT, 2005b), and the importance of knowing the transplant recipient to help decide whether or not to donate a family member's organs (Hodge et al., 2011; CCDT, 2005b) were also noted to influence the decision-making process.

Building on the work of the CCDT (2005b), other researchers (Molzahn, Starzomski, McDonald, & O'Loughlin 2005a; Molzahn, Starzomski, McDonald, & O'Loughlin 2005b) carried out two other studies involving members of a Chinese-Canadian community (Molzahn, et al., 2005a) and members of an Indo-Canadian community (Molzahn, et al., 2005b). Common themes discovered with the Chinese-Canadians included the avoidance of discussions on death, that OTD decision-making was unlikely to happen within the traditional familial context, and that one's values, beliefs, and superstitions could either positively or negative impact an OTD decision (Molzahn et al., 2005a). The major themes that emerged from Molzahn et al.'s (2005b) Indo-Canadian study were how family and community concerns, religious considerations, medical distrust, lack of organ donation knowledge, as well as the significance of one's values and beliefs, influenced the OTD experience. Similar to the first study (Molzahn et al., 2005a), the second study (Molzahn et al., 2005b) revealed the community's reluctance to discuss OTD.

As Indo-Canadian participants' beliefs varied widely, the researchers recommended exploring a family's ethnocultural beliefs and values instead of making general assumptions.

Similar to other researchers (e.g., Davis & Randhawa, 2004; Molzahn et al., 2005a, 2005b; Morgan, 2004; Sherry, Tremblay, & Laizner, 2013; Wittig, 2001), Kurz, Scharff, Terry, Alexander, and Waterman's (2007) literature review of OTD experiences amongst ethnocultural groups found avoidance of discussions on death and organ donation was common. Many participants spoke of a sense of fear that healthcare professionals would not do everything medically possible to save them if the donor card was signed and that organs would be removed before their death (Kurz et al. 2007; Morgan, 2004; Sherry et al., 2013). Furthermore, there was a positive correlation between participants' willingness to engage in OTD family discussions and their level of knowledge about OTD, to attitudes toward donation, and to perceived religious and social norms regarding OTD. For example, African-Americans who talked about donation had lower medical mistrust and higher levels of altruism (Morgan, 2004).

Factors that influence organ and tissue donation decision-making. Studies that explored ethnocultural groups OTD experience have found that working in collaboration with ethnocultural community members, demonstrating respect for the families' wishes, and integrating key values and beliefs into the discussions increased families' knowledge of OTD information and the intent to donate (Radosevich et al., 2010). Factors that positively affected the OTD decision was family support, a driver's licence that designated donor intentions, and church support for OTD. Focus groups with Chinese-Americans (Hebert, Rivera, Eng, Lee, & Seto-Yee, 2010) found that although attitudes toward donation were positive and the benefits were recognized, a lack of knowledge proved to be the biggest barrier to OTD consent.

OTD awareness campaigns that address the specific needs ethnocultural communities have been suggested to increase OTD rates in this population (Allen & Stillwater, 2010; Fahrenwald, 2010; Schulz, Nakamoto, Brinberg, & Haes, 2006). Fahrenwald's (2010) research with members of the American Indian tribe, Alaska Natives, and First Nation (Canadian) resulted in the creation of promotional OTD video and print materials which featured pictures of local tribe members and their families. The pictures, the colors, and the messages were all chosen by a community advisory council. Allen and Stillwater's (2010) community awareness raising study provided recommendations that can be generalized for other cultural communities: (1) make OTD relevant to community members; (2) get community members to tell their stories; (3) use a low-key approach to communicate information on this sensitive subject; (4) ensure that that decision-making is based on informed choice; (5) do not presume that due to limited knowledge a person is not willing to listen and learn; (6) the OTD decision making process takes time as donation can affect not only family members but the community; and (7) use available tools that can be adapted for use by community members for community members.

An exploratory study with members of a Haitian-Canadian community (Sherry et al., 2013) uncovered similar themes to those of other studies involving Black communities (Davis & Randhawa, 2004; Morgan, 2004; Radosevich et al., 2010; Wittig, 2001). Participant narratives expressed a lack of OTD knowledge, a lack of willingness to discuss OTD, the importance of body integrity, the level of family involvement in OTD decision-making, and societal and medical mistrust were factors that influenced the OTD decision. Participants stated that fate and God determined when you died, not doctors looking for organs. Although the older participants expressed reservations with OTD, they acknowledged that younger generations might be more receptive to donation as they were exposed to Canadian / Québec society beliefs and values.

De Groot, et al. (2012) carried out an integrative review of studies on decision-making by relatives of neurologically deceased patients. They discovered that one third of families who declined organ donation regretted their decision, but only one tenth of consenting families expressed regret. Cultural values were not explored but family values regarding body integrity, personal sacrifice, and not knowing the deceased's wishes were common themes. While religion was cited as a reason not to donate, it was rarely mentioned when families were approached by a health care provider for donation (de Groot et al., 2012). Yet, participants in Lira, Pontes, Schirmer, and de Lima's (2012) Brazilian study expressed cultural and religious concerns, as well as a perceived lack of support from hospital staff members' as negatively impacting the OTD decision. De Groot et al. (2012) hypothesized that the circumstances of death and the requester's focus on gaining consent, instead of exploring family values and the deceased's wishes, likely had a negative effect on families' perception the OTD process. This resulted in OTD being declined.

Conversely, Ghorbani et al.'s (2011) retrospective review of Iranian family members who declined OTD highlighted a number of influences stemming from cultural values and beliefs. Participants shared similar concerns to other ethnocultural community members such as medical mistrust, the need to maintain body integrity of the deceased, and not knowing the deceased's wishes. Interestingly, the review noted that 8.6% of the family members declined donation based on religious concerns, a number that is very close to the 8.4% of Québec families identified in another retrospective review of families who declined organ donation for religious and cultural concerns (Baran, Langevin, & Lebeau, 2009).

Montreal area ethnocultural communities involved in the organ and tissue donation process. At the MUHC, the OTD service reviews the charts of patients who have died in the

EDs, the ICUs, and palliative care units. Approximately nine percent are identified and referred to the nurse clinicians for OTD or are directly referred to Héma-Québec for tissue donation. Of these, the majority were Canadian Francophones and Canadian Anglophones. Visible and non-visible minorities represented approximately 35% to 40% of eligible patients for the years 2011 to 2012 (Fernandez, 2013).

Given the representation of different cultures involved in the MUHC OTD process (see Appendix F, it is essential that nurses acquire basic knowledge on different ethnocultural values, beliefs, and needs to care for this population throughout the OTD process. This knowledge would ensure that ethnocultural families are invited to discuss donation in a culturally sensitive manner and enable nurses to provide cultural congruent care (Leininger, 1995) for the deceased and the family members. Providing cultural congruent care, as described by Leininger (1995), guides evidenced-based OTD nursing care that is supported by a family needs assessment. The resource manual accomplishes this goal by helping nurses learn how to carry out an OTD cultural family needs assessment and how to use this information to tailor culturally sensitive interventions that promote culture congruent care (Leininger, 1995).

Summary

In Canada, we have a growing number of multi-ethnic communities whose members are faced with having to make the decision to donate their family member's organs and tissues. The province of Québec is one of the top three provinces where ethnocultural community members reside (Statistics Canada, 2014). Nurses need to be prepared to provide culturally congruent care to address the needs of this population. There is a consensus in the literature that nurses are not prepared to deal with families' complex needs throughout the OTD experience, particularly those from diverse ethnocultural backgrounds (Høye & Severinsson, 2008; Kierans & Cooper, 2013).

Although research has started to highlight the importance of culturally congruent care throughout the OTD experience, resources to support nurses to complete a cultural family assessment and to integrate this knowledge into their practice are limited. This resource manual will fill this gap.

Prevalent throughout the literature are the concerns of families involved in the donation process such as body integrity, medical mistrust, fear of organ trafficking, lack of understanding of the concept of neurological death, and need to respect cultural values, religious beliefs, and family decision-making (de Groot et al., 2012; Irving et al., 2011; Manuel et al., 2010; Sherry et al., 2013); all of which impact OTD. Research draws attention to the need to integrate Leininger's (1988) Culture Care Diversity and Universality Theory into the OTD process in order to provide culturally congruent care in order to address the preceding concerns. Threaded throughout the literature is the significance of creating a nursing resource to support nurses' efforts to assess and provide culture congruent (Expert Panel on Global Nursing and Health 2010). Such a manual, adapted for the needs of the MUHC OTD service, would be a step toward breaking down cultural barriers and to facilitate the development of a therapeutic relationship between the nurse and the family

Theoretical Framework and Conceptual Model

This practicum is guided by Leininger's (1988) Theory of Culture Care Diversity and Universality, and Morrison et al.'s (2011) Model of Instructional Design. The goal of Leininger's theory is to foster critical thinking skills, to develop culturally congruent nursing care skills, and to enhance the nurse-family relationship. Morrison et al.'s (2011) conceptual model of instruction was chosen for the approach it uses to identify resources and skills needed to design a tool to meet the needs of the targeted audience. The nature of the model's design

promotes a holistic view of the practicum project and creates opportunities for evaluative review within the model's elements.

Leininger's Theory of Culture Care Diversity and Universality

Leininger's theory of culture care diversity and universality is based in anthropology and nursing; anthropology informs the concept of culture and nursing informs the concept of caring (Leininger, 1988). The theory encourages different cultures to be examined in order to understand universal and specific customs across populations (Leininger, 1991). The goal of the theory is to prepare nurses to provide culturally congruent care. That is, decisions for diverse cultural groups that safeguards their cultural values, that accommodate their beliefs, and that restructures their cultural viewpoints so that care becomes relevant within a family's frame of reference (Leininger, 1995).

Leininger (1995) views care as a fundamental aspect of nursing and the key to helping people maintain health and cope with illness and death. To achieve culturally congruent nursing care an exploration of an individual or family's interpretation of their cultural values and beliefs is required. Culture is not static, but something that is shaped and reshaped in relation to the nexus of one's social relationships (Heine, 2012; Leininger, 2001; Leininger & McFarland, 2006; Srivastava, 2007). Variance in how people define their culture necessitates that a family cultural assessment be completed with each family during the OTD experience.

Leininger (2006) developed the Sunrise Enabler Model (see Figure 1.1) to facilitate nurses understanding of culture and the development of nursing practice that is culturally congruent. The model represents the tenets and assumptions of Leininger's (1988) transcultural theory (see Appendix G as it moves from a global perspective of culture, to understanding a family's specific cultural interpretations, and to adapting and restructuring nursing care practices

to the family's needs. The seven factors in the middle semi-circle of the Sunrise Enabler (technical, religious and philosophical, kinship and social, cultural values, beliefs, and lifeways, political and legal, economic, and educational), were used in this practicum to guide nurses' exploratory questions to capture the family's cultural needs related to the OTD process. This information will enable a nurse to juxtapose generic care (cultural healthcare practices) against nursing care practices (care that promotes health and well-being) and professional care practices (formal learned care knowledge) (see Figure 1.1). It is out of this juxtaposition that nursing care decisions and actions that reflect culturally congruent care which preserves, accommodates, and restructures the evolving cultural family viewpoint. The Sunrise Enabler (Leininger, 2006) informed the development of the open-ended questions for key stakeholder interviews (see Appendices G and H) which in turn, informed the content of the manual.

Leininger's (1988) transcultural theory captures the significance of nurses' understanding a family's ethnocultural values within the context of OTD in order to provide culturally sensitive care (Guido et al., 2009; Høye & Severinsson, 2008; Kierans & Cooper 2013). Given that the literature has shown that ethnocultural OTD families do not always understand the information being presented to them (e.g., neurological death) and that they have unique cultural needs (Bellali & Papadatou, 2007; de Groot et al., 2012; Ghorbani et al., 2011; Lira et al., 2012; Schirmer & de Aguiar Roza, 2008), it is important that nurses providing information on OTD do so in a manner that demonstrates cultural awareness, and develop nursing interventions that take into consideration one's cultural practices. This manual will assist nurses on how to conduct a family cultural assessment to offer OTD care that is culturally congruent.

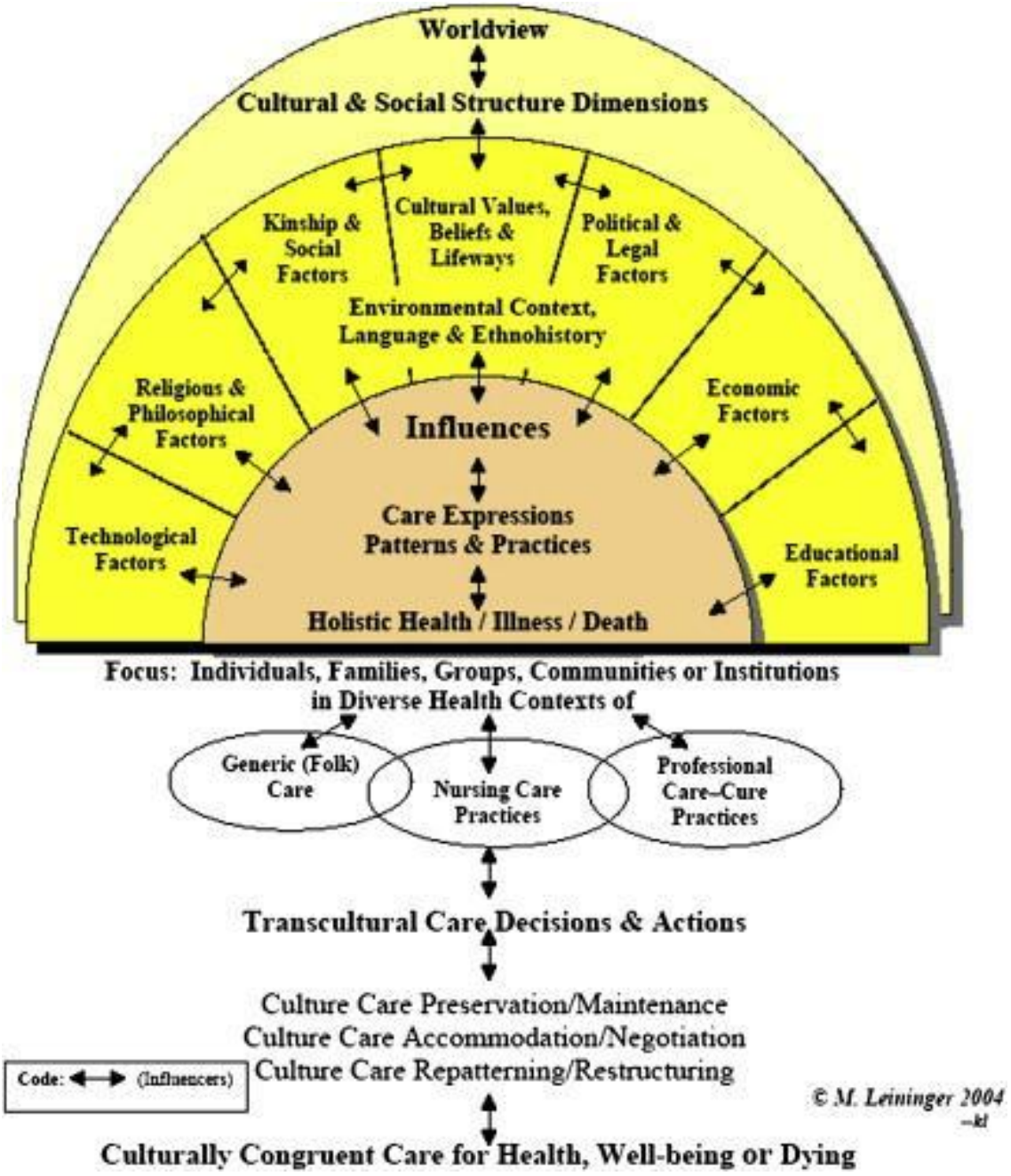


Figure 1.1 Leininger's Sunrise Enabler Model.
Mak, M. W. (2014). *Death plus respect =Cultural safety*. Retrieved from http://pub209healthcultureandsociety.wikispaces.com/Death+plus+Respect%3DCultural+safety

Morrison, Ross, Kalman, and Kemp's Model of Instructional Design

Morrison et al.'s (2011) model was chosen as it provides a learning and evaluation structure based on developed objectives and method of instruction. The instructional design model is compromised of five components that ensure the instructional tool is tailored for its intended target audience: (1) analysis, (2) design, (3) development, (4) implementation, and (5) evaluation (Morrison, et al.) (see Figure 1.2). The model's inner circle is composed of nine elements (instructional problems, learner characteristics, task analysis, instructional objectives, content sequencing, instructional strategies, designing the message, development of instruction, evaluation instruments) which can be used in a non-linear manner as "each designer formulates activities and applies elements of the instructional design plan in individual ways" (p. 13). The middle circle highlights the evaluation and revision elements which are used to continually reassess the inner nine elements so that improvements or changes are made as needed. The outer circle addresses the issues of planning, implementation, project management, and support services that successfully link the targeted learners with the developed educational tool. While each element has been addressed separately below, it is understood that the model does not employ a step wise approach and that elements overlap and interact with each other.

