Challenges in providing culturally-competent care to patients with metastatic brain tumours and their families

By Lianne Longo, RN, MSc(A), CNN(C), and Serena Slater, RN, MSc(A)

Abstract

Being diagnosed with a metastatic brain tumour can be devastating as it is characterized by very low cure rates, as well as significant morbidity and mortality. Given the poor life expectancy and progressive disability that ensues, patients and family members experience much turmoil, which includes losses that bring about changes to family roles, routines and relationships. Crisis and conflict are common during such major disruptions to a family system, as individual members attempt to make sense of the illness experience based on cultural and spiritual beliefs, past experiences and personal philosophies. It is imperative health care providers strive towards increased awareness and knowledge of how culture affects the overall experience of illness and death in order to help create a mutually satisfactory care plan. Providing culturally-competent care entails the use of proper communication skills to facilitate the exploration of patient and family perspectives and allows for mutual decision making. A case study will illustrate the challenges encountered in providing culturally-competent care to a woman with brain cancer and her family. As the patient’s health declined, the family entered into a state of crisis where communication between family members and health care professionals was strained; leading to conflict and sub-optimal outcomes. This paper will address the ethical dilemma of providing culturally-competent care when a patient’s safety is at risk, and the nursing implications of upholding best practices in the context of differing beliefs and priorities.

N.B. The names of the patient and family members have been changed to respect confidentiality and privacy.

Introduction

Brain tumours: A mind/body/family disease

Malignant brain tumours are associated with rapid disease progression and an overall poor prognosis with a median survival of 12 months (Fox & Lantz, 1998; Schmer, Ward-Smith, Latham & Salacz, 2008). Brain cancer is the fifteenth leading cause of cancer in the Canadian population (Canadian Cancer Society, 2013). Based on a recent study, 2,900 Canadians were diagnosed with a brain tumour in 2013 and it is estimated that 1,950 of these patients will die from this disease (Canadian Cancer Society, 2013). Brain metastases account for more than one half of all brain tumours diagnosed in adults (Gavrilovic & Posner, 2005). The most common primary tumours responsible for metastatic brain tumours are breast, lung, and prostate cancers.
for brain metastases include lung, breast, melanoma, renal and colorectal cancers (Norden, Wen & Kesari, 2005). The most common mechanism of metastasis to the brain is by hematogenous spread (Lin, Bellon & Winer, 2004).

In most patients who develop brain metastases, a gradual expanding tumour mass and its associated edema cause clinical symptoms. These clinical manifestations may include headache, focal neurologic dysfunction (e.g., hemiparesis), cognitive dysfunction including memory problems, mood and personality changes, as well as seizures and stroke (Lin et al., 2004). Less commonly, intra-tumoural hemorrhage and obstructive hydrocephalus also result in symptoms (Lin et al., 2004). Contrast-induced MRI and biopsy are the preferred diagnostic tests to determine brain metastases (Lin et al., 2004).

The management of patients with brain metastases includes treatments against tumour proliferation, management to prevent complications and treatment of systemic malignancy (Lin et al., 2004). Treatment modalities include corticosteroids, radiotherapy, surgical therapy and occasionally chemotherapy (Lin et al., 2004). The intended goals of these interventions are to improve neurological function, increase quality of life and extend survival (Norden et al., 2005). For most patients, survival rates depend on their performance status, which is determined by physicians and based on patients’ well-being and activities of daily life, extent of extra-cranial disease, age and primary diagnosis (Gaspar, Scott, Murray & Curran, 2000, as cited in Norden et al., 2005). In patients who have a more favourable diagnosis, the approach used is tumour resection and/or radiation therapy. In those who have a poor prognosis, treatment focuses on control of symptoms and maintenance of neurologic function (Wong & Wu, 2012).

Brain tumour illness trajectory

Patients and families dealing with brain tumours are faced with daily life challenges due to physical, cognitive, and emotional changes during disease progression and management. These changes may occur slowly or rapidly and families must cope, adapt and develop strategies during the illness trajectory (Rosenblum, Kalkanis, Goldberg, Rock, Mikkelsen, et al., 2009). According to Schubart, Kinzie & Farace (2007), the first phase of the illness trajectory for brain tumour patients is the crisis phase in which the diagnosis is obtained and return to normal life is sought while managing current physical and cognitive limitations. The second phase is the chronic phase, which can either be: a) stable, when symptoms are still intrusive, but coping and management is on a long-term basis; b) unstable, when there can be new symptoms and additional treatment to adapt to; or c) deteriorating, when the tumour grows despite treatment and the patient loses more functional abilities. The third phase is the terminal phase when the patient and family prepare for death and palliative care is sought. Patients and families are prone to experiencing strong emotional reactions and high states of stress during these different stages and any unwanted change to their current life situation can cause distress. Anxiety, anger projection, blame and resentfulness are common responses exhibited by patients and families having difficulty accepting a variety of losses (Rolland, 2005).