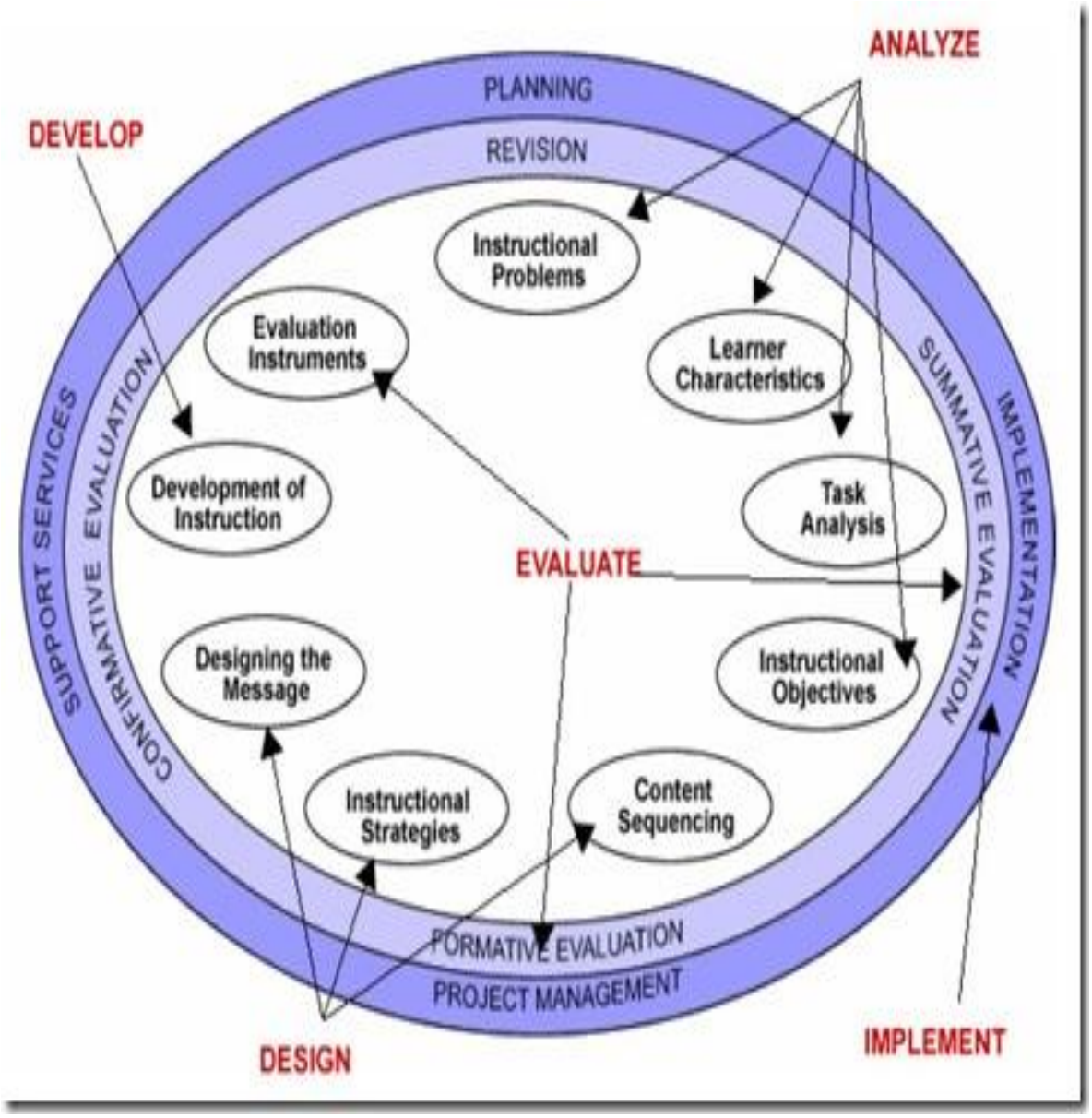


Figure 1.2 Morrison, Ross, Kalman, and Kemp's Model of Instructional Design. King, T. (2013). *Instructional design: A journey in learning.* Retrieved from http://tarynking.wordpress.com/2013/05/17/comparing-models/

Instructional problem. Morrison et al. (2011) state the importance of carrying out a needs assessment to establish whether there is an actual need. A felt need stems from an identified gap between current performance levels and desired performance levels (Morrison et al., 2011). In my position as a nurse clinician for OTD, I felt there was a need based on feedback from nurses caring for ethnocultural families. This felt need was confirmed by a review of the literature, informal interviews carried out for this practicum with key stakeholders from ethnocultural communities, and nurses caring for families involved in the OTD process. The nurses stated a resource manual would aid them to provide culturally congruent care. This in turn, would decrease nursing stress and anxiety as they would learn how to gather cultural information to design nursing interventions that meet expressed family needs. Given that Montréal is Canada's third largest city with a great number of ethnically diverse communities (Statistics Canada, 2014) and that cultural and religious traditions often regain importance when a person is dying (Kemp, 2005; Warren, 2005), critical care nurses need to be attentive to how cultural beliefs influence a family's understanding of the OTD process. The manual supports OTD culture congruent care (Leininger, 1995) by educating nurses on how to assess their own cultural competence, how to complete a family cultural needs assessment, and how to develop a care plan that is respectful and accommodating of identified needs. The creation of a resource manual for nurses on culture and OTD fills a gap in the literature, as none other exists.

Learner characteristics. Learner characteristics describe the people who will be learning a new skill and takes into consideration a range of learning styles based on gender, age, work experience, education, ethnicity, personal, and social characteristics (Morrison et al., 2011). Therefore, it is important to identify characteristics that support achievement of the developed objectives as the nurse's perception of the new skill will affect practice integration (Petty,

Barden, & Wheeler, 2009). Identifying learning styles of the target group is important as it will guide the development of instructional strategies.

Given the target audience are nurses working in critical care areas, there are common characteristics of the group that will guide the development of the manual. For example, they all have received formal training in critical care, all are adult learners, all are registered nurses, all have cared for culturally diverse families, and many have had some experience with OTD. Skill level and experience vary within critical care units; however all nurses are expected to learn how to care for the types of patients admitted to their specialty, including OTD. The nurses have some familiarity with a variety of teaching tools and caring for cultural diverse populations, thus the manual will build on principles familiar to them.

Critical care nurses work in a fast paced environment that requires strong nursing and communication skills. As adult learners, they are internally motivated and self-directed, they refer to personal and professional experience to create relevance, they want learning to be practical and they want to be respected (Knowles, 1984). Identified adult learner needs are reflected in the manual to respond to these needs, to facilitate learning, and to foster culturally sensitive nursing care. For example, the manual contains content that is identified by nurses as important such as a global overview of Québec ethnocultural communities. The manual will be made available via the MUHC intranet for ease of access. The designed on-going OTD case scenario reflects professional experiences familiar to the target audience and therefore builds on acquired knowledge. Language is another important concern as French is the working language of the province of Québec. To accommodate this particularity, the manual must be translated into French before it can be disseminated across the MUHC.

Task analysis. Morrison et al. (2011) describe task analysis as, "the collection of procedures for defining the content of an instructional unit" (p. 78) that begins with the needs identified in the instructional problem. The type of task analysis that was carried out was topic analysis. Topic analysis was used to provide an overview of the content (facts, tools, concepts and principles) to be included in the resource manual and to create a structure to ensure that each section was logically sequenced. It helped create an outline of the main ideas to relate information and examples that supported nurses' development of self-cultural awareness, to inform nurses on how to carry out an ethnocultural family needs assessment, and to reflect identified needs of families throughout the OTD process.

Based on expert consultations, a literature review, and my professional experience in OTD, the manual's content was developed to include things such as key terms related to the OTD process and ethnocultural families (e.g., culture, family, neurological death, etc.). For example, I consulted with two family care ICU clinicians, one nurse ethicist, one nurse clinician for OTD, one critical care nurse, one nurse educator, Dr. Laizner (MUHC nursing research consultant), Dr. Manuel (practicum supervisor), and five representatives from five different ethnocultural communities. The resource manual is divided into eight sections to focus on particular aspects of nursing care needed to explore ethnocultural family concerns. The eight sections are: (1) foundational concepts, (2) nurse cultural self-assessment, (3) major ethnocultural communities in Québec, (4) carrying out a cultural family assessment, (5) what to do with gathered family information, (6) evaluation form for the nursing resource manual, (7) resources, and (8) references.

Instructional objectives. Morrison et al. (2011) stress the importance of developing instructional objectives that indicate what the learner is to accomplish in the cognitive,

psychomotor, and affective domains. The objectives need to be observable and measurable to ensure that learning needs are identified and to facilitate the evaluation processes (Morrison et al., 2011). Cognitive objectives reflect knowledge acquisition; psychomotor objectives reflect the perfection of motor skills; and affective objectives reflect changes in attitudes, beliefs, and values (Morrison, et al., 2011). The resource manual contains cognitive and affective objectives as the goal is to analyze gathered information on an ethnocultural family in order to offer care that is respectful of expressed family needs. Each section starts with specific learning objectives to inform the content of the section and is used to evaluate the nurses' progress.

Content sequencing. Content sequencing refers to the way information is presented, such that each fact or concept builds on the other in a logical manner, helps the learner meet established objectives, and involves a sequencing strategy (Morrison et al., 2011). Concept-related sequencing was selected to logically organize the information (Posner & Strike, 1976). The phenomenon of sophistication was chosen from the concept-related sequencing themes as the contents of the manual are organized from concrete to abstract. This was accomplished by defining key terms such as family to promote understanding of the selected meaning of the term. To promote learning and achievement of program objectives, the sequence of content was presented in such a manner that content familiar to the nurse is presented first then followed by more difficult information. For example, culture was defined, followed by a cultural self-assessment, and then Leininger's Sunrise Enabler Model (2006) was introduced in two stages. The first stage outlined how to organize a family meeting and how to formulate questions reflective of the seven factors of cultural assessment. The second stage focused on an application and integration of the information acquired in family meetings to guide nursing

practice in alignment with culture congruent care (Leininger, 1995). To confirm the content sequencing flow, the manual was shown to several nurse stakeholders for review.

Instructional strategies. An instructional strategy takes into consideration the best methods to teach a fact, a concept, a rule, a procedure, an interpersonal skill, or an attitude to the learner in a meaningful way so that they can achieve the desired objectives (Morrison et al., 2011). Instructional strategies build on prior knowledge and promote constructive learning without overwhelming the learner (Morrison et al., 2011). As noted in the element on learner characteristics, nurses' personal and professional experience will be used to build on awareness of cultural self-competence, to improve family communication skills, and to provide culturally sensitive care. To encourage semantic processing, an icon that draws attention to key points of the OTD process to provide culturally congruent care concludes each section. Tables are provided throughout the manual to provide access to key information and terms quickly; which is important in a fast paced critical care environment. A variety of fonts were used to highlight important material. To evaluate learning of the manual contents, a case scenario was developed. The designed questions will ascertain how nurses integrated cultural care principles by examining responses on how the nurses integrated the ethnocultural community information with the description of the family in the case scenario (see Appendix A). An instructional strategy also includes how the resource manual is made available to the users. Due to the bilingual nature of the MUHC, the manual will be translated into French to promote a wider dissemination. The manual will also be accessible via the MUHC intranet to facilitate its use by nurses working different shifts (days, evenings, nights, and weekends).

Designing the instructional message. This element focuses on how the material is introduced, structured, and communicated in order to engage and signal the learner to significant

points (Morrison, et al., 2011). Each section of the manual begins with learner objectives so that learning expectations are clear. The written text reflects definition of identified key terms and clearly states what the nurse is expected to accomplish. The manual respects publication rules established by the American Psychological Association (2010) to create uniformity in the layout. Woven throughout the manual are references to Leininger's (1988) transcultural nursing theory so that the learner is drawn back to the main objective; to learn how to gather information, to organize it, and to use it to provide culturally sensitive OTD care. The color green is prevalent as it is the color of the OTD ribbon. Hence, this color is used for the headings of each section and tables containing or addressing nursing interactions with families. The color blue was used to define boxes that contained section objectives and for the reflective questions and on-going case scenario. Images have been used sparingly to prevent distraction from key messages (Morrison et al., 2011). This strategy was verified by three ICU nurses, one of whom is a nurse clinician for OTD at another institution.

Development of instruction. At this phase the development of the instructional material must be in alignment with the objectives of the manual, the problem, and pre-instructional strategies (Morrison et al., 2011). Using the pre-instructional strategies, the manual objectives are broken down into easily understood steps that offer essential information to create an active learning experience (Morrison, et al, 2011). This type of instruction ensures communication of consistent information, and is cost effective since printing costs will be decreased by having the manual available via the MUHC intranet.

Based on a learner analysis, I was able to determine the appropriate reading level for the learner, their familiarly with the content, and background knowledge on OTD as a means to develop the instructional material. Translation of the manual from English to French will be

verified by Francophone nurses to ensure the same message is being communicated and that the level of language is appropriate.

Knowledge of Leininger's transcultural nursing theory (1988) and the OTD process vary hence, the step-size (i.e. transition between ideas) was considered (Morrison et al., 2011). That is, I ensured that the nurses had the foundational knowledge about culture and providing culturally congruent care by asking them to complete a cultural self-assessment to identify strengths and challenges. Given that the nurses have background knowledge about OTD the content of the manual did not have to focus as much in this area. For instance, nurses are provided with examples of how to frame questions to compete a cultural assessment before opening a discussion with a family about OTD. Cognitive load (i.e. added mental effort) was considered by designing sections that stand alone; allowing the nurse to read and review the manual's sections within a short period of time and at different moments in time (Morrison et al., 2011). For example, nurses might not provide OTD care to an ethnocultural family for months. A section of the manual could then be reread to prompt recall of needed information. To ensure accuracy and appropriateness of information, ethnocultural community representatives were consulted. I interviewed five members from five different ethnocultural communities drawn from the ten largest ethnocultural communities in Québec (Statistics Canada, 2012), then transcribed the interview notes into the written verbatim. These were returned to the participants in order to ensure that I had captured their experience. All suggested changes were reviewed to ensure accuracy of gathered information. Nurse stakeholders reviewed the resource manual for flow, ease of use, and appropriateness of stated objectives, reflective questions, and on-going case scenario. Suggested changes were integrated to support adult learner needs and learning needs pertaining to how to complete an OTD cultural family assessment.

Evaluation instruments. Development of evaluation instruments to assess whether or not learners attained the developed objectives is the final element of the model of instructional design (Morrison, et al., 2011). Development of an evaluation instrument before disseminating an instructional tool is crucial to ensure evaluation questions reflect objectives. There are three types of learner evaluations: (1) formative, (2) summative, and (3) confirmative.

Formative evaluation is completed while constructing the manual to ensure contents reflect the manual objectives. Formative evaluation also includes a pilot test of the manual with a larger group of nurses to rectify content challenges before the manual is widely disseminated (Morrison et al., 2011). Consultation with several nurse stakeholders was carried out throughout the creation of the manual's sections to ensure the contents reflected the expressed felt need. The nurses will be invited to complete a questionnaire on the perceived value of the resource manual contents to their learning, to write down what they liked about the manual, and to offer suggestions to make improvements (see Appendix A). The nurses will be provided with two options to provide feedback (1) by email or (2) by downloading the questionnaire and mailing it to me via internal mail. Confidentiality will be ensured through the creation of a password protected file for those who select the option of email. Completed forms that are returned in paper format will be secured in a locked filing cabinet. All identifying information will be removed from the submissions.

A summative evaluation measures how well the instructional material was mastered and perceived by the learners. Each section starts with specific learning objectives to inform the content of the section and is used to evaluate the nurses' progress. Reflective questions and an on-going case scenario were compiled to complement each section (see Appendix A). Reflective questions examine nurses' attitudes and feelings about providing culture sensitive care. The on-

going case scenario features one of the ethnocultural communities to gauge the nurses' developing cultural competence skills with the OTD cultural family assessment. However, due to the subjective nature of the reflective questions, only the answers to the on-going case scenario are provided. At any time during this process, the nurse is informed that they may contact the MUHC nurse clinician for OTD.

The confirmative evaluation focuses on the learners' retention of skills and knowledge and its value to the organization (Morrison et al., 2011). The time frame for evaluation of learner integration of knowledge and skills will depend on patient eligibility and whether or not the family is a member of an ethnocultural community. Evaluation of the impact of the nursing instruction on the organization is often performed months or years after clinical practice implementation and is therefore beyond the scope of this practicum. Methods to complete such an evaluation may include interviews with nurses to explore the impact of the manual's contents on care within the critical care unit and if nurses are meeting established MUHC OTD standards of care (MUHC, 2012).

Implementation, and planning, project management and support services.

Implementation involves developing a plan and identifying resources needed to implement an educational project that is perceived as beneficial by the learners and their organization (Morrison et al., 2011). While nurse stakeholders have expressed positive support for the resource manual as it promotes holistic family nursing care, implementation is beyond the scope of this practicum and will be carried out at a later date. Considerations for implementation may include contacting critical care nurse managers and nurse educators to assess interest and to schedule in-services to present the manual to nurses. The organization's intranet news journal

could also be used to announce the creation of a resource to improve culture sensitive OTD family care.

Planning, project management, and support services revolves around how to manage tasks related to project planning and process management activities (Morrison et al., 2011). These components were addressed according to the parameters of the practicum with a crafted timeline and the submission of two mini reports that described the progression and development of the nursing instructional manual on culture and OTD. Post-practicum completion and once the evaluation concerns have been addressed; the manual will be presented to the MUHC OTD Committee to discuss support service needs for translation, and how dissemination of the manual will be carried out across the MUHC's critical care areas. As well, the MUHC Clinical Practice and Staff Development department will be consulted to ensure the manual is adapted to reflect MUHC nursing policy standards for educational publications.

Advanced Practice Nursing Competencies

An objective of this practicum was to demonstrate the use of APN competencies to guide the development of a nurse resource manual for critical care nurses working with culturally diverse families, and whose family member is a candidate for deceased OTD. Hamric's (Hamric, 2009; Hamric et al., 2014) APN model identifies seven competencies a nurse needs to develop in order to provide holistic care: (1) direct clinical practice, (2) guidance and coaching, (3) consultation, (4) collaboration, (5) evidenced-based practice, (6) leadership, and (7) ethical decision-making. Evidence of all seven of the competencies exists within the construction of this resource manual.

Direct Clinical Practice

Direct clinical practice for the advanced practice nurse refers to using clinical judgement, critical thinking, and the provision and accountability for evidenced-based care at a level that surpasses that of an expert registered nurse (Tracy, 2009). During this practicum, I have increased my understanding of transcultural nursing (Leininger, 1988) and explored evidence-based knowledge related to the nursing care of ethnocultural families faced with the OTD experience. This facilitated the creation of a manual for nurses on the need to provide cultural sensitive care to ethnocultural families. For example, Leininger's theory (1988) was used to guide a holistic approach to OTD, and to develop an individualized plan of care and therapeutic interventions that focused on the cultural needs of families throughout the OTD experience. The development of the resource manual fostered the integration of my clinical experience as OTD expert, and my formal and experiential knowledge as a practitioner. This merger is evident in the development of the on-going case scenario embedded within the manual. The development of the content of the manual and sequencing of the material is credited to my own reflections on my practice, in an effort to develop strategies to improve the integration of cultural congruent care (Leininger, 1995) throughout the OTD process. These reflections helped formulate diverse OTD approaches which are threaded throughout the manual.

Guidance and Coaching

Guidance reflects the support offered through teaching while respecting values and expressed needs (Spross, 2009). Coaching is the interaction of sharing expertise to develop a learner's knowledge (Spross, 2009). Guidance is intertwined with coaching. Through active listening, displaying empathy, and understanding a situation from the family's viewpoint, possible solutions are formulated to respond to families' concerns (Spross, 2009). In my role as

an OTD nurse clinician, family discussions often reveal emotional needs related to care of the deceased or saying personalized goodbyes. How these needs can be met are explored in the manual and adapted to meet family needs and requests. For example, the manual addresses a variety of cultural practices such as taking pictures of the deceased to share with family members who reside in another country, making hand prints, and religious bedside services. Guidance in this area is beneficial as provision of nursing care for OTD ethnocultural families is diverse. Using the cultural self-assessment contained in the manual, the nurse can review personally held views, values, and beliefs to identify barriers to creating a therapeutic relationship with family members.

As a specialist in OTD, expert guidance and coaching of nurses is pivotal to ensure that nurses caring for ethnocultural families are able to communicate with similar standards of guidance and coaching to help families navigate the OTD process. The instructional manual accomplishes this by encouraging moments of reflection and self-awareness to promote cultural competence. This helps the nurses make the transition from becoming aware of their own cultural beliefs, to assessing the cultural beliefs of others, in order to develop a plan of care reflective of this population's needs. As well, it facilitates the family's transition from life to acceptance of death.

Consultation and Collaboration

Consultation involves an interaction between two professionals where the consultant acts as a resource to improve the skills and confidence of the person who requested the consult (Barron & White, 2009). Collaboration is a partnership with one or more persons to solve problems and achieve set goals, and that adapts to changing situations (Hanson & Spross, 2009). I consulted with numerous key stakeholders (e.g., ethnocultural community members, nurses

involved with providing care for OTD families, Dr. Laizner, and Dr. Manuel) to develop a resource manual that promotes the provision of culture sensitive care. For example, information in the manual reflects expressed ethnic community concerns on how to broach the subject of OTD, concerns regarding the deceased's bodily integrity, as well as several nurse stakeholder OTD concerns related to gathering pertinent family information. Collaboration was demonstrated with Dr. Manuel, Dr. Laizner, and critical care nurses who provided feedback on the contents of the manual throughout its creation. Future collaboration will occur when manual revisions are carried out based on nurse learner suggestions.

Evidenced-Based Practice

Evidenced-based practice refers to the ability to make research knowledge and evidence available to guide clinical practice (DePalma, 2009). Gaps in the literature were identified in order to support the need for a resource manual that focused on nursing care offered to ethnocultural families involved in the OTD process. Evidenced-based practice also informed the content of the manual and instructional strategies. For instance, interviews were carried out with critical care nurses to identify the felt need. To foster understanding of Leininger's Sunrise Enabler Model (Leininger, 2006), the model was explained in two stages in order for nurses to learn how to complete an OTD cultural family assessment and to develop culturally sensitive interventions from the gathered family information. In addition, information collected from databases of Statistics Canada (2012; 2013; 2014) and the MUHC OTD database (Fernandez, 2013) ensured the manual contained information on ethnocultural communities that seek health care at the MUHC as well as reflecting the expressed felt need of the MUHC critical care nurses. Evaluation of clinical practice is a component of evidenced-based practice and is apparent in the

evaluation element of Morrison et al.'s (2011) instructional process. It will be used to review the learning process and the effectiveness of the manual's contents.

Leadership

A leader is a nurse who recognizes the need to make improvements and modifications, and then implements strategies to achieve it (Spross & Hanson, 2009). Leadership is comprised of three unique characteristics: (1) clinical (mentoring and empowerment), (2) professional (innovation and change), and (3) systems (activism) (Spross & Hanson, 2009). Consultation and collaboration with nurses involved in the OTD process identified a gap in knowledge in how to provide culturally congruent care for ethnocultural families throughout the OTD experience. This knowledge is essential in order to improve patient and family healthcare outcomes. The modeling of culture congruent care (Leininger, 1995) is evident throughout the manual. For example, the nurses are provided with techniques to assess families' cultural needs.

I am also acting as a change agent with the creation of the resource manual as it will serve as a conduit for innovation and change to improve family nursing communication and care skills. Successful implementation and integration of the manual in MUHC critical care units will hopefully foster similar initiatives in other hospital organizations with an OTD service as it represents an evidenced-based standard for OTD care.

Ethical Decision-Making

Difficulties in ethnical decision-making arise when a moral dilemma is created by divergent and opposing courses of action (Hamric & Delgado, 2009). Ethical decision-making skills are used when explaining neurological death and the other OTD process. This promotes understanding and enables an informed family decision based on cultural values, beliefs, needs, and the deceased's OTD wishes if they were expressed. As an OTD expert, I have been privy to

the emotional struggle nurses face when thinking about potential transplant recipients and families who chose not to donate. I have integrated this APN competency in the manual by drawing attention to the need to carry out a thorough exploration of family needs, respect for family decision-making, the importance of informed decision-making, and advocacy for culture congruent care (Leininger, 1995).

Limitations

The resource manual on culture and OTD was designed to meet the felt needs of nurse stakeholders; however it has a number of limitations. Translation costs are a concern due to the bilingual status of the MUHC organization. As the cost of the translation will be paid from the OTD fund that supports OTD projects, approval for funding is needed from the MUHC OTD Committee. While the resource manual is the chosen method of communicating the identified gap in knowledge it does not address visual, tactile, and auditory learning style needs (Fleming, 2014) that may impact the level of learning. Motivation could also play a role as the responsibility for learning new skills lies with the learner (Morrison et al., 2011). Still, instructional strategies were incorporated in the manual to address adult learner needs (Knowles, 1984) and to facilitate learning. A lack of interaction with the nurse clinician OTD expert may limit the effectiveness of the resource manual. This limitation will be minimized as an OTD Nurse Clinician is available 24 hours a day to respond to questions related to potential donation candidates.

Recommendations

Recommendations for the dissemination and evaluation of the instructional manual include the need to conduct a pilot implementation of the resource manual with a small group of critical care nurses. Based on the findings of the pilot project, recommendations to the manual

will be made to reflect feedback. The instructional manual needs to be translated into French to promote accessibility of information and to respect provincial Québec laws (Éditeur officiel du Québec, 2014). Prior to the implementation of the manual, the administrative process for its approval will need to be followed. To promote awareness of the existence of the resource manual, nurses and nurse managers will need to be notified through diverse communication methods. This means close collaboration and consultation with the MUHC Clinical Practice and Staff Development department. The manual should be available as a hard copy on the unit and available via the OTD intranet page as an accredited source of e-learning to meet Québec nursing licensure requirements (Ordre des infirmières et infirmiers du Québec, 2014). Consultation with other healthcare professionals should be carried out to identify how the resource manual can be adapted to meet their needs.

Conclusion

It is evident from the literature review that a family cultural assessment is necessary due to the wide variability in values, beliefs, and understanding of the OTD process (Bellali & Papadatou, 2007; de Groot et al., 2012; Ghorbani et al., 2011; Lira et al., 2012; Schirmer & de Aguiar Roza, 2008). Respect of a families' expertise on their needs enables the nurse to offer tailored therapeutic interventions and to provide culture congruent care to families (Leininger, 1988). However, nurses need education to face the challenges of providing nursing care for ethnocultural families (Høye & Severinsson, 2008; Kierans & Cooper, 2013). A nursing resource manual that incorporates knowledge of Québec ethno-cultural communities will foster a nurse's ability to create a meaningful culturally sensitive OTD experience for family members. Moreover, research has shown that families involved in the OTD process appreciate an individualized approach to care as it conveys that nursing care is not just about procuring body

parts, but about supporting the family as they grieve and to make an OTD decision that reflects held values, beliefs, and needs (Jacoby et al., 2005). As per the Expert Panel on Global Nursing and Health (2010), tools that address culture congruent care (Leininger, 1995) need to be developed. This manual can be a step forward to breaking down cultural barriers and to facilitating a therapeutic relationship between the nurse and the family. Following implementation, evaluation of the educational intervention is planned in order to determine its effectiveness as a resource for MUHC critical care nurses.

References

Allen, M.D., & Stillwater, B. (2010). Organ donation and transplantation: A new tradition of sharing for Alaska natives. In J. T. Siegel, & E. M. Alvaro (Eds.) *Understanding organ donation* (pp. 83-97). West Sussex, UK: Wiley-Blackwell.

American Psychological Association. (2010). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author.

Applbaum, A. I., Tilburt, J. C., Collins, M. T., & Wendler, D. (2008). A family's request for complementary medicine after patient brain death. *Journal of the American Medical Association, 299,* 2188-2193. doi: 10.1001/jama.299.18.2188

Ask. (2013). *G8.* Retrieved from http://www.ask.com/wiki/G8

Baldinazzo, S. (2008). Coping with relatives during end-of-life decisions. *European Journal of Anaesthesiology, 25,* 164-166. doi: 1O.1O17/SO265O215O7OO3195

Baran, D., Langevin, S., & Lebeau, C. (2009). Don d'organes: Portrait des refus des familles au Québec. *Perspective Infirmière, mars / avril,* 20-21.

Barron, A. - M., & White, P. A. (2009). Consultation. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 191-216). St. Louis, MO: Elsevier Saunders.

Bellali, T., & Papadatou, D. (2007). The decision-making process of parents regarding organ donation of their brain dead child: A Greek study. *Social Science & Medicine, 64,* 439-450. doi:10.1016/j.socscimed.2006.09.006

Breitkopf, C. R. (2009). Attitudes, beliefs and behaviors surrounding organ donation among Hispanic women. *Current Opinion in Organ Transplantation, 14,* 191–195. doi:10.1097/MOT.0b013e328329255c

Canadian Council for Donation and Transplantation. (2003). *Severe brain injury to neurological determination of death: A Canadian forum*. Edmonton. AB: Canadian Council for Donation and Transplantation. Retrieved from http://www.giftoflife.on.ca/resources/pdf/Severe%20Brain%20Injury%20.pdf

Canadian Council for Donation and Transplantation. (2005a). *Donation after cardiocirculatory death: A Canadian forum.* Retrieved from http://www.organsandtissues.ca/s/wp-content/uploads/2011/11/Donation-Cardiocirculatory-Death-English.pdf

Canadian Council for Donation and Transplantation. (2005b). *Diverse communities: Consultation to explore perspectives on organ and tissue donation, section iv – Indigenous peoples' dialogue. Report of the CCDT ethnocultural steering committee.* Retrieved from http://www.organsandtissues.ca/s/wp-content/uploads/2011/11/Diverse_Comm_Sask_Winnipeg_Report.pdf

Canadian Institute for Health Information. (2014). *E-statistics report on transplant, waiting list and donor statistics: 2012 summary statistics, January 1 to December 31, 2012.* Retrieved from http://www.cihi.ca/CIHI-ext-portal/pdf/internet/REPORT_STATS2012_PDF_EN

Carey, S. M., & Cosgrove, J. F. (2006). Cultural issues surrounding end-of-life care. *Anesthesia and Critical Care, 17*, 263-270. doi:10.1016/j.cacc.2006.10.002

Cleiren, M. P. H. D., & Van Zoelen, A. J. (2002). Post-mortem organ donation and grief: A study of consent, refusal and well-being in bereavement. *Death Studies, 26,* 837-849. doi:10.1080/07481180290106607

Colorado University School of Medicine - Department of Pediatrics. (2014). Dimensions of culture cross-cultural communications for healthcare professionals. Retrieved from

http://www.ucdenver.edu/academics/colleges/medicalschool/departments/pediatrics/people/diversity/education/Pages/DimensionsOfCulture.aspx

Commission de l'éthique de la science et de la technologie. (2004). Cadaveric donation consent models and raising the subject with families. In *Organ donation and transplantation: Ethical dilemmas due to shortage (position statement).* Retrieved from http://www.ethique.gouv.qc.ca/fr/assets/documents/Don-dorganes/2006-don-par-echanges/Don_transplantation_organes_%20par_echange_%20EN.pdf

Daly, B. J. (2006). End-of-life decision making, organ donation, and critical care nurses. *Critical Care Nursing, 26,* 78–86.

Davis, C., & Randhawa, G. (2004). "Don't know enough about it": Awareness and attitudes toward organ donation and transplantation among the Black Caribbean and Black African population in Lambeth, Southwark, and Lewisham, United Kingdom. *Transplantation, 78,* 420–425. Retrieved from http://journals.lww.com/transplantjournal/Abstract/2004/08150/_Don_t_Know_Enough_about_It____Awareness_and.16.aspx

de Groot, J., Vernooij-Dassen, M., Hoedemaekers, C., Hoitsma, A., Smeets, W., & van Leeuwen, E. (2012). Decision making by relatives about brain death organ donation: An integrative review. *Transplantation, 93,* 1196-1211. doi: 10.1097/TP.0b013e318256a45f

DePalma, J. A. (2009). Research. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 217-248). St. Louis, MO: Elsevier Saunders.

Éditeur officiel du Québec. (2010). *Projet de loi no 125 (2010, chapitre 38): Loi facilitant les dons d'organes et de tissus*. Retrieved from

http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2010C38F.PDF

Éditeur officiel du Québec. (2014). *Charter of the French language*. Retrieved from http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/C_11/C11_A.html

Expert Panel on Global Nursing and Health. (2010). *Standards of practice for culturally competent nursing care: Executive summary*. Retrieved from http://www.tcns.org/files/Standards_of_Practice_for_Culturally_Compt_Nsg_Care-Revised_.pdf

Fahrenwald, N. (2010). Intervention research with American Indian, Alaska Native, and First Nations communities. In J. T. Siegel, & E. M. Alvaro (Eds.) *Understanding organ donation* (pp. 132-147). West Sussex, UK: Wiley-Blackwell.

Fernandez, M. (2013). *McGill University Health Centre organ and tissue donation database* (computer program). Montreal, Qc: Primatabase Concept.

Fleming, G. (2014). *Learning styles: Know and use your personal leaning style.* Retrieved from http://homeworktips.about.com/od/homeworkhelp/a/learningstyle.htm

Flodén, A., Berg, M., & Forsberg, A. (2011). ICU nurses' perceptions of responsibilities and organisation in relation to organ donation: A phenomenographic study. *Intensive and Critical Care Nursing, 27,* 305-316. doi:10.1016/j.iccn.2011.08.002

Flodén, A., Persson, L. - O., Rizell, M., Sanner, M., & Forsberg, A. (2011). Attitudes to organ donation among Swedish ICU nurses. *Journal of Clinical Nursing, 20,* 1-13. doi: 10.1111/j.1365-2702.2011.03756.x

Fondation Greffe de Vie. (2013). Fondation greffe de vie. Retrieved from http://www.greffedevie.fr/

Furukawa, M. (1996). Meeting the needs of the dying patient's family. *Critical Care Nurse, 16,* 51-57.

Ghorbani, F., Khoddami-Vishteh, H.R., Ghobadi, O., Shafaghi, S., Louyeh, A. R., & Najafizadeh, K. (2011). Causes of family refusal for organ donation. *Transplantation Proceedings, 43,* 405–406. doi: 10.1016/j.transproceed.2011.01.031

Goode, T. (2006). *Key definitions.* Washington D.C.: National Center for Cultural Competence, Georgetown University Center for Child and Human Development. Retrieved from http://www.nccccurricula.info/awareness/index.html

Guido, L. D. A., Linch, G. F. D. C., Andolhe, R., Conegatto, C. C., & Tonini, C. C. (2009). Stressors in the nursing care delivered to potential organ donors. *Revista Latino-Americana de Enfermagem, 17,* 1023-1029.

Hamric, A. B. (2009). A definition of advanced practice nursing. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 75-94). St. Louis, MO: Elsevier Saunders.

Hamric, A. B., & Delgado, S. A. (2009). Ethical decision making. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 315-346). St. Louis, MO: Elsevier Saunders.

Hamric, A. B., Hanson, C. M., Tracy, M. F., & O'Grady, E. T. (2014). *Advanced practice nursing: An integrative approach* (5th ed). St. Louis, MO: Elsevier Saunders.

Hanson, C. M., & Spross, J. A. (2009). Collaboration. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 283-314). St. Louis, MO: Elsevier Saunders.

Hebert, P.L., Rivera, J., Eng, K., Lee, R., & Seto-Yee, S. (2010). Improving organ donation in Chinese communities in New York. In J. T. Siegel & E. M. Alvaro (Ed.) *Understanding organ donation* (pp. 119-131). West Sussex, UK: Wiley-Blackwell.

Heine, S. J. (2012). Chapter 10: Living in multicultural worlds. In S. J. Heine (Ed.) *Cultural psychology* (2nd ed.). New York, NY: W. W. Norton & Company, Inc.

Héma-Québec. (2010). *Organ and tissue donations: What is the difference?* Retrieved from http://www.hema-quebec.qc.ca/comprendre/tissus-humains/difference-dons-organes-dons-tissus.en.html

Hibbert, M. (1995). Stressors experienced by nurses while caring for organ donors and their families. *Heart & Lung, 24,* 399-407. Retrieved from http://www.heartandlung.org/article/S0147-9563(05)80062-7/abstract

Hodge, F. S., Bellanger, P., & Norman, C. (2011). Organ donation and transplantation: A dialogue with American Indian healers and Western health-care providers. *American Indian Culture and Research Journal, 35,* 79-90. Retrieved from http://aisc.metapress.com/content/b203585356111l1k5/?p=80df954a480a4f4ebca83f6eb4365844&pi=3

Høye, S., & Severinsson, E. (2008). Intensive care nurses' encounters with multicultural families in Norway: An exploratory study. *Intensive and Critical Care Nursing, 24,* 338-348. doi 10.1016/j.iccn.2008.03.007

Irving, M. J., Tong, A., Jan, J., Cass. A., Rose, J., Chadban, S., ... Howard, K. (2011). Factors that influence the decision to be an organ donor: A systematic review of the qualitative literature. *Nephrology Dialysis Transplantation, 27,* 2526-25-33. doi: 10.1093/ndt/gfr683

Jacoby, L. H., Radecki-Breitkopf, C., & Pease, E. A. (2005). A qualitative examination of the needs of families faced with the option of organ donation. *Dimensions of Critical Care Nursing, 24,* 183-189.

Kagawa-Singer, M., & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives". *Journal of the American Medical Association, 286,* 2993-3001. doi: 10.1001/jama.286.23.2993

Kemp, C. (2005). Cultural issues in palliative care. *Seminars in Oncology Nursing, 21,* 44-52. doi:10.1053/j.soncn.2004.10.007

Kierans, C., & Cooper, J. (2013). The emergence of the ethnic donor: The cultural production and relocation of organ donation in the UK. *Anthropology and Medicine, 20,* 221-231. doi: 10.1080/13648470.2013.845480

King, T. (2013). *Instructional design: A journey in learning.* Retrieved from http://tarynking.wordpress.com/2013/05/17/comparing-models/

Knowles, M. (1984). *The modern practice of adult education: From pedagogy to andragogy.* Chicago, IL: Associated Press, Follett Publishing Co.

Kongnetiman, L. (n/d). *When a child dies: Cultural competency in paediatric palliative care.* Retrieved from http://fcrc.albertahealthservices.ca/pdfs/When_a_Child_Dies_Cultural_Competency_in_Paediatric_Palliative_Care.pdf

Kurz, R. S., Scharff, D. P., Terry, T., Alexander, S., & Waterman, A. (2007). Factors influencing organ donation decisions by African Americans: A review of the literature. *Medical Care Research and Review, 64,* 475-517. doi: 10.1177/1077558707304644

Lazarus, R. S. (2000). Chapter 9: Evolution of a model of stress, coping, and discrete emotions. In V. H. Rice (Ed.), *Handbook of stress, coping, and health: Implications for nursing research, theory, and practice,* 195-222.

Leduc, V., Rachédi, L., Labescat, G., Montgomery, C., & Mongeau, S. (2010). Accompagner les familles immigrantes endeuillées: Des connaissances sur les diverses visions de la mort et les rites dans les grandes religions et confessions au Québec. *École de travail sociale Université de Québec à Montréal,* bulletin synthèse n°2 – avril.

Leininger, M. M. (1988). Leininger's Theory of Nursing: Cultural Care Diversity and Universality. *Nursing Science Quarterly, 1,* 152-160. doi: 10.1177/089431848800100408

Leininger M. (1991). *Culture care diversity and universality: A theory of nursing.* New York, NY: National League for Nursing Press.

Leininger, M. (1995). Transcultural nursing perspectives: Basic concepts, principles, and culture care incidents. In M. Leininger & M. R. McFarland (Eds.), *Transcultural nursing: Concepts, theories, research and practice* (2nd ed.). New York: McGraw Hill.

Leininger, M. M. (2001). *Culture care diversity and universality: A theory of nursing.* Sudbury, MA: Jones and Bartlett Publishers.

Leininger, M. M. (2006). Ethnonursing: A research method with enablers to study the theory of culture care [Revised reprint]. In M. M. Leininger, & M. R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed.), p. 25. Sudbury, MA: Jones and Bartlett Publishers.

Leininger, M. M., & McFarland, M. (2006). *Culture care diversity and universality: A worldwide nursing theory* (2nd ed.). Sudbury, MA: Jones and Bartlett Publishers Inc.