 Patients, families and the brain tumour trajectory

Brain cancer is a mind and body illness, and patients have to adapt while trying to maintain normalcy in their lives (Fox & Lantz, 1998). Alterations in cognitive function and the loss of a patient’s sense of self can create great fear, anxiety and social isolation in brain tumour patients, as well as in their caregivers (Fox & Lantz, 1998; Schubart et al., 2007). Adaptation does not always come easily to patients and families and maintaining hope may be a challenge (Rosenblum et al., 2009). Brain tumour patients survive in a changed form, whether subtle or extreme, and patients and families have to cope with a shortened life, as well as “the loss of the self as known” (Rosenblum et al., 2009, p. 246). This may explain why a brain tumour diagnosis is often associated with stigma (Fox & Lantz, 1998). There have been patient accounts of attempting to maintain social and professional normalcy by avoiding disease disclosure for as long as possible (Fox & Lantz, 1998). Patients also rely on their loved ones for caregiving and the cancer inevitably becomes a disease of the entire family by deeply affecting relationships, roles and dynamics (Fox & Lantz, 1998; Schubart et al., 2007). Families are faced with decision-making, problem solving and adjustment to new roles and responsibilities, as the patient’s care needs change (Baidar & Surbone, 2010; Schubart et al., 2007). Families are most vulnerable when facing crisis moments of the illness and require greater support from surrounding resources. Crisis moments are associated when having to cope with the unknown and typically arise when any of the following occur: a) the brain tumour is newly diagnosed, the patient begins treatments and is re-assessed medically, b) the patient experiences new symptoms, c) the failure of initial treatments, and d) when the tumour is deemed untreatable and the patient enters the palliative phase (Rosenblum et al., 2009).

The process of accommodation, as defined by Corbin & Strauss (1991), is the day-to-day struggle by patients and families to maintain balance and give meaning to their lives while managing the ongoing progression of their illness. Patients and caregivers have to restructure their lives around the physical and cognitive limitations that develop, as the disease progresses (Schubart et al., 2007). The caregiver role inevitably becomes more and more important with time, as the patient’s functional status declines. There is a high associated risk of caregiver burnout due to monetary losses, career sacrifices, coping with a family member’s rapid physical and cognitive decline and neglect of one’s own physical and mental health (Schubart et al., 2007). Schubart et al. (2007) described the ongoing, often hidden struggles faced by family caregivers such as taking on new nursing care tasks that they are not trained to do, making rapid decisions as care needs change, coping with death and bereavement, and balancing hope with realistic expectations.

Case scenario

The following case study centres on Zoe, a woman with brain tumour metastases, and her family during the palliative phase of her illness. The following nursing assessments, interventions and analysis will focus on Zoe’s last admission to hospital, during which time her health status deteriorated significantly and tension amongst her family escalated, leading to multiple family interventions that will be discussed in future sections.
Zoe was first diagnosed with lung cancer in 2003. She had a right lobectomy and received radiation therapy that same year. Three years later, Zoe was diagnosed with brain metastases and had a craniotomy for brain tumour resection. She entered the chronic, deteriorating phase of her illness when her brain tumour became inoperable. During her last hospitalization, Zoe's care went from provision of active treatment to palliative care in a very short timeframe.

Zoe was of Polish descent and an avid practitioner of the Jewish faith. Her occupation was being the at-home caregiver of her three children. Zoe's husband, Jack, was the breadwinner of the family. Jack and the couple's youngest daughter, Lina, were very active in providing care and support during Zoe's many hospitalizations and formed one half of her social support network. Zoe's brother, Nicholas, and her mother, Marianne, formed the second half of Zoe's social support network and were present daily at her bedside. To the health care team, Zoe's family, heavily present in her care, initially appeared as a united front. Lina, Jack and Marianne were always present at Zoe's bedside and repeatedly stated to staff members they hoped for a decrease in the severity of her symptoms and improved functional status, so that Zoe could eventually return home, as had been the result of previous hospitalizations. They stated that religion played a significant part in their lives, as they abided by the laws dictated by their Jewish faith, such as observing the Sabbath. The main value system the entire family agreed on was the strength of their faith in God. The family also had strong faith in Zoe's treating physician, as they repeatedly advised the nurses they believed the medical interventions provided would lead to her improvement, which had also been the case in the past.