Lemes, M. M. D. D., & Bastos, M. A. R. (2007). The maintenance care of potential organ donors: Ethnographic study on the experience of a nursing team. *Revista Latino-Americana de Enfermagem, 15*, 986-981. doi: 10.1590/S0104-11692007000500016

Lira, G. G., Pontes, C. M., Schirmer, J., & de Lima, L. S. (2012). Family considerations about the decision to refuse organ donation. *ACTA Paulista de Enfermagem, 25, special issue 2,* 140-145. Retrieved from http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002012000900022&lng=en&nrm=iso

Lloyd-Williams, M., Morton, J., & Peters, S. (2009). The end-of-life care experiences of relatives of brain dead intensive care patients. *Journal of Pain and Symptom Management, 37*, 659-664. doi: 10.1016/j.jpainsymman.2008.04.013

Lobar, S. L., Youngblut, J. M., & Brooten, D. (2006). Cross-cultural beliefs, ceremonies, and rituals surrounding death of a loved one. *Pediatric Nursing, 32,* 44-50. Retrieved from http://www.medscape.com/viewarticle/525639

Mak, M. W. (2014). *Death plus respect = Cultural safety.* Retrieved from http://pub209healthcultureandsociety.wikispaces.com/Death+plus+Respect%3DCultural+safety

Maloney, R., & Wolfelt, A. D. (2001). *Caring for donor families before, during and after*. Fort Collins, CO: Companion Press.

Manuel, A., Solberg, S., & MacDonald, S. (2010). Organ donation experiences of family members. *Nephrology Nursing Journal, 37,* 229-237. Retrieved from http://www.prolibraries.com/anna/?select=session&sessionID=958

Maroudy, D. (2008). Organ procurement: Proposals for approaching the family of the deceased. *Organs, Tissues and Cells, 3,* 187-195. Retrieved from http://www.editricecompositori.it/flex/FixedPages/Common/OrgansArticolo.php/L/EN/ID/274/BL/aHR0cDovL3d3dy5lZGl0cmljZWNvbXBvc2l0b3JpLml0L2ZsZXgvRml4ZWRQYWdlcy9Db21tb24vT3JnYW5zQXJ0aWNvbG8ucGhwL0wvRU4vSURLLzIwNg%3D%3D

Mazanec, P., & Tyler, M. K. (2004). Cultural considerations in end-of-life care: How ethnicity, age, and spirituality affect decisions when death is imminent. *Home Health Care Nurse, 22,* 317-324

McCubbin, M. A., & McCubbin, H. I. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crises. In H. I. McCubbin, A. I. Thompson, & A. A. McCubbin (Eds.). *Family assessment: Resiliency, coping and adaptation - Inventories for research and practice* (1-64). Madison, WI: University of Wisconsin.

McGill University Health Centre. (2012). *McGill University Health Centre policy and procedure: Organ and tissue donation – deceased donor – administrative policy.* McGill University Health Centre, Montreal, Qc: Author.

Merchant, S. J., Yoshida, E. M., Lee, T. K., Richardson, P., Karlsbjerg, K. M., & Cheung, E. (2008). Exploring the psychological effects of deceased organ donation on the families of the organ donors. *Clinical Transplantation, 22,* 341-347. Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/j.1399-0012.2008.00790.x/abstract

Meyer, K., Bjørk, I. T., & Eide, H. (2012). Intensive care nurses' perceptions of their professional competence in the organ donor process: A national survey. *Journal of Advanced Nursing, 68,* 104-15. doi: 10.1111/j.1365-2648.2011.05721.x.

Molzahn, A.E., Starzomski, R., McDonald, M., & O'Loughlin, C. (2004). Aboriginal beliefs about organ donation: Some Coast Salish viewpoints. *Canadian Journal of Nursing Research, 36,* 110-128. Retrieved from http://docserver.ingentaconnect.com/deliver/connect/mcgill/08445621/v36n4/s8.pdf?expires=1400551710&id=78205265&titleid=6601&accname=Guest+User&checksum=A923C20FCDD74B733727B65D9FB48F58

Molzahn, A.E., Starzomski, R., McDonald, M., & O'Loughlin, C. (2005a). Chinese Canadian beliefs toward organ donation. *Qualitative Health Research, 15,* 82-98. doi: 10.1177/1049732304270653

Molzahn, A.E., Starzomski, R., McDonald, M., & O'Loughlin, C. (2005b). Indo-Canadian beliefs regarding organ donation. *Progress in Transplantation, 15,* 233-239. Retrieved from http://natco.metapress.com/content/q224131k1146/?p=84b3d3c966ee424d852d2c7114b6dab6&pi=32

Monforte-Royo, C., & Roqué, M. V. (2012). The organ donation process: A humanist perspective based on the experiences of nursing care. *Nursing Philosophy, 13,* 295-301. doi: 10.1111/j.1466-769X.2012.00544.x

Morgan, S. E. (2004). The power of talk: African Americans' communication with family members about organ donation and its impact on the willingness to donate organs. *Journal of Social and Personal Relationships, 21,* 112-124. doi: 10.1177/0265407504039845

Morrison, G. R., Ross, S. M., Kalman, H. K., & Kemp, J. E. (2011). *Designing effective instruction* (6th ed.). Hoboken, NJ: John Wiley & Sons Inc.

Ordre des infirmières et infirmiers du Québec. (2014). *Norme professionnelle de formation continue*. Retrieved from http://www.oiiq.org/pratique-infirmiere/deontologie/chroniques/norme-professionnelle-de-formation-continue

Pearson, A., Robertson-Malt, S., Walsh, K., & Fitzgerald, M. (2001). Intensive care nurses' experiences of caring for brain dead organ donor patients. *Journal of Clinical Nursing, 10,* 132-139. doi: 10.1046/j.1365-2702.2001.00447.x

Petty, R. E., Barden, J., & Wheeler, S. C. (2009). The elaboration likelihood model of persuasion: Developing health promotions for sustained behavioral change. In R. J. DiClemente, R. A. Crosby, & M. C. Kegler (Eds.), *Emerging theories in health promotion practice and research* (2nd ed., pp. 185-214). San Francisco, CA US: Jossey-Bass.

Posner, G. J., & Strike, K. A. (1976). A categorization scheme for principles of sequencing content. *Review of Educational Research, 46,* 665-690. doi: 10.3102/00346543046004665

Pottinger, A., Perivolaris, A., & Howes, D. (2007). The end of life. In R. H. Srivastava (Ed.), *Guide to clinical cultural competence* (pp. 227-246). Toronto, ON: Mosby - Elsevier.

Queensland Government. (2013). *Multicultural health*. Retrieved from http://www.health.qld.gov.au/multicultural/

Radosevich, D.M., Larson, S. M., Scott, T., Jones, C., Tendle, W., & Gunderson, S. (2010). The effectiveness of the donate life African American Campaign in Minneapolis-St. Paul. In J. T. Siegel & E. M. Alvaro (Ed.) *Understanding organ donation* (pp. 83-97). West Sussex, UK: Wiley-Blackwell.

Ralph, A. Chapman, J.R., Gillis, J., Craig, J.C., Butow, P., Howard, K., ... & Tong, A. (2014). Family perspectives on deceased donation: Thematic synthesis of qualitative studies. *American Journal of Transplantation, 14*, 923-935. doi: 10.1111/ajt.1266D

Randhawa, G. (2012). Death and organ donation: Meeting the needs of multiethnic and multifaith populations (supplement). *British Journal of Anaesthesia, 108,* i88–i91. doi:10.1093/bja/aer385

RUIS McGill. (2013). *What is RUIS?* Retrieved from https://www.mcgill.ca/ruis/about-us/what-ruis

RUIS McGill. (2014). *Welcome to RUIS McGill.* Retrieved from https://www.mcgill.ca/ruis/

Sadala, M. L. A., & Mendes, H. W. B. (2000). Caring for organ donors: The intensive care unit nurses' view. *Qualitative Health Research, 10,* 788-805. doi: 10.1177/104973200129118822

Schenker, Y., Crowley-Matoka, M., Dohan, D., Tiver, G. A., Arnold, R. M., & White, D.B. (2012). I don't want to be the one saying "we should just let him die": Intrapersonal tensions experienced by surrogate decision makers in the ICU. *Journal of General Internal Medicine, 27,* 1657-1655. doi: 10.1007/s11606-012-2129-y

Schirmer, J., & de Aguiar Roza, B. (2008). Family, patients, and organ and tissue donation: Who decides? *Transplantation Proceedings, 40,* 1037-1040. doi:10.1016/j.transproceed.2008.03.050

Schulz, P.J., Nakamoto, K., Brinberg, D., & Haes, J. (2006). More than nation and knowledge: Cultural micro-diversity and organ donation in Switzerland. Patient *Education and Counseling, 64,* 294-302. doi: 10.1016/j.pec.2006.03.009

Sharif, A., Jawad, H., Nightingale, P., Hodson, J., Lipkin, G., Cockwell, P., Ball, S., & Borrows, R. (2011). A quantitative survey of Western Muslim attitudes to solid organ donation. *Transplantation, 92,* 1108-1114. doi: 10.1097/TP.0b013e318231ea17

Sherry, W., Tremblay, T., & Laizner, A. M. (2013). An exploration of knowledge, attitudes and beliefs toward organ and tissue donation among the adult Haitian population living in the

Greater Montreal area. *Dynamics, 24*, 8-12. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/?term=sherry%2C+tremblay%2C+laizner

Sitzman, K., & Wright-Eichelberger, L. (2011). *Understanding the work of nurse theorists: A creative beginning* (2nd ed.). Sudbury. MA: Jones and Bartlett Publishers.

Spross, J. A. (2009). Expert coaching and guidance. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 159-190). St. Louis, MO: Elsevier Saunders.

Spross, J. A., & Hanson, C. M. (2009). Clinical, professional, and systems leadership. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 249-282). St. Louis, MO: Elsevier Saunders.

Srivastava, R. H. (2007). Chapter 3: Culture care framework I: Overview and cultural sensitivity. In R. H. Srivastava (Ed.) *Guide to cultural competence.* Toronto, Ont: Elsevier Canada.

Statistics Canada. (2012). *Focus on geography series, 2011 census.* Retrieved from https://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-pr-eng.cfm?Lang=eng&GK=PR&GC=24

Statistics Canada. (2013). NHS profile, Montreal, V, Quebec, 2011. Retrieved from http://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/prof/details/page.cfm?Lang=E&Geo1=CSD&Code1=2466023&Data=Count&SearchText=Montr%C3%A9al&SearchType=Begins&SearchPR=01&A1=Ethnic%20origin&B1=All&Custom=&TABID=1

Statistics Canada. (2014). *Immigration and ethnocultural diversity in Canada.* Retrieved from http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-010-x/99-010-x2011001-eng.cfm

Tervalon, M., & Murray-García J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Our of Health Care Poor Underserved Populations, 2,* 117-125.

Tracy, M. F. (2009). Direct clinical practice. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced practice nursing: An integrative approach* (4th ed., pp. 123-158). St. Louis, MO: Elsevier Saunders.

Transplant Québec. (2013). *Multiculturalism and organ donation.* Retrieved from http://transplantquebec.ca/en/multiculturalism-and-organ-donation

Transplant Québec. (2014). *Statistiques 2013.* Retrieved from http://www.transplantquebec.ca/sites/default/files/statistiques_2013_3.pdf

Trillium Gift of Life. (2013). *The importance of culture and religion.* Retrieved from http://www.giftoflife.on.ca/en/donorsupport.htm

Truog, R. D., Cist, A. F. M., Brackett, S. E., Burns, J. P., Curley, M. A. Q., Danis, M., ... Hurford, W. E. (2001). Recommendations for end-of-life care in the intensive care unit: The ethics committee of the Society of Critical Care Medicine. *Critical Care Medicine, 29,* 2332-2348.

University of Washington Medical Center. (n/d). *Patient and family education services.* Retrieved from http://depts.washington.edu/pfes/CultureClues.htm

Van den Branden, S., & Broeckaert, B. (2011). The ongoing charity of organ donation: Contemporary English Sunni Fatwas on organ donation and blood transfusion. *Bioethics, 25,* 167-175. doi:10.1111/j.1467-8519.2009.01782.x

Vanderspank-Wright, B., Fothergill-Bourbonnais, F., Brajtman, S., & Gagnon, P. (2011). Caring for patients and families at end of life: The experiences of nurses during withdrawal of life-

sustaining treatment. *Dynamics, 22(4),* 31–35. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/22282952

Warren, B.J. (2005). The cultural expression of death and dying. *Case Manager,* 16 (1), 44-47. Retrieved from http://www.hawaii.edu/hivandaids/The_Cultural_Expression_of_Death_and_Dying.pdf

White, E. (2014, January 2). Dying woman's family says goodbye online. *The Gazette,* p. A19. Retrieved from http://www.pressdisplay.com/pressdisplay/viewer.aspx

Wittig, D. J. (2001). Organ donation beliefs of African American women residing in a small southern community. *Journal of Transcultural Nursing, 12,* 203-210. doi: 10.1177/104365960101200304

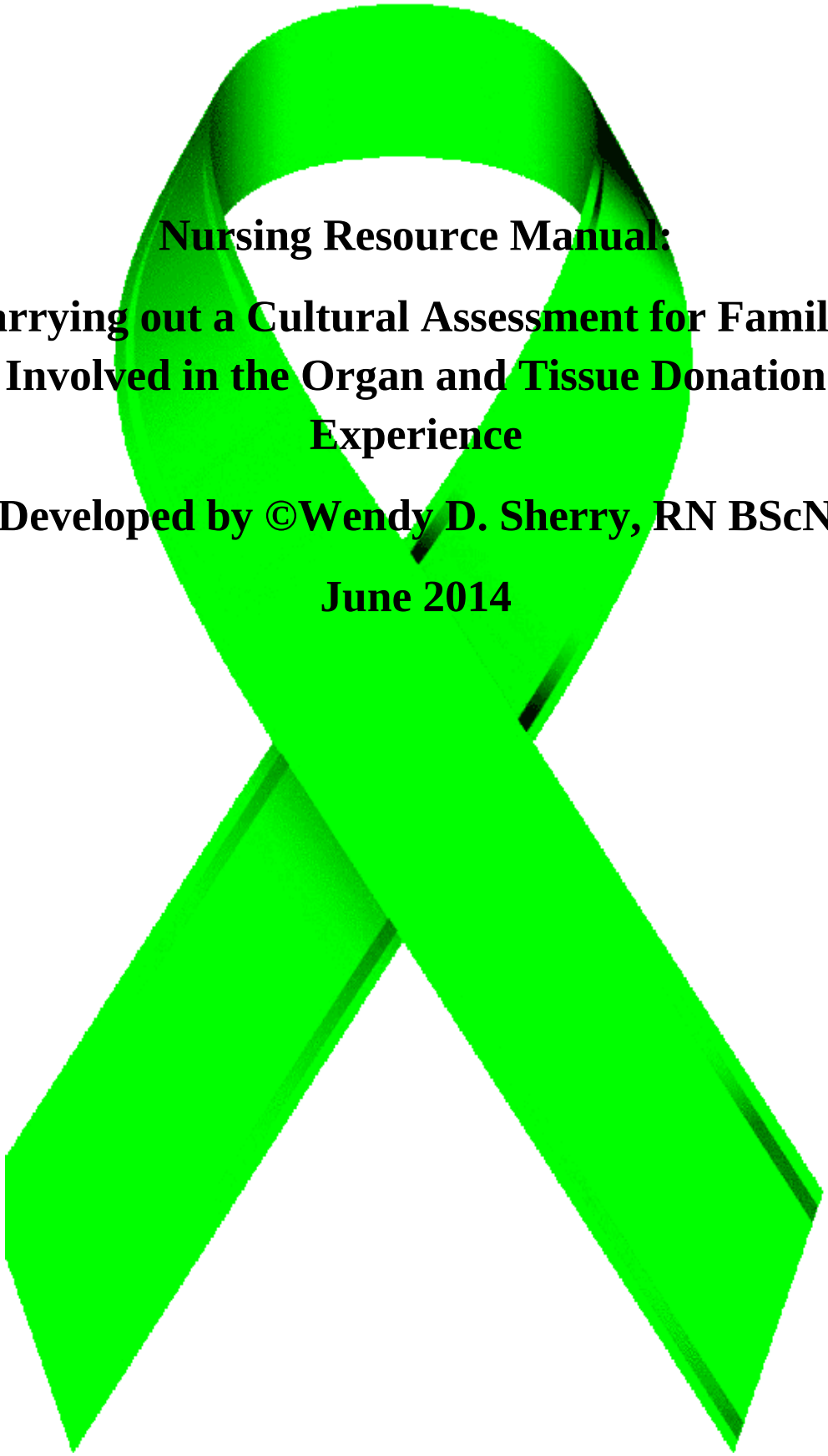
Wood, P., & Schwass, M. (1993). Cultural safety: A framework for changing attitudes. *Nursing Praxis in New Zealand, 8,* 4-15. Retrieved from http://www.nursingpraxis.org/81-cultural-safety-a-framework-for-changing-attitudes.html

Wright, L. M., & Bell, J. M. (2009). *Beliefs and illness: A model for healing.* Calgary, AB: 4th Floor Press Inc.

Appendices

Appendix A

Nursing Resource Manual:
Carrying out a Cultural Assessment for Families Involved in the Organ and Tissue Donation Experience



Nursing Resource Manual:

Carrying out a Cultural Assessment for Families Involved in the Organ and Tissue Donation Experience

Developed by ©Wendy D. Sherry, RN BScN

June 2014

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Introduction

In 2010, the Expert Panel on Global Nursing created a set of standards to promote cultural competence. The objective was to identify universal transcultural nursing standards that could be translated into practice. The document specifically addressed the need to increase awareness of nurses' cultural knowledge, and the creation of resources for nurses caring for ethnocultural communities. Given that more than one third of McGill University Health Centre (MUHC) eligible organ and tissue donors are members of an ethnocultural community, nurses working with this population need resources to help them provide care unique to this population's needs. The goal of this manual is to guide nurses to provide culturally competent nursing care for Québec ethnocultural families throughout the organ and tissue donation (OTD) process. The content of this manual is guided by Leininger's (1988) Theory of Culture Care Diversity and Universality, and based on discussions with members of key ethnocultural communities living in Quebec, nurses, OTD clinicians, and the literature.

Instructions on how to use the Manual

The manual is divided in to eight sections: (1) foundational concepts, (2) nursing cultural self-assessment, (3) major ethnocultural communities in Québec, (4) carrying out a cultural family assessment, (5) what to do with gathered family information, (6) evaluation form for the nursing resource manual, (7) resources, and (8) references. The first five sections begin with section objectives that reflect the contents of that particular section. When working through this manual, it is important that you complete each section in sequence as each section builds on the previous section(s).

Section one, provides an overview of foundational key terms and concepts. You are introduced to some of the common family needs throughout the OTD process cited in the

literature. In section two, you are asked to complete a cultural self-assessment. Statements to assess your knowledge, awareness, skills, and to help you identify your strengths and challenges when interacting with ethnocultural community members are reviewed. Sections one and two conclude with reflective questions on how you felt as you moved through these sections of the manual.

Section three provides an overview of five of the ten major ethnocultural communities in Montréal , which were determined from collected statistics (Statistics Canada, 2013; 2014). The information contained in this section will serve as a foundation to the development of potential questions you will ask as you care for an ethnocultural family. Section four guides you through the process of taking the broad information acquired in section three, to asking specific questions related to a particular family's view of their culture, beliefs, and needs. In section five, you will learn how to use obtained information about a family's culture to develop nursing interventions reflective of their needs as they engage in the OTD process. Sections three, four, and five include an on-going case study to provide you with an opportunity to apply what you have learned in a real life clinical scenario. The answers are provided to help you evaluate your progress. In the event that you require additional guidance or would like to discuss your reflections on sections of the manual please contact Wendy Sherry using the email listed below.

You are asked to complete an evaluation form in section six. This information is confidential and will only be used to revise contents of the manual. Completed forms can be emailed wendy.sherry@muhc.mcgill.ca or sent via internal mail to Wendy Sherry, RN, BScN, MUHC-RVH S11, MUHC Nurse Clinician for OTD. She can also be reached by phone at (514) 934-1934, extension #36590.

Section seven contains available MUHC resources, pertinent external resources (e.g., Transplant Québec, Héma Québec), the ethnocultural family assessment checklist that will help you to remember the type of information that needs to be gathered, a visual representation of Leininger's (2006) Sunrise Enabler Model of the different components guide the family cultural assessment, and answers to the on-going case scenario. Section eight contains the reference list.

When you see the icon below, it indicates an important fact related to family culture sensitive care and the OTD experience.

Section One: Foundational Concepts

Objectives
○ To discuss the need to develop skills that foster culture congruent care for ethnocultural families involved in the OTD process. ○ To define key terms and concepts related to OTD. ○ To discuss the concept of culture. ○ To identify common family needs in the OTD process.

Data from Statistics Canada (2014) has shown that Montréal is the third largest metropolitan area for immigration. At the MUHC, ethnocultural communities represented 35% to 40% of organ and tissue donors for the years 2011-2012 (Fernandez, 2013). Given the large number of ethnocultural families who are faced with the OTD decision, nurses need to be equipped with the knowledge and skills to provide culturally congruent care to this population. The first step in this process is becoming familiar with common terms to help you understand culturally congruent nursing care within the context of the deceased donation process. If you click on the following hyperlink (MUHC OTD service information) you will find information on deceased OTD and related MUHC OTD policy and procedures. You need to be familiar with this information before you proceed with the resource manual. Box one provides a brief introduction of key terms and concepts.

Box One: Key Terms and Concepts

Term	Definition
Acculturation	"The process by which people migrate to and learn a culture that is different from their original (or heritage) culture" (Heine, 2012, p. 386).
Culture Congruent Care	"Acts or decisions that are tailor made to fit with individual, group, or institutional cultural values, beliefs, and *lifeways* in order to provide or support meaningful, beneficial, and satisfying health care or well-being services" (Leininger, 1995, p. 106).
Donation after Cardiocirculatory Death (DCD)	Patients who do not fulfill neurological criteria for death and for whom continuing medical care maybe considered futile. Death is anticipated to occur imminently upon withdrawal of life-sustaining therapy (Canadian Council for Donation and Transplantation [CCDT], 2005).
Family	"A group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives" (Wright & Bell, 2009, p. 46).
Human Leukocyte Antigen (HLA)	Refers to cell surface antigens that are detected through blood tests and vary between people and cultural communities (Spondylitis Association of America, 2012). HLA antigens are often used to match potential organ donors with organ recipients.
Neurological Determination of Death (NDD)	The irreversible loss of the capacity for consciousness combined with the irreversible loss of all brainstem functions, including the capacity to breathe (CCDT, 2003)
Tissue Donation	The donation of eyes (corneas), cardiac valves, skin, bone and / or tendons following death (Héma-Québec, 2010)

To provide care that is culturally sensitive it is important that nurses are familiar with what is meant by the concept of *culture*.

What is Culture?

Culture is "the learned, shared, and transmitted knowledge of values, beliefs, norms, and lifeways of a particular group of people that guides an individual or group in their thinking, decisions, and actions in patterned ways" (Leininger, 1995, p. 60). In other words, culture shapes who you are, how you act, and how you perceive situations that are new or different; ethnicity does not define culture. Learning about a family's culture and how it impacts the OTD experience will help you to offer culturally sensitive care based on expressed family needs.

The dying process can create an intense emotional time for family members, especially when families are also approached to make a donation decision (Monforte-Royo & Roqué, 2012). This requires nurses to practice family centered care that incorporates recognition of cultural values and beliefs. Research studies have identified a number of common family needs and concerns that you can expect to encounter during your interactions with families throughout the OTD process (see Box Two).

Box Two: Common Family Needs

Family Needs	
To perceive support from nurses.	To participate in care decisions involving their family member and to express their emotions.
To have time to understand and process information (e.g., concept of neurological death).	To incorporate end of life care needs (e.g., frequent bedside visits, spiritual needs, rituals, creation of keepsakes, etc).

(Furukawa, 1996; Jacoby, Radecki-Breitkopf, & Pease, 2005; Irving, et al., 2011; Maloney & Wolfelt, 2001; Pottinger, Perivolaris, & Howes, 2007; Randhawa, 2012; Truog, et al., 2001; Wright & Bell, 2009)

Although ethnocultural family needs can include those common family needs listed in box two, families at the MUHC have expressed unique needs related to the OTD experience. At

the MUHC, reasons given by ethnocultural family members for declining donation involved body integrity issues, lack of knowledge on deceased donation, not accepting the diagnosis of neurological death, and a lack of family discussion on OTD. This underscores the importance of exploring ethnocultural family values, beliefs, and needs. In addition, nurses have expressed discomfort coping with ethnocultural families throughout the OTD process. Nurses described feelings of being unprepared to deal with a family's needs, grief, and questions (Guido, Linch, Andolhe, Conegatto, & Tonini, 2009; Høye & Severinsson, 2008; Pearson, Robertson-Malt, Walsh, & Fitzgerald, 2001). In order to provide holistic cultural competent care it is critical that nurses understand how their beliefs influence their perceptions, decisions, and coping skills (Maloney & Wolfelt, 2001; Pottinger et al., 2007; Srivastava, 2007). Nurses who are aware of their own cultural beliefs and those of OTD families can develop a plan of care reflective of their patient and family's unique cultural needs. Therefore you will be asked to explore your personal and professional perceptions of cultural competence in the next section.

Not all ethnocultural communities are visible. A person can be Caucasian and a member of an ethnocultural community (e.g., Italian, Romanian). This distinction is important as while all human beings share similar blood types, HLA differs. HLA matching is only used for organ donation as tissues are universally shared.

Reflective Questions

- Think about your experience caring for families throughout the OTD process. Did your nursing care take into consideration the needs of the family?
- Have you ever cared for a family that has experienced some of the family needs listed in Table Two?
- Are your nursing interventions the same or different when caring for culturally diverse families?
- Referring to the defined terms in Table One; how is the definition of family similar or different from how you would define "family"?

Individual responses to questions will vary. As you move through the manual consider how your responses to the above reflective questions have informed your practice. If you have any concerns about the questions contained in this section, please note them in the evaluation form found at the end of section five (pages 42 - 43).

Section Two: Nurse Cultural Self-Assessment

Objectives
○ To complete a cultural competence self-assessment checklist. ○ To identify your strengths and challenges when caring for diverse ethnocultural populations. ○ To analyse how cultural awareness, cultural knowledge, and cultural skills affect culture sensitive care.

Nurses' attitudes and knowledge about OTD, and nurses' experiences with ethnocultural families involved in the donation process are the two main factors noted in the literature that impact a nurse's role in caring for ethnocultural families throughout the OTD process. In order to provide holistic cultural competent care, it is critical to gain an understanding of how your personal and professional cultural values, beliefs, and attitudes influence your perceptions, coping skills, and nursing practice decisions. Nurses who are aware of their own cultural beliefs and those of OTD families can develop a plan of care reflective of their patient and family's unique cultural needs and hopefully influence families' OTD experience in a positive manner. A self- awareness regarding your cultural competence will help you to gain insight into any prejudices that may exist as you offer care to ethnocultural families. Recognition of prejudices avoids stereotyping and discrimination, which may jeopardize your ability to recognize and integrate OTD families' unique cultural beliefs and practices into their plan of care.

The following pages contain a cultural competence self-assessment checklist that will aid you to identify your strengths and any challenges that you may have related to providing care that is culturally sensitive. The checklist asks you to examine your views on people perceived as being part of a distinct group (e.g., member of an ethnocultural community, people with

disabilities, gay, transgendered, low socioeconomic status, etc). This will provide you with an opportunity to reflect on some of the challenges you may encounter while conducting a cultural family assessment.

This exercise offers you an opportunity to reflect on your cultural awareness, cultural knowledge, and cultural skills. Cultural awareness assesses your attitudes, beliefs, and feelings. Cultural knowledge reflects what you have learned through personal and professional experience. Cultural skills look at your behavior when interacting with people who are members of an ethnocultural community. The checklist is for personal use and growth and does not need to be shared with your colleagues. The scores on the three checklists will vary from person to person due to personal and professional experiences. A low score indicates a need to review how to incorporate nursing actions that reflect cultural sensitive care. In the event that this happens, you are encouraged to notify the OTD nurse clinicians in order to review and discuss your results.

Box Three: Cultural Competence Self-Assessment Checklist Instructions

Instructions

1. The check list has three parts: (1) Awareness, (2) Knowledge, and (3) Skills.
2. After reading a statement, place an "X" in the column that most closely describes your feelings.
3. When finished, add up the totals of each column.
4. Multiply the number of "Xs" by 1 for the Never column; multiply the total by 2 for the Sometimes / occasionally column; multiply the total by 3 for the Fairly often / pretty well column and multiply the total by 4 for the Always / very well column.
5. Each part is worth 40 points, the higher your score, the more cultural competence you have developed.

Cultural Competence Self-Assessment Checklist

Awareness					
		Never	**Sometimes / Occasionally**	**Fairly Often / Pretty Well**	**Always / Very Well**
Value diversity	I view human difference as positive and a cause for celebration.				
Know myself	I have a clear sense of my own ethnic, cultural, and racial identity				
Share my culture	I am aware that in order to learn more about others I need to understand and be prepared to share my own culture.				
Be aware of areas of discomfort	I am aware of my discomfort when I encounter differences in race, colour, religion, sexual orientation, language and ethnicity.				
Check my assumptions	I am aware of the assumptions that I hold about people of cultures different from my own.				
Challenge my stereotypes	I am aware of my stereotypes as they arise and have developed personal strategies for reducing the harm they cause.				
Reflect on how my culture informs my judgement	I am aware of how my cultural perspective influences my judgement about what are “appropriate”, “normal”, or “superior” behaviours, values, and communication styles.				
Accept ambiguity	I accept that in cross cultural situations there can be uncertainty and that uncertainty can make me anxious. It can				

	also mean that I do not respond quickly and take the time needed to get more information.				
Be curious	I take any opportunity to put myself in places where I can learn about difference and created relationships.				
Aware of my privilege if I am White	If I am a White person working with an Aboriginal person or Person of Colour, I understand that I will likely be perceived as a person with power and racial privilege, and that I may not be seen as "unbiased" or as an ally.				
Number of check marks					
Multiply by		**x 1=**	**x 2 =**	**x 3=**	**x 4 =**
Addition of four columns		**/40**			

Knowledge					
		Never	**Sometimes / Occasionally**	**Fairly Often / Pretty Well**	**Always / Very Well**
Gain from my mistakes	I will make mistakes and will learn from them.				
Assess the limits of my knowledge	I will recognize that my knowledge of certain cultural groups is limited and commit to creating opportunities to learn more.				
Ask questions	I will really listen to the answers before asking another question.				
Acknowledge the importance of difference	I know that differences in colour, culture, ethnicity, etc. are important parts of an individual's identity which they value and so do I; I will not hide behind the claim of "colour blindness".				
Know the historical experiences of non-European Canadians	I am knowledgeable about historical incidents in Canada's past that demonstrate racism and exclusion toward Canadians of non-European heritage (e.g., the Chinese Head Tax, the Komagata Maru, Indian Act and Japanese internment).				
Understand the influence culture can have	I recognize that cultures change over time and can vary from person to person, as does attachment to culture.				

Commit to life-long learning	I recognize that achieving cultural competence involves a commitment to learning over a life-time.				
Understand the impact of racism, sexism, homophobia, etc.	I recognize that stereotypical attitudes and discriminatory actions can dehumanize, even encourage violence against individuals because of their membership in groups which are different from myself.				
Know my own family history	I know my family's story of immigration and assimilation into Canada.				
Know my limitations	I continue to develop my capacity for assessing areas where there are gaps in my knowledge.				
Number of check marks					
Multiply by		**x 1=**	**x 2 =**	**x 3=**	**x 4 =**
Addition of four columns		**/40**			

Skills					
		Never	**Sometimes / Occasionally**	**Fairly Often / Pretty Well**	**Always / Very Well**
Adapt to different situations	I am developing ways to interact respectfully and effectively with individuals and groups.				
Challenge discriminatory and / or racist behavior	I can effectively intervene when I observe others behaving in a racist and / or a discriminatory manner.				
Communicate across cultures	I am able to adapt my communication style to effectively communicate with people who communicate in ways that are different from my own.				
Seek out situations to expand my skills	I seek out people who challenge me to maintain and increase the cross-cultural skills I have.				
Become engaged	I am actively involved in initiatives, small or big, that promote understanding among members of diverse groups.				
Act respectfully in cross-cultural situations	I can act in ways that demonstrate respect for the culture and beliefs of others.				
Practice cultural protocols	I am learning about and put into practice				

	the specific cultural protocols and practices which are necessary for my work.				
Act as an ally	My colleagues who are Aboriginal, immigrants, or People of Colour consider me an ally and know that I will support them with culturally appropriate ways.				
Be flexible	I work hard to understand the perspectives of others and consult with my diverse colleagues about culturally respectful and appropriate courses of action.				
Be adaptive	I know and use a variety of relationship building skills to create connections with people who are different for me.				
Number of check marks					
Multiply by		**x 1=**	**x 2 =**	**x 3=**	**x 4 =**
Addition of four columns		**/40**			

Adapted with permission from the Central Vancouver Island Multicultural Society (n/d). Funding was provided by the Government of Canada and the Province of British Columbia. Retrieved from http://static.diversityteam.org/files/414/cultural-competence-self-assessment-checklist.pdf?1342126927

Reflective Questions
○ Did any of the cultural self-assessment statements make you feel uncomfortable? ○ Do you believe that your attitudes, beliefs and feelings were captured by the cultural awareness statements? ○ Based on your cultural knowledge results, do you adapt your nursing care to meet ethnocultural family's OTD process needs? ○ Are your cultural skills reflected in the care offered to ethnocultural families involved in the OTD process? ○ Did your results surprise you?

Individual responses to questions will vary. If you have any concerns about the cultural self-competence checklist, please note them in the evaluation form found at the end of the last section (pages 42-43).

"If you can't see that your own culture has its own set of interests, emotions, and biases, how can you expect to deal successfully with someone else's culture?" (Kleinman as cited by Fadiman (1997), p. 261)

Section Three: Major Ethnocultural Communities in Québec

Objectives
○ To identify the cultural needs of five ethnocultural groups in Montréal. ○ To discuss why it is important to provide culturally congruent nursing care to ethnocultural families involved in an OTD process. ○ To complete part one of a case study on an ethnocultural family who will be approached for OTD.

In Canada, we have a growing number of multi-ethnic communities whose members are faced with having to make the decision to donate their family member's organs and tissues. The province of Québec is one of the top three provinces where ethnocultural community members reside (Statistics Canada, 2014). There is a consensus in the literature that nurses are not prepared to deal with families' complex needs throughout the OTD experience, particularly those from diverse ethnocultural backgrounds (Høye & Severinsson, 2008; Kierans & Cooper, 2013). These findings solidify the importance of exploring cultural values and religious beliefs with family members in order to develop a plan of care reflective of their unique needs.

At the MUHC, the OTD service reviews the charts of patients who have died in the EDs, the ICUs, and the palliative care units. Approximately nine percent are identified and referred to the nurse clinicians for OTD or are directly referred to Héma-Québec for tissue donation. Of these, the majority were Canadian Francophones and Canadian Anglophones. Visible and non-visible minorities represented approximately 35% to 40% of eligible patients for the years 2011 to 2012 (Fernandez, 2013).

Given the diverse cultures represented in the MUHC OTD process, it is essential that you acquire basic knowledge on different community ethnocultural values, beliefs, and needs. This will ensure that ethnocultural families are invited to discuss donation in a culturally sensitive manner and enable you to provide culturally congruent care for the deceased and their family members. This section provides an overview of five ethnocultural communities based on data collected from ethnocultural community members living in the Greater Montreal area and agreed to collaborate regarding the development of this manual. Nurses, who have cared for ethnocultural families throughout the OTD process, were also consulted. This is followed by a case study wherein you are given the opportunity to apply the knowledge acquired in this section with a family who will be approached for OTD.

Each of the five tables identifies a Québec ethnocultural community. The purpose of the tables is to provide a general guide on how the OTD process could impact ethnocultural community members. The description of the expressed needs of the community is divided in three categories. Each category is further divided into subdivisions. Religion takes into consideration one's belief system, one's bedside needs, and special considerations unique to the ethnocultural community. Donation includes one's OTD knowledge, issues related to the OTD family approach, decision-making concerns, and other considerations of the OTD process. Family encompasses bedside needs, and considerations with regards to a family's social structures and social interactions. This information was included since families have rituals and / or social norms that are activated when someone is dead or dying, and which will impact the OTD experience. A fourth category has been created for some ethnocultural communities to reflect important information as identified by community members that did not fit into the other

three categories. These tables can be used as a quick reference when you are caring for a potential donor who is a member of an ethnocultural community.

The offered information presents a global overview of an ethnocultural community and does not replace the need to explore a family's interpretation of their cultural values and beliefs toward the OTD process.

Arabic Speaking Communities	
Religion	**Belief System** - Muslim (majority): Sunni and Shiite, Ismailism, Wahhabism, others - Coptic Christian (Orthodox) - Roman Catholic **Bedside needs** - Explore need to have family spiritual leader at the bedside or a member of the MUHC Spiritual Care Team. - MUHC Spiritual team members should avoid approaching family members with items or wearing clothing that reflects a particular religion. **Considerations** - Not all people from Arab countries practice Islam - Immigration time has modified end of life rituals for Arab Christians, however this is not the case for new immigrates. - Only the family views the body, there is no open casket visitation. - Importance of body integrity varies. - Need a space to pray. - Ask questions; don't base impressions on the wearing of religious symbols. - Use open-ended questions and propose ideas to encourage communication of needs.
Donation	**OTD knowledge** - In general, have little OTD knowledge. **Approach** - Approach legal next of kin directly. This person consults with other family members. **Decision-making** - Includes grand-parents, especially the grand-mother. - Practice consensus decision-making. **Considerations** - Living donation valued (especially blood donation). - Bodies are often sent for burial "back home" due to lack of suitable cemeteries as Sunni and Shiite burial rituals are not the same. - Family members living overseas carry out burial rituals so bedside family members worry about the reaction to the decision to donate. - Lack of OTD understanding could create emotional trauma.