This united front dissipated when Zoe's neurological status rapidly deteriorated during the last few months of her life. As Zoe's care needs increased, conflict arose as the family struggled to accept her decreased functional status and imminent death. This resulted in some family members exhibiting a strained, antagonistic relationship with each other, which led to emotional turmoil for both Zoe and the nursing staff. In short, Marianne and Jack appeared to detest each other and would often fight even in Zoe's presence over their opposing points of view related to her care plan. For example, Jack wanted Zoe to go home so he could care for her, even in her deteriorating state, while Marianne considered his plan irresponsible and thought his decision was for selfish reasons. In addition, Jack and Marianne criticized each other's care of Zoe with regard to their choice of meals and communication approach.

**Escalating discord**

Discord mounted to an extreme level when Jack and Marianne involved the health care team in their personal conflict. They spoke very poorly of each other to the nurses and each demanded that the other be forbidden to visit and care for Zoe while she was hospitalized. In terms of decision-making capacity, Jack had the legal right to make decisions on behalf of his wife, as she was declared unable to make her own medical decisions at the time of the mounting conflict. This put the health care team in a predicament because the staff did not have any legal responsibility to prevent family members from visiting patients, despite the internal conflict observed. Such an intervention would only have been instituted had there been identification of violence or abuse. Additionally, as Zoe grew less able to communicate her wishes, Jack became her advocate and did not always act in accordance with the plans imparted by the health care team. This escalated conflict between the treating team and Jack. For example, Jack fed Zoe when she was clearly at risk for aspiration, mobilized Zoe when she was at high risk of falls, and threatened to take her home without medical consent as her neurological status deteriorated and care needs increased. The nursing team saw this behaviour as denial, a common coping mechanism for family members facing terminal illness (Ogle, 1999). Jack's true intentions were unclear and the nurses were afraid Zoe would suffer from complications due to her husband putting her at risk. Despite repeated attempts at setting care goals, frustration on both sides increased.

**Nursing interventions**

The nursing team made a significant effort to ensure Zoe's daily care plan was consistent and reinforced. Specifically, safety, comfort and maximizing Zoe's autonomy were the main care goals communicated. Active listening and acknowledgement of conflicts presented by Jack and Marianne was done to ensure the family felt their goals and views were being validated and considered. According to Rose (1999), "Failure to comprehend what carers are communicating, either verbally or nonverbally, will adversely affect the support that nurses can offer and may thereby increase the suffering and isolation experienced by families in this situation" (p. 87–88). Effort was also made in drawing the family's attention to how their personal conflict was physically and mentally draining Zoe when her energy levels were already depleted. This was done to increase the family's awareness of the situation and increase Zoe's quality of life. The team recognized the family's need for additional support and ensured there was direct involvement and assistance from the Jewish community. Multiple attempts were made to grant the patient's and family's wishes for a home discharge. There were also attempts at mediating the internal family conflict by having separate visiting hours.

The nursing team's top priority for Zoe was to maintain a peaceful frame of mind and avoid distress while she was in the end-of-life phase of her illness. In order to accomplish this, part of the care plan was to work on decreasing the frustration displayed by the nursing team, Jack and Marianne. Various attempts were made to objectively assess each family member's level of dissatisfaction by allotting daily, weekly, and, as needed "venting" sessions. These sessions were for all parties involved, including the nursing team, with the intent to benefit Zoe and the family, and to enlighten the nursing team on building a more therapeutic and trusting relationship. If the nursing team was successful in lessening the family's frustration levels, it would leave room for an essential nursing goal in end-of-life care: instilling hope (Tutton, Seers & Langstaff, 2009). Fostering hope can be accomplished by facilitating anticipatory grief behaviours and interactions with the family in order to provide them with a purposeful outlook for the future (Sullivan, 2003). However, grief counselling can only begin once a trusting relationship has been established between the health care provider and the family (Sullivan, 2003).