Family	**Bedside needs** - Use of touch acceptable, shows caring. - Say "Salam" (hello) when greeting an Arab family. Demonstrates empathy and respect and will strengthen nurse-family relationship. - Immediate, extended family members, and close friends will be present as demonstration of respect and support. - If the deceased does not have any family present, community members will visit. - Kosher and Halal food will be brought to the hospital; many families are vegetarian. **Considerations** - Don't generally talk about illness, perceived as a personal subject. - Generally reserved but friendly
Other	- An Arab is a person who speaks Arabic, most learn "classic" Arabic at school but each country has their own dialect. - Iran is NOT an Arab country and people speak Persian. - Berbers are from Morocco and are the equivalent of our First Nation (original Morocco natives). Have a distinct culture and dialect. - Non-practicing recent immigrants don't have a support system (have colleagues but likely no close friends). - As much as possible have nurse sex match patient sex, especially if the patient is veiled.

Chinese Community	
Religion	**Belief System** - Many practice Chinese folk religion (Buddhism, Taoism, and Confucianism). - Often do not go to a temple but create a sacred place at home to pray and make offerings to family ancestors. - Small group of practicing Muslims **Bedside needs** - Explore need to have family spiritual leader at the bedside or a member of the MUHC Spiritual Care Team. **Considerations** - Bodily integrity very important. - Burial or cremation is chosen based on beliefs.
Donation	**OTD knowledge** - In general, have little OTD knowledge. **Approach** - Check back of Medicare Card for signature, VERIFY understanding (some believe they need to sign it like a credit card). - Medical mistrust: Members may not sign the back of the card as they fear sub-standard medical care in order to get the organs. **Decision-making** - Decision made by the legal next of kin, consultation with other immediate family members likely. **Considerations** - OTD is viewed as big decision.
Family	**Bedside needs** - Immediate and extended family, and close friends at the bedside. - Soup might be brought in for family members staying at the bedside. **Considerations** - Respectful of family elders.

Italian Community	
Religion	**Belief System** - Population almost 100% Roman Catholic; **Bedside needs** - Explore need to have family spiritual leader at the bedside or a member of the MUHC Spiritual Care Team. **Considerations** - Body integrity is important. - Presence of a heart beat denotes presence of a person's spirit.
Donation	**OTD knowledge** - In general, have little OTD knowledge. **Approach** - Preferably indirect, especially if the deceased is an older adult. Speak with an extended family member first. This person will communicate with legal next of kin. - If OTD is presented directly to the legal next of kin, the answer will likely be a firm "no", without possibility of reopening the discussion. Family members will be polite but will talk among themselves and to others about inappropriate approach. **Decision-making** - The decision will be made by the person closest to the deceased but is often influenced by the mother and children. **Considerations** - The family does not want the deceased to suffer.
Family	**Bedside needs** - Immediate and extended family members will be at the bedside. Reasons are family obligation, to demonstrate respect, and to show support. - People will bring food as the bedside gathering creates a family reunion. **Considerations** - Some members naturally talk loud but they are not angry. - Everyone has an opinion and wants to be involved. - Respectful of family elders.

Romanian Community	
Religion	**Type** - 90-95% of the community is Christian Orthodox (follow primarily Greek Orthodox rituals) - Other practiced religions are Protestant (Baptist and Seventh Day Adventist), Roman Catholic, small groups practicing Judaism and Islam. **Bedside needs** - Explore need to have family spiritual leader at the bedside or a member of the MUHC Spiritual Care Team. - Need for end of life rituals vary due to time since immigration. - Prayers are important as is the sharing of food when a person dies. Food feeds the spirit and is shared with everyone around them. **Considerations** - Some family members will bring flowers. - Families prefer to bury their relatives but cremation is acceptable. - Need a space to pray. - Body integrity values vary.
Donation	**OTD knowledge** - In general, have little OTD knowledge. **Approach** - Support and empathy from nurses facilitates discussion of the donation process. - Approach legal next of kin directly. **Decision-making** - Legal-decision maker will ask for immediate family members to be present for the discussion or will consult with them afterwards. **Considerations** - No religious contraindications to donation.
Family	**Bedside needs** - Only immediate family members will be at the bedside, extended family members and friends are not typically invited. - Family members might bring a special sweet bread, coliva or alms (i.e., coliva is a donation for the soul of the dead person).

	Considerations - Offer psychological support to help family cope with grief and loss. - Language barriers impact understanding, need to identify an interpreter (family, volunteer).
Other	- 10% of Romanian population are Gypsies, they have their own culture and rituals - Moldavian traditions are almost identical.

Spanish-American Communities	
Religion	**Belief System** - Approximately 70% Roman Catholic: Practicing Roman Catholics have declined over past three decades - Approximately 30% Protestant (mostly Evangelical and Baptist) **Bedside needs** - Explore need to have family spiritual leader at the bedside or a member of the MUHC Spiritual Care Team. - End of Life rituals vary due to diversity within the different nationalities. **Considerations** - The ultra religious do not support scientific advances and will not even donate blood. - Families may prefer burial over cremation. - Families open to the exploration of their needs (cultural, spiritual, etc). - Need a space to pray.
Donation	**OTD knowledge** - In general, have little OTD knowledge. **Approach** - Approach legal next of kin directly. This person consults with other family members. **Decision-making** - Legal decision-maker is not always the final decision-maker as there is a hierarchy in decision-making (i.e. blood relative versus spouse). - Family is patriarchal. - Multiple generations might be present. **Considerations** - Support and empathy from nurses will facilitate discussion of the donation process with the family.
Family	**Bedside needs** - Immediate and extended family members along with close friends will be at the bedside. Reasons are family obligation, to demonstrate respect, and to show support. **Considerations** - All countries speak Spanish but are culturally different; some have developed

	dialects. - Like to create a natural home environment atmosphere. - Generally an extroverted group. - Offer psychological support to help family cope with grief and loss.
Other	- Demonstration of empathy is a key component to developing a positive nurse-family relationship. - Try to understand the traumatic event / OTD process from their point of view - Language barriers can impact understanding; political views, ethnic strife, and historical events impact the family / interpreter relationship if an outsider is used (trained volunteers or trained interpreters are recommended) - Consular representatives are not recommended as interpreters due to political conflicts.

An OTD approach is a multidisciplinary team decision and families should be respectfully approached at an appropriate time and place.

Now that you have a good understanding of the major concerns related to religion, donation, and family for five of the major ethnocultural communities in Montréal; you will be asked to apply the information to a case study. This will provide you with the opportunity to practice your knowledge and skills to offer culture sensitive care with a family involved in the OTD process. The answers are provided in section eight. If you would like to discuss any aspects of the case study, please contact an MUHC nurse clinician. The same case study will be used in the remaining sections of the manual, allowing you to build on what you have learned in each section.

Case Scenario - Part One

Maria, a 24 year old Brazilian-Canadian female, has just completed a Bachelor of Science degree at a local university. Maria, her French-Canadian boyfriend of two years, and a group of friends head out to their favourite Montreal dance bar to celebrate their graduation.

At the end of the evening, the group of friends cross a street to gain access to the metro. They are halfway across the street when an impatient driver turns onto the street the friends are crossing before they are safely on the other side. Maria is trailing behind her friends and is hit by the car; the impact sending her body ten feet in the air and then crashing head first into the pavement.

Maria's head injuries are so severe the neurosurgeon is unable to offer any medical or surgical interventions. The parents and siblings are at the bedside. Maria's boyfriend and friends are in the intensive care waiting room and are also taking turns spending time at the bedside.

You are Maria's nurse. Based on the provided description of Latin-American communities, what initial information would you want to have in order to offer culture congruent care?

Case scenario answers are found in Section Eight (pages 48 - 52)

You have now translated your knowledge into practice. Section four builds on this knowledge to enable you to carry out a family cultural assessment. A family cultural assessment enables you to gather information on an ethnocultural family's interpretation of their culture, values, and beliefs that are pertinent to the OTD experience. The format used to gather the needed information will allow you to offer culturally sensitive care.

Section Four: Carrying out a Family Cultural Assessment

Objectives
○ To carry out a cultural assessment. ○ To formulate appropriate questions to gather family ethnocultural information. ○ To discuss the importance of engaging in a family in a discussion on cultural values and beliefs. ○ To demonstrate use of the Ethnocultural Family Assessment Checklist ○ To complete the second part of the ongoing case scenario.

The content of this manual is guided by Leininger's (1988) Theory of Culture Care Diversity and Universality. The Sunrise Enabler Model (Leininger, 2006) was developed to collect a family's cultural information. Leininger states that nurses need to integrate families' cultural needs into their care in order to provide care that is culturally congruent. Culturally congruent care are "acts or decisions that are tailor made to fit with individual, group, or institutional cultural values, beliefs, and lifeways in order to provide or support meaningful, beneficial, and satisfying health care or well-being services" (Leininger, 1995, p. 106).

Culturally congruent care facilitates nurses to create meaning and context for patients and families throughout the OTD experience. Being that culture is something that is not static, but develops, changes, and grows in response to one's experiences and the meanings that one assigns to these experiences (Heine, 2012; Leininger, 2001; Leininger & McFarland, 2006; Srivastava, 2007), it is important that nurses are able to complete a cultural assessment with each and every family to assess their interpretation of their needs. The information gathered from the cultural

assessment can then be used to make nursing care decisions and actions that reflect culturally congruent care.

Conducting a family cultural assessment for OTD is similar to other types of nursing assessments as it fosters the development of individualized nursing interventions. The knowledge you have acquired in your personal and professional life from being exposed to different values and beliefs, as well as different types of end of life rituals will support your efforts to gather relevant information to provide culturally sensitive care. A completed cultural family assessment enables you to identify a family's unique needs that impact the OTD process and to develop tailored interventions. Remember the assessment process is on-going in nature as families might reveal important information at a later time (Baldinazzo, 2008; Daly, 2006; Maroudy, 2008). As the cultural self-assessment in the previous section emphasized, your attitude during an exploration of family needs should be non-judgemental and demonstrate caring, respect, concern, empathy, and curiosity (Wright & Leahy, 2013).

In this section you are asked to think of questions that you might ask the family in order to gather relevant cultural information that might impact the donation experience. There are two types of questions that can be asked when needing to gather knowledge about a family. Box four explains the differences between the two types of questions.

Box Four: Formulating Family Questions

Formulating Family Questions

1) Linear questions explore a family's description or perception of what is happening to them or going on around them.
   Example: How did the Doctor explain neurological death to you?

2) Circular questions reveal relationships between family members, experiences and beliefs.
   Example: "Who in the family is struggling most with the death?"

Prior to beginning an exploration of ethnocultural family needs, consider the following:

Where will the discussion take place?

Who will be approached for this information?

Does the family require an interpreter? If yes, who will interpret?

Do other team members have information about the family that could help you with your cultural assessment?

Box five draws on the seven key factors of the Sunrise Enabler Model (Leininger, 2006) (see Appendix A). This will enable you to gather pertinent family information. These factors address kinship and social, religious and philosophical, technological, cultural values, beliefs and lifeways, political and legal, economic, and educational aspects. These seven factors are listed in the first column of the table. The second column provides examples of potential questions reflective of each of the model's seven factors that could be asked during an ethnocultural family assessment. Your observation of verbal and non-verbal communication between family members will shape how the questions are formulated.

An OTD approach is a multidisciplinary team decision and families should be respectfully approached at an appropriate time and place.

Box Five: The Seven Factors of a Family Cultural Assessment

Factors	Example Questions
Kinship & Social Family Composition Description of cultural background Decision-making structure Spoken languages Family end of life rituals	Would you tell me about the people gathered at the bedside and how they are related to (*name*)? Would your family tell me about your culture? What is important for me to know when caring for (name)? What has the Doctor told you about (*name*)'s condition? Who would you like to have with you when we discuss OTD? Is there someone that should be at this meeting that is not here? I can speak (*languages*), will everyone present be able to understand me or is an interpreter needed? Are there any young children in the family who are close to (*name*)? How do you feel about bringing them in to say goodbye? Are there any family traditions you would like us to honour (*name*)?
Religious & Philosophical Family views and / or cultural influences on spiritual beliefs, religious affiliations and death	Would you like a member of our Spiritual Care team to come be with you or would you like to invite your own spiritual leader? Do you have any religious customs that you would like to do?
Technological The machines and equipment used in care of potential donor Family computer literacy (i.e. search for information using web browser; communicate with family & friends).	Do you have any questions about the (*technology*) being used to care for (*name*)? Can you share with me what you know about OTD, brain death? How do you communicate with your family back home?

Factors	Example Questions
Cultural Values, Beliefs & Lifeways Knowledge of OTD Perception of medical professionals Health and illness practices	Families have told me that brain death is hard to understand; would you like to share with me your understanding of what brain death means? We want to offer nursing care that supports your values and beliefs; what do we need to know about your family member and you? Who will be at the family meeting to talk about OTD?
Political & Legal Political and social affiliations beliefs Perception of legal documents Immigration status	I understand you may have concerns about your family being treated in a language that is different from what you speak at home. If so, could you explain to me what they are? Would you like a photocopy of the OTD consent form? How long have you been living in Canada?
Economic Socioeconomic status - Financial resources - Family support - Community support - Work place support	Do you live near the hospital? Do you have a place to stay while you are in town? How are you traveling to the hospital? Who is looking after the children while you are at the hospital? Do you have concerns about the cost of parking? You have not been to work in a few days; does your employer understand why you are absent?
Educational Level of completed education	Do not use medical / nursing jargon and verify understanding of communicated information. Use clear and simple language to explain procedures and answer questions. Did you understand what the doctor said about the tests that are used to declare brain death?

A checklist has been created to ensure that all seven factors have been reviewed with the family. It can be found in the resource section of the manual on page 45. This checklist can be used during your sessions with families as a reminder of the type of information you are seeking.

Now that you have learnt how to ask questions related to the seven factors identified in Leininger's (2006) model; you will be asked to apply the information to the second part of the case study. This will provide you with the opportunity to develop questions that will collect information to offer culture sensitive care to a family. The answers are provided in Section Seven. Your answers to the second part of the case scenario will be needed to answer the final part of the case scenario found in the next section.

Case Scenario - Part Two

The family immigrated to Québec when the father accepted a promotion and transfer from the company where he works. Maria and her three siblings were less than ten years of age at the time of the move. Maria's mother was able to be a full-time caregiver to her children as her husband makes a good salary. The family has returned to Brazil every five years to visit with relatives. Once the children are self-sufficient, the parents have expressed a desire to return to Brazil to live out their retirement years.

Maria has been declared neurologically dead by two physicians not involved in transplantation. You are told by a nursing colleague that the back of Maria's Medicare card is signed for organ and tissue donation. The physician has met with the family to explain neurological death and ascertained an interest in learning about OTD.

Based on the above, what questions would you ask Maria's family? What concerns do you foresee when caring for Maria and her family? Who else in Maria's extended family would benefit from such a discussion?

Case scenario answers are found in Section Eight (pages 48 - 52)

You have developed the questions you would ask Maria's family. If you would like to discuss any aspects of the case study, please contact an MUHC nurse clinician. Section five builds on these questions and the description of Latin-American community OTD needs to

develop potential family interventions. The potential family interventions are based on expressed cultural values, beliefs, and needs. How you integrate this information into the plan of care will promote care that is culturally sensitive.

Section Five: What to do with Gathered Family Information

Objectives
○ To integrate family values, beliefs, and needs regarding OTD, into a plan of care. ○ To develop tailored interventions to offer culturally congruent care to families involved in the OTD process. ○ To complete the third part of the ongoing case scenario.

Once you have gathered the cultural views of the family outlined in section four it is important that you take a moment to look at the information. Review this information and reflect upon which cultural practices fit with your current nursing care. That is, how you converse with ethnocultural families. Which cultural practices require some adjustments to the way you provide nursing care, and how you balance the family's cultural request within the parameters of the critical care environment and organizational boundaries. The integration of families' cultural needs into nursing care often requires nurses negotiate with the family, other health care providers, and hospital administration to decide how this process will unfold. At times this may require that interested parties restructure their cultural values and in some respects cultural expectations within the context of the care environment. It is important that everyone involved keep an open mind and be respectful of each other's perspective. The goal is to provide the highest level of culturally congruent care to the potential donor and the family.

In this section you will use the questions developed in section four to think about how the family might answer them. Use these hypothetical answers to determine what type of culture care decision it represents. Box six provides an example of the three types of cultural sensitive care and potential solutions (integration, negotiation, and restructuring). Solutions will vary by

family, so it is important to verify their cultural needs with family members. This will ensure that proposed solutions are culturally sensitive to the needs of the family members and the deceased.

The family cultural assessment is an on-going process. As new information is presented to the family, new concerns can emerge. New concerns should be assessed, addressed and evaluated for their impact on the family's well-being and the OTD process.

Box Six: Culturally Congruent Care Decisions and Actions

Type of Culture Care	Example	Potential Solution
Integration	The family communicates the importance rosary beads had for the deceased.	The beads are wrapped around the deceased's hand.
Accommodation / Negotiation	The last rites ceremony the family described involves the lighting of candles.	While multiple candles would pose a danger because of the flammability of oxygen, one candle enclosed in a glass container set on a table at the foot of the bed, away from the oxygen tank is possible.
Restructuring Cultural Viewpoints	The family struggles to understand the concept of neurological death.	Family members are invited to watch the physicians carry out the neurological determination of death tests (typically the apnea test).

The third part of the case scenario asks you to use the ethnocultural family needs you identified in the second part of the case scenario. Use these identified cultural values, beliefs, and needs to categorize the type of culture care they represent. The results create an individualized plan of care that promotes culturally congruent nursing care.

Case Scenario - Part Three

The questions you developed has provided you with important cultural information on the family. Thinking about the information you would have collected, answer the following questions:

What cultural needs might Maria's family express?
What type of culture care (negotiation, etc) is represented within their cultural needs?

If Maria's family did not want to include the boyfriend in the OTD discussions, what could you do to support his needs and his potentially differing values and beliefs?

Case scenario answers are found in Section Eight (pages 48 - 52)

When a family is well supported and they understand what we are asking of them, the OTD decision will be what best suits the family and the deceased.

You have completed all the sections related to the provision of culturally congruent care. The contents of this resource manual has provided you with tools that helped you identify your strengths and challenges when interacting with other cultures, to learn how to carry out a family culture assessment, and to learn how to analyze gathered information in order to develop individualized ethnocultural family interventions. The final step is to complete the evaluation form on the nursing resource manual. Your comments will remain confidential, and will be used to revise the contents of the manual.