Although Zoe's family and nursing team were not on the same page with regards to the care provided, their mutual goal was to optimize Zoe's quality of life. From the nursing team's perspective, this meant providing comfort when needed in treating
Zoe's physical pain, ensuring optimal comfort and repositioning while bed-ridden, and avoiding treatments that might cause further pain because of complications. As well, her family and friends were encouraged to visit and bring valuable mementos from home, prompting a more familiar and comforting hospital environment.

Though all individuals involved had their own ideas of what Zoe's best interests were, they all made her their priority. There was an expectation that the nursing team, Zoe's husband Jack, and mother, Marianne, would eventually agree to disagree, yet still arrive at the same conclusions in identifying Zoe's basic care needs. However, while the health care team wanted to provide Zoe with a palliative approach to care, Jack focused on providing her nourishment and enforcing mobility, a perceived contradiction to the palliative approach at her stage of illness. At the same time, Marianne requested more quality time with Zoe, as long as Jack would not interfere, and also provided Zoe with oral nourishment. Most importantly though, during multiple conversations, the nursing team repeatedly acknowledged Jack's primary motivation, which was to be able to care for Zoe at home in order to preserve and optimize her life.

Despite all the interventions put forth, Zoe's family and the nursing team felt that the overall result was not optimal. No one involved felt satisfied with the care and services provided to Zoe. Jack was disappointed by the reasons conveyed by the health care team against taking Zoe home, which included Zoe's medical instability and insufficient government funding for appropriate adapted equipment for their home. Consequently, Jack's ultimate wish at this stage, for Zoe to die at home, was not realized. The nursing team never managed to break through the communication barrier to establish trust with Jack, leaving the nurses feeling powerless in their ability to offer a more palliative approach to this dying patient.

Case analysis

The analysis of this case study is broken down into three themes central to understanding and improving its management: a) understanding the family's religious views in exploring the Jewish perspective on health, b) ethics, and c) cultural competence.

Jewish perspectives on health

While it is important not to generalize religious beliefs to all who practise a particular faith, uncovering basic principles and perspectives of a certain religion is important to understanding and building a therapeutic relationship with a patient/family that practises that faith. However, each individual has his or her own personal beliefs in which there is variation both within, as well as between different doctrines.

Many beliefs and actions by those of Jewish faith surrounding a patient near the end of his/her life stem from the Jewish observation that life is supreme and worthy of preserving at almost all costs (Charnes & Moore, 1992; Steinberg, 1998). Quantity of life may supersede quality and all Biblical principles can be waived if a life is being saved (Bonura, Fender, Roesler & Pacquiao, 2001; Steinberg, 1998). This is exemplified in our case by Jack insisting on continuing to feed his wife solid food despite the danger of aspiration, and trying to get her out of bed despite her high risk of falling.

According to the literature, unlike other religions, Judaism views death with uncertainty (Bonura et al., 2001), which also could explain the push for extending life even if treatment is deemed medically futile. Strict delimitations that the Jewish faith associates with palliation may also make it difficult to face the uncertainty of a patient's deteriorating condition. Secular ethics tends to draw less focus on the timeframe of survival and instead emphasizes the approach to palliative care, while the Jewish faith uses terms such as Treifah (a palliative state where survival is projected as less than one year), and Goses (the state in which one is actively dying and is not more than three days in duration) to denote specific timelines for care to take place (Prosser, Kornman & Feinstein, 2012). Prognosis in brain tumour patients can be uncertain (Schubart et al., 2007), thus the point at which death may occur is difficult to predict. As a result, patients and families may be left with conflicting emotional opinions of how best to care for the patient and often struggle to find a balance between relieving suffering and hastening death (Prosser et al., 2012). Some sects of Judaism even believe a hastened death is equivalent to murder (Bonura et al., 2001; Kinzbrunner, 2004).

In this case, the family's perspective appeared to be consistent with that found in the literature in regards to general concepts such as the immense value placed on the preservation of life, maintaining close ties with the Jewish community, and not leaving a dying patient alone. The family's wish to preserve life is suggested by Jack's actions; for example continuing to feed his wife despite her being minimally receptive to it, and in his persistent quest to take Zoe home. Even if these actions were not going to prolong Zoe's life from a medical perspective, one could argue that from a Jewish faith perspective, Jack was acting in accordance to God in doing good and giving all he could for the comfort and, in his eyes, quality of his wife's last few days. Jack stated that he believed his wife's life and death were in “God's hands.”