Send the completed evaluation form to Wendy Sherry via internal mail to the MUHC-Royal Victoria Hospital, S-11 or via email to wendy.sherry@muhc.mcgill.ca

Section Six: Manual Evaluation Form

Evaluation Form for the Nursing Resource Manual on Ethnocultural Families and Organ and Tissue Donation

Please circle the statement that best corresponds to your evaluation of the identified section contents of the manual.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Section on Nursing Cultural Self-Assessment					
The presented content is relevant and important to current practice.	5	4	3	2	1
The content meets stated objectives.	5	4	3	2	1
I am satisfied with the contents of this section.	5	4	3	2	1
The cultural self-assessment is a useful tool to explore your held views.	5	4	3	2	1
The reflective questions support the learning process.	5	4	3	2	1
My views were challenged by the cultural self-assessment.	5	4	3	2	1
Sections on Family Cultural Assessment					
The presented content is relevant and important to current practice.	5	4	3	2	1
The content meets stated objectives.	5	4	3	2	1
I am satisfied with the contents of this section.	5	4	3	2	1
The contents of the manual have provided me with additional information on how to care for culturally diverse families and their OTD needs.	5	4	3	2	1
The on-going case scenario supports the learning process.	5	4	3	2	1

Evaluation Form for the Instructional Manual on Ethnocultural Families and Organ and Tissue Donation

Please circle the statement that best corresponds to your overall evaluation of the manual. Space has been provided for written comments.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Overall Evaluation of the Manual					
The contents of the manual have provided me with important information on culturally diverse families and their OTD	5	4	3	2	1
I feel empowered to conduct a conversation with a family to explore their cultural values, beliefs and needs.	5	4	3	2	1
I feel enabled to offer culture congruent nursing care.					
I would recommend this instructional manual to a colleague.	5	4	3	2	1
The contents of the instructional manual met my expectations.	5	4	3	2	1
The contents of the instructional manual are presented in a logical manner.	5	4	3	2	1
The section objectives were met.					
Key terms were clearly defined.	5	4	3	2	1
The icon messages were helpful.	5	4	3	2	1

What did you find most interesting about the manual?

What did you find least interesting about the manual?

What would you change in the manual?

Section Seven: Resources

MUHC Resources

- Available MUHC resources to support provision of culture congruent care: Nurse Clinician on-call for OTD, Spiritual Care, Social Worker. They can be contacted by calling locating (33333).
- MUHC OTD binder available in all critical care areas across the MUHC
- MUHC intranet OTD information page: MUHC OTD service information

Pertinent External Resources

Frequently Consulted Resources

- **Héma Québec (Tissue donation): 1-888-366-7338, option 2**

  http://www.hema-quebec.qc.ca/tissus-humains/professionnels-sante/referer-un-donneur/index.en.html

- **Transplant Québec (Organ donation): 1-888-366-7338, option 1**
  http://www.transplantquebec.ca/en/professionnels

Other

- Canadian Blood Services (Healthcare professionals: Organ & tissue donation and transplantation) http://www.organsandtissues.ca/s/english-expert/welcome
- Canadian Institute of Diversity and Inclusion (Cultural competence assessment and development) http://www.cidi-icdi.ca/what-we-do/consultancy/offerings/cultural-competence/
- Canadian Nurses Association (Position statement on the promotion of cultural competence) http://www.cna-aiic.ca/~/media/cna/page%20content/pdf%20en/ps114_cultural_competence_2010_e.pdf
- Professional Interpreters: Professional interpreters are available via La *Banque interrégionale d'interprètes (514-597-3284). This represents a cost to the unit utilizing its services; therefore all requests must be made via the Nurse Manager or her / his representative. Need 24 – 48 hours notice.*
- The Center for Organisation Cultural Competence http://www.culturalcompetence.ca/
- Transcultural Nursing Society http://www.tcns.org/

Ethnocultural Family Assessment Checklist

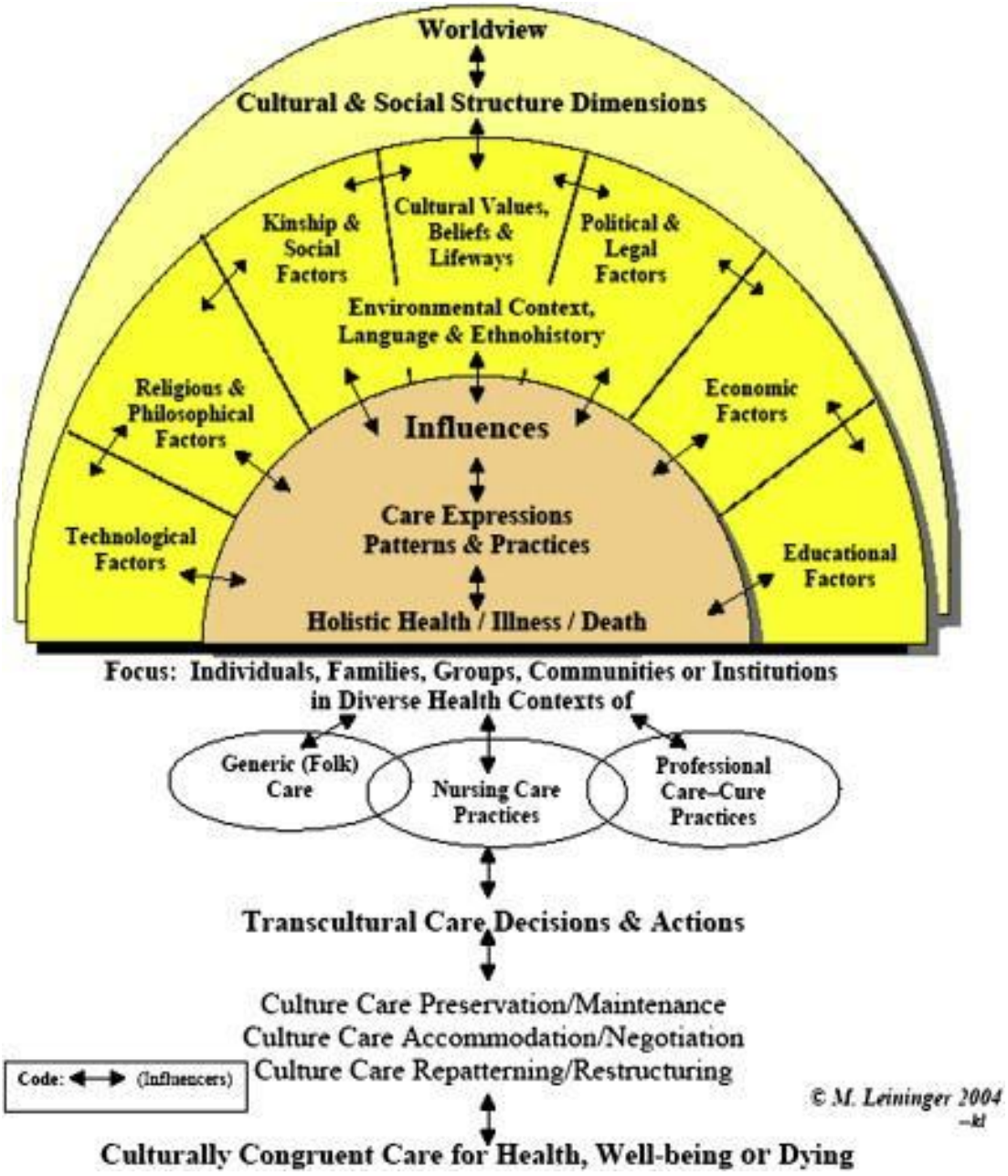
Family

- Identification of key family members
- Family values, beliefs and social needs explored
- Presence of children at the bedside
- Language spoken with healthcare professionals
- Language spoken by family and need for an interpreter
- Bedside technology explained
- Understanding of neurological death verified
- Religious / spiritual needs explored
- Integration of end of life rituals
- Need for Social Worker consultation explored
- Reflects understanding of OTD process

Nursing

- Consulted with team members to gather information on the family
- Identified personal / professional strengths and challenges that could affect culture congruent care
- Verified family's knowledge and understanding of OTD, and explained OTD process terms and concepts in simple language
- Care plan updated to reflect family needs, values and beliefs
- Unit contact information given to family members

Leininger's Sunrise Enabler Model



Source: Mak, M. W. (2014). *Death plus respect = Cultural safety.* Retrieved from http://pub209healthcultureandsociety.wikispaces.com/Death+plus+Respect%3DCultural+safety

On-going Case Scenario Answers

Case Scenario - Part One

Based on the provided description of Latin-American communities, what initial information would you want to have in order to offer culture congruent care?

- The family's' understanding of Maria's accident and injuries.
- The relationship between Maria's boyfriend and her parents since he is from a different culture; with an explanation why this is important.
- Identification of legal next of kin.
- Spiritual needs and resources.
- Need for a social worker to support crisis counselling, social resources, etc.
- Family need for an interpreter.
- Who will be given updates on Maria's condition; this person then communicates the information to the others.
- Who is considered to be part of Maria's family?

Case Scenario - Part Two

What questions would you ask Maria's family? What concern do you foresee when caring for Maria and her family? This list is not exhaustive and you might have identified concerns different from those listed.

- Would you tell me about the people gathered around the bedside and how they are related to Maria?
- We want to offer nursing care that supports your values and beliefs; what do we need to know about your family member and you?
- Could your family tell me about your culture? What is important for me to know when caring for Maria?
- Does your family back home know about the accident? How are you giving them updates?
- Are there any religious customs to be respected?
- Would you like a member of our Spiritual Care team to come be with you or what you like to invite your own spiritual leader?
- What has the Doctor told you about Maria's condition?
- Do you have any questions about the machines being used to care for Maria?
- Families have told me that neurological death (brain death) is hard to understand; please explain your understanding of what the Doctor told you.
- Who would you like to have with you when we discuss OTD? Is there someone that should be at this meeting that is not here? I can speak English and French, will everyone present be able to understand me or is an interpreter needed?
- Who will be at the family meeting to talk about OTD?
- Are there any young children in the family who are close to Maria? How do you feel about bringing them in to say goodbye?
- Who is looking after the children while you are at the hospital?
- Are there any specific rituals you would like us to honor?

- Would you like a photocopy of the OTD consent form?
- Do you live near the hospital?
- How are you traveling to the hospital?
- Do you have concerns about the cost of parking?
- Question for Maria's father: You have not been to work in a few days; does your employer understand why you are absent?

Who else in Maria's extended family would benefit from such a discussion? Explain. This list is not exhaustive and you might have identified concerns different from those listed.

Maria's francophone boyfriend of two years will need support and respect of his cultural values and beliefs. Depending on what type of relationship he has with Maria's parents (i.e., adversarial, civil, or friendly), will affect his ability to express his needs and feelings of grief and to say his goodbyes in a manner that is meaningful to him. Questions for him could include:

- What have you been told about Maria's condition? Do you have any questions about the machines being used to care for Maria?
- Does your family know about the accident? How are you giving them updates? Are they coming to the hospital?
- Could you tell me about your culture?
- Would you like a member of our Spiritual Care team to come be with you?
- Is there something you would like to do for Maria that holds meaning for you?
- If the boyfriend is not included in the OTD family meeting: Would you like to speak with me after the family meeting to explain OTD?
- If the doctor met with you, please explain your understanding of what the Doctor told

you. Families have told me that neurological death (brain death) is hard to understand; please explain your understanding of what the Doctor told you.

- If the boyfriend is the identified next of kin or included in family meetings: Would you like a photocopy of the OTD consent form?
- Do you live near the hospital?
- How are you traveling to the hospital?
- Do you have concerns about the cost of parking?
- If you have not been to work in a few days, does your employer understand why you are absent?

Case Scenario - Part Three

What cultural needs might Maria's family express?
What type of culture care (negotiation, etc.) is represented within their cultural needs?
This list is not exhaustive and you might have identified concerns different from those listed.

Integrated:

- To place religious articles or personal items at the bedside or with Maria's body (i.e., rosary beads, photos, etc.).
- Private room (when possible) to facilitate open visitation privileges.
- Chair at the bedside for a family member who wants to stay close to Maria's body.
- Lowered bedside rails to facilitate access to Maria's body.
- Tissues for grieving family members.

Accommodation / Negotiation:

- Organization of bedside prayer service with Spiritual Care team member or family spiritual leader.
- Discussions about the importance of rest (i.e., identification of a space where a family members can get some sleep); get something to eat and drink, and other health concerns and well being in the family (i.e., concerns about exhaustion or other stressors the family might be dealing with).
- Where cell phones can and cannot be used.
- ICU team needs that require all family members to leave the unit (i.e., patient reassessments, change of shift, etc.).
- Post-donation body viewing: Identify a space where the family members can spend time with Maria's body. Ensure the family understands that the body will feel extremely cold and have a greenish tinge due to the presence of the fluid to preserve the organ for transplant.
- Crowd control (volume of immediate family members, extended family members and close friends of the family and Maria): Do not want to not disturb other patients and families in the unit, need to keep hallways clear, and the location of the waiting room).

Restructuring:

- If the family is struggling to understand the concept of brain death have physician review brain scan results with the family and / or if they want to watch the physicians complete the neurological determination of death (i.e. usually the apnea test).
- Religious rituals carried out post-death but cannot be accommodated in the ICU setting: Discussions with family members and spiritual leader how they could be respected once Maria's body is transported to the funeral home.

If Maria's family did not want to include the boyfriend in the OTD discussions, what could you do to support his needs and his potentially differing values and beliefs? This list is not exhaustive and you might have identified concerns different from those listed.

Depending on the type of relationship the boyfriend has with Maria's parents, it is likely that you will act as an intermediary between the two parties.

Integrated:

- To place a personal item at the bedside or with Maria's body that is of significance to both of them (assuming the parents allow the boyfriend to do so).
- Spending time at the bedside to grieve and say goodbye to Maria.
- Lowered bedside rails to facilitate access to Maria's body.
- Tissues

Accommodation / Negotiation:

- If the boyfriend is not included in the family bedside prayer service then he might benefit from meeting with a Spiritual Care team to discuss his needs. Any requests will need to be negotiated with Maria's parents.
- Boyfriend's support resources: Bedside visitation to pay respect and location of waiting room.
- Discussions about the importance of rest (i.e., identification of a space where a he can get some sleep); get something to eat and drink.
- Where cell phones can and cannot be used.
- ICU team needs that require all family members to leave the unit (i.e., patient reassessments, change of shift, etc.).

- Post-donation body viewing: Needs to be negotiated with Maria's parents.

Restructuring:

- If the boyfriend is struggling to understand the concept of brain death have the physician review brain scan results with the boyfriend; ask the boyfriend if he wants to watch the physicians complete the neurological determination of death (i.e. usually the apnea test).

Section Eight: References

About.com. (2014). *Clip art: Green awareness ribbon* (image). Retrieved from http://webclipart.about.com/od/specialtyclipart/qt/Green-Awareness-Ribbon.htm

Baldinazzo, S. (2008). Coping with relatives during end-of-life decisions. *European Journal of Anaesthesiology, 25,* 164-166. doi: 1O.1O17/SO265O215O7OO3195

Canadian Blood Services. (2014). *Organ and tissue donation and transplantation.* Retrieved from) http://www.organsandtissues.ca/s/english-expert/welcome

Canadian Council for Donation and Transplantation. (2003). *Severe brain injury to neurological determination of death: A Canadian forum*. Edmonton. AB: Canadian Council for Donation and Transplantation. Retrieved from http://www.giftoflife.on.ca/resources/pdf/Severe%20Brain%20Injury%20.pdf

Canadian Council for Donation and Transplantation. (2005). *Donation after cardiocirculatroy death: A Canadian forum.* Retrieved from http://www.organsandtissues.ca/s/wp-content/uploads/2011/11/Donation-Cardiocirculatory-Death-English.pdf

Canadian Institute of Diversity and Inclusion. (2013). *Cultural competence assessment and development.* Retrieved from http://www.cidi-icdi.ca/what-we-do/consultancy/offerings/cultural-competence/

Canadian Nurses Association. (2010). *Position statement on the promotion of cultural competence.* Retrieved from http://www.cna-aiic.ca/~/media/cna/page%20content/pdf%20en/ps114_cultural_competence_2010_e.pdf

Center for Organisation Cultural Competence. (2013). *Welcome to the center for organizational cultural competence.* Retrieved from http://www.culturalcompetence.ca/

Central Vancouver Island Multicultural Society. (n/d). *Cultural competence self-assessment checklist.* Retrieved from http://static.diversityteam.org/files/414/cultural-competence-self-assessment-checklist.pdf?1342126927

Daly, B. J. (2006). End-of-life decision making, organ donation, and critical care nurses. *Critical Care Nursing, 26,* 78–86.

Ethnic to Ethnic Ministries. (2014). *Hands in circle around the world* (image). Retrieved from http://www.ethnictoethnic.org/wp-content/uploads/2010/06/Hands-in-circle-around-world.jpg

Expert Panel on Global Nursing and Health. (2010). *Standards of practice for culturally competent nursing care: Executive summary.* Retrieved from http://www.tcns.org/files/Standards_of_Practice_for_Culturally_Compt_Nsg_Care-Revised_.pdf

Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors and the collision of the cultures.* New York, NY: Farrar, Straus and Giroux.

Fernandez, M. (2013). *McGill University Health Centre organ and tissue database* (computer program). Montreal, Qc: Primatabase Concept.

Furukawa, M. (1996). Meeting the needs of the dying patient's family. *Critical Care Nurse, 16,* 51-57.

Guido, L. D. A., Linch, G. F. D. C., Andolhe, R., Conegatto, C. C., & Tonini, C. C. (2009). Stressors in the nursing care delivered to potential organ donors. *Revista Latino-Americana de Enfermagem, 17,* 1023-1029.

Heine, S. J. (2012). Chapter 10: Living in multicultural worlds. In S. J. Heine (Ed.) *Cultural psychology* (2nd ed.). New York, NY: W. W. Norton & Company.

Héma-Québec. (2010). *Organ and tissue donations: What is the difference?* Retrieved from http://www.hema-quebec.qc.ca/comprendre/tissus-humains/difference-dons-organes-dons-tissus.en.html

Héma-Québec. (2014). *How to refer a donor?* Retrieved from http://www.hema-quebec.qc.ca/tissus-humains/professionnels-sante/referer-un-donneur/index.en.html

Høye, S., & Severinsson, E. (2008). Intensive care nurses' encounters with multicultural families in Norway: An exploratory study. *Intensive and Critical Care Nursing, 24*, 338-348. doi 10.1016/j.iccn.2008.03.007

Irving, M. J., Tong, A., Jan, J., Cass. A., Rose, J., Chadban, S., ... Howard, K. (2011). Factors that influence the decision to be an organ donor: A systematic review of the qualitative literature. *Nephrology Dialysis Transplantation, 27*, 2526-25-33. doi: 10.1093/ndt/gfr683

Jacoby, L. H., Radecki-Breitkopf, C., & Pease, E. A. (2005). A qualitative examination of the needs of families faced with the option of organ donation. *Dimensions of Critical Care Nursing, 24*, 183-189.

Kierans, C., & Cooper, J. (2013). The emergence of the ethnic donor: The cultural production and relocation of organ donation in the UK. *Anthropology and Medicine, 20*, 221-231. doi: 10.1080/13648470.2013.845480

Leininger, M. M. (1988). Leininger's theory of nursing: Cultural care diversity and universality. *Nursing Science Quarterly, 1*, 152-160. doi: 10.1177/089431848800100408

Leininger, M. (1995). Transcultural nursing perspectives: Basic concepts, principles, and culture care incidents. In M. Leininger & M. R. McFarland (Eds.), *Transcultural nursing: Concepts, theories, research and practice* (2nd ed.). New York: McGraw Hill.

Leininger, M. M. (2001). *Culture care diversity and universality: A theory of nursing.* Sudbury, MA: Jones and Bartlett Publishers.

Leininger, M. M. (2006). Ethnonursing: A research method with enablers to study the theory of culture care [Revised reprint]. In M. M. Leininger and M. R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed.), p. 25. Sudbury, MA: Jones and Bartlett Publishers.

Leininger, M. M., & McFarland, M. (2006). *Culture care diversity and universality: A worldwide nursing theory* (2nd ed.). Sudbury, MA: Jones and Bartlett Publishers.

Mak, M. W. (2014). *Death plus respect = Cultural safety.* Retrieved from http://pub209healthcultureandsociety.wikispaces.com/Death+plus+Respect%3DCultural+safety

Maloney, R., & Wolfelt, A. D. (2001). *Caring for donor families before, during and after*. Fort Collins, CO: Companion Press.

Maroudy, D. (2008). Organ procurement: Proposals for approaching the family of the deceased. *Organs, Tissues and Cells, 3,* 187-195.

Monforte-Royo, C., & Roqué, M. V. (2012). The organ donation process: A humanist perspective based on the experiences of nursing care. *Nursing Philosophy, 13*, 295-301. doi: 10.1111/j.1466-769X.2012.00544.x

Pearson, A., Robertson-Malt, S., Walsh, K., & Fitzgerald, M. (2001). Intensive care nurses' experiences of caring for brain dead organ donor patients. *Journal of Clinical Nursing, 10,* 132-139. doi: 10.1046/j.1365-2702.2001.00447.x

Pottinger, A., Perivolaris, A., & Howes, D. (2007). The end of life. In R. H. Srivastava (Ed.), *Guide to clinical cultural competence* (pp. 227-246). Toronto, ON: Mosby - Elsevier.

Randhawa, G. (2012). Death and organ donation: Meeting the needs of multiethnic and multifaith populations (supplement). *British Journal of Anaesthesia, 108,* i88–i91. doi:10.1093/bja/aer385

Spondylitis Organization (2012). *Resources / Glossary.* Retrieved from http://www.spondylitis.org/patient_resources/glossary.aspx

Srivastava, R. H. (2007). Culture care Framework I: Overview and cultural sensitivity. In R. H. Srivastava (Ed.) *Guide to cultural competence.* Toronto, Ont: Elsevier Canada.

Statistics Canada. (2013). *Focus on geography series, 2011 census.* Retrieved from https://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-pr-eng.cfm?Lang=eng&GK=PR&GC=24

Statistics Canada. (2014). *Immigration and ethnocultural diversity in Canada.* Retrieved from http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-010-x/99-010-x2011001-eng.cfm

Transcultural Nursing Society. (2014). *Transcultural nursing society.* Retrieved from http://www.tcns.org/

Transplant Québec. (2014). Healthcare professionals. Retrieved from http://www.transplantquebec.ca/en/professionnels

Truog, R. D., Cist, A. F. M., Brackett, S. E., Burns, J. P., Curley, M. A. Q., Danis, M., ... Hurford, W. E. (2001). Recommendations for end-of-life care in the intensive care unit: The ethics committee of the Society of Critical Care Medicine. *Critical Care Medicine, 29,* 2332-2348.

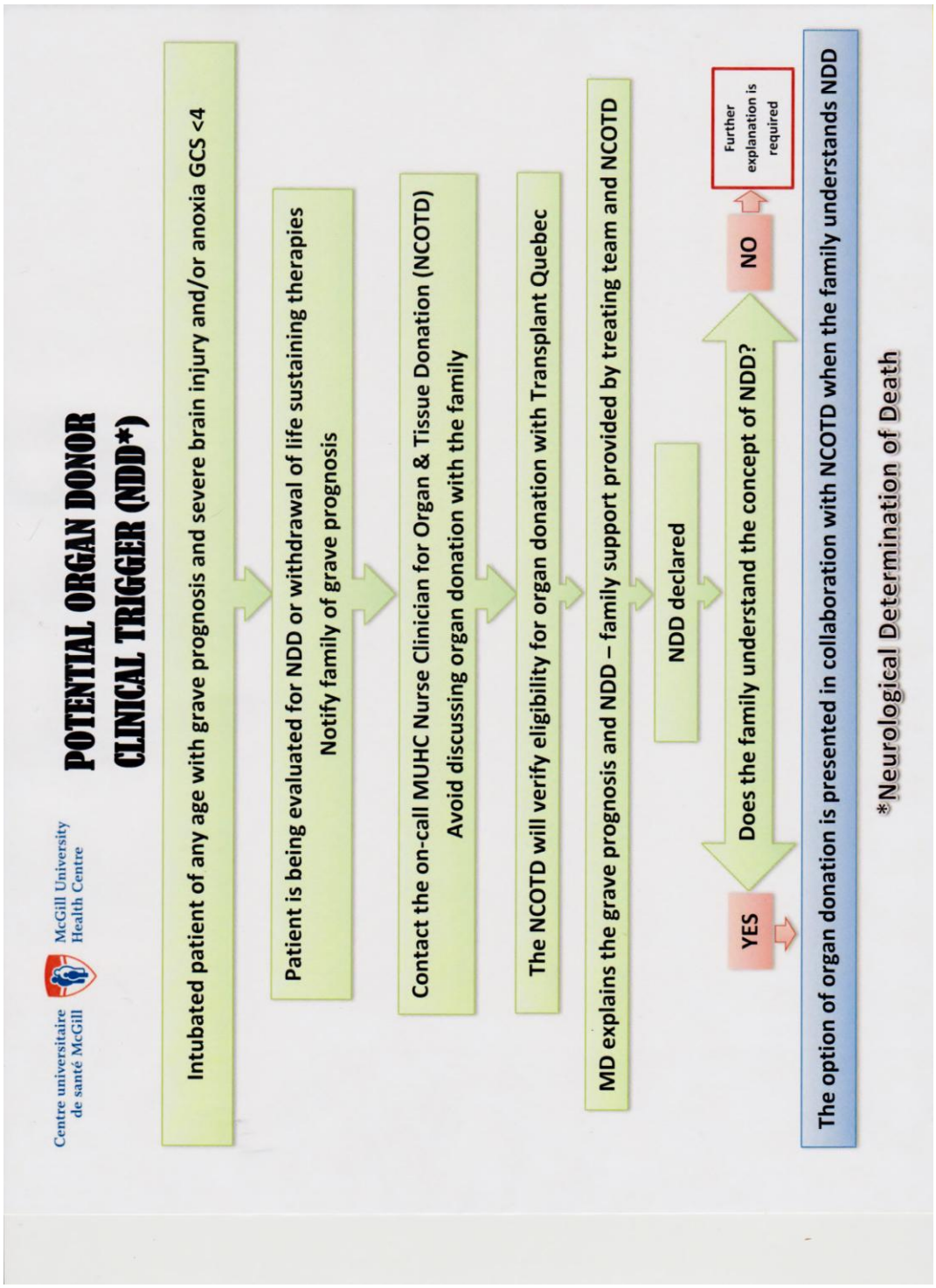
Wright, L. M., & Bell, J. M. (2009). *Beliefs and illness: A model for healing.* Calgary, AB: 4th Floor Press Inc.

Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). Philadelphia, PA: F.A. Davis Company.

Yeates, K.E., Schaubel, D.E., Cass, A., Sequist, T.D., & Ayanian, J.Z. (2004) Access to renal transplantation for minority patients with ESRD in Canada. *American Journal of Kidney Disease*, 44, 1083-1089. doi.org/10.1053/j.ajkd.2004.08.031

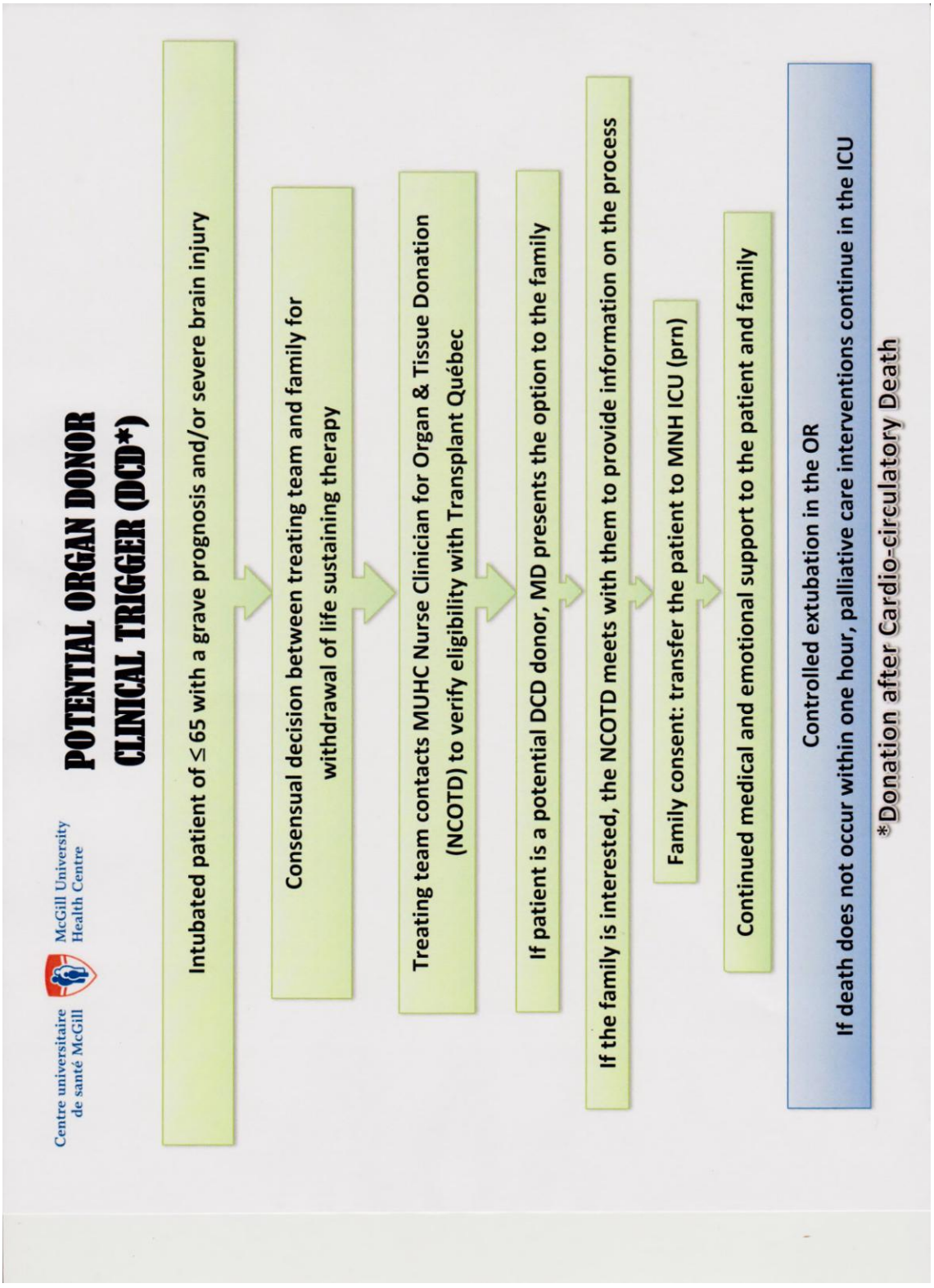
Appendix B

MUHC OTD Clinical Trigger for Impending Neurological Death



Appendix C

MUHC OTD Clinical Trigger Donation after Cardio-circulatory Death



Appendix D

Provincial (Québec) Clinical Trigger for Tissue Donation

Reproduced with permission from Héma-Québec. Personal communication with L.-P. Gagné, January 18, 2012.

Appendix E

Definitions of Culturally Related Care

Term	Definition
Cultural Awareness	"Being cognizant, observant, and conscious of similarities and differences among and between cultural groups." (Goode, 2006).
Culture Congruent Care	"Acts or decisions that are tailor made to fit with individual, group, or institutional cultural values, beliefs, and lifeways in order to provide or support meaningful, beneficial, and satisfying health care or well-being services." (Leininger, 1995, p. 106).
Cultural Humility	"Cultural humility incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations." (Tervalon & Murray-Garcia, 1998)
Cultural Safety	"Actions which recognize, respect and nurture the unique cultural identity..., and safely meet their needs, expectations and rights." (Wood & Schwass, 1993, p. 5-6)
Cultural Sensitivity	"Awareness, understanding, and attitude toward culture, and places the focus on self." (Srivastava, 2007, p. 57)

Appendix F

Ethno-cultural Communities Involved in the MUHC OTD Process

Ethno-culture	2011	2012	2013 (Jan –Sept)
Algerian	●		
Arab	●		
Asian			●●●
Brazilian		●	●
Cambodian			
Caribbean		●	
Chinese	●	●●	●
Cuban	●		
Dutch			●
Eastern European			●
First Nation		●	●●
German		●	
Greek	●	●	●
Haitian		●	
Hungarian			●
Indian (India)	●	●	
Inuit	●●	●	●●
Iranian			●
Italian		●●	●
Korean		●	●●
Latino	●		
Polish	●		
Romanian	●		
Russian	●		
Mix of French Canadian and First Nation		●	

Information obtained from the McGill University Health Centre Organ and Tissue Donation Database (computer program) (Fernandez, 2013)

Appendix G
Tenets and Assumptions of Leininger's Theory

Tenets

- **Care** is to assist others with real or anticipated needs in an effort to improve a human condition of concern or to face death.

- **Caring** is an action or activity directed towards providing *care*.

- **Culture** refers to learned, shared, and transmitted values, beliefs, norms, and lifeways of a specific individual or group that guide their thinking, decisions, actions, and patterned ways of living.

- **Cultural care** refers to multiple aspects of *culture* that influence and enable a person or group to improve their human condition or to deal with illness or death.

- **Cultural care diversity** refers to the differences in meanings, values, or acceptable modes of care within or between different groups of people.

- **Cultural care universality** refers to common *care* or similar meanings that are evident among many cultures.

- **Nursing** is a learned profession with a disciplined focus on care phenomena.

- **Worldview** refers to the way people tend to look at the world or universe in creating a personal view of what life is about.

- **Cultural and social structure dimensions** include factors related to religion, social structure, political/legal concerns, economics, educational patterns, the use of technologies, cultural values, and ethnohistory that influence cultural responses of human beings within a cultural context.

- **Health** refers to a state of well-being that is culturally defined and valued by a designated culture.

- **Cultural care preservation or maintenance** refers to nursing care activities that help people of particular cultures to retain and use core cultural care values related to healthcare concerns or conditions.

- **Cultural care accommodation or negotiation** refers to creative nursing actions that help people of a particular culture adapt to or negotiate with others in the healthcare community in an effort to attain the shared goal of an optimal health outcome for client(s) of a designated culture.

- **Cultural care repatterning or restructuring** refers to therapeutic actions taken by culturally competent nurse(s) or family. These actions enable or assist a client to modify

personal health behaviors towards beneficial outcomes while respecting the client's cultural values.

Assumptions

- Care is the essence and central focus of nursing.
- Caring is essential for health and well-being, healing, growth, survival, and also for facing illness or death.
- Culture care is a broad wholistic perspective to guide nursing care practices.
- Nursing's central purpose is to serve human beings in health, illness, and when dying.
- There can be no curing without the giving and receiving of care.
- Culture care concepts have both different and similar aspects among all cultures of the world.
- Every human culture has folk remedies, professional knowledge, and professional care practices that vary. The nurse must identify and address these factors consciously with each client in order to provide wholistic and culturally congruent care.
- Cultural care values, beliefs, and practices are influenced by worldview and language, as well as religious, spiritual, social, political, educational, economic, technological, ethnohistorical, and environmental factors.
- Beneficial, healthy, healthy, satisfying culturally based nursing care enhances the well-being of clients.
- Culturally beneficial nursing care can only occur when cultural care values, expressions, or patterns are known and used appropriately and knowingly by the nurse providing care. Clients who experience nursing care that fails to be reasonably congruent with the client's cultural beliefs and values will show signs of stress, cultural conflict, noncompliance, and ethical moral concerns.

Source: Sitzman, K., & Wright-Eichelberger, L. (2011). *Understanding the work of nurse theorists: A creative beginning* (2nd ed.), pp. 95-97. Jones and Bartlett Publishers: Sudbury.

Appendix H

Nursing Stakeholder Questions

Development of a Resource Manual for Nurses Working with Culturally Diverse Families

Whose Deceased Family Member is a Potential Organ and Tissue Donor

Families who are members of an ethnocultural community have expressed the need to have their cultural values and beliefs respected when approached about or taking part in the organ and tissue donation (OTD) process. In order to create a resource manual that helps nurses care for diverse cultures during the OTD experience and meet their unique health care needs, I would like to get your feedback on what you think is important for nurses who are caring for this population to know. That is, from your experience what do you think would be important for a novice nurse to consider when planning care for these groups of individuals? Exploring a nurse's professional experience as well as ethnocultural background could shed light on the type of information needed to develop tailored therapeutic family interventions for culturally diverse families considering OTD.

Questions

MUHC Site or Hospital Organization:

Job Title:

Type of Unit:

- ☐ Cardiac Care ICU
- ☐ Emergency
- ☐ Medical-Surgical ICU
- ☐ Neonatal ICU
- ☐ Neurological ICU
- ☐ Pediatric ICU
- ☐ Respiratory Care ICU
- ☐ Trauma ICU
- ☐ Other _____

Are you a member of an ethnocultural community?

- ☐ No
- ☐ Yes Specify:

Do you practice a particular religion?

- ☐ No
- ☐ No, but I consider myself a spiritual person
- ☐ Yes Specify:
- ☐ Other:

Gender

- ☐ Female
- ☐ Male

Age Group

- ☐ 20-25
- ☐ 26-30
- ☐ 31-35
- ☐ 36-40
- ☐ 41-45
- ☐ 46-50
- ☐ 51-55
- ☐ 56-60
- ☐ > 60

Years of Experience

- ☐ < 5
- ☐ 6-10
- ☐ 11-20
- ☐ 21-30
- ☐ > 30

Have you ever cared for a potential donor and family who are members of an ethnocultural community?

- ☐ No
- ☐ Yes

Can you tell me about some of the challenges you have experienced when dealing with a family from another culture and the OTD process?

Is there anything you feel could have helped you throughout this experience?

What do you think nurses need to know in order to provide care to families from different ethnic backgrounds?

Do you think your cultural values and beliefs influence how you care for donor families?

What do you believe would be important to know about an ethnocultural family who are considering OTD?

What would you tell a nurse who is caring for their first donor family?

Are there any resources that you think could have been helpful?

What do you envision a resource manual such as this looking like?

What content would be important?

How do you think the content should be presented in the manual?

Is there anything that has not been discussed that you would like to talk about?

Appendix I

Community Stakeholder Questions

Development of a Resource Manual for Nurses Working with Culturally Diverse Families Whose Deceased Family Member is a Potential Organ and Tissue Donor

Families who are members of an ethnocultural community have expressed the need to have their cultural values and beliefs respected when approached about or taking part in the organ and tissue donation (OTD) process. In order to create a resource manual on culturally diverse families and OTD it would be important to explore what ethnocultural community leaders believe nurses need to know to offer culturally congruent care.

Questions

Ethnocultural community:

Why has this person been chosen to represent the community?

What are the common religious affiliations in the community?

Do you know someone who has donated organs or tissues?

- ☐ No
- ☐ Yes, explain:

Do you know someone who has received an organ(s) or tissue(s)?

- ☐ No
- ☐ Yes, explain:

Are there any cultural practices that you think would help nurses provide better care to the patient and their family members during this time?

Why do you believe this information is important?

Is there anything that has not been discussed that you would like to talk about?