Although the sense of community was strong in this family, conflict within the family unit, most notably between Zoe's husband and mother, was not typical of the close family ties alluded to in the Jewish medical literature (Bodell & Weng, 2000; Bonura et al., 2001; Charnes & Moore, 1992). Another difference from the literature was the lack of any relationship between the rabbi and physician. This may have fragmented Zoe's overall care and decreased Jack's trust in the health care team once Zoe deteriorated to the palliative phase. Perhaps Jack perceived certain interventions as hastening death, which is a misconception that continues to exist in some Jewish communities (Prosser et al., 2012). Nevertheless, the strong faith that Jack and Marianne shared led both sides of the family to rely heavily on the Jewish community for support during Zoe's illness and after her death, which was consistent with what has been described in the literature (Bodell & Weng, 2000; Charnes & Moore, 1992).

Ethics

In an effort to better understand this family's religious views and how they influenced the care provided, the differences between Jewish medical ethics and traditional, secular medical ethics are reviewed. It is stated that Jewish ethics are based on the belief in God and His Torah, in contrast to secular ethics,
which is based on humanism and rational intellect (Kinzbrunner, 2004; Prosser et al., 2012; Steinberg, 1998). The principles of Jewish ethics include commandments governing the relationship between man and God (Prosser et al., 2012). Accordingly, one of the main differences between secular medical ethics and Jewish medical ethics lies in Judaism's decreased emphasis on the principle of autonomy, as defined by secular ethics. In the Jewish faith one is granted autonomy, but within the constraints of Jewish law and what is right and wrong in God's terms (Kinzbrunner, 2004). The human body is seen as a gift from God (Bonura et al., 2001), which draws away from the individualism alluded to in secular ethics. According to Steinberg (1998), “Judaism requires self-fulfillment based on obligatory and binding moral requirements that are beyond the personal, temporal feeling of individuals, but rather founded on values mutually beneficial to society” (p. 39). Furthermore, rabbis and doctors are seen as partners in determining the appropriate treatment (Dorff, 2005), which restricts full patient autonomy. End-of-life decisions are made in consultation with a rabbi, who is considered an expert in God's law, and not merely based on what the patient wants, thinks and feels (Kinzbrunner, 2004). Jack consulted the family's rabbi on many occasions, but it is not known what was discussed in terms of decision-making for Zoe.

It is difficult to know how Zoe felt about her loss of autonomy, as she was no longer able to express herself verbally. Nonetheless, Zoe's mother, Marianne, paraphrased what her daughter continuously expressed: “She is such an active woman and works hard so that her children will all benefit and now she feels stuck, depressed and hopeless”. Both Zoe and Jack worked hard to give their children a good education and future, and her sense of autonomy was likely linked to feeling instrumental in what she could offer her children. For Zoe, not seeing and being there for her children was a significant source of stress. In this situation, Zoe's decrease in autonomy appeared to be linked to a lack of ability to do good unto others. Based on observations of this family, we can hypothesize that Jack may have had a stronger belief in the traditional Jewish view of autonomy because of his strong emphasis on taking Zoe home and having her with the children. In contrast, Marianne's hesitance towards Zoe going home suggests a more contemporary, patient-focused perspective.

Another difference between the two ethical streams is the Jewish faith's focus on expanding the principles of beneficence (doing good) and non-maleficence (do no harm) beyond merely protecting the patient from harm to an obligation to do good. The focus of an intervention is often on its intent, which if, to do good, is acceptable (Prosser et al., 2012; Steinberg, 1998). For example, administering morphine for pain control may reduce respiration rate, thus making the patient seem closer to death, but the intention is to relieve suffering by taking away pain. Although a nurse's intent should always be good, do families believe and accept the intent for the patient's benefit or does mistrust prevail? Perhaps Jack's persistent behaviour in nourishing his wife by feeding her home-cooked meals was his way of upholding beneficence or, doing good for her. Not only did Jack commit to feeding his wife, but also to providing her with the best possible food. Jack took pride in carefully preparing nourishing meals for his wife and would often show and describe them to the nurse. To a lesser extent, Marianne also fed Zoe despite the high risk of aspiration. It is possible the family found solace in prolonging Zoe's life by preventing death by starvation (Krishna, 2011).

Nurses are taught to act as moral agents and “work with persons receiving care including families, groups, populations and communities, to take into account their unique values, customs, and spiritual beliefs, as well as their social and economic circumstances” (CNA, 2008, p. 13). As well, nurses have a professional duty to uphold principles of the institution in which they work. But what if this duty conflicts with that of being a moral agent to the patient and family? For example, in this situation the nursing team advocated for Jack by involving the social worker and occupational therapist in an attempt to accommodate his wish to take his wife home. Many of the nurses shared Jack's view that the home environment would be more ideal for Zoe's comfort. However, due to the lack of resources and services to make this possible, the nurses had to maintain a firm stance along with the rest of the treating team that Zoe returning home was not feasible and had to continually relay this reasoning to Jack.

Situations such as this prompt us to question what our role, as nurses should be in maintaining hope. Shifting hope away from recovery to a peaceful and dignified death is constrained by circumstances such as those discussed in this situation, but is necessary for a nurse to undertake if truly offering comfort care to a patient and family. Zoe's attachment to her children seemed to be a huge source of hope and the nurses involved in her case tried to focus on the children's legacy. They used interventions such as commending Jack and Zoe on how hard they had worked to provide their children with a successful life, and how Jack could continue to do this after his wife was no longer there. When Jack discussed plans for the time when his wife would no longer be with him, it opened up the opportunity for the nursing team to understand and facilitate the family's coping, as the nurses could lend support towards building the family's future success, which appeared to be of high importance to both Zoe and Jack. Zoe's family also engaged in prayer, which the nurses encouraged because it appeared to instill hope and appease them.

**Cultural competence**

Culture is a concept that defines individuals and guides their behaviour patterns, decision-making style, beliefs, communication patterns and overall lifestyle (Jenko & Moffitt, 2006). The way in which an individual perceives the world and acts accordingly is governed by the standards set forth by one's value system. These standards reveal an individual's identity and can fluctuate over time because of the ever-changing physical, social, economic and political environment in which one lives (Jenko & Moffitt, 2006). Certain habits and behaviours are open to change, but others are more static and have been passed down through generations (Dreher & MacNaughton, 2002). Culture can be subdivided into what is visible to an outsider: behaviour and artifacts, as well as the invisible: beliefs, values and assumptions, which only become apparent from repeated encounters and interactions. It is important to make the distinction that ethnicity, spirituality and religion shape cultural identity, but do not define it.
Illness and dying are significant universal concepts to both patients and families involved, yet there are many cultural and symbolic meanings associated with care of the ill. Decisions made about withdrawal of life support or continuing artificial nutrition are culturally driven. Many families grapple with the dilemma of "extending the dying" or "extending the living" (Konishi, Davis & Aiba, 2002, as cited in Jenko & Moffitt, 2006, p. 179). In the context of health care, the medical team should be aware that patients and families allot different meanings towards a) who, how and what health care information is being communicated, b) the nature, trajectory and meaning of illness, suffering and death, and c) end-of-life decisions. When one is ill, one looks for unconditional love, forgiveness, hope, faith affirmation, or meaning in life (Charnes & Moore, 1992). Nurses' recognition of spiritual and cultural needs is vital to providing holistic care, yet nurses can neglect the importance of this if they do not understand their role in meeting their patients' cultural needs (Charnes & Moore, 1992).

"Cultural competence requires acknowledging the fundamental ethnocentrism of contemporary Western health care and the differences in the way patients and families respond to illness and treatment and end-of-life care" (Dreher & MacNaughton, 2002, p. 182). The overall goal in providing culturally-competent care is for health care professionals to acquire enough cultural information to anticipate and deal with possible barriers to compliance with care. The end result should be decreased cultural conflicts and errors, improved patient/family/provider communication and increased patient and family satisfaction with care. Cultural knowledge can help health care professionals understand troubling non-compliant behaviours of patients and families so that it is not regarded as pathological, thus ensuring a more therapeutic caregiving experience (Dreher & MacNaughton, 2002).

Although the knowledge and skills necessary for cultural competence develop over time, it is necessary to incorporate them into everyday practice. Patients and families have an ethical right to be understood. There are, however, organizational and situational obstacles that might create barriers for nurses to consistently provide culturally-competent care, such as time constraints and nursing shortages, the absence of capable translators, increasing diversity of the population, and negative stereotyping of patients from particular communities (Crawley, Marshall, Lo, & Koenig, 2002; Kagawa-Singer & Blackhall, 2001). There is also an inherent difficulty for nurses to explore the meaning behind family decisions and behaviours, as not all patients and families are openly willing to discuss their beliefs and motivations.

When the nursing staff attempted to explore Jack's beliefs to explain his conflicting behaviour, he did not openly provide answers, despite the emphasis on Zoe's safety. However, during private meetings with the clinical nurse specialist, Jack was able to identify his awareness of his wife's impending death and that there were cultural preparations that needed to take place. Continuous support was provided to Jack to assist him with anticipatory grief such as suggestions on how to present the notion of death to his children and mobilize community resources. Jack was receptive to these initiatives, as they supported his caregiving goals and cultural beliefs. When asked if he thought the medical system was failing him, Jack did provide one reason for the culture clash. He perceived that the medical team's belief was in opposition to his faith that Zoe's life and death were in "God's hands." Jack felt the team believed that her dying phase and death could be controlled or managed by them and was very much opposed to this Western, medical belief.

Although a full cultural assessment did not take place with Zoe and her family, there were important details that emerged about her husband's beliefs and cultural background that provided some insight into his goals and purpose in providing care for her. This information was valuable, and had it been thoroughly communicated and disseminated to the entire nursing team, it could have provided further guidance for the nursing staff to develop improved communication with Jack. It can be surmised that a more therapeutic relationship between the family and the nursing team would have been possible if the nursing staff had been more focused on developing their cultural competence and had the internal communication amongst the medical team members been more complete.

**Nursing implications**

In order to carry out holistic care, culturally-competent care must be included in our nursing approach. First and foremost it is essential to be aware of our own spirituality, as nurses, before attempting to understand others' views (Charnes & Moore, 1992). Cultural and spiritual assessments of the patient and family are an extension of psychosocial assessments and, as in all evaluations, prioritizing concerns and using intuition should be key. The degree to which spirituality and religion influence a patient's care should be determined by exploring patient and family expectations of care, identifying signs of spiritual distress that could manifest as guilt, fear and anxiety and anger at one's own faith (Charnes & More, 1992), and addressing perspectives on quantity versus quality of life (Prosser et al., 2012).

This case study has led us to emphasize general nursing interventions applicable to providing overall effective patient care. These include: a) remaining transparent with the patient and family, b) maintaining open communication to promote trust, c) helping the family feel in control by remaining flexible and providing them with choices (Kirsch, 2009; Prosser et al., 2012), d) exploring their expectations of care and finding ways to preserve their hope (Bonura et al., 2001), and e) helping them cope with loss and end-of-life transitions (Schubart et al., 2007). Being able to identify and direct the patient and family to appropriate resources and services, such as a spiritual leader, a social worker or translator, is another nursing responsibility that should be done as early as possible and followed-up on regularly during the illness trajectory (Schubart et al., 2007). Continuity of care and regular communication with the multidisciplinary team is a must to meet patient and family needs and for the above interventions to run smoothly.

**Limitations**

As this is a case study, information and findings, especially those pertaining to the cultural and religious beliefs of this particular case, cannot be generalized.
Conclusion
In challenging cases such as this, it is vital for the nurse and team members to have a therapeutic relationship with the patient and family in order for both the nurse and patient/family to understand each other in setting care goals. The challenge lies in acknowledging and managing the gap between the family’s and nurses’ perspectives and in setting boundaries. A delicate balance to providing health care services to the individual patient/family while maintaining specific professional duties mandated by the environment and health care system at large needs to be achieved. In order to manage the gap between patient/family and nurses’ perspectives, identifying patient and family expectations and facilitating open-ended discussions about beliefs and meanings attributed to illness at the outset of care is one approach that may be of great benefit. This may facilitate shared decision-making and result in more consensual perspectives. Providing culturally-competent nursing care is a necessary skill to develop as the health care needs of an ethnically diverse population become more complex. Further nursing research on patient and family satisfaction levels following a consistent cross-cultural approach to care over time would be of interest. Developing better techniques on how to initiate and sustain meaningful ethical dialogue in today’s current fast-paced hospital environment in order to provide more effective nursing care is crucial for future analysis.

Author contact information
Lianne Longo, Montreal Neurological Hospital, McGill University Health Center, Montreal, Quebec, Canada. lianne.longo@mail.mcgill.ca
Serena Slater, Montreal Neurological Hospital, McGill University Health Center, Montreal, Quebec, Canada. serena.slater@mail.mcgill.ca

REFERENCES